

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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From the CEO

Welcome to the Spring Edition of *Stand by Me*.

In my message in the Winter edition of this magazine, we talked about a reception held for us at NSW Parliament House to raise awareness of the need for increased Government funding for more Parkinson's Specialist Nurses.

At the time I expressed optimism that our message had been heard, and so it was.

Since then, the NSW Treasurer has announced that the 2021-22 NSW State Budget includes an \$8.6 million package to support people living with movement disorders – including Parkinson's – over the next four years.

While we are grateful for the promise of increased funding, we have reservations about the nursing model proposed by NSW Health and how the funding will be disbursed.

Therefore advocacy and negotiations are ongoing as we strongly put the case for a model based on the successful, well-established partnerships between Parkinson's NSW and Local Health Districts (LHDs) in several areas of NSW.

On the subject of advocacy, I am delighted to welcome John Watkins AM, former Deputy Premier of NSW, who is living with Parkinson's, to the Board of Parkinson's NSW. He will be a wonderful advocate for our cause.

John brings to our organisation the respect and experience gained during his political career, plus an impressive list of accomplishments in his post political life – including stints as CEO of Alzheimer's Australia NSW and on the Boards of major not-for-profit healthcare and aged care organisations.

In addition to this good news, this Spring Edition of *Stand by Me* includes a mix of articles on exercise, stress management, dealing with grief and the experience of living with Parkinson's in a rural area.

Jo-Anne Reeves
Chief Executive Officer



John Watkins AM joins Board of Parkinson's NSW

Former Deputy Premier of NSW John Watkins, AM – who is living with Parkinson's – has been appointed to the Board of Parkinson's NSW.

"John is highly respected in both the political and not-for-profit spheres," said Margaret Scott, President of Parkinson's NSW.

"His career in the NSW State Government spanned six Ministerial portfolios and culminated in his appointment as Deputy Premier in 2005. Following his retirement from politics, he became CEO of Alzheimer's Australia NSW for nine years and subsequently held an extensive range of non-executive director roles on the Boards of not-for-profit healthcare and international aid organisations.

"John's expertise will be invaluable to the Board in advocacy, as well as health and aged care policy and planning," said Margaret.

In 2015, John was announced as a Member of the Order of Australia (AM) in the Queen's Birthday Honours List for his significant service to the community through leadership in health, education, and the Parliament of NSW.

John also was an Australia Day Ambassador from 2011 to 2017 and was awarded an Honorary Doctorate by Macquarie University for his services to the community.

His previous not-for-profit Board experience includes:

- Chair of the Board of the Little Company of Mary Health Care Ltd (Calvary Health) which is one of Australia's largest not-for-profit healthcare providers, responsible of over 20 public and private hospitals, aged care institutions and extensive community care services.
- Chair of the Catholic Health Australia Board, which represents all Catholic hospitals and aged care providers in Australia
- Member of the Council of the Australian Healthcare and Hospitals Association
- Member of the Governing Council of Neuroscience Research Australia (NeuRA)

Macquarie Hospital Building 17
51 Wicks Road
North Ryde NSW 2113
1800 644 189

pns@parkinsonsnsw.org.au
www.parkinsonsnsw.org.au
www.facebook.com/parkinsonsnsw
www.instagram.com/parkinsons_nsw

Parkinson's NSW applies to become Aged Care service provider

Parkinson's NSW is working through the complex process of registering to become an Approved Provider of Parkinson's-specific support services under the Commonwealth subsidised Aged Care system.

"The recommendations of the Royal Commission into Aged Care Quality and Safety are very clear about encouraging people to live at home for as long as possible, delivering flexible care services that follow people as they transition in and out of hospital and aged care, and building capacity in the sector," said Jo-Anne Reeves, CEO of Parkinson's NSW.

"We support an ageing cohort of people living with Parkinson's so the changes in the sector provide us with a unique opportunity to leverage our experience to deliver the services our community requires under subsidised Aged Care programs."

The Aged Care system aims to give consumers more choice, power, and control over their support – including the ability to mix and match services from different providers with special expertise in certain areas, such as Parkinson's NSW.

"Our organisation will not enter the Residential Aged Care system because there are already a lot of providers in that space. Instead, we will offer Parkinson's-specific services under the Home Care Program and Flexible Care Program," said Jo-Anne.

The Home Care Program (HCP) is designed for frail people aged 65 and over who may have some functional limitations. The focus is on providing supports that enable them to live independently at home.

