

In Touch Newsletter April 2026

Promising Potential Treatment for Parkinson's

Researchers at Case Western Reserve University in Cleveland, Ohio, say they have developed a promising potential treatment for Parkinson's disease.

It targets toxins that damage the energy factories of nerve cells in the brain, known as the mitochondria.

Professor Xin Qi has studied how mitochondrial damage can lead to neurodegenerative diseases. Her lab was the first to identify tangles of a rogue protein called alpha synuclein as the culprit of the cascade that leads to nerve damage, and eventually Parkinson's disease.

Now she's developed a custom molecule, a peptide dubbed CS2, which blocks alpha synuclein from attacking mitochondria.

"I truly believe the peptide could be one of the therapeutic options in the near future," Qi said.

The CS2 molecule only attacks the toxic form of alpha synuclein and has few potential side effects, she added.

"We found CS2 shows protection with causing any damaging effects," she said.

It's one of the first therapies that attack the root cause of Parkinson's disease rather than just addressing the symptoms.

The peptide has only been tested in mice and on human neurons in a Petri dish so far, but Qi is hopeful it will someday be a frontline defence in slowing the progression of Parkinson's.

She's formed a start-up company called JanusQ to pave the way for clinical trials.

Parkinson's caregivers are under strain, need more support: Report

Average caregiver spends more than 30 hours a week providing care

The average caregiver for someone with Parkinson's disease spends more than 30 hours per week doing unpaid work to provide care, and many report substantial emotional and physical strain.

That's according to a new report from the [National Alliance for Caregiving](#) (NAC), with support from [The Michael J. Fox Foundation for Parkinson's Research](#) (MJFF) and Arcadia University, in Pennsylvania.

"This new research coupled with powerful caregiver stories, shines a light on the important role that family caregivers play in supporting people living with Parkinson's disease," Jason Resendez, president and CEO of the NAC, said in a press release.

"Parkinson's caregivers are navigating one of the most complex care journeys imaginable, often at a great personal cost, yet they do so without the support they need and the recognition they deserve."

The symptoms of Parkinson's disease can make day-to-day activities difficult or impossible to do independently, so many people with Parkinson's rely on a caregiver to help them. Often the caregiver is a friend or family member, such as a spouse or child.

In this report, researchers analysed data from a survey of 72 Parkinson's caregivers, as well as interviews from a handful of caregivers.

Report shines spotlight on caregiver experience

"This report shines a critical spotlight on the experiences of caregivers, offering an evidence-based roadmap to better equip, acknowledge, and empower them as essential partners in Parkinson's care," said Margaret Longacre, a professor of public health and dean of the College of Health Sciences at Arcadia University.

The average age among the caregivers was 61, and most identified as female. Most caregivers had been providing care for more than a year, with more than a third having acted as caregivers for five years or more. Most of the caregivers were married, with nearly 40% providing care for their spouse. Nearly two-thirds of the caregivers said they felt they didn't have a choice in giving care.

More than 60% of the caregivers said they needed to give help with getting dressed and getting in and out of bed or chairs, and nearly half of the caregivers said they needed to give help with using the toilet or bathing. Most caregivers also reported helping with housework and finances, preparing meals, and giving medications.

The report notes that these rates are markedly higher among caregivers for Parkinson's than for other broader conditions. Overall, caregivers were spending on average 31 hours per week doing unpaid labour to help their charge.

"These data suggest that caregivers provide substantial time commitment and extensive care needs," the report states.

Caregiving has impact on employment

Half of the caregivers reported they were working while acting as caregiver, spending an average of 37 hours per week at their jobs. But caregiving had a

substantial impact on employment, with many caregivers saying they missed work or had to cut back to meet their caregiving responsibilities. Most also said they'd had to dip into savings to help manage financial obligations.

Nearly half of the Parkinson's caregivers reported high emotional strain, and nearly a third reported substantial physical strain – rates that are markedly higher than among caregivers of people with other conditions, the report notes.

