In Touch Newsletter
October 2025

Coping with 'on/off' changes

'On/off' describes sudden changes in your symptoms throughout the day. Clinical neuropsychologist Jennifer Foley explores what these changes are and how to cope with them. You may find this article helpful if you experience these symptoms yourself, or if you care for or support someone who does.

What is 'on/off'?

After taking Parkinson's medication for a long time, it can become less effective at controlling your symptoms.

This can mean that there may be times of the day when your medication appears to be losing its effect, and your motor symptoms (symptoms that affect movement), become more noticeable. For some people with Parkinson's, this can be quite severe.

This is sometimes referred to as 'wearing off' or 'off time'. Your 'on' time is when your symptoms are well controlled. This usually happens before the next dose of Parkinson's medication is due, but for others it can happen suddenly, and even after taking medication.

How can these changes affect me?

During off times, it is very common to feel very vulnerable, anxious or low. Some people also experience pain or feel unable to think clearly.

These feelings can happen very suddenly and usually pass quickly but can feel overwhelming at the time.

How can I cope with these sudden changes?

Keep a diary and notice any patterns

Although off times can feel like they come out of the blue, there is often an underlying pattern. By writing down when they happen and how long they last, alongside when you take your medication, you may be able to see a pattern.

By being more aware of this, you may be able to make better use of your on time, when your symptoms are well controlled. It will also help you prepare for your off times.

If you notice a pattern between your off times and medication, it is important to talk to your doctor about this. They may review and adjust your medication, and when you take it, to avoid off times.

You may also want to consider if there is a link between your off times and your diet. What and when you are eating might be affecting your body's ability to absorb your Parkinson's medication. Talk to your doctor about this.

Use coping strategies

Coping strategies can help you anticipate and prepare for the off times and the negative emotions that they can bring. The right strategy will be different for each person. It's likely you'll feel the most benefit from using a combination of different coping strategies.

Rest and relaxation

Off times can make you feel that your body is out of control, which can cause anxiety and panic. Finding a way to allow your body to relax can reduce anxiety and the impact of the off time.

This might be through:

- Mindfulness
- Relaxation exercises
- Self-massage techniques to help with painful areas of the body.

Physical activity and exercise

Doing regular aerobic exercise can help you maximise your on time, and may reduce the impact of off times. Doing gentle activities, like walking or stretching, or mindful exercises like yoga or Pilates, might help during the off time itself.

You may find that the exercise can help relieve some of the stiffness and enable you to feel calmer and more able to cope.

Distraction

You may find it easier to cope with the off time if you are already in the middle of doing something. If you know when you are most likely to have off time, you may be able to plan an activity during that time.

This could be anything that might help distract you. From watching a funny or stimulating TV program, doing a crossword or puzzle, to doing some gardening.

What if I struggle to cope?

It is very common to feel distressed during off times and sudden changes can be hard to cope with. Make sure to speak to your Parkinson's nurse or specialist. As well as reviewing your medication regime, they may be able to offer other treatment options to help manage the changes.

They may also be able to refer you to a counsellor for mental health support.

Source:
Parkinson's UK

Successful Kiama Walk in the Park fundraiser

Brilliant spring weather greeted the Kiama Parkinson's Support Group for its Walk in the Park fundraiser on 28 November at Black Beach near the centre of the township.

It was a great success. Many people with Parkinson's were joined by dozens of relatives and friends. Participants ranged from babies to people in their late 70's.

Local physiotherapist Matt Cook conducted a warm-up session before the walk began.

Kiama Rotary Club ran a sausage and drink stall which was well supported by the walkers and sightseers.

A total of $3,220 in funds raised from the Walk and a raffle are going towards supporting people from the local area with Parkinson's.

More than $7,500 in sponsorship contributions from the Walk have been graciously donated to Parkinson's NSW to support its work for the Parkinson's community.

My DBS Journey

By Debby Pitchford

"When my very intuitive three-year-old granddaughter asked me why her nan shook all the time, it made me get serious about Deep Brain Stimulation," recalls Debby Pitchford, who lives with her husband Keith in Tathra, on the south coast of New South Wales.

Debby and Keith grew up in the Wollongong region, living and working there until moving to Tathra in 2015. It was about the time that Debby retired from full-time teaching that she began to have a series of falls, among them a broken foot and broken wrist.

After one particularly bad fall dislocated her shoulder in 2010, Debby's family doctor treated her with pain killers and physiotherapy. Over the next year the local Wollongong medical advice and intense physio treatment was not effective at improving her muscle function and so her GP suggested specialist intervention.

