

Anxiety and Parkinson's

Some people with Parkinson's may experience anxiety. This information sheet describes what anxiety is and how it can make you feel. It also looks at steps you can take to help manage your symptoms, and what treatments are available.

What is anxiety?

Anxiety is a feeling of unease, such as worry or fear. Everyone has feelings of anxiety from time to time. It is a natural reaction to situations we find threatening or difficult, such as moving house or money problems. Usually anxiety disappears when the situation changes, or if we get used to the situation or can move away from it. But some people become anxious for long periods of time and for no clear reason. This can make life difficult and may affect your work and social life.

If you feel anxiety is affecting your daily life, it's important to seek help from professionals as well as finding things you can do to manage your symptoms effectively.

What are the main symptoms of anxiety?

It is important to be able to recognise the symptoms of anxiety, so it can be treated as soon as possible.

People with anxiety may experience some of the following:

- a sense of dread
- constant worry
- difficulty concentrating

You may also experience physical symptoms if you're feeling anxious. Symptoms may include:

- sweating
- pounding or racing heart (palpitations)
- feeling breathless

- dizziness
- trembling
- indigestion
- nausea and stomach cramps
- a pale face and dry mouth
- muscle pain
- restlessness

When anxiety and panic carry on for a long time you may experience feelings of hopelessness. These feelings may affect your ability to carry out everyday activities.

Sometimes, you may have symptoms of depression as well as anxiety. Depression is more than temporary feelings of unhappiness or frustration. It is usually diagnosed when someone has lasting feelings of extreme sadness for days, weeks or months.

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

Are there different types of anxiety?

There are three main types of anxiety, though these can overlap. Many people will experience more than one type.

Generalised anxiety disorder

This is when you experience excessive and uncontrollable worrying most of the time about every day events in your life.

Panic attacks

These are short periods of sudden, intense feelings of fear. They often happen in situations that are likely to make you feel anxious. You may also experience a racing heart, sweating and shortness of breath. Some people think these symptoms are a sign that they are going to die, and they rush to the hospital for help. A panic attack may last between five and 20 minutes.

Phobia

This is when you feel frightened of something that is not dangerous, and would not usually make other people feel scared. For example, agoraphobia is the fear of going out where there are other people around.

How does anxiety affect people with Parkinson's?

Anxiety may be related to changes in brain chemicals, which control and regulate your mood. Any concerns you have about living with a long-term condition may also cause anxiety.

Some people with Parkinson's have anxiety that happens when they are 'off'. When a person takes their medication, their symptoms will improve. But these symptoms can sometimes recur before the next dose is due, causing a person's condition to fluctuate. This is called 'wearing off'.

If you go 'off' and have difficulties moving, it can make you feel anxious or even cause a panic attack. It's not only mobility problems that can be affected by wearing off. Some people may also experience an 'off' period

“My husband is a laid-back person, but lately he suffers panic attacks when out of his comfort zone. He hates being in crowded places, such as noisy restaurants, and generally doesn't like being anywhere that he feels he can't get out of if he needs to.”

Jenniferchristine, from our online forum

with symptoms that are not related to movement, which can cause them to feel anxious.

You may find that when your movement symptoms are better controlled by medication, your anxiety improves. If your anxiety symptoms increase when your medication is wearing off before the next dose is due, talk to your specialist or Parkinson's nurse (if you have one). Changes to your medication regimen may improve your symptoms.

Even if you don't have 'on' and 'off' periods, you may still have generalised anxiety if your Parkinson's symptoms aren't properly treated. Again, changes to your medication may help.

Always speak to your specialist or Parkinson's nurse about any adjustments to Parkinson's medication. Remember, don't stop taking your medication without talking to a healthcare professional, as this can be dangerous.

How is anxiety treated?

In the majority of cases, anxiety can be treated. And there are different things you can try to help manage your symptoms.

Finding ways to relax

Simple measures such as making time to relax can be helpful. Try doing things you enjoy, such as reading a book or listening to some music.

Diet

Try to maintain a healthy, balanced diet. It can also help to avoid too much caffeine (found in tea, coffee and some fizzy drinks), and alcohol, especially late in the evening, as these can make some of the physical symptoms of anxiety worse.

Find out more: see our booklet *Diet and Parkinson's*.

Exercise

You can help combat stress and release anxiety through regular exercise, such as walking or swimming.

Complementary therapies

We hear from many people with Parkinson's who find complementary therapies relaxing.

Types of therapy include:

Yoga

Yoga is a gentle exercise that aims to improve flexibility, strength, balance and breathing. There is some evidence that yoga could help with anxiety and stress.

Massage

Many people find that having a massage helps them to relax. A massage therapist may use various techniques, including stroking, kneading and rubbing, to manipulate the body using pressure. It is not suitable for people with certain medical conditions, such as a history of bleeding disorders.

“ I had some mild anxiety after breakfast so cut out my morning cup of coffee. It has helped somewhat. I don't experience the feeling well up in me like I used to.”

Sheryll, from our online forum

Acupuncture

Acupuncture is part of traditional Chinese medicine. It involves a therapist inserting thin needles at particular points on your body. Although the evidence that acupuncture can reduce anxiety is mixed, some people may find it helpful.

T'ai chi

T'ai chi is a Chinese martial art that puts emphasis on balance and movement. It involves moving the body slowly and gently – there's no physical contact. There is not enough evidence yet to say that it reduces anxiety but it may have psychological benefits.

If you want to take anything by mouth or apply it to your skin as a complementary therapy, check with your GP, specialist or Parkinson's nurse first.

