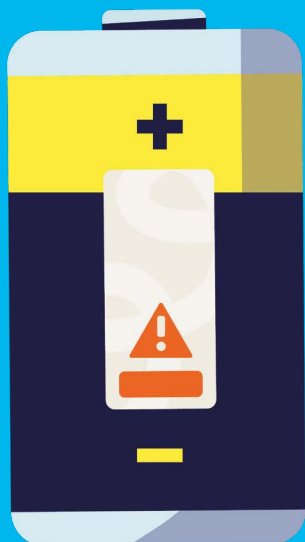


Fatigue in Parkinson's

Symptoms

Find out more about fatigue
in Parkinson's and ways to
help manage it



Fatigue in Parkinson's

Many people use the words fatigue and tiredness to mean the same thing, but they're not.

You can feel tired after things like exercising or a bad night's sleep, but tiredness usually goes away with rest.

Unlike tiredness, people can experience fatigue at any time, and it doesn't improve with rest.

What is fatigue?

Fatigue can be described as an overwhelming feeling of tiredness, exhaustion and a lack of energy. It's more than a one-off feeling of tiredness that goes away after a good sleep or nap.

Anyone can feel fatigued when they're working too hard, or when pressures at work or home make you stressed. But fatigue can also be a specific symptom of Parkinson's and other conditions.

Is fatigue common in Parkinson's?

Up to half of people with Parkinson's experience fatigue at some point.

The length of time that people have had Parkinson's doesn't seem to make much difference to their risk of experiencing fatigue. Fatigue may be one of the earliest symptoms you have, or it could appear after living with Parkinson's for a long time.

How does fatigue affect people with Parkinson's?

The effects of fatigue and Parkinson's vary from person to person. They can change day-to-day or even hour-to-hour.

You may feel quite fit and able one day and then too fatigued to do much the following day. This might be because things that came naturally before your diagnosis now take more effort.

If you're working, you may feel exhausted after you've finished work and you might not want to do anything else.

What causes fatigue in Parkinson's?

Many people with Parkinson's experience fatigue, but it's also common in people with other long-term health conditions. Researchers are working to uncover what causes fatigue in Parkinson's, as this is something we don't yet fully understand.

Fatigue in Parkinson's is thought to be linked to chemical changes that happen in the brain. It may also be related to other symptoms or features of the condition. Such as:

- the timing and dosage of your medication. This can mean that you feel energetic and capable of doing everyday jobs at certain times of the day, but not at other times
- tremor, stiffness or involuntary movements, which may put stress on your muscles. It means they work harder, often against each other, in order to move or complete a task and can become fatigued quickly
- slowness of movement (bradykinesia). If you experience this, tasks can take you longer to complete than they used to, leading to fatigue
- stress. Parkinson's and its symptoms can cause stress at work or home and this can make fatigue worse, particularly if stress builds up over a period of time

It's also important to remember that mental (cognitive) fatigue can be just as difficult to manage.

Mental fatigue is usually worse the more complex the activity or task is. Some people find it hard to concentrate for a long time without a break. This can cause problems if you are still in work.

Parkinson's is not the only health condition that causes fatigue. Thyroid problems, vitamin deficiencies, anaemia and diabetes can also cause it.

You should discuss any feelings of mental or physical fatigue with your GP, specialist or Parkinson's nurse.

Can fatigue be treated?

If your feelings of fatigue are related to other Parkinson's symptoms, such as tremor, stiffness or involuntary movements, Parkinson's medication might help.

However, sometimes Parkinson's drugs don't help with fatigue. There's currently not enough scientific evidence showing that Parkinson's medication is an effective treatment for fatigue on its own.

But Parkinson's drugs can help you manage your other symptoms, so you might feel you have more energy to do things that might otherwise be difficult.

Also, remember that fatigue might not be related to your Parkinson's, but could be caused by another health condition, such as a thyroid problem.

In some cases, non-drug treatments can help you manage your fatigue.

One example is cognitive behavioural therapy (CBT), which is a type of talking therapy.

CBT can help you manage fatigue practically by helping you to focus on what's causing it and how it impacts you.

Fatigue is often related to sleep disturbance or depression. If this is the case, other medications may help. Your GP, specialist or Parkinson's nurse will be able to discuss options that might work for you.

What can I do about fatigue?

Fatigue can be made worse by doing too little or trying to do too much.

