

# STANDBYME

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IN THIS TOGETHER  
**parkinson's**  
NSW

# From the CEO

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

Spring is a great season for optimism – and especially for Parkinson's NSW.

The 2019-20 fiscal year has drawn to a close and we anticipate the auditors will confirm a positive financial result for our organisation.

This outcome reflects the energy of our Board and staff, plus our investment in new methods of fundraising – essential when less than 10 percent of our funding comes from Government grants.

Speaking of energy, read the story in this edition about Board Member Steve Schiemer's determination to overcome his Parkinson's with intensive exercise.

Other articles include how to manage fatigue associated with Parkinson's and a look at promising new research into converting brain cells called astrocytes into neurons – unlocking a potential treatment for Parkinson's.

There are also items about opportunities for you to participate in research in Australia, a creative new way of educating the community – particularly younger people – on the challenges of living with Parkinson's, and good advice on transitioning gradually back to exercise after living in social isolation.

Enjoy the change of seasons and please use our resources to keep up to date with NSW Government advice on COVID-19. We want all of the Parkinson's NSW family to remain safe and well.

**Jo-Anne Reeves**  
Chief Executive Officer



# No Escape Room campaign boosts Parkinson's awareness

Parkinson's NSW worked with marketing agency Wunderman Thompson and production company AIRBAG to launch an escape room campaign in July to raise awareness about the daily challenges of living with Parkinson's.

To attract participants in the project, the organisers put out a call on social media to fans of escape room games, offering them the opportunity to be the first to trial a new escape room.

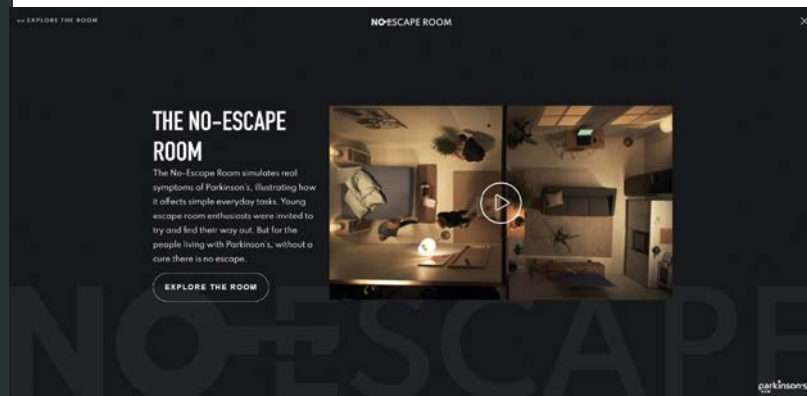
However, what the participants didn't know was that the room was rigged with secret cameras and microphones – and that each task and puzzle represented a Parkinson's symptom including memory loss, tremor, blurry vision, stiffness, and more. View the video here.

Seemingly simple tasks such as pouring tea, using a computer mouse, or tying shoelaces were made frustratingly difficult, emulating the challenges people with Parkinson's face every day.

When participants finished all the challenges and were able to open the final door, they were faced with a sign telling them that the room represented Parkinson's – the symptoms of which people cannot escape from.

In addition to video interviews with participants on how they felt after the experience and what they had learned, the escape room is duplicated as 360-degree digital experience on a dedicated web site, allowing more people around the world to take part and gain an understanding of Parkinson's and its challenges.

"For people living with Parkinson's, there is no escape from their symptoms. Day to day activities and movements such as pouring a cup of tea or tying a shoelace can be a daily challenge. We understand this can be hard to relate to, which is why we have launched this campaign, to allow Australians to step directly into the shoes of a person living with Parkinson's." Jo-Anne Reeves, CEO Parkinson's NSW



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# Cell conversion opens possibility of Parkinson's treatment

A new study may overturn existing theories on the cause of motor symptoms in Parkinson's.

It was conducted by a joint research team from the Institute for Basic Science, the Korea Institute of Science and Technology and the Asan Medical Center in South Korea.

So far, the prevalent view among Parkinson's specialists has been that the motor symptoms occur when dopaminergic neurons – the brain cells that synthesize the chemical messenger dopamine – start dying off abnormally.

