

Fatigue and Parkinson's

Many people use the words fatigue and tiredness to mean the same thing but they are separate. You can feel tired after many things like exercise, a bad night's sleep or mental effort. Tiredness usually goes away with rest. However, fatigue happens without the effort of any activity and does not improve with rest.

What is fatigue?

Fatigue has been described as an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion. It is more than a one-off feeling of tiredness that will go away after sleeping well.

Anyone can feel fatigued when they are working too hard, or when pressures at work or at home cause stress. But fatigue can also be a specific symptom of a medical condition such as Parkinson's.

Is fatigue common in Parkinson's?

Up to half of people with Parkinson's say they experience fatigue.

People who are newly diagnosed with Parkinson's are just as likely to experience fatigue as those who have had the condition for some time. In fact, it may be one of the earliest symptoms you have.

How does fatigue affect people with Parkinson's?

The effects of fatigue and Parkinson's vary from person to person. They can change from 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 are working for example, you may feel much more exhausted in the evenings than you used to and you may not want to do anything else.

What causes fatigue in Parkinson's?

Many people with Parkinson's experience fatigue but it's common in people with other long-term physical health conditions too. We don't yet fully understand what causes it in Parkinson's but it may be because of chemical changes in the brain.

Fatigue in Parkinson's can also be related to other symptoms of the condition.

- For example, you may feel energetic and capable of doing everyday jobs at certain times of the day, but not at others. This may sometimes be related to the timing and dosage of your medication.
- Tremor, stiffness or involuntary movements that some people with Parkinson's experience 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.
- If you experience slowness of movement (bradykinesia), tasks will take you longer to complete than they used to, leading to fatigue.
- Parkinson's and its symptoms can cause stress at work or home and this can make fatigue worse. This is particularly true if stress builds up over time.

It's also important to remember that mental fatigue can be just as difficult to manage. Some people may find it hard to concentrate for a long time without a break. For example, this may cause problems if you are still in work.

Although it's natural to associate any health problems with Parkinson's, there are other causes of fatigue that are unrelated. These may include treatable conditions such as thyroid problems, vitamin deficiencies, anaemia and diabetes.

Because of this, you should discuss any feelings of fatigue with your GP, specialist or Parkinson's nurse. Together, you can look at the possible cause and discuss treatment options.

Can fatigue be treated?

Fatigue can sometimes be overlooked by doctors, but it's important that it is managed properly.

If your feelings of fatigue are related to other Parkinson's symptoms, such as tremor, stiffness or involuntary movements, they may be helped with Parkinson's medication. This will also help you manage your symptoms better, so you have more energy to do things that may otherwise be difficult.

However, remember that fatigue in Parkinson's may not be related simply to these symptoms.

Also, Parkinson's medication is not always successful at treating fatigue. In some cases, non-drug treatments may work better. One example is cognitive behavioural therapy (CBT) which is a type of talking therapy. This can help you manage fatigue practically by focusing on what is causing it and its impact.

Fatigue can often be related to more complex difficulties such as sleep disturbance or depression. If this is the case, other specific medication 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 activity (both physical and mental) is an important way to manage the problem.

People who try to cram everything into a short period of time while they have the energy, tend to 'crash' afterwards, making their fatigue worse. Other people avoid activity to stop themselves becoming fatigued. However, this also seems to make fatigue worse over time.

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.

At work

If you are working, it may 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 employment and Parkinson's.

Around the home

If you live with someone, it may 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 expert advice on this.

Find out more: see our information on occupational therapy.

Physical 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.

Exercise can help you manage your fatigue, boost your mood and help you sleep well. The more you can do the more benefits you'll get. So find something that suits you at the right level and go for it. This could be as simple as chair-based exercise or a brisk walk that gets your heart rate up.

To get started, a physiotherapist can recommend exercise that is right for you. Also, exercise referral schemes may be organised in your local area through your GP, local council or sports centre.

Find out more about the benefits of exercise and the different types to focus on at [parkinsons.org.uk/exercise](https://www.parkinsons.org.uk/exercise)

Mental exercise

Fatigue is not just physical. Mental exercise is also important so try to stay involved with any 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 are 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 the feeling of tiredness in the short term.

It is also important to try not to become constipated (when stools are hard and difficult to pass), as this can make you feel sluggish. Ask your GP or Parkinson's nurse if you need help managing constipation.

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

Find out more: see our information on diet and 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 are 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 may find that even after a good night's rest you are feeling more fatigued than usual. This may be due to having overworked the day before or it may simply be due to the way your condition fluctuates. Whatever the cause, keep in mind that you will have days when you feel more energetic than others.

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

If you are on medication you can also plan around the times when it is most effective. Achieving a good balance between rest and activity will help you handle fatigue and improve your general quality of life.

Monitoring fatigue

Measuring fatigue accurately can be difficult as it is unique to each individual, so assessing your own fatigue and what works for you can be a good place to start.

We have a non-motor symptoms questionnaire available to help you and your healthcare professional assess symptoms such as fatigue.

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

Find out more: see our information on monitoring your Parkinson's

Problems you may experience relating to fatigue

Sleep and night-time problems

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

This can often leave you feeling tired and lethargic during the day and may mean you are not able to complete tasks so well. Poor sleep does not cause fatigue but may make it worse.

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

It is important that you find the reasons for sleep and night-time problems because many of them can be treated and that may help you feel better during the day.

Understanding the causes 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 are not formally diagnosed with it.

Depression involves more than just feeling 'down' for a short while. A person who is depressed can experience a range of symptoms, as well as low mood, for long periods of time.

It is common for people with depression to experience fatigue and depression may make fatigue worse. However, not everyone with fatigue feels depressed.

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

If you have fatigue and are concerned about depression, speak to your GP, specialist or Parkinson's nurse.

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

Apathy

Apathy is described as a lack of enthusiasm and emotion for everyday activities.

This can feel like depression and fatigue. You may find you lose interest in activities that you previously enjoyed.

Apathy, like depression, needs to be diagnosed so it can be treated. You may find it helpful to speak to a mental health specialist or counsellor about it.

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 times each day or whenever necessary. There is similar equality legislation in Northern Ireland.

If you are 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. 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**.

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:

Richard Brown, Professor of Neuropsychology, Institute of Psychiatry, King's College London

Lee Kieft, Parkinson's Nurse, Queen Elizabeth Hospital NHS Trust

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**

Fatigue and Parkinson's (FS72/2017)

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

If you've answered yes to any of these options, please complete your details below.

Name

Address

Email

Telephone

How would you prefer us to contact you? Email Post Phone

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](https://www.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



Last updated December 2017. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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