

STANDBYME

IN THIS TOGETHER
parkinson's
NSW

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STEP
UP
FOR
PARKINSON'S



THANK YOU!

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appointed in Goulburn**

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Making a harp for Judy

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From the CEO

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

I have received many questions recently about the advocacy and collaboration activities of Parkinson's NSW – not least because these activities are conducted out of the public eye on an organisation to organisation, or organisation to Government basis.

In response to your interest, in this edition we have included an update on both of these activities, ranging from our outreach to State and Federal Government to our cooperation with other Parkinson's organisations and healthcare influencers.

We also report on the success of the Step Up for Parkinson's online fundraising initiative and share the good news that we have appointed a jointly-funded Parkinson's Specialist Nurse in Goulburn – within the Southern NSW Local Health District.

The Goulburn Support Group played a key role in making this appointment possible, thanks to its fundraising efforts and the support of generous local sponsors. I also acknowledge the work of local MP Wendy Tuckerman who helped us achieve a co-funding agreement with the Local Health District.

Other interesting stories in this edition of *Stand by Me* include the tale of a man living with Parkinson's who decided to build a harp from scratch, ways to improve sleep, and news on diets from around the globe which are proven to boost the body.

Enjoy the read and the warmer weather.

Jo-Anne Reeves
Chief Executive
Officer



Outstanding response to Step Up for Parkinson's



There was an outstanding response from members and supporters of the NSW Parkinson's community to the May Step Up for Parkinson's online fundraising campaign.

More than 160 participants logged over 17,000 kilometres to raise \$124,700.21 which will go towards supporting the work of Parkinson's NSW in communities across the state.

Participants walked, ran, wheeled, and did yoga and other exercise to raise funds from individual sponsors who pledged dollars to their online appeals. Favourite pets got lots of exercise too, as their owners clocked up the kilometres for a good cause.

A virtual 'wall' was created for participants to declare why they were involved in this fundraiser and post photos to match. Here are some examples of their motivation:

"I'm stepping up as my husband has recently been diagnosed with Parkinson's."

"Little Penny is a 7-week-old miniature foxy and she is stepping up with me to raise funds for Parkinson's NSW."

"I'm Stepping Up for Parkinson's in memory of my Dad."

"I am stepping up for an inspirational woman who is living with Parkinson, my employer Christina."

"I was diagnosed 2020 with Young Onset PD. It has taken me on a journey of self-reflection."

"I'm stepping up for aged care residents with Parkinson's that I have the pleasure to help look after."

"I am stepping up for my gorgeous mother who passed away too early due to Parkinsons."

In response to the enthusiasm generated in 2022, the Step Up for Parkinson's online fundraiser will return in 2023.

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New Parkinson's Specialist Nurse appointed in Goulburn

A new Parkinson's Specialist Nurse has been appointed in Goulburn to support people living with Parkinson's in the Goulburn, Yass and Crookwell areas.

Nurse Lauren Hogan is a Goulburn local who has spent 13 years working at Goulburn Base Hospital – nine of which have been as a Registered Nurse. Her most recent role was Clinical Nurse Educator on the surgical ward. She has also had experience in nursing, assessment and planning for Parkinson's patients, reduction in falls causing serious injury, working in multidisciplinary teams, and infection control.

The new nurse position is 50/50 funded by the Southern NSW Local Health District and contributions by the Parkinson's NSW Goulburn Support Group which has been fundraising for years to underwrite this role.

The Group had the support of loyal local donors including the Goulburn Workers Club and Goulburn Golf Invitational. Both organisations also made additional surprise donations during the announcement event for the nurse position. Ganter Constructions has also been extremely generous but its representatives were unable to be present on the day.

"We are extremely excited to see our hard work come to fruition; this has been our dream for over 10 years. The support of the local community, our family and friends who all had faith in our dreams has made this all possible," said Gill O'Connor of the Goulburn Support Group.

"Lauren will make an immense difference in the lives of all those living with Parkinson's in our community – not just for our Support Group participants but for all people living with this disease, their caregivers, and families in our region.

"It's a great outcome for us all. It has been so wonderful to have people stop us in the street to congratulate us – news has spread!" said Gill.

