inmotion

ISSUE 3
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A MAGAZINE FOR THE PARKINSON'S COMMUNITY

IN THIS ISSUE:

RESEARCH PROJECTS

COVID-19 AND GRIEF

HALLUCINATIONS

IN THIS TOGETHER
parkinson's
VICTORIA

CEO UPDATE

Reflecting on the past three months, it's hard to comprehend the impact of COVID-19. We know people are hurting.

From those experiencing the heart-break of losing loved ones or missing family and friends, to others whose symptoms are worsening as movement slows and anxiety increases. It's for all these people that we are here.

We have worked with individuals to manage the impact of cancelled exercise classes and help keep them moving. We have provided strategies for people living with Parkinson's and their carers to manage anxiety.

We have guided others to navigate the new world of telehealth medical appointments and supported families facing the anguish of being unable to visit and care for loved ones in aged care.

We have spoken to staff in health, aged and residential care to improve their knowledge of Parkinson's and worked with the Department of Health and Human Services to offer frontline health and care staff access to our specialist health team, seven days a week during Stage 4 lockdown.

We can help you too. Our focus is on supporting people living with Parkinson's, or caring for someone with Parkinson's, to navigate COVID-19 to stay safe, well and focused on the future.

This support comes in many ways, including our telephone service. The benefit of speaking with our health specialists is that they can often identify issues impacting symptoms that were not the initial reason for the call.

I encourage you to reach out and call the health team on 1800 644 189 for even the smallest of queries – and see for yourself, the difference we can help make.

Support has also come through the Living Well seminar series in August, with weekly interactive, online conversations covering topics including telehealth, multi-disciplinary healthcare, exercise and mental health and wellness.

We are running more seminar sessions in September. Check out the Parkinson's Victoria website event's page for registration details.

In this edition of *InMotion*, we have included a thought-provoking article about COVID-19 and grief, acknowledging the impact it is having on our economic security, physical connection and even the insecurity of the future and plans that were halted or postponed.

We also preview a new online community event, *27forParkinson's.* We know many people were looking forward to being part of the 12th annual *A Walk in the Park*. But this year is different as we work hard to suppress the spread of COVID-19 in our community.

With social distancing, travel and even exercise restrictions, our need to come together and support 27,000 people living with Parkinson's in our community has never been greater - so we have a new challenge.

27forParkinson's is free to join and accessible to everyone. Just register and commit to walk 27 times, over 27 days, in October and fundraise along the way. There's no pressure on distance or time, you simply walk what you can, when you can, where you can.

It provides the opportunity to join together as families, teams and communities, to commit to regular exercise and engage online with others undertaking the challenge.

I can't wait to see images of the stunning locations where people will be taking part – the local beaches, suburban parks, the bush and even paddocks where people will be able to get their walk in.

Parkinson's Victoria CEO Emma Collin

We are also excited to welcome our first confirmed Ambassador, the Member for Lara, John Eren, who recently revealed his Parkinson's diagnosis. John is keen to raise awareness of men's health and Parkinson's.

More details are on pages 8 & 9, including an event calendar you can cut out and mark off as you complete each walk.

27forParkinson's is about community and awareness, but is also an important fundraiser. We know the current environment is financially challenging, and are extremely appreciative of those who plan to fundraise and who contributed to the $88,000 donated to our recent Winter Appeal.

This support means we can continue to deliver critical services to the community in a time of great need and when we have no guarantees from the State Government for funding past 31 December 2020.

Rest assured we continue to advocate strongly so our politicians and health bureaucrats are fully aware of the importance of the specialist advice and education we provide to ensure all Victorians impacted by Parkinson's are supported throughout their journey.

Stay safe,

Emma Collin

Emma Collin
CEO
Parkinson's Victoria

Cover: COVID-19 has created so many changes, but we have still been able to enjoy walking in our local streets and parks. Pictured in their local park are City of Yarra PSG leader Sheenagh Bottrell, with her husband Andrew and their dog Riley.

NEWS & HIGHLIGHTS

SPECIALIST NURSES BOOST TO REGIONAL CARE

Parkinson's Victoria has welcomed Federal Government funding for a pilot project to give accessible, specialised care for people living with Parkinson's and other movement disorders in Victoria's Great South Coast, Wimmera and Grampians regions.

The pilot will support four movement disorder nurses in Horsham, Warracknabeal, Stawell and Warrnambool, building local specialist knowledge in clinical support and providing care coordination.

The nurses will support people living with Parkinson's and other complex movement disorders to better manage their condition, increase their access to referral pathways, treatments and therapies in order to deliver better health outcomes in the region.

Western Victoria Primary Health Network (WVPHN) and Parkinson's Victoria applied for the funding ($1.69 million over four years) in partnership with South West Healthcare, Wimmera Health Care Group, Rural Northwest Health and Grampians Community Health.

"We see enormous need to build the clinical capacity and specialist knowledge of movement disorders in rural and remote areas of western Victoria," said Parkinson's Victoria CEO Emma Collin.

"Parkinson's is a highly complex condition and access to specialist local advice will help people to better manage their condition and live well," she said.

Local Parkinson's Peer Support Groups welcomed the pilot program.

John McRoberts, Secretary of the Wimmera Parkinson's Peer Support Group, said he had been advocating for several years to gain local support.

"Easy access to a movement disorder nurse will address the issue of mobility and cost, which can be difficult - even prohibitive - for some who need clinical support beyond a neurologist.

> *"To have a local trusted specialist will build continual care and provide confidence that you are getting the best care possible and that relieves a lot of stress."*

Bev Boag, recently retired Grampians Parkinson's Support Group leader, said people in the region needed one-on-one timely advice from an expert to make sure their health stayed as good as it can.

"So many people will benefit from having better access to a movement disorder nurse. This funding will really boost the support here beyond the Parkinson's Support Group."

Andrew Suggett from Warrnambool Parkinson's Support Group, has also been a strong advocate for better support.

"The placement of a specialist nurse in the area will be absolutely life changing for some of us.

"To have local help to answer queries and access services will give the support needed to live with Parkinson's day-to-day rather than to wait and travel to get support."

A TEAM EFFORT FOR PEOPLE WITH PARKINSON'S

Thank you to everyone who responded to our Winter Appeal.

Your generosity has resulted in more than $88,000 raised for people living with Parkinson's – to keep them connected to vital support, information and care especially during this most challenging time.

The support we have received through our Winter Appeal means we can continue to reach out and support people with individualised plans of action, so they not only manage their condition and symptoms, but also their overall health and wellbeing.

This includes an outreach program, through which we are contacting people with Parkinson's to reassure, support and encourage them to look after themselves.

We are also continuing to expand our Telehealth, phone and online services.

Technology is providing people with access to our staff to talk through issues, to read information, to attend online webinars, forums and seminars, and so much more.

And over the next few months, we will continue to provide more sessions and support using our Telehealth, website and social media channels.

Your support continues to make a tangible and life-changing difference. Thank you.

SHARING THEIR JOURNEY

We also thank John (left) and Col for so openly sharing their experiences with Parkinson's as the 'faces' of our winter appeal.

It is through these personal stories that we are able to illustrate, in a tangible way, how Parkinson's Victoria can and does help so many people.

OAM AWARDED FOR SERVICES TO PEOPLE WITH PARKINSON'S

Anne Atkin OAM is one of those special individuals who keeps giving to the community, no matter what she is going through herself.