"He referred me to a neurologist in Wollongong and I was diagnosed with Parkinson's Disease within a few minutes on my first consultation," says Debby.

"I was 61 years old and it was devastating news, but Parkinson's wasn't a complete surprise as my mother had it and she lived with Parkinson's for more than 20 years, until she was 92. I was pretty upset but I knew the disease progresses differently in everyone.

"I was fortunate that my neurologist was a Movement Disorder specialist neurologist, and a fairly conservative one when it came to prescribing medication. Initially, I responded well to the medication but I was on a low dose of Levodopa. When I asked why so low, my neurologist replied, "I can give you a high dose of medication now, and you'll feel great for a while, but you will come to hate me in the long run. The effectiveness of the drug will lessen over time",

Need to better control symptoms
Her family adjusted to the news and continued with their busy lives, but as the years passed Debby felt she needed to be able to better control her symptoms without the ever-changing swings in the 'on' and 'off' periods each day.

"My little granddaughter's comment really made me think," says Debby. "I also knew that my family and friends had trouble reading my emotions because Parkinson's can cause 'masking'. Facial muscles don't work as well and your expression isn't easily seen. On the inside I felt like I was smiling, but people didn't see that. I was becoming more stressed as my drugs wore off during the day and the night terrors became worse. It was time to look at a new approach to better handle my Parkinson's.

"I had an excellent Movement Disorder specialist and he encouraged me to investigate DBS surgery. After consultation with a DBS Movement Disorder specialist neurologist and a DBS surgeon, I felt that this was the right step for me. A few more consultations and an interesting psychiatric interview later, I was prepped and ready for the big day at Westmead Hospital in June 2021.

"The hospital operating theatre staff were wonderful. While they attached the special frame around my head I listened to my favourite Queen songs, and even had someone ready to scratch my nose because I wasn't able to move very much at this stage. I couldn't see what was going on and could barely hear the drill as the surgical team went about the procedure.

"There was absolutely no pain and I was feeling pretty good until I heard one of the surgeons say 'Well, that's that side done, now for the other side'! It was 'lights out' when the surgical team implanted the neurostimulator and I spent a bit of a restless night in ICU until the next day. A visit from the DBS neurologist and the surgeon then confirmed that all had gone well and 24 hours later I got to be 'switched on'.

"I opted for the rechargeable type of implanted neurostimulator as I believed I wouldn't have to worry about a battery replacement operation for another 15 years or so. All that was four years ago. I always say that the DBS surgery was 'one day out of my life that makes every other day possible'. I would do it again in a heartbeat!.

DBS technology is amazing

“The DBS technology is amazing. I have complete control over adjusting the stimulation settings as necessary. I only have to visit the DBS clinic at Westmead once per year and they are only a phone call away if I have any concerns about how I’m feeling, or if I notice any changes in my Parkinson’s.

“My DBS Movement Disorder specialist neurologist was able to reduce my medication by 60 per cent after the surgery, and while I don’t know what the future will bring, it’s made things so much better for me now. I play golf twice a week, and I only took that up during Covid.

“I also exercise and walk three days a week and I do sewing for a fundraising group. I’ve been very lucky with how things are. I aim for a positive attitude and a determination to never to give up or give in to the Parkinson’s.”

At a recent Parkinson’s conference, Debby says she was quite touched when someone asked her who had Parkinson’s; her or her husband?

“I know it’s hard and the disease progresses differently for everyone, which is where I’ve been very lucky,” says Debby. “I say that I have Parkinson’s, but It doesn’t have me.”

Debby’s husband Keith, secretary to the Bega Valley Parkinson’s Support Group, says he sees the big change DBS has made for them.

“I don’t see Deb going through daily mood and motor fluctuations and I don’t even think about it now,” he says. “I’m guilty of forgetting she has Parkinson’s. We’re doing now what we hoped we’d be doing, enjoying retirement and visiting kids and grandkids. We celebrated our golden wedding anniversary in the Cook Islands last year.”

Tips on preparing for DBS surgery

Debby’s tips for anyone preparing for Deep Brain Stimulation surgery are:

- Find a good Movement Disorder specialist neurologist and ask lots of questions
- Don’t assume you’re too old for DBS
- Relax and be kind to yourself (have a massage, take a long bath, enjoy a date night)
- Don’t be afraid to tell your story. Listen, too; most people know someone who has Parkinson’s
- Stay positive, mental attitude is important. It’s understandable to ask ‘why me’ but it’s not helpful
- Exercise regularly; it’s a great way to improve social interaction and stay committed. It also shows you are ARE committed. Once you’ve had DBS there is a commitment.
- Ask questions; stay informed.

