

STANDBYME

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From the CEO

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

We're close to the end of the year already and this issue has some articles particularly relevant to the Festive Season that is almost upon us.

There are tips on how to get the most from your exercise routine (which we all need to do following Festive feasting).

There is also information on how to manage stress and anxiety over the holiday period when routines change and you may find yourself amid large crowds and unfamiliar places.

We provide updates on the latest research and report on our intensive advocacy campaign to communicate the importance of increased funding for Parkinson's at all levels of Government.

Looking ahead, we will be launching a new series of first-person articles on individual experiences with Deep Brain Stimulation (DBS) surgery. DBS is a topic of great interest to many people with advanced Parkinson's symptoms; however, it is a treatment not a cure.

We thought sharing the experiences of individuals with DBS would help to explain the decision-making process, and highlight the various degrees of success of this treatment.

All the best for the Festive Season to you and your family from myself and the Parkinson's NSW family.

Jo-Anne Reeves
Chief Executive Officer



Events & Education

Want to register or learn more about events and education seminars?

Make a free call to the Parkinson's NSW InfoLine: 1800 644 189

What's On

3 December: Parkinson's Education Seminar in Five Dock at Canada Bay Club

Information for people living with Parkinson's, family members, carers and other interested parties

April 2020: Parkinson's Awareness Month

11 April 2020: World Parkinson's Day

Seminars

Seminars will resume in the first quarter of 2020 and will be announced in our publications InTouch and Stand by Me, as well as on our web site and social media.

Want to be first in line for upcoming events and news? Stay up to date by signing up to our mailing list and have updates delivered to your inbox. .

Sign up on our website www.parkinsonsnsw.org.au/ subscribe so we can direct you to seminars and events in your area and keep you informed of the latest news and breakthroughs.

Parkinson's NSW does not share or sell your contact details to any other not-for-profits or marketing organisations.

You can view our full Privacy Policy here: www.parkinsonsnsw.org.au/privacy-statement

If you have questions about your privacy and how your information is used, make a free call to the Parkinson's NSW InfoLine: 1800 644 189.

Have you changed your email address recently? Head to our website and sign up using your new email address so you don't miss out on the latest news www.parkinsonsnsw.org.au/subscribe

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Managing anxiety during the Festive Season

The Festive Season is a time of joy and celebration for Australia's multiple cultures and religions.

However, it can also be a time of stress and anxiety.

Over December and January your usual routines will probably change as you host family members, mingle with neighbours, meet new people, and catch up with old friends who you haven't seen for a while.

Some people might not be aware that you are living with Parkinson's. Others may know yet be surprised by how your Parkinson's symptoms have progressed since last you met.

Anxiety and depression are part and parcel of Parkinson's for up to 40 percent of people living with the disease. Situational factors can add additional stress.

Some common symptoms of anxiety include:

- Hot and cold flushes
- Racing heart
- Tightening of the chest
- Snowballing worries
- Obsessive thinking
- Compulsive behaviour.

Depression is more serious than feeling sad, moody or low from time to time – we all experience that. Depression is when you experience these feelings intensely for long periods of time – weeks, months or even years.

Some people living with Parkinson's also have anxiety related to the 'on/off' state of their motor symptoms. When 'off' and less able to move well, they may experience symptoms of anxiety – and even panic attacks.

So, what can you do for yourself during the Festive Season to avoid or manage anxiety and depression?

- Since this time of year can bring up tensions with family, it is a good idea to have a plan in mind for how you will manage your feelings of anxiety.
- Plan to take time out for sleep or simply resting in a quiet room.
- If you have a high tension, high conflict family situation, arrange with your carer to go out somewhere for the main festive meal rather than have it at home.

If having it at home is unavoidable, make sure you have a private space you can go to take a break from the tension.

- Drink only moderate amounts of alcohol, particularly if it's a hot day. Alcohol is dehydrating. It's a good idea to drink two glasses of water in between glasses of alcohol.
- If Christmas brings up painful feelings that you are struggling with, make sure you reach out. There are free services like Lifeline that are available 24 hours.

Lifeline phone: 13 11 14

Grounding exercise for coping with worry or anxiety

Take a breath and look around you

5

things you can see

4

things you can touch

3

things you can hear

2

things you can smell

1

thing you can taste

Resources

Parkinson's NSW InfoLine Tel:1800 644 189; US National Parkinson's Foundation <https://www.parkinson.org/>;
Parkinson's Disease Society UK <https://www.parkinsons.org.uk/>; beyond blue <https://www.beyondblue.org.au/>

Nurse research delivers positive results

Research into the strategy and value of the Parkinson's Specialist Nurses model commissioned by Parkinson's NSW has delivered hard data to support this approach to supporting people living with Parkinson's in their own communities.