Despite the substantial burden of caregiving, caregivers often reported lacking resources, with many citing a need for additional resources to help manage their own health and the safety of their charge. The report concludes with recommendations to provide more support to Parkinson's caregivers.

Sources:

Original article by Marisa Wexler, MS

[Parkinson's News Today](#)

Stay Steady - Exercises for Postural Instability

You've probably heard how important exercise is. But let's talk about exercise for one specific challenge: postural instability.

That feeling of being unsteady, having trouble with balance, or the risk of falls are among the biggest challenges for those living with Parkinson's. Fortunately, the right types of exercise can really make a difference.

Here's a list of exercise styles that have been shown to help improve balance and reduce the risk of falls in people with Parkinson's:

Tai Chi: The Slow, Powerful Flow

Think slow-motion martial arts. Tai Chi focuses on weight shifting, body awareness, and smooth transitions. Studies have found it's especially effective for improving balance and preventing falls in people with Parkinson's.

It works to improve your balance by enhancing proprioception (your sense of body position) and strengthens your postural muscles through low-impact movement.

Boxing and/or Dancing

Both have been shown to improve balance, gait, and even mood, as most people find it fun to do. Boxing and dancing combine rhythm, movement coordination, weight changes that challenge balance and social interaction—all things that stimulate the brain and body together.

Yoga: Stretch, Strength and Stillness

Yoga incorporates stretching, strength and stillness and isn't just about flexibility. It helps with posture, core strength, and focus, all of which play a part in better balance. Chair yoga and gentle yoga are great options if mobility is more limited.

Yoga improves your balance by improving core stability and postural alignment, making it easier to stay upright and move confidently.

Resistance or Strength Training

Building strength in the legs and core helps support better posture and control. Weight training, resistance bands, or even bodyweight exercises like squats can all help. Stronger muscles provide better support and control for posture and movement control.

Physiotherapists trained in Parkinson's-specific exercise programs such as LSVT BIG, PWR! Moves or PD Warrior focus on issues such as balance and posture issues as they are designed and aimed at improving Parkinson's symptoms. They focus on tailored exercises that focus on big, deliberate movements help reset posture and improve coordination.

Exercising and staying active with Parkinson's isn't just about not falling over, it's about maintaining independence, confidence, and quality of life. And while no single exercise is a magic fix, combining different types, such as Tai Chi for balance, yoga for core strength, and dance or boxing for coordination, can create a powerful, rounded balance routine.

References:

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My [Parkinson's Carer] Life

John*

As a boy growing up in central western New South Wales. John enjoyed visiting his Italian nonna (grandmother) in western Sydney.

"We visited quite often," recalls John, now 25. "She was managing her day-to-day life, had a community of people she knew around her and enjoyed going to Bingo or seeing friends. She had a brother in the area, too."

John, an only child, lived with his parents in a regional town where his father worked as a security guard.

"I completed my schooling and TAFE there," he says. "Outside school I liked watching movies and playing video games, particularly the car-racing ones."

But as John finished his education, it became clear that his nonna was needing more care than they could manage from a few hours' drive away.

"It was at the start of Covid that we realised that she was going to need to be closer to us," says John. "Her brother had passed on a few years before that. She had been diagnosed with Parkinson's for a period of time and had been coping, but we realised that she was seeing the effects of dementia and Parkinson's as well, and needed full-time care."

After discussions with her doctor, the family found a respite care placement for her while they waited for a place for her in a residential care home in their town.

"It wasn't an easy conversation to have," recalls John or explaining the changes to come. "She was losing all her independence and moving away from the area she'd lived for decades."

His grandmother's house also had to be sold, and John and his family had to go through the household goods to sort and dispose of most of them.

"Going through her belongings was not an easy job," says John. "Her house had been my 'second home' and so many things had memories. It was weird entering the house, knowing she wasn't there. We'd had a tradition of honking the horn a couple of times in the driveway and we didn't need to do that any more.

We had a skip bin and the Salvation Army picking up donations. Eventually we packed the clothes she'd need and photos for her room. My friends hadn't been through anything like that, but I could open up about it one or two friends."

