STAND BY ME

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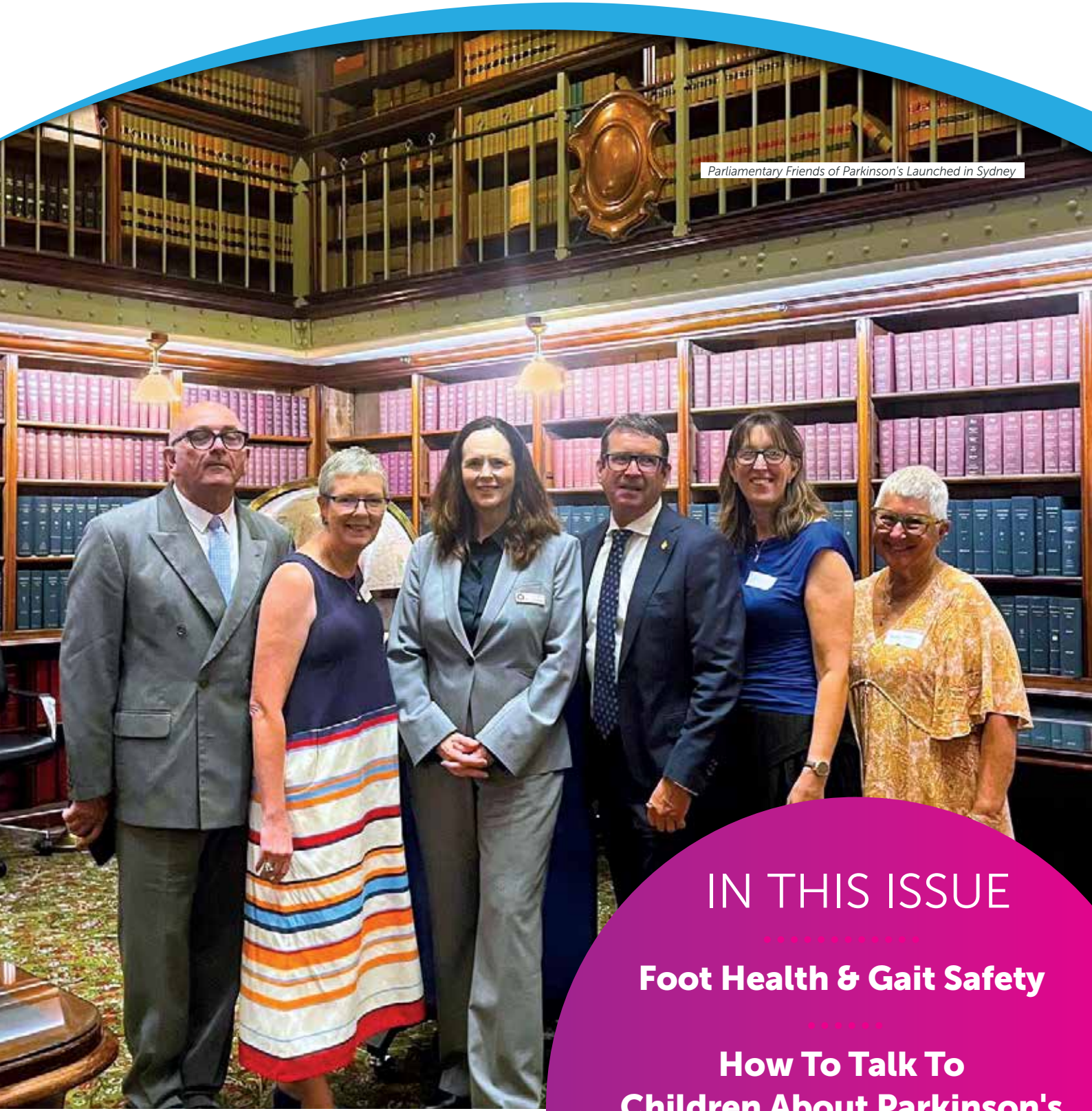

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parkinson's NSW

In this issue...