She was single-handedly responsible for setting up Painting with Parkinson's in Victoria and has written two books, *Living and Laughing with Parkinson's* and *Still Laughing*.

Just last year she organised a fundraising art exhibition and picnic in the beautiful gardens of the historic Berwick Old Cheese Factory and she has plans to introduce Painting with Parkinson's in her home town of Warragul, where she helps out the local Parkinson's Peer Support Group.

This is all still while running her original Berwick Painting with Parkinson's group and mentoring and sharing ideas with other group leaders through the Victorian Painting with Parkinson's Network.

Anne's commitment to others was formally recognised when she was awarded the Medal of the Order of Australia in the Queen's Birthday 2020 Honours List for service to people living with Parkinson's.

Anne said she could have been "knocked over by a feather" when she received the letter from the Governor-General confirming the award.

"It was an unexpected honour I never anticipated receiving. I feel immensely proud," Anne said.

Anne was working as a librarian and school art teacher when diagnosed with Parkinson's in 2005. She soon put her skills to use in the Parkinson's community, as a volunteer librarian and Ambassador with Parkinson's Victoria, speaking to community groups across Melbourne.

We love to hear about – and share - examples of recognition received by members of our community. Send us the details via email, info@parkinsons-vic.org.au

But it was her decision to set up a therapeutic arts program, combining her passion for art with her desire to help others with Parkinson's, that's made the greatest impact.

Painting with Parkinson's was created to help people with Parkinson's to express their creativity through painting in a social setting, which in turn brings positive physical and emotional benefits for participants.

From the initial one group in Berwick that started with four attendees, some groups have come and gone, but today there are six Painting with Parkinson's groups in Melbourne and regional Victoria.

An example of Anne's resilience – and creativity - came to the fore in 2012 when an arson attack on the Old Cheese Factory, where the group met, destroyed much of the art work, supplies and equipment.
She convened a Devonshire tea breakfast and proceeded with the class, where participants used charcoal from the building to capture the blaze and burnt out remains to create a wall mural.

In the same year, Anne was nominated and named the Parkinson's Victoria 2012 Sir Zelman Cowen Award recipient.

She was nominated for the award by then Berwick Painting with Parkinson's member, Michael Dee Prose for her "expertise given with unquestionable selfless voluntary kindness by her utmost concentrated six year development of the Painting with Parkinson's program in Victoria."

Anne's talent saw her achieve international recognition in 2010 when a painting depicting the Parkinson's symptom of sweating through the face of a female, was displayed at the 2010 World Parkinson Congress in Scotland.

But more-so, her passion and dedication has been for the benefit of others, and she is credited with using her talent to 'give a voice' to people with Parkinson's.

She did this through art shows and facilitating professional development workshops across Victoria to spread the prototype of her Berwick Painting with Parkinson's Group to a wider audience.

She also allowed her artwork to be used on Parkinson's Victoria merchandise sold to raise funds for the organisation, such as Christmas cards for quite a few years.

"I love doing things for people - I love making people laugh and I just find that people with Parkinson's can go down so quickly, especially at the moment when they are stuck in a house so if I can give them some pleasure, and help them in any way, it works out well."

Parkinson's Victoria CEO Emma Collin said the Queen's Birthday honour was fitting for a devoted and passionate woman who had positively changed the lives of so many people with Parkinson's and their families.

"Anne has raised the profile of Parkinson's in the community in various ways over many years, but it is through her building inclusion and support for people living with Parkinson's through painting that she has made the strongest mark," Emma said.

"I congratulate Anne on this wonderful accolade and on behalf of the Victorian Parkinson's community, thank her for her continued dedication and compassion that means so much, to so many people."

RESEARCH SUPPORTS PARKINSONG™ BENEFITS

The therapeutic benefits of Parkinson's Victoria's ParkinSong™ singing program have been evidenced by a 12-month controlled clinical trial conducted in Victoria.

The study found ongoing benefits to communication and wellbeing for people living with Parkinson's, as well as their carers.

ParkinSong™ is an activity-based peer support program involving vocal warm-up and exercise, practical communication activities, group singing and social engagement, that started in Williamstown in 2013.

The *Journal of Parkinson's Disease* recently published the effects of 12 months of ParkinSong™ group singing sessions on people with Parkinson's and their caregivers.

The study found that ParkinSong™ had "positive and sustained effects on vocal loudness and voice-related quality of life". People in the ParkinSong™ singing groups recorded better outcomes in voice loudness than the non-singing control groups.

Parkinson's Victoria CEO Emma Collin welcomed the results.

"There was already a body of evidence around the benefits of music therapy and anecdotally, we believed people were benefitting from ParkinSong™, but to have this evidence-based research confirming the positive impact is truly exciting for the Parkinson's community."

Ms Collin said research was not only about the quest for a cure, but to also to develop effective treatments and therapies to improve quality of life for people now. Dance as a Parkinson's therapy is currently subject to a separate research project.

> *"Having an evidence base provides the platform from which we can continue to refine and develop ParkinSong™ as a recognised and consistent therapeutic program that can be rolled out to help even more people."*

Lead researcher Dr Jeanette Tamplin said it was "fantastic to have such promising empirical results from this preliminary study, which is the largest of its kind and the first to compare singing to a control condition in Parkinson's."

THE CLINICAL TRIAL

Music Therapy and Speech Pathology disciplines collaborated to shape the ParkinSong™ program and evaluate its benefits - 75 people living with Parkinson's and 44 care partners participated in the 12 month study.

In the controlled trial, a proportion of participants attended ParkinSong™ (weekly or monthly) and the others attended other groups, such as Parkinson's Peer Support Groups, Tai Chi Groups, Dancing Groups or Painting with Parkinson's Groups, also at weekly or monthly intervals.

Results indicated that ParkinSong™ participants made a statistically significant improvement in vocal intensity (voice loudness), maximum expiratory pressure (respiratory strength), voice-related quality of life (more positive perceptions about their voice and communication) and anxiety.

Caregivers who attended ParkinSong™ showed greater reductions in depression and stress scores.

WHY SINGING?

Singing shares neural networks and structural mechanisms used during speech. It requires greater respiratory support, higher vocal effort, and can provide rhythmic cues to regulate tempo, and stress, through stimulation and organisation of motor output.

Further, during singing the brain releases neurochemicals that increase feelings of pleasure and alertness and decrease anxiety and stress.

Targeted group therapy programs that utilise singing also afford social participation and active engagement in addition to creative musical expression.

THREE MONTH COMPARISON

Although the 12-month results found little difference in the outcomes between those who attended ParkinSong™ weekly or monthly, this was a marked change from the three-month results published in the journal, *Neurorehabilitation and Neural Repair*.

The results of testing done three months into the study showed people who attended ParkinSong™ weekly had greater improvement in their voice compared to the monthly singers.

By the end of the 12 month study, outcomes between weekly and monthly ParkinSong™ attendees were effectively the same.

Dr Tamplin hypothesizes that "this may be due to the increased amount of practice by weekly ParkinSong™ participants during the first 3 months.

"Monthly ParkinSong™ participants may 'catch up' over longer time periods, but we need further research to explore this further," she said.

RESEARCH BACKGROUND

The ParkinSong™ research was funded by the Hugh Williamson Foundation, Parkinson's Victoria and The University of Melbourne and La Trobe University.

