STAND BY ME

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IN THIS ISSUE

IN THIS TOGETHER
parkinson's NSW

In this issue...

We have Parkinson's covered from many different angles in this summer issue of *Stand by Me*. Articles range from a novel approach to early diagnosis to housing modifications, diet and exercise.

Read the inspirational story of Michael Bohnke who is living with Parkinson's but still maintains a full life in country NSW while running marathons and competing in triathlons. If running is not your style, consider the benefits of walking. We have an article on that very subject which delivers the message of 'think big and step bigger'.

Did you know that up to 80% of people living with Parkinson's have gut issues? The association is so strong that some experts are now asking if following an anti-inflammatory diet could lessen the severity of symptoms or even delay their onset. Read more in our article: *Can an Anti-Inflammatory Diet Help Parkinson's?*

What if there was a way to diagnose Parkinson's earlier on, before brain cells are irreparably damaged? That's no longer hypothetical and you can read more in *The Surprising Ways Parkinson's Can Now be Spotted Years Early.*

Finally, don't miss our Christmas appeal article on the back page. It's the story of Graham and his service dog Archer. "With Archer, I got my freedom back. He helps when I freeze, and suddenly I could go out again without worrying. He gave me my life back," said Graham.

Enjoy your summer reading!

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

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Walking in Parkinson's: Let's Get Moving!

If you or someone you love is living with Parkinson's disease, you probably know that walking can be a bit of a challenge. Sometimes there's shuffling, freezing, or your feet aren't doing what you want them to do.

But here's the good news: the right kind of exercise can make a big difference. We're not just talking about any exercise (although all will help) but specific, intentional movement that helps the brain and body work better together.

The best styles of exercise that can help walking when you have Parkinson's are firstly, to think big and step bigger! For example, taking big steps, doing wide arm swings, or even exaggerated sit-to-stands will all help fight off the small, slow movements that Parkinson's can cause.

Visit a Parkinson's-trained exercise specialist to help learn more about doing big, exaggerated movements and then put them into your regular exercise routine.

Dance (especially the tango) has also been shown to help improve walking by improving balance, coordination, and gait in people with Parkinson's. The rhythm and partner-based structure of tango helps with timing and stride, and it's also fun.

Walking on a treadmill (even at slow speeds) is a safe and steady exercise that really helps people with Parkinson's improve their gait steadiness and walking endurance. It's like giving the brain a metronome or rhythm to walk to, which helps regulate and reduce missteps or freezing.

Tai Chi is like moving meditation. It's gentle, flowy, and perfect for building balance and core strength. Several studies have shown that Tai Chi helps reduce the number of falls and improves walking steadiness in people with Parkinson's. It also helps with focus and relaxation, which is great because stress tends to make Parkinson's symptoms worse.

Practicing walking using anything with a beat such as a metronome, clapping, or music with a steady rhythm. These rhythmic cues help the brain stay in sync with the body, making walking smoother. It's called Rhythmic Auditory Stimulation (RAS) and it's been proven to improve step timing and gait in Parkinson's patients.

So, which one is the best? All of them. Whether that's a tango class once a week, a daily walk on the treadmill, or a few minutes of Tai Chi in the morning, consistency is key. And always check in with your Parkinson's exercise specialist or doctor before starting any new activity. They can help tailor a safe plan just for you.

Parkinson's makes walking harder but if you do a variety of exercise, you're not just improving your walking, you're boosting your brain health, your confidence, and your independence. So start moving those feet, pick your groove, and get moving. Every step counts – literally.

References:

Training BIG to move faster.
Effects of dance on movement control in Parkinson's disease.
Tai Chi and postural stability in patients with Parkinson's disease
Rhythmic auditory stimulation in gait training for Parkinson's disease patients.

Home Modifications for Parkinson's Disease

There are many ways to enhance accessibility and improve the safety of a home belonging to someone with Parkinson's. It may be helpful to have a physical therapist or occupational therapist trained in Parkinson's disease do a walk-through of your home to identify particular areas of concern.

These are some adaptations to consider for easier living with Parkinson's:

At the Entrance

As stairs and doors become more challenging, these fixes can make it easier for someone with Parkinson's to come into their home.

- Add threshold ramps. These make it easier to cross door frames or low steps with a walker or scooter.
- Use lever-style door handles or a keyless door entry system. This can reduce strain on hands affected by rigidity or tremors.

Throughout the Home

Help avoid trip hazards and improve mobility with these changes.

