

Depression and Parkinson's

It is common for people with Parkinson's to get depression but not everyone with the condition will experience it. With the right help, support and treatment, you can overcome depression and enjoy a good quality of life.

What is depression?

Depression is usually diagnosed when someone has feelings of extreme sadness or a sense of emotional 'emptiness' for a long time. It's more than temporary feelings of sadness, unhappiness or frustration. These feelings may affect someone's ability to carry out day-to-day activities.

A person who is depressed will typically have one or more of these symptoms:

- Lack of interest in, or pleasure from, usual activities.
- Feeling down or hopeless nearly every day.
- Feeling anxious or experiencing feelings of constant worry and fear.

It's rare to experience all of the following symptoms, but if you're depressed you might also have:

- difficulty concentrating
- low energy and tiredness
- trouble sleeping (waking in the early hours of the morning can be a typical sign) or excessive sleeping
- a loss of appetite, usually connected with weight loss
- increased appetite and weight gain
- feeling worthless or guilty
- in severe cases, thoughts of death, suicidal ideas and thoughts of self-harm

Like any illness, depression can affect anyone at any time. It is no one's fault, and it is not a sign of weakness.

Do I have depression?

Some of the symptoms of depression are also common in Parkinson's, which means it is often difficult to diagnose.

For example, many people with Parkinson's experience sleep and night-time problems. These difficulties will probably make you feel tired and lacking in energy, but they don't necessarily mean you're depressed.

Fatigue, which is an overwhelming sense of tiredness, can also be a symptom of both Parkinson's and depression.

You may experience ups and downs in your mood because of the changing nature of your Parkinson's symptoms throughout the day. These changes in mood aren't necessarily a sign of depression.

In some cases, these feelings may be related to changes in your Parkinson's medication.

With this in mind, if you think you may be depressed it's very important to speak to your GP or specialist. They can make an accurate diagnosis and discuss your medication with you.

Severe depression may result in suicidal thoughts or plans. It may also disrupt a person's sense of reality or make it much harder for them to function on a day-to-day basis.

This requires very specific treatment by a mental health specialist. Speak to your GP, specialist or Parkinson's nurse if you have any concerns.

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

What causes depression in people with Parkinson's?

We don't know for sure why people with Parkinson's get depression. There are several possible explanations.

Some research has suggested that a lack of the chemical dopamine, which causes the symptoms of Parkinson's, can be a trigger for depression, worry and anxiety.

Depression can be related to genetics, so if you have a family history of depression, you are more likely to experience depression yourself.

Being diagnosed with Parkinson's can be very stressful and upsetting for many reasons and the condition can have an impact on every aspect of life. So it's completely understandable that you might sometimes experience feelings of depression because of Parkinson's.

For example, as Parkinson's symptoms progress, some people may find that they have to reduce certain activities like socialising. This could lead to loneliness and isolation, which may increase the risk of depression.

In some cases people have experienced depression months before they notice any Parkinson's symptoms.

Depression can also be part of non-motor fluctuations. This links to the effect of levodopa 'wearing off' before the next dose is due. This type of depressed mood or anxiety usually gets better after the next dose of levodopa starts working.

Apathy

Apathy is being increasingly recognised in Parkinson's.

It is described as a lack of enthusiasm and emotion for everyday activities. This can feel like depression. Unlike depression though, apathy is not linked to low self-esteem or a negative outlook on the future.

So just because you experience apathy, it doesn't mean you have depression.

Apathy needs to be diagnosed so it can be treated. A mental health specialist or counsellor will be able to provide you with the best advice.

How can I get help for my depression?

Treating Parkinson's symptoms to help your depression

The first step is to talk to your GP, specialist or Parkinson's nurse to make sure your Parkinson's drugs are working well. It is important that your treatment is tailored specifically to you.

Treatment will depend on how severe your symptoms are and what has helped in the past. Treatments should be introduced step by step, starting with the simplest self-help measures. After your Parkinson's medication is adjusted appropriately, depression may be treated.