As the family organised John's grandmother's move, John was chosen to become her carer, as his father was working and his mother had some health issues of her own.

"It was near the end of Covid and we were visiting Nonna when we could," explains John. "I took on responsibility as the primary contact for discussing medical issues, supporting her with visits and transport if she needs to go somewhere. I could comprehend issues more easily, and my work situation was more flexible.

"Her situation can change from week to week. Lately she's had a few falls, so I am always on call, which can make things a bit of a challenge for my life. Each week I'd be involved for at least two or three hours with my nonna's care. If I need to go away, I need to plan in advance, and see if Mum and Dad are able to help out."

John's experience as a young carer started with assisting his mother with her own health challenges 'for as long as I can remember', he says. Fortunately John was eventually able to find assistance with young-carer programs designed to help children with family caring responsibilities.

“I received a young-carer bursary which allowed me to purchase educational equipment and to go on camps with other young carers,” says John, who is now a Young Carer Advocate and Lived Experience Advocate. He is also currently studying for a Diploma in Counselling through the Australian Institute of Professional Counsellors, and hopes to be able to work in counselling in his community in the future.

John’s tips for young carers:

- Don’t hesitate to reach out for support – personally I have had nothing but positive support from school and friends
- Identify as a young carer; you may not initially realise the responsibilities you take on mean you are acting as a carer, and help is available
- Remember to try and take time out for yourself to switch off and recharge – I enjoy walking, swimming, going camping, exercising and meditation as well as being able to connect with other young carers and like-minded people

**Full name removed upon request*

Take 5

A monthly review of the top five issues raised in calls to the Parkinson’s NSW InfoLine team (call 1800 727 567).

1. Falls and Freezing of Gait

Falls are one of the most common concerns we hear about on the InfoLine. They can happen for many reasons in Parkinson’s, changes in balance, muscle stiffness, slower reaction times, or freezing of gait, where the feet feel ‘stuck’ to the floor when trying to move.

Preventing falls often involves a combination of strategies such as reviewing medications, working with a physiotherapist on balance and gait training, making small changes to the home environment, and learning techniques to manage freezing episodes.

If falls are becoming more frequent, it’s important to mention this to your neurologist or health team so adjustments can be made.

2. Continuous Therapies and the 5-2-1 Rule

We’ve had a number of calls asking about advanced or continuous therapies and when they might be appropriate. A helpful guide sometimes used by clinicians is the 5-2-1 rule:

- Taking 5 or more doses of levodopa per day
- Experiencing 2 or more hours of 'off' time daily
- Having 1 or more hours of troublesome dyskinesia

This rule doesn't replace a medical assessment, but it can signal that it may be time to discuss advanced treatment options with your neurologist.

3. Medication Timing – 'On Time, Every Time'

One of the most common issues we hear about is medication timing. Parkinson's medications work best when taken on time, every time, as prescribed by your doctor.

Delays or missed doses can lead to increased symptoms, reduced mobility, and more 'off' periods.

Using phone alarms, pill boxes, or written schedules can help keep medication timing consistent. If you're finding it difficult to keep up with medication schedules, the InfoLine team can talk through practical strategies.

4. Allied Health Support

Many people are surprised by how important allied health professionals can be in managing Parkinson's. Physiotherapists, speech pathologists, occupational therapists, dietitians, and exercise physiologists all play a role in maintaining mobility, communication, swallowing, and overall wellbeing.

Working with professionals who understand Parkinson's can make a big difference in maintaining independence and quality of life. If you're unsure which services might be helpful, the InfoLine can help point you in the right direction.

5. Apathy – When Motivation Disappears

Apathy can be one of the more difficult symptoms of Parkinson's. It may look like loss of motivation, reduced interest in activities, or difficulty starting tasks. Because it can feel like "just being tired" or "not trying hard enough," people sometimes delay seeking help.

It's important to recognise that apathy is a symptom of Parkinson's and support is available. Talking with your neurologist, GP, or a counsellor can help identify strategies to manage it. Sometimes simply reaching out and starting the conversation is the hardest step.

