STANDBYME

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parkinson's
NSW

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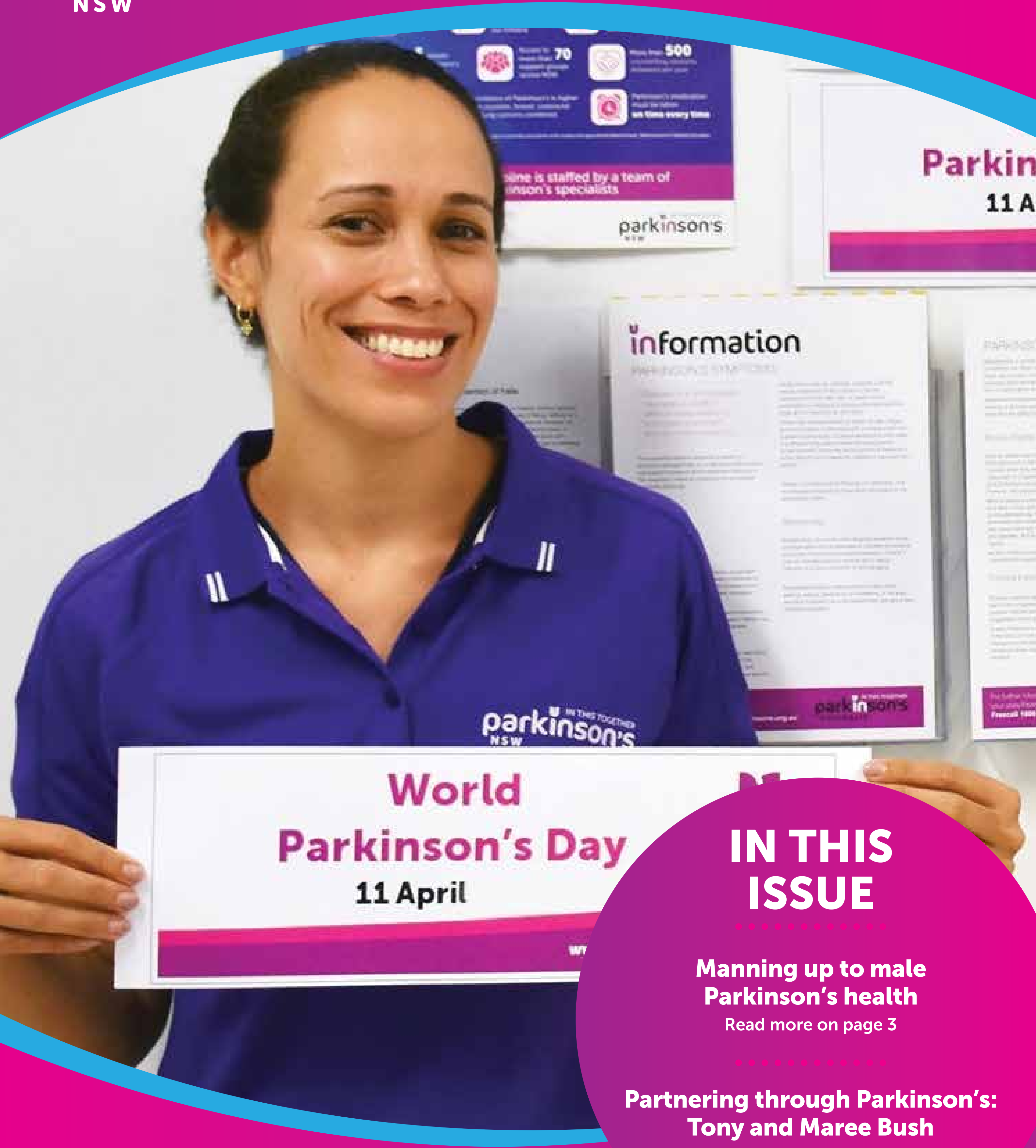

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From the CEO

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

As I write, it is good to see so many Support Groups emerging from the two-year COVID pandemic hiatus and starting the process of reconnecting with their communities in person.

Sadly, it is also a time when so many in our Parkinson's community are struggling to recover from the catastrophic floods which affected the Northern Rivers region of NSW. Our Parkinson's Specialist Nurse in that region has been working hard to ensure displaced people receive their medications and any additional medical attention required.

