In Touch Newsletter
July 2025

8 tips to help with freezing for people with Parkinson's

by Sarah Dawson and Josefa Domingos

Freezing in the home or in busy public places can be upsetting, embarrassing, or even frightening. The anxiety that comes with this symptom of Parkinson's may make you feel tempted to avoid situations that are more likely to make you freeze – whether that's crowded rooms, narrow walkways or something else.

However, we understand that avoiding these situations is not always practical. It is important to know that freezing of gait does not have to stop you from enjoying your social life or the activities you love. There is lots you can do to prevent or overcome freezing.

Physiotherapist (and President of Parkinson's Europe) Josefa Domingos – who has spent decades specialising in physiotherapy for Parkinson's – has approved the following advice.

Here are our top tips to help with freezing with Parkinson's:

1. Stop, don't force it
If you think you're about to freeze, stop moving. This gives you time to think about your balance. Try to stay calm, take a deep breath and don't rush. Think about your next movement and plan out how you're going to carry it out before you actually move.

2. Keep a diary
Understanding the triggers of freezing is a powerful way to help take back some control. Keep a diary to record the timing, location, activity being performed, duration and frequency of freezing episodes. Also note down the timing and dosage of each medication. This can help your doctor look at adjusting medication to try and overcome freezing problems.

3. Optimise medications & manage 'Off' periods
Take medications on time to prevent motor fluctuations and improve 'off' freezing. Discuss with your doctor about adjusting Parkinson's medication to reduce freezing. If freezing worsens, deep brain stimulation (DBS) may be an option to consider.

4. Use visual cues to help when freezing with Parkinson's
For some people with Parkinson's, visual cues can be effective at managing freezing. Stick a line of tape across a threshold or on the edges of steps – this can act as a prompt to step over and reduce the risk of freezing. Patterned carpets or

cracks between tiles can also act as visual clues. You may even find it useful to use a small torch or laser pointer to project onto the floor ahead as your cue.

5. Follow the beat (auditory cues)

A steady beat, whether from counting out loud, a metronome or a piece of music, can help prompt you to lift your feet and step. Decide which foot you want to step forward with.

Then, either silently or out loud, say 'one, two, three, step' or 'left, right, left, right' to cue the feet to walk. You may like to try closing your eyes to take the first step (as long as it's safe), then open your eyes to continue.

A trigger word, like 'go', 'step' or 'march' helps to restart your walking if you do freeze. There are mini metronomes, or similar, which can be clipped onto your clothing – a physiotherapist or occupational therapist should be able to suggest something suitable.

6. Use your imagination (mental imagery)

Rehearse certain movements in your mind, focusing hard on the sequence. For example:

- Concentrate on putting your heel down firmly on the ground as your foot makes contact
- Imagine yourself walking smoothly before starting to move or
- Mentally picture stepping over an object when freezing starts.

This technique is called an attentional strategy, and it's a valuable tool to help with freezing. Attentional strategies require concentration – thinking about moving and rehearsing a sequence uses the same part of your brain as when you actually move.

7. The weight shift method for freezing with Parkinson's

When you freeze, gently shift your weight onto the other leg, rather than trying to move forward. This technique will allow you to move forward on your other leg. Try gently rocking your head and shoulders from side to side to help achieve this weight shift.

Other strategies may include taking a step sideways and then forward. Taking a small step back and then forward with the same foot might also be helpful. Try marching in place for a few steps before moving forward.

Also try to avoid sudden direction changes – turn slowly and deliberately. Turn using a U-shape, rather than pivoting sharply.

8. Touch

Using touch as a cue to unblock freezing can be helpful for some people. For example, lightly tap your leg to signal when to step, or have a caregiver touch your back when freezing occurs.

Source:
Original article published by Parkinson's Europe

Support Group Round-up

By Stacey Foster, Support Group Coordinator

A little bit of a different Support Group Round Up this month!

Did you know we have several online support groups? They are held over Zoom on a monthly, bi-monthly, or quarterly basis.

Let's Talk Parkinson's – various topics presented by health and allied health professionals. These meetings are recorded and added to our Living Well with Parkinson's library on our YouTube channel. There is time for discussion and Q&A. They run every 2 months.

