

MESSAGE FROM THE PRESIDENT



Nearly April already!

At our last monthly meeting we had Anne Hogan talking about her early years growing up in New Guinea and the Solomon Islands. It must have been a huge adjustment from there to boarding school in New Zealand. The photos were delightful.

Then Wendy Barker took us through the process of completing a survey for the *WE HEAR YOUR VOICE* project being conducted by Professor Simon Lewis (see page 6).

There will be no meeting on the first Friday of April (3/4) because that is Good Friday. And then Friday May 1st is our Barbeque at Bobbin Head.

I ran into Angela Hogan at the Opera House last week. She is very excited about coming to perform for us at our annual concert in August. We can only make 120 tickets available, so let us know if you are coming when the booking opens in July.

It is very pleasing to see our Friday exercise class with the Fabulous Felicity nearly full with 20 people attending. And don't forget walking group which meets at Asquith Park on Tuesdays at 10am.

Stay fit, stay positive.

Rose



Angela Hogan, much-lauded Sydney-based mezzo-soprano, with reputation as one of Opera Australia's most diverse and powerful performers.



ACTIVITIES / EVENTS

Tuesdays 10.00am	Walking Group (each Tuesday - free)	Asquith Park, Mills Ave, Asquith
Thursdays 10.00am-11.30am	Parkinsong (each Thursday, \$15 per session) See 30 April below	Turrumurra Seniors Centre Gilroy Rd, Turrumurra
Fri. 3 April	NO Members' General Meeting will be held as it coincides with Good Friday.	
Thurs. 9 & 23 April 12.15pm - 2.00pm	Craft Group (2 nd and 4 th Thursdays - free)	Contact Rose on 0412346301
Fri. 10, 17 & 24 April 11.30am-12.30am	Exercises (each Fri. except first Fri. of month, \$10 per session)	Mt Colah Community Centre 6X Pierre Cl, Mt Colah
Thurs. 30 April 10.30am-11.30am	Choir - Performance Regis Hornsby Nursing Home	245-247 Peats Ferry Rd Hornsby
Fri. 1 May	Members' Picnic at Bobbin Head (free National Parks pass can be obtained at Services NSW)	Details to be advised
Fri. 5 June	Members' General Meeting - <i>Guest Speakers from Medtronic Deep Brain Stimulation</i>	Mt Colah Community Centre 6X Pierre Cl, Mt Colah
Sat. 6 June 10.30am-11.00am	Market Stall & Choir performing at Berowra Uniting Church (see details below)	Berowra Uniting Church Alan Road, Berowra
Fri. 3 July	Members' General Meeting - Guest Speaker on <i>Search Dogs</i> , Sydney	Mt Colah Community Centre 6X Pierre Cl, Mt Colah
Fri. 7 August	Members' CONCERT - Angela Hogan from Opera Australia	Mt Colah Community Centre 6X Pierre Cl, Mt Colah

The Parky Choir will be performing from 10:30 until 11:00 a.m. Delicious scones are available to have with your morning tea/coffee and you can also enjoy a sausage sandwich for lunch to top up your energy levels!!!

We'd also appreciate any hand made knitted or crocheted garments AND any biscuits, slices or cakes to sell on our stall. Diana Sidney



STEPUP STUDY - UNSW & NEUROSCIENCE RESEARCH AUSTRALIA

I was diagnosed with Parkinson's Disease 7 years ago. Almost 2 years ago I started to develop stiffness & difficulty walking with my left leg.

My Facebook page posted an advertisement seeking candidates for a research Study on Gait Training for Parkinson's Disease. The study aims to understand why treadmill training can improve gait & balance for those living with Parkinson's Disease.



I want to do whatever I can to help myself and I think this study could help me. I phoned the coordinator who was friendly & interested in my problems and she organised an assessment appointment.

My 3 hour assessment was in Randwick where I completed puzzles, cognitive testing, walking tests and more, before being hooked up to a treadmill. I wore a safety harness and a cap to register brain activity together with many sensors adhered to my body in order to measure muscle and motion activity.

After passing the assessment I am scheduled for treadmill training once a week for 12 weeks. Some participants will experience virtual reality.

