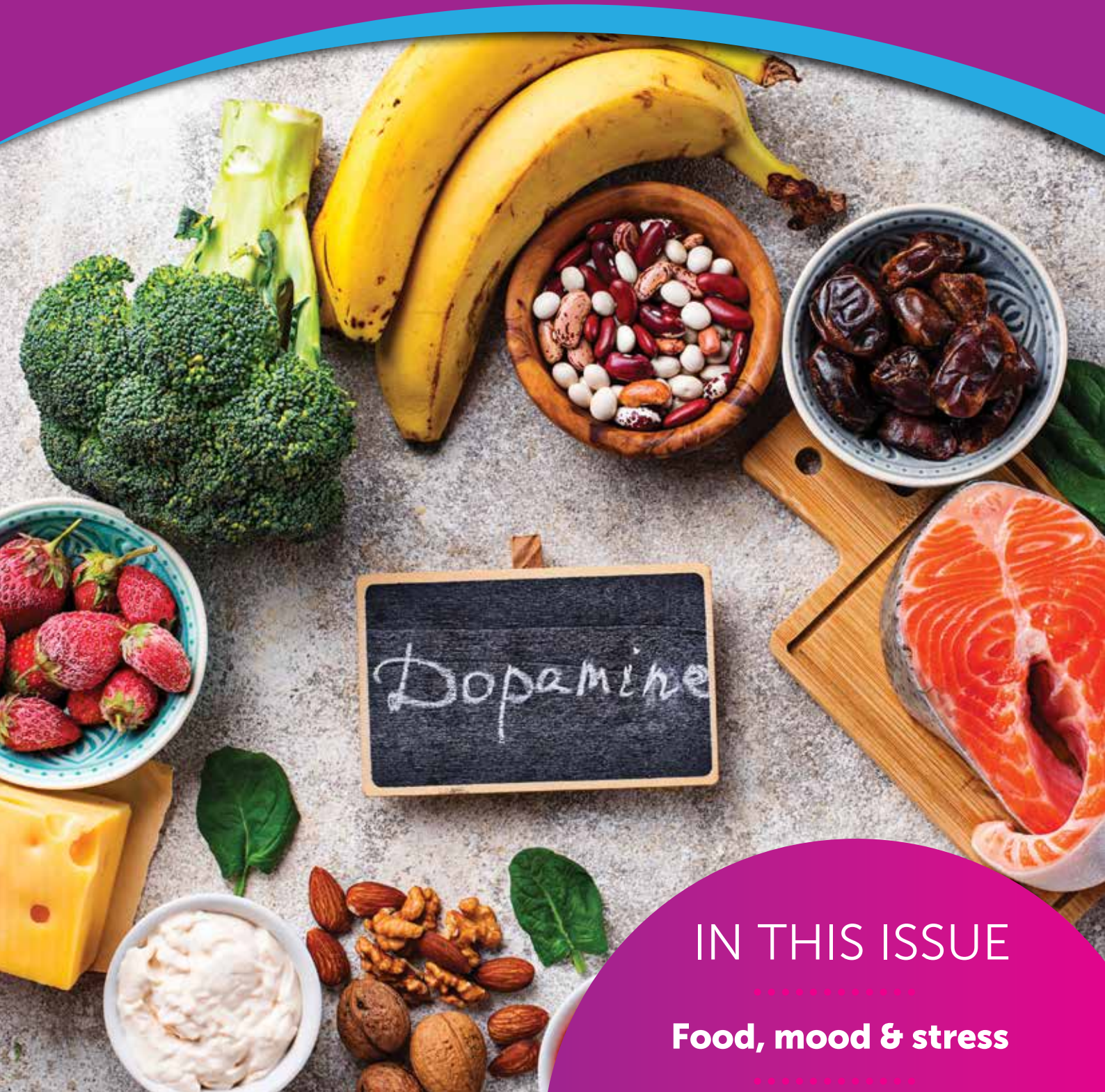


# STANDBYME

OFFICIAL PARKINSON'S NSW MAGAZINE

Issue 154 AUTUMN 2024  
ISSN 1839-0269



IN THIS ISSUE

.....  
**Food, mood & stress**  
.....

