

# STANDBYME

IN THIS TOGETHER  
**parkinson's**  
NSW

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# Message from the CEO

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

As promised in the Spring edition of this publication, I will be keeping our community up to date on our advocacy campaigns with the objective of gaining more Government funding for our essential services for people living with Parkinson's – particularly in regional and rural areas.

Over the past two months we have been particularly active in reaching out to both the key Ministers of the NSW Government and their Shadow Minister counterparts. The reason is because an election is coming up in early 2023 and we want to be visible to all current and future decision makers around Government funding.

We were successful in obtaining a significant capacity-building grant in fiscal 2021-22 and want to build on that with further grants in 2023 – particularly to support our 1800 HealthLine which is the gateway to all of our other services for the NSW Parkinson's community.

On behalf of all of us at Parkinson's NSW, I would like to wish you all a safe and happy Christmas, New Year, and summer holiday season. Enjoy the time with your loved ones and friends, and perhaps the opportunity to travel.

If you do plan to travel, you may be interested in some related stories in this edition of *Stand by Me* – including advice on the practicalities of travel with Parkinson's, preparing and carrying your medications, and maintaining a healthy exercise routine while you are away from home.

Enjoy the read and the Festive Season.

Jo-Anne Reeves  
Chief Executive  
Officer



## Give the gift that helps people living with Parkinson's this Christmas



Generous Parkinson's NSW donors often ask what their donated funds will be spent on.

Well this Christmas, the choice will be yours – and you can donate as a Christmas gift on behalf of one of your friends or family members.

The new Parkinson's NSW Virtual Christmas Gift Store allows you to choose exactly what you would like your donation to be spent on – and for whom.

Perhaps something as basic (but important) as an information kit to be sent out by our 1800 HealthLine? Or you could choose to underwrite an education seminar, a nurse's visit, or some other Parkinson's support activity.

There is a wide range of choices at an equally wide range of prices – the choice will be yours.

And when you give, a Christmas card will automatically be generated and emailed to the person for whom you donated.

**It's Christmas giving with practical and social value.  
Christmas shopping solved!**

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# What if the first signs of Parkinson's could be heard in the voice?



Parkinson's disease is best known for causing movement disorders. But brain-damaging protein aggregates may also be linked to changes in patients' voices that appear long before motor symptoms. American researchers have followed this promising line of research.

Parkinson's disease is primarily known for tremors, rigidity, and the difficulties of movement that it induces, but there is another, more subtle symptom, which appears before motor disorders: speech disorders.

Gradually, the voice of people with Parkinson's softens and becomes more monotonous. University of Arizona researchers think that the Lewy body – compounds of  $\alpha$ -synuclein, a protein naturally present in the brain, but which is no longer evacuated because of a mutation – located in the brain areas involved in speech would be responsible for this early manifestation of Parkinson's.

To test their hypothesis, they did not experiment on humans, but on birds, diamond mandarins.

## Birdsong and Parkinson's disease

At first glance, these small birds originating from Australia and sold as pets do not have much in common with human beings. However, the brain of males (females do not vocalize) uses neural circuits comparable to ours to sing.

In addition, young birds practice by imitating adults, as a child learns to speak by repeating what he hears around him, especially the voice of his parents.

To make the birds show the symptoms of Parkinson's disease, the scientists injected them with a viral vector containing a mutated version of the  $\alpha$ -synuclein gene specifically in area X, involved in the singing and his learning.

The song of healthy birds was compared to that of parkinsonian birds one, two and three months after injection using software which analysed their tone, amplitude, and duration.

The first results indicate that the presence of abnormal  $\alpha$ -synuclein in the brain alters the song of birds: it becomes shorter and less full, like what happens in humans.

At three months post-injection, the birds have more difficulty starting their song. These experiences do not reflect the typical progressive nature of Parkinson's disease.

## How transferable are these results to humans?

This is the big unknown and probably the next line of research for the University of Arizona team. If such an association between speech impairment and  $\alpha$ -synuclein is confirmed in humans, doctors would then have the opportunity to manage patients before the disease is too advanced.

*Source: Original story by Tammy Sewell oicanadian*

# How to choose the best nutrient-rich foods for Parkinson's



## Why is nutrient-rich food important to people living with Parkinson's?

Because no matter how perfect your medication regime, no matter how much, how often, and how hard you exercise, you need nourishing food for good health.

