

# PARKINSON'S DEMENTIA

## Symptoms

Find out more about  
Parkinson's dementia  
and the practical  
support that can help



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# PARKINSON'S DEMENTIA

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Not everyone living with Parkinson's will develop dementia. But some people might after living with Parkinson's for a long time, or if they are diagnosed with Parkinson's in later life.

This information looks at the symptoms and causes of Parkinson's dementia. It also provides some practical advice for people living with the condition, as well as people who provide support or care for someone with Parkinson's dementia.

## What is dementia?

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The term dementia describes a group of symptoms that gradually get worse over time and affect daily life. Dementia symptoms happen because brain cells become damaged and eventually die.

Symptoms vary, but commonly involve problems with memory, thinking, mood and communication.

Parkinson's dementia is one form of dementia, but there are many different types. The most common is Alzheimer's.

Parkinson's dementia is very similar to another type of dementia, called dementia with Lewy bodies, and they share the same group of symptoms. They are the two main types of dementia that can affect people with Parkinson's.

**Find out more:**  
see our information  
on dementia with  
Lewy bodies.

## What are the symptoms?

The experience of dementia varies from person to person – not everyone is the same.

If you have dementia, you may find that symptoms fluctuate from hour to hour and day to day, and at times, especially in the early stages, they're so mild that they're hardly noticeable.

If you have Parkinson's dementia, you might experience the following:

### Memory and thinking problems

You may experience forgetfulness, slowed thinking and difficulty concentrating. You might find it harder to follow conversations, and remember some words and names.

You may also find it increasingly difficult to make decisions, plan activities and solve problems.

This can make everyday activities harder.

### Sleep disturbances

You might experience changes in your energy levels and sleeping patterns, so you could find yourself sleeping more during the day.

### Changes in appetite

You may find that your appetite changes. Feeling tired and a lack of activity during the day can mean you eat less. Changes in appetite can also be a sign of depression or anxiety, which are common in people with dementia.

### Mental health changes

You might find that at times you feel less engaged with what's going on around you. You may also lack interest in activities you used to enjoy (apathy).

You might experience anxiety, depression or agitation. You may have sudden outbursts of anger or distress, although this is not common.

You may have hallucinations where you see, hear or feel things that aren't really there. You may talk about things you believe that aren't based in reality (delusions). You might feel paranoid, although these thoughts may be irrational.

**Find out more:**  
see our information  
on hallucinations and  
delusions in Parkinson's.

If you haven't been diagnosed with dementia, but are worried about your symptoms, keep in mind that some of the symptoms of Parkinson's dementia are similar to those caused by other health conditions.

Side effects from medication, infections, thyroid problems, vitamin deficiencies, stress

and depression can cause symptoms similar to dementia.

## Mild memory and thinking problems

If you have Parkinson's but don't have Parkinson's dementia, you may still experience mild memory and thinking problems. This is common.

You might experience a slowness in thinking (bradyphrenia) which becomes worse when your Parkinson's medication isn't working at its best.

Parkinson's dementia is only diagnosed if your thinking and memory problems are serious enough to affect your ability to carry out everyday tasks.

If you're worried, speak to your GP, specialist or Parkinson's nurse.

**Find out more:**  
see our information  
on mild memory and  
thinking problems.

## What causes Parkinson's dementia?

We still don't fully understand why some people with Parkinson's get dementia and others don't, but there are factors that increase the risk.

The likelihood of developing most types of dementia increases with age, and this is true for people with and without Parkinson's. You're more likely to develop dementia if you're 65 or over, and your risk increases as you get older. A family history of dementia also increases your risk.

You're at a greater risk of Parkinson's dementia if you were diagnosed with Parkinson's in later life, or have been living with the condition for many years.

If you have hallucinations or delusions early on in your condition, this may mean you have an increased risk of developing Parkinson's dementia.

## How is Parkinson's dementia diagnosed?

There's no single test – diagnosis is made through several different assessments, usually starting with an appointment with your GP or Parkinson's nurse.

Some people find it helps to go to the appointment with someone who knows them well, who can give the GP or Parkinson's nurse information about changes they've noticed.

Your GP can discuss your symptoms with you and carry out a physical examination, including blood and urine tests, to rule out other potential causes of the symptoms (such as infections, thyroid problems and vitamin deficiencies).

Your GP may also review your medication, in case your symptoms are side effects.

If your GP thinks you have dementia, they can refer you to a specialist, such as a neurologist, psychiatrist or geriatrician. You might be referred to a memory clinic or memory service. In some areas of the country, you can refer yourself to these services.

The specialist will look at your medical history and carry out some pen-and-paper tests to assess your memory and thinking.