**Parkinson's Specialist Nurses**  
.....

**World Parkinson's  
Awareness Day**

IN THIS TOGETHER  
**parkinson's**  
NSW

## In this issue...

Welcome to the Autumn 2024 issue of *Stand by Me*. As the weather cools and we transition away from Daylight Saving, there is a great variety of stories here to keep you engaged and informed.

Learn about a new piece of research which has found that people with Parkinson's tend to have high numbers of pro-inflammatory bacteria in their noses – and what this means.

April is Parkinson's Awareness Month, a time to join forces with the rest of the nation and the world to spread awareness and understanding of this complex disease. Read about how you can get involved.

Take a quirky look at livening up your exercise routine by working up a sweat with your pet and consider some practical advice on making the most of dentist appointments while living with Parkinson's.

We also present the latest installment of our Partnering Through Parkinson's series – the story of Carol and Alan Rose who for more than 40 years have been tackling life, work, hobbies, and Parkinson's together.

Finally, consider an article on the links between food, mood, and stress – helpful advice on managing those troubling non-motor symptoms.

**Enjoy your Autumn reading!**



## Mary Kay Walker appointed CEO of Parkinson's NSW

Mary Kay Walker has been appointed Chief Executive Officer of Parkinson's NSW. She succeeds Jo-Anne Reeves who has left the organisation.

Mary Kay was previously Chief Operating Officer of the charity, responsible for planning, implementing, managing, and controlling all of its operational and financial-related activities.

She held this role for five years before being promoted to Acting CEO last year, and now being confirmed as permanent CEO.

*“My priorities in this new role are to win increased funding for Parkinson's NSW from Government, build and leverage relationships with other Parkinson's organisations and thought leaders to avoid duplication of effort, and advocacy to raise awareness of the impact and challenges of Parkinson's among key decision-makers,”*  
said Mary Kay.

*“I will be building on the foundations laid by Jo-Anne Reeves, who leaves the organisation with our thanks and best wishes for the future.”*

Mary Kay joined Parkinson's NSW following a 32-year career in key finance and administration roles in Australia and the United States. Her sector experience spans superannuation, credit management, retail, commercial aviation, and accounting.

She holds a Bachelor of Science with a double major in Mathematics and Bachelor of Science (Honours) in Psychology from the University of Sydney. In addition, she has a Diploma in Securities and Financial Markets from the Financial Services Institute of Australasia and is a Fellow of the Australian Institute of Company Directors.

IN THIS TOGETHER  
**parkinson's**  
NSW

# Help people living with Parkinson's today by supporting Parkinson's Specialist Nurses like Jody



*"A lot of people who are diagnosed with Parkinson's live in regional and rural areas. But the services for Parkinson's are generally in metropolitan areas. Nurses like me fill an important gap." - Jody, Parkinson's Nurse*

Hundreds of people living on the Mid North Coast rely on Jody, our local Parkinson's Specialist Nurse.

She covers an area of more than 4,000 square kilometers while supporting a wide range of patients, from those who have recently been diagnosed to people in the advanced stages of Parkinson's who are approaching the end of their lives.

They come from all walks of life, and what they all have in common is the local support they know they can rely on – support available from nurses like Jody but made possible from the generosity of supporters like you.

Parkinson's NSW offers services which are free to the consumer, yet less than 3 percent of our operating costs are covered by government grants. Our ability to underwrite services delivered by dedicated professionals like Jody strongly depends on charitable fundraising and the supportive responses of donors like you.

Parkinson's knows no geographic boundaries. Many people who are diagnosed live in regional areas which are not conveniently close to city-based specialist care. For them, a neurology appointment can mean a trip of several hours or more – not an easy journey when you are living with Parkinson's.