With Parkinson's, nutrition takes on an additional role in supporting the brain and nervous system, as well as the body. So let's take a look at the foods that fortify the brain and the body.

**Plant foods** Whole grains, fresh vegetables and fruits, legumes. These provide complex carbohydrates, vitamins and minerals, antioxidants, and fibres.

Whole barley, rye, and oats have all been found to improve aspects of our health, such as improved colon health, regular bowel movements, control of blood glucose and cholesterol, and strengthening the immune system.

Blueberries may help prevent or slow neurodegeneration and appear to boost memory. Apples and onions contain quercetin, a flavonoid and antioxidant, which may help protect against damage to DNA.

Legumes and dry beans, split peas, lentils, chickpeas are rich in protein, fibres, and the B vitamins that are so important in Parkinson's.

**Animal foods** Fish and seafood, meat, poultry, eggs, and dairy foods all contain vitamin B12, which isn't found in plant-based foods. They also contain all nine essential amino acids.

Fatty fish and seafood, and to a lesser extent, eggs, also have omega-3 fatty acids and vitamin D. These are especially important in Parkinson's as the grey matter of the brain is largely made up of omega-3 fats, and deficiency is associated with dementia and depression. Omega-3 fats also support heart health.

Fatty fish and eggs are among the few foods that naturally contain vitamin D. This includes the more powerful form called 25-hydroxyvitamin D, which is not found in supplements or fortified milk.

Deficiency is associated with loss of muscle mass and bone density, falls, fractures, some cancers, irritable bowel syndrome, and cognitive decline.

*Note: Some people are very sensitive to the milk of cows, sheep, and goats. These contain an especially high ratio of the amino acids that compete with levodopa for absorption. If milk blocks levodopa absorption, choose a milk alternative such as almond, soy, or rice milk.*

**Prebiotic and probiotic foods** Probiotic foods contain the living organisms such as friendly bacteria and yeasts that make up the microbiome. These are especially important for those with Parkinson's.

Research is increasingly finding a relationship between the brain, the gut, and the colony of cells in the gut called the microbiome. It appears that the microbiome may influence the onset and progression of Parkinson's. Some speculate that Parkinson's actually begins in the gut, due to poor gut health<sup>1</sup>.

Prebiotic foods contain fibres that humans can't digest, but that serve as food and fuel for the probiotic organisms.

*Note: If you are using the drug rasagiline you should not eat aged and fermented foods, as they have high levels of tyramine. Such foods can cause hypertensive crisis.*

Yoghurt can be a good choice, as it's safe for those using rasagiline. The more different strains of organisms it has, the better – look on the label to see which organisms it contains.

Kefir is a fermented drink that may be made with milk, water, or coconut milk. It has more different strains of probiotic bacteria than yoghurt. If you are sensitive to milk protein, try water kefir or coconut milk kefir.

Fermented pickles are made by immersing vegetables in a salt and water brine solution. They are not the same as pickles made with vinegar, which do not have probiotic properties. Fermented pickles must not be canned or heat-treated; heat will destroy the live organisms.

Sauerkraut is fermented cabbage and is a good source of probiotic bacteria. Kimchi is a Korean version and is spicier. Both must be unpasteurised, as heat will kill the organisms.

Miso is fermented soybean paste.

**Prebiotic foods** Whole wheat, oats, onions, leeks, garlic, asparagus, Jerusalem artichokes, lettuce, eggplant, sweet potatoes, bananas, tomatoes, cashews, peanuts, and legumes (dried beans, peas, lentils). Each of these foods has different types of indigestible fibres, known as prebiotics. Also high-quality dark chocolate is a prebiotic food.

Prebiotics are used as food by the colony of friendly bacteria in our gut. Each prebiotic food supports different kinds of friendly bacteria so, if possible, eat a variety of these foods.

One study found eating whole grains had an increase in one kind of the friendly gut bacteria, and a decrease in harmful bacteria. An animal study discovered that prebiotic foods improved sleep. So don't skimp on fibre; keep those good microbes well-fed.