Parkinson's NSW Supports Rural Health Campaign

Parkinson's NSW has thrown its support behind a Rural Health campaign initiated by Dr Joe McGirr, Independent Member for Wagga Wagga.

The 'Better Care, Closer to Home' campaign is an alliance of business groups, communities and medical experts who are demanding urgent action on the rural health crisis in NSW.

The 'Better Care, Closer to Home' Alliance's Rural Health Action Plan is built on the recommendations of the Legislative Assembly Select Committee on Remote, Rural and Regional Health, which Dr McGirr chaired.

Dr McGirr said the plan was a targeted approach to reforming the system which would not require the expenditure of huge sums of money.

"My plan presents simple, common-sense reforms that will make a real difference in health care to thousands of people across rural and regional NSW," he said.

"The idea is to redirect funding to be more effective, with the $270m spent annually on fly-in, fly-out health providers to be diverted towards hiring local health professionals who will live and work in their communities, rather than coming and going at great expense."

The plan has six action points:

- A GP guarantee – every town should have a doctor.
- Birth closer to home – restoring rural maternity services.
- Local staff, not fly-ins – replacing expensive temporary doctors (locums) with permanent teams.
- Local voices, real power – embedding community input in health decisions.
- A watchdog for rural health – an independent commissioner to keep the health system at its best.
- One system, working together – integrating hospitals, GPs, councils, and community care.

The plan will deliver:

- Patients – faster access to care, closer to home.
- Families – safer local birthing options and better access to children's health.
- Healthcare workers – secure jobs, proper support, and better conditions.
- Communities – a real say in local decisions and services they can rely on.
- Taxpayers – better value for money by investing in permanent care, not stop-gap locums.

"Through this alliance, I hope to harness the powers of regional decision makers from across the state to bring about changes that will deliver quality healthcare closer to home for our communities," he said.

"Rural people don't want special treatment. They just want the same quality of care that people in Sydney take for granted.

"This plan is how we deliver that — by fixing what's broken and making the system work again so that rural and regional families get the health care they need and deserve."

Anyone wishing to voice their support for this campaign can write to:

Dr Joe McGirr MP
Member for Wagga Wagga
64 Baylis Street
Wagga Wagga NSW 2650

Or email: waggawagga@parliament.nsw.gov.au

In the spotlight: Murwillumbah Support Group

Murwillumbah Support Group in the Northern Rivers region is celebrating its one-year anniversary – the direct result of the right person being in the right place at the right time.

That person is Group Coordinator Leigh Matthews, whose day job is Community Liaison Manager of Dovida, a provider of home care services. In this role, Leigh does a lot of community engagement which brought her into contact with the residents of the local Aveo retirement village.

There she learned of an unmet need for a local Parkinson's Support Group. Through her experience engaging with the Lismore Parkinson's Support Group – also within the Northern Rivers catchment – and its leader Marie Dudgeon, Leigh gained valuable insight into facilitating an established group.

"It really took off from there because I thought I'd be able to use the contacts I make in my community liaison role to find good speakers for support group meetings," said Leigh.

She was right; speakers over the past year have included the local Parkinson's Specialist Nurse, an exercise physiologist, an expert in mobility aids, an occupational therapist, a pharmacist, a speech therapist, and the local Member of Parliament.

Meetings usually attract 20 to 30 participants, not only from Murwillumbah but also surrounding districts such as Brunswick Heads, Pottsville and Kingscliff. The group meets on the first Friday of each month at the Murwillumbah Services Club which offers a room for free. That schedule was chosen to avoid conflicts with other meetings happening in the community.

“We don’t serve tea and coffee in the room, but we always take refreshments at the Club after our meeting. We believe in supporting the Club because they support us. Our group includes both people living with Parkinson’s and carers, but we don’t have any breakout sessions for carers because people said they’d rather stay together in one meeting to ensure everyone is well supported.”

Managing restless leg syndrome

Restless legs syndrome, sometimes called Willis-Ekbom disease, is a condition that causes an overwhelming urge to move your legs. This can cause discomfort. People with Parkinson’s have described it as a ‘creepy-crawly’ feeling, or that it feels like they have fizzy water in their veins.

