

# STANDBYME

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## In this issue...

As winter closes in, are you lacking the motivation to continue your exercise program? We can help with that... take a look at the article Start Small with Exercise for tips on getting started, staying motivated, and exercise for indoors if you find it too cold outside.

Graham Saxby now has some additional help as well. Read a My [Parkinson's] Life update on Graham and his service dog Archer.

Learn some more good news as well from our article on Parkinson's NSW joining the National Parkinson's Alliance (NPA) – it is a new national collaboration of key

stakeholders and leaders in the Parkinson's community of Australia.

Don't go past the hints and tips on eating out with Parkinson's. Also find out how Parkinson's NSW Board Member Steve Schiemer dealt with his Parkinson's diagnosis at age 40 and then committed to boxing to fight his disease progression.

And just when you thought you'd heard it all about ongoing Parkinson's research, think again. Read about a new frontier: Parkinson's research being conducted on the International Space Station

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

## Parkinson's NSW joins National Parkinson's Alliance



### Parkinson's NSW has joined the National Parkinson's Alliance (NPA).

It is a new national collaboration of key stakeholders and leaders in the Parkinson's community of Australia who have come together to shape policies, strategies, and initiatives to enhance the lives of people living with Parkinson's across the country.

The Alliance is leveraging national collaboration and leadership to work across regions and populations to shape policies, strategies, and initiatives to enhance the lives of individuals affected by Parkinson's.

**Parkinson's is now the fastest-growing neurological condition in the world and affects more than 200,000 Australians. It poses a significant threat to our health and aged care systems and is estimated to cost the Australian community \$15 billion annually.**

This disease is progressive and highly debilitating, taking a huge personal and financial toll on individuals, care partners, families, and communities. This highlights

the importance of increased funding for research and multidisciplinary care and support for those affected by this debilitating condition.

#### The Alliance includes:

- U Parkinson's NSW
- U Fight Parkinson's
- U Parkinson's Tasmania
- U Shake it Up Australia Foundation
- U Menzies Medical Research Institute
- U Neuroscience Research Australia (NueRA)
- U Queensland University of Technology
- U University of Tasmania
- U Walter and Eliza Hall Institute
- U Wings for Parkinson's





# How Steve fights his Parkinson's diagnosis, head on

*"Boxing is actually a perfect exercise for Parkinson's. Not only does it give you bouts of high intensity interval training, but it works your brain because you have to remember the combinations and think about a lot of things all at once," he said*

Today, he acts as a personal trainer for many clients with Parkinson's themselves and he credits exercise for helping him dramatically slow the progression of his disease.

Six years ago, he also decided to support the Parkinson's community even more by joining the Board of Parkinson's NSW.

And he knows first-hand the power our services have to make a real difference, from our Parkinson's nurses to our InfoLine.

When one of Steve's clients turned up for a personal training session one day, unable to remember even his own name or basic details of his life, Steve thought perhaps he was having a stroke.

A call to the Parkinson's NSW InfoLine saved the day.

*"We talked to a Parkinson's nurse who worked out he just hadn't drunk enough water. She got the situation under control fast, without the need to visit hospital."*

Even though this is one of the fastest growing diseases in Australia, there's not nearly enough support for the complex needs of people living with Parkinson's.

The government only provides three percent of the funding required to operate Parkinson's NSW. Finding the money for everything we do is a huge challenge every year and we rely on generous donors to help us do it.

Every single dollar donated helps us keep our services afloat. Donations ensure we can give people with Parkinson's a number to call, a listening ear, expert help to manage a situation and find an answer.

Steve had a thriving career in the fitness industry and a loving wife, Rebecca, when he noticed a tremor in his fingers and hands.

*At first, doctors told him it couldn't be Parkinson's, "...because I was too young and too healthy", Steve remembers.*

He was put on a range of medications, but nothing really worked. Eventually, a specialist asked him to try some tablets. Steve felt fantastic on them and reported back to the specialist, who told him that the diagnosis could be confirmed as Parkinson's.