We have a very diverse range of stories in this issue of *Stand by Me*, starting with news of the launch of a new Parliamentary Friends of Parkinson's chapter in NSW Parliament.

This is a very important development as it will help to raise the profile of Parkinson's among parliamentary decision-makers and influencers.

On the research front there is news from Sweden and Norway where scientists have discovered a way to detect biomarkers of Parkinson's disease in the blood up to decades earlier than the current approach to diagnosis.

Also, a new study led by researchers in Canada is calling into question a long-standing idea about how dopamine influences movement. The findings suggest a shift in how scientists understand Parkinson's disease and how its treatments work.

Other health topics covered in this issue include a reminder about the importance of foot health and gait safety – creating an action plan for confident walking. Mental health has not been neglected either with quotes from famous people living with Parkinson's and how they cope in life.

We also have useful advice on how to talk to children about your Parkinson's. Then there is a first-person story by Pamela Tilbrook on her decision to go through Deep Brain Stimulation surgery.

Finally, we can read the heart-warming story of Mei, a relative newcomer to Australia who found that the hardest part of Parkinson's isn't the diagnosis. It's everything that comes after. However, her life turned around in just 50 days after contacting Parkinson's NSW.

Enjoy your diverse autumn reading in this edition of *Stand by Me.*

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Parliamentary Friends of Parkinson's Launched in Sydney

The Parliamentary Friends of Parkinson's was officially launched on Thursday 5 February at a function for more than 70 people at NSW Parliament House.

The initiative aims to strengthen understanding of Parkinson's and support better access to services for people living with Parkinson's, their families and carers.

Phil Donato, Member for Orange, and Dr Joe McGirr, Member for Wagga Wagga, are Co-Chairs of the group and Robert Dwyer, Member for Port Macquarie, is Vice Chair.

Parkinson's NSW CEO Mary Kay Walker was MC for the event and also gave the keynote presentation. The audience included the Minister for Mental Health, Rose Jackson who also spoke to the gathering, Members of Parliament, parliamentary staffers, people living with Parkinson's and family members from across the state, movement neurologists, researchers, Parkinson's Specialist Nurses, allied health practitioners and Parkinson's NSW Board Members and staff.

The Parliamentary Friends of Parkinson's launch event can be viewed on the Parkinson's NSW YouTube channel by clicking on this link: *Parliamentary Friends of Parkinson's*

Foot health and gait safety: An action plan for confident walking

Original article by Patricia Weiser, PharmD
Fact-checked by Patrícia Silva, PhD
Parkinson's News Today

If you or a loved one is living with Parkinson's disease, you already know it can affect movement. But you might be surprised by how much it can impact your feet.

Understanding how Parkinson's affects your feet — and what you can do about it — can help you stay more comfortable, confident, and mobile.

How Parkinson's affects the feet

Parkinson's symptoms (such as stiffness, tremors, and posture changes) can shift your weight forward, putting extra pressure on your feet and making it harder to stay balanced.

These issues are closely linked to changes in gait or the way you walk. Over time, these gait changes can lead to painful foot problems, a higher risk of falls, and even a fear of walking.

You may also notice cramping or spasms that come and go, known as dystonia, which often causes clenched or curling toes and painful spasms in the feet. It's common in Parkinson's, especially in the morning when medications wear off.

Nail issues and ankle discomfort are also common. In a 2022 study comparing adults with and without Parkinson's, those with Parkinson's reported more challenges with tasks like toenail trimming and walking.

They also perceived a worse health state of their feet compared with people without Parkinson's, with some reporting that their foot problems negatively affected their quality of life.

The good news is that with the right foot care and support, many of these problems can be effectively managed, helping you stay active and safe.

What is Parkinson's gait?

One of the most recognisable signs of Parkinson's disease is a change in how you walk. This is often referred to as Parkinson's gait, and it can affect your stability, step pattern, and overall mobility.

Common features of Parkinson's gait include:

- Short, shuffling steps
- Reduced arm swing
- Forward-leaning posture
- Trouble turning
- Freezing episodes (suddenly being unable to move).