It established that Parkinson's Specialist Nurses can function effectively as part of a multidisciplinary team to deliver support across multiple settings – including home, clinics, hospitals and residential aged care facilities.

The research project also provided evidence that this nursing model will result in significant savings for NSW Health by reducing the length of hospital stays required for people living with Parkinson's.

The School of Nursing, Midwifery & Indigenous Health of Charles Sturt University undertook the research project for Parkinson's NSW over a two-year period.

First Phase

Phase 1 of the project was an integrative literature review that began in late 2017 and was completed in April 2018.

Evidence was found that nurse-led management strategies and therapeutic measures that minimise disease progression and maximise quality of life should help to contain acute and residential care costs, and expenses arising from changes related to disease progression.

It was also determined that it is important to link quality and effectiveness of service progression to consistent measures – for both people living with Parkinson's and carers.

Measures of sustainability are also an important consideration for recruitment and retention strategies for rural and remote nurses.

Second Phase

The second phase of research began in May 2018. Its intent was to collect data that would enable two different nursing models to be compared and contrasted – the Public Health Network model in Shoalhaven and the Local Health District model in Mid North Coast.

Since the Shoalhaven model did not involve the Parkinson's Specialist Nurse being embedded in the Local Health District, there was found to be a lack of electronic records available to provide qualitative data for analysis.

In the Mid North Coast Local Health District model, there were extensive electronic files available for evaluation. The decision was then made to focus on the Mid North Coast community as the prime source of quantitative data.

Key Benefits of Parkinson's Specialist Nurses

Consumers and carers identified the following key benefits of Parkinson's Specialist Nurses:

- Accessibility and availability whether at home, in a nursing home, in hospital or via telephone
- Able to act as a single point of contact with the expertise to assess and solve problems
- Able to act as the bridge between the GP, neurologist and the hospital
- Has knowledge of Parkinson's disease and the provision of disease-specific education around medications, symptom management, and treatments
- Able to develop healthcare plans and coordinate access to services and supports
- Able to provide psychosocial support to consumers and carers
- Can take on the role of advocates and raise awareness of Parkinson's in the community
- Point of engagement with Parkinson's Support Groups

Health professionals identified the benefits of Parkinson's Specialist Nurses as:

- Improving the quality of care and clinical outcomes for people living with Parkinson's through the implementation of best practice guidelines
- Fulfilling advocacy and leadership roles
- Raising awareness of Parkinson's among health care professionals
- Engaging and working collaboratively with clinicians across the healthcare system.

Impact of Parkinson's on the community

Parkinson's does not just impact individuals, their carers and families – it also places a significant burden on Australian society as a whole.

Parkinson's is the second most common age-related neurodegenerative disease after dementia with age being the greatest risk factor for developing it.

Research by Deloitte Access Economics indicates that Parkinson's is more prevalent than many common cancers in Australians over the age of 50 – including prostate, breast, colorectal, and lung cancers.

However, despite cancers being declared a National Health Priority Area (NHPA) for Federal and State Governments, Parkinson's is not.

The prevalence of Parkinson's increases by a factor of three after the age of 65. The growth rate in the number of people living with this illness is expected to increase dramatically as the Australian population ages.

It is estimated that the average growth rate in Parkinson's will be 40 percent over the next 20 years, compared with a general population growth rate of just over one percent.

Deloitte Access Economics research in 2015 estimated the prevalence of Parkinson's in Australia was 84,000 people.

However, 2018 research by a joint Monash University and University of Melbourne team boosted that estimate to 212,000 Australians – and it is expected to grow by 79 percent through to 2034.

Based on this latest research, the number of people living with Parkinson's in NSW is estimated as 63,750.

Parkinson's is one of Australia's most burdensome economic and social chronic illnesses now, and this burden will increase over the decades to come.



More than
200,000
people in Australia are affected
by Parkinson's



1 in 5
people living with Parkinson's are
of working age



Prevalence of Parkinson's is higher
than prostate, breast, colorectal
and lung cancers combined.



\$160,000
average lifetime financial cost for someone
living with Parkinson's for 12 years.