- Remove throw rugs and runners. With an increase in shuffling gait, throw rugs are hazardous and can create a significant fall risk. Reduce the risk of tripping by removing these from your home.
- Install handrails alongside steps or small flights of stairs. If going in and out of your front door or up one level in your home is challenging, adding handrails can help aid your movement.

In the Bedroom

You spend a lot of time in the bedroom, so it's important that it is a safe space. Consider the following.

- Move the bedroom to the ground floor. This can help minimise daily stair use if balance is an issue.
- Add a bed rail or floor-to-ceiling transfer pole. Both of these tools can make it easier to reposition or get out of bed safely.
- Use motion-sensor lighting in the bedroom. This helps with nighttime mobility while minimising the need to flip a light switch.

In the Bathroom

There's a high risk of falls on slippery surfaces in the bathroom. Here's how to make it safer.

- Install grab bars. This is especially important around the toilet and shower: Using grab bars versus towel racks, for example, are more reliable for stability and safety.
- Add a shower seat and bench. Inexpensive ones be bought online or in a store. More extensive bathroom renovations may include step-in tubs or built-in seats.
- Use a toilet riser and a bidet. A toilet riser can make going from sitting to standing less strenuous, whereas a bidet promotes comfortable hygiene.

In the Kitchen

Simplify meal prep and other kitchen tasks by including more adaptive tools in the kitchen.

- Incorporate seated workstations or sturdy stools in the kitchen. Sitting often decreases tremors, making it easier to do fine motor tasks, like chopping vegetables.
- Install easy-access kitchen cabinets and counters. Also, keep frequently used items within arm's reach to reduce the need for stepladders, which can increase fall risk when your balance is off.
- Use weighted utensils and a one-handed cutting board. Kitchen tools like these can help support cooking and eating when you have hand tremors.

Continued...

Smart Home Technology for Parkinson's

Advances in home technology are making it easier than ever to support safety and independence for people with Parkinson's. Here's what experts recommend adding to the home.

- Timed medication dispensers. These devices help ensure the right medication is delivered at the correct time each day. They can be set up in advance and will automatically dispense the pre-specified dose at regular intervals. Because Parkinson's can affect memory and cognitive function, this technology helps ensure doses aren't missed.
- Voice-activated assistants. Artificial Intelligence (AI) voice assistants like Alexa, Siri, and Google Assistant can be connected to smart speakers placed throughout your home. Voice-activated assistants can be used to set reminders about medication, exercise, or appointments. These assistants can also type emails or texts for you, make phone calls, activate emergency services, turn on and off lights, and even lock your front door.
- Medical alert systems. If you can't reach your phone, a medical alert system can be lifesaving. You can set it up to contact an emergency contact, like a family member or emergency services. Some systems can even auto-detect a fall or near-fall using built-in accelerometers.
- Doorbell cameras. Seeing who is at the door with a camera like those from Ring can reduce the urge to rush to answer it, which can help prevent falls.
- Remote thermostats or light switches. These simplify tasks that require fine motor skills. Using a remote tool like Google Nest to change the temperature in your home or turn a light on and off with smart lights can help you conserve energy and reduce the risk of falling.

Source:
Original article by Cheyenne Buckingham, HealthCentral

Can an Anti-Inflammatory Diet Help Parkinson's?

Parkinson's disease is a neurodegenerative disorder that causes damaging inflammation in the brain. Yet, scientists who study Parkinson's will tell you that your gut health can be involved, too and that your daily diet may even affect your risk of Parkinson's or its progression.

In fact, emerging evidence increasingly suggests that gastrointestinal (GI) issues, including nausea, constipation, and bloating, frequently precede the classic motor symptoms of Parkinson's, often by decades, according to the Parkinson's Foundation. This may be due to an inflammatory response that's caused by changes in gut bacteria, research shows.

What you eat influences the types and amounts of microbes, both good and bad, that live in your digestive tract. An imbalance there, called dysbiosis, may lead to an increase in pro-inflammatory chemicals, which may cause inflammation throughout your body and brain, a recent study published in npj Parkinson's Disease shows.

Now consider that up to 80% of people with Parkinson's are known to have gut issues – an association so strong that some experts are now asking if following an anti-inflammatory diet could lessen the severity of Parkinson's symptoms or even delay their onset.

Brain-Gut Connection

Your brain and intestines are connected in ways that you might never imagine: They send signals back and forth to one another, something known as the gut-brain axis, according to the Cleveland Clinic.

There are two possible ways a gut imbalance can lead to brain inflammation, says Michael Kaplitt, M.D., Ph.D., a neurosurgeon and the Director of Parkinson's Disease and Movement Disorders at Weill Cornell Medicine and New York-Presbyterian in New York City.