**We urgently need more nurses like Jody in regional areas, working in and near communities where unmet needs for specialised Parkinson's care exist.**

Jody and her colleagues meet those needs, all the way from the first conversation about a new diagnosis through ongoing advice and support as Parkinson's advances, which it inevitably does.

Usually, people come to a nurse like Jody just after they have been diagnosed, which is probably one of the worst conversations they've ever had in their lives.

*"Often patients have been told this horrible news and they go into shock and can't process anything else. Often, I can make the first big difference right at this moment," said Jody.*

She always starts by asking people what they feel about Parkinson's. Then she goes into the biology of the disease a bit to explain what is happening in their brain, using visual aids, and why it's so important to take their medication on time.

But most importantly, Jody finds that this first conversation can give patients hope that they can still enjoy quality of life.

For some, a diagnosis may have been a long time coming because their symptoms have been so hard to pin down. For others, the news may bring anger and denial.

Parkinson's Specialist Nurses like Jody help people realise they are not alone.

Nurses like Jody do an incredible job – but it wouldn't be possible without generous donors. They are the reason why Parkinson's NSW can reach out with practical help for people who need it right now.

You can assist with both the co-funding of existing nurses like Jody now, and the creation of more positions in underserved areas in future. With your help, patients like those supported by Jody can get the healthcare and support they need, when and where they need it.

A donation towards nurses who work in regional areas of need can help people living with Parkinson's to feel healthier, happier, and more in control of their lives.

But without nurses like Jody on the ground, many of the most advanced treatments for Parkinson's are simply out of reach for many regional patients.

*"I truly hope that one day there will be a cure for Parkinson's, and I am out of a job. But until then, people living with Parkinson's need the kind of support nurses like me can give."*



You can help people living with Parkinson's today by supporting a local Parkinson's Specialist Nurse like Jody.





# Inflammatory Bacteria in Nose Linked to Parkinson's Risk

by Marisa Wexler

## People with Parkinson's tend to have high numbers of pro-inflammatory bacteria in their noses, according to a new study.

Researchers think these bacteria may be a trigger for inflammation in the brain, which could help to set the stage for the development of Parkinson's.

The study – Deep nasal sinus cavity microbiota dysbiosis in Parkinson's disease – was published in *npj Parkinson's Disease*.

Our bodies are home to billions of bacteria and other microorganisms, collectively referred to as the microbiome. These tiny creatures play important roles in health and disease that are only beginning to be understood.

An emerging body of research has suggested the microbiome is dysregulated in Parkinson's. Prior studies have found abnormalities in patients' gut and mouth bacteria, for example.

Prior studies looking at bacteria toward the outside of the nose have failed to find noteworthy Parkinson's-specific differences. However, a team at Rush University in Chicago analysed bacteria in the deep nasal sinus cavity of 30 people with Parkinson's. The team noted that the deep nasal sinus cavity – far up in the nose – is close to the olfactory bulb, a brain structure involved in the sense of smell.

*"We posit that the unexplored deep nasal sinus cavity is a more relevant site for neuroinflammation (brain inflammation) in Parkinson's and hypothesised that the deep nasal microbiota community has a pro-inflammatory profile in PD," the scientists wrote.*

Bacteria diversity was analysed in 30 individuals with Parkinson's using a technique called 16S rRNA gene amplicon sequencing. This involves sequencing a specific part of the genome in a sample of bacteria, which researchers can use to deduce which species are in the sample and their relative abundances.

For comparison, the researchers also analysed bacteria in the deep nasal sinus cavities of 11 of the patients' spouses who did not have Parkinson's. Spouses were chosen in order to account for environmental factors (e.g., bacteria that happen to live in a person's house). Bacteria from 17 non-spousal healthy controls also were analysed.