There is some limited evidence to suggest that some dopamine agonists – for example, bromocriptine or pramipexole (Mirapexin) – may improve a person's mood as well as any mobility problems. But there can be side effects, so this treatment might not be an option for everyone.

What can I do about depression to help myself?

Although you should get advice from mental health professionals about depression, there are a number of things you can do that may help improve your mood.

One recommended way of helping mild depression is to understand it better.

Try contacting the organisations in our useful contacts section. Some produce guides or recommend books about how you can help yourself to manage depression. Others offer helpline services where you can talk to someone about your feelings or how to find help.

Other types of self-help include:

Exercise – Exercise is good for you if you have Parkinson's and it can be as important as your medication in helping you manage symptoms. In fact, research has shown that exercising two to three times a week, especially as part of a group, can help with depression. It can also boost your mood and help you sleep well.

So find something that suits you 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 different types to focus on at parkinsons.org.uk/exercise

Sleep – To help improve the amount and quality of your sleep, make sure your bedroom is quiet and comfortable, and go to bed at the same time each night.

Relaxation – You may find relaxation therapies such as aromatherapy useful, although there is limited evidence that they can help with depression.

You could try complementary therapies such as massage, exercises such as tai chi or yoga, or meditation.

Self-help computer programmes – Some GPs provide access to computerised cognitive behavioural therapy courses. You will go through the same type of session as you would if you were with a therapist.

Beating the Blues is a commonly used one. There is also an online course, MoodGYM, which you may find helpful.

If you are interested in any of these activities then speak to your GP about what may be suitable for you and about getting a referral.

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

Treatment and therapies for depression

If self-help measures do not improve your symptoms, or if your depression is severe, your GP may recommend a course of talking therapy. This includes counselling and cognitive behavioural therapy.

Cognitive behavioural therapy (CBT)

For persistent or significant depression, group or individual therapy using cognitive behavioural techniques can be useful.

Cognitive behavioural therapy usually involves a course of weekly sessions. This is a therapy designed to change your emotions and lift depression. It looks at how you think about yourself, your environment and the people around you, and how these thoughts affect your mood and behaviour.

Your therapist will try to teach you new skills to help deal with negative thoughts and problems more effectively. They may use techniques including relaxation, distraction and goal setting.

Counselling

A professional counsellor can work with you to understand any underlying issues that may be contributing to your depression.

Counsellors may also be trained in other psychological therapies and could possibly apply different techniques.

It's always a good idea to ask about qualifications and experience before making decisions of who to get help from. Some GP practices have a counsellor, or your GP, specialist or nurse can refer you.

If you want to make your own enquiries about cognitive behaviour therapy or counselling services in your area, you could try contacting the British Psychological Society or the British Association for Counselling and Psychotherapy.

Antidepressants

Antidepressants are medications that can be used to treat moderate to severe depression. They may be prescribed alone, or alongside a course of talking therapy.

There are 3 main types of antidepressant, and they work by stimulating chemicals in the brain. If your GP or specialist thinks that antidepressants are right for you they can talk through your options.

It's important to remember that some antidepressants will be more suitable for you than others – it depends on your symptoms and what other medications you're taking.

Your specialist will also be able to advise you on how to take antidepressants alongside your Parkinson's medication. Taking antidepressants won't always improve your mood immediately, and it may take two to four weeks before you notice any change in your symptoms.

As with most medications, antidepressants can have side effects, but they are generally safe.

There is no evidence that antidepressants are addictive, although some people may experience symptoms, such as irritability or nausea, when they stop taking them.

You can speak to the professional prescribing your medication if you have any concerns about the potential side effects. They should also be able to advise you on how to take antidepressants alongside your Parkinson's medication.

It is very important that you take antidepressants as prescribed, even if you feel better.