Announcing the new role, Parkinson's NSW CEO Jo-Anne Reeves said the Local Health District-based Parkinson's Specialist Nurse model had already been proven to deliver benefits for people living with Parkinson's and their caregivers.

"This model permits the Specialist Nurses to work across a number of settings including hospitals, clinics, patient's homes and Aged Care facilities," she said. "There is also evidence that this model of care helps to reduce the sense of isolation many people with Parkinson's experience, along with the high rates of depression and anxiety associated with the disease."

"Where communities have access to a Specialist Nurse, carers and family members also show significant improvements in their own well-being, with reduced levels of depression," she said.



Parkinson's NSW, in partnership with Local Health Districts in NSW, now co-funds and co-manages neurological nurse positions in five regional areas – Port Macquarie, Coffs Harbour, Shoalhaven, Tweed and Goulburn. A sixth position is based at Hornsby Ku-ring-gai Hospital in Sydney.



Parkinson's NSW advocacy and collaboration update

Advocacy is the process of seeking support for a cause or policy.

In this case the cause is support for the NSW Parkinson's community and funding for services. However because of its highly targeted and often confidential nature, much of the advocacy done by this organisation goes unseen by the community it serves.

This article is intended to give some insight into the advocacy and collaboration activities of Parkinson's NSW.

Political outreach

Thanks to advocacy by two prominent State MPs with an interest in our cause, Parkinson's NSW over the past year was twice invited to participate in information evenings at Parliament House.

The receptions were attended by MPs and their advisors from across the political spectrum and featured speeches from the President and CEO of Parkinson's NSW.

"The latest research tells us that there are already 69,600 people living with Parkinson's in New South Wales. If you add in caregivers and immediate family that brings the total of people affected by Parkinson's in some way to more than 200,000... and most of them are voters!"

"The general population growth rate of Australia is just over one percent. However, the average growth rate in Parkinson's will be 40 percent over the next 20 years. This presents a major public health challenge that can't be ignored."

Extract from speech to parliamentarians by Parkinson's NSW Chair, Margaret Scott

Former Deputy Premier of NSW, The Hon. John Watkins AM, who is living with Parkinson's, also spoke movingly about the impact of the disease on his physical and mental wellbeing.

Annual mailing campaigns around Budget time have also been conducted. They addressed every MP in NSW along with the State and Federal Health Ministers, requesting recurrent funding for the delivery of services to the Parkinson's community.

This is a priority because almost 90 percent of funding for Parkinson's NSW activities currently comes from fundraising. This is not sustainable.

“Parkinson's has become... a hated influence that has invaded my body to deform my abilities and sense of self.”

Extract from Sydney Morning Herald opinion article by The Hon. John Watkins AO

Co-funded Parkinson's Specialist Nurses

Research conducted by the Faculty of Nursing, Midwifery and Indigenous Health of Charles Sturt University indicates that the most effective model for Parkinson's Specialist Nurses is:

- To have them jointly funded by Local Health Districts (LHDs) and Parkinson's NSW
- Jointly managed by the two organisations
- Based in the LHD offices in order to provide nurses with access to health records and data, professional development opportunities and peer support.

Therefore advocacy to the management of LHDs across NSW where nurses are not yet placed is ongoing. Our most recent success has been the placement of a co-funded nurse based in Goulburn, within the Southern NSW LHD.

Joint advocacy with Parkinson's NSW Support Groups

Parkinson's NSW encourages all Support Groups to engage in joint advocacy at their local level to raise the profile of Parkinson's in the community and enlist the support of MPs to make submissions to key Ministers.

Pro forma letters and advice on how to engage with MPs are provided by Parkinson's NSW upon request.

A video message from the Chair on World Parkinson's Day goes out to all Support Groups and via social media to help raise the profile of the Parkinson's community across NSW.

Joint advocacy in the not-for-profit and healthcare sectors

Parkinson's NSW is working with Fight Parkinson's (formerly known as Parkinson's Victoria) to jointly target the Federal Health Minister, advisers, and other members of the national health bureaucracy. This involves multiple meetings and outreach, backed by a well-researched document supporting our request for funding.