*"My jaw hit the floor, I said, "What are you talking about?" The specialist said, "Well, it's Parkinson's medication you're on. So, it has to be Parkinson's."*

Suddenly, at the age of 40, Steve's world came crashing down.

While it was a relief to finally have a diagnosis, the news was a devastating blow for Steve and Rebecca. For the first 18 months afterwards, Steve was in complete denial.

*"My life, my job and everything I was used to was pretty much over. At least, I thought it was," he recalled.*

Struggling with depression, Steve and Rebecca eventually reached out to Parkinson's NSW.

We connected them with a counsellor, who helped them change the way they were seeing things.

Thanks to this support, Steve found the strength to begin rebuilding his life – through boxing.

He started with just one session every fortnight or so and gradually developed the strength and confidence to do sessions every day.

**Most of all, you're letting people with Parkinson's know that they aren't alone.**



 **Donate**

**Can you help us support people through the realisation that their life may have changed, but it's not over?**





## Brain organoids derived from patients taken to space station

***Studies in microgravity may help to better understand and treat Parkinson's.***

R3D 'mini-brains', or brain organoids, derived from people with Parkinson's disease and primary progressive multiple sclerosis (MS) were taken to the International Space Station (ISS) as part of ongoing research in the unique effects of space on the human brain.

How brain cells interact in microgravity, a condition under which people or objects appear to be weightless, may help in understanding the mechanisms that underlie these and other neurodegenerative disorders. Such insights are paramount to finding novel biomarkers for an earlier disease diagnosis, and in accelerating the development of new therapies.

The research was part of a partnership between the National Stem Cell Foundation (NSCF) and the European commercial Axiom Space (Ax-3) astronaut mission, which carried the brain organoids to the station.

### **Parkinson's research in the 'unique environment of microgravity'**

*"These commercial astronaut missions expand our access to the ISS for additional research in the unique environment of microgravity, accelerating data collection and moving this ground-breaking project forward at an accelerated pace," said Paula Grisanti, CEO and a founding member of the NSCF.*

The Ax-3 astronaut mission left the Kennedy Space Center at Cape Canaveral, Florida, on January 18, 2024, as part of the NSCF Cosmic Brain Organoid project – the first to study mechanisms of neurodegeneration in space. It marks the fifth Cosmic Brain Organoid project flight since 2018.

Organoids from 30 Axiom Space research studies stayed for two weeks at the space station. Besides neurodegeneration and cancer research, studies into protein aggregation and astronaut health were also undertaken. Findings aim to benefit future astronauts, and potentially all of us on Earth by leading to new ways of protecting the brain against cognitive decline.

*"The world is increasingly looking to space for answers to questions about improving human health on Earth. Space offers a completely unique research environment for the advancement of biological, agricultural, environmental, and additive manufacturing discoveries. We are excited to continue our innovative neurodegeneration research," Grisanti said.*

This is the first collaboration on the role of microgravity in neurodegeneration involving experts in the fields of Parkinson's disease and MS, including scientists at the New York Stem Cell Foundation Research Institute and Scripps Research in San Diego.

Source: First published in Parkinson's News Today

## Start small with exercise for longer term gains

Many of us start our exercise programs being too ambitious and trying to do too much in too short a time.

The approach is to start small with a goal of building a regular, long-term fitness program. Research suggests that even one muscle contraction a day, five days a week for a month can improve muscle strength.

Over 85 percent of Australians don't meet the Australian physical activity recommendations for cardiovascular (aerobic) and muscle-strengthening exercises. The activity guidelines recommend we do 150 minutes of moderately intense exercise a week, as well as at least two muscle-strengthening exercise sessions.

Not meeting these recommendations dramatically increases the risk of many chronic diseases such as heart disease, diabetes, cancer, osteoporosis, dementia, depression and anxiety. And for people with Parkinson's these illnesses will exacerbate the existing symptoms.

