STANDBYME

OFFICIAL PARKINSON'S NSW MAGAZINE

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In this issue...

This Autumn issue of Stand by Me contains a mix of interesting, useful, and visually stunning articles.

The visuals come courtesy of Hamish 'Rocky' Sutherland who is living with Parkinson's – but doesn't let that stand in the way of taking creative and impactful photographs. We tell his story in the latest installment of our My [Parkinson's] Life series.

There is also rich content around the challenges of daily life, including a useful web site on driving safely as we age, and articles on the importance of looking after your bone health, and the latest update on the Walking Tall digital phone application which helps combat difficulties with walking.

Parkinson's NSW CEO Mary Kay Walker gives an update on our most recent advocacy efforts on behalf of the community, and don't miss the opportunity to participate in some new research by Neuroscience Research Australia (NeuRA) which is conducting a study of the Natural History of Parkinson's Disease.

Our autumn fundraising appeal is also underway, so read the story of Wendy, a dedicated schoolteacher and busy mum, who recounts how her life would be a lot tougher without the support of Parkinson's NSW.

It's all here in the Autumn edition of *Stand by Me.*

Rocky Sutherland Nullawill silo Victoria

Intensive advocacy to the NSW Government

Mary Kay Walker, the CEO of Parkinson's NSW, has had a very busy couple of months conducting an intensive advocacy campaign aiming to reach as many NSW Government decision-makers as possible.

Her campaign followed on the heels of a formal budget submission proposing that the NSW Government co-invest with Parkinson's NSW and commit to a 3-year funding cycle to grow essential services delivered by our organisation.

Parkinson's NSW is a not-for-profit entity, not a government organisation. It receives less than 10 percent of its operating costs from NSW Government grants. The balance of funding for essential services to the Parkinson's community comes from hard-earned community fundraising, including support from individual donors, corporate partners, fundraising events, and people leaving gifts in their will (bequests).

> ***"While equivalent peak bodies for other degenerative neurological disease have been well supported to execute their missions, Parkinson's NSW has received modest funding from the NSW Government in recent years, and currently has no significant ongoing funding in place," said Mary Kay***
>
> ***"It has become unsustainable for our organisation to keep pace with growing demand without co-investment by the NSW Government – which is what we proposed in our formal 2026 Budget submission some months ago."***
>
> ***"What I have been doing since then is meeting as many key Government Ministers, Members of Parliament and Policy Advisors as possible to strongly put our case for increased investment in services for the NSW Parkinson's community."***

Philip Donato MP and Mary Kay Walker

This intensive advocacy campaign involved 27 meetings with key officials in electoral offices and Parliament House over a six-week period, plus the gathering of a dozen letters of support from Members of Parliament to the Minister for Health, urging favorable consideration of the Parkinson's NSW proposal.

If successful, the co-investment with the NSW Government over a three-year period will fund:

- Additional clinical nurse support for the **1800 InfoLine**
- Expansion of Counselling services
- Update and expansion of clinical information
- Establishment of additional Support Groups and an additional Support Group Officer.

Life would be a lot tougher **without** Parkinson's NSW

In her early 50s, Wendy, a dedicated schoolteacher and busy mum, started feeling unusually tired. She lost weight without trying, and a cold she caught on holiday simply wouldn't go away. Her doctor eventually delivered the news no one wants to hear:

"I think it's Parkinson's."

Wendy was shocked, as was her husband and their teenage children. Life had always been full and fast-paced. But suddenly, Wendy was the one who needed support. That's when she turned to Parkinson's NSW.

> ***"I went to an information day and I was so impressed," Wendy recalls. "I knew this was an organisation that knew what they were talking about. I've been in touch with them ever since."***

A Parkinson's diagnosis can feel overwhelming. It brings fear, uncertainty, and often a deep sense of isolation. At Parkinson's NSW, we are here to change that experience, to be a support crew for people like Wendy and their families.

From practical services and information to compassionate guidance and connection, we give people what they need to find a path forward. No one should have to face Parkinson's alone and thanks to generous supporters, they don't have to.

Parkinson's is one of the most common neurological conditions in our community and unfortunately, it's on the rise. It's also deeply misunderstood. Wendy was surprised to learn how varied and complex the symptoms can be, ranging from tremors and movement issues to brain fog, anxiety, speech difficulties and more.

Having Parkinson's has changed Wendy's outlook in many ways, she says. In 2023, she and her husband went on a long overseas holiday together. As she says,

> ***"If something comes up, I try to do it immediately. don't wait for later."***

She's also keen to do everything she can to give back to the Parkinson's NSW community, including taking on the Step Up for Parkinson's challenge in May.

