

**From the  
President  
– Mike Whitehouse**



People and families living with Parkinson's is at the heart of every commitment made by members of your Parkinson's Tasmania Committee. The current amount of activity reflects ongoing programs for all concerned as well as major new developments at statewide and national levels.

**URGENT NEED FOR THREE ADDITIONAL  
PARKINSON'S NURSES IN TASMANIA**

Tasmania's peak Parkinson's advocacy body [Parkinson's Tasmania] has called on the new State Government for the immediate new investment in three additional specialist Parkinson's nurses as a priority. Two in the South and .5 each in the North and the Northwest.

There are over 3,000 Tasmanians living with Parkinson's, approximately 1,500 in the South, 750 in the North and 750 in the Northwest.

Currently, there are Parkinson's nurses in Hobart [2.2 FTE], Launceston [2 FTE] and Ulverstone [2 FTE]. However, this is critically under resourced, particularly in the South, leading to nurses being overworked and experiencing "burnout". One resignation has now occurred because of this in

the South with fear that more resignations of the current nurses will follow.

The role of the Parkinson's nurse is highly specialised and demanding. The nurses play an essential and critical role in preventing hospital admissions, reducing wait list times for medical specialists and keeping people out of residential care. They deliver advanced therapies for people at home and ensure both the carer and person living with Parkinson's achieve the best possible health and wellbeing through education, medication advice, counselling and co-ordinating referrals to other multidisciplinary team members and organisations.

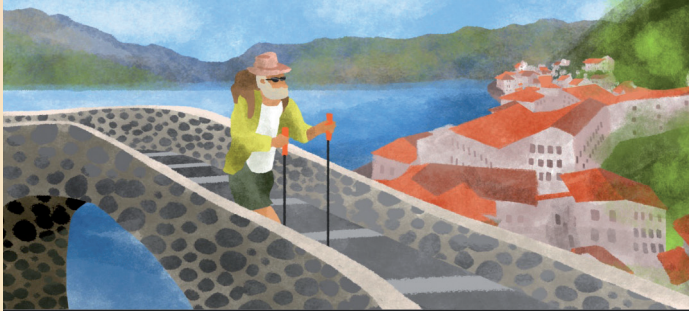
**Quotes From People  
Living with Parkinson's**

From Barbara, Canada – diagnosed at age 65  
*I tell everyone: "I am not my disease. I am a person with Parkinson's, and I aim to live life fully. For me, it's all about giving back. How can I leave the world a shade more beautiful".*

From Samantha, UK – diagnosed at age 21  
*Young onset is not a death sentence. Yes, some days are going to suck, but you can live your life. It takes some adapting and hard work."*

# from the **NURSES DESK**

## **Planning on travelling? Here are some Top Tips**



### **Preparation is key to travelling with Parkinson's. Here are some good tips to help you prepare**

1. Consult your GP for a medical check-up before you travel and consider vaccinations prior going on your trip.
2. A dental check-up is also advisable.
3. Consider using a travel agent. Explain to them clearly what you need, as they usually have good suggestions about where to stay given your personal circumstances. For example, you may prefer to use a lift rather than the stairs, or it may be helpful to have access to a hotel restaurant.
4. Organise travel insurance with pre-existing illness cover.
5. Find out about medical facilities in the areas you will be visiting.
6. Check with Medicare for an up-to-date list of countries participating in reciprocal health care agreements with Australia.
7. Ensure you have an up-to-date list of your medications and ask your GP to give you a prescription for extra medication to cover more than the length of your trip just in case your travel plans are disrupted.

8. If you are taking larger amounts of medication with you, then you will need to take a letter of explanation from your doctor.
9. Request airline assistance in advance if you need it. They can arrange a wheelchair and escort you through check-in. They can also arrange for you to be taken to your departure gate and boarded first. At your destination, you can be assisted off the plane and taken through passport control and customs. Even if you do not normally use a wheelchair, it can be particularly helpful for long flights or flights involving transfers.
10. Be prepared for an emergency and consider wearing a Medic Alert bracelet, pendant or carrying an alert card in your purse or wallet that states you have Parkinson's in the event you cannot communicate. Consider getting it translated into the language of the country you are visiting.