And as always, our InfoLine team is standing by to provide support, advice, and referrals – or a sympathetic ear if required. Just call **1800 644 189** to speak to a Registered Parkinson's Nurse or be connected with our other essential services.

In addition to coping with these upheavals, the Parkinson's NSW team has been very busy advocating for its community to the State and Federal Governments.

An information evening was held at State Parliament House late in March to brief MPs and their advisors on our activities. We also strongly advocated for recurrent funding from the Government in order to grow our capacity for service delivery – particularly the InfoLine and the essential services to which it provides a referral pathway.

We will keep you up to date on progress in Stand by Me and our other publications.

Meanwhile, in this edition, we have an article on how to manage constipation in Parkinson's and feature the first story in our new series Partnering through Parkinson's.

Enjoy the read and stay well.

Jo-Anne Reeves
Chief Executive Officer

New Director appointed to Board of Parkinson's NSW

Graeme Cartwright, an expert in finance and governance, has been appointed to the Board of Parkinson's NSW as a Director.

He also serves on the Boards of Northside Community Services and the Hurstville and Rockdale Friendly Society.

Graeme has over twenty years of experience in managing Australian share portfolios for industry super funds and governments. He has expertise in finance, governance, compliance, and audit.

Graeme's qualifications include a Bachelor of Engineering, as well as Graduate Diplomas in Applied Investment, Finance and Business Administration. He is also a graduate of the Australian Institute of Company Director's Company Directors Course.

For **information and links**

to resources visit the Parkinson's NSW website
www.parkinsonsnsw.org.au/information-and-fact-sheets/

Manning up to male Parkinson's health

Men often don't like discussing anything health related. Subsequently, serious health concerns and potential resources and places to go for assistance are not easily shared among male friends.

In Australia, men on average live five years less than women for a variety of reasons including:

- Lower awareness and understanding of male health by the individual and community.
- Men are 4 times less likely to visit the doctor than women.
- Men may engage in risky activities that jeopardize their health.
- Allocation of less time and lower priority to medical appointments.
- Men with mental health problems, such as depression, are much more likely to self-medicate with alcohol and other drugs.
- Men comprise over 75 per cent of all suicides in Australia.

Parkinson's also effects men differently

More men than women are diagnosed with Parkinson's, by almost 2 to 1. Several studies support this number, including a large study in the American Journal of Epidemiology. Yet researchers aren't sure why this variation occurs.

Some suggest that estrogen might offer some protective effect for women. However, there is also a higher rate of head trauma, exposure to occupational toxins and potentially a genetic susceptibility for men.

One study implies that men on average develop Parkinson's approximately two years earlier than women. However, other studies have found no differences for onset age between men and women.

Early studies indicated that Parkinson's progresses more rapidly in men. Other studies have shown that men and women who are diagnosed with Parkinson's at the same age, appear to have similar progression, duration, and life expectancy. This varies greatly from the non-Parkinson's population.

Overall, men and women have similar motor and non-motor symptoms. However, men more frequently report having problems with REM Sleep Behaviour Disorder (physically acting out whilst dreaming) and report rigidity more frequently than women.

These differences in reported motor symptoms, were significant only in patients who had Parkinson's for more than five years.

Tremor-dominant Parkinson's is generally associated with a slower progression and better quality of life for men and a poorer quality of life for women.

Parkinson's can affect mental abilities and the senses as well as muscle control.

Men appear to maintain a better spatial orientation, while women often retain more verbal fluency. Different skills, such as spatial abilities, are more dominant on a one side of the brain.

Therefore, some abilities are influenced by which side of the brain is most effected by Parkinson's and not simply by gender.

One study regarding emotional communication implies that both men and women with Parkinson's can have difficulty communicating anger and surprise, but that men are more likely to lose the ability to interpret fear.

However, the mask-like appearance that occurs with Parkinson's, due to muscle rigidity, may lead to a distorted expression or interpretation of emotions.

Another noticeable difference is with medication. Levodopa is a standard medication for treating Parkinson's.

Men with Parkinson's metabolise Levodopa differently. Subsequently the dosage is often higher for men than women. Men also exhibit fewer side effects such as levodopa-induced dyskinesia (involuntary movements) from taking levodopa.

However, the dosage difference may be explained by men generally having a larger body mass.

Men have more Parkinson's related surgery and generally their symptoms are less severe than for a woman undergoing the same surgery.

