

Freezing in Parkinson's

Some people with Parkinson's will experience a symptom called freezing.

This information explains what freezing is, what treatments are available and what you can do to manage it. It also gives you tips on how to get moving again and how to reduce the risk of falling if you freeze.

What is freezing?

Freezing can be a common symptom of Parkinson's. People describe it as feeling like their feet are 'glued' to the ground.

If you experience freezing you may suddenly not be able to move forward for several seconds or minutes. You may also feel like your lower half is stuck, but the top half of your body is still able to move. You may experience this interruption to movement when you start to walk or while walking. You may also experience it when trying to turn around. However, freezing might also affect you during other activities such as speaking, or during a repetitive movement like writing.

Having trouble starting a movement is sometimes called 'start hesitation'. This may happen when you try to step forward just after you've stood up, when you want to start getting out of bed or when you try to swallow food or drink.

Why do people with Parkinson's freeze?

We still don't know exactly what causes freezing. We only know that it happens when something interrupts or gets in the way of a normal sequence of movement.

It can get worse if you're feeling anxious, stressed or if you lose concentration. Freezing is also more likely to happen the longer you've had Parkinson's. Freezing can also happen if you do not get your medication on time or miss a dose, or become severely constipated.

Where and when can it happen?

You're most likely to freeze when you're walking, as walking is a series of individual movements that happen in a particular order. If one part of the sequence is interrupted, the whole movement can come to a stop.

Freezing is common when:

- you're walking towards doorways, chairs or around obstacles
- you're turning or changing direction
- you're distracted by another task when you're walking, and the 'flow' of walking is interrupted by an object, someone talking or if something else draws your attention
- you're in a crowded place

All of these will interrupt and stop you being able to keep a rhythm going.

Usually, the length of the steps we take changes when walking from smooth to uneven ground. If you have Parkinson's you may find it difficult making these changes automatically. For example, you may be able to walk without a problem on uneven surfaces, but freeze when the floor is smoother or has a patterned surface.

Or, the opposite might happen. You may find your walking pattern gets out of control and your steps get smaller and smaller. Many people who experience freezing are surprised that they have no problems going up or down stairs, but might freeze as soon as they are back on flat ground.

Will freezing happen to me?

Not everyone with Parkinson's experiences freezing. Freezing sometimes happens in the early stages of being diagnosed with the condition. In particular it can happen to people who don't take medication for their condition straight away.

But it's more likely to happen if you've had Parkinson's for some time, and if you've been taking levodopa for a number of years. This is because after a while, you may have a milder response to levodopa.

Is freezing the same as going 'off'?

No. Some people with Parkinson's have 'on' and 'off' periods. Being 'on' is when a person's symptoms are controlled, while being 'off' is when Parkinson's symptoms come back and are difficult to manage.

Going from one to the other can happen very quickly. Some people have described it as like a light switch being turned on and off. Going 'off' can be a sign that your levodopa medication isn't working as well as before.

Being 'on' or 'off' is different from freezing. People with Parkinson's have told us that during 'off' periods, they might not be able to move at all, so walking, going up stairs or reaching for a cup will be very difficult. But when they freeze, it only affects certain movements or parts of their body. So, you might not be able to walk, but you might still be able to reach for an object. Be careful if this happens to you. If your feet freeze and you try to reach for support too far away, you may overbalance and fall.

There are different ways of managing freezing and 'on/off' swings, so your specialist or Parkinson's nurse should treat them as separate problems.

Find out more: see our information on wearing off and involuntary movements (dyskinesia).

Can freezing be dangerous?

Freezing or shuffling can affect your balance and make you more likely to fall over.

Take care with activities such as walking along the side of waterways and crossing busy roads. Swimming may also be difficult if you experience freezing. Some people have told us they avoid using escalators or automatic walk-ways, for example in shopping centres, train stations and airports. You may find it helpful to have someone with you when doing these activities, where possible.

Find out more: see our information on falls and Parkinson's, for more about how to reduce your risk of falling.

Are there treatments for freezing?

Speak to your GP, specialist or Parkinson's nurse about the best treatment for your freezing. They can also refer you for therapy that may help. Treatments include:

Drugs

If you tend to freeze during 'off' periods, changes to the type and timing of your medication may help you 'switch off' less often. Talk to your specialist or Parkinson's nurse about any changes to your medication. Don't suddenly stop taking your medication as this can be dangerous.

When freezing happens during 'on' periods, or if it's nothing to do with the change between 'on' and 'off' periods, this usually can't be treated with Parkinson's drugs.

Occupational therapy

An occupational therapist is a health professional who helps people be as independent as possible. They look at your everyday activities and can give advice on making your home or workplace safer or easier to manage. This may include showing you easier ways to do a task or activity such as getting in and out of bed. They can also give advice about aids or equipment to make doing things easier and safer.

An occupational therapist can help you find specific ways to move more easily around your home in areas that can cause you to freeze. They can also help you find ways to manage a freezing episode in other situations. If you have difficulties organising day-to-day life, or feel very anxious, an occupational therapist can help you learn techniques to manage these concerns.