These changes often develop later in the disease and are tied to slower, smaller, and more rigid movements. You may notice your legs feel stiff or heavy, and lifting your feet can be difficult. Walking flat-footed instead of heel-first is also common and can affect balance.

Common foot and gait issues

Foot and gait issues can lead to or worsen a variety of foot and walking problems in people with Parkinson's disease, including:

- Postural instability, which occurs when you have trouble catching yourself after losing your balance
- Balance problems
- Freezing episodes d
- Slower movement
- Repeated cramping episodes, often in the feet (dystonia)
- Foot pain or weakness
- Trouble turning or walking
- Loss of foot sensitivity
- Challenges with self-care, like nail trimming or washing between your toes.

Importance of proper footwear

Supportive shoes are essential for gait safety. However, for people with Parkinson's, finding comfortable, well-fitting footwear can be a challenge, especially with symptoms such as swelling or changes in foot shape.

In fact, in one study of people with Parkinson's, about two-thirds of participants wore the wrong shoe size, in length and/or width.

Shoes that don't fit properly can increase pain, worsen balance, and raise your fall risk.

Gait safety strategies

Even with foot support and exercise, walking with Parkinson's requires extra care. The following gait safety strategies can help reduce fall risk and improve confidence.

- Step forward with your heel first.
- Focus on taking bigger steps — not faster ones.
- Keep your head up and look ahead, not down.
- Stop and restart if you freeze or shuffle.
- Don't carry too many items at once.
- If you need to turn, shift your weight and lead with your foot (not your body).

How can I talk to children about Parkinson's?

If you've been diagnosed with Parkinson's and have children or grandchildren, you may be thinking about how to talk to them about your condition. Here are some tips to help guide the conversation.

1. **For younger children, keep it simple**
   For younger children (under the age of around 7), try to avoid medical terms. Even with older children, try to describe new words or ideas in a way without using medical language. Try to use the same words or kinds of words your child uses when they ask questions or talk about their feelings about your condition.
2. **Take the lead from your children about how much to say**
   Children may not be able to take everything in at once. Afterwards, check with them what they've heard and make sure they've not misunderstood anything. How much the condition currently affects you is probably a good place to start. You might ask if they have noticed any changes in you. Or you might start by saying something like, "Nanna has something called Parkinson's, which is why her arm is sometimes shaky."
3. **Parkinson's is different for everyone**
   Make sure children understand that Parkinson's affects people differently, and it may affect you differently to other people they know or have seen in the media with the condition.
4. **Be open and honest**
   Be specific and clear in describing your condition. Be honest in what you tell them – children may feel mistrustful if they discover later on that you haven't told them the truth. Also, don't assume anything. For example, you know that Parkinson's is not contagious, but do they?
5. **Older children may want more information**
   They may even have questions you don't know the answers to. That's OK. Remember you don't have to discuss everything in one go. Just try to get the message across that it's OK to carry on talking about Parkinson's.
6. **Encourage your child to ask questions**
   Let them know it's ok to ask questions not just when you speak to them, but at any time. This way they can really join in the conversation and feel listened to. They'll also feel more involved and able to share their worries.
7. **Be clear about your feelings**
   Whatever the age of the children in your family, don't forget to remind them that although you may not be able to do everything you used to do, you still love them just the same.

Sources: Parkinson's UK

live

IN THE MOMENT

Michael J Fox - The celebrated star of Hollywood movies such as Teen Wolf and Back to the Future has proved an inspiration to many since launching the Michael J Fox Foundation in 2000. He publicly shared his Parkinson's diagnosis in 1991, at the age of 29.

"I wake up and get the message of what the day is gonna be like, and I try to adjust to it. I keep getting new challenges physically, and I get through it."

Early Parkinson's could be detected decades before symptoms with simple blood test

A new study from Chalmers University of Technology in Sweden, along with Oslo University Hospital in Norway, may have discovered a way to detect biomarkers of Parkinson's disease in the blood up to decades earlier.