The first "...is dysbiosis that causes more generalised body inflammation and illness, which could predispose the brain to being more sensitive to Parkinson's, or to progress more quickly," he explains.

The second way is when that inflammation spreads through your vagus nerve, a major nerve that connects your brain to your gut and many other organs, Dr. Kaplitt says. "There's evidence from a variety of both human and animal studies that supports the idea that – at least in some patients – that pathology in the gut may actually spread through the vagus nerve into the brain to eventually cause Parkinson's disease," he notes.

Dr, Kaplitt also clarifies that while Parkinson's is an inflammatory disorder, "...it's not like arthritis, where inflammation is the primary cause and the primary reason why people have the problem." If that were the case, if people with Parkinson's suddenly started taking anti-inflammatory drugs their Parkinson's would immediately get better – but it doesn't.

"Having said that, one of the most important areas of research right now in Parkinson's disease is inflammation," Dr. Kaplitt says. " It seems to be a very critical factor, influencing potentially whether or not someone develops Parkinson's and how rapidly and severely it progresses."

Can the Right Diet Reduce Parkinson's Risk?

So, if an imbalance of gut bacteria causes GI inflammation, and dysbiosis there is associated with the onset and symptoms of Parkinson's disease, can changing how you eat, or even adding supplements to your daily meals, correct that imbalance and help protect your brain?

The science is still young on this, so not every expert agrees on how strong the association is between diet and the slowing, or even stopping, of Parkinson's onset and progression. Still, Jeff M. Bronstein, M.D., Ph.D., a Professor of Neurology and the Fred Silton Family Chair of Movement Disorders at the University of California in Los Angeles believes that eating a Mediterranean diet, specifically, can play a role in both Parkinson's prevention and symptom progression.

"This diet, which is believed to be anti-inflammatory, reduces the risk of Parkinson's," says Dr. Bronstein. "People eating a Mediterranean diet for a long time can have up to half the risk of developing Parkinson's."

The Mediterranean diet consists of olive oil, fruits, vegetables, whole grains, nuts, and fish. Another hallmark of this dietary approach is that it focuses on whole foods and shuns overly processed foods that are associated with the Western diet, according to the Cleveland Clinic.

A review of the evidence supports Dr. Bronstein's view; it shows that the Mediterranean way of eating could help protect against Parkinson's onset and progression, and the review's authors attribute those benefits to the anti-inflammatory, antioxidant-rich foods in the diet. They recommend starting a Mediterranean diet from an early age – and add that it's never too late to adopt it – since imbalanced and negative gut-related changes are often seen decades before the motor symptoms of Parkinson's first emerge.

While he stops short of recommending the Mediterranean diet specifically, Dr. Kaplitt says he does tend to see improvements in his Parkinson's patients' health and Parkinson's symptoms when they regularly consume healthier foods, including those promoted by the Mediterranean diet. Still, it's a complicated issue, he notes.

"The evidence is not great that improving your gut health can actually slow Parkinson's or stop the disease itself," he clarifies. "But [eating healthfully] does make people better because it makes you healthier, overall."

Dr. Kaplitt says there is a lot of variability in the research, and more studies need to be done, before we have a definitive understanding about how impactful diet truly is on Parkinson's.

"As we understand more about the questions we need to ask, the studies can get better and allow us to really understand this better," he adds. "There's no question that improving your gut health does improve symptoms in Parkinson's – but [again], the studies right now are not great." He hopes future studies will give us concrete answers.

Sources:
Parkinson's Foundation
HealthCentral.com

The surprising ways Parkinson's can now be spotted years early

Parkinson's is the fastest-growing neurological condition in the world. A staggering 25 million people are expected to be diagnosed by 2050, more than double today's figures.

In short, it's a big problem. But with people living longer and populations growing, such rates are not exactly unexpected. Yet what is surprising is how unprepared we are for this oncoming wave.

No cure. Limited treatment. Poor diagnostic tools. We don't even really know what causes Parkinson's.

But there is hope: scientists across the globe have been busily working away to change the Parkinson's story.

In particular, we're about to see a revolution in how to spot Parkinson's. Armed with cutting-edge new gadgets, Artificial Intelligence (AI) and a radically evolving understanding of how the disease manifests across the body, researchers are on the cusp of detecting Parkinson's not years, but decades before symptoms appear in some cases.

Currently, there is no single, definitive test for Parkinson's. Instead, as physical symptoms – such as tremors, slow movement and muscle stiffness – emerge, a doctor may diagnose a patient based on their ability to carry out tasks such as writing or speaking.