Our organisation also works with others in the healthcare sector. For example, we supported St Vincent's Hospital's bid for increased funding to treat Movement Disorders and joined the Australasian Neuroscience Nurses Association (ANNA) to lobby the Minister for Health for a rapid resolution of the SinemetTM shortage.

Parkinson's NSW has also made formal written submissions to Government inquiries into:

- The National Disability Insurance Scheme
- Aged Care Quality and Safety
- Regional, Rural and Remote Health

Most recently, in July we were invited to participate in a consultation session to develop the new NSW Regional Health Plan. The plan will be a long-term strategy to meet the health needs of regional, rural,





Diets proven to boost the body against Parkinson's

So, how do you pick the best diet for Parkinson's disease? Start with two basic ideas:

1. Eat whole foods. There is a strong association between pesticide and herbicide use and risk for Parkinson's disease. Whether you choose animal or plant foods, select those that are raised as naturally as possible: meat and dairy from grass-fed cows; meat and eggs from pastured poultry; organically-grown whole grains, fresh vegetables, and fruits.

These nourish and maintain the body's brain, bones, and organs. They may be more expensive, but consider the cost of disease, which is much greater.

2. Avoid foods that have been made from refined or highly-processed ingredients, such as refined flour and sugar, canned meats and soups, frozen ready-to-eat meals. Over time, these rob the body of health, strength, and thinking ability, and lead to cancer, diabetes, heart disease, stroke, and other diseases.

Who are the healthiest people and what do they eat?

Next, consider the diets of the longest-lived populations in the world. According to National Geographic Fellow Dan Buettner, who wrote influential diet and nutrition book *The Blue Zones: Lessons for Living Longer from the People Who've Lived the Longest*¹, the places where people live the longest, and the foods that make up their diet, are:

Icaria, Greece Staple foods: potatoes, wild greens, goat's milk, honey, garbanzo beans, black-eyed peas, lentils, fruit, wine, and small amounts of fish.

Okinawa, Japan Staple foods: tofu, sweet potatoes, seaweed, turmeric, sake, bitter melons, garlic, brown rice, green tea, shiitake mushrooms, and small amounts of fish.

Sardinia, Italy Staple foods: goat's and sheep's milk and cheese, durum wheat, barley, fennel, fava beans, chickpeas, tomatoes, olive oil, almonds, milk thistle tea, and red wine.

Nicoya Peninsula, Costa Rica Staple foods: beans, rice, corn, squash, yams, green vegetables, papayas, bananas and other fruits, cheese, eggs, and small amounts of meat.

Loma Linda, California Staple foods: avocados, nuts, beans, oatmeal, whole wheat bread, soy milk, grains, fruits, nuts, and vegetables. They drink only water; some choose to eat small amounts of meat and fish.

But what about you?

Choose a plan that appeals to you and try it for a few months. Keep a daily journal and write down what you ate, at what time, how you felt afterwards – whether your Parkinson's symptoms are affected, and in what way.

This will tell you whether the diet choice is a good one for you personally and meets your individual needs as a person with Parkinson's disease.

If you have gastroparesis – a digestive problem that's a non-motor system of Parkinson's – you may find that a diet lower in fat helps your medications take effect more quickly.

If you suffer from constipation, a diet that includes plenty of prebiotic foods and fibre is ideal. Yet, you might have both gastroparesis and constipation and still find that a paleo diet improves your Parkinson's symptoms and that you can cut back on your medications.

You are the best judge

Your doctor only sees you for a few minutes every few months. Diet gurus will probably never meet you at all. You, on the other hand, live in your body 24 hours a day, seven days a week.

No one knows you better than you, yourself. That makes you best person to discover and take control of the optimal eating plan for you.

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

References: Buettner, Dan, The Blue Zone: Lessons for Living Longer from the People Who've Lived the Longest, National Geographic Books, 2008

How not to lose sleep over Parkinson's disease

Did you know that 90 percent of people with Parkinson's suffer sleep disturbance? Here is advice from an advanced nurse practitioner, a physiotherapist and a person living with Parkinson's about why good sleep hygiene matters.