The research collaboration included staff from The University of Melbourne (research lead Dr Jeanette Tamplin, Prof Felicity Baker and Prof Adam Vogel), La Trobe University (Prof Meg Morris), Parkinson's Victoria (Caterina Marigliani), Monash Health and the Parkinson's community.

INTERESTED IN GIVING IT A GO?

Parkinson's Peer Support Groups, including ParkinSong™, are currently unable to meet face-to-face due to COVID-19 restrictions.

However, if you are interested, we can put you in touch with a leader of one of the eight groups currently operating in Victoria. Call us on 1800 644 189 to find out more.

ParkinSong™ is designed to complement speech pathology therapy intervention, NOT to be a substitute for it.

GOVERNMENT FUNDING FOR PSP CLINICAL TRIAL

A $2.6 million Federal Government grant has been awarded to a national group led by Monash University and the Alfred Hospital to undertake a clinical trial of sodium selenate as a disease-modifying treatment for Progressive Supranuclear Palsy (PSP).

The team includes Monash University research scientist, Dr Lucy Vivash, who is leading the project, together with Director of Neurology at The Alfred, Professor Terry O'Brien and neurologist, Dr Kelly Bertram from The Alfred Movement Disorder Clinic.

PSP is a neurodegenerative condition for which there is currently no cure or disease-modifying treatment.

The pathology of PSP is characterised by the abnormal accumulation of tau proteins in parts of the brain responsible for body and eye movement, speech and some cognitive (thinking) areas, leading to atrophy (brain shrinking) in these regions.

The clinical trial, which is expected to start early next year, will see participants receive sodium selenate or a placebo for 12 months, with researchers looking for a reduction in the tau protein on PET scanning.

The project is one of ten research projects into neurological disorders funded through the Government's Medical Research Future Fund.

Neurological disorders are becoming increasingly prevalent in Australia, accounting for a third of all diseases.

The projects are also supported through the Government's Clinical Trials Activity initiative, designed to help Australian researchers and patients test new treatments through national and international clinical trials.

PARKINDANCE UPDATE

After a temporary halt due to COVID-19 social distancing restrictions, the ParkinDANCE research project is now continuing online.

ParkinDANCE is a two-year, randomised control trial looking at the specific dose of physical activity, in the form of dance, needed to have a positive benefit on the symptoms of Parkinson's.

The collaborative research project with La Trobe University and led by internationally-recognised physiotherapist and researcher, Professor Meg Morris, commenced in February 2019.

Through close collaboration between the research team and Parkinson's Victoria, we are excited to launch online delivery of ParkinDANCE, believed to be the first time an activity-based clinical trial has been delivered online.

It will start with a four week feasibility trial, followed by a 12 week online program.

Lewis Johnstone

Narelle Warren

LET'S TALK ABOUT SEX

A new research project will explore the experiences of sex and relationships for people with Young Onset Parkinson's (YOPD).

The project is being led by Monash University honours student, Lewis Johnstone, who is keen to be part of a growing area of research interest linking anthropology (the study of what makes us human) and disability.

> *"Parkinson's can have significant impact on a patient's sexual wellbeing, but most of the research approaches this problem as an individual medical issue. If it continues to be treated this way, barriers will remain."*

Instead, his research project will look into how social, cultural, economic and geographical factors influence a person's adjustment to sexuality and relationships after a YOPD diagnosis.

The research objectives are to:

- explore the effects of Young Onset Parkinson's on sex and relationships
- describe and analyse how sex is experienced, and if at all, how it is re-framed
- highlight the needs of people worried about impacts on their sexual wellbeing and relationships.

"The potential significance of this research will be in identifying new procedures to approach sex when faced with a YOPD diagnosis, along with possible interventions to help people continue to experience their sexuality, intimacy and sexual relationships," Lewis said.

If you are interested in participating in this project, you will need to be:

- currently aged between 18 – 60 years
- prepared to take part in an hour-long interview (your name will be recorded, but not be made public).

Interviews will be conducted until the end of September.

If you would like to take part, register your interest: **tinyurl.com/ParkinsonsRelationships**

This project is being supervised by Dr Narelle Warren, Senior Lecturer in Anthropology and Sociology in the School of Social Science at Monash University.

Dr Warren has previously been involved in Parkinson's research, as part of a five year study into the everyday challenges faced by people living with Parkinson's and another looking into disease prevalence.

FOCUSING ON DEXTERITY IN PARKINSON'S

If there's a positive to come out of the worldwide coronavirus pandemic, it is the renewed focus on the importance of research.

Every day, dedicated researchers work behind the scenes to try to discover new ways to prevent and cure disease, and improve quality of life for those living with chronic conditions.

The understandable desire for a vaccine for COVID-19 has brought research to the forefront of our minds and reminded us of these 'heroes' striving to make the world a better place.

But research is not only about pharmaceuticals. It goes deeper into ways we can live – things we can do or change – that will improve lives.

Dr Libby Proud is a physiotherapist, University of Melbourne researcher and educator, and member of the Parkinson's Victoria Physiotherapists Special Interest Group. She is particularly interested in how Parkinson's affects hand function and dexterity.

This developed through her involvement with the 3-year, Melbourne-based clinical trial funded by the Michael J Fox Foundation in 2006 that looked into reducing the risk of falls by improving balance using different interventions.

"I was doing assessments for Prof Meg Morris (who led the research) and at that stage, I became very interested by the fact a lot of people I was assessing were having problems with their hand function.

"So that became a particular interest of mine and that's what my PhD research was about - assessing hand function."

Dr Proud was awarded her PHD in 2017, after seven years of working on her research part-time. Her study looked at dexterity (the ability to perform an activity quickly and skillfully with your hands) assessment in Parkinson's.

"People with Parkinson's have problems with dexterity, even in the early stages of Parkinson's. Writing is a common one; doing up buttons, handling coins, those finer hand activities can become a problem."

Dr Proud's research looked at two commonly used peg board tests and their reliability in measuring dexterity in people with Parkinson's, with the results suggesting one type may be more reliable than the other.

Since then, she's had several articles published, including one in April this year in *Disability and Rehabilitation*, an international, multidisciplinary journal that seeks to encourage a better understanding of all aspects of disability, and to promote the rehabilitation process.

The article concluded that people with mild to severely disabling Parkinson's experience dexterity loss and problems with hand function and that it was important for clinicians to assess dexterity and hand function in people with Parkinson's.

This leads to Dr Proud's next stage of research.

"A study I did before the PHD looked at how doing two things at once, dual tasks, affects hand function. People with Parkinson's are more susceptible to problems with their hand function while they are doing something else at the same time.


Dr Libby Proud

"People with Parkinson's will often tell me they have problems dual tasking, like getting things out of a wallet while talking to the person on the checkout or they might be stressed about the people in the queue behind them."

Given there is currently not as much evidence about the benefits of physiotherapy and occupational therapy on hand function and dexterity as there is for walking and balance, Dr Proud and her colleagues are completing a systematic review of the existing research.

"And with help from Parkinson's Victoria, we hope to run a small pilot study in the future, but this has been put on hold because of COVID-19."

This study will look at exercise and training to improve hand function and will involve a training program with monitoring and assessment. Dr Proud and her co-researchers are currently looking at how and when the study could be run if social restrictions continue into the longer term.