But what if there was a way to diagnose Parkinson's before the disease rears its ugly head? To catch – and perhaps stop – it in its tracks, before brain cells are irreparably damaged.

That's no longer just a hypothetical. In fact, there's not even just one way to do it – there are several.

AI desk accessories

Not all diagnostic breakthroughs require a blood sample. Some could sit quietly in your office.

At the University of California, Los Angeles, Professor Jun Chen's lab claims it has developed a diagnostic pen that can detect Parkinson's disease simply by analysing how you write.

Its soft tip is made from a unique magnetoelastic material that shifts its magnetic field in response to pressure or bending. This effect, long known in rigid metals, was only recently discovered in soft polymers by Chen's group, opening the door to new kinds of highly sensitive, body-friendly sensors.

"Using the magnetoelastic effect in soft materials is a new working mechanism," Chen explains. "It is able to convert tiny biomechanical pressure, such as artery vibration, into electrical signals with high fidelity."

The pen, which uses magnetised ink, captures both on-paper and in-air hand movements. It then sends this data to a computer, where an AI model analyses patterns associated with Parkinson's motor symptoms.

In a pilot study, the system distinguished people with Parkinson's from healthy controls with over 96 per cent accuracy. Even better, Chen believes that at scale, the pen could be manufactured for as little as $5.

"We've already filed a patent and want to commercialise this pen," Chen says. "In the meantime, we want to optimise it to enhance the diagnostic accuracy."

But if writing the old-fashioned way isn't your thing, Chen's team has you covered. They've also created a smart keyboard that works on the same principle.

As people type, the keyboard picks up subtle changes in key pressure and rhythm – often too slight to notice – and feeds that data into a machine learning algorithm.

Early tests show it can identify motor abnormalities characteristic of Parkinson's, and the team has paired it with a mobile app to support continuous, remote monitoring.

Continued...

Together, these intelligent desk tools offer a glimpse of what Chen calls a "personalised, predictive, preventive and participatory" future for Parkinson's healthcare. A future where diagnosis could be as simple as jotting down a note or typing an email.

An eye test that could detect Parkinson's 20 years earlier

Imagine finding out you're at risk of Parkinson's disease during a routine eye checkup, decades before symptoms appear. That's the promise of a new, non-invasive diagnostic technique developed by Victoria Soto Linan (and her colleagues at Laval University, Canada) using a well-established eye test called electroretinography (ERG).

The eye, Soto Linan and colleagues wrote in a recent study, offers a "window to the brain." It's part of the central nervous system, and visual problems like blurry vision or reduced contrast sensitivity often show up long before the better-known tremors or stiffness.

Soto Linan's team measured how the retina – the light-sensitive layer at the back of the eye – responds to flashes of light, both in mice engineered to develop Parkinson's-like symptoms and in newly diagnosed human patients.

They discovered a distinctive 'disease signature' in the retinal signals, especially in women. Crucially, this weakened signal appeared in mice well before they showed behavioural signs of the disease – suggesting the same might be possible in humans.

If so, Soto Linan believes this eye test could eventually spot Parkinson's up to 20 years before symptoms emerge.

And unlike other early diagnostic tools still stuck in the lab, this one already has a head start.

"ERG is already used in clinics – it's used to diagnose eye diseases," she says. "It has a big advantage of being non-invasive, too."

Patients sit in front of a dome that flashes lights while small sensors record how the retina responds – a process that could one day be as simple as adding an extra few minutes to your annual vision test.

The team is now working to refine the test so it can be faster and even portable, with hopes of linking it to a machine learning algorithm that gives immediate results straight to your smartphone.

The research is still in its early stages, but the implications are massive. As Soto Linan puts it, "The reason why this is so important is because this tool could potentially tell you someone's at risk up to 20 years before that point. So, imagine how much less damage there will be by then.

"Even if we don't have a cure, the treatments we do have could be more effective and give a better quality of life in the long term."

Technology that spots Parkinson's through your vocal patterns

Could your voice reveal Parkinson's before your body does? In a recent preprint study, researchers explored whether AI could detect Parkinson's disease simply by listening to how someone speaks.

Around 90 per cent of people with Parkinson's develop a motor speech disorder called dysarthria, which can cause hoarseness, breathiness and an irregular pitch.

These vocal changes often show up earlier than the more visible motor symptoms like tremors, making them a promising early warning sign.

The team collected 195 short voice recordings from 31 people, including 23 with Parkinson's. They used some of these to train four different AI models to recognise the vocal patterns associated with the disease. When tested on new recordings from the same participants, the models could identify Parkinson's with over 90 per cent accuracy.