"Have you ever been fishing and caught a fish – and it's landed, flipping around, on the bank?" asks Matt Eagles.

He is describing his typical night in bed with Parkinson's.

"I can be very, very still, then start flapping. My wife leans over and puts her hand on my leg or my tummy and, usually, it stops. During that time I'm semi-conscious, but it's not a good quality of sleep."

Throughout his 46 years of having Parkinson's, Matt has tried many ways of getting to sleep. Like 90 percent of people living with the condition, he suffers from sleep disturbance brought on mainly by troubles with movement when lying in bed – although he admits things are not as bad as they once were. His limbs can go from being highly active, to completely rigid.

"Trying to move your legs in the middle of the night can be like you've got somebody else's legs, or you're stuck in treacle, frozen in your bed," he says.

Years of trial and error have taught him what makes a difference. He is now a firm advocate of good sleep hygiene which, these days, involves going to bed between 22:30 to 23:00 every night, and waking up at 7:30. He aims to get at least seven hours of sleep a night.

What is sleep hygiene?

To ensure we get a good night's sleep, the human body has an internal alarm clock that regulates our sleep-wake cycle. Keeping to a regular night-time routine, creating an ideal sleeping environment, and getting into healthy habits during the day can all help you develop good sleep hygiene.

Brian Magennis, an advanced nurse practitioner in Parkinson's disease and movement disorders, thinks sleep hygiene is vital to improving your sleep.

"It's one of the most important things I consider when assessing the sleep problems of a person who has Parkinson's. There are other things like insomnia, urinary issues, movement problems and mind disturbances – but sleep hygiene is an obvious first step," he says.

"If you get this right, you'll be on your way to improving the quality and quantity of your sleep. If you still have problems, you need to talk to your doctor or neurologist, who can help adjust your medication as getting the timing and dosage of this right is essential too."

How to get a good night's sleep

General habits like having regular mealtimes and going to bed at the same time every night, keeping alcohol and caffeine to a minimum and ensuring your bedroom is cooler during the night have all been shown to improve the quality and quantity of your sleep.

Sleeping in total darkness and making sure you have the right bedding can also be important as Matt testifies.

"We have black-out curtains in the bedroom which really help," he says. "And a good mattress is essential. I have a

memory foam mattress which is very comfy. The only issue for me is that it mimics my body shape and sometimes it means when I want to turn over, I have to climb out of the dip I've just created for myself!"

One thing that's not a healthy habit is exposure to blue spectrum light before bedtime. Computer monitors, smartphones, tablet screens and televisions all produce light in the blue spectrum, which tricks the brain into believing it's daytime, thereby reducing the production of melatonin – a hormone that helps you sleep.

Getting your nutrition right is also key to a good night's sleep. It's important not to eat too late and to ensure you don't have too many high-protein foods, or carbohydrates, which can sometimes interfere with the absorption of Parkinson's medications or be associated with poor sleep quality.

A good dose of exercise can also aid sleep quality. Physiotherapist Josefa Domingos helps people with Parkinson's to improve their functional wellbeing.

She says: "During the day, it's important to get proper aerobic exercise when you have Parkinson's – not only because it potentially helps delay progression of the disease, but also because it's been shown to improve sleep and relieve a variety of motor and non-motor symptoms."

Stretching and slow mobility exercises before bed can also help in reducing rigidity and some discomfort during the night too, according to people with Parkinson's.

For Matt, improving his sleep hygiene has helped to boost his energy and cope better with the condition.

"Parkinson's is exhausting," he says. "If you wake up and you're tired, apathy can kick in and you really don't feel like doing anything. I think sleep is so important to Parkinson's."

7 ways to improve your sleep

1. Keep to a regular routine, including a regular pattern of meals, exercise and going to bed and getting up – it will help your body clock get into the habit of sleeping.
2. Get your nutrition right – regular mealtimes and a well-balanced Mediterranean-type diet has been shown to have therapeutic effects on sleep.
3. Stay hydrated during the day, depending on your body type and needs, and avoid caffeine and alcohol which are stimulants.
4. Exercise on a regular basis – how much you should do depends on your personal fitness and circumstance.
5. Sleep in a cool, dark room – but take care to have some kind of lighting should you need to get up in the night.
6. Upgrade your sleeping accessories – pillows, mattresses and sheets can all make the difference between a comfortable and uncomfortable night.
7. Avoid electronics at least one hour before bed. Computer monitors, smartphones, tablet screens and televisions all produce blue spectrum light, which mimics daylight.