Find out more: see our information on occupational therapy and Parkinson's.

Physiotherapy

If you freeze in a position where you're stooped forward with your knees bent, heels off the ground and head forward, you're more likely to fall, as the reflex that helps you keep your balance doesn't work so well. The more you try to move your feet, the more unsteady you may become, making it more likely you'll fall.

A physiotherapist can help you with techniques to reduce your risk of falling and hurting yourself when you freeze. These include exercises to strengthen the muscles that keep you upright (such as your leg muscles) and improve your posture and the way you walk. Examples include:

- learning to put your heel down first when you walk this will help you stay steady
- learning to deal with doing two things at the same time (like carrying something while walking) and making sure you know where to focus your attention
- straightening your body into a posture that will make you more stable

- learning to move your weight to one side ready to step forward with the opposite leg
- using different 'cues' (things you can do to encourage a movement to restart)
- learning to control your freezing in a variety of places and situations, so your memory will be triggered more
 quickly in real-life situations. Practising in areas of your home where you usually freeze can be particularly
 useful

Your physiotherapist can also give you advice on walking aids. It's important to get professional advice because if you don't choose the right one, they might make freezing worse rather than better. Some walking aids, such as Zimmer frames, aren't always recommended for people with Parkinson's, so speak to a professional before you use one.

Many people with Parkinson's walk better without any aids, but only once they've learned movement skills to manage the problem.

Find out more: see our information on physiotherapy and Parkinson's and falls and Parkinson's.

Surgery

Deep brain stimulation is a type of surgery that can help some people with Parkinson's. It's not suitable for everyone, but some people find it helps their freezing.

Find out more: see our information on deep brain stimulation for Parkinson's.

What can I do to help myself?

Freezing can be an upsetting, and sometimes even frightening, symptom. If you freeze often you may avoid the places where you're most likely to freeze, such as narrow spaces, crowded or new places, or doorways.

But freezing shouldn't stop you doing the things you enjoy and there are things you can do to manage it. Everyone needs to find their own way of coping with freezing. It's important to find out what's best for you and not to let worrying about freezing stop you doing anything you enjoy. Worrying makes you more likely to freeze.

Remember, if your feet freeze and you then try to reach out for support that's not close enough, you may overbalance and fall.

Movement strategies and cueing techniques

A tendency to freeze won't disappear, but you can improve control over your freezing by using a range of strategies. There is a wide range of techniques that use a specific strategy or a 'cue' to trigger your movement once you've frozen. Knowing these will help you to deal with freezing, may reduce any worries you have when it happens and will help you take control.

We've listed some methods below that have been recommended by occupational therapists and physiotherapists with experience of working with people with Parkinson's.

Remember that different methods may work in different situations and at different times during your condition. So, try a few things to find out which strategies work best for you and use them to restart your movement.

Many of the methods can also help you swallow food and drink too if this doesn't happen automatically. You may even find ways to reduce or avoid freezing altogether.

What to do when you freeze or can't get started

If a movement isn't flowing well, making the effort to think about each separate part of a familiar or simple movement can help you get going.

If your feet freeze you may fall over so make sure that any family, friends and carers know about your freezing and know how to help when it happens.

The first thing to do when you feel yourself freeze is to stop moving, or to slow down. This gives you time to refocus on balance, think about your next move and prepare your body to start again, which can reduce any risk of falling.

The plan method

Try the following:

• **STOP:** calm yourself and take a breath.

• THINK: what do you want to do?

• PLAN: how are you going to do it?

• **DO:** complete the task or movement.

The weight shift method

- When you freeze, don't try to move forward straight away. Instead, gently move most of your weight to one leg (this is what normally happens when you go to walk). Shifting your weight to your one supporting leg like this will let you step forward with the opposite foot. To help with this count 'one, two, three, step' or say 'ready, steady, go' to yourself to get moving again.
- You may be able to re-start walking again by gently rocking your head and shoulders from side to side. This rocking can help you shift your body weight to your supporting leg.
- It may help to say something to yourself as you do this, like 'move my weight to left leg, then step with right' (or vice versa). You may have to rock from leg to leg to release the weight on each foot before stepping off.

Sound and vision cueing methods

Using counting, sound or a rhythm can often help – for example:

- Walk on the spot to keep the stepping rhythm going, such as when you stop to open a door.
- Decide after freezing and pausing which foot you're going to step with first, then step forward after saying something like 'one, two, three, step' or 'ready, steady, go'. You can say this out loud or silently to yourself. If you have someone with you when you freeze, they could say this for you.
- If an area causes you to freeze, using rhythm might help you pass through a 'trouble spot' without a problem. You could sing or hum a tune as you walk (in your mind or out loud). Count your steps from one to 10 (start counting again when you get to 10), or say out loud, 'one, two, one, two, one, two' or 'left, right, left, right, left, right'. This sort of method helps keep a rhythm going and can reduce freezing in doorways etc.
- Say a 'trigger' word silently to yourself such as 'step', 'go' or 'swallow' to re-start walking or to swallow food or drink.
- If freezing is a frequent problem, you could download music on to an MP3 player, so you can listen to it as you walk, to help prevent freezing.
- Use a metronome to re-start your walking. A metronome is a device used by musicians.