The services Parkinson's NSW could potentially deliver under various Home Care Programs include:

- Parkinson's specific Nursing Care
- Speech pathology
- Occupational therapy
- Exercise physiology
- Counselling
- Social work
- Specialised support services such as client advocacy and behaviour support.
- Service System Development including Aged Care staff training.

As its name suggests, Flexible Care Programs (FCP) enable services to be provided across a variety of settings including home, residential care, in the community, or in a combination of these.

This Program includes two important Sub-Programs: Short-Term Restorative Care (STRC) and Transition Care Program (TCP). The focus of this Program and its Sub-Programs is to restore and maintain as much independence as possible.

The Short-Term Restorative Care Program will enable the delivery of a variety of in-home, time-limited support services including:

- Parkinson's Specialist Nursing
- Occupational therapy
- Social work
- Physiotherapy
- Counselling
- Speech therapy

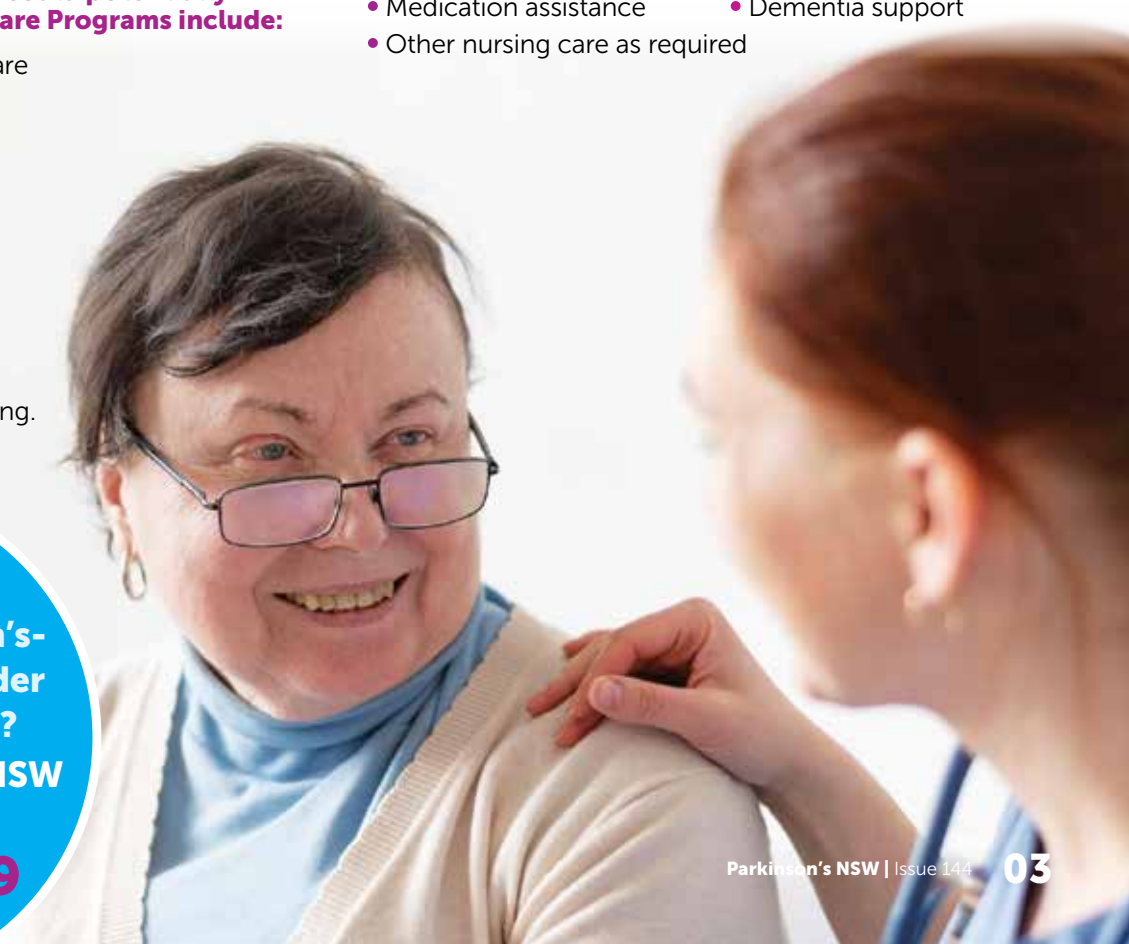
The Transition Care Program provides time limited supports intended for people who are leaving hospital and returning home. It also has a focus on low-intensity therapies including:

- Physiotherapy
- Speech Pathology
- Social work to connect people with wider community support
- Social activities, including exercise
- Occupational therapy
- Counselling

The TCP program will also provide clinical care during hospital-home transitioning by a Parkinson's Registered Nurse who could offer:

- Pain management
- Medication assistance
- Other nursing care as required
- Wound care
- Dementia support

Want to register your interest in Parkinson's-focused services under Aged Care funding? Call the Parkinson's NSW InfoLine: 1800 644 189





The future is now for Parkinson's education

What started as a COVID-driven necessity has become a path to the future for Parkinson's NSW Education.