63,750
estimated number of people
living with Parkinson's in NSW

Consider a Personal Trainer for Parkinson's exercise

The benefits of exercise for the general population are well recognised. They include preventing heart disease, reducing the risk of chronic illness, decreasing stress and generally boosting wellbeing.

However, people living with Parkinson's benefit far more from exercise than the average person in the street. Specific benefits for the Parkinson's community include:

- Improved overall quality of life
- Reduced speed of disease progression
- Improved muscle control (dyskinesia and freezing) making you stronger and reducing cramping and pain
- Reduced social isolation
- Improved management of constipation and bladder control
- Improved bradykinesia (slow movement)
- Reduced tremor
- Improved mobility and flexibility of rigid muscles
- Improve posture (the Parkinson's stoop)
- Improved physical stability and balance
- Reduce automatic movements
- Improved speech and throat muscles – which in turn improves eating, swallowing and spoken communication
- Slows handwriting changes
- Enhanced efficacy of Levodopa therapy
- Reduced fatigue
- Improved management of gait disturbances
- Improved cognitive function
- Reduced depression, anxiety, apathy, and emotional changes

All exercise is good, but working with a Parkinson's-experienced Personal Trainer will tailor and maximise its benefits.

Resources

FJ Penedo, JR Dahn, Exercise and well-being: a review of mental and physical health benefits associated with physical activity. *Current opinion in psychiatry*, 2005; DER Warburton, CW Nicol, SSD Bredin, Health benefits of physical activity: the evidence 2006, Canadian Medical Association; <https://www.webmd.com/fitness-exercise/ss/slideshow-exercise>; <https://parkinsonsdisease.net/treatment/exercise/>; <https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-20376055>; <https://fitness.edu.au/15-benefits-personal-trainer/>; <https://www.livestrong.com/article/401290-what-does-a-personal-trainer-do/>; <https://vitals.lifehacker.com/the-real-benefits-to-hiring-a-personal-trainer-1729693042>

An educated and experienced trainer will help to motivate you, maximise the effectiveness of each exercise and reduce risk of injury. They will work with you to develop a personalised exercise plan to meet your personal goals, and then ensure your exercise is fun, varied, engaging and challenging.

Going after achievable, small goals and then working up to larger goals will give you a sense of pride and progress in what you are doing. A trainer can also help you manage your time better – enabling more exercises in a shorter period of time to fit in with your busy life.

Most convincing of all: Research evidence has shown that people living with Parkinson's who exercise with a trainer derive more benefits than those who don't.

Parkinson's NSW has a qualified and Parkinson's experienced Exercise Physiologist on staff who is also a Personal Trainer.

She can provide advice over the phone, set up and lead Parkinson's exercise groups and provide individual Personal Training in Sydney.

Want to know more about the benefits of exercise for people living with Parkinson's, and the added value that an experienced Personal Trainer can bring?

Phone the Parkinson's NSW InfoLine: 1800 644 189



Advocacy for increased Parkinson's funding

More than 16 percent of the population of NSW is over 65 and by 2030 more than 1.8 million people in NSW will be 65 or older.

The growth of this age demographic – along with the unmet needs of people living with Parkinson's in regional and rural communities – are driving an intense advocacy campaign headed by Parkinson's NSW President David Veness and CEO Jo-Anne Reeves.

The campaign began late last year with letters sent to more than 120 Members of Parliament across NSW, backed by Support Groups which volunteered to reach out to local MPs and media in their communities.

This year the focus has been on meetings with senior Government officials including the Deputy Prime Minister, State and Federal Health Ministers, the NSW Minister for Families, Communities and Disability Services, and the Senior Policy Advisor of the Premier of NSW.

"Our consistent message is that Parkinson's is underfunded when compared with the money allocated for other chronic illnesses," said Jo-Anne Reeves, CEO of Parkinson's NSW.

"Parkinson's is more prevalent than many common cancers combined, yet we are allocated funding that is just a fraction of what is given to breast cancer alone. It is clear the current support for Parkinson's is way out of line with other NSW Health priorities.

"We aim to change that through persistent advocacy supported by the outcomes of research by Charles Sturt University that validates the community-based Parkinson's Specialist Nurse Model."

In addition to working with willing Support Groups on this campaign, Parkinson's NSW is in discussions with the Country Women's Association to obtain its support and influence on this urgent healthcare funding issue.

How to improve your handwriting

People living with Parkinson's have difficulty in controlling movement because of chemical changes taking place in their brains.

This can make fine motor skills like writing more difficult. As a result, their handwriting can look small and cramped.