With a little bit of effort, you can reduce the risk of these illness and improve your Parkinson's symptoms.

### **The most common issues that inhibit people meeting the recommended exercise requirements are:**

- 👉 I'm too tired
- 👉 I can't afford a gym or trainer
- 👉 I don't have time
- 👉 I don't have any motivation
- 👉 I don't like to, or can't exercise alone
- 👉 It's boring and not fun
- 👉 I'm too old, overweight, injured, sick etc.

Try to include some exercise in your day. You will see and feel improvements by doing just one or two minutes of exercise a couple of times a day for a month.

Many of us sit down on a chair or a sofa more than ten times a day. So, if we use these opportunities to sit and re-stand 10 times each time we sit, we've performed 100 squats.

This will build leg strength, knee stability, balance, lower blood pressure and cholesterol levels to mention some of the benefits.

You could add any of these other exercises whenever you sit or whilst watching TV, standing in the kitchen etc. Maybe starting with 5 to 10 repetitions three times a day.

Any is better than none, and of course do each exercise in a slow and controlled pace. If you start by doing small, achievable, easy exercise you will be more inclined to build momentum to do more.



After consistently doing these micro-exercise sessions each day for a month to six weeks you'll feel healthier and stronger, and more motivated to continue on your exercise journey.

### **References:**

Mindtools, ABC news, Fitnessvolt and The Heart Foundation.

# Coming to terms with Parkinson's progression

Parkinson's is a chronic progressive neurological condition. The symptoms are caused by the loss of dopamine producing cells in the brain. Dopamine affects memory, mood, and movement.

Even after a diagnosis of Parkinson's, the dopamine producing cells in the brain continue to die off. Everyone's journey with PD is unique.

## When you first receive a diagnosis

When you receive a diagnosis of Parkinson's it is important to remember that the disease is not your fault – and you are still the same person. All that's changed is that you are now managing a health condition.

The progression of Parkinson's is slow, and you have time to choose how you will react to your disease. It is an individual choice because everyone is affected differently, and symptoms may vary from day to day.

Be kind to yourself. It takes time to come to terms with your diagnosis and there is no 'right' way to react. Some people want to learn all they can about Parkinson's whereas others prefer to limit their knowledge.

It is completely normal to feel scared, sad, and angry and to feel very emotional. Remember also that your diagnosis will have an impact on your partner, friends, and family members – and it will take time for them to readjust to the new future with Parkinson's in their orbit.

## Steps to managing the diagnosis

- U Educate yourself about Parkinson's. Knowledge means that you can make informed choices about how to manage the symptoms and not allow the symptoms to manage you. Good symptom management is key to quality of life.
- U Determine your personal goals. Be proactive, practical, and realistic.
- U Stay positive, retain your sense of humour, and laugh!
- U Find and connect with a neurologist who you feel comfortable with and where there is two-way communication.
- U Build a team to support and assist you with managing symptoms. This can include a neurologist, speech pathologist, physiotherapist, dietician, occupational therapist, and counsellor
- U Seek someone to talk to about your diagnosis and future plans.
- U Create healthy habits – be active, exercise and eat a healthy diet
- U Take your medication on time every time. Also keep a diary on medication effectiveness to share at medical appointments.
- U Particularly focus on managing stress because it makes the symptoms worse.
- U Maintain your social connections. For example, join a Support Group and exercise group, or explore online options



- U Review your hobbies and look at how you can do things differently in order to maintain them. In general, it is good to be flexible, adapt to change and consider all options.

- U Ask for help; professional support can be very positive.

## Managing the progression of Parkinson's

It is inevitable that Parkinson's will progress. However, a healthy approach is to focus on yourself as a whole person, not the disease itself. You have Parkinson's but Parkinson's does not have you!

Since there can be issues with cognition and making informed decisions as Parkinson's progresses, it is better that early discussions occur with your caregiver and family members about long-term care requirements and management.