Wendy with her sisters, Lyne (centre) and Jenny (right)

Wendy with her family

Our support crew is needed more than ever

This year, we've seen more people living with Parkinson's and their carers reach out to us for help

- **3,400 calls to InfoLine**
- **240 in-patient and clinic consultations with Parkinson's Nurses**
- **230 counselling sessions**
- **Over 2,500 support group members**

Find out more

Please help Parkinson's NSW to keep supporting people like Wendy to navigate the challenges of Parkinson's in the years ahead

Useful resources on driving safely as we age

The Driving Ageing and Health Research Team (DART) has launched a very informative and useful web site called Ageing Well on the Road.

DART is led by Professor Kaarin Anstey, Director of the University of NSW Ageing Futures Institute and Senior Principal Research Scientist at Neuroscience Research Australia (NeuRA). This research team is dedicated to pioneering research in cognitive ageing, dementia, and automobile driving safety, among other areas.

Professor Anstey and her team are particularly well known for their innovative work in older driver safety.

DART
Driving, Ageing & Health Research Team

The web site features helpful tips and tools including:

- How to manage vision to ensure safe driving
- How medical conditions affect driving
- How memory and reaction speed affect driving
- How medication affects driving
- How to manage your physical abilities for safe driving
- Tips on driver knowledge and skill development
- Information on new technology in cars which enhances safety
- A cognitive health and dementia risk assessment

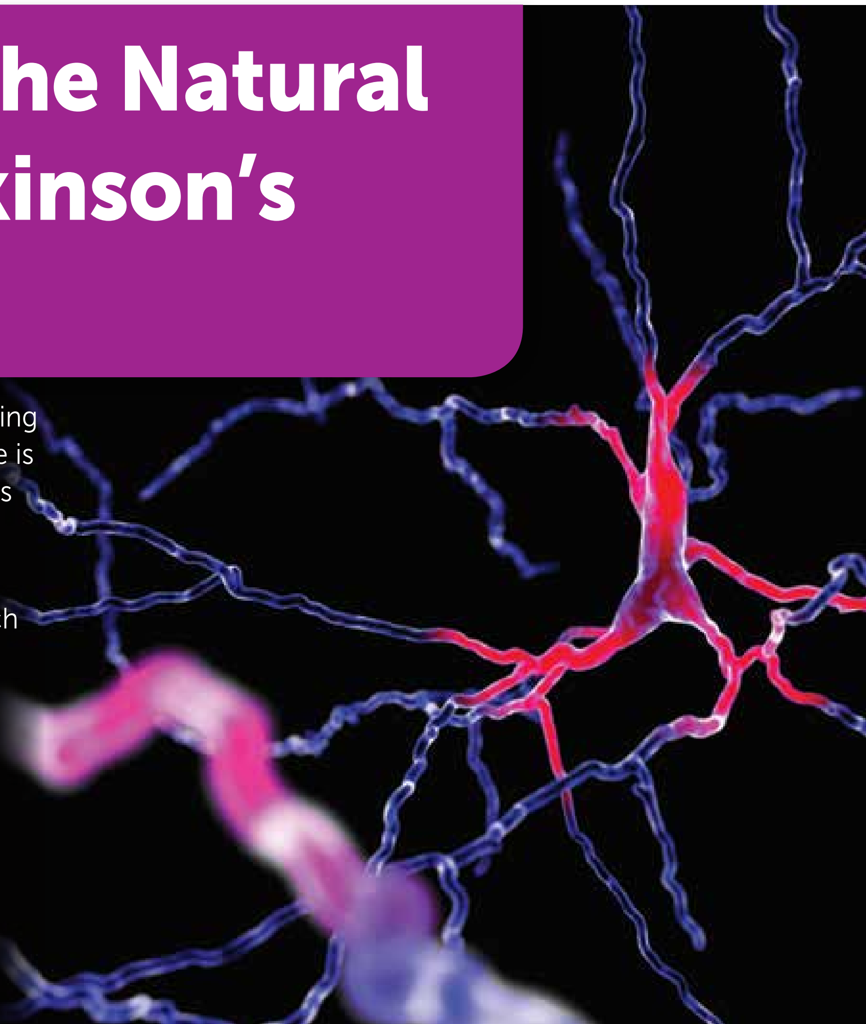
To visit this useful web site, go to:
https://ageingwellontheroad.com.au/