### **During travel**

1. Consider requesting an aisle seat, so you can get up frequently to move around and access the toilet.
2. Always carry your medications in their original packaging. A clear sealable bag is helpful to carry them in, particularly through airport security.
3. Keep your medications and any other valuables in your carry-on luggage (be prepared in case check in luggage is delayed in transit).
4. If you are travelling across time zones, you may need to alter your medication regime whilst you are travelling. As everybody's regime is different, it is important to speak with your medical or nurse specialist prior to your trip so they can help you work out the best way to take your medications while you are away.

5. Drink plenty of fluids during your flight to stay well and hydrated. If you are prone to low blood pressure or constipation this is particularly important. Be vigilant with your bowel management regime. Ensure you have an aperient (medication to relieve constipation) with you, or at hand if you do not usually take them.

6. Allow an easy day or two to recover from jet lag.

\*If you are using CBD oil have a Doctor's letter to support your use on hand and check if there are any restrictions on taking your medication into the country you are visiting, as it may be illegal in some parts of Europe, Asia and Africa. Contact the Australian embassies in the countries you intend visiting to check.

\*If you are carrying needles and syringes, ask your doctor to provide you with a medical certificate explaining why you have them.

\*if you have a Deep Brain Stimulation be aware metal detectors used at Security screening may affect your device. Advise Security you have a 'pacemaker-like device' so you can pass through a different security screening process.

For more general travel tips check out [www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au) "Travel tips for Seniors"

From Parkinson's Nurse Consultants, North-west

## Computer Hints:

A common symptom of Parkinson's is uncontrollable tremors. This results in extra keystrokes and difficulty with mouse control. In Windows, turning the Bounce Key function on will help to control the number of keystrokes made when keys are pressed. This can be accomplished on Windows 7 or later.

# National Parkinson's Alliance

The National Summit to End Parkinson's was held at the New Parliament House on Tuesday 26 March 2024. A funding submission for the development of a National Parkinson's Action Plan was presented to members of the Parliamentary Friends of Parkinson's to seek their support for a Federal Budget allocation. This Summit provided an update on global progress to end Parkinson's and the key areas and initiatives required to support a new agenda for the Australian Parkinson's community.

Over 80 people attended the summit, including clinicians, researchers, politicians and people living with Parkinson's, as well the patron of the alliance, the Governor General, His Excellency General the Hon. David Hurley AC DSC [Ret'd]

The following evening in the Senate, Senator Catryna Bilyk, congratulated Dr. Harley Stanton, from Launceston, whose own inspirational journey after being diagnosed with Parkinson's ultimately led to the creation of this new national alliance. "For the first time, thanks to the efforts of the National Parkinson's Alliance, we now have a memorandum of understanding between all the State Parkinson's associations for a comprehensive and collaborative national plan to tackle Parkinson's disease."

The summit was a demonstration of unity, commitment and determination by the Australian Parkinson's community, to take serious national action on not only improving the lives of patients and their families, but one day ending Parkinson's.

**Mike Whitehouse OAM**  
**President**

# On World Parkinson's Day, (11th April 2024) a New Theory Emerges on the Disease's Origins and Spread

**The nose or the gut?** For the past two decades, the scientific community has debated the wellspring of the toxic proteins at the source of Parkinson's disease. In 2003, a German pathologist, Heiko Braak, MD, first proposed that the disease begins outside the brain. More recently, Per Borghammer, MD, with Aarhus University Hospital in Denmark, and his colleagues argue that the disease is the result of processes that start in either the brain's smell center (brain-first) or the body's intestinal tract (body-first).

A new hypothesis paper appearing in the *Journal of Parkinson's Disease* on World Parkinson's Day unites the brain- and body-first models with some of the likely causes of the disease—environmental toxicants that are either inhaled or ingested. The authors of the new study, who include Borghammer, argue that inhalation of certain pesticides, common dry cleaning chemicals, and air pollution predispose to a brain-first model of the disease. Other ingested toxicants, such as tainted food and contaminated drinking water, lead to body-first model of the disease.