Spreading out or 'pacing' your activities (both physical and mental) is a useful way to manage the problem. People who try to fit everything into a short period of time tend to 'crash' afterwards, making their fatigue worse.

Other people avoid activity to stop themselves becoming fatigued, but this also seems to make fatigue worse over time.

Stress can make fatigue worse too. Anything that you can do to manage your stress levels is likely to have a positive effect on your fatigue.

Practically this means that there are a number of things you can do yourself to try to avoid fatigue or help minimise it.

An occupational therapist can suggest ways to manage fatigue at work and at home, and advise on adaptations and equipment that can help.

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

At work

If you're working, it might not be easy to rearrange your daily tasks. Instead, try to take regular, short breaks.

This can help your concentration and avoid fatigue building up.

A break can be something as simple as making a cup of tea, having a chat with a colleague, or sitting back for a few moments with your eyes closed.

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

Around the home

If you live with someone, it might be useful to divide household tasks, so that you do the jobs you can manage more easily.

There are also a number of gadgets and home adaptations that can help you make your daily life with Parkinson's easier. An occupational therapist can provide advice on this.

Physical activity and exercise

Exercise is good for people with Parkinson's, especially if you experience fatigue.

Fatigue can often trigger a cycle in which you become less and less active. This can happen if your daily activities make you feel tired. But the less you do, the weaker your muscles become, and the more fatigued you'll feel over time.

Exercise can help you manage your fatigue, boost your mood and help you sleep well. The more you can do the better. Find something that suits you at the right level and go for it. This could be as simple as chair-based exercises or a brisk walk that gets your heart rate up. To get started, a physiotherapist can recommend exercise that is right for you.

Exercise referral schemes may be organised in your local area through your GP, local council or sports centre. You can also be referred for physiotherapy by your GP, specialist or Parkinson's nurse.

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

Mental exercise

Fatigue is not just physical. Mental exercise is also important. Try to stay involved with your hobbies and interests.

If you have time during the day, try to do a variety of activities, as boredom can also lead to fatigue.

Diet

Eating a healthy, balanced diet is important, so try to make sure you're eating a variety of foods.

Some people find that a small snack every couple of hours provides them with a constant supply of glucose, which is used for energy and can help reduce feelings of tiredness in the short-term.

However, this strategy will not suit everyone, particularly people who have diabetes. It's a good idea to discuss any significant changes in your diet with your GP or Parkinson's nurse.

Sometimes, you might feel fatigued after a large midday meal. A short nap at this time may reduce the sense of fatigue. You could also try having a smaller, lighter meal at lunchtimes.

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

A poor diet can sometimes lead to constipation. Constipation is common in Parkinson's, and it can leave you feeling sluggish, which can make fatigue worse. Speak to your GP or Parkinson's nurse if you experience constipation, as they can help you manage it.

Find out more: see our information on looking after your bladder and bowels when you have Parkinson's.

Daily routine

It's important to do what you can, but try to pace yourself – don't ignore feelings of fatigue.

Try to perform as much of your daily routine as you can by yourself, but take a rest or get help when you think you need it.

If you're feeling fatigued, it may help to spread what you do over the course of your day rather than forcing too much into a short amount of time.

You might find that even after a good night's rest you're feeling more fatigued than usual. This may be due to having overworked the day before or it might simply be due to the way that your condition fluctuates.

Whatever the cause of fatigue, keep in mind that you will have days when you feel more energetic than others.

Remember, fatigue won't go away immediately or completely. However, with time you should be able to recognise what you can do and when you might have difficulty. You can then plan your time so that episodes of fatigue are manageable.

If you're on medication, you can also plan around the times when it works best.

Getting a good balance between rest and activity will help you handle fatigue and improve your quality of life.

Monitoring fatigue

Assessing your fatigue and what works for you can be really helpful.

Parkinson's UK has a non-motor symptoms questionnaire available, which can help you and your healthcare professional assess your symptoms, including fatigue.

Visit parkinsons.org.uk/professionals/resources/non-motor-symptomsquestionnaire-nmsq or call our helpline on **0808 800 0303**

You could also try keeping a diary to monitor your fatigue and work out how to manage it. Keeping a diary may help you to arrange to do more difficult daily tasks when you're feeling less tired.

Problems you may experience related to fatigue

Sleep and night-time problems

Many people with Parkinson's experience problems with sleep. You might wake up during the night because of tremor or stiffness, when you're having difficulty turning over in bed, or if you need to go to the toilet.