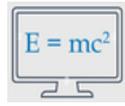
For any questions please contact the team at stepup@neura.edu.au 0492 832 949

Beverley Dind





CHOIR



Working with the Chris Davis choir while Naomi was in Hungary was a great experience, and I'm looking forward to returning next term!

I've been singing my whole life. I studied various Maths-Physics-Computer Science things at university but, during my studies in 2017, I joined the *Spooky Men's Chorale*, jumping in the deep end with tours of regional NSW, Australian capital cities, the UK, and Denmark in my first year. I continue to perform with them frequently, and the musical journey that they kick-started eventually derailed my plans to work in a more technical field.

In 2019, I joined Naomi's community choir *Alternata*, and started leading some songs later that year; I've been co-leading it with Naomi ever since, and have really enjoyed watching the community grow and deepen. Naomi and I also run *Sing Summit*, singing weekends open to all, where we learn songs and generally have a lovely time.

I'm also in a few other musical acts. I play guitar and sing in *The Sofa of Fools*, a lovely little semi-acoustic trio that enjoys cake as much as (if not more than) playing music. I play bass guitar and sing in *Ant Gallery*, a funky-folky four-piece alongside two sisters and my brother. I also teach several students privately, and I'll be taking on several of Naomi's choirs and most of her guitar students while she's on maternity leave. This will be quite an interesting year!

John Fitzgerald Sice (Jack)
jfitzgeraldsice@gmail.com





EXERCISE TIP A Simple Hand Challenge for your Brain

Make a peace sign (✌) with one hand and an OK sign (🍷) with the other.

Now switch them.

The hand making the peace sign changes to the OK sign, and the hand making the OK sign changes to the peace sign.

Then switch again.

At first it might feel slow or a bit confusing – that’s completely normal. The goal is simply to keep practising the switch and gradually see if you can speed it up. This little drill works on two things at once:

- Manual dexterity – controlling the fingers
- Brain coordination – getting the brain to manage two different actions at the same time.

If you practise for a minute or two each day, you may find the switching becomes quicker and smoother.

One small note: This is best practised at home! In some cultures the “OK” symbol means something very different and can even be considered extremely offensive. Best not to accidentally send the wrong message in public.

Felicity Neale

Body Management Systems
Program creator & head instructor
Strength With Purpose
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Peace sign in one hand



OK sign in other hand - then swap them as quickly as you can

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'WE HEAR YOUR VOICE' RESEARCH

Our Wendy Baker, is involved with this research and, together with the research team, is very grateful to those who have submitted their selection. If you don't have a copy of the research document, please complete the following condensed form and email to nicole.scholes-robertson@sydney.edu.au. Number from 1 being the most important phrase ie the phrases you think you and your family would use the most in your day-to-day life. Please add any other phrases you think are important, and include them in the ranking.

NAME: (https://www.parkypeople.org/)

Email Address: **Date:**

Diagnosis: **Age:**

Circle One: Person with : **Neurologic diseases** : **Caregiver** : **Family member**

I give/do not give consent to list me as a co-author for *We Hear Your Voice* purposes only.

The research is co-designed with consumers to customize, evaluate, and implement a new mobile-phone based Speech Recognition Technology called JASPER (Joint-development Application for Speech Recognition). JASPER aims: (1) improving quality of life for people with Chronic Degenerative Neurologic Diseases through better verbal communication, and by (2) maintaining independence through better access to other voice-controlled assistive technologies. The forms that people fill out will help us to identify the top 10-20 commands to include in the voice recognition software for use by people with Parkinson's Disease.