Parkinson's education for workers in the Aged Care sector has always been a priority and it was usually delivered face-to-face – but the COVID-19 pandemic changed all that.

Pandemic or no, the need for education was still there. So Parkinson's NSW moved quickly last year – using the skills and tools it had at hand – to create a self-guided, online learning module for support workers and nurses in Aged Care facilities.

It was well accepted, but also made it apparent that more sophisticated education tools were required.

So with the pandemic ongoing and recommendations from the Royal Commission into Aged Care Quality and Safety placing even more emphasis on education for the sector, Parkinson's NSW developed an ongoing strategy based around online education – for the Aged Care sector and beyond.

It formed an Advisory Group which includes Parkinson's Specialist Nurses, physiotherapists, speech therapists and neurologists. This Group provides input to an in-house Education Working Group as it plots the future of the organisation's educational offerings.

First up in September will be a more sophisticated education module for the Aged Care sector. It will use the Articulate Rise online training module and content developed in partnership with learning solutions designer.

Next up will be a project called Parkinson's 101 – a multi-pronged approach to upskilling Allied Health and exercise providers on the unique needs of people living with Parkinson's.

"There are some good Allied Health and exercise providers with expertise in Parkinson's, but we need more to meet the current and future demand," said Christine McGee, Education and Quality Assurance Manager of Parkinson's NSW.

"Many people in these fields tend to graduate as generalists or have a special interest such as particular sports, injuries, or parts of the body – but they are not necessarily knowledgeable about the special needs of people living with Parkinson's. Our aim is to develop a larger pool of Parkinson's-experienced talent in these vital fields which are essential to building and maintaining wellbeing."

Lottery winner drives away new car

The inaugural Pitch in for Parkinson's Lottery has been won by Mrs. M who bought a ticket even though she never dreamed of winning.

As the first prize winner, she is now driving a brand-new Suzuki Swift and is considering purchasing a new television with her \$1,500 gift card from Harvey Norman.

It was a timely win because Mrs. M had been driving an eighteen-year-old car and was discussing her need for a new vehicle with her family.



Food, mood, and stress

Stress is a demand made on your body. A stressor can be people, places, or events that you see as a threat. Stress is a normal chemical reaction in your body which can be either good or harmful.

Parkinson's is a chronic condition that can lead to many different kinds of stress. People with Parkinson's are often under great stress which can lead to health problems. If stress does not stop then your body never gets a chance to heal itself.

It is important to try to identify the stressors in your life.

These could include:

- U Change of personal circumstances
- U Moving house
- U Changing your job
- U Concerns about family or friends
- U Medications new or changed

Learn to recognise the signs of stress:

- U Dry mouth
- U Headache
- U Confusion
- U Nightmares
- U Clammy hands
- U Tearfulness
- U Depression
- U Feeling faint
- U Fingernail biting
- U Decreased talking
- U Speaking too much or too quickly
- U Chain smoking
- U Over or under eating
- U Heart palpitations
- U Fatigue/weariness
- U Anger, resentment, or irritability
- U Gut issues including constipation, nausea, diarrhoea, or indigestion

These signs and symptoms occur because the body and mind become exhausted from trying to deal with the constant state of stress. Identifying stressors can lead to taking action to manage and reduce stress.



The best ways to manage stress are:

1. Nutrition – Eating a well-balanced diet of smaller, more frequent meals results in smaller serves of protein reducing the interference with levodopa. It will also maintain blood sugar levels instead of fluctuations and this produces a calming effect.

Foods that assist the body to form serotonin (a chemical that signals the body to relax) are bananas, pineapple, papaya, dates, plums, figs, pecans, walnuts, tomatoes, and kiwi fruit.

Eat six serves of complex carbohydrates per day as well as two or three moderate portions of protein and less fatty foods. Drink plenty of water as it decreases fluid retention and aids in the management of constipation.

2. Exercise – A natural stress buster that can help to work off anxiety and muscle tension. Regular exercise aids in giving a better outlook on life generally.