KEEP MOVING

In the meantime, as a physiotherapist specialising in Parkinson's, Dr Proud encourages everyone to keep moving.

Research is increasingly pointing to a link between exercise and neuroplasticity (the brain's ability to form new connections and pathways and change how its circuits are wired).

"Exercise is important for everyone but particularly for people with Parkinson's," Dr Proud said.

"People with Parkinson's can have problems with motivation, so that can make it even more difficult, particularly at the moment. The key thing is to find something you enjoy – if you don't enjoy it, you won't sustain it."

At the very least, she recommends getting out for a walk every day for both physical and mental health benefits.

Other tips:

- Take part in one of the many international Parkinson's-specific exercise programs now available online.
- Following a routine can help keep you motivated.
- Book a telehealth physiotherapy appointment. Your physio can give you tips and exercises to do at home. Some are also holding virtual exercise classes.
- If you live by yourself, it may be safer to do seated exercise. If not, use a solid chair or table if you need to hold onto something for balance and have your phone within reach.
- Follow the tips outlined in the May edition of InMotion. You can also find these online: parkinsonsvic.org.au/about-us/media-release/physical-activity-during-covid-19/

27FORPARKINSON'S
COME TOGETHER THIS OCTOBER

Parkinson's Victoria is proud to announce plans for a new online community fundraising event to be held in October.

27forParkinson's is free to join and accessible to everyone, no matter where you live.

A Walk in the Park could not be held this year due to COVID-19 community restrictions – and ongoing uncertainty over when and how people will be able to gather.

"A Walk in the Park is much loved in the community, so we knew it was important to come up with an idea that could still bring people together virtually in a public show of unity and support," Parkinson's Victoria CEO Emma Collin said.

The concept of 27forParkinson's is simple – we want people to get out and move at their own pace, walking 27 times for 27 days in October. The time, location and distance is up to you – taking into account any COVID-19 restrictions in place.

The event will officially start on 1 October.

"COVID-19 has changed the way we live in 2020," said Ms Collin.

"A Parkinson's diagnosis is also life changing. Being resilient, adapting and arming yourself with knowledge is key to living life to the fullest. As is not facing the journey alone."

She said 27forParkinson's will create a sense of togetherness within a community who understand and support each other, which is even more important now in these times of extended social isolation for so many.

The event will also be an important fundraiser.

HELP RAISE FUNDS TO SUPPORT PEOPLE LIVING WITH PARKINSON'S

- **$27** raised provides three people recently diagnosed with an individual information kit
- **$70** raised allows one person living with Parkinson's to receive individual planning and support from our multi-disciplined health team
- **$125** raised allows one person living with Parkinson's to access online education
- **$200** allows one person to participate in the online Living Well with Parkinson's Series
- **$540** establishes two Peer Support Group Online Networking Groups

"Virtual fundraising events such as 27forParkinson's are more important than ever to raise funds to allow us to continue to provide the enhanced level of support required for those living with Parkinson's during these challenging times," Ms Collin said.

It is also poignant that November will mark the 40th anniversary of the creation what is now Parkinson's Victoria.

"Our roots go back to four women with Parkinson's who met at an outpatient group in Melbourne. 27forParkinson's is an example of us continuing their legacy of support by adapting services to meet the changing and growing needs of the Parkinson's community," she said.

EVENT AMBASSADOR

Parkinson's Victoria is proud to welcome John Eren as a 27forParkinson's ambassador. He will join actor Shane Jacobson and Australian Olympian Steve Moneghetti who both pledged their support to the new event.

Mr Eren is the ALP member for Lara and former Minister for Tourism and Major Events. He recently publicly revealed his Parkinson's diagnosis.

Keen to kick-start a conversation about Parkinson's and encourage men to see their doctor if they're not feeling right, Mr Eren is looking forward to being part of 27forParkinson's.

HOW IT WORKS

Visit the event website, **www.27forparkinsons.org.au**, register for free and make a personal commitment to walk 27 times, across 27 days, from 1 to 27 October 2020.

You will be able to create your own online team, join a team or be part of a Parkinson's team and start fundraising.

Once registered, you will also be able to join a special event community Facebook group, where you can share photos and stories to inspire each other.

You'll be provided with online milestone badges, social media resources to share. We will also include some fun theme days to mix things up a bit.

Full details can be found at www.27forparkinsons.org.au but remember, if you have any questions, give us a call on 8809 0400.

CUT OUT THE CALENDAR

27 for Parkinson's

IN THIS TOGETHER
parkinson's
VICTORIA

WALK 27 TIMES IN 27 DAYS

1 - 27 OCTOBER, 2020

Use this calendar to mark off your walks. Be sure to share your progress on social media **#27forParkinsons**

				1 Let's do this!	2	3
4 Tribute day	5	6	7	8	9	10
11 Wear purple day!	12	13	14	15	16 Fundraising Friday	17
18	19	20	21	22	23	24
25	26	27 You did it!				

27FORPARKINSONS.ORG.AU

SUPPORT FOR YOU

A STROKE OF COLOUR

When life can seem grey, it's important to inject hope and light.

And what better way to do that than to highlight some of the beautiful artwork produced by members of Victoria's Painting with Parkinson's groups?

This specialist peer support group network was recently recognised with Berwick Painting with Parkinson's Group leader Anne Atkin (Image 8) awarded for her contribution to Parkinson's by establishing the Painting with Parkinson's program in Victoria (story on Page 4).

Essendon Painting with Parkinson's: Sue enjoys using acrylic paint, painting flowers that mean something to her (Image 1). She likes to create her artwork in her laundry, where she has water and good light. Margaret has been using watercolours to paint Coates Willow which reminds her of the holidays she had in England (Image 2).

Darebin Painting with Parkinson's: Group members have been sharing their art via their new Facebook group page. They include works by Jaffer, created the works entitled Kikombo (Image 3) and Resilience (Image 4). Among the paintings created by Peter have been Postcard from Paris (Image 5) and Sunflower Study (Image 6). Group leader Sarah is a talented illustrator and created this stunning postcard for her daughter (Image 7).

Image 3

Image 1

Image 4

Image 2

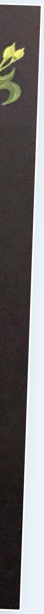
Image 7

Image 5

Image 6

Image 8

Parkinson's Peer Support Groups, including specialist Painting with Parkinson's groups, are currently not meeting face-to-face but are continuing to connect online and via new Facebook groups, and can welcome new participants. Contact us on 1800 644 189 for details.



Grief can be a reaction to events other than death.

LOSS AND GRIEF DURING THE COVID-19 PANDEMIC

The COVID-19 pandemic has forced us to change the way we go about our daily lives. With those changes, some of us are experiencing a wave of losses: economic, social, physical and emotional.

For some, these losses may build up and lead to feelings of grief. It may come as a surprise to realise that grief can be a reaction to events other than death.

Such emotional reactions may include shock, numbness, denial, anger, fear, anxiety, panic and guilt as individuals learn to live with loss.

UNDERSTANDING GRIEF

Ambiguous grief is a loss that occurs without closure or clear understanding and often results in unresolved feelings. The rapidness of our lives changing during the pandemic has caused many to be left with a real sense of unease.

The losses we are experiencing are not typically acknowledged as losses by our friends and families, such as losing our confidence in the future, losing our security that we'll graduate by a specific date or losing our feelings of control over our own lives.