Men with Parkinson's tend to experience less depression and take less antidepressants than women. It appears though that men have more behaviour and aggression problems.

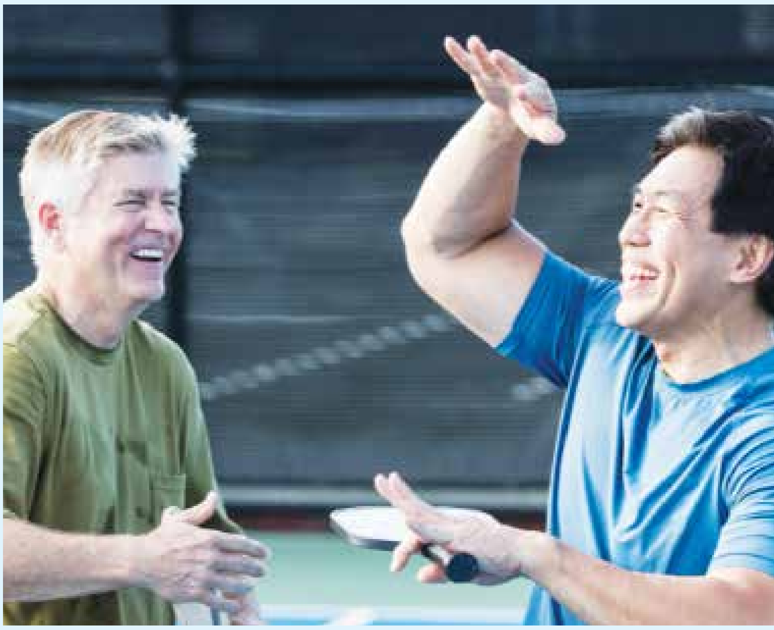
Men are at greater risk of wandering, inappropriate or abusive behaviour and are more likely to be prescribed antipsychotic medications to treat this behaviour.

It will require much larger scale, placebo-controlled studies to be conducted, to obtain more conclusive evidence on the differences between men and women with Parkinson's.

However, men need to be more active in their approach to health. Even if you don't feel sick, schedule annual check-ups.

It's important to know about your general health, not just your Parkinson's. You will live longer and have a better quality of life.

Source: Australian Government Department of Health



Managing constipation in Parkinson's

Constipation is the infrequent passage of hard, dry bowel motions which are difficult to pass.

It is a common problem in Parkinson's and can also predate the Parkinson's diagnosis. Most importantly, constipation can reduce the quality of life for people living with Parkinson's.

Constipation is problematic in Parkinson's due to slow movement of the muscles of the gastro-intestinal tract.

The autonomic nervous system is a complex network of cells that controls the body's internal state. It regulates and supports many different internal processes, often outside of a person's conscious awareness – and it is responsible for the function of smooth muscle in the gastro-intestinal tract.

Constipation occurs due to slowness of the muscles of the bowel moving the food products from the stomach, along the small bowel to the large bowel and onto excretion.

Research shows that Parkinson's can affect the nerves that line the gastro-intestinal tract. At the same time, brain changes that cause stiffness and slowness also affect the muscles in this tract.

That that is why swallowing and the passage of food along the gastro-intestinal tract is slowed down. The slower the transit time, the more water is absorbed from the waste products and the harder the stools become – and the more difficult they are to pass.

There are several reasons why constipation is problematic for a person living with Parkinson's:

- **Medication:** Slow gastric emptying makes it more difficult for the medication to get to the top of the small intestine where it is best absorbed.

Many of the medications which are used to treat Parkinson's can also cause constipation. Antacids used in treating gastric reflux can also increase the risk of constipation.

- **Diet:** Swallowing issues and chewing problems may make it difficult to ensure that a healthy diet is maintained.

Measures you can take to manage constipation include:

- **Hydration:** It is essential to maintain a good fluid intake to maintain bowel health. Many people living with Parkinson's try to reduce their fluids so that they do not have to rush to the toilet – but this has real impact on the risk of constipation.
- **Exercise:** It helps to maintain overall health and well being.
- **Maintaining regular toileting habits:** Maintain a good routine and do not avoid the urge to open the bowels.