Find out more: see our booklet *Complementary therapies and Parkinson's*.

There may be relaxation classes in your local area. Your local Parkinson's UK information and support worker may have details of these. See page 6 for contact details. Some Parkinson's UK local groups also offer these types of classes. Visit parkinsons.org.uk/localgroups for details of your local group or contact our helpline (0808 800 0303).

Friendships and meeting others

Sharing your worries and fears with a trusted friend or family member can help reduce anxiety. Talking to other people with Parkinson's can also help, as you share your experiences and find out how others cope with similar problems. Parkinson's UK has local groups across the UK. Visit parkinsons.org.uk/localgroups to find your nearest group or call **0808 800 0303**.

You can also talk to other people with Parkinson's online at parkinsons.org.uk/forum, or be put in touch with someone who has been similarly affected through the peer support service – see page 6 for details.

Counselling

If you prefer to speak to a professionally trained counsellor, ask your GP for information (many surgeries have counsellors attached to their practice). There are also counselling organisations that can give you information and details of private counsellors, including the British Association for Counselling and Psychotherapy (see page 6 for contact details).

The mental health charity Mind has a guide, *Making Sense of Talking Therapies*. The booklet explains the different types of talking therapies available, including counselling, how they can help and what they involve. You can read the guide for free online at www.shop.mind.org.uk/shop/booklets/515 or order a hardcopy for a small charge. Contact details can be found on page 7.

Cognitive behavioural therapy (CBT)

You may find cognitive behavioural therapy (sometimes called 'talking' therapy) effective in dealing with anxiety. It works by changing 'unhelpful' everyday thoughts and behaviours that can lead to feelings of anxiety or make anxiety worse.

CBT can take place in groups or individually with a therapist, who may be a clinical psychologist, psychiatrist or specially trained nurse. It usually involves a course of weekly sessions.

“ I find any activity or hobby can help me unwind by taking my mind off things.” ”

Hugh, diagnosed in 2007

You can also find CBT courses online, such as 'FearFighter', which may be available through your GP. Talk to your GP or Parkinson's nurse for advice, or visit www.fearfighter.com

There are a number of self-help CBT books that are recommended by the NHS for people with anxiety. Many of these are available at your local library via the 'Books on Prescription' scheme. Again, ask your GP or Parkinson's nurse for more advice or visit www.booksonprescription.org.uk

Medication for anxiety

There is no evidence to suggest that the symptoms of anxiety in people with Parkinson's can be treated effectively with medication, additional to those you take for Parkinson's. But your GP or specialist may discuss this option if severe anxiety is affecting the quality of your day-to-day life.

The most common medications used to treat anxiety in these circumstances are antidepressants. These may improve both anxiety and depressive symptoms. There are other types of medication available for anxiety, so speak to your GP, specialist or Parkinson's nurse about what may be best for you. They should also be able to advise you on how to take antidepressants alongside your Parkinson's medication.

Advice for family, friends and carers

Anxiety symptoms can significantly affect someone's quality of life. If this happens, you should try to encourage the person affected to speak to their GP, specialist or Parkinson's nurse. They may be referred to a mental health specialist who can recommend treatment.

If you are a carer, it's completely natural for you to feel many of the same feelings as the person with Parkinson's. These feelings may include anxiety, fear about the future, depression, fatigue and concern about any changes in your relationship.

With this in mind, you should also try to look after your own physical and mental health as much as you can. Taking care of yourself can be difficult, but it is important. It will also help you be better able to care for your loved one.

Many carers find it helpful to join a support group where they can meet other people in a similar situation. Many Parkinson's UK local groups have special activities for carers. Visit parkinsons.org.uk/localgroups for details of your local group or contact our helpline (0808 800 0303). Carers UK and the Princess Royal Trust for Carers also run groups for carers. See page 7 for contact details.

Find out more: see our booklet *The carer's guide*.

“Anxiety stopped me in my tracks last year. I had sessions of cognitive behaviour therapy, and while it didn't 'cure' my anxiety it certainly helped me to recognise the symptoms of an attack.”

Djemm, from our online forum

More information and support

Useful contacts

Anxiety UK

0844 477 5774
info@anxietyuk.org.uk
www.anxietyuk.org.uk

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

www.babcp.com

Carers UK

Carers UK provides information and support to people who are caring at home. The charity has support groups, branches and local offices throughout the UK.

0808 808 7777
advice@carersuk.org
www.carersuk.org

Mind

0300 123 3393
info@mind.org.uk
www.mind.org.uk

No panic

This charity offers telephone mentoring and recovery groups for people suffering from anxiety disorders.

0800 138 8889
www.nopanic.org.uk

Northern Ireland Association for Mental Health

028 9032 8474
www.niamh.co.uk

The Princess Royal Trust for Carers

This charity provides support, information and centres for carers throughout the UK and most centres run carers' groups.

London Office 0844 800 4361
Glasgow Office 0141 221 5066
Cardiff Office 02920 090 087
info@carers.org
www.carers.org

Royal College of Psychiatrists

For mental health resources and information.

www.rcpsych.ac.uk

Scottish Association for Mental Health

0141 530 1000
enquire@samh.org.uk
www.samh.org.uk

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:

John Hindle, Consultant Physician, Llandudno Hospital, Llandudno, Conwy

Linda Prendergast, Parkinson's Disease Nurse Specialist, Stafford Hospital, Stafford

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**



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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 **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
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- 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 or Asian British Black or Black British Chinese Mixed White British White other Other (please specify)

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 March 2015. 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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