Therefore, to offset motor symptoms, doctors may prescribe people with Parkinson's disease a drug called levodopa which helps boost the brain's reserve of dopamine.

However, the long-term use of levodopa can lead to serious side effects, including erratic, involuntary movements.

But what if motor symptoms do not start with the death of dopaminergic neurons? If this were the case, it could change how researchers and medical practitioners understand Parkinson's disease and the best way of treating it.

The South Korean research, which appears in the journal *Current Biology*, found that symptoms of Parkinson's appear before the premature death of dopaminergic neurons.

In their study, the investigators worked with mouse models of Parkinson's disease and analysed brain samples from both healthy people and people with Parkinson's.

They found that before the dopaminergic neurons die off, they stop functioning – that is, they stop correctly synthesising dopamine – and this sets off the symptoms associated with Parkinson's disease.

Looking at the mouse models of the condition, the researchers saw that astrocytes – star shaped, non-neuronal cells – in the brain started increasing in number when neurons in their vicinity began dying off.

At this point, a key chemical messenger called GABA also starts increasing in the brain, reaching an excessive level and stopping dopaminergic neurons from producing dopamine, though not killing them.

The researchers confirmed that this process occurs not just in animal models, but also in the brains of people with Parkinson's disease.

However, the researchers also found that there is a way to restore the function of affected dopaminergic neurons by stopping astrocytes from synthesizing GABA.

Doing this, they saw this significantly decreased the severity of motor symptoms associated with Parkinson's disease.

Further experiments in rats revealed another way of restoring function in dopaminergic neurons. The researchers inhibited dopamine synthesis in these neurons in otherwise healthy rat brains by using optogenetic tools – technology that uses light to control the activity of living cells.

This induced Parkinson's-like motor symptoms in the rats. But when the researchers used optogenetic tools once more, this time to restore function in the dormant dopaminergic neurons, the Parkinson's-like symptoms decreased in severity.

The team argues that in the future these findings may lead to better ways of treating Parkinson's disease – ways that may reverse some of the damage to important brain mechanisms.

**Sources** *Nature Journal*

Jing Hu of the Sichuan Provincial Key Laboratory for Human Disease Gene Study, Sichuan Provincial People's Hospital, University of Electronic Science and Technology

Yuanchao Xue of the Key Laboratory of RNA Biology, Institute of Biophysics, Chinese Academy of Sciences

## Research participation opportunity: Genetic factors influencing risk of Parkinson's

Researchers at QIMR Berghofer Medical Research Institute are seeking participants for an Australian research study that will investigate the genetic factors that influence a person's risk of Parkinson's disease. The study is trying to find genetic variants that can help researchers understand, predict, and eventually prevent Parkinson's onset and progression.

If you choose to participate, you will be asked to fill in a short questionnaire (online, over the phone, or via mail). Then a kit will be mailed to you so a sample of your saliva can be collected, which will be used to extract your DNA.

A care partner or support person may help you complete the questionnaire if you feel you are not able.

**The questionnaire is available online here:**  
<https://www.qimrberghofer.edu.au/pgd6/>

QIMR Berghofer is a world-leading medical research institute that researches chronic disorders, cancer, mental health, and infectious diseases. It has around 900 researchers, scientists, students, and support staff based in Brisbane.

*You do not have to be in Brisbane to participate in this study.*

# Dealing with Parkinson's fatigue

Fatigue is a common symptom of Parkinson's. In fact, one-third of people living with the disease consider it their single, most disabling symptom.

It can be caused, or worsened, by slow movement, muscle stiffness, depression, changes in being able to move or sleep well, and medications. It may be experienced throughout the day or only when medications are wearing off.

Tiredness usually goes away with rest. However, fatigue can happen without the effort of any activity and does not improve with rest.

It is a pervading factor in people's sense of identity loss in Parkinson's because it raises questions around one's ability to function – which can trigger self-doubt and loss of self-esteem.

Fatigue can add a level of intensity to feelings of depression and undermine all kinds of daily activities and rehabilitation programs. It feeds into our emotional reactions to Parkinson's symptoms and makes them harder to bear.

It also makes it more difficult to connect with others, increasing social isolation. It can be increasingly demanding to get out the door and interact with other people when we feel drained of energy.