Because these changes are subtle and develop early, the researchers suggest voice-based screening could offer a low-cost, non-invasive diagnostic tool – possibly even delivered remotely via smartphone.

A Parkinson's blood test

In April 2025, Soreq and her colleagues – including her son, making it a true scientific family affair – published a breakthrough new study.

What they laid out in this research was remarkable: a simple, cheap blood test based on PCR technology (remember that from COVID?) that can accurately pick up Parkinson's, years in advance of symptoms showing up.

It works by measuring the ratio between two markers of the disease that Soreq and her team uncovered in human blood.

First, in people with Parkinson's, the researchers found unusually high levels of certain tiny molecules called transfer RNA (tRNA) fragments. These molecules seem to follow a specific repeating pattern – called a conserved sequence motif – that sets them apart.

Simultaneously, the team found the blood of people with Parkinson's had reduced levels of tRNA from the mitochondria (the parts of your cells often called the 'powerhouses' because they generate most of the energy your body needs to function).

"So we said, okay, 'if we have an increase in one sequence and a decline in another, we can calculate the ratio between the increase and the decrease and then we have two factors that increase our assurance a result is real'," Soreq says.

If the ratio passes a certain threshold, it likely means a diagnosis.

According to Soreq, a typical Parkinson's diagnosis today may cost up to $6,000. The two PCR tests needed for this? A mere $80.

"It's huge. It makes a big, big difference," she says. With any luck, the team hopes this could be widely available within a decade, offering a potential lifeline to patients around the globe.

Sources:
Original article by Tom Howarth
BBC Science Focus

U.S Food and Drug Administration Approves Bilateral Focused Ultrasound to Treat Symptoms of Advanced Parkinson's Disease

The Food and Drug Administration's (FDA) recent approval of staged bilateral focused ultrasound for the treatment of advanced Parkinson's disease expands the therapeutic options available for patients with symptoms that cannot 'be controlled by medication.

Focused ultrasound is a non-invasive approach to brain surgery that uses ultrasound waves to precisely ablate tissue, allowing surgeons, who are guided by MRI, to target areas of the brain that affect movement disorder symptoms.

The bilateral approach is already approved for the treatment of essential tremor. For Parkinson's disease, the FDA first approved unilateral use in 2018 for tremor-dominant Parkinson's, then expanded approval in 2021 for mobility issues, rigidity, bradykinesia, and dyskinesia due to advanced disease.

The current approval marks the first time Parkinson's patients can receive focused ultrasound on both sides of the brain.

The bilateral approach gives physicians another way to tackle the multiple symptoms that many Parkinson's patients must live with.

"A lot of the patients we've treated over the years accepted tremor as their main symptom, and felt that if we got that under control – even if we couldn't improve the other symptoms – that would be enough," says Michael Kaplitt, MD, PhD, a neurosurgeon at New York-Presbyterian and Weill Cornell Medicine and vice chair for research in the Department of Neurological Surgery at Weill Cornell Medicine, who was the lead investigator in the clinical trial that led to the FDA's decision. "Now with this new FDA approval, we don't necessarily have to make that choice. It's a new era."

The Benefits of a Bilateral Approach

Most Parkinson's disease patients can control their symptoms with medication, but for those who cannot tolerate medications or who experience increasing resistance to these therapies, surgical options may be appropriate.

"Deep brain stimulation, which we've been doing at this institution for decades, had been the most common brain surgery to manage the freezing and tremor-related symptoms of Parkinson's," says Dr. Kaplitt.

This approach involves implanting into the brain an electrode that is connected via wiring to a pulse generator, which is implanted underneath the skin of the chest.

"This equipment must be maintained over time, there can be mechanical issues, and as with any surgery, it carries a risk of infection. Many patients would like an option that allows them to potentially avoid these issues, and focused ultrasound provides an important new alternative for those who are candidates for the procedure."

By the time a medication is no longer effective, most patients have reached a point where symptoms are prominent on both sides. This makes bilateral treatment of much greater value to these patients.

Unilateral focused ultrasound marked a major step forward, but it only enables surgeons to fix symptoms in the dominant hand; those with bilateral symptoms would still experience tremors or rigidity in their nondominant hand.

"There are patients with symptoms on only one side who would benefit from one-sided surgery, but they tend to be earlier-stage patients," says Dr. Kaplitt. "By the time a medication is no longer effective, most patients have reached a point where symptoms are prominent on both sides. This makes bilateral treatment of much greater value to these patients."

