

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 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 in Parkinson's. Many people describe it as like their feet getting 'glued to the ground'. You may not be able to move forward again for several seconds or minutes. You may feel like your lower half is stuck, but 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 or during a repetitive movement like writing or brushing their teeth.

If you have trouble starting a movement, this 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.

Find out more: see our information sheet *Eating, swallowing and saliva control in Parkinson's*.

Freezing may also happen with thinking. Some people find this when they are trying hard to remember something in particular, for example names or dates. Switching your attention to new topics and ideas can also be a problem sometimes.

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 feeling anxious, stressed 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
- you are distracted by another task when you are walking, and the 'flow' of walking is interrupted by an object, someone talking or if attention is drawn to something else
- you are in places that are crowded

All of these will 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. But 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 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.

Will it happen to me?

It's not possible to know if you will experience these symptoms. Freezing can be seen in the early stages of Parkinson's and in people who aren't taking medication for their condition. But it is 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. Levodopa is one of the main drugs used to treat Parkinson's symptoms. After a while, you may have a milder, less predictable response to levodopa. You may still experience freezing even if you don't take levodopa.

Is freezing the same as going 'off'?

Some people with Parkinson's have 'on' and 'off' periods. Being 'on' describes when a person's symptoms are controlled and they are feeling at their most capable. Being 'off' is when Parkinson's symptoms recur and are at their most debilitating. This can happen very quickly. Some people have described it as like a light switch being turned on and off. This may be a sign that your levodopa medication is not working as well as before.

Being 'on' and 'off' is different from freezing. During 'off' periods, you might not be able to move at all, so walking, going up stairs or reaching for a cup will be very difficult. But people with Parkinson's have told us that 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 ahead of you to try to help move forwards again. Be careful if this happens to you. If your feet freeze and you try to reach for support that is not close enough, you may overbalance and fall.

“If I've frozen for a while and then get going, I find my balance is sometimes a little off. So, I sit for a little while before I feel ready to move again. For me, I feel it's mind over matter a lot of the time. I have to look at my feet and will them to move, which I find really helps.”

Paul lives in Birkenhead and enjoys visiting museums in his spare time. He was diagnosed with Parkinson's in 2013.

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

Find out more: see our information sheet *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. It can happen at any time and may be brought on by being in crowded places.

Take care with activities such as walking along the side of waterways and when crossing busy roads. Swimming may also be difficult if you experience freezing. Some people have told us that they avoid using automatic moving stairs and walk-ways, especially when 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 sheet *Falls and Parkinson's*, for more about how to reduce the risk of falls.

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 any therapy that you both think may help you. Treatments include:

Drugs

If you tend to freeze during 'off' periods, changes to the type and timing of medication may help you 'switch off' less often. Talk to your specialist or Parkinson's nurse about any changes to your medication. Don't 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 can't normally be treated by Parkinson's drugs.

Occupational therapy

An occupational therapist is a health professional who aims to help people be as independent as possible. They look at how everyday activities are done 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 areas that tend to cause you to freeze in and around your home. They can also help you find ways to manage a freezing episode in other situations. If you have difficulties with thinking and organising day-to-day life, or feel very anxious, an occupational therapist can also help you learn techniques to manage these concerns.

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

Physiotherapy

As Parkinson's can affect your balance and the way you stand (your posture), physiotherapy may be helpful. 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 will fall.

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, change the way you walk and 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 (such as carrying something when walking) and making sure you know where to focus your attention
- straightening your body into a posture that will make you more stable
- ways to stop you leaning backwards
- 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 that your memory will be triggered more quickly in real-life situations

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 walking aids, but only once they have learnt movement skills to manage the problem.

Exercise

Exercises to keep your legs moving can help stop you from freezing. Exercise may also help your posture and balance.

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 a long time. Get up and move around every 20–30 minutes, if you’re able to.

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 can help some people with Parkinson’s. Some people find it helps their freezing, but brain surgery is not suitable for everyone.

Find out more: see our booklet *Surgery and 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. Every individual needs to find their own way of coping with freezing. It’s important to find out what is best

“If you have difficulty getting through doorways, it can be helpful to paint a brightly coloured line (or stick securely a strip of contrasting carpet) across the opening. This seems to encourage me to lift my feet. Obviously this is only appropriate in your own home. I doubt that friends, hotels or restaurants would appreciate the gesture!”

Annebernadette,
Parkinson's UK online
forum user

for you and not to let worrying about freezing stop you doing anything you enjoy. Worry makes you more likely to freeze. Remember, 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

There are a wide range of techniques that use a 'cue' to trigger your movement once you've frozen. We've listed some methods below that have been recommended by occupational therapists and physiotherapists with experience of working with people with Parkinson's.

Try a few things to find out which method or methods work best for you. Different methods may work in different situations. Once you've found what suits you best, you'll be able to use your method or strategy to restart walking or swallow food and drink, if this doesn't happen automatically. You may even find ways to reduce or avoid freezing altogether. Unfortunately, a 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 may reduce any worries you may have when it happens.

As Parkinson's develops, methods you normally use to manage freezing might not work as well. If this happens, you should try other cues and methods to find something that works for you.

If a movement is not flowing well, making the effort to think about each separate part of a familiar or simple movement can help.

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

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. This reduces the risk of falling and gives you time to refocus on balance, think about your next move and prepare your body to start again.

You could try the following method when you freeze:

- 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 – so you may like to try some of the ideas below:

- Walk on the spot to keep the stepping rhythm going, when you stop to open a door, for example.
- Decide after freezing and pausing 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 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 that is used by musicians. It produces a regular tick or beat that helps them to keep to a rhythm. You can find them easily by doing an online search or checking in a musical instrument shop. Check you can operate 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 that are used 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 imagine standing 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 tend to freeze often in the same places at home and the methods we’ve mentioned in this information sheet don’t work, you could try using floor strips to help overcoming freezing trouble spots. These are made using strips of tape stuck to the floor. 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. The way to do this is explained below.

- Take some sticky tape, such as masking or duct 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 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 you notice that 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, eg 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. You could also try stepping over the up-turned handle end of a walking stick, umbrella or 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.

To do this:

- step to one side, out of the main flow of other people, and if possible touch something solid like a wall to aid your balance and look at the area ahead of you
- check for anything in the way, such as boxes, children, benches, street lights or trolleys
- decide the exact route you will take for as far as you can see or want to go before walking to that point
- repeat this method of 'pause, look, plan and walk' as often as you need to

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 also 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 also 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

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 Nin Bajaj, Consultant Neurologist

Sophia Hulbert, Research Fellow and Clinical Physiotherapist

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/information-support. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at parkinsons.org.uk/ordering-resources 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

We're the Parkinson's charity that drives better care, treatments and quality of life.

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

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk



Order code: PKFS63
Last updated November 2015. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.

©Parkinson's UK. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).

Freezing in Parkinson's (2015)

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 **Editorial and Creative Services, 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

Have you found the publication easy to read/use? Yes No

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

- NA It hasn't helped It has helped a little It has helped a lot

What aspects did you find most helpful?

.....

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

.....

Do you have any other comments?

.....

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/Asian British Black/Black British White

- Mixed/multiple ethnic backgrounds Other (please specify)