Carers Chat – only for carers/spouses of someone living with Parkinson's. These monthly meetings are facilitated by Parkinson's NSW counsellors. Meetings are not recorded. Previous topics have been: empathy burnout, Carer Gateway services, panic attacks, journalling, resilience, mindfulness.

Early/Young Onset – quarterly meetings for people living with Parkinson's who are under the age of 65 years. Various topics presented by health and allied health professionals with discussion and Q&A. Meetings are recorded and shared only with people who register for the meetings.

DBS and Advanced Therapies – quarterly meetings for those considering or who have DBS or an advanced therapy (Apomorphine, Duadopa). Facilitated by a health professional, recorded and shared only with people who register for the meetings.

If you would like to join any of these groups, please reach out to me at supportgroups@parkinsonsnsw.org.au so I can add you to the relevant support group mailing list.

Support Groups we visited in July

- Taree
- Nowra
- Chatswood

Upcoming Support Group Visits

- Murwillumbah
- Narrabri

- Macarthur
- Orange

Applying makeup when you have Parkinson's

Some people living with Parkinson's have a tremor or struggle with dexterity, which can make it more difficult to apply makeup. Here are some tips that may help.

1. Preparation

- Sit down at a dressing table or bathroom counter, rather than standing up. If you have a tremor, resting your elbow on a surface can help give you more stability.
- Use a mirror on a wall or stand so it will stay in a fixed position.

2. Products

- Consider using palettes that can be opened without using much force. Slimmer-style or single palettes can be more fiddly to open.
- Pump-style bottles can be easier to dispense liquid makeup, such as foundation, from rather than tubes.
- Use brushes that are thicker as they can be easier to grip. You can also try putting a rubber band on the handle of a brush to help with grip.
- Creams can be easier to blend than powder, so you might find cream eye shadow or blusher for example, easier to use.
- Using a mascara shield that you hold over your eye can help stop smudges when you apply mascara.

3. Techniques

- Think about what part of your makeup routine takes you the longest to do and start with that area first. For example, eye makeup may involve more precise movements, so start with this first when your hands are strongest.
- If you find it difficult to apply lipstick carefully, you may find it easier to put some on your finger and use your finger to apply it to your lips.
- For eye liner, aim for short strokes on your eye lid and then you can connect these lines, rather than doing a single line in one go.
- If you smudge makeup as you put it on, use a cotton bud with a small amount of makeup remover on it to tidy up areas at the end.
- Take your time and don't rush.

An occupational therapist can show you different ways to do a task more easily, or give you advice about using strategies, techniques, gadgets, or equipment where you need them.

Call the Parkinson's NSW InfoLine on 1800 644 189 for more information on occupational therapists.

Source:
[Parkinson's UK]

Parkinson's caregivers are under strain, need more support: Report

Average caregiver spends more than 30 hours a week providing care

The average caregiver for someone with Parkinson's disease spends more than 30 hours per week doing unpaid work to provide care, and many report substantial emotional and physical strain.

That's according to a new report from the National Alliance for Caregiving (NAC), with support from The Michael J. Fox Foundation for Parkinson's Research (MJFF) and Arcadia University, in Pennsylvania.

"This new research coupled with powerful caregiver stories, shines a light on the important role that family caregivers play in supporting people living with Parkinson's disease," Jason Resendez, president and CEO of the NAC, said in a press release.

"Parkinson's caregivers are navigating one of the most complex care journeys imaginable, often at a great personal cost, yet they do so without the support they need and the recognition they deserve."

The symptoms of Parkinson's disease can make day-to-day activities difficult or impossible to do independently, so many people with Parkinson's rely on a caregiver to help them. Often the caregiver is a friend or family member, such as a spouse or child.

In this report, researchers analysed data from a survey of 72 Parkinson's caregivers, as well as interviews from a handful of caregivers.

Report shines spotlight on caregiver experience

"This report shines a critical spotlight on the experiences of caregivers, offering an evidence-based roadmap to better equip, acknowledge, and empower them as essential partners in Parkinson's care," said Margaret Longacre, a professor of public health and dean of the College of Health Sciences at Arcadia University.

The average age among the caregivers was 61, and most identified as female. Most caregivers had been providing care for more than a year, with more than a third having acted as caregivers for five years or more. Most of the caregivers were married, with nearly 40% providing care for their spouse. Nearly two-thirds of the caregivers said they felt they didn't have a choice in giving care.