Future Applications for Focused Ultrasound

New York-Presbyterian's experience in focused ultrasound – the institution recently completed its 500th procedure – puts it at the forefront of this evolving technology. Dr. Kaplitt was the first neurosurgeon in New York to use the procedure to treat essential tremor, and he continues to lead clinical trials for its use in movement disorders, with plans to further expand the scope of non-invasive brain surgery.

For example, at lower energy levels, focused ultrasound could be used to disrupt the blood-brain barrier to better deliver medications, such as chemotherapy or gene therapies, directly to the brain. It can also be used for neuromodulation, which changes the biology of the targeted brain tissue.

Dr. Kaplitt and his colleagues in psychiatry are currently preparing to start a clinical trial at New York-Presbyterian and Weill Cornell Medicine that tests neuromodulation for this use.

Managing anxiety during the Festive Season

The Festive Season is a time of joy and celebration for Australia's multiple cultures and religions.

However, it can also be a time of stress and anxiety.

Over December and January your usual routines will probably change as you host family members, mingle with neighbours, meet new people, and catch up with old friends who you haven't seen for a while.

Some people might not be aware that you are living with Parkinson's. Others may be surprised by how your Parkinson's symptoms have progressed since last you met.

Anxiety and depression are part and parcel of Parkinson's for up to 40 percent of people living with the disease. Situational factors can add additional stress.

Some common symptoms of anxiety include:

- Hot and cold flushes
- Racing heart
- Tightening of the chest
- Snowballing worries
- Obsessive thinking
- Compulsive behaviour.

Depression is more serious than feeling sad, moody or low from time to time – we all experience that. Depression is when you experience these feelings intensely for long periods of time – weeks, months or even years.

Some people living with Parkinson's also have anxiety related to the 'on/off' state of their motor symptoms. When 'off' and less able to move well, they may experience symptoms of anxiety – and even panic attacks.

So, what can you do for yourself during the Festive Season to avoid or manage anxiety and depression?

Since this time of year can bring up tensions with family, it is a good idea to have a plan in mind for how you will manage your feelings of anxiety.

Make sure that you have some space for rest. You may plan this with your partner or carer beforehand that you take some time out for sleep or simply resting in a quiet room.

If you have a high tension, high conflict family situation, arrange with your carer to go out somewhere for the main festive meal rather than have it at home.

If having it at home is unavoidable, make sure you have a private space you can go to take a break.

Drink only moderate amounts of alcohol, particularly if it's a hot day. Alcohol is dehydrating. It's a good idea to drink two glasses of water in between glasses of alcohol.

Alcohol can also be a disinhibitor and sometimes we may turn to it to cope with stress. But it is also a depressant, so it is wise to know your limits.

Grounding exercises for coping with worry or anxiety

Take a breath and look around you

5 things you can see

4 things you can touch

3 things you can hear

2 things you can smell

1 things you can taste

If your Christmas brings up painful feelings that you are struggling with, make sure you reach out. There are free services that are available 24 hours.