### Refined and highly-processed foods

Refined ingredients like white flour and refined sugar have been stripped of their nutrients and prebiotic fibres. Highly-processed foods, such as many canned soups, boxed macaroni and cheese, and frozen ready-to-eat meals contain refined ingredients and also have potentially harmful additives, such as emulsifiers, thickeners, artificial dyes, and preservatives.

Food ingredients that have been sprayed with pesticides and herbicides

We've long seen an association between agricultural use of herbicides, and increased incidence of Parkinson's among farming communities. Now research is beginning to uncover possible causes.

Some degenerative diseases appear linked to

glyphosate, a common herbicide. Animal studies show that it may interfere with the normal working of the gut, which eventually damages motor neurons<sup>2</sup>.

Source: Kathrynne Holden, former National Parkinson Foundation dietician (UK)

Visit her website, [nutritionucanlivewith.com](http://nutritionucanlivewith.com), for more Parkinson's-related nutrition information

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## Exercise on the go – Park or Playground

December and January for many of us means having a holiday. Sometimes going away can be a good excuse to abandon our daily exercise routine. However, holidays can be a great chance to exercise in a non-routine way.

So instead of doing the same exercise routine as you do at home, here is the chance to mix it up while having fun without feeling like you are exercising. You could go walking on the beach, play volleyball, tennis or bowls, swim, or have a game of golf. If these types of activities aren't available or you don't enjoy them, there are still many exercises you can do with what's available nearby.

Wherever you find yourself, there is usually a park or children's playground close by. Even on a road trip, where you'll find a picnic table or bench to do some exercises. Here are some suggestions.



### Incline Push Ups (chest)

Place your hands slightly wider than shoulder-width apart on a bench or other stable, elevated surface, with your feet together and body straight from head to heels. (Alternatively place

your palms against a wall.)

Keeping your back flat and stomach engaged, bend your elbows, and lower your chest to the bench. Pause, and then push yourself back up and repeat.



### Squats (butt & legs)

Stand with feet hip width apart, toes facing front. Push your hips back, bending at the knees and ankles moving into a squat position.

Keep your heels and toes on the ground, chest up and shoulders back. Push yourself back up and repeat.



### One Arm Rows (upper back)

Find something to use as a weight e.g. a tin of baked beans, a full water bottle, a tool from the car, etc.

Lift your right knee onto the bench. Bend over and place your right hand on the bench in front of you for support. Pick up the weight in your left hand.

Keep your back straight. Using your upper back muscles, pull the weight straight up beside of your body, keeping your upper arm close to your side. Hold for a count of one and squeeze your back muscles. Return to the start position and repeat.



### Knee Tucks

Place your hands on the seat or back of the bench, so your hands are directly below your shoulders.

Step your feet back and together forming a straight line from ears to ankles. Draw your abs in and brace, allowing a natural curve in your lower back.

Tighten your stomach and pull your left knee forward into a tuck. Allow your lower back to round. Hold for a second. Return your foot to the starting

position and tuck the other leg. Continue alternating legs for a total of ten repetitions.

**So, there's really no excuse for not continuing your exercise routine – with a bit of a change to make it really feel like a holiday.**

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# Tips on travelling with Parkinson's

**The Christmas-New Year period is peak travel season for Australian families and singles – including those living with Parkinson's.**



**Here are some quick tips on travelling with Parkinson's to make your journeys easier and safer.**

- Always carry your Parkinson's Passport. Don't have one yet? It can be downloaded from the Parkinson's NSW web site here.  
<https://www.parkinsonsnsw.org.au/parkinsons-passport/>
- Use a 'fanny' pack or backpack so that you have both hands free to balance as you walk, especially if walking any distance.
- Pack snacks and carry a water bottle to take medications.
- Wear comfortable, loose-fitting clothing and good walking shoes.
- When making hotel reservations, request a room on the ground floor or near the lifts. Ask if they have rooms that are accessible because these usually include grab bars in the shower and bathroom and have wider spaces between furniture for easy access.