If constipation is left untreated it can lead to many serious problems including:

- **Poor symptom management** of Parkinson's as medications cannot reach the area of the intestine where they are best absorbed
- **Nausea** and a reduction in appetite and fluid intake, increasing the problem.
- **Lethargy and discomfort**, reducing exercise and again increasing the problem
- **Bladder** involvement as the constipated bowel can place pressure on the bladder causing urinary incontinence. It can also prevent complete bladder emptying and this raises the risk of the development of a urinary tract infection.
- **Bowel obstruction** is the worst-case scenario. A bowel obstruction is a medical emergency and must be treated as such or it could prove fatal.

Here are four steps to preventing and managing constipation:

1. Eat Well - A healthy diet rich in dietary fibre can be attained by eating fruit, vegetables, grains, legumes, nuts, and seeds.

2. Drink sufficient fluids - Drink 1.5 - 2 litres daily. The best fluid is water. It is best to limit hour intake of alcohol, energy drinks, tea, coffee, and fizzy drinks (they are high in caffeine and act as bladder irritants).

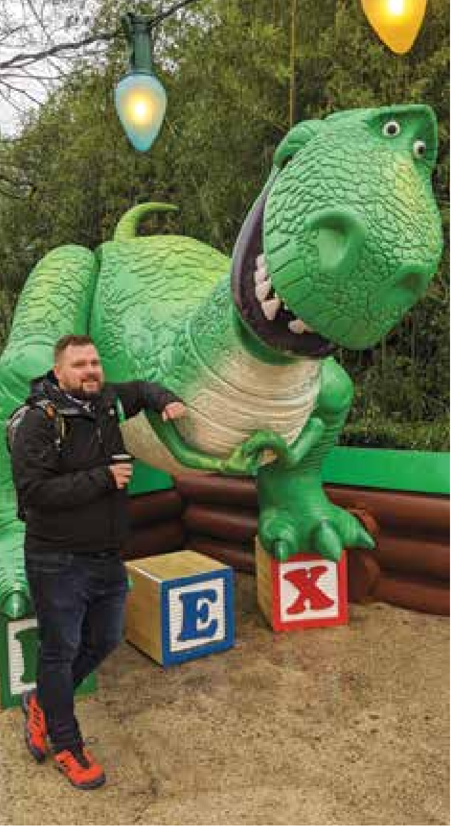
3. Exercise regularly - Exercise for 30 minutes per day as it plays a significant role in managing constipation. Varied exercise is best, but walking is great.

4. Practice good toileting habits - Go to the toilet as soon as you feel the urge as this is the most effective time to empty the bowel. Sit on the toilet with your elbows on knees, leaning forward and supporting your feet. Relax your tummy, breathe naturally, and draw up your anal muscles when your bowel action is complete.

Laxatives help to soften the stools, making them easier to pass. They are not the first step in managing constipation but are very important – particularly for people with living with Parkinson's for whom constipation can be very problematic.

Coloxyl, Movicol, Senekot, and Agarol are useful laxatives and can be used on a regular basis to manage constipation. Warm drinks in the morning and prune juice can also aid in the management of constipation.

While constipation is common in people living with Parkinson's it should be never be ignored or dismissed as a trivial problem. Good bowel management is necessary for quality of life and needs to be well managed every single day.



Meet our Team Member

Peter Evans, Digital Campaigns Manager

Peter Evans – who prefers to be called Pete – has a role at Parkinson's NSW which bridges the work of the Fundraising and Digital Marketing teams.

He is responsible for helping to conceive, then building, driving, and measuring all of the Parkinson's NSW online sponsorships and events. It's a job which requires knowledge and experience of both the event management and fundraising worlds – with a large dose of technology skills thrown into the mix.

Pete began his career almost 20 years ago in event management in his hometown of Brisbane – from where he still works remotely. He then made his first foray into the not-for-profit world by joining Drug ARM, an organisation that provides a range of services to support individuals and families affected or at risk of being affected by drugs and alcohol.

From there, he moved into fundraising for Guide Dogs Australia, Seeing Eye Dogs and Vision Australia.

"During my time at Vision Australia I was fortunate to be mentored by Jo-Anne Reeves and Margaret Scott, who are today the CEO and Chair of Parkinson's NSW, respectively.

"Jo-Anne and Margaret were among the pioneers of modern, more targeted, and efficient fundraising. As new trends emerged, they would urge me to explore and develop new skills – particularly in the online space," he said.