All of these are losses that we may grieve, but we have no rituals or even language to acknowledge them as such.

Anticipatory grief refers to our feelings of grief even before a loss occurs. For example, we may be worried about a very ill family member and already feel that we are grieving them.

Or we may be anticipating even more loss of income and financial insecurity. Even though our worst fears may not come to pass, anticipating them can lead to legitimate feelings of grief.

LOSSES AND COVID-19

COVID-19 has brought dramatic changes to our lives, including many losses, such as:

- **Economic security:** The pandemic has resulted in large unemployment numbers, a fear of further job loss and an economic recession. Self-funded retirees may have had their income affected too.
- **Health:** Fears of contracting COVID-19 have led to increased health risks for the most vulnerable. Of particular note is secondary harm for people who need care but are avoiding hospitals or visiting their doctor. Telehealth has also changed our interaction and made discussing health concerns more difficult.
- **Friends and Peer Groups:** Despite the virtual connections available, for many the inability to connect with friends and family in the same physical space has led to isolation and loneliness. Using technology can also be stressful for some people. Humans need connection.
- **Ceremony/tradition (graduation, funerals, weddings):** The traditional markers for milestones have been cancelled, restricted or moved online. Not being able to participate in these life milestones reduces our sense of connection and removes our capacity to farewell a friend or a loved one.
- **Stability/safety:** The home environment may not feel the same when we are confined to it. Without the normal distractions of life outside home, our relationships are placed under greater strain and pressure, frustrations and anger can occur.
- **Sense of personal freedom:** While physical distancing measures are now a necessity, they may leave individuals feeling disconnected. Wearing face masks can make it harder to be heard when we are speaking and to read people's expressions.

- **Future dreams:** With the turmoil of the pandemic, many have put future plans and hopes on hold. This insecurity about the future can be particularly painful loss.
- **Academic stability:** For parents, grandparents and students alike, the added stress of home-schooling and concerns about impact on their future and employment has created great strain.

WAYS TO COPE

- **Name it.** In naming our feelings as grief, we can begin to understand the underlying emotions it brings and address them. Emotions are not right or wrong. However, we need to recognise that we'll experience such feelings as denial, anger, frustration and sadness, and that we need to feel the depths of our pain in order to work through our grief. Responses to loss and how people experience and express grief vary greatly by individual. It's also important to remember grief is a process, not an event or a race. With support and the willingness to do the difficult work, we can get through it.
- **Validate it.** We need to recognise all feelings and acknowledge them as important without judgement. Suppressing our feelings or feeling guilty for having them doesn't allow us to take steps to resolve them. Encouraging ourselves and those around us to mourn all losses, big and small, is key.
- **Mourn.** To assist in further understanding the difficult journey of grief, Dr. William Worden developed The Four Tasks of Mourning. Again, these are not linear, and everyone's journey is unique. While the tasks were created around mourning the death of an individual, they can also be applied to other loss. They include:
  - to accept the reality of the loss
  - experience and process the pain of grief
  - adjust to the world without the deceased or with the loss
  - find a way to maintain a connection to the deceased/loss, while embarking on your own life.
- **Celebrate the good.** While COVID-19 has brought great uncertainty and loss, we can also find meaning in the good it may have brought into our lives: closer ties, time for reflection, realisation of what is important to us and what our priorities are. Spending time writing in a journal and acknowledging the things for which we're grateful can be a simple yet valuable exercise.
- **Routine.** At a time when life feels particularly chaotic, setting a routine is important and ensures we have a mixture of social, physical and educational activities in our day. Routine doesn't mean rigidity, but it can offer a sense of control.
- **Self-care.** Time constraints still exist. Virtual work, study, child and elder care, and even socialising can result in a hectic schedule. Ensure there's still time for self-care (however that may look). Walking, exercising and meditating are all ways we can be kind to ourselves.
- **Avoid comparing.** It's easy to compare ourselves to individuals who are coping differently with the current situation. Especially when we're already feeling low, it can drain us of our limited energy and can lead to resentment towards others and towards ourselves. Instead, focus on your own strengths and coping strategies. Listing your strengths and issues you have overcome is an effective way of highlighting and celebrating your own ability to cope.
- **Lean on friends/family.** Free applications like Zoom and FaceTime provide a platform for human connection. For those who have developed "Zoom fatigue," a simple phone call may provide that needed human connection.

This information is based on an original article produced by the Canadian Mental Health Association (CMHA), Ontario.

Seek support.

Now more than ever, it's important to reach out and seek the support of professionals.

Parkinson's Victoria's health professionals can listen, help identify concerns and work with you to overcome them or to find pathways to access specific assistance. **Call 1800 644 189**

Black Dog Institute has been running a Settling the Mind: Mental Health and Coronavirus webinar series. Past webinars can be found at: blackdoginstitute.org.au/education-services/webinars/

The Australian Centre for Grief and Bereavement has COVID-19 resources on its website, including a webinar designed for people unable to visit a family member in aged care (see Grief, Bereavement and Coronavirus (COVID-19) under the Bereavement Support tab): grief.org.au

Beyond Blue has a range of coronavirus-specific resources and community forums, as well as a phone support service: coronavirus.beyondblue.org.au/

Lifeline has tips and strategies and access to 24 hour phone support: lifeline.org.au/get-help/information-and-support/covid-19/

SYMPTOM MANAGEMENT

DEALING WITH INCONTINENCE

Did you know Parkinson's can affect bladder control in relation to urgency, frequency, retention and nocturia (the desire to urinate frequently once you are in bed)?

These are related to fluctuations in the level of dopamine affecting the function of the bladder muscle. This also means symptoms may fluctuate depending on your medication level.

Underlying conditions such as weak pelvic floor muscles or an enlarged prostate can also contribute. Constipation can worsen bladder symptoms by putting pressure on the bladder, making the symptoms more apparent.

FREQUENCY

The sensation to pass urine frequently is often accompanied by a feeling of urgency, and commonly only passing a small amount of urine. This symptom can occur day or night and many people living with Parkinson's associate it with "wearing off" (when Parkinson's symptoms occur or worsen between doses of medication).

Developing good medication habits will help and trying pelvic floor exercises may help reduce this symptom.

NOCTURIA

The sensation to pass urine at frequent intervals at night commonly occurs in the first few hours after bed, often affecting sleep. It relates to "wearing off" and blood pressure fluctuations causing fluid retention during the day.

This retained fluid is re-absorbed by the body when we lie down with our feet elevated and is then passed as urine, causing the need to pass urine on several occasions throughout the night.

Discuss this symptom with your doctor. Anti-cholinergic or antimuscarinic medications may improve bladder control, but need to be used with caution as they may worsen Parkinson's symptoms.

A simple way nocturia can be managed is by an afternoon rest, with your feet elevated, allowing some of the excess fluid to be re-absorbed and passed. Other practical ways of managing this symptom include reducing the amount of fluid you drink before bed and avoiding caffeinated drinks after 5pm.

URINARY RETENTION

Developing urinary retention can occur in Parkinson's but is uncommon. It is diagnosed through an ultrasound. Sometimes medications used to assist in managing urgency can cause retention.

If you are affected by urinary retention, your doctor will advise you on management or refer you to a specialist.

NEED TO GO?