"In both the brain-first and body-first scenarios the pathology arises in structures in the body closely connected to the outside world," said Ray Dorsey, MD, a professor of Neurology at the University of Rochester Medical Center and co-author of the piece. "Here we propose that Parkinson's is a systemic disease and that its initial roots likely begin in the nose and in the gut and are tied to environmental factors increasingly recognized as major contributors, if not causes, of the disease. This further reinforces the idea that Parkinson's, the world's fastest growing brain disease, may be fueled by toxicants and is therefore largely preventable."

## ***Different pathways to the brain, different forms of disease***

A misfolded protein called alpha-synuclein has been in scientists' sights for the last 25 years as one of

the driving forces behind Parkinson's. Over time, the protein accumulates in the brain in clumps, called Lewy bodies, and causes progressive dysfunction and death of many types of nerve cells, including those in the dopamine-producing regions of the brain that control motor function. When first proposed, Braak thought that an unidentified pathogen, such as a virus, may be responsible for the disease.

The new piece argues that toxins encountered in the environment, specifically the dry cleaning and degreasing chemicals trichloroethylene (TCE) and perchloroethylene (PCE), the weed killer paraquat, and air pollution, could be common causes for the formation of toxic alpha-synuclein. TCE and PCE contaminates thousands of former industrial, commercial, and military sites, most notably the Marine Corps base Camp Lejeune, and paraquat is one of the most widely used herbicides in the US, despite being banned for safety concerns in more than 30 countries, including the European Union and China. Air pollution was at toxic levels in nineteenth century London when James Parkinson, whose 269th birthday is celebrated today, first described the condition.

The nose and the gut are lined with a soft permeable tissue, and both have well established connections to the brain. In the brain-first model, the chemicals are inhaled and may enter the brain via the nerve responsible for smell. From the brain's smell center, alpha-synuclein spreads to other parts of the brain principally on one side, including regions with concentrations of dopamine-producing neurons. The death of these cells is a hallmark of Parkinson's disease. The disease may cause asymmetric tremor and slowness in movement and, a slower rate of progression after diagnosis, and only much later, significant cognitive impairment or dementia.

When ingested, the chemicals pass through the lining of the gastrointestinal tract. Initial alpha-synuclein pathology may begin in the gut's own nervous system from where it can spread to both sides of the brain and spinal cord. This body-first pathway is often associated with Lewy body dementia, a disease in the same family

as Parkinson's, which is characterized by early constipation and sleep disturbance, followed by more symmetric slowing in movements and earlier dementia, as the disease spreads through both brain hemispheres.

