Depression and Parkinson’s

Some people with Parkinson’s may be affected by depression during the course of their condition.

This information sheet explains what the symptoms of depression are and some of the potential causes. It also describes how depression can be treated and gives details of where to find more information and advice.

What is depression?
Depression is an illness that is usually diagnosed when someone has lasting feelings of extreme sadness for days, weeks or months. Some people experience a sense of emotional ‘emptiness’, rather than sadness, though. These feelings may affect someone’s ability to carry out day-to-day activities.

Depression is more than temporary feelings of unhappiness or frustration. A person who is depressed will typically have one or both of the following two symptoms:

- lack of interest in, or pleasure from, usual activities
- feeling down or hopeless nearly every day

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

- difficulty concentrating
- low energy and tiredness
- trouble sleeping (waking in the early hours of the morning can be a classic sign) or excessive sleeping
- a loss of appetite, usually connected with weight loss, but sometimes also increased appetite and weight gain
I have not suffered from serious depression, but I have certainly experienced the desire to just do nothing and to sink into apathy.

Caroline, diagnosed in 2003

- feeling worthless or guilty
- in severe cases, thoughts of death, suicidal ideas and thoughts of self-harm

For more information, see the NHS website
www.nhs.uk/conditions/depression

People who suffer from depression may also suffer from anxiety.

**Find out more:** see our information sheet *Anxiety and Parkinson’s.*

**Do I have depression?**

Some of the symptoms of depression are also common in Parkinson’s. 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.

**Find out more:** see our information sheet *Sleep and night-time problems in Parkinson’s.*

Fatigue, which can be described as an overwhelming sense of tiredness, can also be a symptom of both Parkinson’s and depression.

**Find out more:** see our information sheet *Fatigue and Parkinson’s.*

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 the above in mind, if you think you may be depressed it’s very important to speak to your GP or specialist. This will allow you to get an accurate diagnosis. You can also speak to your Parkinson’s nurse, if you have one. A Parkinson’s nurse is a qualified registered general nurse or registered mental health nurse with specialist experience, knowledge and skills in Parkinson’s. They play a vital role in the care of people with Parkinson’s. You can read more about them on page 7.

**What causes depression in 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.

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. As their Parkinson’s symptoms progress, some people may find that they have to give up certain activities that are important to them. This change in lifestyle may lead to sadness or depression. If Parkinson’s causes someone to stop socialising, this can lead to loneliness, which may increase the risk of depression.
How a person responds and reacts to the effects of their condition will probably depend on their personality, general attitudes and their life circumstances. But it’s completely understandable that some people will sometimes experience feelings of depression because of Parkinson’s. And in some cases people may have experienced depression months before they notice any Parkinson’s symptoms.

**Other causes of depression-like symptoms**

Whether you have Parkinson’s or not, depression could also be related to other physical conditions, such as thyroid problems, nutritional deficiencies (such as low vitamin B12 and folate levels) or anaemia. Speak to your GP, specialist or Parkinson’s nurse about any concerns.

It may also be possible that you are under-medicated for the physical symptoms of Parkinson’s – or depression could be a side effect of other drugs. Again, it is best to speak to your healthcare professional about this.

Alcohol can be a depressant, so drinking too much can cause low moods and affect your sleeping pattern.

Whatever the cause for your depression, it is important to try not to get too distressed about why you feel the way you do.

Depression, like any illness, can affect anyone at any time. It is no one’s fault, and it is not a sign of weakness. The important thing is that you speak to a healthcare professional about your feelings as soon as possible, so that an accurate diagnosis can be made and you can get the right treatment for you.

**What can be done about depression?**

Not a lot is known about treating depression in Parkinson’s, but there are some things you can try. It is important that your treatment is tailored specifically to you.

**Treating Parkinson’s symptoms**

The first step is to talk to your GP, specialist or Parkinson’s nurse to make sure your Parkinson’s drugs are working well.

There is some limited evidence to suggest that some dopamine agonists – eg 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.

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

**What can I do to help myself?**

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

One recommended way of helping with mild depression is to get a better understanding of it. Try contacting other organisations that provide information, such as those listed in the more information and support section on page 8. 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 self-help measures include:

**Exercise** – Research has shown that exercising two to three times a week, especially as part of a group, can help with depression. Swimming, walking and cycling are low-impact sports that can be done alone or with a friend.

**Find out more:** see our exercise DVD and booklet *Keeping moving*.

A structured physical activity programme may be useful. Exercise referral schemes may be organised in your local area through your local council or sports centre. Speak to your GP about getting a referral. Talk to your GP, specialist or Parkinson’s nurse about what may be suitable for you.

**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. Try not to eat or drink too much before going to sleep. Also try to have a regular routine for getting up in the morning. Smoking should be avoided, and regular exercise should help you sleep better.

**Find out more:** see our booklet *Sleep and night-time problems in Parkinson’s*.

**Relaxation** – You may find relaxation therapies helpful, although there is limited evidence that they can help with depression. You could try complementary therapies such as massage, exercises such as t’ai chi or yoga, or meditation tapes or classes.