Ozzy Osbourne - Legendary Black Sabbath singer Ozzy Osbourne died in July 2025, less than three weeks after performing a memorable farewell concert in his hometown of Birmingham, England. He was diagnosed with Parkinson's in 2019, aged 76.

"You learn to live in the moment, because you don't know [what's going to happen]. You don't know when you're gonna wake up and you ain't gonna be able to get out of bed. But you just don't think about it."

Linda Ronstadt - Eleven-time Grammy Award-winning US singer-songwriter, Linda Ronstadt, was diagnosed with Parkinson's aged 66 shortly after retiring from music.

"When you've been able to do certain things all your life, like put your shoes on and brush your teeth or whatever – when you can't do that, you sort of go, 'What's this?'. You know, what's happening here? Come help me with this. And then you have to learn to ask people to help, and that – that took a little doing. But I do that now, because I need the help."

Alan Alda- Multi-award-winning actor Alan Alda, known for his role as Hawkeye Pierce in CBS wartime sitcom M*A*S*H, retains his trademark humour even when talking about the challenges of living with Parkinson's.

"When all is said and done, I think the main thing that keeps me alive is laughing. When something goes wrong, I often see it as funny. Take my Parkinson's. (Please.) The night I accidentally fell into the dishwasher, I reassured our dinner guests by telling them, "I'm fine. It was only on rinse cycle." Fortunately, when you're old, pretty much any bizarre thing you say gets a laugh."

In the very early stages of the disease, the body goes through changes related to DNA repair and stress in cells. These changes leave detectable clues in the blood before major brain damage occurs, according to a press release for the study.

This could allow for early detection of Parkinson's, when treatments might have a better chance of slowing or preventing serious damage.

The processes of DNA repair and cellular stress response can occur for up to 20 years in Parkinson's patients before motor symptoms fully develop, according to the researchers.

The team used machine learning to discover patterns linked to these processes, which were not found in healthy individuals or patients who were already diagnosed with Parkinson's.

Window of opportunity

Annikka Polster, assistant professor at the Department of Life Sciences at Chalmers, who led the study, suggested in a statement that the study has found an "important window of opportunity" in which the disease can be detected "before motor symptoms caused by nerve damage in the brain appear."

"The fact that these patterns only show at an early stage and are no longer activated when the disease has progressed further also makes it interesting to focus on the mechanisms to find future treatments," she added.

Polster confirmed that the study highlighted biomarkers that "likely reflect some of the early biology of the disease," which "paves the way for broad screening tests via blood samples: a cost-effective, easily accessible method."

The researchers plan to further develop tools to more easily detect these active mechanisms and understand how they work, according to the university.

The team predicts that within five years, blood tests for early Parkinson's diagnoses could become more common within clinical practice. They are also optimistic about the development of new drugs to prevent or treat the disease.

"If we can study the mechanisms as they happen, it could provide important keys to understanding how they can be stopped and which drugs might be effective," Polster said.

New and repurposed drugs

"This may involve new drugs, but also drug re-purposing, where we can use drugs developed for diseases other than Parkinson's because the same gene activities or mechanisms are active."

The researchers acknowledged that the study had some limitations, including that the gene activity measured in the blood only partly matches what's happening in the brain.

External factors, such as medication use, may have affected the results, they added.

Also, the study population may not represent all people, so findings may not apply broadly.

Parkinson's breakthrough changes what we know about dopamine

Dopamine isn't the brain's throttle – it's the oil that keeps movement running, and that insight could change Parkinson's care.

A new study led by researchers at McGill University in Canada is calling into question a long-standing idea about how dopamine influences movement. The findings suggest a shift in how scientists understand Parkinson's disease and how its treatments work.

The research, published in Nature Neuroscience, shows that dopamine does not directly control how fast or how forcefully a person moves, as many experts previously believed. Instead, dopamine appears to provide the basic conditions that allow movement to happen in the first place.