Did you know there is an app you can download to locate public toilets? Download the National Public Toilet map: toiletmap.gov.au

WHERE TO GET HELP?

Discuss bladder problems with your GP or neurologist, who may perform some tests to rule out a urinary tract infection, or other problems that may impact on normal bladder function. You may be referred to an Urologist, a doctor who specialises in bladder function.

You can be connected with a Continence Nurse through your local GP, Community Health Centre or Hospital or via the Continence Foundation of Australia website, continence.org.au

As bladder difficulties can be a sign of "wearing off", it is important to take your medication on time, every time, to help reducing fluctuations in medication, therefore helping to reduce bladder difficulties.

Managing constipation and making sure that you have regular bowel movements will also assist in minimising bladder problems.

EXERCISE

Bladder problems in Parkinson's are related to changes in muscle function and the way the brain interprets signals from the bladder.

Pelvic floor exercises will help to improve bladder tone and potentially increase the control you have in the muscles surrounding the bladder neck. Speaking to a physiotherapist or continence nurse can help in developing some pelvic floor exercises specifically for your needs.

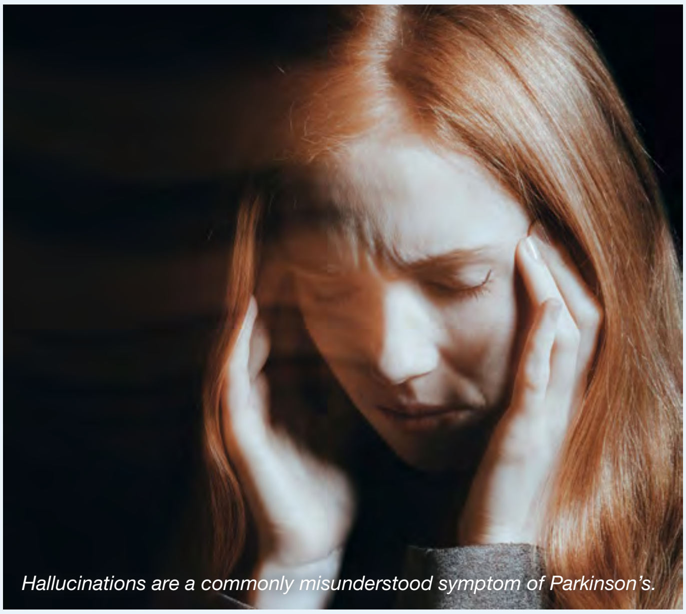
Learn more about pelvic floor exercise: continence.org.au/pages/pelvic-floor-muscle-exercises.html

DEVICES AND AIDS

There are a number of products that can assist managing continence. Some people find it reassuring to wear an incontinence product, particularly if they are away from their homes and are worried they may not be able to get to a toilet in time.

Funding assistance may be available to support the cost of incontinence aids.

The National Continence Helpline 1800 33 00 66 can provide details of the nearest services to you.



Hallucinations are a commonly misunderstood symptom of Parkinson's.

HALLUCINATIONS, DELUSIONS AND COGNITIVE CHANGE IN PARKINSON'S

Seeing, hearing, feeling and smelling things which aren't there can be common when you are living with Parkinson's. Up to 40% of people with Parkinson's may experience hallucinations.

Hallucinations are a commonly misunderstood symptom of Parkinson's, ranging from feelings of a presence, to lifelike and vivid visual hallucinations.

Most people experiencing them have been taking Parkinson's medication for some time, however there have been several studies identifying hallucinations in people not taking any medication.

This symptom is usually slow to evolve and may initially be a visual misinterpretation, eg seeing an image in a patterned wallpaper or carpet. Over time the images become more vivid and can be frightening.

It is important to understand that hallucinations are not a symptom of dementia or psychiatric illness and many people experiencing them are still participating in full lives.

Sleep disturbance, cognitive change and depression all appear to be linked to experiencing hallucinations.

In his review published in *Nature*, Melbourne-based Associate Professor Peter Kempster was able to identify that hallucinations caused significant carer strain and were a trigger for admission to residential care.

While hallucinations are a concerning symptom, and it is not fully understood why they occur, managing symptoms such as depression and poor sleep is likely to reduce their impact. There are some medications that can assist, but which need to be carefully selected by treating neurologists.

DELUSIONS, PARANOIA AND PSYCHOSIS

Like hallucinations, some people living with Parkinson's may experience delusions and psychosis (false fixed beliefs not linked to reality).

Depression, poor sleep and cognitive changes may relate to developing these symptoms, as can experiencing another illness such as an infection or having an anesthetic.

In Parkinson's, common themes of delusions are often of persecution or marital infidelity. The reason why they occur is poorly understood, however like hallucinations they frequently respond to carefully selected atypical antipsychotic medication.

COGNITIVE OR THINKING CHANGES

It is important to recognise that having Parkinson's does not mean you will get dementia. Changes in thinking does occur in Parkinson's and many people experience them early in their condition.

The most common symptom is called "word finding difficulties", which means difficulty in retrieving the word you want to use from your memory. This symptom is often worse when you are tired, or your medication levels are low.

Some people also experience some difficulties with multi-tasking, so performing a complex task becomes more difficult and you may be more prone to making mistakes.

This symptom can intersect with movement and can be associated with freezing in Parkinson's - walking and managing external distractions such as someone talking to you or the visual distraction of moving through a doorway becomes difficult and causes your feet to stop and freeze.

WHERE TO GET HELP

If you have any concerns about your memory or thinking, the first thing you can do is to discuss the symptoms with your neurologist who can test for cognitive changes and consider using medications that may slow memory changes.

Your doctor may also arrange a referral to a Neuropsychologist, a health professional who can conduct an in-depth assessment and provide some strategies to help manage any thinking changes.

To help identify non-motor symptoms, a questionnaire has been developed for people living with Parkinson's to complete. This can be a useful tool to help communicate with your neurologist some of the hidden symptoms you may be experiencing.

There is a link to the questionnaire here: parkinsons.org.uk/professionals/resources/non-motor-symptoms-questionnaire

The Parkinson's Victoria Team can also answer any questions or discuss any concerns you may have about the non-motor symptoms you are experiencing. Call 1800 644 189.

Paul with his mum Debra and wife, Ruby

FOR THE LOVE OF MUM – RAISING AWARENESS OF PSP

Many of us dream about being 'lucky' enough to win Tattslotto. The chances are so slim, but there is chance. But what if those odds are reversed? It's how a PSP diagnosis was described to the Manolitsas family – like winning Tattslotto, but in reverse.

Paul Manolitsas is a passionate young man whose own life, along with that of his parents and two brothers, was changed forever when Mum, Debra, was diagnosed with PSP in 2015.

Debra, who had raised three sons and dedicated herself to the care of others as a nurse, was referred to a neurologist after experiencing multiple, unexplained falls. A series of scans found nothing abnormal, but "things were still not right" and a second opinion was sought.

Debra was then referred to a Movement Disorder Specialist at the Alfred Hospital.

"The neurologist had written a letter to the MD specialist and Mum had brought it home. I remember it quite profoundly – she read it and obviously the neurologist had a suspicion of PSP.

"At that stage Mum hadn't been told about what it could or could not be, but the power of the internet, looking things up, it was quite shocking to her.

"She shared the letter with me – it was quite a confronting thing to read. A couple of days later she was diagnosed. There was an element of fear of what's to come."

