

Freezing in Parkinson's

Many people with Parkinson's will experience freezing. This information sheet explains what freezing is, why it happens, what treatments are available and what to do if it happens to you. It also gives you tips on 'cueing' to get you moving again and how to stop yourself from falling if you freeze.

What is freezing?

Many people with Parkinson's describe freezing as times when their feet get 'glued to the ground'. You might not be able to move forward again for several seconds or minutes. You may feel like your feet are 'frozen' or stuck, but that the top half of your body is still able to move.

You may freeze when you start to walk or when you try to turn around. But freezing does not just affect walking. Some people freeze during speaking, eating or during a repetitive movement like writing or brushing their teeth.

If you have trouble starting a movement, this is sometimes called 'start hesitation'. You may freeze when you try to step forward just after you've stood up, when you lift a cup to drink, or when you start to get out of bed.

Freezing may also happen with thought processes. Some people find this when they are trying hard to remember something in particular, for example trying to remember names.

Why do people with Parkinson's freeze?

Freezing often happens when something interrupts or gets in the way of a normal sequence of movement. But we still don't know exactly what causes freezing.

It can get worse if you're worried, are in a place you don't know or if you lose concentration. As Parkinson's progresses, freezing is more likely to happen.

Where and when can it happen?

You're most likely to freeze when you are 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. You're also more likely to freeze when:

- you are walking towards doorways, chairs or around obstacles
- you are turning or changing direction, especially in a small space
- you are distracted by another task when you are walking
- you're in places that are crowded, cluttered or have highly patterned flooring
- the 'flow' of your walking is interrupted by an object, by someone talking, or if you begin to concentrate on something else. All of these will stop you from being able to keep a rhythm going
- your medication isn't working very well
- you're in a group situation, during conversation

Usually the length of the steps we take changes when walking from smooth to uneven ground, or from open to narrow spaces.

But people with Parkinson's won't always react in the same way to these things. For some people with Parkinson's, changes in stride length and speed are not made automatically like in other people. You may be able to walk without a problem on uneven surfaces, but may 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 or you speed up as you walk.

Will it happen to me?

It's impossible to know if you will experience freezing, but it's more likely to happen if you've had Parkinson's for some time, and if you've been taking levodopa drugs for a number of years. Freezing can be experienced by people who are not taking levodopa, so it isn't just a side effect of medication.

Is freezing the same as going 'off'?

Some people with Parkinson's have 'on' and 'off' periods, when they suddenly switch from being able to move (on) to being unable to move without difficulty (off). People can shift between being 'off' and 'on' very quickly. This can be a side effect of levodopa experienced by some people who have been taking the drug for a while. Many people notice that freezing is worse when their medication level is low, when they are 'off'. But freezing is not the same as being 'on' or 'off'.

“When I freeze or am about to freeze, I stop and count up to 10 and can resume walking. I focus on a point beyond that I wish to approach. For instance, if I am approaching a doorway, I focus on something beyond the doorway to avoid freezing.”

Kris, diagnosed in 2004

There are different ways of managing freezing and 'on/off' swings, so they must be seen as separate problems. During 'off' periods you'll hardly be able to move at all, so walking, going up stairs or reaching for a cup will be impossible, but when you freeze, it only affects certain movements. So you may not be able to walk, but you could still be able to reach for a cup.

Find out more: see our information sheet *Motor Fluctuations in Parkinson's*.

How can freezing be treated?

Speak to your GP or specialist about the best treatment for your freezing. You can also speak to your Parkinson's nurse, if you have one. A Parkinson's nurse is a qualified registered general nurse with specialist experience, knowledge and skills in Parkinson's. They play a vital role in the care of people with Parkinson's. You can read more about them on page 8.

They can also refer you for any therapy that you both think may help you. Treatments include the following.

Drugs

If you tend to freeze during 'off' periods, then changes to your medication might help. 'On' and 'off' periods are thought to be caused by the brain's reaction to small changes in the level of dopamine in the blood. You may switch 'off' less often if the type and timing of your Parkinson's medication is changed. You should talk about any changes to your medication with your specialist or Parkinson's nurse.

Research on the drug selegiline (also known as Eldepryl or Zelapar) found that people who were prescribed it were less likely to freeze later on in their Parkinson's. But this study only suggests that there is less chance of freezing. It doesn't say that selegiline can treat freezing and it hasn't been found to do so.

When freezing happens during 'on' periods, or if it's nothing to do with the change between 'on' and 'off' periods, this can't normally be treated by Parkinson's drugs. In some cases, though, reducing the amount of dopamine medication a person takes may make them less likely to freeze during 'on' periods. This can also make 'wearing off' symptoms worse, though.