Waking during the night can leave you feeling tired and lethargic during the day, and it might mean you're not able to complete tasks so well. Poor sleep doesn't cause fatigue but it can make it worse.

Night-time problems will also make you feel sleepy during the day. Resting can help. However, frequent napping can make sleeping at night more difficult.

It's important that you find out the reasons for sleep and night-time problems, because many of them can be treated. Treating these problems can help you feel better during the day.

Understanding the causes of your fatigue can also help you to develop good sleeping habits that give you more energy overall.

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

Depression

Many people with Parkinson's experience depression, even if they're not formally diagnosed with it.

Depression involves more than just feeling 'down' for a short while. If you're depressed, you might experience a range of symptoms for long periods of time.

It's common for people with depression to experience fatigue, and depression can make fatigue worse. However, not everyone with fatigue feels depressed.

If you're diagnosed with depression, there are effective treatments available. They might involve a combination of medication, talking therapies or counselling.

If you have fatigue and you're concerned about depression, speak to your GP or Parkinson's nurse for advice. They can refer you to a mental health specialist if needed.

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

Apathy

Apathy can be described as a lack of enthusiasm and emotion for everyday activities. Apathy can feel a lot like depression and fatigue. You may find you lose interest in activities that you previously enjoyed.

Like depression, apathy needs to be diagnosed so it can be treated. Speak to your GP, Parkinson's nurse or specialist if you think you may be experiencing apathy.

Your rights at work if you experience fatigue

The Equality Act 2010 (England, Scotland and Wales) states that employers must make reasonable adjustments for people with disabilities.

These could include flexible or reduced hours, or allowing for a little extra rest, either at a regular time each day or whenever necessary.

There is similar equality legislation in Northern Ireland.

If you're a member of a trade union, they should be able to negotiate on your behalf to ask your employer to make reasonable adjustments. They should also be able to advise on other disability discrimination issues.

If fatigue or any other symptoms of Parkinson's have an impact on your daily life, you may be entitled to some benefits, such as Personal Independence Payment (PIP), or Adult Disability Payment (ADP) in Scotland. This can be paid to people who are in work, as well as to people who are not.

If you have any questions about your rights under The Equality Act 2010, or you would like to speak to someone about welfare benefits, call our free confidential helpline on **0808 800 0303**

Driving

Feeling fatigued or excessively tired can affect your driving. You must tell the DVLA (DVA in Northern Ireland) if you have a medical condition that affects your driving. If you do not you can be fined up to £1,000.

We advise people who are newly diagnosed with Parkinson's to tell the DVLA (DVA in Northern Ireland) as soon as possible, even if their symptoms are mild.

Having Parkinson's doesn't necessarily mean you have to stop driving. The DVLA (DVA in Northern Ireland) will ask for more information about your condition and assess if it's safe for you to continue driving.

For more information, visit **gov.uk/parkinsons-disease-and-driving** or call **0300 790 6806**

For Northern Ireland, visit **nidirect.gov.uk/articles/how-tell-dva-about-medical-condition** or call **0300 200 7861**

You can also speak to your GP, specialist or Parkinson's nurse for advice.

More information and support

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's. They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics.

Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's.

Get help managing your diagnosis. Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

Read our up to date, reliable health information. Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

Find ways to get active, stay active and live well with Parkinson's. Whatever your fitness level, we'll help you find the right activities for you.

Connect with other people with Parkinson's, families, friends and carers. Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

Find out more

- Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** to speak to an expert adviser.
- Visit **parkinsons.org.uk/information-and-support** to read our information or find support that's local to you.
- Call **0330 124 3250** or visit **parkinsons.org.uk/order-print-booklets** to order free printed information.

Thank you

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

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

All of our information is checked by experts and other people with Parkinson's, so you know it's information you can trust.

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at Parkinson's UK, 50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our information together or be part of the team that reviews our health content, please contact us at **healthcontent@parkinsons.org.uk** or visit our website at **parkinsons.org.uk/health-content**.

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 Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**.

Thank you.

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We're Parkinson's UK,
the charity that's
here to support every
Parkinson's journey.
Every step of the way.

Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm,
Saturday 10am to 2pm (interpreting available)
Relay UK **18001 0808 800 0303** (for textphone users only)
hello@parkinsons.org.uk | parkinsons.org.uk

Parkinson's UK, 50 Broadway, London SW1H 0DB



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