Ensure that you discuss with your partner, caregiver, and family members how you would like to be cared for when your symptoms begin to escalate. It is best for this discussion to start at the beginning of the Parkinson's journey so that everyone is aware of your wishes and the way that you see the care plan heading.

This plan needs to be flexible and reviewed often. Advanced Care Directives are a good way to start the conversation.

Be aware that medication reviews can help to manage symptoms but will be less effective as your condition progresses. For example, if you experience hallucinations then a reduction in medication may be required – and this may be a trade off with mobility.

Not everyone can fulfil the role of caregiver and this needs to be discussed so that all the people involved have choices.

Nobody wants to reside in an aged care facility but if the care required cannot be provided by the caregiver and family then an informed decision needs to be made about how best that the person living with Parkinson's can have their care needs met.

If this has raised any queries or concerns for you, please call the **InfoLine on 1800 644 189** to talk with Registered Nurses or make an appointment to consult a Parkinson's NSW Counsellor by phone, online, or in person.

*Sources: Parkinson's NSW Counsellors, Parkinson's Disease Foundation, Wolters Kluwer Palliative Approach to Parkinson's, American Parkinson's Disease Association, Parkinson's UK*





# Tips on Eating Out With Parkinson's

Eating out should be an enjoyable activity. However, for those living with Parkinson's unexpected challenges can diminish the enjoyment and discourage many from eating out. Following are some tips which may help.

Choose a restaurant that serves you at your table. Buffet-style restaurants mean you will need to carry your tray and/or dinner plate and a drink to your table.

This can add stress and difficulties when managing a tray with a tremor. There is also risk in concentrating on the tray instead of where you are walking, which can potentially cause a fall.

Make your reservation early, so you miss the busiest restaurant times, and you are eating out at a time when your medications are most effective. Booking earlier, maybe 5pm instead of 6pm will give you quicker seating, faster food service and a more private dining experience.

## Check in advance

Contact the restaurant or look at the menu on its web site beforehand – especially if you will need specific food choices due to dietary restrictions.

Confirm the restaurant has accessible facilities and policies and ask about any special concerns such as wheelchair-accessible seating or chairs with armrests – which make it easier to get in and out of the chair and table.

When calling ahead, if you use wheelchairs or other mobility devices confirm that the restaurant is near accessible parking and offers easy access to the dining area.

Confirm that you can get through the main entrance door and that any stairs or steps can be 'ramped'. Also ask where the toilets are located, whether they can be accessed, and check the availability of an accessible toilet facility.

Ask if the restaurant's dining tables and seats are height accessible – should you want to transfer from the wheelchair to a seat – and whether your chair or walker can be moved to an area with less traffic.

## Difficulties with speech

Most restaurants are happy to assist if you experience difficulties with speech. The restaurant's employees should allow you enough time to speak or supply a pen and paper if you request it.

You can also ask if they can supply bendable straws, a glass or plate of a different size, and whether they can cut difficult foods into bite-sized pieces before serving and only fill drinks halfway to lessen spills or burns.

If you have your own utensils – such as cutlery, straw, cup, sticky placemat, plate, or bowl – think about bringing them to the restaurant to make eating easier.

If you experience eating, swallowing and saliva problems please speak to your health management team for ways to improve and manage these issues.

Your Speech Pathologist can identify specific areas of eating difficulties such as, poor posture, lip seal, swallowing problems, tongue awareness – and suggest ways to improve these problems.

Your Physiotherapist can give advice on exercises to improve posture so that saliva doesn't pool at the front of your mouth, and your Occupational Therapist can advise on seating that will improve swallowing. Your GP or specialist can also advise on medications which can help you.

So don't give up on joining your friends and having the pleasure of dining out. Think ahead and plan your meal experience, and you can make sure everybody has an enjoyable evening.