Your feedback and ranking of phrases will be summarised into a report/s which will be submitted for publication in a scientific journal with all people who have helped invited to be named as co-authors. No statements contained in the report/s will be identified by name. On behalf of the research team, we thank you for your support and providing vital lived experience insights to our project. *Nicole*

- | | |
|---|--|
| <u>My name is xx. I have xx (PD,HD,MND)</u> | <u>What's the weather like today?</u> |
| <u>Find my phone.</u> | <u>Stop listening</u> |
| <u>What's on my shopping list?</u> | <u>Hey Facebook</u> |
| <u>Hang up</u> | <u>Lower the temperature</u> |
| <u>Make the text larger</u> | <u>I have pain today/feel unwell</u> |
| <u>Decrease volume to minimum</u> | <u>Tell me the news</u> |
| <u>What's the temperature in living room?</u> | <u>Turn off the heat</u> |
| <u>Add this music to favourites</u> | <u>Increase volume to maximum</u> |
| <u>Hey Google/Alexa/Siri</u> | <u>Start listening</u> |
| <u>Open reminders</u> | <u>Turn on cooling</u> |
| <u>What's on my calendar tomorrow?</u> | <u>Turn on all switches</u> |
| <u>What restaurants are nearby?</u> | <u>Please call xxxxxxxx</u> |
| <u>Answer the call</u> | <u>I am hungry.</u> |
| <u>Turn off the TV</u> | <u>Calling an uber/taxi</u> |
| <u>Cortana</u> | <u>I am unable to talk, but I can hear you</u> |
| <u>What's the time?</u> | <u>Find the car keys</u> |
| <u>Skip this song</u> | <u>Can you take me to the bathroom?</u> |



MANAGING FATIGUE AND PARKINSON'S DISEASE: SIX TIPS FOR MORE ENERGY

Medically reviewed by [Federica Polidoro, M.D.](#) ; Written by Heather Lander, PhD. and Emily Van Devende. (Updated on January 14, 2026)

Key Takeaways

- Fatigue is a common symptom affecting up to 80 percent of people with Parkinson's disease at some point, causing deep exhaustion that doesn't improve with rest and can feel both physically and mentally draining.
- This tiredness can be constant or come and go, making everyday activities like showering or socializing feel overwhelming. Research suggests fatigue in Parkinson's is mostly caused directly by the disease itself through inflammation and changes in specific parts of the brain that control movement and important chemical messengers.
- Managing fatigue may include planning activities during your most energetic times, staying physically active with exercises you enjoy, allowing yourself to rest when needed, and talking with your healthcare provider about whether your medications might be adjusted to help reduce tiredness.

If you're living with Parkinson's disease, you may often feel run-down or low on energy. You might even feel a deep, bone-tired exhaustion that doesn't improve with rest. These feelings of intense tiredness are known as fatigue. Fatigue is a symptom that affects up to 80 percent of those with Parkinson's at some point in their Parkinson's journey.

Many MyParkinsonsTeam members talk about living with fatigue. One member shared, *"I have been just unbelievably tired and unable to make myself have energy for anything. I didn't know what was happening. I have raised three kids and ran a mini farm with lots of critters. Now taking a shower is exhausting."*

The Impact of Fatigue on Those With Parkinson's

Fatigue in Parkinson's disease can be debilitating. It may feel like physical exhaustion that leaves you completely drained. Some people describe it as a level of tiredness that makes moving feel nearly impossible. It's not just sleepiness – it's a deep sense of weariness, with so little energy that even getting out of bed or off the couch can feel like too much.

"I am exhausted ALL the time! I sleep at least 10 hours at night," shared one member. *"After work, I crash in my chair and don't move until it's time for bed. I just want some energy back!"* *"I'm always fatigued. Before Parkinson's disease, I worked full-time as an infection control nurse. I walked 4 miles a week (1 mile a day) at lunchtime and did water aerobics on Saturdays. Now, I am too tired to do most anything."* – A MyParkinsonsTeam member



Fatigue can also show up as mental exhaustion. Mental fatigue makes concentrating nearly impossible and makes it difficult to remember things or follow simple directions. Fatigue may cause excessive daytime sleepiness, no matter how much rest you get. *"Just tired, always tired, no matter how many hours I sleep or how much activity during the day,"* said another member.

Fatigue Can Be Constant and Disabling

For some people with Parkinson's disease, fatigue is constant. For others, it comes and goes. One member shared that they are not always tired or lethargic, but rather, *"it hits me for a whole day. I fall asleep often when sitting after eating, while watching TV, during quiet times, and generally 'doze' when I used to not do it."*

Having mental and physical fatigue can be challenging. At times, they may even feel disabling. These symptoms can make it difficult to do things you love or to participate in social activities. As one member wrote, *"I can't keep my eyes open. I can't walk, drive, or even feel up to socializing, even by phone. I just want quiet."*

What Causes Fatigue in Parkinson's Disease?