More than 60% of the caregivers said they needed to give help with getting dressed and getting in and out of bed or chairs, and nearly half of the caregivers said they needed to give help with using the toilet or bathing. Most caregivers also reported helping with housework and finances, preparing meals, and giving medications.

The report notes that these rates are markedly higher among caregivers for Parkinson's than for other broader conditions. Overall, caregivers were spending on average 31 hours per week doing unpaid labour to help their charge.

"These data suggest that caregivers provide substantial time commitment and extensive care needs," the report states.

Caregiving has impact on employment
Half of the caregivers reported they were working while acting as caregiver, spending an average of 37 hours per week at their jobs. But caregiving had a substantial impact on employment, with many caregivers saying they missed work or had to cut back to meet their caregiving responsibilities. Most also said they'd had to dip into savings to help manage financial obligations.

Nearly half of the Parkinson's caregivers reported high emotional strain, and nearly a third reported substantial physical strain – rates that are markedly higher than among caregivers of people with other conditions, the report notes.

Despite the substantial burden of caregiving, caregivers often reported lacking resources, with many citing a need for additional resources to help manage their own health and the safety of their charge. The report concludes with recommendations to provide more support to Parkinson's caregivers.

Sources:
Original article by Marisa Wexler, MS
Parkinson's News Today

Managing apathy when you have Parkinson's

Apathy can be temporary but is often frustrating for both the person affected and the people around them. But there are ways to manage the symptom.

Apathy is a loss of motivation for doing things. It can appear in different ways, including not being interested in activities you used to enjoy, difficulties planning tasks, or even having trouble thinking of what to do.

People with apathy might find themselves less motivated to take medication, exercise or live healthily. Apathy can also be hard for partners and family members.

Apathy and depression are different. People with depression feel low and pessimistic about the future, whereas people with apathy might feel indifferent or not bothered.

But apathy and depression, and anxiety, can overlap. If you are feeling low or anxious, you might have less energy to do things, feel it's futile, or be worried about certain situations. All of these will impact your motivation to do things.

How can I manage apathy?

1. Reflect on how you feel

Consider why you feel apathetic and try to see things from a different perspective. For example, if you're worried about the things you can't do anymore, try thinking about the things you can still do.

If you are feeling low or anxious, then think about ways you can improve your mood. This might mean being more physically active, or spending time doing something you enjoy.

2. Think about what you used to enjoy

Is there a way you can engage with activities you used to enjoy? For example, reconnecting with a friend you used to see regularly or going back to an exercise class.

3. Follow a regular routine

Following a regular routine means you don't need to plan and organise as much and doing things takes less effort.

4. Stick to your plans

If you're living with apathy, it can be easy to cancel plans. But meeting friends or doing an activity can have a positive impact on your mental health.

5. Set a goal

Try to make your goal realistic and not something that might overwhelm you. Break down bigger tasks into smaller chunks, so you are more likely to achieve what you have set out to do.

6. Consider your energy levels

Manage fatigue by planning activities you enjoy for the times of the day when you have the most energy.

7. Exercise regularly

Physical activity is good for you and is especially good for you if you have Parkinson's. Being active for 2.5 hours a week can help manage Parkinson's symptoms and has a positive impact both physically and mentally.

8. Talk to family and friends

Talk to friends or family about how you are feeling. It can help everyone to know that your lack of motivation isn't personal.

Your friends and family can also help by providing support for planning activities and giving lots of positive feedback when activities are completed.

Tasks will be easier to achieve if broken down into smaller steps.

9. Speak to your GP, specialist or Parkinson's nurse

You should also speak to your GP, specialist or Parkinson's nurse. They can arrange a medication review, to make sure your medication is managing your symptoms well. If necessary, they can also refer you to a mental health specialist or counsellor.

Source:
Parkinson's UK

Drug Molecule Targets Early Onset Parkinson's Disease

A new drug molecule could reactivate housekeeping functions in the brain cells of young Parkinson's patients.

A novel drug molecule being studied by researchers from McGill University in Canada could reactivate housekeeping functions in brain cells of younger Parkinson's patients, paving the way for potential future treatments for this incurable, degenerative disease.

"We are excited about this drug compound because it raises the possibility of a cure for Parkinson's disease for a subset of patients," said Kalle Gehring, a biochemistry professor at McGill University.