### References:

Parkinsons Foundation, Fight Parkinson's and Everyday Health



# My [Parkinson's] Life Update

## Graham Saxby and his assistance dog Archer

Just over three years ago Graham Saxby shared his life story with the Parkinson's NSW team.

His story included his career in hospitality and his volunteer work as a swimming instructor in the summer months, with about half the students having learning or physical limitations. He was also busy raising his two daughters after his marriage broke down.

Graham had been diagnosed with Parkinson's six years before, but he had continued employment until the COVID-19 lockdown put paid to many jobs.

When we first talked with Graham, he explained he'd decided to apply for a special assistance dog to prepare for the time when he would be living alone with his condition deteriorating. Now he explains why it took so long to be approved for a special assistance dog – along with changes to his house to help with his disabilities.

*"Back then I had attended a Parkinson's support group meeting where an assistance dog trainer attended with their dog, to give a talk on how dogs can assist people with particular issues," recalls Graham. "I was trying to plan for when my children leave home, and I knew that pets are good for a number of reasons."*

*"An assistance dog would also be able to help me in certain ways as my condition deteriorated and would keep me motivated to get out and get exercise and talk to people each day, as well as providing company."*

### Beginning the application process

Graham duly put in an application through the NDIS process, filing the appropriate forms and lengthy reports from his occupational therapist, his clinical neuropsychologist, his neurologist, and other healthcare supports – as well as gaining acceptance of an application to the dog trainer.

*"COVID interrupted the process but once it was put in, it was declined," says Graham. "There were no formal reasons why and a new NDIS plan was just sent in the mail."*

Graham was shocked but followed up with an updated round of reports from all of those involved with his healthcare, and it was again declined.

*"This time I was informed it was for duplication of supports, risk of harm (self or others), and the reasonable and necessary clauses," says Graham. "There were a number of things which I didn't agree with."*

*"This time I decided, with help from Disability Advocacy, to appeal through the Administrative Appeals Tribunal (AAT) which again included all of the updated information on why an assistance dog would be appropriate for me."*

### Missing documentation

*"This became even messier, as I discovered that 75 pages of medical and allied health reports had not been included in the original application appraisal and internal NDIS appeal. I had to resubmit the missing documentation to the AAT and to the NDIA. The home modifications were added at this time to the appeal."*



*"At the next AAT conference, I was asked to see an 'independent' neurologist by the NDIA. This was altered at the last minute to a review of only my medical records provided by the NDIA. So, without full and up to date records, physically seeing me, a video conference or a phone call, the short report supplied by this professional questioned my diagnosis. Which meant it also questioned eight years of treatment, the competency of my treating health professionals, the value of support groups and finally the benefits that an assistance animal would provide me."*

*"That did my head in for a significant amount of time. I went from seeing my psychologist every few months to seeing them once a fortnight. I had to get more information to refute it with a specialist, physiotherapist, a dog trainer, and other things progressing on from there. It took quite a while, and it was still being refused by the NDIA. I ended up with a couple of thousand pages of documentation in this application and appeal process."*

In February 2023, Graham applied to have a review by an Independent Expert Review (IER) panel which had become available through the new Labor Federal Government.

*"By April I had an acceptance and acknowledgement of all recommendations by the NDIA of the IER report," says Graham. "After all the work, time, and delays before which took years, this review only took six weeks. During those three years I'd had my name down for three different dogs, two of which had finished their training and been placed with other people while I was still awaiting approval."*

### Graham and Archer together at last

The third dog, a labradoodle named Archer, has recently finished general training, and Graham and Archer are now getting settled in his newly modified house.

*"He's 20 months old," says Graham. "We are working on him being able to do particular things like put certain items on a bench, pick up things, pull my socks off for me. They are specific tasks to help with my symptoms."*

*"An important one is that he does tactile prompting to get me out of reactive freezing – when I can't move without tactile stimulus. We have bonded so well together, and he is giving me confidence to go out again to places with him, that I had found too difficult on my own."*



# 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."*