Parkinson's symptoms are grouped into motor symptoms, which affect movement, and nonmotor symptoms, which do not. Fatigue is considered a nonmotor symptom of Parkinson's.

When fatigue is caused directly by a disease itself, it is called primary fatigue. When fatigue is caused by other symptoms of the disease, it's known as secondary fatigue. In Parkinson's disease, research suggests that fatigue is mostly primary. Many people experience fatigue before motor symptoms begin.

Fatigue often happens alongside other conditions, such as depression, apathy, sleep disorders, and anxiety. Because these conditions can also cause fatigue, it can be hard for researchers to pinpoint the exact cause.

Current studies suggest that the pathophysiology (underlying causes) of primary fatigue in people with Parkinson's is related to inflammation and dysfunction in specific parts of the brain. This inflammation and dysfunction particularly affects the basal ganglia - the part of the brain that helps control motor function and balance important neurotransmitters, like dopamine and serotonin. Some research also suggests that fatigue in Parkinson's might be related to dysfunction in the frontal lobe. In simple terms, Parkinson's disease affects specific parts of the brain in ways that can directly cause fatigue.



6 Ways To Manage Parkinson's Fatigue

Researchers are still working to better understand the specific causes of fatigue in Parkinson's disease and develop more effective treatment options. In the meantime, there are steps you and your loved ones can take to help manage fatigue caused by Parkinson's.

1. Plan and Pace Your Day

If you've lived with Parkinson's-related fatigue for some time, you likely have a sense of when during the day you feel the most tired and when you have a bit more energy. If any of your medications cause sleepiness as a side effect, you probably know when you take them and when you feel tired as a result.

When possible, plan tasks and activities to happen during those times when you're more energetic or "awake." That way, you can leave space for rest when you'll need it most.

"It may sound strange, but exercise will make the exhaustion go away. Not immediately, but slowly over the course of your exercise." – A MyParkinsonsTeam member

Pace your work when possible, too. The workday can feel long, especially if you experience Parkinson's-related fatigue. But taking short, regular breaks throughout the day can help you stay productive without burning yourself out early on.

2. Avoid Alcohol

Doctors at Johns Hopkins recommend avoiding alcohol if you experience Parkinson's-related fatigue. Even though alcohol can make you feel sleepy while it's in your system, it can negatively affect your sleep cycle and overall sleep quality. Although it might help you fall asleep at first, it can leave you feeling even more tired the next day.

3. Adjust Your Medications

Talk to your doctor about all the medicines you take. Sedating medications, such as antihistamines and sleep aids, can make you feel more tired during the day, so it's important to review them with your doctor, even if they are available over the counter.

Certain Parkinson's medications, like pramipexole dihydrochloride, are called dopamine agonists and act like dopamine. Dopamine agonists can cause daytime sleepiness or sleep episodes, and higher doses may increase fatigue.



MANAGING FATIGUE AND PARKINSON'S DISEASE: SIX TIPS FOR MORE ENERGY (Continued)

As one member shared, "My neurologist recently increased my daily dose of medication to see if it would help with my left-handed tremor. It doesn't seem to help, and the fatigue has worsened, especially in the afternoons."

Medications can be very helpful in managing Parkinson's symptoms, but if you're taking them and still experiencing severe fatigue, a change in dose or medication may be helpful. Always talk to your healthcare provider before adjusting the dosage of a medication you're taking. On the other hand, some medications may help reduce fatigue. Again, talk to your doctor about medication options for managing fatigue.

4. Get Moving

Although fatigue can make exercise feel daunting or out of reach, engaging in physical activity can give you an energy boost that can last for much of the day.

It might be best to avoid vigorous exercise late in the day, but starting your day off with some yoga or a brisk walk may help increase your energy levels. Choose activities you enjoy, such as dancing to your favorite songs or gardening. Working out with another person or in a group might help motivate you. Any activity that raises your heart rate and boosts endorphins will be beneficial.