Here are some tips for managing restless legs syndrome.

Get a good night’s sleep

Establish a regular sleeping pattern and make sure you have a cool and comfortable sleeping environment. Try to avoid heavy blankets or clothing.

Warm your legs up

Have a warm bath or try a hot (but not too hot) or cold compress on your legs.

Stimulate your legs

Try massaging your legs, going for a walk and gently stretching your muscles.

Manage your diet with a dietitian

Not having enough iron in your body can cause restless legs syndrome. Your healthcare professional can check your iron levels for you.

You could try an iron supplement or eating iron-rich food such as red meat, fish or certain fruit like prunes. Talk to an accredited dietitian to get support before making changes to your diet.

Yoga and restless legs syndrome

Some new studies suggest that yoga might help ease symptoms of restless legs syndrome, but research is ongoing, so there isn’t enough evidence yet to understand the full benefits. We do know that people with Parkinson's tell us that yoga is useful for managing their Parkinson's in general.

Physiotherapist Bhanu Ramaswamy explains in more detail:

"We know from anecdotal stories, and from research evidence, that yoga can help lessen slowness and stiffness, improve balance and flexibility (especially in hips and ankles), and increase muscle strength and power. There are lots of different forms of yoga, and specific poses can work on different parts of the body. "

"Some research has also shown the benefits of yoga in helping to reduce the symptoms of restless legs syndrome, especially if done with slow stretches combined with breathing techniques. So overall, yoga might be a great all-round activity for people with Parkinson's to ease a number of issues and improve day to day life."

Source:

Parkinson's UK

The risk of environmental toxins on Parkinson's disease.

Air pollution, pesticides and chemicals – along with genetic factors – can increase your risk

While there's no single cause of Parkinson's disease, the degenerative brain condition may be linked to your genes. But is that the only factor? Are there environmental causes of Parkinson's disease that you should be avoiding?

"Parkinson's disease is rarely caused just from genetic *or* environmental factors," says researcher Ignacio Fernandez Mata, PhD, from the Genomic Medicine Institute at the Cleveland Clinic in the U.S.

"In most cases, the interaction between both factors into your predisposition for Parkinson's disease."

What toxins cause Parkinson's disease?

Environmental toxins have been strongly linked to Parkinson's disease, but it's still hard to prove that they directly *cause* it. Toxins that play a role include:

- **Air pollution**, especially in larger, urban areas
- **Certain pesticides and herbicides**, such as paraquat and 2,4-dichlorophenoxyacetic acid (also known as 2,4-D)
- **MPTP**, a synthetic neurotoxin often found in illicit drugs

- **Agent Orange**, a chemical primarily used during the Vietnam War
- **Certain metals**, like manganese (sometimes used in batteries) and lead
- **Certain solvents and cleaning chemicals**, like TCE, found in paint removers, household cleaners, and products used in dry cleaning and manufacturing

These environmental toxins can be *risk factors* — meaning they can increase your chances of developing Parkinson's disease.

"Not everybody who is exposed to these toxins gets Parkinson's disease," clarifies Dr. Mata. "They don't cause Parkinson's disease, but they increase the risk of developing it."

And it's important to note that the amount of exposure to these environmental toxins plays a role, too.

"It's not like you're exposed to something one day, and then you automatically get Parkinson's disease – the same way that somebody who smokes a cigarette one day, doesn't automatically get lung cancer," he illustrates. "It's really about chronic exposure."

And "chronic exposure" can mean different things for different people.

"It's very hard to put a threshold or a limit on how much exposure you'd need to have, but the more exposure you get – and the more years of exposure you have – then the higher your chances are that you're going to develop a neurological disorder," he adds.

Challenges in researching the risk of environmental toxins

Dr. Mata says there's more research on genetic factors and Parkinson's disease than on how environmental factors may play a role. So, why is this?

When it comes to genetics, researchers can use a blood sample to look at your DNA. But with environmental factors, it's harder to measure how much exposure somebody has had over their lifetime.

"We think that Parkinson's disease might start 20 or 30 years before you see symptoms," explains Dr. Mata. "So, that means for somebody who's in their 60s, you would have to figure out what they did in their 30s and 40s to see if that had an impact."

Healthcare providers may use questionnaires to make some of those environmental connections by looking at people's history, he notes. They may ask questions about living in a rural area, job history (for example, welders may be exposed to manganese and other heavy metals) and even if you drink well water. The problem? Those questionnaires aren't always accurate.

And that makes it difficult for researchers to draw any broad conclusions.