It can also strengthen your immune system, maintain bone strength, and manage cholesterol. Examples of exercise are walking, gardening, cycling, swimming, dancing, stretching, yoga, boxing, and tai chi.

3. Relaxation – Reduces stress and improves quality of life. Examples of stress reducers are meditation, yoga, going to bed on time, and delegating tasks to others.

In general it is good to ask for help, have a back-up plan, and find some time for yourself. Remember how important you are, join a support group, and think of what you are grateful for every day.

Our next Pitch in for Parkinson's Lottery is now open.

For your chance to drive away in a brand-new Suzuki Swift call the dedicated Lottery Hotline to purchase your tickets

1800 806 277

Carer de-stressing exercises

Whether caring begins gradually or happens suddenly, most carers will need to develop new knowledge and skills. One of the most experienced effects of caring is stress.

Learning to manage your stress is an important and possibly new skill you will need to learn. If you don't care for yourself, you won't be able to care for someone else.

These five simple tips can help you manage your stress.

1. Stay positive. Laughter lowers stress hormones levels, reduces inflammation in the arteries, and increases 'good' HDL cholesterol levels.
2. Meditate. Practice focused thought and deep breathing. They have been shown to reduce heart disease risk factors such as high blood pressure. Meditation's close relatives – yoga and mindfulness – can also relax the mind and body.
3. Exercise. When we exercise our body releases endorphins. Exercising not only helps you to de-stress, it also protects against heart disease.
4. Disconnect. It is difficult to de-stress when it follows you everywhere. Unplug yourself. Avoid emails and TV news. Take some quiet time for yourself each day.
5. Things you enjoy. Simple things like a warm bath, listening to music, or spending time on a favourite hobby, and being creative can all help to lower the stress in your life.

Make time to exercise. Many of us find it difficult to carve out time to exercise – but 30 minutes of moderate activity daily will assist you to manage the emotional and physical challenges of being a carer.

Regular exercise improves resilience, promotes better sleep, reduces stress and depression, increases strength and flexibility, and increases your energy and alertness. It also helps maintain a healthy weight and build immunity, and protects against common health problems.

Here are some easy de-stressing exercises you can do at home.

Belly Breathing or Abdominal Breathing

When we are stressed, we generally breath shallowly in the chest. Taking deeper breaths and filling the lungs completely triggers many physiological changes. Your heart rate slows, blood pressure decreases, and muscle tension eases.



Lie down and put one hand below your belly button. Breathe in through your nose to completely fill your lungs (your stomach should rise). Slowly release, breathing out through your mouth. Continue for a few minutes.

Knee Hug

This exercise will help relieve a tired back and release stress.

Lie down and hug 1 or both knees to your chest. If you can hug both knees at the same time, rock from side to side to massage your spine.

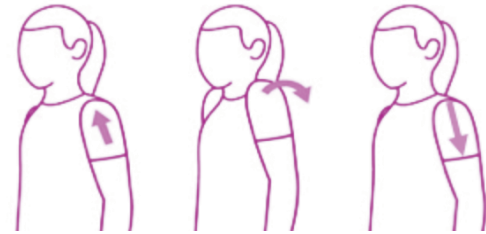


Shoulder Shrug

Holding tension in your neck and shoulders is common. Shoulder shrugs can help release the tension.

Sitting comfortably with good posture.

Breathe in and bring your shoulders up towards your ears. Tighten your arm and shoulder muscles. Breathe out and relax your neck and shoulders pulling your shoulder blades down. Repeat a few times.



Corpse Pose

In this exercise you're trying not to do anything. Sounds a bit contradictory but it's more difficult than you think. It's about noticing and acknowledging your thoughts and feelings but not dwelling on them.

Lie down with your arms, palms up, relaxed at your sides. Close your eyes and focus on the rise and fall of your breath. If you have invasive thoughts, acknowledge them, and visualise them floating away. Return to focusing on your breathing and relaxing any tight muscles.

If one method doesn't work for you, try another. Learning to de-stress takes practice. Be patient with yourself and you will reap the benefits.

Getting help from a professional is always a good idea, especially if you feel that nothing seems to help. Talking to your primary care doctor is a great place to start.



Contact Carers NSW on 02 9280 4744 or Carer Gateway on 1800 422 737 or visit www.carergateway.gov.au

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Parkinson's in the Country: Geoff Bourne

For Geoff Bourne, his farm is not just his home. Those who know him say it's his reason for being.