Results showed that, compared to the controls, people with Parkinson's tended to have higher amounts of certain bacteria that are likely to have pro-inflammatory effects.

For example, many patients had high abundances of *Moraxella catarrhalis*, which is known to be an opportunistic pathogen – a bacteria that usually does not cause disease but can under certain circumstances.

The team noted that *M. catarrhalis* was not always linked with Parkinson's – indeed, some patients had no detectable amounts of this type of bacteria. But microbiomes with the highest abundances of this bacteria consistently came from people with Parkinson's.

Statistical analyses indicated that patients with higher amounts of *M. catarrhalis* and other pro-inflammatory bacteria tended to display more severe Parkinson's symptoms.

*"Although the presence of Moraxella was not always associated with the nasal microbiome of Parkinson's subjects, an increased relative abundance of M. catarrhalis in Parkinson's subjects ... as well as other pathogens (disease-causing microorganisms), suggests a role promoting nasal inflammation and possibly neuroinflammation in Parkinson's," the team wrote.*

In addition to high levels of pro-inflammatory bacteria, Parkinson's patients also tended to have lower amounts of bacteria with anti-inflammatory properties, including *Blautia wexlerae*, *Lachnospira pectinoschiza*, and *Propionibacterium humerusii*.

*"These organisms and other similar taxa (biological groups) may play an important role in maintaining a balanced (anti-inflammatory) microbial composition in the nasal microbiome," the researchers wrote.*

*Collectively, the team said this study "...supports the hypothesis that gut and deep nasal dysbiotic microbiota communities are triggers/enablers of neuroinflammation," which may help to drive the onset of Parkinson's.*

The researchers noted this study was limited by its small sample size and highlighted a need for more research to understand how the microbiome affects the development of Parkinson's.

Source: First published in *Parkinson's News Today*



Do yourself  
and your best  
friend a favour  
and exercise  
together!

# The benefits of exercising with your pet

We all know exercise is what you need if you have Parkinson's. However, with Parkinson's you also often have trouble mustering the motivation to exercise at all.

If you have a pet, not only you miss out, but your pet also often misses out on quality time with and their exercise. Let's solve the problem by exercising with and for each other.

If you're thinking about going for a run or walk, take your pet with you because both of you will benefit. Regular workouts will help you and your pet maintain a healthy weight.

Exercise will also help prevent other weight-related conditions, such as diabetes and high blood pressure for both of you. Other benefits for you both are reducing the chances of stiff joints, arthritis, or hip dysplasia. And of course, exercise improves the mental health of both humans and animals.

You know how exercise can just put you in a good mood? It does the same for animals. It's been shown that aerobic exercise can increase serotonin production in not only your brain but your dog's brain as well. This helps them feel more relaxed and less aggressive.

One of the best reasons to exercise with your pets is that you get a workout buddy! Having a workout buddy can help keep you motivated even on days you'd rather stay in bed.

One study discovered that dog owners were 34 percent more likely to get at least 150 minutes of exercise per week than those without a dog.

There are loads of options to vary your pet-buddy workout. You could go kayaking, paddleboarding, Nordic walking, walking on the beach, by a lake, or in the park. Take a ball or Frisbee so that you can both play fetch to break up your workout.

Make sure to consider both you and your pet's health and fitness ability. Can your dog keep up with you, or can you keep up with your dog?

Keep both of you safe and drink lots of water, wear sunscreen and both of you take a break when needed. Dogs can dehydrate and overheat just the same as we can. Look out for excessive panting or drooling.

Try and go early in the morning in summer before it gets too hot. This will also stop your dog's feet from burning from hot pavement.

If you can't get out of the house to get in your workout, try a home workout. There are even yoga classes for you and your dog.

Sit ups at home are great for whatever pet you have. A co-operative cat or dog can be held and used as added weight or you can throw a treat each time you raise your head and shoulders and hopefully your pet will return to you for another.

Squats or lunges are great if your pet is obliging. Hold them in your arms and bend your knees up and down. Repeat as many times as your pet allows.