MyParkinsonsTeam members have shared their experiences using exercise to combat fatigue. "I do two hours of exercise every day," said one member. "There are many days when I don't feel up to it, but most of the time I get through it and feel much better."

Another member shared some words of motivation: "It may sound strange, but exercise will make the exhaustion go away. Not immediately, but slowly over the course of your exercise," they said. "You're not going to go full speed right off. You start slow. Anything to get you moving will help. Walking is best. Don't walk alone. Until you're feeling better, you're going to need to have someone with you."

5. Let Yourself Rest

Exercise is great, but it's also OK for you to rest. As one member wrote, "Breaks are essential for your mental health and well-being."

Don't push yourself too hard, even on "good" days. This can leave you feeling even more energy-sapped afterward.



Napping during the day may also help you get a quick energy boost when you feel fatigued. If napping makes it hard for you to sleep at night, you may want to try napping earlier in the day and taking short naps. According to scientists, taking longer naps later in the afternoon can make you feel groggy and interfere with nighttime sleep. Experiment with the length and timing of your naps to see what works best for you.

"I have developed a 'do as much as you can' plan. Then I nap. The naps are usually quite short. I feel refreshed and get back to work." – A MyParkinsonsTeam member

6. Take Care of Your Mental Health

Fatigue can also be a symptom of depression, which can happen alongside fatigue in people with Parkinson's. Get screened for depression and anxiety, and talk to your doctor about possible treatments. Pharmaceutical approaches (like antidepressants) and therapy might help ease mental health issues that make your fatigue worse.

Join the Conversation

On MyParkinsonsTeam, people share their experiences with Parkinson's disease, get advice, and find support from others who understand.

How do you manage Parkinson's-related fatigue?

Let others know!





COMMITTEE MEMBERS

- President, Rose Parkin
- Vice President, Michael Parkin
- Treasurer, Ian Madden
- Public Officer/Membership, Dick Babb
- Welfare Officer, Pam Beattie
- Event Co-ordinator, John Moore
- Music Co-ordinator, Peter Sidney
- Asst. Music Co-ordinator, Diana Sidney
- Secretary, Helen Jordan
- Assistant Secretary, Keith Kennedy



The Committee welcomes advice or suggestions regarding the Association's activities. Please don't hesitate to contact any of the Committee Members as feedback and new ideas are important to ensure we are addressing the needs of our members.



HAVE A STORY FOR THE NEWSLETTER?

Please send to the Newsletter Editor, Helen Jordan (keithandhelenjordan@iinet.net.au) or phone: 0425 339 841 -

- any tips or ideas for inclusion in the next Newsletter;
- any news and photos you would like to share.



CRAFT GROUP

Our Craft Group members would appreciate any buttons which you might have stored away for many years. The newer buttons are mostly plastic and don't last the test of time. If you have any of the older buttons you don't need, they would be very much appreciated. Just bring them along to any of the activities and give to Rose or a Committee Member. Thank you to those who have already contributed - very exciting.



WELFARE CALLS

Please advise Pam Beattie, our Welfare Officer, if you know someone who would welcome a call from Pam - 0435 716 392



Q & A THIS MONTH

Cover this side until questions answered

QUESTION	ANSWER
<i>What kind of room has no walls, doors or windows?</i>	Mushroom
<i>What has many teeth but can't bite?</i>	Saw
<i>What has branches, but no fruit, trunk or leaves?</i>	Bank
<i>I cannot talk, but I always reply when spoken to. What am I?</i>	Echo
<i>Two fathers and two sons are in a car, yet there are only three people in the car. How?</i>	Grandfather, father & son
<i>What goes through cities and fields, but never moves?</i>	Roads
<i>Take off my skin - I won't cry, but you will! What am I?</i>	Onion
<i>Who makes it, has no need of it. Who buys it, has no use for it. Who uses it can neither see nor feel it. What is it?</i>	Coffin
<i>You'll find me in Mercury, Earth, Mars, Jupiter, Saturn and Uranus. But never in Neptune or Venus. What am I?</i>	Letter R