Geoff grew up on an 1800-acre property at Ben Lomond, between Armidale and Glen Innes and has been farming the land ever since. It's a family concern for Geoff, who works the property with his wife Myreen, his son Nigel and Nigel's family.

"My father was an accountant in Sydney. My mother came from a farm near Guyra and she hated the city. They bought the farm in 1952 when I was four, so while I'm not quite a local I've been here a long time, and my granddaughters are the fourth generation to work on the farm."

"I enjoy the peace and quiet here. You can open the blind in the morning and look out and see green fields and nothing else... if there's not a drought."

At age 65, Geoff was just starting to think about his farm succession planning.

"My son moved back 16 years ago but I was still managing the farm on my own, basically. I was very healthy and fit, and I was pleased with myself. At 65 I had nothing wrong. I thought if I can just find out why my hand keeps shaking, I'll be fine."

"My diagnosis with Parkinson's came as a bit of a kick in the guts to put it bluntly. It took a while to get used to it, for both myself and my wife, but after a while you learn that that's what life dealt to you, so you make the most of it."

Geoff has a slow progressing form of Parkinson's that has affected his movement. He also experiences anxiety and depression at times. Fortunately, he is still able to drive, which makes getting to medical appointments that much easier.

"I regularly see my GP in Armidale, which is about 50 minutes away and my neurologist is in Tamworth, which is a four-hour roundtrip."

"When I first was concerned about my condition, I went to Brisbane and consulted a neurologist up there and he diagnosed me with Parkinson's. However, I decided there was no point in going to Brisbane all the time, so we found a neurologist in Tamworth and I generally see him every six months."

"It's okay at the minute. I'm still driving. My wife's not very keen on driving distances, so I don't know what'll happen when I'm not driving. My son would probably take me, but I don't wish to impose on him all the time."

Being able to keep in contact with his GP and neurologist is just one of the challenges Geoff faces as someone living with Parkinson's in a regional area.

"It would be an advantage to the patients of Glen Innes to have a Parkinson's nurse to help us in our travels through the disease – particularly on a practical level for day-to-day living and for any problems that you might run into."

Geoff said he and his wife Myreen have both benefitted from taking part in the Glen Innes Parkinson's Support Group. Geoff has also been Secretary of the Group for the past five years.

"It's a place to go and talk about things. To share problems and hopefully share solutions. My wife always comes with me and talks with other patients and carers."

"At the Support Group, medication is a big topic. People have tried different ones and encountered problems and discuss how they solved them. We also support people financially if

Making peace with 'Parky'



Geoff and Myreen

Geoff with some of the Glenn Innes Support Group

they need to see a physiotherapist or travel away. It's mainly just being able to talk to people with the same problem and trying to help each other.

"You have to talk to other people with the disease, otherwise you feel on your own and isolated with the problems of the whole thing. If you can just talk to people and compare notes and treatments, I think it helps."

While his Parkinson's – or 'Parky' as he and Myreen have come to call it – may mean one day he has to leave the farm he loves, Geoff plans to stay put for as long as he can.

"I just take it day-to-day. There's no good making long-term plans but staying on the farm is what I hope to do."

"I still own part of the farm and work on it. My son is the manager now, which means I don't have the stress of that job. I basically do what I want and not what I don't. I think my son forgets that I've got Parkinson's every now and again, but that's not a bad thing."

"I find working on the farm gives me motivation. It keeps me moving and is a reason to get up in the morning and do things. When I get depressed, I go and do something and it cheers me up, so I'll certainly stay here while ever I can."

Help us support people living with Parkinson's during lockdown



COVID-19 has again resulted in necessary but challenging lockdowns.

During this time, vulnerable people living with the physical and psychological symptoms of Parkinson's – and their dedicated carers – need extra support.

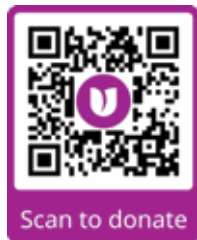
Now more than ever, there are heavy demands on our services and programs – which look like they will only increase.

Since the start of the pandemic last year, we've been working hard to expand, to adapt our supports, to make sure that when someone needs our help, we're there.

Using technology, we're connecting with people in new, virtual ways so lockdowns can't prevent them getting the immediate help they need.

Every change comes at extra cost. Your donation will mean additional support is available for people and their carers when they need it the most.

Please donate to help Parkinson's NSW give people a safe place to turn to for expert knowledge, answers, referrals, connection, and guidance during these challenging times.



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IN THIS TOGETHER

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

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Address: _____

Email: _____ Phone: _____

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\$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:

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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

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