Paul was living with his parents until he moved to Sydney in December last year.

"It's one of those things that no-one thinks will happen to them, or to someone who they care about, but when it does its one of those life-changing things, everything pivots on a dime and you just have to adapt."

Paul's Dad, Andrew, is Debra's primary carer, and Paul is also keen to make sure he also gets the support he needs.

"Because PSP is such a rare condition and there's not a whole lot known about it in the community compared to MND, I think there's been a mixed bag in the level of psychological and emotional support," Paul said.

COVID-19 has thrown an extra layer of difficulty, watching his parents cope from afar, although Paul said telehealth was the one positive, removing a lot of the need to travel.

"It's definitely concerning, particularly with a neurological condition like PSP, where people are susceptible to respiratory illnesses. Mum has difficulty eating and swallowing so any upper respiratory tract infection is not ideal.

"Where possible mum will stay home 99.9% of the time. Dad is able to go shopping and my youngest brother is still at home with them.

"It has been difficult being in Sydney and away from it; there is nothing like a coronavirus to give you some perspective on life and what is important, particularly when dealing with unwell family members."

He is also keen to promote awareness of PSP and raise funds for the support Parkinson's Victoria provides. This follows on from raising just over $2000 last year, when he linked fundraising to a Himalayan trek in October.

"We were going to do the trek anyway. We had booked it, then as the year went on and Mum's condition worsened, we thought about how we could try and bring some awareness to PSP, so we blended the two together."

Paul said it was difficult to describe PSP to people, and the level of emotional support it requires.

"It's a disease not a lot of people know about and when you speak about it, you have to explain that it's similar to MND but a bit different – it's got a similar prognosis, but different," he said.

Paul said while search for a cure was important, so too was providing support for those living with the condition.

"That was one of the reasons why we tried to look at supporting some of the important work Parkinson's Victoria do."

When he is able to, Paul is also keen to continue combining his love of adventure with fundraising and awareness of the debilitating condition that is taking away his Mum's ability to talk and walk.

"One of thing things Mum said to me after she got diagnosed and was starting to really progress, was that one of her biggest regrets is not doing more, so she is very encouraging of Ruby and I travelling and doing as much as possible while we can."

Paul used a trek to the Himalayas to raise money for, and awareness of, PSP.

PERSONAL STORY

Professor David Blacker is a neurologist from Western Australia. He recently documented his experience of being diagnosed with Parkinson's.

I could feel Parkinson's creeping up on me, so when I finally summoned up the courage to have a colleague assess me and make the diagnosis, it was of no surprise; in fact, it was almost a relief.

In my mid-30s, I had taken up long-distance running, mainly to shed the weight I'd stacked on during training and fellowship years. About 10 years later, I developed a gait disturbance, manifesting as an exercise-induced dystonia in my leg.

Initially, it appeared only after running a significant distance, but gradually it became more problematic, eventually leading me to stop participating in competitive events. My leg would spasm, twist and generally tighten up. I knew it was dystonia but told others it was just cramp or a 'hip problem'; that was easier than explaining what this could become.

I was otherwise fine and made a concerted effort to keep fit and to continue exercise as best I could. I also abandoned plans to reduce my caffeine intake given the possibility of this being neuroprotective in Parkinson's. Sadly, my sense of olfaction became impaired, so the great pleasure of the aroma of coffee was lost.

Within a few years though, other symptoms emerged, including a tremor of my right hand and leg. The first time it caused a problem was at a national conference when I stood to ask a question, and with the nervousness my hand and leg trembled. I don't think it was visible to others, but I sat quickly, shocked to realise that symptoms were making an impact.

Gradually and pervasively, more tasks became difficult. My handwriting was clearly shrinking and at work that was causing problems. The striking issue though, was bradykinesia; when demonstrating rapid alternating movements and finger tapping to patients, it was clear that my dominant hand was inferior, and seemingly becoming slower each month.

It became obvious to me that some of my Parkinson's patients were performing better than me. What really started to bother me was the impact on my ability to play golf. Generating club head speed was difficult, again related to bradykinesia. Simply walking the course was becoming a challenge, and getting a tee out of my pocket and placing the ball on it was becoming difficult.

Dr Blacker is Medical Director at the Perron Institute for Neurological and Translational Science and a member (and former Chair) of the Neurosciences Advisory Group to the WA Department of Health. This article was original produced in Practical Neurology. Dr Blacker was also interviewed for World Brain Day 2020. Watch his video: wfneurology.org/world-brain-day-2020

> *I have shared my own experience with several new patients with Parkinson's, and this has been extremely powerful and positive. The experience has deepened and enriched my understanding of the doctor–patient relationship, and I hope it has helped me to become a better neurologist.*

So it was clear that it was time to get onto treatment and that I should have a proper assessment and diagnosis. I spent some time thinking about whom I should consult. I chose a respected colleague who worked in another hospital on the other side of the city. I obtained an MR scan of my brain before this and was struck by how normal it looked. I remember staring at the images, frustrated that the structure looked so normal, but the function was not.

My colleague was kind, sensitive and caring, and agreed completely with the diagnosis. Straight on to L-dopa was the plan; no fiddling around with a dopamine agonist.

I filled the script for Madopar the next day and took the first tablet late that afternoon. I remember tapping my right hand and fingers to test for a response; 45 min after the dose, I could feel it working.

I was almost shocked to feel this. For some reason, my expectations were low, so I felt encouraged. Over the next few days, I started to take it regularly. What I wasn't prepared for was the nausea. The worst part was the worry that this might continue. Thankfully, with time this passed and I've continued to have an excellent symptomic response.

Shortly after the confirmation of diagnosis and start of treatment, I revealed the diagnosis to my colleagues.

In a way, there was a sense of relief with 'coming out'; I hadn't realised how much energy I was expending hiding my symptoms. I was also tired of misleading friends and colleagues with my story about a bad hip being the cause of my gait issues; it had just seemed easier at the time.

Some people reacted with strong emotion, which was quite uncomfortable and made me cautious about timing future disclosures. I also revealed the diagnosis to selected patients; some of whom had already astutely suspected something was wrong with me.

I had to deal with a range of logistical issues that come with many neurological diagnoses. The mandatory driving reporting, insurance issues and my medical registration. All of these needed documents and had stressful elements. I developed a new-found appreciation of how important the clinician's prompt attention to these things is.

My subspecialty in neurology is stroke, but I've always done general neurology as well, and have a steady stream of Parkinson's patients. I now feel much more confident with the early diagnosis and management, and have a much greater insight into the condition.

COMMUNITY FUNDRAISING

Meg raised $300 for Parkinson's Victoria buy selling off some of her Mum's vintage clothing.

KEEPING MUM

By Meg Gannon

My mother Mary had Parkinson's and spent her final years in a nursing home in my hometown of Colac.

She had always been fiercely independent and stylish; in a former life, she'd spent the 1960s and 70s working as a nurse and travelling the world… and not thinking twice about spending a week's wages on a pair of designer shoes.

She died in October last year and clearing out her wardrobes (yes, plural) was, in my mind, easily the most important and complicated task.

I inherited Mum's aversion to throwing anything out, especially vintage clothes and accessories. Sadly, I didn't inherit her petite proportions so there was no way my size 11 feet would ever fit into her shoes, unless some toes were amputated.