"I really enjoy working for an organisation where everyone gets along and shares the same goals," said Pete. "I'm also in a role where I can experience and appreciate the services actually delivered by the organisation. I can be exposed to Support Groups and see exactly what our nurses, counsellors and support coordinators are delivering for people living with Parkinson's and their families."

When he is not on his computer for work, Pete prefers to take a distinctly non-digital approach to life. He enjoys watching movies, walking his dog, and building Lego models.

Resuming travel is high on his future agenda. Pete and his partner were on the first leg of an overseas adventure when COVID-19 struck and Queensland closed its borders. They quickly returned and were able to quarantine at home instead of in a hotel.

Fast forward two and a half years, and now Europe and America have re-opened. "I can't wait to get on a plane again!" said Pete.

Tamworth Support Group celebrates 30th anniversary

The Tamworth Parkinson's Support Group celebrated thirty years of service with a dinner held at the North Tamworth Bowling Club on 6 December. Over sixty people attended – both those living with Parkinson's and their caregivers.

The function was chaired by former Group Leader, Len Hutton who spoke about the disease and measures which are being taken to control and eventually cure it.

Special guest was the member for Tamworth, Mr Kevin Anderson who congratulated the group for its support of and advocacy on behalf of those living with Parkinson's.

Brian Sullivan who has had Parkinson's for about fifteen years proposed a toast to all who lighten the burden by sharing it. He referred to the work being done by researchers, the doctors, nurses, and fitness instructors. He also thanked the caregivers who provide assistance by day and by night.

Current group leader, Kevin Robinson thanked all who helped to make the function so successful. He made a presentation to the group's hard-working secretary, Jenni Fergus.

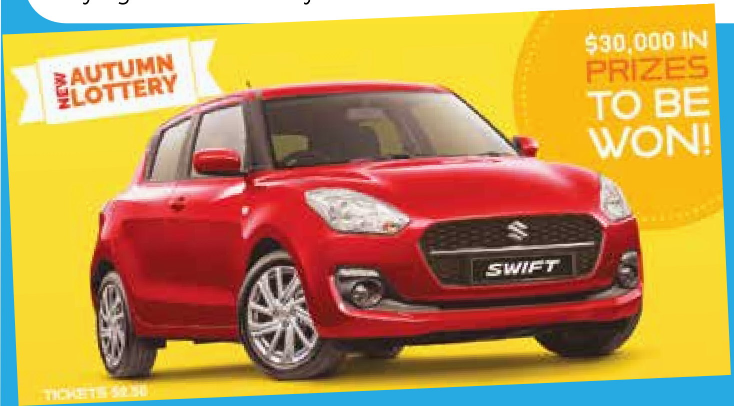
Winner of Pitch in for Parkinson's Summer Lottery

The third Pitch in for Parkinson's Lottery has been won by Mrs. J from Northern NSW.

Mrs. J was thrilled and was considering gifting the car to her eldest grandchild who is in their first year of university. Mrs. J had been affected by the recent floods so she was very excited to be able to share the good news of her win with the rest of her family.

Mrs. J is now driving a brand-new Suzuki Swift GL Navigator from Nepean Motor Group – and she is looking forward to going on a shopping spree with the other part of the prize, a $1,500 gift card from Harvey Norman.

The second prize of a $3,000 Harvey Norman gift card was won by Mr. P of Denistone East. He was looking forward to buying a new sound system or a comfortable recliner.



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

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

1800 806 277

Purchase your tickets by
17 June 2022

(Permit Number NSW GOCAU/2362)

Parkinson's-related grief and loss

Various strategies can help people living with Parkinson's who have difficulty walking, but a new study finds that many people have never heard of or tried these strategies.

It is common to experience feelings of grief and loss as a person's Parkinson's progresses. These feelings can impact both the person living with Parkinson's, as well as caregivers and family members.

Such feelings are complex and may include physical, intellectual, psychological, emotional, social, and spiritual dimensions – or a combination of these.

The three most common emotions are anger, guilt, and fear. When we have Parkinson's, we are particularly susceptible to anger and fear.

Instead of being able to look forward to a better tomorrow, our optimism is replaced with feelings that frighten us and worries we can't seem to get under control.

Loss is a part of life whether we have Parkinson's or not. However, what is different about living with Parkinson's is that the progression of the disease continuously reignites the sense of loss – and there is no time frame for grief.

As the illness progresses, we may find we are faced with new losses along the way.