If any of these topics sound familiar, remember our InfoLine team is here to help you find information, support, and the services that can make living with Parkinson's easier.

For information or personalised guidance on any of these topics, please contact the Parkinson's NSW InfoLine on 1800 727 567. We're here to support you every step of the way.

This complex brain network may explain many of Parkinson's stranger symptoms

Parkinson's disease does more than cause tremor and trouble walking. It can also affect sleep, smell, digestion and even thinking.

That may be because the disease disrupts communication in a brain network that links the body and mind, a team reports in the journal *Nature*.

"It almost feels like a tunnel is jammed, so no traffic can go normally," says Hesheng Liu, a brain scientist at Changping Laboratory and Peking University in Beijing and an author of the study.

The finding fits nicely with growing evidence that Parkinson's is a network disorder, rather than one limited to brain areas that control specific movements, says Peter Strick, a professor and chair of neurobiology at the University of Pittsburgh who was not involved in the study.

Other degenerative brain diseases affect other brain networks in different ways. Alzheimer's, for example, tends to reduce connectivity in the default mode network, which supports memory and sense of self. ALS (amyotrophic lateral sclerosis) primarily damages the motor system network, which controls movement.

Understanding the network affected by Parkinson's could change the way doctors treat the disease.

A mystery solved?

People with Parkinson's often have symptoms that vary in ways that are hard to explain.

For example, someone who usually is unable to stand may suddenly leap when faced with an emergency. And Parkinson's patients who can still walk may freeze if they try to carry on a conversation.

"So you know that their movement problems [are] not simply related to their motor circuits," Liu says, but also to circuits involved in thinking and emotion.

For decades, scientists struggled to explain how these circuits are linked.

Then in 2023, a team led by researchers at WashU Medicine in St. Louis discovered a brain network that does seem to connect movement and thinking.

They named it the somato-cognitive action network, or SCAN. And Liu's team thought it might explain some of the odd symptoms seen in Parkinson's.

So they used MRI data on more than 800 brains to compare the SCAN networks in healthy people with those in Parkinson's patients.

The team found that patients had abnormally strong connections between the SCAN network and brain areas known to be affected by their disease.

Instead of making communication better, Liu says, those strong connections were causing a traffic jam that kept signals from getting through.

Treating the network

Next, Liu's team looked to see what happened to the SCAN network when people with Parkinson's got deep brain stimulation — a treatment that delivers pulses of electricity to areas affected by the disease.

"When the stimulator is turned on, the connectivity was immediately lowered," Liu says, allowing brain traffic to flow normally again.

To see how other treatments altered the SCAN network, the team studied patients receiving the drug levodopa, transcranial magnetic stimulation, and focused ultrasound stimulation.

"All these effective treatments are actually acting on this same circuitry," Liu says, "and the effect is, remarkably, identical."

The finding is just the latest to show how the conventional wisdom about Parkinson's has changed.

"In the past, people thought of Parkinson's disease as the classic movement disorder," Strick says. "But it's clear now that multiple systems are involved."

People with Parkinson's often describe symptoms that go far beyond problems with voluntary movement, such as tremor, slurred speech and a shuffling gait.

Lesser known symptoms include chronic constipation, a reduced sense of smell, sleep disorders, memory lapses and fatigue — all of which involve brain systems with no direct link to voluntary movement.

Not a drunk

This sometimes-unpredictable mix of symptoms can be misinterpreted in a way that feels stigmatizing to patients, doctors say.

Strick recalls one man whose early symptoms included a sudden drop in blood pressure when he stood up.

"He would fall down, unexplainably, and people thought he was a drunk," Strick says, adding that the man was actually pleased when he got a medical diagnosis that explained his behaviour.

The new study appears to explain odd symptoms like that, Strick says. They're occurring, he says, because the SCAN network includes brain areas that normally control involuntary functions, like heart rate, digestion and blood pressure.

SCAN areas also include those that affect REM sleep, and certain types of memory and thinking.