"It's very easy for us to collect information from thousands of people and look at their genetics," says Dr. Mata. "But extracting environmental information is extremely hard and not always correct."

What you can do to reduce your exposure to environmental toxins

While the risk of chronic exposure to many of these toxins is low for most of us, there are still a few things you can do to further decrease your risk:

- **Wear protective gear when necessary.** If you have a job where you handle or are in contact with chemicals or pesticides, Dr. Mata says you should wear the appropriate equipment, such as a mask and gloves, to limit your exposure.
- **Consider your family history.** If someone in your family has Parkinson's disease, you may want to avoid certain environmental toxins as much as possible, he says. "If you already have a genetic predisposition for developing Parkinson's disease, exposure to certain toxins is just adding to your risk."
- **Rethink how you drink water.** Certain water supplies may contain high amounts of chemicals, like lead, that may not be good for you. If you're concerned, consider installing a water filter to your home's faucets or drinking from bottled water.
- **Raise awareness.** Support measures to limit or ban certain chemicals or support initiatives to restrict use. This is one way to reduce everybody's risk of developing Parkinson's disease or other diseases, says Dr. Mata.

More research is needed

It can be hard to pinpoint what may lead to a Parkinson's disease diagnosis – it's likely due to a combination of factors like your genetics and environmental factors.

"The best thing that we can do is continue to research any connection and try to find out what all these chemicals are and how they may contribute to the disease," concludes Dr. Mata.

Source:

Cleveland Clinic

Take 5

A monthly review of the top five issues raised in calls to the Parkinson's NSW InfoLine team (call 1800 727 567).

1. Getting Moving After Winter

With the colder months behind us, many people living with Parkinson's find it challenging to restart regular movement after a quieter winter. It's important to take it gently and to ease back into exercise, listen to your body, and set realistic goals. Even short walks, light stretching, or a gentle class can help rebuild strength and confidence. If you're unsure where to start, our InfoLine can connect you with Parkinson's specific exercise programs and physiotherapists who understand your needs.

2. Voluntary Assisted Dying (NSW)

This month we've had some sensitive conversations around Voluntary Assisted Dying (VAD). Understandably, it can be a confronting and emotional topic for people living with Parkinson's and their families. VAD laws are now active in most states across Australia, but the details can vary depending on where you live.

What we often hear from callers is a need for clear, compassionate information. People want to understand eligibility criteria, how the process works, and what support is available, both medically and emotionally, when these conversations arise. Others simply want a safe space to talk about the ethical and personal considerations without judgement.

If VAD is something you've been thinking about, you don't need to go through those thoughts alone. Your neurologist, GP, or Parkinson's Nurse can help guide you with information relevant to your situation. And if you'd just like to talk it through or ask questions confidentially, our InfoLine team is always here to listen and provide support.

3. Dystonia

Dystonia involves involuntary muscle contractions that cause twisting, irregular postures, or repeated movements. Around 30% of people with Parkinson's experience dystonia, with cervical dystonia (affecting the neck) being the most common. It can appear in specific situations, for example, calf tightness or toe cramping while running, "writer's cramp" when holding a pen, or hand and arm symptoms while brushing teeth or eating.

Because these symptoms often don't appear during a medical appointment, it's important to tell your neurologist if you notice them. Management strategies may include adjusting levodopa around exercise, changing sensory input (such as using toe separators), running on softer surfaces, or altering cadence. Our InfoLine can provide further information and referral pathways.

4. The Role of Speech Pathologists

Speech pathologists don't just help with speech clarity; they can also support swallowing and safe eating. This might include strategies for swallowing tablets, managing coughing or choking after meals, or making small changes in diet and posture to reduce risk. Early referral is best, as interventions can prevent complications and improve quality of life. The InfoLine can link you with speech pathologists who understand Parkinson's.

5. Medication Formats

As Parkinson's progresses, it can become harder to take medications in tablet form. Fortunately, there are other options such as dispersible tablets, patches, intestinal gel pumps, and subcutaneous infusions. These alternatives can support more consistent symptom control and reduce the burden of frequent pill-taking. If you're finding tablets difficult to manage, talk with your neurologist about what might be suitable. For more information and referral to specialists experienced in advanced therapies, call the InfoLine.

For information or personalised guidance on any of these topics, please contact the Parkinson's NSW InfoLine on 1800 727 567. We're here to support you every step of the way.

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For evidence-based information and advice call the Parkinson's NSW InfoLine

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