### **New models to understand and study brain diseases**

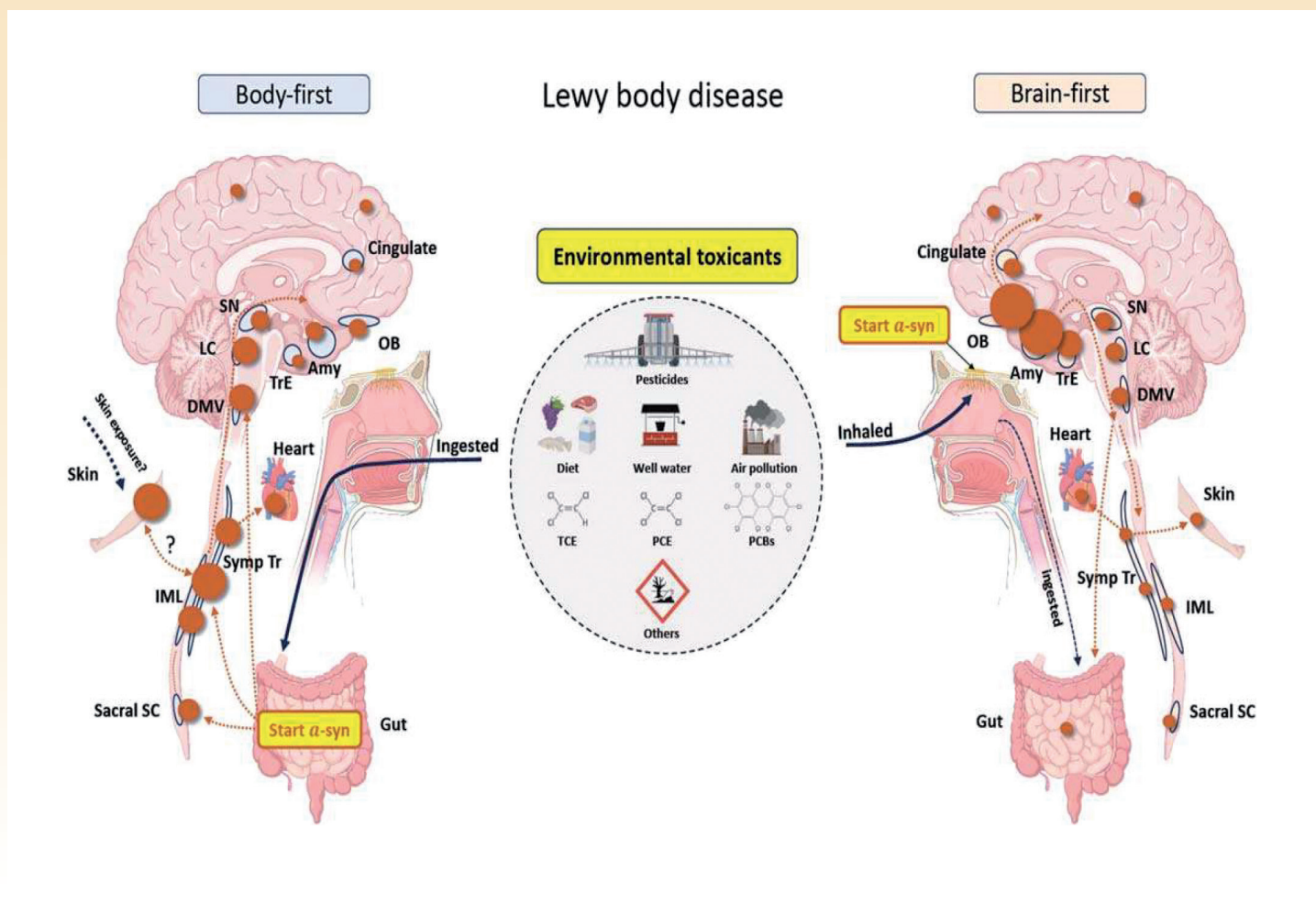
"These environmental toxicants are widespread and not everyone has Parkinson's disease," said Dorsey. "The timing, dose, and duration of exposure and interactions with genetic and other environmental factors are probably key to determining who ultimately develops Parkinson's. In most instances, these exposures likely occurred years or decades before symptoms develop."

Pointing to a growing body of research linking environmental exposure to Parkinson's disease, the authors believe the new models may enable the scientific community to connect specific exposures to specific forms of the disease.

This effort will be aided by increasing public awareness of the adverse health effects of many chemicals in our environment. The authors conclude that their hypothesis "may explain many of the mysteries of Parkinson's disease and open the door toward the ultimate goal—prevention."

In addition to Parkinson's, these models of environmental exposure may advance understanding of how toxicants contribute to other brain disorders, including autism in children, ALS in adults, and Alzheimer's in seniors. Dorsey and his colleagues at the University of Rochester have organized a symposium on the Brain and the Environment in Washington, DC, on May 20 that will examine the role toxicants in our food, water, and air are playing in all these brain diseases.

Additional authors of the hypothesis paper include Briana De Miranda, PhD, with the University of Alabama at Birmingham, and Jacob Horsager, MD, PhD, with Aarhus University Hospital in Denmark.



# Hallucinations Can Be a Scary Side Effect of Parkinson's

*(Parkinson's News Today: Extract by Samantha Felder)*

According to the Parkinson's Foundation, 20%–40% of Parkinson's patients say they've experienced hallucinations or delusions.

