

Dementia with Lewy bodies

This information explains what dementia with Lewy bodies is and describes some common symptoms.

It also provides practical advice for people living with dementia with Lewy bodies, and for those who support or care for someone with the condition.

What is dementia?

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.

There are many different types of dementia. The most common is Alzheimer's. Dementia with Lewy bodies is the third most common type, affecting at least 100,000 people in the UK.

What is dementia with Lewy bodies?

In this condition, there is an abnormal build-up of proteins in the brain. One of these proteins is called alpha-synuclein.

These proteins form small round clumps called Lewy bodies. They form within brain cells in areas of the brain that are involved in thinking, perception, memory and movement.

Dementia with Lewy bodies is very similar to Parkinson's dementia, and they share the same group of symptoms. Although many people with Parkinson's never develop dementia, Parkinson's dementia and dementia with Lewy bodies are the main two types that affect people with Parkinson's.

Find out more: [see our information on Parkinson's dementia.](#)

What are the symptoms?

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

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 dementia with Lewy bodies, you might experience the following:

- **Fluctuating attention and confusion**
You may swing from feeling alert to confused. You might stare into space, or have problems saying words in the right order. This can happen randomly, and last for varying amounts of time.
- **Sleep disturbances**
You may feel sleepy during the day and fall asleep suddenly. You might talk in your sleep or act out your dreams.
- **Mood changes**
You may find you have times where you feel down or depressed, or lose motivation or interest in activities you used to enjoy (apathy).
- **Hallucinations and delusions**
You might experience hallucinations, where you see, hear or feel things that aren't really there. It's common to see small children or animals. You may also talk about things you believe that aren't based in reality (delusions). You might feel paranoid, although these thoughts may be irrational.
- **Changes in visual perception**
You might have difficulties recognising objects and the spaces between them. You may find it hard to judge distances and movements. You might also misunderstand things you see, such as mistaking a pattern on a rug for an animal.
- **Memory, decision-making and planning problems**
You may have problems retrieving information from memory. You might take a long time finding an answer to a question, or recalling a word or name. You may also find it difficult to make decisions, plan activities or solve problems.
- **Parkinson's-like symptoms**
You might develop symptoms such as slowness of movement, stiffness and tremor. Other common

symptoms include dizzy spells and fainting. Sometimes blood pressure is affected. You might also experience constipation, incontinence and swallowing problems.

What causes dementia with Lewy bodies?

Researchers are working hard to uncover what causes Lewy bodies to develop within brain cells, as this is something we don't yet fully understand.

We do know that, like with most forms of dementia, increasing age is a risk factor for the condition. The older you are, the greater your risk of developing dementia with Lewy bodies - the condition is rare in people under 50.

How is dementia with Lewy bodies diagnosed?

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

Some people find it helps to go to the appointment with someone who knows them well, who can give the GP 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 has been 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?

Medication and other treatment options

There's no cure for dementia with Lewy bodies, but there are medications that can help with symptoms:

- **Cholinesterase inhibitors**

Research has found that drugs used to treat Alzheimer's, called cholinesterase inhibitors, can help with the symptoms of dementia with Lewy bodies. You might find these drugs help thinking, memory and attention problems. Some people find they help with hallucinations and delusions too.

- **Parkinson's medication**

You may benefit from taking Parkinson's drugs, especially if you have symptoms like stiffness or rigidity. But some side effects of Parkinson's drugs make dementia symptoms worse, especially confusion. Specialists should try to find a balance.

- **Antipsychotics**

Very low doses of these drugs might be prescribed if hallucinations and delusions are becoming a huge problem. But these drugs are prescribed with caution because they can cause serious side effects, including severe rigidity and immobility, which can be dangerous. About half of people with dementia with Lewy bodies react badly to antipsychotics.

- **Other treatment options**

Other medications might be prescribed to treat specific symptoms, such as sleep disturbance. It's always a good idea to speak to your GP or specialist about other options.

Non-drug treatments can also help manage symptoms, such as physiotherapy, speech therapy, occupational therapy, and care and support services.

Admiral nurses (dementia specialist nurses) can also provide support. For contact details, see the 'More information and support' section.

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 support and information' 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

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.

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.
- 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.
- 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

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 act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

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**.

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.

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.

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

Thank you

Thank you to everyone who contributed to or reviewed this information, including experts and people 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 **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/orderingresources** 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**



Dementia with Lewy bodies (FS33/2019)

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

We're the Parkinson's charity that drives better care, treatments and quality of life.

Together we can bring forward the day when no one fears Parkinson's.

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

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

Order code: PKFS33

Last updated October 2019. 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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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