Source: European Parkinson's Disease Association

Making a harp for Judy

By Geoff Grundy

Geoff Grundy, 70, lives with his wife Sue in a retirement village on the Central Coast. He was diagnosed with Parkinson's when he was 63. This is his story of how he put his musical and wood-working skills together to make his sister-in-law a harp.

Judy, my wife's sister, came to visit. I was playing a few tunes on my guitar. She said she would have liked to learn to play a musical instrument.

This was difficult now as Judy had a stroke which had left her paralysed on her left side.

I thought, what could she play? A harp! I had previously attempted to make a harp, but this was a failure. I underestimated the tension placed on the soundboard by the strings.

So I proceeded to design and make a harp, limiting myself to two octaves. I looked up a chart for string lengths, tensions, and sizes. Looked at a few different designs.

This time it worked – or at least didn't pull itself apart. It sounded terrible (twang twang). I tried a string change which made a difference. Tried a different harmonic arc. Finally sounds and looks ok.

I hope she enjoys learning to play it. I have put her in touch with fellow 'Parky' musical mate Martin Prior to assist her.

I have found making small instruments is good for my Parkinson's. The concentration, calculations, and planning keep me going.

There are days I am unable to do anything. Tools are very sharp, and one slip can cause a lot of damage – best not to touch when having shaky days. Frustrations when my mind is not quite connecting to the body.

The village where I live has a workshop where I can get assistance to break down the pieces of timber that I need. I try to recycle as much as I can: timber from old pianos, furniture and building materials.

After I get the timber roughly to size, everything is done by hand. There is not a lot needed – a good Japanese pull saw, a few sharp chisels of assorted sizes, a plane, scraper, measuring tapes, rulers, and lots of clamps. Oh... and patience – do a bit, wait for the glue to dry; do a bit more, wait for the glue to dry.

What once would take me one hour now takes two or more. There is confusion when doing calculations. Some days I can do nothing at all. Others I can manage.

I have built guitars, having made my first locally at the Australian Guitar Making School. So I was able to use the woodworking skills learned from this to make the harp.

Through Parkinson's I met Martin, who also has Parkinson's. We both have music interests. Martin has made several recordings. Hopefully, we will be able to get together and make a CD of our music using homemade instruments. (I will have to learn to play a harp first!)

It has now been seven years since my diagnosis. There have been some difficult times. I have learned to live within my limitations and have a good life with my wife, Sue, who puts up with the dust from sanding wood and hearing the same songs over and over until I get it how I want it (not necessarily as written).

“ I am 70 years young. Now my days start with meditation and tai chi. I walk when and where I can, One helps the brain, the other the body. I hope to have many good years ahead, Never give up. ”



Help empower people with knowledge as they learn to live with Parkinson's



A Parkinson's diagnosis is confronting, and people often feel extremely distressed to discover they have this incurable, degenerative neurological disorder, which has up to 50 symptoms affecting movement and mood.

Parkinson's is a progressive disease that is different for everyone, so there is a question mark over tomorrow and the uncertainty can be crushing.

This is where the Parkinson's NSW Newly Diagnosed Seminars are a chance for people recently diagnosed and their carers to receive vital information and practical advice from experts.

“ I wanted to gather the latest information available, because I am a firm believer that knowledge is power. By the end I felt enlightened and invigorated and the weight of the world had been lifted from my shoulders. **”**

Lorraine sharing her experience of attending one of our newly diagnosed seminars.

The beginning of a person's journey with Parkinson's can be terrifying and it is made even harder by confusion about the condition.

Your generous donation will help give people like Lorraine the support of our newly-diagnosed seminars, which shed light on the path ahead and provide invaluable guidance in the tough days after diagnosis.

Please give now

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