Enter COVID-19. In April this year I was back living in the country, but with no caregiving responsibilities, just all the time in the world to go through Mum's stuff. It was a joy, actually - I called it 'mindful' sorting or 'slow' decluttering.

It was bittersweet sorting through all her Italian leather shoes, handbags and accessories that had been meticulously preserved, some for decades, which deserved to be worn and admired for many years to come.

I couldn't take anything to charity shops - they were all shut - and garage sales and family get-togethers were out of the question. So I launched an online project to re-home some of Mum's things via my website, *Keeping Mum*.

Keeping Mum is a community project and podcast that explores the often-invisible experience of being a carer - which can be especially isolating when you're in your 30s, like me.

> *When you're navigating Parkinson's and aged care on behalf of your loved one, having a network of people who can support you, share a laugh or commiserate with, can be crucial for feeling seen and supported.*

Meg and her mum, Mary.

Keeping Mum's 'Covid care packages' have been a hit - and not just because they're an excuse to offload some of the 'treasures' I've found cleaning out the linen press (regardless of whether you rehome some shoes, gloves or a handbag, chances are you'll get some doilies too).

It turns out, when you're in lock-down and working from home, having the postie deliver a parcel to you is the grown up's version of garbage truck day, i.e. highlight of the week.

Best of all, my customers' generosity to support this project has helped fundraise for Parkinson's Victoria, which provided amazing resources to Mum and her nurses in her final years.

I'm thrilled we could return the favour with this effort. And, honestly, thrilled it provided an excuse to make a novelty cheque, since coronavirus has kept us house-bound in Colac.

To find out more about the project (especially if you fit a size 38-39 shoe!), follow @KeepingMum_network on Instagram or visit keepingmum.net

We thank Meg for including us in her heart-warming project honouring her Mum.

Her COVID-care package is an example of the unique ways people are helping to raise valuable funds to provide ongoing support for people with Parkinson's around Victoria.

If you have a fundraising project, be sure to let us know by calling 8809 0400.

HAIR TODAY, GONE TOMORROW

Personal trainer and myotherapist Ambrose Swindon has again shown his support for Parkinson's, turning a dare to shave off his receding locks into a fundraising opportunity for Parkinson's Victoria.

It's not the first time Ambrose has raised money for Parkinson's. In 2018, in the lead up to running the New York City Marathon, he used his training regime and a charity boot camp to raise $3000.

"I've had a strong connection with Parkinson's Victoria due to a close client/friend having the condition and seeing first hand the challenges it presents," Ambrose said.

This time around, it was over some drinks with friends that the suggestion was raised that it was time for Ambrose to "shave the receding cranium".

"They knew how much I've valued my hair but after much debate, I declared I would shave it if they donated to a charity close to my heart, Parkinson's Victoria.

"On the back of this I did a reverse charity campaign, where the actual event had already taken place but encouraged donations, which was well received."

Thanks to Ambrose, his friends and clients, another $4100 has been raised to help support Victorians living with Parkinson's!

SHINING A LIGHT FOR NONNO

As Kate Lentini launched a new business in July, she decided to do something to incorporate the memory of her Nonno Johnny, who passed away aged 87 in 2015 after a Parkinson's diagnosis five years prior.

Kate was doing her Year 12 studies when she lost her beloved grandfather. She wanted to know more about the condition.

"I googled 'Parkinson's' to try and learn about what had happened and what we could have done differently when I came across A Walk in the Park. I committed to doing the walk every single year in memory of him," Kate said.

"My Dad Santo and I have done the walk every year since 2016."

My main goal is to keep his name alive and for him to be remembered for what he did for our family.

However, with the walk not able to be held this year due to COVID-19 social restrictions, Kate wanted to find another way to raise money for the cause that is close to her heart.

So, she decided to make and sell candles, with $5 from every candle sold between 18 July and 27 August - the time she would normally be fundraising for A Walk in the Park - donated to Parkinson's Victoria.

In the first two days alone, she sold 56 candles, so Santo, mum Maria, her sisters Julia and Lisa, and partner Nicholas, joined in production to meet the demand.

The candle is a way to keep a light shining for Nonno Johnny – and to also give something back to those who have supported her.

"When we travel to Italy, the first thing you do when you go there is visit a church and light a candle in memory of someone," Kate said.

Kate with her much-loved Nonno Johnny.

"Asking people to donate is also tough, especially in COVID times, and I didn't want to ask family and friends, who have already donated so much to our family and Parkinson's, so figured I could do something else that could also give back to them."

Although this fundraiser has officially ended, Kate has kindly offered to extend it for readers of InMotion until 27 September.

Use the exclusive code, InMotion5 when purchasing your candle and $5 will be donated to Parkinson's Victoria.

See scentimentalcandlesau.com

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NOMINATIONS SOUGHT FOR PARKINSON'S VICTORIA AWARDS

Each year, Parkinson's Victoria recognises the significant contribution members of the community make in supporting people living with Parkinson's and their families.

Our annual awards program recognises the services of both individuals and groups for their contribution to activities, years of services and outstanding commitment to the Parkinson's community. If you would like to see an individual or group acknowledged for their service to your local community or the wider Parkinson's community, why not nominate them for a Parkinson's Victoria Recognition Award?

It may be a support group leader, local business supporter, a health care professional or anyone who has shown outstanding support.

The following awards are open to nominations:

Sir Zelman Cowen Award: This award, the highest honour available, is presented annually to an individual, recognising their outstanding service to Parkinson's Victoria and services to people living with Parkinson's.

Harold Waldron Carer's Award: This new award will honour a family member or friend who has been touched by Parkinson's and has made a significant difference to the Parkinson's community.

Honorary Life Membership: Recognises outstanding service, normally over a period of at least 15 years.

Five, Ten and Fifteen Year Services Awards: Recognises the continuous service of volunteers in an administrative, project or service capacity.

Community Recognition Award: Recognises the significant contribution of an individual or an organisation to events or activities.

Nominations close on 20 September, 2020.

For information and nomination forms, see parkinsonsvic.org.au/about-us/media-release/awards/ or call us on 8809 0400.

Awards will be announced at the Parkinson's Victoria AGM in November.

UPCOMING EVENTS

In line with Victorian Government COVID-19 restrictions, Parkinson's Victoria has suspended all face-to-face events. However, a number of online events are being held.

DATE	NAME	EVENT DETAILS	WEBSITE
2 – 30 September	**Living Well with Parkinson's**	This online, interactive seminar series continues every Wednesday in September.	parkinsons.org.au/events
Thursday 10 September	**Atypical Parkinson's Peer Support Group**	Now meeting online	parkinsonsvic.org.au/atypical
Thursday 8 October	**Maurice Blackburn webinar series**	Wills & Delegated Decision Making	parkinsonsvic.org.au/events
Thursday 15 October	**Maurice Blackburn webinar series**	Super and Insurance	parkinsonsvic.org.au/events
Thursday 22 October	**Maurice Blackburn webinar series**	Advanced Care Planning	parkinsonsvic.org.au/events
Thursday 29 October	**Maurice Blackburn webinar series**	Employment Rights	parkinsonsvic.org.au/events
1 – 27 October	**27forParkinson's**	Join us for this online community event and fundraiser to support people with Parkinson's	27forparkinsons.org.au
Friday 27 November	**Annual General Meeting**	Join us online for the AGM	TBC