## Traveling With Parkinson's Medications



- Always have at least a day's dosage of medication in your pocket or purse.
- When flying, try to carry all of your medications in your cabin baggage, in the event that your check-through luggage gets misplaced.
- Pack enough medications to last the entire trip – ideally more than you will actually need in case of delays in your itinerary.
- Do not rely on out-of-town – or especially out-of-the-country – pharmacies for medication refills.
- Find out if your medications are temperature sensitive and plan to carry them in cooled or insulated packs accordingly.
- Use a watch with an alarm or an alarm pillbox. If you are traveling across time changes it may be difficult for you to remember on your own. It is best to stick to your routine according to the time zone you are in, not your home time zone.

## Leading neuroscientist Glenda Halliday named NSW Scientist of the Year

Internationally acclaimed neuroscientist Professor Glenda Halliday FAA FAHMS from the University of Sydney is the 2022 NSW Scientist of the Year.

Professor Halliday, who received a prize of \$60,000, is one of 10 exceptional researchers, innovators and educators honoured in the 2022 Premier's Prizes for Science & Engineering.

Premier Dominic Perrottet said Professor Halliday received the award for her groundbreaking work on neurodegenerative diseases, which has changed the way

we diagnose and treat these conditions globally.

Professor Halliday's research looks at how the human brain is affected structurally and biochemically by neurodegenerative diseases.

Her current focus is on the underlying causes of the non-Alzheimer's neurodegenerative diseases – particularly Parkinson's disease and frontotemporal dementia.

*"It is incredibly satisfying to know our work is recognised by our peers in this way, even though we feel there is always more work to do," Professor Halliday said.*

*"I hope this award will inspire those I am working with and others to find the cures needed in this area of research."*





# My [Parkinson's] Life

## Linda Boulton

Linda Boulton was a 17-year-old dance teacher when she met her husband-to-be 50 years ago.

*"My old dance teacher was looking for more boys to learn ballet for an end-of-year concert and Steve and some of his friends were told it would help their footy skills," recalls Linda, who was then living with her family in Newcastle.*

Steve Boulton, who was also 17 at the time, enjoyed the lessons and met up with Linda at rehearsals as they progressed.

And as his dance skills also progressed, so did their romance. At age 25 the couple married and set up their own home in Newcastle. Linda continued with her dance school while Steve worked as a teacher and helped Linda with her school.

Two daughters completed their family, and they enjoyed a busy and active lifestyle over the next two decades. By the time Steve turned 46 the couple's children were 17 and 13, the dance school was three decades old, and they looked forward to their future after many years of hard work.

But Steve had an issue with one arm. His arm wasn't swinging as he walked, and he was concerned he had nerve damage. Two GPs hadn't found anything, so he headed off to a neurologist for specialist testing.

*"The neurologist recognised what was wrong and he came away with a diagnosis of Parkinson's, which neither of us were expecting," says Linda. "Steve went to the gym every day and loved all sports.*

*"I just thought it was cruel for him when he was still so active and only in his 40s. I just hoped it would be a slow progression to getting worse. We didn't tell anyone we didn't have to, and he kept working as a teacher."*

All that changed over the next few years as Steve's symptoms became more difficult and he developed psychosis as a side-effect of a medication. He also had terrible foot cramps and panic attacks; he couldn't roll over in bed at night or get up without help.

*"He was forced to retire as the result of a psychotic episode, and it was done in quite a hurtful way," says Linda. "Since diagnosis I'd organised all his appointments and medications, but by this stage I was his carer for so many things.*

*"He was at home all the time and I was finding it more difficult as I was still working part-time. In just four years we had lost our normal lives, but our daughters were still dependent. I just tried to hold it all together."*

In late 2006 Steve had a Deep Brain Stimulator unit fitted, which helped with some of his symptoms. Unfortunately, the disease and its medications were affecting his behaviour and he also developed dementia as his illness progressed.

*"Aside from being his carer I was now doing everything else because he couldn't deal with anything," says Linda. "Getting assistance from Centrelink for Disability Support and a Carer's Pension was incredibly wearing. I had to be his advocate for everything, and I had to develop the confidence to do that.*

*"Socially I used to be quiet, but I had to hold conversations for both of us because he couldn't. A lot of his friends couldn't deal with his condition and didn't visit him. They found it too confronting as he was so changed from the man he was. That was very difficult for him, too.*

*"Eventually I had to put him into care as his needs became more complex and I found it harder to manage. I felt incredibly guilty doing it. I would go and visit him every day, often twice a day.*