The foundation's website states, "Hallucinations are when someone sees, hears or feels something that is not actually there." Unlike dreams, these episodes occur when the person is awake and can happen at any time during the day or night.

Hallucinations may be caused by various factors. They could be a symptom of Parkinson's, a side effect of medication, or even a complication of an issue like a urinary tract infection.

There are five types of hallucinations, the most common being visual. People may see animals or people, including deceased loved ones, who aren't there. Auditory hallucinations involve hearing sounds that aren't real. Less common among those with Parkinson's are hallucinations that are olfactory (smelling an odour that's not real), tactile (feeling imaginary sensations), and gustatory (sensing a strange taste in your mouth). Experiencing any of these can be disconcerting.

## **Changes in Nerve Network of Brain May Cause Presence Hallucinations**

My first experience with hallucinations was terrifying – not for me at first, but for my husband, who watched it happen.

We were on a cruise, and my anti-nausea medications interacted with my Parkinson's medications, resulting in two episodes. The first occurred in the middle of the ship around tons of people. I was sitting in the theatre waiting for a show to start when my husband walked up and asked me to scoot over a seat. I told him that my mom was sitting there and had just walked over to the bar to get a drink. He was very confused because my mom was not with us on the trip.

Later that night, I had another episode. While my husband was sleeping, I tore apart our room, thinking I was packing. He woke up and asked, "What are you doing?" I told him that we had to go pick up our dog from doggy day care. After a few moments of total confusion, he reminded me that it was the middle of the night and we were in the middle of the ocean. He also told me that our dog was safe at my parents' house and not at day care.

To learn more about Parkinson's hallucinations, I spoke with Andrea Frost, whose brother has the disease. She shared the following story with me:

"During a period of great stress, my brother experienced hallucinations. He described it as a family, always with their backs to him, that were in his house. Moving around, sitting at the table. He said he went to go to bed once and one of them was lying in his bed, so he just said, 'I have to go to bed now.' The guy got up and went to the living room. He said they were quiet, so he just ignored them until they went away. Originally, he thought his landlord had mistakenly rented his place to another family."

I also talked with Alan Tobey, a 77-year-old living with Parkinson's, who said:

"I've had auditory hallucinations off and on for years. Deep into sleep, in complete darkness, I hear an adult male with a professional baritone voice reading a long text document, but not quite loud and clear enough to make out more than a few words in a row. No logical explanation."

Hallucinations can occur in many forms. If you notice that a loved one is seeing or hearing things that aren't there, be sure to consult their Doctor, Neurologist or Parkinson's Nurse. Hallucinations could be a sign of depression, stress, or medication interactions. People with Parkinson's face plenty of "real" issues; we don't need our minds throwing us another curveball.

*(About the Author: Samantha Felder was diagnosed with Young Onset Parkinson's at the age of 21. She advocates for Parkinson's patients, travels with her husband and spends time with her pets).*

# My Husband's Guide to Living with Parkinson's: Humour and Support

Eyebrows may raise when my husband says he's "living the dream" (Parkinson's News March 19, 2024)



Whenever anyone asks my husband, Arman, how he is doing, his standard reply has become, "Living the dream." He usually gets a good laugh from this response, and they quickly move on to other topics.

This has become his tagline, which seems to work well for him.

Living with a neurodegenerative disease with no known cure is probably not anyone's dream. But Arman always looks for the humour in life, and it's easy for him to find it. He doesn't complain, sulk, or ever feel sorry for himself. I genuinely believe he thinks he is "living the dream."

Since Arman's diagnosis of early-onset Parkinson's disease in 2009, he has remained steadfast in his pursuit of enjoying his life despite the difficulties of Parkinson's disease. Although he was only 38 at the time and had to step away from his lucrative career as a cardiologist, he was able to find the positive side of his situation. Instead of focusing on all that he had lost, he turned his attention to what he was gaining.

You heard that correctly: He focused on what he had gained.