Your specialist might also arrange for brain scans, which can help to identify the cause of your symptoms.

Once a correct diagnosis is made, the specialist should discuss your treatment plan with you. You'll then normally be discharged back to the care of your GP. But if you feel you need to see the specialist again, you can ask to be referred back.

## What can be done to help?

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### Reviewing your medication

If you've been diagnosed with dementia, your specialist or Parkinson's nurse should look at what medication you're taking.

This is because some of the side effects of Parkinson's medication can make the symptoms of dementia worse. But reducing the dose or stopping these drugs may mean that the motor symptoms of your Parkinson's are not as well controlled as before. For this reason, treating the dementia symptoms needs to be balanced with managing physical symptoms.

### Dementia medication

You may be prescribed dementia drugs. This depends on the stage of dementia and your general health. If you're prescribed these drugs, you may be asked to do more

pen-and-paper tests of memory and thinking to see how your symptoms change.

The dementia medications used for Parkinson's dementia are the same as those used to treat Alzheimer's. They're called cholinesterase inhibitors. Some people find they help with their symptoms.

Very low doses of antipsychotics or neuroleptics might be prescribed to treat severe mood and behavioural symptoms, such as aggression. But doctors prescribe these drugs with extreme caution because they can cause serious side effects.

Speak to your GP, specialist or Parkinson's nurse for advice about medication.

### **Non-drug treatments and services**

Physiotherapy, speech therapy and occupational therapy may help you manage your symptoms.

Care and support services can also help you manage with your daily life.

Call our helpline on **0800 800 0303** to find out more or visit our website **[www.parkinsons.org.uk](http://www.parkinsons.org.uk)**

### **Planning ahead**

If you've been diagnosed with dementia, you might want to make some important decisions about your finances, your Will, and what sort of health and social care you'd like in the future.

You may also want to choose someone you trust to handle your affairs by setting up Power(s) of Attorney.

For more information and advice, contact the Office of the Public Guardian (England and Wales), the Office of Care and Protection (Northern Ireland) or the Office of the Public Guardian (Scotland).

Contact details are listed in the 'More information and support' section.

**Find out more:**

Parkinson's UK has information that can help you plan for the future. Contact our helpline on **0800 800 0303** or visit our website **www.parkinsons.org.uk**

## Supporting or caring for someone with dementia

### Accessing support services

People with dementia may eventually need more support and help with things like shopping, housework, cooking or personal care. Despite this, it's important they continue to use their existing strengths and skills for as long as possible.

If you regularly provide support or care for someone with dementia, you have a right to a 'carer's assessment'.

This is done through your local authority. After your assessment, if your local authority agrees you have needs, they will arrange services to help you. To find out more, contact your local authority or speak to your GP.

Parkinson's UK also has local advisers and local groups that can offer advice and support to anyone affected by Parkinson's and dementia. Go to **www.parkinsons.org.uk/information-and-support/local-groups** or contact our helpline on **0800 800 0303** for more details.

The Alzheimer's Society and Dementia UK's Admiral Nurses can also provide support. See the 'More information and support' section for contact details.

### Practical advice

If you're supporting or caring for someone with dementia, there are some practical things you can do to help reduce their agitation or confusion:



- Keep to a daily routine as much as you can to help them remember when certain things, like meal times, will happen
- Try to use familiar objects and phrases
- Avoid unfamiliar environments – these can be quite stressful and confusing
- Encourage someone with dementia to keep up with hobbies and keep engaging and interacting with people

### Helping with communication

Difficulties with communication can be upsetting and frustrating for the person with dementia. But there are some basic things you can do to make it easier.

The following information has been provided by the Alzheimer's Society. You can find this and more helpful advice on the Alzheimer's Society website. Visit **[www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

### General advice

- Listen carefully to what they say
- Make sure you have their full attention before you speak
- Pay attention to body language
- Speak clearly
- Consider whether any other factors are affecting their communication
- Use physical contact to reassure the person
- Show respect and keep in mind they have the same feelings and needs as they had before developing dementia

### Listening skills

- Try to listen carefully to what they're saying, and give plenty of encouragement
- If they have difficulty finding the right words or finishing a sentence, ask them to explain in a different way. Listen out for clues

- If you find their speech hard to understand, use what you know about them to interpret what they might be trying to say. But always check back with them to see if you're right – it can be very frustrating to have your sentence finished incorrectly by someone else
- If someone is feeling sad, let them express their feelings without trying to 'jolly them along'. Sometimes the best thing to do is to just listen, and show that you care

### Attracting the person's attention

- Try to catch and hold their attention before you start to communicate
- Make sure they can see you clearly
- Make eye contact. This will help them focus on you
- Try to minimise competing noises, such as the radio,