"Our findings suggest we should rethink dopamine's role in movement," said senior author Nicolas Tritsch, Assistant Professor in McGill's Department of Psychiatry and researcher at the Douglas Research Centre. "Restoring dopamine to a normal level may be enough to improve movement. That could simplify how we think about Parkinson's treatment."

What dopamine does in Parkinson's disease

Dopamine plays a key role in motor vigour, which refers to the ability to move with speed and strength. In people with Parkinson's disease, the brain cells that produce dopamine gradually break down. This loss leads to hallmark symptoms such as slow movement, tremors, and problems with balance.

Levodopa, the most common treatment for Parkinson's, helps restore movement by increasing dopamine levels in the brain. However, scientists have not fully understood why the drug is so effective. In recent years, improved brain-monitoring tools detected brief spikes of dopamine during movement. These rapid bursts led many researchers to think dopamine directly controlled movement intensity.

The new findings challenge that assumption.

Dopamine acts as support, not a speed controller

The study suggests dopamine does not act as a moment-by-moment controller of movement. Instead, it serves a more fundamental role.

"Rather than acting as a throttle that sets movement speed, dopamine appears to function more like engine oil. It's essential for the system to run, but not the signal that determines how fast each action is executed," said Tritsch.

Tracking dopamine in real time

To test this idea, the researchers monitored brain activity in mice while the animals pressed a weighted lever. Using a light-based method, they were able to switch dopamine-producing cells 'on' or 'off' during the task.

If rapid dopamine bursts were responsible for movement vigour, changing dopamine levels at that exact moment should have altered how fast or forcefully the mice moved. Instead, adjusting dopamine activity during movement made no difference.

When the researchers tested levodopa, they found that the drug improved movement by raising the brain's overall dopamine level. It did not work by restoring the short-lived dopamine bursts that occur during motion.

Toward more targeted Parkinson's treatments

According to the researchers, a better understanding of why levodopa works could guide the development of future treatments that focus on maintaining steady dopamine levels rather than targeting rapid dopamine signals.

The findings also encourage researchers to reexamine older treatment strategies. Dopamine receptor agonists have shown benefits in the past but often caused side effects because they affected large areas of the brain. The new insight may help scientists design safer therapies that act more precisely.

Sources:

Haixin Liu, Riccardo Melani, Marta Maltese, James Taniguchi, Akhila Sankaramanchi, Ruoheng Zeng, Jenna R. Martin, Nicolas X. Tritsch. Subsecond dopamine fluctuations do not specify the vigour of ongoing actions. Nature Neuroscience, 2025; 28 (12): 2432 DOI: 0.1038/s41593-025-02102-1

My [Parkinson's] Life

Pamela Tilbrook on Deep Brain Stimulation

Recently I was telling anyone who would listen how much I enjoyed the company of others while I drank a good cup of coffee plus how happy I was that I could still participate at Pilates, gym and PD Warrior classes. But this was about to change.

At my six-monthly visit to the neurologist in January 2025, it became evident that an increase in my medication, especially levodopa would be necessary. Levodopa is a neurotransmitter, which helps to alleviate symptoms like tremors, stiffness, and slow movement. The time was coming when I had to consider alternatives to taking the levodopa orally in tablet form.

One alternative was Deep Brain Stimulation (DBS). I had heard of this treatment but had never seriously considered it for myself. In fact it horrified me!

However, my Parkinsons was now at that stage that I needed to consider it because my body was reacting to the levodopa resulting in quite noticeable dyskinesia (involuntary, uncontrolled body movements).

I investigated other non-tablet oral methods, two of which involved wearing a bag.

One meant I would have to inject myself in the tummy every day, the other required a shunt to be inserted in my tummy. Neither of these alternatives appealed to me so I started investigating the DBS procedure.

I mentioned to my GP and all my specialists what I was thinking of doing and I didn't hear any negativity. I was referred to a neurologist who has a team of three to carry out these procedures at North Shore Private Hospital.

He arranged for me to attend a number of appointments and sessions with the team members. For example I had several sessions with the neurologist himself, about an hour each in length, another hour with the neurosurgeon and two separate sessions with a psychiatrist.