Lifeline
13 11 14
www.lifeline.org.au

Beyond Blue
1300 22 4636
www.beyondblue.org.au

Sources:
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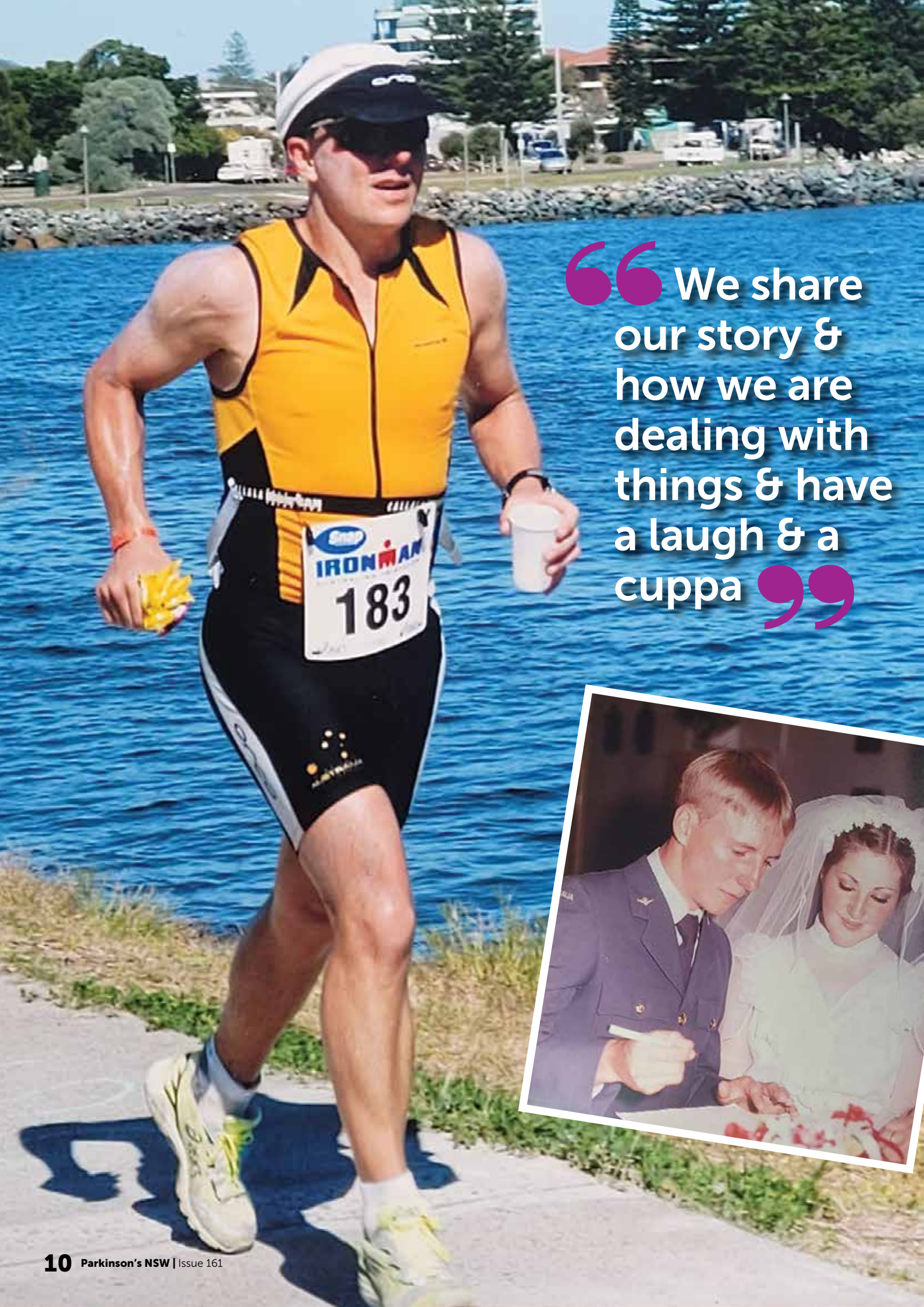

> We share our story & how we are dealing with things & have a laugh & a cuppa

My [Parkinson's] Life
By Michael Bohnke

Michael Bohnke, now 61, was born in Melbourne and grew up in Melbourne's western suburbs. After leaving school in Year 11 he joined the air force, where he spent nine years before moving into the information technology field.

It was while in the air force based at Wagga Wagga that an 18-year-old Michael met his now-wife, an even younger Sue, just 16.

"We married within the year," recalls Michael. "I got posted to Richmond in New South Wales initially, working as an instrument fitter and we moved around with different postings. We had a son and daughter and spent another eight years in Wagga Wagga before we moved back to Melbourne, where I had a new job with IBM. I spent most of the next 20 years working with IBM, including a move to Canberra where I worked on government projects and became a project manager."

But having a growing career and a young family wasn't the only thing keeping Michael busy, he was also a keen runner.

"A teacher of mine in high school got me into running," says Michael. "I entered my first marathon at 16. You wouldn't do that today, but I've run more than 50 marathons since then. I also have a keen interest in triathlons and I've run in a few ultra marathons, including the 1990 Westfield Sydney to Melbourne Ultramarathon. Out of 32 competitors I came 19th and was the last official finisher."

It was training for triathlons and iron man events later on which first made Michael wonder why he wasn't improving his times.

"I got a coach to help, but it was my family who noticed that my running had changed, and I was leaning to one side, not my normal, fluid self," says Michael.

"I was in my 50s and my GP thought I might have had a stroke or some other condition. But a scan in March 2022 got me a referral to a neurologist. I had no idea what a neurologist was when I walked into the consulting rooms, and he followed me from behind. He asked me what I thought might be wrong. I had no idea, and it was a bit of a shock when he told me I had Parkinson's. But I am a fairly positive person, and I was pleased I finally had an explanation for my issues.

"He told me I could take my time to think about starting medication, but I was happy to just get on with dealing with it. I've got a really supportive family and friends. Many people are unaware of what the disease is, and I don't get caught up with explaining in social situations, unless someone notices something and asks about it."