## Factors which make fatigue worse include:

- U Pushing yourself beyond your limits with exercise and activity
- U Eating too much animal protein, or too big a meal
- U Not resting when needed
- U Getting overheated and not hydrating
- U Being overly stressed
- U Being sick with a virus
- U Missing a levodopa dose

Fatigue needs to be managed, not ignored. Focus on taking your medications on time, every time. Stay hydrated and exercise regularly to build up your stamina.

Plan your day and be realistic about what you can achieve. That means prioritising what you really need or want to do each day.

Understand when your best 'on' time is, then plan activities within this time frame. For example, if you are best in the mornings then arrange appointments before noon instead of later, when you will be tired and likely to be more symptomatic

Take regular breaks and have a proper rest by lying down for 1.5 hours then getting back up; do not sit in a chair nodding off.

Be kind to yourself. Give yourself permission to be satisfied with what you achieve in the day and don't be disheartened if you can't tick everything off your daily to-do list.

Acknowledging your accomplishments (no matter how small or large) rather than focusing on what you aren't able to do will give you an energy boost. Also, don't compare yourself with others. You are on your own personal journey with Parkinson's, so take one step at a time.

Consider joining a Parkinson's NSW Support Group. Having peer-support will not in itself take away your fatigue – but finding out that there are others just like you coping with the same issues can lessen the stress of wishing you had your old energy levels back.

Support Groups are also good for sharing and receiving ideas on what helps. They are a great source of connection, mutual understanding, and a sense of being okay – despite living with Parkinson's.

It is also useful to seek support from professionals who understand the physical and psychological aspects of fatigue and other Parkinson's symptoms.

Call the Parkinson's NSW InfoLine on **1800 644 189** to talk to a Parkinson's Registered Nurse and/or make an appointment for a phone or video-chat consultation with a specialist Parkinson's Counsellor.

**Manage  
fatigue**

**Take medication on  
time, every time**

**Stay hydrated  
Exercise regularly**



# Safely transitioning back to exercise

COVID-19 (Coronavirus) restrictions have disrupted everyone's lives. However, people living with Parkinson's have been particularly affected because they depend on strict routines for rest, medications, and exercise to maintain daily health and wellbeing.

So now that restrictions on exercise facilities and locations (indoor and outdoor) have been lifted, how do we re-adjust our isolation-based routines to the 'new normal'?

Most gyms are now up and running again with up to 90 percent of members glad to be back training. It is understandable if you feel hesitant to return to this environment – especially if you are living with Parkinson's, have a compromised immune system or are aged 70 or over.

However, you can be reassured by the fact that Fitness Australia – the fitness industry Peak Body – has put in place strict health and safety protocols to protect people returning to exercise and staff members alike.

So now you know that you can return to exercise safely, here are some tips on getting you up off the couch and breaking a healthy sweat.

**First, talk to your doctor.** Get the 'all clear' to start exercising again. It's best if you start slowly and build gradually. Also don't forget to do some stretching before and after your activity.

Also speak to your Parkinson's physiotherapist, exercise physiologist or class instructor. Let them know what changes you've experienced, and they will be able to advise the best exercises and levels to restart your exercise.

**Decide what is important to you, then relate your exercise to that.** Do you want to keep working, continue looking after the garden or play with your children or grandchildren? We all have something we want to be able to continue doing. Being active will keep you active.

**Consider what will happen if you don't get back into exercise.** You'll lose your heart and lung health and may end up taking more medications with more side effects. You'll lose strength – which impacts your bones, gardening, walking, shopping, and carrying the grandchildren. Your muscles and joints will stiffen and will make everything harder to do.

**Put on your workout gear.** Get dressed in what you would normally wear for the activity you enjoy. Research has suggested that our brains are susceptible to 'enclothed cognition'. Which means dressing the part will help you complete a chosen task.

**Make a commitment with a friend.** This will keep you accountable. Make plans to meet up for a swim, walk, dance class or exercise session. Being active with a friend can motivate you to push yourself harder and then you can both celebrate your progress.

**Plan your activity for early in the day.** Plan to be active in the morning. If you plan to exercise later in the day you potentially have 8 to 10 hours to find an excuse not to. You are also at your best and will get the most out of activity in the morning.