Occupational therapy

An occupational therapist is a health professional who aims to help you to be as independent as possible. They look at and assess how well you can do everyday activities and can give you advice on making your home or workplace safer or easier to manage. This may include showing you easier ways to do a task and giving advice about aids or equipment you can use to make doing actions easier and safer.

An occupational therapist can help find ways to negotiate areas that tend to cause you to freeze in and around your home. They can also help you find ways to get over a freezing episode in other situations. If you feel very anxious, an occupational therapist can also help you learn techniques to manage this.

Find out more: see our information sheet *Occupational therapy and Parkinson's*.

Physiotherapy

As Parkinson's progresses, it can affect the way you stand (posture) and your balance.

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.

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

- 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 and making sure you know where to focus your attention
- straightening your body into a better posture – this will make you more stable, as it is the natural way we stand and walk
- ways to stop you leaning backwards
- using different ‘cues’ (things you can do to encourage a movement to restart)
- learning to keep control of your freezing in a variety of places and situations, so that your memory will be triggered more quickly in real-life situations

Your physiotherapist can also give you advice on walking aids. 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 you should speak to a professional before you use one.

Exercise

Exercises to keep your legs moving can help stop freezing from happening. For example:

- try marching on the spot when standing or even when sitting down. March in slow motion swinging your arms and lifting your legs up high
- try not to sit still for long period. Get up and move around every 20–30 minutes

Exercise may also help to maintain a better posture and balance.

Find out more: see our information sheets *Physiotherapy and Parkinson’s* and *Falls and Parkinson’s*.

Surgery

Deep brain stimulation is a type of surgery that is effective for some people with Parkinson’s. It has been found to work well for some people’s freezing, but not in every case.

Find out more: see our booklet *Surgery and Parkinson’s*.

What can I do to help myself?

For lots of people, freezing can be an upsetting and sometimes even frightening symptom. If freezing makes you feel embarrassed or uncomfortable, you may not want to meet with people or go to events. You might avoid the places where you’re most likely to freeze, such as narrow spaces, crowded places or doorways. This isn’t always possible, and it’s not really a good solution, as it can stop you doing the things you enjoy. However, if you lose the ability to move easily, making the effort to think about each separate part of a familiar or simple movement can help.

“ Like a lot of people, I use cues like lines on the pavement, or patterns in the carpet. I use a walking stick to walk and sometimes I hold the stick in front of me and aim to hit the walking stick with my foot. If you’ve found a strategy for overcoming freezing that works, don’t be embarrassed by what other people around you think, just use it and try to put what they might think to one side. ”

Linda, diagnosed in 2002

It's useful to have ways to overcome freezing when it happens. Every person needs to discover their own way of coping with freezing. It's important to find out what is best for you and not to let worrying about freezing stop you doing anything you enjoy. Worry makes you more likely to freeze.

If your feet freeze and you then try to reach out for support that is not close enough, you may over-balance and fall.

Cueing techniques to try

There are techniques that can give you a 'cue' to trigger you to move again once you've frozen. We've listed some methods below that have been recommended by physiotherapists. There are several to choose from, as different methods may work in different situations.

Try a few things to find out which method or methods work best for you. Once you've discovered what suits you best, you'll be able to use your method or strategy to restart your walking, or even to avoid freezing in problem areas altogether. Your tendency to freeze will not disappear, but you can improve control over your freezing by using a range of strategies. Having the knowledge of how to deal with freezing can reduce any worries you may have when it happens

Over time, as your condition develops, your method might not work as well as it used to. If this happens, you should try others to find another one that works for you.

What to do when you freeze

The first thing you should try when you feel yourself about to freeze is to stop moving. This reduces the risk of falling and gives you time to refocus your balance, think about your next move and to prepare your body to start again. If your feet freeze you may fall over so make sure that family, friends and carers know about your freezing and know how to help when it happens.

You could try the following method when you freeze:

- STOP: calm yourself.
- 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.
- 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).

Sound and vision cueing methods

Using counting, sound or a rhythm can help – so you may like to try some of the ideas below.