Losses experienced by those living with Parkinson's, caregivers and family members include:

- Changes in family roles
- Work and social situations that result from a person's illness.
- Loss of independence
- Changes to identity
- Loss of financial security
- Significant changes to our familiar lifestyle
- Being defined by your disease, rather than as an individual

The intensity and scope of loss can also create feelings of shame and fear from reaching out for support. Often the overwhelming feeling for people living with Parkinson's is that they are continually losing and not gaining anything.

It is inevitable that grief will be triggered from time to time, but the good news is that it is likely to be temporary – unlike the sense of loss which is often ongoing.

Grief comes in waves. It is not a constant feeling. Getting over it takes time, and that time varies by individual.

Grief is experienced differently by everyone, depending on social, historical, cultural, and spiritual influences. There is no 'normal' way to grieve.

The best defense is to develop self-compassion. That may mean putting time and energy into new hobbies and new relationships or looking for opportunities for personal development or spiritual growth.

We can do this at our own pace – one small step at a time if need be.

Most importantly, focus on the here and now. Develop thoughts, interests and activities that generate positive feelings in the here and now.

Parkinson's may be able to affect your future, but it can't take away what you have right here in this moment.

Practice mindfulness – the recognition and non-judgmental acceptance of painful emotions as they arise in the present moment.

That will enable us to recognise and change negative self-talk or images of ourselves that are not useful. Focus on attitudes that nurture personal strengths and positive outcomes of the illness experience, rather than limitations.

Also give yourself something to look forward to. Make plans with family and friends.

And as you are planning, consider what support you need more or less of right now?

Dealing with the progression of Parkinson's is an ongoing process of reassessing and reaching out for support.

If this has raised any issues or concerns for you, please contact the Parkinson's NSW Infoline on

1800 644 189.

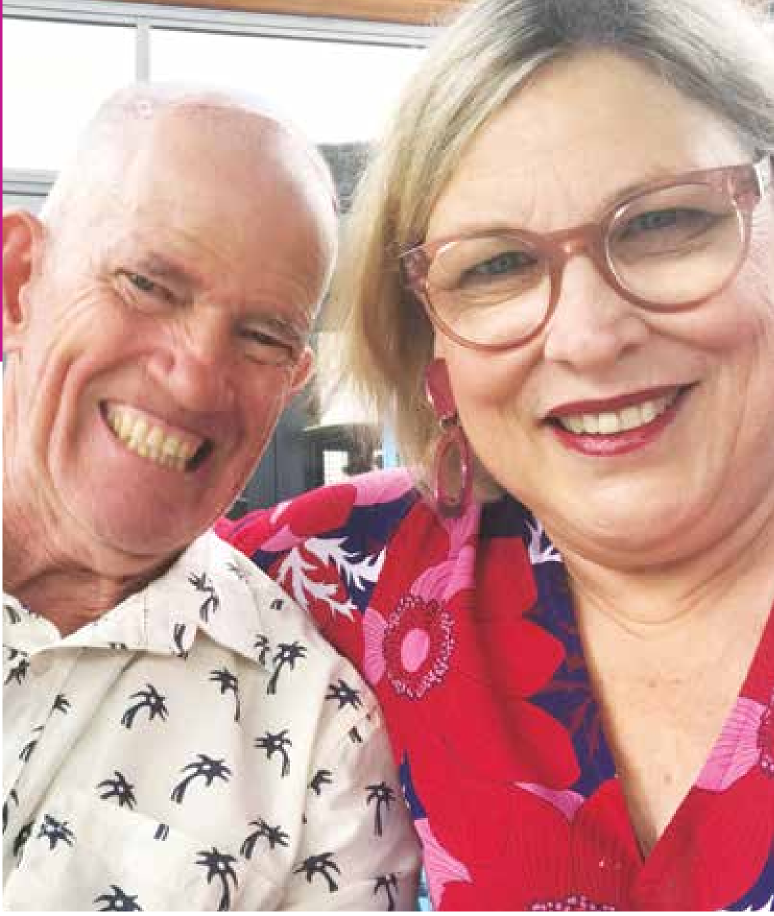
If the issue or concern is really serious, please contact

Lifeline

131114

Partnering through Parkinson's:

Tony and Maree Bush



Tony Bush was at work as a builder in Coffs Harbour when he fell from a ladder back in 2012.