Doing a push-up is very similar to the body language of animals when they want to play. Front paws lower than their rear and a great tail wag. Your push-up can be the same. Or train them to sit on your back to add a challenge to your push-ups

Make sure you end with stretches; your pet will be right there with you.

***Ensure you and your pet get a check-up from the GP and vet to say you're both good to go.***



# WORLD PARKINSON'S AWARENESS DAY

Here are some ways you can get involved:

April marks World Parkinson's Awareness Month, a time dedicated to spreading knowledge about Parkinson's and supporting people living with this condition. Parkinson's is a neurodegenerative disease that affects millions of people worldwide, including 70,000 right here in New South Wales.

At Parkinson's NSW, we are committed to supporting individuals and families affected by Parkinson's. But we can't do it alone – we need your help to raise awareness and make a difference in the lives of those living with Parkinson's.



**Spread the Word:** Share information about Parkinson's on your social media platforms, in your community, and among your friends, family and colleagues. Educating others about the symptoms, challenges, and available support for Parkinson's can help reduce stigma and increase understanding.



**Learn and Educate:** Take the time to learn about Parkinson's and the challenges faced by those living with this condition. The Introduction to Parkinson's is a free, short online course about Parkinson's disease, its symptoms and practical ways to improve quality of life.



**Step Up for Parkinson's in May:** Join the Parkinson's community and challenge yourself to get fitter and healthier and raise funds for people living with Parkinson's.



**Donate and Support:** We can't do this without the generosity of your support.

Access resources, fact sheets and more on the Parkinson's NSW website [www.parkinsonsnsw.org.au/world-parkinsons-day-2024](http://www.parkinsonsnsw.org.au/world-parkinsons-day-2024)



## Food, mood, & 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.

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 Over or under eating U Heart palpitations U Fatigue/weariness

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 can strengthen your immune system, maintain bone strength, and manage cholesterol.

**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.*

## Partnering Through Parkinson's Carol & Alan Rose

For 43 years of marriage, Carol and Alan Rose have been partners – not just in life, but for many years in work and hobbies as well.

Alan, a builder and plumber, and Carol lived at Deepwater, in the New England area, for four decades. They ran a successful building business until Alan retired at age 64.

For many of those years Carol worked side by side with him, as they travelled 'putting houses together,' as Alan describes those hectic times.

*"I used to do a lot of the sawing of the treated pine," recalls Carol, who says she had concerns about working with the chemically treated timber. "I rang the company and they told me that provided I didn't use it for firewood it was fine. I'm not so sure now."*

Carol, 77, was first diagnosed with Parkinson's a few years ago and has since had a tentative diagnosis of Multiple Systems Atrophy, which is similar to Parkinson's but more severe.

*"She is still being treated for Parkinson's," explains Alan, 81. "We still don't know which it is, but Parkinson's is the closest and we have the most information and support there. Carol doesn't have the shakes, and it was a very slow progression."*

*"In her early 50s Carol had essential tremor in the head, and then got past that. Then she would fall down sometimes in the early stages, and stumble on walks. She has had some speech deterioration and is losing some control in her hands and in using the computer."*

Alan and Carol sold up their large Deepwater home to downsize and move to Evans Head, where they would have warmer weather year-round and be closer to services and support.

*"When we retired we would always travel with our caravan from April for six months each year," says Alan. "We travelled this section of the New South Wales coast for many years and would sometimes go as far as Western Australia fishing and fossicking. We'd go back and check out the places we liked so when it was time to move we knew Evans Head was where we wanted to be."*

The massive task of downsizing and setting up a new home has taken Alan longer than he would prefer, as he is Carol's main carer.