- Try walking on the spot, to keep the stepping rhythm going, when you stop to open a door, for example.
- Decide which foot you are going to step with first, then step forward after saying something like 'one, two, three, step' or 'ready, steady, go'. You can say this aloud or silently to yourself, or it could be said by someone who is with you when you freeze. Whichever you choose, a strong, clear voice will encourage you to get started again.
- Count your steps from one to 10 (start counting again when you get to 10), or chanting, 'one, two, one, two, one, two' or 'left, right, left, right, left, right'.
- Try re-starting your walking by saying a trigger word or phrase such as 'step', 'big step' or 'go'.
- You may find that it works to close your eyes and take a step. Then open your eyes again to continue safely.
- Use a rhythm by singing or humming a tune as you walk (in your mind or aloud). Using rhythm as you get to an area that causes you to freeze might help you pass through a 'trouble spot' without a problem.
- If freezing is a frequent problem, you could download music with a good rhythm 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 that is used by musicians. It produces a regular tick or beat that helps them to keep to a rhythm. These are widely available from musical instrument suppliers.

Floor strips

If you tend to freeze in the same places at home and the previous methods described here don't work, you could try using floor strips to help you in overcoming freezing trouble spots. These are strips of tape stuck to the floor. They can help in doorways, wherever you need to turn a corner, in a corridor or in other narrow areas.

- Take some sticky tape, such as masking or electrical insulating tape, in a colour that's different to the floor or carpet.
- Cut the tape to lengths 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 is 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 strips the same distance on each side of the threshold.

When you walk over the strips, don't worry where you put your feet. Step on or between the lines to suit yourself. You'll need to replace the strips with fresh tape when they become worn.

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.

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 as you imagine standing up easily.

Exercise may also help to maintain a better posture and balance

- 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

Thinking about actions in this way is sometimes called 'mental rehearsal'. This technique is often used by sports people and musicians to practise and improve their performances. It works because thinking about moving uses the same areas of the brain that are used when you actually make these movements.

Other cueing tips

- If you notice that different coloured rugs or mats make you freeze, remove them from your usual route through a room. Plain coloured flooring and uncluttered space tends to make moving around your home 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. You could also try stepping over the end of a walking stick, umbrella or rolled up newspaper.
- If your steps are too fast for your body to keep up with, slow down your stepping rhythm and think about making large steps. This can help to overcome shuffling, as shuffling often happens before a freeze.

What if I freeze in a busy place?

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

To do this:

- step to one side, out of the main flow of other people, and look at the area ahead of you and take control of your stepping
- check for anything in the way, such as boxes, children, or trolleys
- decide the exact route you will take for as far as you can see or want to go, like you plan a car journey before you set off. Set off to walk to that point
- repeat this method of 'pause, look, plan and walk' as often as you need to

If none of the methods you use work and you urgently need to start moving again quickly after freezing, try sinking to your knees and walking on in that position.

Can freezing be dangerous?

If you take lots of small shuffling steps (called festination) before freezing, this can affect your balance and make you more likely to fall over.

There are other risks of freezing too, because it can happen at any time without warning. You should take care with activities such as swimming, where it's best to be with someone else at all times.

Find out more: see our information sheet *Falls and Parkinson's*.

More information and support

The Rescue project

Funded by the European Commission, the project looked into a cueing therapy programme to improve walking and freezing problems in Parkinson's. They produce information sheets about cueing for people with Parkinson's and their carers, and made a CD-Rom for physiotherapists.

www.rescueproject.org

Parkinson's nurses

Parkinson's nurses provide expert advice and support to help people with Parkinson's and those who care for them to manage symptoms. They can also act as a liaison between 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 a 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 now 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 and they will match you with a peer support volunteer.

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

Our website has information about your local support team and how to contact them at parkinsons.org.uk/localtoyou. You can find details of our local groups and your nearest meeting at parkinsons.org.uk/localgroups. You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.

Thank you

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

Ana Aragon, Associate Senior Lecturer and Independent Occupational Therapist.

Dr Ronald Pearce, Consultant Neurologist and Honorary Senior Lecturer, Division of Neuroscience, Imperial School of Medicine, Charing Cross

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



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If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Resources and Diversity, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at **publications@parkinsons.org.uk**. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- GP, specialist or Parkinson's nurse
- Information and support worker
- Parkinson's UK local group or event
- Ordered from us directly
- Our website
- Other

How useful have you found the information sheet? (1 is not useful, 4 is very useful) 1 2 3 4

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Has this resource given you information that might help you manage your condition better?

- NA
- It hasn't helped
- It has helped a little
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What aspects did you find most helpful?

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Were you looking for any information that wasn't covered?

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Do you have any other comments?

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If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- Membership
- Information review group (who give us feedback on new and updated resources)

Name

Address

Telephone..... Email.....

What is your ethnic background? Asian or Asian British Black or Black British Chinese Mixed
 White British White other Other (please specify)

We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

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 **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday

10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website

at **parkinsons.org.uk/publications**

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this information sheet can be found in the Microsoft Word version at **parkinsons.org.uk/publications**

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