> *"I had torn ligaments in my shoulder and went to a specialist to sort it out," he recalls. "I also had a tremor in my right hand, which my GP had said was a pinched nerve. That was when I was told I had Parkinson's."*
>
> *"It's often misdiagnosed," says his wife, Maree."I had noticed the tremor prior to the fall. I was concerned at his prognosis but the neurologist we saw said that it was our own journey – everyone's is different. That really stuck in my mind, and we have basically just dealt with what has come along. We just run our own race."*

Tony was still able to continue working for the next four years but eventually it became too difficult, more because he had a double hip replacement than issues with Parkinson's. But there were also other business problems which were stressing the couple.

> *"We had people not paying," recalls Maree. "We were not doing well enough in the business. It was a real stress in our relationship."*
>
> *"It was a relief to retire," says Tony, who was able to get a disability pension and some NDIS assistance. "It was a problem that I just couldn't keep the productivity up."*
>
> *When Tony retired, Maree began working.*
>
> *"That was something I wanted to do," she says. "I also get a carer pension. After Tony retired he was pretty self-sufficient, and we were able to go to New Zealand for a holiday for two weeks.*
>
> *"He would take his meds every four hours and was able to go for slow bushwalks and take himself to the toilet. But when he got back he started to lose weight and had lost quite a bit before we realised the old medication had stopped working.*
>
> *"It wasn't long before he really needed 24/7 care. He would be getting up two or three times a night. That was the biggest shock. He had been progressing so well. It started to impact on our relationship. I was always tired. I just wasn't getting enough sleep and I don't handle things well when I'm really tired."*

Fortunately, Tony was able to get more NDIS funding to support his increased needs, which took some of the pressure off Maree.

> *"Before, I was able to do everything needed," she said. "But I was losing spontaneity. I couldn't just get in the car to go and have coffee or go for a walk on the beach with Tony anymore. But it is what it is, and it hasn't pulled us apart."*
>
> *"It was really hard for me: going from being a carer for the family to the one needing all the care was very hard to accept," says Tony.*

Maree adds that Tony is a very patient man, and not hard to care for.

> *"He never complains, just gets on with it," she says. "He has real dignity and self-respect. He didn't used to have hobbies; his hobby was his work. But now he does a bit of woodwork here and there, with support. He's made bedside tables and a hallstand and there are more things he'd like to do. And he keeps the garden nice.*
>
> *"We used to do everything together. I loved going away on holidays and doing things, now I'm not free to walk out the door any time. You give up a lot of your life when something like this happens, but we are in this thing together."*

Since Tony has been able to access more support, Maree is building in some activities to look after her own wellbeing.

> *"I have a massage every month," she says. "I need to do more regular exercise, and I used to also catch up with girlfriends. But we still have each other. Tony lost his best friend to a melanoma recently. We know things could be worse, and we try to look for the positives."*
>
> *A big positive has been Tony's very recent Deep Brain Stimulation surgery a week prior to this interview.*
>
> *"It's been fantastic, I feel fantastic," says Tony. "The neurologist put it this way: 'The way you were was you were a horse-drawn buggy, now you're cruising.' There are not so many bumps."*
>
> *"I'm getting more sleep," says Maree. "He's been able to get up to the toilet himself, although he's had a fall, he will get used to getting up again on his own. If it's just those little things and nothing else, it's wonderful. People don't realise what a difference it can make. He looks ten years younger, because his face isn't always screwed up with concentration. He hasn't had cramps, so many little things.*
>
> *"The ultimate would be to be able to go on a beach walk together. I don't need a million dollars. I'd be happy with that. You've got to laugh, really. If you don't, you cry. Laughing has got us through many hard times."*

Can you help fund more Parkinson's Specialist Nurses like Suliana?

An increasing number of people are being diagnosed with Parkinson's. You can help to fund more Parkinson's Specialist Nurses like Suliana to help them.

Suliana and her colleagues can evaluate their impact from the thanks they receive from people they have supported.

> *"The positive feedback we receive from patients and their carers is the highlight of my work," she says.*
>
> *"This is such a challenging illness, and a horrible illness. But when I hear that positive feedback from people I know that we are making a difference, providing the support and reassurance they need."*

You can make a difference too, by making a donation now to support the important work of our Parkinson's Specialist Nurses.

IN THIS TOGETHER
parkinson's
NSW

☑ 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** ______________

Scan to donate

☐ **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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