TV, or other people's conversation

### Using body language

- Just because someone has dementia it doesn't mean they can't read your body language
- Agitated movements or a tense facial expression can upset them, and can make communication more difficult
- Be calm and still while you communicate. This shows that you're giving them your full attention, and that you have time for them
- Never stand over someone to communicate – it can feel intimidating. Instead, drop below their eye level. This will help them feel more in control of the situation
- Standing too close to someone can also feel intimidating, so always respect their personal space

- If someone is struggling to speak, pick up cues from their body language. The expression on their face, and the way they hold themselves and move about, can give you clear signals about how they are feeling
- People with dementia can become frustrated if they can't find the answer to questions, and they may respond with irritation or even aggression. If you have to, ask questions one at a time, and phrase them in a way that allows for a 'yes' or 'no' answer

### Speaking clearly

- As the dementia progresses, people will become less able to start a conversation, so you may have to start taking the initiative
- Speak clearly and calmly. Avoid speaking sharply or raising your voice, as this may distress them even if they can't follow the sense of your words
- Use simple, short sentences
- Processing information will take someone longer than it used to, so allow enough time. If you try to hurry them, they may feel pressured
- Try not to ask the person to make complicated decisions. Too many choices can be confusing and frustrating
- If the person doesn't understand what you are saying, try getting the message across in a different way rather than simply repeating the same thing
- Humour can help to bring you closer together, and can relieve tension. Try to laugh together about misunderstandings and mistakes – it can help

## Whose reality?

- As dementia progresses, fact and fantasy can become confused. If someone says something you know isn't true, try to find ways around the situation rather than telling them what they think is wrong
- Always avoid making the person with dementia feel foolish in front of other people

## Physical contact

- Even when conversation becomes more difficult, being warm or affectionate can make the person with dementia feel supported
- Communicate your care and affection by the tone of your voice and the touch of your hand
- Don't underestimate the reassurance you can give by holding or patting their hand or putting your arm around them, if it feels right

## Show respect

- Make sure no one speaks down to the person with dementia or treats them like a child, even if they don't seem to understand what people say. No one likes being patronised
- Try to include them in conversations with others. You may find this easier if you adapt the way you say things slightly. Being included in social groups can help a person with dementia to keep their sense of identity. It also helps to protect them from feeling excluded or isolated
- If you are getting little response from someone with dementia, it can be very tempting to speak about them as if they weren't there. But disregarding them in this way can make them feel very cut off, frustrated and sad

## Other causes of communication difficulty

It's important to know that communication can be affected by things other than dementia. For example:

- pain, discomfort, illness or the side effects of medication. If you suspect this might be happening, talk to the person's GP as soon as you can
- problems with sight, hearing or ill-fitting dentures. Make sure the person's glasses are the correct prescription, that any hearing aids they have are working properly, and that their dentures fit well and are comfortable
- Parkinson's symptoms can cause difficulties with communication

## More information and support

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### The Alzheimer's Society

Information, advice and support for people with dementia and their families.

**0300 222 1122**

**enquiries@alzheimers.org.uk**

**www.alzheimers.org.uk**

### Dementia UK (Admiral Nurses)

Dementia specialist nurses.

**0800 888 6678**

**enquiries@dementiauk.org**

**www.dementiauk.org**

### Alzheimer's Research UK

Provides information about dementia research.

**0300 111 5111**

**enquiries@alzheimersresearchuk.org**

**www.alzheimersresearchuk.org**

### Alzheimer Scotland

Dementia organisation  
in Scotland.

**0808 808 3000**

**helpline@alzscot.org**

**www.alzscot.org**

### Office of the Public Guardian (England and Wales)

**0300 456 0300**

**customerservices@**

**publicguardian.gsi.gov.uk**

**www.direct.gov.uk/  
mentalcapacity**

### Office of Care and Protection (Northern Ireland)

**028 9072 4733**

**officeofcare&protection@**

**courtsni.gov.uk**

**www.courtsni.gov.uk**

### Office of the Public Guardian (Scotland)

**01324 678300**

**opg@scotcourts.gov.uk**

**www.publicguardian-  
scotland.gov.uk**

### Carers UK

**0808 808 7777**

**adviceline@carersuk.org**

**www.carersuk.org**

### 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

You can read our most up-to-date information at **parkinsons.org.uk**. You can order printed information by calling **0330 124 3250** or visiting **parkinsons.org.uk/orderingresources**

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can

find friendship and support through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

## 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.

## 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, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

### 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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Funded by you.  
Improving life for everyone  
affected by Parkinson's.  
Together we'll find a cure.

**PARKINSON'S<sup>UK</sup>**

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

Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ



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