Current treatments for Parkinson's don't fix these non-motor problems, Liu says. But future ones might, he says, by targeting overlooked areas in the brain's SCAN network.

Source:

[NPR News](#)

Update on 2026 Parkinson's Community Heroes

By Support Group Coordinator, Stacey Foster

This year, many of our support groups participated in the annual Parkinson's Community Heroes initiative.

Each April, during Parkinson's Awareness Month, support groups are invited to nominate an individual or organisation that has supported them over the past 12 or more months. Their Community Hero is then presented with a framed certificate at a special presentation.

The Community Heroes for 2026 are:

Jo Lavelle, Parkinson's Specialist Nurse

Narrabri Support Group Leader, Patricia Hadley says, "Jo Lavelle is a wonderful nurse. She moved to Tamworth to take on the position of Parkinson's support about four years ago, working from Rural Fit. She was just amazing, contacting community members with Parkinson's in the Hunter New England region.

She has been very supportive and informative. She set up a timetable for our Narrabri Group where she would attend our monthly meetings every second month. During these meetings she would always be able to update our group of any seminars or health expo's in our region. Jo would meet with newly diagnosed people as soon as possible when contacted by them. Nothing was ever too much trouble... It is my honour to nominate Jo Lavelle for this award and we can't think of a more deserving person as a Parkinson's Community Hero."

Penrith RSL, venue for Nepean Blue Mountains Support Group

Support Group Leader, Vivienne Ross says, “Penrith RSL Club has been providing a meeting room for Support Group meetings for many years. The staff go out of their way to make sure our meetings are in a comfortable room, with technical equipment and refreshments.”

East Maitland Bowling Club, venue for Maitland Support Group

Douglas Cottrell, Support Group Leader, says “The East Maitland Bowling Club has supported us for many years with free room hire for our monthly meetings and has also given access to two bowling greens once a month for members to play bowls. They are always happy to help if we have any problems, the Events team is very supportive of our needs.”

Charlie Pope, Balgowlah RSL

Manly-Mosman SG leader, Robyn Lindsay says, “She sets up our room and gives us such great service for our meetings.”

Corrimal RSL, venue for Illawarra North Support Group

Co-leaders, Jill Peirce and Sue Buchhorn say they are very appreciative of the RSL providing their venue free of charge for their monthly meetings.

Club Banora, venue for Tweed Heads Support Group

Marie Bakker, leader of Tweed Heads says, “The Slice and Fork Restaurant at Club Banora host our meetings twice a month. They provide sound amplification and go the extra mile delivering orders directly to members instead of members having to respond to the electronic prompters. They are very caring. Their staff are always ready to assist members who are experiencing any difficulty.”

The Late Jenny Dowell

Lismore Support Group nominated Jenny Dowell as their Community Hero this year. Sadly, Jenny has since passed away but Leader of Lismore Support Group, Marie Dudgeon, wanted to make sure Jenny’s contribution was known and acknowledged. “Jenny has been a crucial advocate for the support group as well as a vocal representative in organising funding and recognition for people living with Parkinson’s in the Lismore and surrounding areas.”

Member for Port Macquarie, Robert Dwyer

Port Macquarie Support Group Leader, Kim Dahler says, “Since Rob won his seat in the by-election 12 months ago, he has been an active supporter of our Group. I emailed him last year inviting him to join our event at WPD and he turned up. He has since attended SG meetings, the Christmas Party and is one of three founding MPs of the Parliamentary Friends of Parkinson’s. We are very fortunate to have a Local Member like Rob.”

Rod McKenzie, President of the Woopi Senior Centre

Woopi Support Group Leader, Wendy McCallum says, "Supporting Woopi Parkinsons Support Group both personally and financially through his positions as President of The Senior Centre and President of Woopi Rotary Club."

Club Blacktown, venue for Blacktown Support Group

Leader of the Group, Kathy Gilchrist says, "I would like to nominate Club Blacktown for having us every month and providing our room free of charge."