**Change your routine.** If the thought of going back to the same old routine and activity is what's deterring you, change it. Go to a different style of class and meet some new people. If you don't enjoy the change you can always go back to your previous routine.

**Don't over-promise yourself.** Don't set yourself up for failure. Goals are great but they need to be realistic. Major achievements are possible, but you need to approach them gradually and celebrate the small milestones along the way.

**Consider a trainer.** Fitness instructors may add to the cost of your exercise, but they also add great value. You'll get an individual program tailored to you and your goals, that is safe and at your current fitness level. They will guide you through correct techniques and give you someone to be accountable to.

Log your exercise. By recording distances, weights, and or other meaningful milestones, you'll be able to see your progress on paper. It helps to keep you going when you are lacking motivation.

Don't overdo it. Make sure to build some recovery time into your weekly routine. That could mean doing something relaxing like art or singing or temporarily turning your activity level down. That way, you'll avoid being too tired to tackle your next session.

## How fitness facilities are keeping you safe

For fitness facilities and group exercise classes, halls, and parks to reopen, the operator must adhere to the Australian health recommendations – including physical distancing, hygiene, contact tracing, illness, and employer's duty of care.

Class areas have been marked with tape to ensure people keep their distance.

Equipment has been moved further apart and everyone must bring a bench-size towel.

All equipment and mats must be wiped down with a sanitiser after use and everyone is keeping an eye out to ensure this is done. Then staff are also coming through and cleaning everything multiple times during the day.

For more information on these health and safety protocols: <https://fitness.org.au/announcements/available-now-framework-for-safely-operating-a-fitness-facility-under-covid-19-restrictions/129>

# Parkinson's NSW nurses drive education benefiting people living with Parkinson's

Clinical Nurse Consultant Vince Carroll – who is based in the Mid North Coast Local Health District – and Sydney-based Parkinson's Registered Nurse Julie Austin recently participated in a collaborative project with the Health and Education Training Institute (HETI) and the Clinical Excellence Commission (CEC).

As a result, Caring for people with Parkinson's Disease is now a state-wide education program in place for all NSW Health staff, and the NSW Health Safety Notice for people admitted to hospital with Parkinson's has also been updated.

See the Health Safety Notice here.



## Safety Notice 002/20

### Management of medication for patients with Parkinson disease

11 March 2020

#### Distributed to:

- Chief Executives
- Directors of Clinical Governance
- Director Regulation and Compliance Unit

#### Action required by:

- Chief Executives
- Directors of Clinical Governance

#### We recommend you also inform:

- Heads of departments
- Directors of Nursing and Midwifery
- Directors of Medical Services
- Directors of Pharmacy
- Drug and Therapeutics Committees

#### Expert Reference Group

Content reviewed by:

- Medication Safety Expert Advisory Group
- Parkinson's NSW
- ANNA Movement Disorder Chapter

#### Clinical Excellence Commission

Tel. 02 9269 5500  
Fax. 02 9269 5599

Email:  
[CEC-MedicationSafety@health.nsw.gov.au](mailto:CEC-MedicationSafety@health.nsw.gov.au)

Internet Website:  
<http://www.health.nsw.gov.au/sabs>

Intranet Website  
<http://internal.health.nsw.gov.au/quality/sabs/>

#### Review date

March 2021

#### Background

Patients with Parkinson disease (also known as Parkinson's disease) have symptoms controlled through a personalised medication regimen. The control of symptoms may be compromised if their medications are delayed, omitted or abruptly changed.

#### Consequences of compromised therapy

- Motor and non-motor symptoms of Parkinson disease patients is individualised and dependent upon personalised prescription and medication administration. **Even minor delays in dosing (i.e. 15 minutes) may make a significant difference to symptom control.**
- Omitted and delayed doses can result in emergencies, adverse events and worsening of symptoms, such as; tremors, rigidity, akinesia (difficulty initiating movement), gait and balance disturbance, depression, anxiety and impaired swallowing ability.
- Prolonged withdrawal from Parkinson medications or severe intercurrent illness can cause a rare but potentially fatal neuroleptic malignant-like syndrome and dopamine agonist withdrawal syndrome featuring muscle rigidity, fever, autonomic instability, cognitive changes and altered level of consciousness.
- Interacting drugs, including anti-emetics and anti-psychotics (e.g. metoclopramide, prochlorperazine, haloperidol), interfere with the action of Parkinson medication and should be avoided.