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

**Self-help computer programmes** – Some GPs provide access to a computerised cognitive behavioural therapy course called ‘Beating the Blues’. There is also an online course that anyone with a computer and internet access can use, called ‘MoodGYM’ ([www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au))

See the more information and support section on page 8 for details of how to find more resources on depression.

**Talking therapies**
If self-help measures do not improve your symptoms, or if your depression is significant, 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 therapy or individual therapy using cognitive behavioural techniques can be useful.

This is a therapy designed to change your everyday thoughts and behaviour to help improve 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.

Cognitive behavioural therapists may be clinical psychologists, psychiatrists or specially trained nurses. Your therapist will try to teach you new skills to help deal with negative thoughts and problems more effectively. Techniques used include relaxation, distraction and goal setting. Cognitive behavioural therapy usually involves a course of weekly sessions.
Counselling
A professional counsellor can work with you to try 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 can refer you. Speak to your GP, specialist or Parkinson’s nurse for more information about the help available in your area.

If you want to make your own enquiries about cognitive behavioural therapy or counselling services in your area, you could try contacting the British Psychological Society or the British Association for Counselling and Psychotherapy. You can find their contact details on page 8.

Antidepressants
Antidepressants are not recommended for the routine treatment of mild depression, unless the above measures haven’t worked for you, or if your symptoms persist for at least two years.

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

There are three main types of antidepressant, and they work by stimulating chemicals in the brain. Some will be more suitable for you than others – it depends on your symptoms and what other medications you’re taking.

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 a variety of 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 long term, depending on your health professional’s advice. There is no evidence that there are any long-term side effects from staying on antidepressants.

Be aware that the herbal remedy St John’s Wort, which can be used for depression, is not recommended for people with Parkinson’s.

Severe depression may result in suicidal thoughts or plans, or may 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 psychiatry specialist. Speak to your GP, specialist or Parkinson’s nurse if you have any concerns.

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 tend to share problems or experiences and can offer understanding and good advice based on what has helped them in the past.
Parkinson’s UK has local groups across the UK that offer friendship and support. Visit parkinsons.org.uk/localgroups to find your nearest group. 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. The service is free and confidential – ring the helpline on 0800 800 0303 and they will match you with a peer support volunteer.

Other organisations that run support groups that might be helpful include Depression Alliance, Carers UK and Princess Royal Trust for Carers. Please see the More information and support section for contact details on page 6.

**Advice for family, friends and carers**

The effects of depression can spread beyond the individual, so it is important for family, friends and carers to recognise that their own emotions can be negatively affected by the mood of someone with Parkinson’s who is depressed. If untreated, depression may continue for many years, so it is important to recognise it and seek 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’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, fatigue and confusion about the changes in their role in your relationship.

For these reasons 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 all run groups for carers. See the More information and support sections for contact details on page 6.

**Find out more:** see our booklet *The carer’s guide.*
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 local information and support workers, 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 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.
Depression Alliance
This is the national organisation supporting anyone with depression and their families. They have groups throughout the UK for self-help and mutual support, and also offer a ‘pen friend’ scheme, for support by correspondence.
0845 123 2320
information@depressionalliance.org
www.depressionalliance.org

Action on Depression
This is a national charity working specifically with and for people affected by depression in Scotland.
0808 802 2020
info@actionondepression.org
www.actionondepression.org

Samaritans
If you need someone to talk to, the Samaritans provides a place for people to explore their feelings in confidence and without prejudice. The charity offers services by phone, face to face, email and by letter.
0845 790 9090
jo@samaritans.org
www.samaritans.org

Mental Health Foundation
This charity produces a range of information booklets on mental health problems including depression. Go to the website to listen a range of podcasts on topics such as relaxation and how to get a better night’s sleep.
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

Journeys
For people living in Wales, Journeys can provide information and support to people affected by depression, their friends, families and carers.
029 2069 2891
info@journeysonline.org.uk
www.journeysonline.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
advice-line@carersuk.org
www.carersuk.org

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

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 this 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.
08451 20 29 61
help@aware-ni.org
www.aware-ni.org

Resources on depression
There are some general books on depression, some of which you can find on the Depression Alliance website (www.depressionalliance.org). For further information about self-help for depression, see www.nhs.uk
Thank you
Thank you very much to everyone who contributed to or reviewed this information sheet:

Linda Prendergast, Parkinson's nurse

Iracema Leroi, Senior Lecturer and Honorary Consultant, Royal Blackburn Hospital and University of Manchester

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.
Depression and Parkinson's (2014)

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 Resources and Diversity, 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?

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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).................................................................
We’re the Parkinson’s support and research charity. Help us find a cure and improve life for everyone affected by Parkinson’s.

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 020 7932 1303 or visit our website at parkinsons.org.uk/support. Thank you.

Parkinson’s UK
Free* confidential helpline 0808 800 0303
Monday to Friday 9am–8pm, Saturday 10am–2pm. Interpreting available.
Text Relay 18001 0808 800 0303
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk
*calls are free from UK landlines and most mobile networks.

How to order our resources
0845 121 2354
resources@parkinsons.org.uk
Download them from our website at parkinsons.org.uk/publications

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this information sheet can be found in the Microsoft Word version at parkinsons.org.uk/publications

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