Developed by the biotech company Biogen, the new compound has shown promising results activating parkin, a key protein in the brain responsible for 'cleaning up' and recycling damaged mitochondria – the energy powerhouse of the cell. When parkin doesn't work properly, these damaged mitochondria accumulate, leading eventually to Parkinson's disease.

In studies published in 2013 and 2018, Gehring shed light on the functions of parkin based on data collected at the Canadian Light Source (CLS) at the University of Saskatchewan, Canada.

In this new follow-up study, Gehring used the CMCF beamline at the CLS to determine how the Biogen compound activates parkin. They found that it glues together parkin and a natural activator present in the cell. This molecular-level information is essential for the drug's future development.

"The way the drug molecule turns on parkin is through a secondary route, which is effective for specific mutations of parkin that occur in younger patients," he said.

After turning proteins into tiny crystals, Gehring and his team used a technique called protein crystallography to identify their 3D structures and learn where the novel drug binds and how it affects the proteins.

"We need quality data to solve the protein structures and see their 3D pictures. It takes a facility like the CLS to take Canadian research to an international level," said Gehring.

While Parkinson's symptoms – slowed movements, tremors, and balance problems – often appear in people in their 60s, onset at an earlier age is not uncommon and five to 10 per cent of people diagnosed are affected before they turn 40.

"The hope is that one day we'll find compounds that can treat Parkinson's disease in general," said Gehring. "As the population in Canada is aging and better treatments for other diseases are becoming available, neurodegenerative diseases such as Parkinson's will be a major health concern."

While Gehring will keep studying the pathways of parkin activation as part of his ongoing research about understanding the causes of Parkinson's disease, it will be up to Biogen to apply the results of this new study in future drug development, he said.

Sources:
Nature Communications
Canadian Light Source

Reference:
Sauvé V, Stefan E, Croteau N, et al. Activation of parkin by a molecular glue. *Nat Commun*. 2024;15(1):7707. doi: 10.1038/s41467-024-51889-3

What affects how well my Parkinson's drugs work?

What you eat, constipation and medications you may take for other conditions can affect how well your body absorbs your Parkinson's drugs. Here we look at ways to make sure you get the best from your Parkinson's medication.

Levodopa and protein

Diet can affect how well your Parkinson's medication is absorbed. For some people with Parkinson's, protein seems to interfere with how well levodopa medications are absorbed in your body. Protein is found mainly in meat, fish, eggs, cheese, beans and pulses.

Because of this, it may help to take your medication on an empty stomach 30 minutes before you eat a meal with protein in it, or a minimum of 60 minutes after a meal.

Other things that might help:

- Having most of your daily protein in the evening can help your levodopa medication work better in the daytime, when you're likely to need it more. This is known as the protein redistribution diet and should only be tried after consulting an accredited dietitian.

- Reducing the amount of protein you eat earlier in the day may help to increase the response your body has to the medication. This can help avoid unpredictable muscle fluctuations.

Protein is an important part of a healthy diet. It can help you maintain your muscles and strength, and fight infection. So it's important you don't stop eating it altogether.

If you would like to review the timing of your protein intake, you should talk to your GP, specialist or Parkinson's nurse, or ask to see an accredited dietitian.

Constipation

Constipation is common in people with Parkinson's. It can be caused by a number of things, including slowness of movement and rigidity.

These Parkinson's symptoms can affect the muscles in the bowel wall, so food isn't moved along in the bowel. This causes constipation.

If you experience this symptom, it often means your body isn't able to absorb your Parkinson's medication properly. This can lead to your symptoms getting worse.

Many people with Parkinson's find that delaying having a large meal until an hour or two after taking their medication can help with drug absorption and improve their symptoms.

Some medication makes constipation worse. It might be your Parkinson's drugs or other types of medication, such as antidepressants or prescription painkillers. Speak to your GP, specialist or Parkinson's nurse for advice if you're worried about this.

Indigestion and heartburn

Antacids are used to relieve heartburn or indigestion. They shouldn't be taken at the same time as your Parkinson's drugs as they may affect the absorption of your medication.

If you do experience heartburn or indigestion, speak with your GP, specialist or Parkinson's nurse, who can advise on treatments.

Other types of drugs you may take

If you have Parkinson's, it's likely you'll have symptoms that don't just affect movement. These are known as non-motor symptoms, and include things like anxiety, pain or fatigue.