*"We do get a few hours of housework and gardening assistance, and some meals on wheels and we have a Parkinson's Specialist Nurse, but I sometimes feel frustrated that I'm not out and working on something," says Alan, whose time is taken up with daily household tasks for both of them.*

*"I do have my down days," he says. "But generally we just take things one day at a time. We've joined Probus and we enjoy that, and we do the Parkinson's Support Group meetings which are very informative."*

# Love gives you strength

# Being loved gives you courage

*"We live in an over-50s housing complex, and we love it here. People visit and will pop in a few times a day. The biggest problem is if Carol falls over and can't get up."*

*"Carol has trouble walking and standing up straight because she has crushed vertebrae. She has delicate skin and cuts can turn into ulcers. It's so hard for her to do exercises because she can't go into the pool because of the ulcers. Each problem is only minor, but one thing stops her doing another."*

Alan has put his building expertise into making their home and caravan more accessible for Carol.

*"I put in a car ramp so Carol can go from the patio level and take a lift down," explains Alan. "We have an electric scooter downstairs and one inside the house for her to get around. We have rails inside the caravan so Carol can move about."*

While the long fossicking trips they enjoyed together are in the past, Alan and Carol still enjoy days out and travel when they can.

*"We used to go fishing and fossicking and we would dig really big holes," says Alan. "We dug one 14 feet deep and the top four feet was solid clay! At home I'd cut gemstones and do silverwork and Carol would do jewelry."*

*"I'm also an artist and paint. We used to do line-dancing and loved it. We've always done most things together. Some people have a hard time knowing what to do when they retire but we didn't; it gave us time for our hobbies."*

*"These days we still go fossicking when Carol feels like it and I'll set her up with the shaker-sieve while I'm doing the digging. We are going away to Fraser Island for a week, and we are going on a cruise over Christmas."*

*"We can't book too far ahead because we don't know how Carol will be. But every few months we go away for at least a week. We cope because we take one day at a time, and we've always been good mates."*

*"We are still trying to do as much as we can," says Carol. "I'm hoping to increase my exercise and get my mobility going. We are really good mates."*

*"We've worked together seven days a week with long hours and had a few barneys on building sites. We built our own home and got top price when we sold. We've packed a lot into our lives and unfortunately this has happened."*

*"We've just got to learn to accept it. Take every day as it comes."*

# Be part of a future

where no-one has to  
face Parkinson's alone.

By leaving a gift in your Will, you can give people living with Parkinson's a better future.

Without access to specialist information and supports, the Parkinson's journey can be a lonely one. It can be filled with fear, grief – and misinformation.

But through your legacy, people with Parkinson's – and their carers and loved ones – don't have to feel they're going it alone. You can empower them every step of the way.

You'll be making sure people can always access expert, specialist supports and information that helps them be part of life in their community and make the most of every moment.



**Your legacy** Your kindness will impact the lives of countless people into the future, giving them expert, specialist support so they don't have to face Parkinson's alone.

**Our shared vision** You'll be part of the greater mission to empower people through knowledge, information, education and advocacy.

**Their future** Your gift gives people living with Parkinson's a better future – a future where they have more chance to make the most of every precious moment and a future where they will have access to expert and quality services whenever needed, and wherever they live.

## A legacy that lives on: John's story

John decided to leave a gift in his Will to Parkinson's NSW to honour his late mother Patricia, who had Parkinson's for 20 years.

*"She was only 59 when she was diagnosed, just when she was looking forward to retirement. I saw what she went through.*

*I also donate to Parkinson's NSW every year, and I know exactly what they do with my money because they tell me about the difference I'm making. They have such a personal approach. They make me feel like my gift is really valuable.*

*I know I'm helping employ nurses in regional areas to help people with Parkinson's. Their services are really hands-on. This is stuff that really, really helps people."*



We welcome the opportunity to discuss how you can be part of a future where no-one has to face Parkinson's alone. We are happy to help with any questions you may have about leaving a gift in your Will. Please call our Donor Development team on **1800 644 189**.

*"Thank you for thinking of people living with Parkinson's now and into the future."*