Treatment should normally continue for six months after your symptoms improve, but may need to be for longer, depending on your health professional's advice.

There is no evidence of any long-term side effects from staying on antidepressants.

St John's Wort

Be aware that the herbal remedy St John's Wort, which can be used for depression, is not recommended for people with Parkinson's. This is because St John's Wort can interact with your Parkinson's drugs.

St John's Wort is also often mixed with other components to create different brands of the herbal remedy. This could increase the possibility of side effects and interactions.

What about support groups?

Some people find it useful to talk to others who may know how they feel because they have been in a similar situation.

People in support groups can offer understanding. They tend to share problems or experiences and can offer understanding based on what has helped them in the past, which you may find useful.

Parkinson's UK has local groups across the UK that offer friendship and support. Parkinson's UK can provide information on these local groups and how to contact them.

There is also 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.

Ring our free confidential helpline on **0808 800 0303** and they will match you with a peer support volunteer.

Advice for family, friends and carers

If you care for someone who has Parkinson's and depression you may want to think about support for yourself too.

It's important for family, friends and carers to recognise that the mood of someone with Parkinson's can negatively affect their own emotions.

If untreated, depression may continue for many years, so it's important to recognise it and get help.

Sometimes, a carer, or someone close to a person with Parkinson's, may recognise the symptoms of depression more clearly than the person themselves. If this is the case, they should talk about their concerns to the person with Parkinson's' GP, specialist or Parkinson's nurse.

It is also quite normal for a carer to feel many of the same feelings as the person with Parkinson's. These feelings may include difficulty accepting the diagnosis, fear about the future, anxiety, depression, and fatigue.

They might also experience confusion about the changes to their role and the relationship with the person they care for.

Because of this carers should also try to look after their physical and mental health as much as they can, which can help them maintain their caring role.

This can be difficult, but it is important to remember that by taking care of their own health they will be better able to care for the person with Parkinson's and not burn out.

Many carers find it helpful to join a support group where they can meet other people in a similar situation – Carers UK and the Princess Royal Trust for Carers both run groups for carers.

Find out more: see our information about caring for someone with Parkinson's.

Useful contacts for depression

Samaritans

If you need someone to talk to, the Samaritans provides a place for you to explore your feelings in confidence and without prejudice.

The charity offers services by phone, face to face, email and by letter.

UK and ROI 116 123

jo@samaritans.org

www.samaritans.org

Mental Health Foundation

This charity produces a range of information booklets and podcasts on mental health problems including depression.

020 7803 1100

www.mentalhealth.org.uk

Mind

Mind is a leading mental health organisation serving people in England and Wales. The charity provides support and advice on all kinds of mental health problems, including depression. It has a range of publications and local support groups.

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

Scottish Association for Mental Health

For people living in Scotland, the Scottish Association for Mental Health can provide information and support.

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

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
info@carersuk.org
www.carersuk.org

Carers Trust

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

London Office 0300 772 9600
Glasgow Office 0300 123 2008
Cardiff Office 0292 009 0087
info@carers.org
www.carers.org

Breathing Space

A free, confidential phone and web-based service for people (especially young men) in Scotland experiencing low mood, depression or anxiety.

0800 838 587
www.breathingspacescotland.co.uk

British Psychological Society

Contact the society or use its website to find a clinical or counselling psychologist in your area.

0116 254 9568
enquiries@bps.org.uk
www.bps.org.uk

British Association for Counselling and Psychotherapy

You can find contact details for local counsellors and psychotherapists on their website.

01455 883300
Text 01455 560606
www.bacp.co.uk

Aware Defeat Depression

This charity provides support to people living with depression in Northern Ireland.

Derry/Londonderry 028 7126 0602

Belfast 028 9035 7820

help@aware-ni.org

www.aware-ni.org

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:

K Ray Chaudhuri, Professor of Movement Disorders, Kings College Hospital

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**

Depression and Parkinson's (FS56/2017)

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

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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