Treatments for the non-motor symptoms of Parkinson's are normally the same types of drugs that anyone might use or be prescribed. For example, you may be prescribed a drug called Movicol for constipation. But some medication can interfere with how Parkinson's drugs work. This means that a particular drug can become weaker or stronger.

Whoever prescribes you new medication should check what you're already taking. And before you take something, it's always good to double check with your specialist, Parkinson's nurse or pharmacist whether there are any risks. This includes over-the-counter medication, such as:

- **Cold and flu remedies.** These can stop your Parkinson's medication working properly. This is especially important to remember if you're taking selegiline, rasagiline and safinamide. They can also increase the risk of side effects.
- **Iron tablets.** These can affect how much levodopa is absorbed in your body. If you're taking supplements, you should aim to leave around two hours between taking the iron tablet and levodopa.
- **Anti-sickness drugs.** Parkinson's medication can cause nausea and vomiting. Your specialist will usually prescribe domperidone (Motilium) to prevent and treat this side effect. But some anti-sickness drugs will interact with Parkinson's drugs.
- **Antipsychotic medication.** This is used to treat hallucinations and delusions when someone experiences psychosis or schizophrenia. Because antipsychotics and Parkinson's medication both affect the levels of dopamine in the brain, it's a delicate balance to keep the symptoms of both conditions well controlled.

If you have any concerns about your medication, talk to your GP, specialist, Parkinson's nurse, or pharmacist.

Sources:
Parkinson's UK
Parkinson's NSW InfoLine

What is a Gift in Will?

A bequest or gift in Will is a donation left to a charity or individual of your choice, as stated in your will.

Such gifts can help to support the daily activities of charities you want to support and enable them to continue to support the community. In this way, it can be the perfect way to make an impact with your will.

What can you leave as a gift in will?
A gift in will can be a specific monetary amount, property, shares, or percentage of these assets. For example:

- A monetary gift of a set amount
- A percentage of your share portfolio
- A piece of land or title deed
- A percentage of the residue of your estate

How can you leave a gift in Will?

When writing your Will it is important to ensure your final wishes are recorded accurately.

Many charities will outline the specific wording required to ensure your gift reaches them safely and will generally include the organisation's business name and ABN. This information is available on the Parkinson's NSW web site.

If using an online platform such as Willed, this information is prefilled and requires you to select your charity from the Fundraising Institute of Australia's database and outline your bequest.

Do I need to let the charity know that I have included them in my Will?
There is no legal requirement to notify the charity that you have included them in your Will. However, many charities appreciate the opportunity to acknowledge your kindness and generosity before your passing.

Writing a Will is not difficult
The complexity of your Will depends on things like the size of your estate and the number of beneficiaries. However, for most people writing a Will can be a simple and inexpensive process. There are even free Will kits available online to step you through the process if you'd like to write your Will yourself.

Once written, you can change and update your Will whenever necessary. Your assets remain 100% yours while you are living, and you have full control of when and how to update your Will.

You don't have to be wealthy to leave a gift in your Will for a charity. It is possible to look after the needs of your family and leave a bequest or a gift in Will to charity, no matter the size of your estate.

There are three ways that are worth considering if you'd like to include a charity like Parkinson's NSW in your Will.

1. Residuary
The residue of your estate is what is left after all estate debts and expenses are settled and specific gifts are made. This is the simplest and most effective way to support a charity and guarantee your family and loved ones are looked after first.

2. Percentage
This is where you nominate a percentage of your estate to leave to a charity. The benefit of this kind of gift is that it gives longevity to your Will. It is not subject to inflation or changes in the value of your estate.

3. Specific
This can include the gift of property (such as real estate) or a specific dollar amount. However, the value of a specific gift like this can be subject to inflation over time.

You can also make a charity like Parkinson's NSW the beneficiary of your life insurance policy.

A bequest or a gift in your Will is one of the most enduring gifts you can leave behind. It means your generosity lives on in future generations.

Visit the Parkinson's NSW web site for more information:

Wills and Bequests | Parkinsons NSW

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

(02) 8051 1900
Parkinson's NSW InfoLine
Email: **pnsw@parkinsonsnsw.org.au**
Web: **www.parkinsonsnsw.org.au**