*"I would think, should I move him back home, but it was too hard to keep him safe, he was too restless and agitated. Centrelink cut off my carer's pension because I was no longer caring for him. It was very difficult.*

*"He was in there three years and four months before he passed away. Suddenly I had lost my identity, too. I'd had 16 years of constant changes and challenges in caring for him. My children were very supportive, and I was grateful that he'd met his first grandchild, but now there are four grandchildren.*

*"I felt cheated, for us and for him. Very early on I'd lost the partner who was active and funny and helpful, and we'd also missed out on the things that other couples were doing as their children left home. I hadn't really had time to process my emotions much while I was caring for him."*

The one thing Linda had managed to do was to start a PhD in English back in 2011 and begin writing a memoir on her life as a carer.

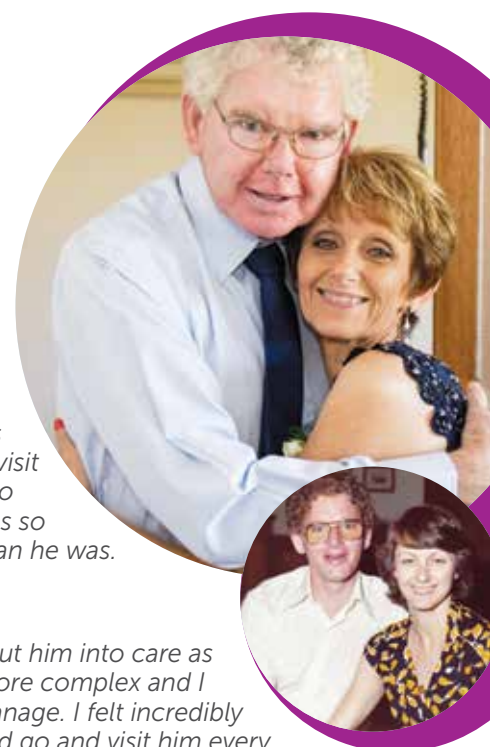
*"I started writing as soon as I began the PhD and wrote from memory and then added to it as life progressed," she says. "I wrote with Steve's blessing, and it provided an outlet and had therapeutic benefits. I submitted it in 2019 and it is available, titled Pas de Deux, a Carer's Story through Ginninderra Press and other online sites such as Amazon, Booktopia and eBay."*

The memoir is unflinchingly honest, and Linda says she didn't want to hide how difficult being a carer could be.

*"I lost my cool, I'd be fed up, frustrated at having my life taken over by being a carer and missing out on other things," she says. "I'd caution anyone just coming into caring reading this as everyone's experiences are different. I felt we were quite young and not everyone's Parkinson's progresses so rapidly.*

*"My best advice is to try and have something else to think about in your life as well as your caring responsibilities.*

*"But despite the challenges, caring for Steve was also a labour of love and I discovered strengths I never knew I had. I hope my story offers support and solace to other carers in similar situations."*



# Your Christmas gift will make sure people don't struggle alone with Parkinson's

In 2018, GP Helen Tolhurst gave up her much-loved career as a GP to care for her partner who was diagnosed with bone marrow cancer.

A year later, as he was dying, she learned she had Parkinson's disease. The diagnosis absolutely shocked her. But at a neurologist's suggestion, she found an online Support Group, and it gave her a glimmer of hope again.

*"Gradually I sort of came to terms with the diagnosis and started to think, 'Well, it's going to be a while until I'm disabled. And until then I'm just going to regard every day as a gift,'" she said.*

Helen saw what a difference support made to her and realised that there was a real need for other people in her area. In January 2020, she and a small group of locals with Parkinson's had its first meeting. By the end of the first lockdown, the Group had grown to more than 70 members.

Parkinson's NSW backs Support Groups like Helen's with crucial administrative, financial, and practical help. We understand what a vital source of information, activities, and emotional nourishment these groups can be for people with Parkinson's, their caregivers, and families.



A  
little  
help from  
you goes a long  
way this Christmas

IN THIS TOGETHER  
**parkinson's**  
NSW

Donate today to help us maintain and grow the number of Support Groups like Helen's, making sure people with Parkinson's never feel they are alone with their condition.

☒ **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)

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

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

Signature \_\_\_\_\_

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☐ 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