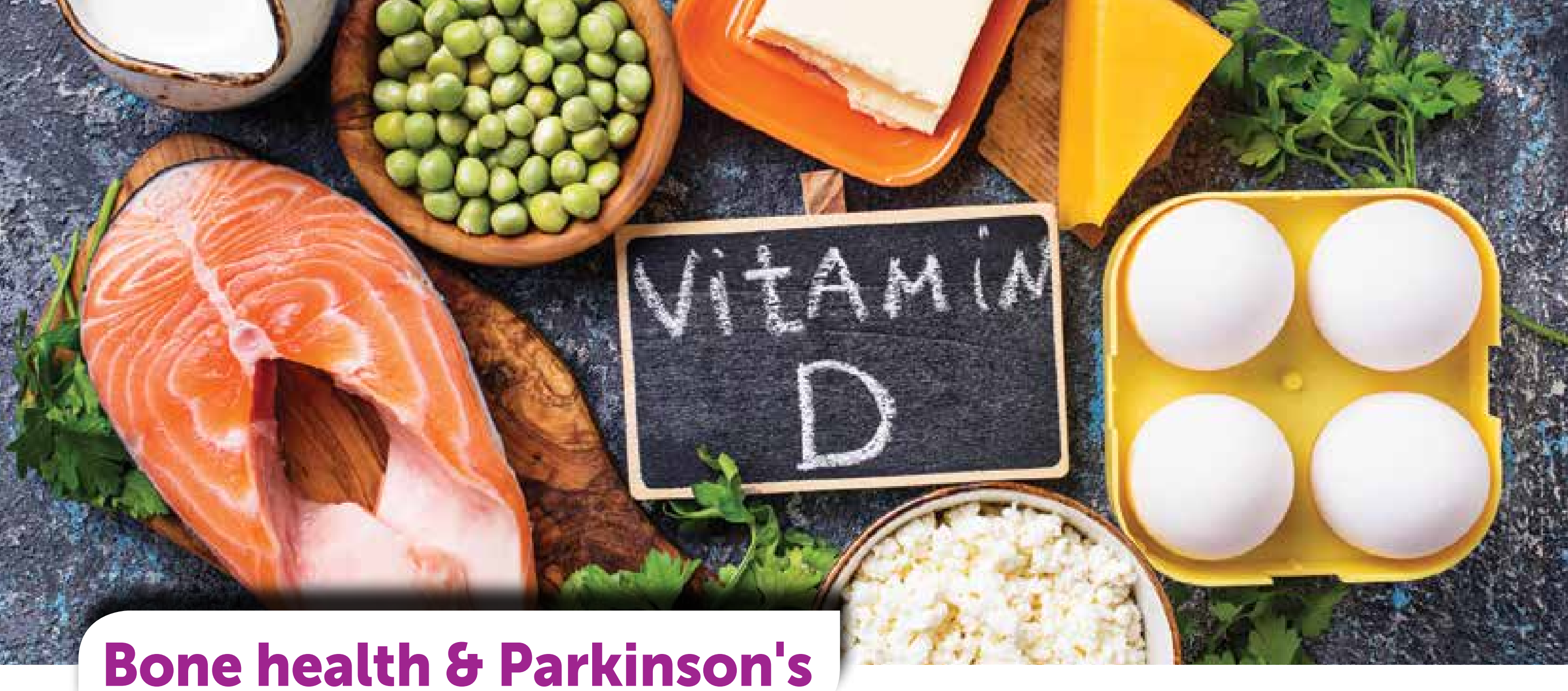
Participate in the Natural History of Parkinson's Disease Study

Neuroscience Research Australia (NeuRA) is conducting a Natural History of Parkinson's Disease study. There is an opportunity for 100 people living with Parkinson's and 50 individuals without Parkinson's (who would make up a control group) to participate.

This study is an opportunity to contribute to research that could lead to breakthroughs in Parkinson's treatment and care.

Sign up for the study by completing the form found here: https://forms.gle/fHnj3BnKsKjgM48v5 or **email clinics@neura.edu.au** to express interest, ask questions and obtain further information.





Bone health & Parkinson's

People with Parkinson's have a higher risk of fracturing a bone than the general population, so it's especially important to look after your bone health.

Key points

- Bone health is important for everyone, but especially if you have Parkinson's.
- You are at more risk of getting osteoporosis when you have Parkinson's, which can weaken bones and make them more likely to break.
- Your healthcare team can assess you and may prescribe medication to help improve your bone health.
- Strength exercises and maintaining a good diet can also help.

What is bone health?

Bone health really means having 'healthy bones'. Healthy bones are strong enough to prevent fractures, for example when we have a fall. Our bones are more healthy when we have enough calcium in our diet (from milk, and dairy products like cheese) and when we use our arms and legs (such as with exercise).