#### Contributing factors

- When patients with Parkinson disease are admitted to hospital, clinical staff may not be aware of the time-critical nature of the treatment regimen.
- The medication regimen may be complex, and Parkinson medications are available in different formulations (e.g. immediate release vs slow release), various drug combinations and strengths – hence errors in prescribing can occur.
- Although patients often bring their own medication into hospital, they may be prevented from self-medicating due to local protocols, or doses may be omitted or delayed until hospital supply can be obtained.

#### Suggested actions by Local Health Districts/Networks

1. Distribute this Safety Notice to all relevant clinical staff and all clinical departments.
2. Introduce strategies to ensure the best management of inpatients with Parkinson disease. Strategies could include:
  - a. Notifying the patient's neurologist or specialist nurse of each Parkinson patient's admission when possible, particularly if unplanned.
  - b. Obtaining a clear and accurate medication history. Confirm details with a second information source e.g. patient's own medicines, the patient's carer, GP and/or local pharmacy.
  - c. Prescribing Parkinson medication using generic and brand name, and specifying formulation where possible.
  - d. Documenting the time medications are normally taken by the patient and ensure medications are administered at these personalised times. **Parkinson medication is time-critical, administer doses on time, every time.**
  - e. Administering from the patient's own medicine supply until hospital supply is established. Refer to [Medication Handling in NSW Public Health Facilities policy](#).
  - f. Reviewing the range of Parkinson medications available in the Emergency Department and after-hours drug cupboard. Consider use of a Parkinson medication identification chart with images of products (e.g. tablets, intestinal gel, patches, injection) active ingredient and brand names, strengths and dosage forms, to assist correct product selection.
  - g. Assessing the patient's ability to self-medicate (consistent with [Medication Handling in NSW Public Health Facilities policy](#)), noting that acutely unwell or unstable patients may not be suitable.
  - h. Switching to a non-oral route (e.g. nasogastric) when a patient is unable to take or tolerate oral medication. Seek expert advice if possible before changing the route of medication.
  - i. Considering the following eMR options:
    - i. documentation and identification of patients who have Parkinson disease
    - ii. on-time administration of Parkinson medications
    - iii. configuration in eMR to support the high level of frequency for some Parkinson medications (e.g. 6 times per day) and that appropriate order sentences are available
  - j. Educate staff on how to manage patients with Parkinson disease. An e-Learning module is available from HETI (course code 283839943).
3. Report any incidents associated with Parkinson medications in the Incident Information Management Systems (IIMS)

# My [Parkinson's] Life

*Having Parkinson's is just one aspect of a person's life story. We want to share more stories of the varied lives of people currently living with Parkinson's.* **Steve Schiemer**

Steve Schiemer's life journey has taken him from Coolah NSW (population 900) to a university degree in Business, an Australian then international career as a Personal Trainer and fitness industry entrepreneur – then to a Parkinson's diagnosis at age 40, followed by a personal and professional reinvention, and a seat at the boardroom table of Parkinson's NSW.

"I have always loved the gym and fitness and was very much involved in martial arts while I was studying at Charles Sturt University, in Wagga," said Steve.

"Then I became interested in becoming a Group Fitness Leader. Only thing was, I made my decision just two weeks before the course began – so I worked for that entire period participating in 4 classes a day just to get an idea of what I was supposed to do. I passed with flying colours and was teaching two weeks after I completed the course."

That determination has been a feature of Steve's fitness and business career ever since. He moved to Sydney where he rose to become a senior manager in the fitness industry, while training and competing in Competitive Aerobics.

A visit to a fitness studio to evaluate a potential Step instructor for Steve's business had a very positive outcome. Rebecca indeed won the instructor's role – and they have also been partners in life and business for the past 23 years.

Then came a move to Germany.

"At the top levels of the fitness industry, you look forward to presenting at conventions," explained Steve. "At the time, there was only one convention per year in Australia so we decided to move to Germany for six months where we would have the opportunity to showcase our skills at multiple conventions.

"Well, six months turned into 14 years – eight in Germany and six in the UK where we established a business selling top-of-the-line German manufactured fitness equipment throughout the UK," he said.