What could someone possibly gain from a diagnosis of early-onset Parkinson's disease besides pain, suffering, loss, and complete devastation? Beyond the obvious negative things that come with any diagnosis, you might also be able to find a few positives intertwined. For Arman, while he lost the career that he had prepared his entire life for, he gained time at home with his wife and children. The time that he was gifted enabled him to be 100% present as his kids were growing up, something he would've missed otherwise. He also enjoys the perks of preferred parking on days when walking is difficult.

I "interviewed" Arman to share his wisdom and the tools he uses in order to help others who may be struggling. Here is what I learned from him, which continues to inspire me every day.

## Arman's Guide to Living the Dream

A strong support system is the most important part of my life. This is absolutely at the top of my list.

Keep your friends and family close; maintain and nurture those relationships.

Your cards have been dealt, so play them your way.

It really doesn't matter what anyone thinks, so try not to worry about that.

Things can always be worse.

Look at time as a gift that has been offered to you.

Happiness, enthusiasm, and positivity are contagious, so spread them around often.

Laugh at yourself as much as possible, because laughter is free medicine with no side effects.

Although having a chronic illness is difficult, it doesn't have to ruin your life. You can still have a wonderful and fulfilling life; it just might look different from what you envisioned.

Choosing to live the dream and find the good in times of stress can make all the difference. Seek out the positive side of any situation. If you look hard enough, you just might find it.



IN THIS TOGETHER  
**parkinson's**  
TASMANIA

Dates to Remember



**SUPPORT GROUP MEETINGS**

**SOUTH**

2.00pm Senior Citizens Club Rooms  
Lambert Ave., Sandy Bay  
29th May, 26th June, 31st July,  
28th August 2024

**NORTH**

2.00pm Launceston Conference Centre,  
Door of Hope Church, 50 Glen Dhu St., Launceston  
11th June, 9th July, 13th August 2024

**NORTH WEST**

2.00pm Gnomon Pavilion,  
3 Wharf Road, Ulverstone  
12th June, 10th July, 14th August 2024

**CARERS GET-TOGETHER**

**SOUTH**

10.00am 12 Adelle Place, Kingston  
23rd May, 18th July 2024

**NORTH**

2.00pm Launceston Conference Centre,  
Door of Hope Church,  
50 Glen Dhu St., Launceston  
14th June, 13th September 2024

**NORTH WEST**

2.00pm Willaway Apartments,  
2 Tucker Street, Ulverstone  
13th June, 12th September 2024

**Stay On-Time!**



Medicine Reminders | Timers | Electronic Pill Boxes | Vibrating Watches | Vibrating & Talking Clocks  
visit: [www.TabTimer.com.au](http://www.TabTimer.com.au) or call: **1300 TAB TIMER (1300 822 846)**

For terms and conditions of sale visit [www.TabTimer.com.au](http://www.TabTimer.com.au). TabTimer™, 'helps keep medications on time™', 'helping to keep people on time™' and the TabTimer™ logo are trademarks of TabTimer Pty Ltd © 2017 ABN: 99 137 415 948

**Disclaimer**

Parkinson's Tasmania Inc., has endeavoured to ensure that the information in this Newsletter is accurate, however, we accept no responsibility for any errors, omissions or inaccuracies in the respect of the information contained in the material provided by Parkinson's Tas, Nor is it to be construed that other material on any of the subject matter is unavailable. Further, Parkinson's Tas. takes no responsibility for the persons who may rely on this information for whatever purpose. The views expressed in these articles are not necessarily the views of the editorial committee.

**Contact Details**

**Mike Whitehouse** President  
42 Auburn Road, Kingston, TAS 7050  
Mobile: 0448 710 882  
Email: [mike.whitehouse@bigpond.com](mailto:mike.whitehouse@bigpond.com)

**Pauline Domeney** Secretary/Treasurer  
12 Adelle Place, Kingston, TAS 7050  
Phone: (03) 6229 2509 Mobile: 0407 314 933  
Email: [pdomeney@netspace.net.au](mailto:pdomeney@netspace.net.au)

**Business Address**  
PO BOX 608, Kingston, Tasmania 7051