The medical term for this is Micrographia which literally means 'small handwriting'. Individual letters tend to be smaller than normal, and words are closely spaced.

Some tips on resolving handwriting include:

- Chose a good, easy flowing pen- one that glides over the paper
- Use an accessory pen grip (a round or triangular shape that slips over the pen) or a larger size pen to keep your hand more relaxed
- Use a clipboard or non-slip mat to prevent the paper from slipping
- Practice your handwriting using lined paper.

When writing, think BIG and concentrate on the size and form of each letter.

Focus on one letter or word at a time and write short sentences.

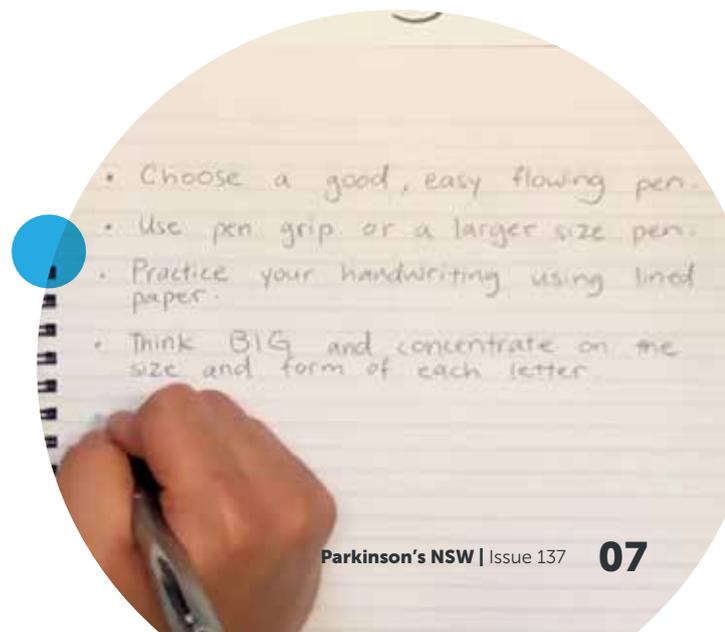
It is important to consciously think about your letter size and the words or letters before you write them. Plan bigger, spaced out letters

After writing a line, stop, relax and breathe deeply. Stretch using wide arm movements and then recommence writing.

Practice helps. Remind yourself to slow down, aim BIG and pause often!

To learn more about improving your writing:

- Download the handy guide from the Parkinson's NSW website www.parkinsonsnsw.org.au/living-well-with-parkinsons
- Watch the video on Youtube https://youtu.be/0bGP6sz_LHw
- Phone the Parkinson's NSW InfoLine: 1800 644 189



Help us connect people like Martin to life-changing services

Martin was in his early 60s and looking forward to an active retirement of cycling, traveling, sailing, and spending time with his wife and two sons. Then he found out he had Parkinson's.

Living with an incurable and degenerative condition changed everything.

"I find it very hard to walk," Martin said. "I have balance problems and I'm just so tired all the time. I can have dreadful nights where my legs are shaking, and my arms are twitching so much I just can't sleep."

Martin called the Parkinson's NSW InfoLine which is staffed by experienced health professionals who can connect you with the Parkinson's services and support you need.

The InfoLine team referred Martin and his wife Andrea to our NDIS Nurse Advocate, Margi Edmondson in the Parkinson's NSW Connect team.

She was able to guide the couple through the complex application process for funding from the National Disability Insurance Scheme (NDIS)

Obtaining this funding made possible a range of services to improve Martin's health and quality of life – including speech therapy, occupational therapy, physiotherapy and massage. These were services he had previously been trying to fund out of his diminishing retirement nest egg.

"Parkinson's NSW has taken a huge weight off both of our shoulders," said Andrea. "The treatments Martin's getting have increased his independence and that's really important, and he's feeling better in himself,"

This is just one of the success stories brought about by the Parkinson's NSW InfoLine and Connect Team – all made possible by generous donors like you.



parkinson's
NSW

IN THIS TOGETHER

YES, I would like to help improve the lives of people living with Parkinson's and their families...

Title: _____ First Name: _____ Last Name: _____

Address: _____

Email: _____ Phone: _____

Please accept my donation of the following amount:

\$15 \$30 \$50 Other \$ _____

I would like to make a monthly donation of \$ _____ (\$15 minimum)
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below) Visa Mastercard American Express

Card number _____

Name on card _____

Signature _____

Exp date _____

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

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