During this period, Steve added another string to his bow. He became a television presenter, making regular appearances on the Ideal World home shopping channel to demonstrate his company's fitness equipment.

It was also around this time that Steve began to show the first symptoms of Young Onset Parkinson's – although like most people he did not recognise it at the time.

"I noticed some weakness in my left hand when I was doing equipment demonstrations, but I attributed it to a pinched nerve," he said.

This symptom was followed by tremors in his hand and hamstring muscles – which prompted him to visit a General Practitioner.

That was the start of a year-long period of multiple medical consultations at which GPs and neurologists told Steve he was too young and far too fit to have Parkinson's.

Finally, as his condition deteriorated, a neurologist tried him on a course of Levodopa. There was immediate improvement, leading to a definitive diagnosis of Parkinson's at the age of 40.

"Rebecca and I were both stunned by my diagnosis because we had been told repeatedly that I was too young and too fit to have Parkinson's. It was a shock, and frankly I lived in denial for about 18 months after that.

"I couldn't even look at a person with Parkinson's on TV or the internet; I'd have to turn away," he said. "But eventually it became harder and harder for me to walk so I could deny it no longer," said Steve.

Steve and Rebecca were by this time living back in Australia. Steve was on four high doses of Levodopa daily and feeling very depressed.

That led to his first contact with Parkinson's NSW; he and Rebecca made an appointment with a Parkinson's Counsellor.

"Counselling was a turning point in my Parkinson's journey," said Steve. "That support enabled both of us to change our whole mindset about the disease and think about how we could fight it."

Steve fell back on his professional skill and personal passion: exercise. He took up boxing because it combines so many different factors including balance, coordination, and continuous movement.

The combination of an intense exercise regime and sound nutrition has worked to the point where Steve has almost reversed the effects of his Parkinson's.

Today he is back in the fitness industry, teaching boxing classes and personally training and innovating exercises for people living with Parkinson's.

Eighteen months ago, Steve was invited to join the Board of Parkinson's NSW based on his business skills, fitness knowledge and life experience with Parkinson's.

"My skills do not match the level those of some of the other Board members who have really strong corporate backgrounds, but what I bring to the table is an understanding of the fundamentals – both of business and life with Parkinson's.

In addition to exercise and representing the Parkinson's community, Steve has three other passions in life: His wife Rebecca ("...my greatest supporter"), his dogs, and "...I never miss a chance to play a game of darts!"



# Thank you for supporting people with Parkinson's through this challenging time...



COVID-19 has made life more difficult for our vulnerable Parkinson's community, introducing new fears, isolating people and disrupting health services.

At this challenging time, the reassurance and care of a Parkinson's Nurse is more important than ever. So, if you can, I hope you'll help us to keep funding these essential workers.

"For many people, having access to a Parkinson's Nurse is their only hope after getting a diagnosis," says Gavin. "People definitely need this service."



## How your donation today can help someone like Gavin:

**\$33** can provide a person with a telephone consultation with a Parkinson's Nurse to give information and advice in between neurologist's appointments.

**\$102** can help provide one hour of services in the community by a Parkinson's Nurse, supporting people and their carers throughout their journey.

**\$308** can provide a home visit from a Parkinson's Nurse giving answers and reassurance to someone living with Parkinson's and their carer.



**YES, I would like to help improve the lives of people living with Parkinson's and their families...**

Title: \_\_\_\_\_ First Name: \_\_\_\_\_ Last Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email: \_\_\_\_\_ Phone: \_\_\_\_\_

Please accept my donation of the following amount:

\$15  \$30  \$50  Other \$ \_\_\_\_\_

I would like to make a monthly donation of \$ \_\_\_\_\_ (\$15 minimum)  
Please debit my credit card monthly, until further notice.

I would like to pay by:

Cheque/Money order (payable to Parkinson's NSW)

Credit Card (details below)  Visa  Mastercard  American Express

Card number \_\_\_\_\_

Name on card \_\_\_\_\_

Signature \_\_\_\_\_

Exp date \_\_\_\_\_

Please send me at no obligation, information on how I can leave a bequest to Parkinson's NSW

I have already included Parkinson's NSW in my will