Both women and men need to make sure that they do the right things to keep their bones healthy.

Why is bone health so important if you have Parkinson's?

Bone health is important for everyone, but especially if you have Parkinson's. This is for lots of reasons.

Osteoporosis is a condition that affects the bones, causing them to become weak and fragile and more likely to break. It's often diagnosed in people with Parkinson's.

The absorption of important nutrients like calcium is reduced if you have Parkinson's. This can result in thinner bones that increases the risk of a fracture.

Loss of balance and falling affects many people with Parkinson's. If your bone health is poor, a fall could lead to a broken bone.

Women are generally more likely to have 'thinner' bones than men, and bones become thinner as we get older. But men who have Parkinson's may also develop thinning bones. So both women and men need to make sure that they do the right things to keep their bones healthy.

How does someone know how good their bone health is?

A number of different factors can help to work out what your risk of poor bone health is. These are combined in a 'risk calculator' that works out your future chance of having a bone fracture (usually over the next 10 years).

Your specialist, Parkinson's nurse or GP can calculate your risk score. The Royal Osteoporosis Society also has a risk checker you can use. Visit the website **https://theros.org.uk/risk-checker**

When the risk is high, there are treatments that help to thicken bones and prevent fractures.

When you're at medium risk, you may be sent for a bone scan, also called a DEXA scan. This takes a scan of your bone density and can help decide if any treatment is needed.

When the risk is low, medication is not needed, but you should try to protect your bone health. See below for ways you can do this.

What can someone do to look after their bone health?

If we become inactive our bones get thinner, which increases the risks of having a fracture. Physical activity and exercise is good for bone health, as well as helping you manage your Parkinson's symptoms.

Diet is also very important, particularly calcium. Sources of calcium include milk and dairy products like cheese. Try to aim for 3 servings of milk or dairy foods every day to get the calcium you need.

Vitamin D helps to keep your bones healthy and helps your body absorb calcium. Most of the vitamin D you need comes from the effect of sunlight on your skin but what you eat can also help, especially during the winter. Good sources of vitamin D include oily fish (such as salmon and mackerel), red meat and eggs.

Sources:
Professor Donald Grosset, Consultant Neurologist Parkinson's UK

Walking to a new beat

The simple yet powerful app helping people around the world improve their gait and better support their general health.

A simple yet powerful digital phone application called Walking Tall is helping people around the world improve their gait and better support their general health. Launched in 2023, the concept of Walking Tall has now been further developed.

University of NSW biomedical engineer Associate Professor Matthew Brodie developed the application which is helping tens of thousands of individuals combat difficulties in walking. With the help of research fellow and Director of Parkinson's NSW, Martin Ostrowski, the two have focused their efforts on assisting those suffering from health concerns that impact their ability to walk.

These include but are not limited to Parkinson's disease, diabetes, stroke, heart failure, kidney disease, dementia and sleep issues. The Walking Tall application has been translated into multiple languages and made freely available for worldwide community use via the Apple App Store and Google Play.

> *"We wanted to create technology that could help people walk because insufficient physical exercise is a major risk factor for a number of conditions," said Associate Professor Brodie. "This is what's inspired me to create research that one day could potentially help over 100 million people walk with confidence."*

The Walking Tall application works by delivering a simple metronomic beat across three different walking speeds that have been designed to trigger movement. With everyday use of the application, individuals can not only learn to walk better but walk for longer, reduce falls, and improve overall mobility.

A personal connection

With his own history of Parkinson's disease, Dr. Ostrowski has used his lived experience to help with the application's development.

> *"When I first came into contact with Matthew, I was running 35km a week but over time that degraded into less than 2km per week," he explained.*

Following his participation in the application's first trial, Dr. Ostrowski was able to return to running 35km a week within two months. What truly surprised him, however, was how his other health concerns also improved.

> *"I'd had trouble with breathing but simply going out and walking gave me a chance to stand up straight and fill up my lungs," he adds. "I had to learn how to walk and run again, but without the app I'm not quite sure where I'd be."*

The next step

Thanks to the application's ongoing success, Associate Professor Brodie is now committed to the next phase of the project. This includes a wearable band solution that can be strapped to the users' arms or ankles.

In this instance, a prototype is to be attached to bands and worn above the ankles. The new device will work by synchronising neuronal stimulation across limbs, which has already been proven to help people with spinal cord injury regain function.

While the Walking Tall application provides the metronome beat and can measure how you're walking, the bands work in combination with the app.