The psychiatrist even evaluated me for dementia! (And no, I don't have dementia, thank goodness). I found two other women through the Parkinsons Support Group that I attend, who had been through the surgery themselves. One of these women was particularly enthusiastic and assured me it was the right thing to do.

I made up a list of pros and cons based on the information I had after nearly six months of investigation and research to help me make a decision. One con mentioned to me, was my age.

Anyone over 80 years old, would have to make a very strong case to be eligible. I am now 77 years old, and I was reminded that if I was going ahead with the procedure that I should have it 'sooner rather than later'.

The decision was made to go ahead with the surgery. Everyone, professionals and friends, were excited for me and I couldn't wait for the surgery to be completed.

The big day came – 24 June 2025, a Wednesday. I had been admitted two days prior for a number of tests in preparation for the procedure. The first thing that occurred after I was wheeled to theatre was also the last thing I remember of that day.

I had to have my head shaved, so as my head could be contained in a structure that was stapled to it in order to keep my head still. Hence all hair had to go. Oh well it wasn't as if I had beautiful blond locks cascading down my back!

The first thing that everyone noticed about me, was my baldness. I felt like DBS had taken over my life. I didn't exist. Everyone I met, the first question after they enquired about how I felt, was how much my hair had grown back. Is it going to grow back curly or grow back the same colour? Are you going to colour your hair if it grows back grey?

Every day I became super-aware of the stimulator below my right clavicle and how important it is to my well-being. Every day there is a new symptom which becomes of heightened importance. Every day I am told to rest, that I have had major surgery, stay home, don't do too much. And I am bored!

For at least 12 weeks after surgery I could not do any exercise apart from walking. Nothing from the waist up!

I wanted to be able to go to the gym and really move again. I didn't want to look or act like a silly old woman, but unwittingly that is what I am becoming. I see my reflection in a mirror or shop front and that is what I am – slightly bent over one side, fiddling with something in my bag, (probably getting out my bus ticket) and trying to juggle everything with a walking stick stuck under my arm.

And now, present day? How do I feel? It is six months since I had surgery and everyone (and I mean everyone) is impressed with my lack of movement and swaying due to dyskinesia.

Perhaps I don't appreciate it as much because I couldn't see myself continually moving and swaying. Areas which haven't improved or even deteriorated include my balance (as foretold by the neurologist).

I am coming to grips with my body which is slowly functioning differently. DBS has reduced my dyskinesia by at least 85% which on its own was very debilitating.

What I have learned, like any big decision, is that always some bad gets mixed in with the good.

My conclusion is that DBS has done what it was supposed to do. That may not be saying much but being objective that is the truth.

Finding support when it was needed most

"I didn't know where to turn," Mei says. That changed with one phone call.

"I couldn't believe how much could change in just 50 days," she says.

Sometimes the hardest part of Parkinson's is not the diagnosis. It's everything that comes after.

For Mei, the changes were small at first. Her arm stopped swinging when she walked. Simple things, like washing her hair or putting on shoes, began to take longer. Easy to dismiss, until they weren't.

Mei had spent her life caring for others as a gynaecologist in China. After retiring, she moved to Australia to be closer to her daughter and start a new chapter. She was 58 when she was diagnosed with Parkinson's.

Like many people, she tried to manage quietly. But as symptoms changed, so did her confidence. Some days were manageable. Others brought fatigue, anxiety and the sudden "wearing off" of medication, when movement becomes difficult without warning.

When Mei contacted Parkinson's NSW, she was connected to counselling, guidance through the NDIS, speech therapy services and a local support group. Just as important was something harder to describe - being able to speak with people who understood.

Today, Mei feels more confident to try new things and connect with others. The journey has not changed, but she no longer feels alone in it.

Across NSW, many people with Parkinson's face that same moment of uncertainty — between diagnosis and knowing what to do next. Access to the right support can make a real difference to how someone lives with the condition.

Support services like these depend on community support.

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