They also nominated **Dane Glover** from Club Blacktown. "From the Club I wish to nominate is the very friendly and helpful concierge, Dane Glover who always lets us into the Club before it opens so we can set up our room before all the members arrive and we can grab a coffee before we begin the meeting. He does this every month and is very helpful and polite to all our members, he deserves this nomination."

Jane Butler of Evans Head

Di Lymbury, leader of Evans Head Support Group says, "Jane is a resident with us, an ex-RN who has adopted our support group. She attends every month always arriving with a plate of fresh, nutritious, delicious sandwiches. As the group members arrive, Jane is always looking for ways to help. She is very quick to assist those members arriving with food and bags to carry. Jane just magically appears by their side every time. Jane sets up for morning tea, helps serve it and cleans and washes up afterwards."

Creative Print Group

Nominated by St George Sutherland Support Group. Creative Print Group have been designing and printing the group newsletter, name badges and any other signage for the past eight years.

Orange Support Group nominated several Community Heroes this year!

Sue and Michael Schmich

Bernie Duffy, leader of the group says, "Sue and Michael Schmich have provided practical, hands-on support to the Orange Parkinson's community over several years, contributing their time, energy and personal resources to help raise both funds and awareness.

On 8 November 2025, they opened their beautiful and sizeable garden, "Mejuluelda" at Borenore, to host the Group's Mad Hatter's Tea Party. They undertook the preparation themselves. Sue set up the garden and helped ensuring the day ran smoothly for people living with Parkinson's, their families and friends. Their efforts created a relaxed and welcoming atmosphere, and the event raised \$1,639 for Parkinson's.

In November 2024, Sue also worked as a key volunteer at the 'Hazelhome' Open Garden. She contributed throughout the day, assisting visitors and supporting the

organisers. This event raised \$5,650 and helped broaden local awareness of Parkinson's."

They also nominated **Miriam Dawes**, "An artist who has been associated with the Group since the early 2000's. Her brother had Parkinson's and Miriam was friendly with the then Leader, Martha Brown. Over the years she has provided many art works as raffle prizes. We have a raffle open at the moment with Miriam's painting 'Flowers for a Friend' as first prize."

Justin Porter, "...who has been coming to monthly meetings since mid-2024 and other events and plays the guitar. He adds a measure of energy and joy which is missing if he is an apology."

Tony Crow "is a speech therapist who leads the monthly Parkinson's Voice Therapy sessions attended by many of our Support Group members. His sessions are practical, supportive and delivered with an encouraging and sensitive manner that helps people feel comfortable and confident. Tony's consistent presence has become an important part of the ongoing support our group relies on.

In addition to running his own therapy group, Tony has also presented to our Support Group on the mechanics of voice and swallowing. His clear explanations have helped members better understand the changes associated with Parkinson's and why this knowledge matters for maintaining health and quality of life. Tony's contribution is genuinely valued by our community."

On behalf of Parkinson's NSW, I would like to sincerely thank every Community Hero for their commitment and willingness to support our groups. Reading through the reasons of why they were nominated, it is obvious their contribution and support is deeply valued by the leaders and participants. Thank you.

Awareness Month Activities

Several of our support groups also participated in Awareness Day and fundraising activities:

- Picnic in the Park, by Kiama Support Group
- Awareness Table and Raffle, by Armidale Support Group
- Walk around the lake and information table, by Temora Support Group
- World Parkinson's Day Lunch and Meal Raffle, by Port Macquarie Support Group
- Static display, information table and raffle, by Orange Support Group
- Community Walk, Pancakes for Parkinson's, Pizza for Parkinson's, by Evans Head Support Group
- World Parkinson's Day lunch, by Yass Support Group
- Morning tea, sausage sizzle and information table, by Narrabri Support Group
- Other community members also participated with a high tea in their retirement village, a staff lunch with donation entry and a PingPong Parkinson tournament.

For evidence-based information and advice call the Parkinson's NSW InfoLine

1800 727 567

Parkinson's NSW InfoLine

Email: pnsw@parkinsonsnsw.org.au

Web: www.parkinsonsnsw.org.au