> *"I've been a scientist for more than 25 years but being able to work on something that has direct impact is really attractive," said Dr. Ostrowski. "The moment you start walking well, everything gets better."*

Sources:
University of NSW www.unsw.edu.au/engineering/research-technology/is/walking-to-a-newbeat

My [Parkinson's] Life

Hamish 'Rocky' Sutherland

Hamish 'Rocky' Sutherland was born in Albury, New South Wales, and grew up on a farm in the Upper Murray area.

"Dad nicknamed me Rocky as a child and everyone calls me that," explains Rocky, now 53. "I had an idyllic childhood and did all the things kids don't seem to do much today. I would go up to the hills to check rabbit traps, milk the cows and do things before and after school and I loved the lifestyle.

"After I finished my HSC, I had a gap year working on the farm and then I went to England on a holiday to visit friends. I discovered travel there and loved it, and ended up going all round the world for seven years. I would spend half my time working and then travel and I was going to all different countries. I went to North and South America, Africa, the Middle East and Southeast Asia. It was an amazing experience."

After that Rocky moved to working on a cattle station in Texas, Queensland, for a few years.

"While I was there I met a Dutch backpacker and we fell in love and got married," says Rocky. "There was a bit of a drought in Queensland and farming wasn't going well but there was a mining boom on in Western Australia, so we bought a caravan and headed across the Nullabor to do a lap of Western Australia and find a place to settle.

"When we got to Kunanurra it was our last stop, and I got a job in construction and worked over there for eight years."

Unfortunately, the marriage ultimately broke up and in 2017 Rocky made the move back to Albury.

"While I had been working in Western Australia I'd found I was increasingly really struggling with fatigue," says Rocky. "It was really hot and it was really oppressive fatigue, and I was struggling to cope. I was eventually diagnosed with CLL (chronic lymphocytic leukaemia), which is a type of leukaemia which creates fatigue.

"I had that and all these different symptoms, and when I moved back to Albury in 2018 I was diagnosed with Parkinson's. It was the worst experience of my life. The neurologist had no bedside manner, and it was a huge shock. I was on my own and came out crying my eyes out and they're just saying here's the bill, you have to pay $500.

"Afterwards I remembered that my left hand had been dodgy and really slow, and that arm didn't swing when I walked. I spoke to friends later who said they had noticed I wasn't talking as clearly to them."

After a visit to the local Parkinson's support group, Rocky, then 47, decided he would try to form a group for younger people.

"It was all old people in wheelchairs," recalls Rocky. "I wanted to find people under 60. I did a bit of research and the people from Parkinson's NSW helped me set up Young@Park. Most people in it would be in their mid-60s and they're all lovely people, but I really want to help younger ones. But we are gradually getting more members.

"Every Wednesday we have a coffee meet-up, we also do Sunday lunches and Wednesday night dinners at someone's house," he explains. "We have had a few guest speakers and enjoy the camaraderie as we are all in the same boat.

"I found that being diagnosed I went through the same stages of grief as a death. Shock, I was dumbfounded; anger, sadness; but the sooner you can start to accept it the better. The quicker you can get through to the other side and become at ease and accept it, the easier it becomes.

"It opened my eyes a bit, going from a very deep, dark place. My girlfriend had left me, and I had to adjust to a whole new normal."

Rocky now has a good support system of friends and family.

"My father died a while ago, but Mum is 88 and loves to cook for me. My sister and my ex-wife look after me as well. My son is 14 now and is a lovely boy with a very caring side.

"We'll go out to the farm and do a few jobs, I pay him for work he does and he'll give me a hand when I need it. If I need assistance when I'm out – such as in a supermarket – I will just ask people, and explain that I have Parkinson's. Most people will help with something."

Rocky is also a keen photographer and uses drones, both for landscape photography and for checking on cattle on the farm.

"I love photography, particularly astrophotography which is photographing the stars and the Milky Way," says Rocky. "You need to get out of town and away from the light pollution for that. I drove across the Simpson Desert with a few friends in a four-wheel drive.

"Got some nice photos from that trip. Now a gallery in France wants to do an exhibition of my photos and I am getting information on that."

Mountain biking is another unexpected hobby Rocky took up when he was told to 'do the exercise that you hate least'!

"I do more exercise now than I would have if I didn't have Parkinson's," says Rocky. "And mountain biking also helps with balance.

"I always say to people that Parkinson's is your new normal. Get over any stigma about having it. You're at a higher risk of depression with it, and I take antidepressants which helps me manage it.

"The future starts now, don't worry about what might happen later. Get on with today."

IN THIS TOGETHER
parkinson's
NSW

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."