• It produces a regular tick or beat that helps them keep to a rhythm. You can find them easily online or in musical instrument shops. Check you can use the small control buttons before you buy one.

Using your imagination

If you find it hard to start a movement, try doing the action in your mind first. Try to imagine or remember doing the action in detail, without any movement difficulties. Thinking about actions in this way is sometimes called 'mental rehearsal'.

Sports people and musicians often use this technique to practise and improve their performances. It works because thinking about moving uses the same areas of the brain we use when we actually make these movements.

For example, to get up from an armchair when you feel stuck:

- Imagine moving your bottom to the front of the seat, keeping your feet slightly apart and tucked close to the chair, your hands ready to push down on the armrests.
- Then imagine the feeling of pushing down through your legs and arms and leaning forward as you stand up easily.
- After you've run through the actions in your mind, get ready to move by saying, 'one, two, three, stand', as you do the set of actions you've just imagined.

Floor strips

If you often freeze in the same places at home and the methods already mentioned don't work, you could try using floor strips to help you overcome freezing trouble spots.

They can help if you have problems turning or changing direction on patterned flooring. They can also help in doorways, wherever you need to turn a corner, in a corridor or in other narrow areas. Here's how to use them:

- Take some sticky tape, such as masking or duct tape, in a colour that's different from the floor or carpet.
- Cut the tape into three or four strips of around 40cm to 55cm (15in to 22in).
- Stick them firmly to the floor or carpet, around 35cm to 50cm (13in to 20in) apart.
- Where there's a corner, place the strips in a fan shape around the bend.
- If the floor colour or texture changes through a doorway, put a strip on the joint. If the flooring is the same on each side of the doorway, put some strips at the same distance on each side of the threshold.

When you walk over the strips, don't worry about where you put your feet. Step on or between the lines to suit yourself. When they become worn or unstuck at the edges, you'll need to replace the strips with fresh tape or arrange for someone to do this for you regularly.

Other cueing tips

- If different coloured rugs or mats make you freeze, remove them from your usual route through a room. Try placing them somewhere that you don't walk often, for example under the window. Plain coloured flooring and uncluttered spaces make moving around easier.
- If someone who knows about your problem is with you when you freeze, they can help by putting one of their feet in front of yours at a right angle. This will give you something to step over to get you walking again. Some people report that what works for them is stepping over the up-turned handle end of a walking

stick or umbrella, or stepping over a rolled-up newspaper.

• If your steps are too fast for your body to keep up with, concentrate on slowing down your stepping rhythm and think about making larger steps. This can help to overcome shuffling, as shuffling often happens before a freeze.

What if I freeze in a busy place?

Some people have told us they freeze in busy places, such as supermarkets, stations, social events or town centres. If this happens, learn to give yourself time to stop, look and plan your route at regular points.

You can try the following:

- Step to one side, out of the main flow of other people, and if possible touch something solid like a wall to help your balance.
- Look at the area ahead of you, checking for anything in the way, such as boxes, other people, benches, street lights or trolleys.
- Decide the exact route you'll take, or guess the number of steps you'll need, before walking towards that point.

Repeat this method of pause, look, plan and walk as often as you need to. Or, if you have guessed the number of steps, start counting them and aim to be at your destination by the number of steps you have guessed.

If none of these methods work and you urgently need to start moving again after freezing, try gently bending your knees and walking on in that position.

More information and support

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**.

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

Visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

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Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/informationsupport** If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

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Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ, or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.
☐ I have Parkinson's and was diagnosed in ☐ ☐ ☐ ☐ ☐ ☐ I care for someone with Parkinson's
☐ I have a friend or family member with Parkinson's ☐ I'm a professional working with people with Parkinson's
Other (please specify)
2. Where did you get this information from? GP Specialist Parkinson's nurse Parkinson's UK local group Parkinson's UK local adviser Ordered directly from us Call to the helpline Other (please specify)
3. Has it answered all your questions?
Yes, completely Yes, mostly Not sure Partly Not at all
4. How easy was it to understand?
☐ Very easy ☐ Easy ☐ Not sure ☐ Quite difficult ☐ Very difficult
5. Has it helped you manage your condition better, or make choices that have improved your life in some way?
☐ It helped a lot ☐ It helped a little ☐ No change ☐ It didn't help ☐ It made things worse
6. What is your ethnic background?* Asian or Asian British Black or Black British Chinese Mixed White British White other Other (please specify) *We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.
Want to hear more from us? I would like a response to my feedback I would like to be a member of Parkinson's UK I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information
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We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**Monday to Friday 9am-7pm, Saturday 10am-2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **www.ngts.org.uk**hello@parkinsons.org.uk

parkinsons.org.uk