Michael did a course with the University of Tasmania on Parkinson's to enhance his knowledge and understanding.

"It gave me the facts, rather than reading all kinds of things online," he says. "Some of it, particularly about how it advances, was fairly confronting, but I'd rather know now so I am aware for the future. I am now at the point in my career where I can retire, which I will be doing in December this year. I'll be doing some volunteer work after that, and I've been training as a Community Emergency Response Team (CERT) member."

Michael and his wife live in The Rock, New South Wales, a small town of just under 1600 people south of Wagga Wagga.

"It takes an ambulance about half an hour to get here, so I'll be providing early clinical support for people needing the ambulance while we wait," explains Michael. "I'm lucky to have both my children also living here with their families, and there are a lot of older folk, so having Community Emergency Response Team is important for the town."

Michael was put in touch with Parkinson's NSW through the local Parkinson's Specialist Nurse when he was diagnosed, and he did some fundraising for them.

"I also try to attend all the webinars they have," he says. "They're fantastic, and I read a lot of their newsletters. I also do a PD Warrior exercise course at Wagga Wagga hospital with another four or five patients. Our little sessions at the end of the training are almost more valuable; we share our stories and how we're dealing with things and have a laugh and a cuppa.

"My wife will probably retire in a few years, and we'll do more travelling. She has relatives in the UK, and my heritage is in Germany. I went when I was ten with my parents, but I'd like to go back and do a bit of a trip. Most of our travel is based around Australia. We love the country we live in and enjoy visiting Darwin and Hobart. We also did a trip on The Ghan (train) for our wedding anniversary. I did a lot of travel when I was younger with running and triathlons. These days I really have to plan things and sometimes I have to pull out of events, which is not something I would have done back in the day."

Michael has also recently joined a male rugby choir, which helps him overcome symptoms associated with speech difficulty.

"They're a good bunch of blokes, really welcoming," he says. "I've never sung in my life before but now I've sung in a male choir festival in Adelaide with over 1000 in the audience and we also sang at the Opera House this year.

"We live on a property of seven and a half acres and Sue and I talk about our ability to maintain that in the future.

We have gardens, fish, six grand-children and four rescue Chihuahuas that keep us busy and we'll do it as long as we can and then find other options. You can be all depressed about what the future might bring, or you can live your life to the fullest and deal with Parkinson's.

"We have a lot of good friends; I have really close friends in Melbourne. The train to Melbourne stops in The Rock and I can jump on it and go into Melbourne with no issues. You have to live while you can."

Still Moving Forward:

Graham's Story of Connection and Hope

At Christmas, what we value most isn't what's under the tree — it's who's around it. The laughter of family, the comfort of familiar faces, and the simple joy of belonging. But for thousands of Australians living with Parkinson's, those connections can quietly slip away.

Graham's Parkinson's began with a tremor in one hand. "I was about 42 when I was diagnosed," he recalls. "After months of tests and uncertainty, I felt relief — some of the other possibilities could have meant I'd be gone within five years. Parkinson's was the best of a bad bunch."

At the time, Graham was working in the club industry, teaching swimming, and raising two daughters. Life was busy and full. But as symptoms progressed, confidence gave way to caution. Crowds became harder to navigate, simple outings took more planning, and his world slowly began to shrink.

"With my freezing of gait, if I think someone's going to bump into me, I just freeze," Graham explains. "It's not that I don't want to move — my body just locks in place."

That all changed when he met the staff at Parkinson's NSW. Through the organisation's Parkinson's Specialist Nurse program for regional and rural NSW, Graham found a lifeline — practical advice, tailored care, and connection to a wider community who truly understood.

"Without that connection with the Parkinson's Specialist Nurse, I'd probably be in a wheelchair by now," he says. "They helped me stay independent, plan ahead, and find the confidence to keep going."

Today, Graham is a passionate advocate for others living with Parkinson's. He leads several local support groups, helps fundraise for Parkinson's NSW, and even teaches swimming to children and people with disabilities — finding purpose and motivation in helping others.

"I've learned that motivation can be the hardest battle," he admits. "You need something external that gets you moving — something bigger than yourself. For me, that's helping others."

One of the biggest boosts came when Archer, his assistance dog came into Graham's life. "I didn't realise how much I'd limited myself," he says. "With Archer, I got my freedom back. He helps when I freeze, and suddenly I could go out again without worrying. He gave me my life back."

Connection changes lives. Your support helps keep people affected by Parkinson's connected to their families, their community and the care that supports them.

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Thank you — your generosity helps fund counselling, the Parkinson's NSW InfoLine health service and Support Groups across NSW.

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