

Dementia with Lewy bodies

Dementia with Lewy bodies is diagnosed when someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems with movement (called motor symptoms). But in some cases of dementia with Lewy bodies, no motor symptoms may develop at all.

The name comes from the Lewy bodies – tiny protein deposits – that can be found in certain parts of the brains of people with the condition.

This information looks at the symptoms and causes of dementia with Lewy bodies. It provides some practical advice on how life can be made easier for the person affected and their family, friends and carers.

What is dementia?

Dementia symptoms are caused by a significant loss of brain function. There are different forms of the condition and each person will experience dementia in a different way.

Some people develop dementia after living with Parkinson's for some time. When someone has Parkinson's motor symptoms for at least a year before experiencing dementia, this is known as Parkinson's dementia. Dementia with Lewy bodies is diagnosed when someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems.

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

What are the symptoms of dementia with Lewy bodies?

Dementia with Lewy bodies affects a person's memory, language, concentration and attention. It also affects their ability to recognise faces, carry out simple actions and their ability to reason.

People with this form of dementia commonly experience visual hallucinations, which can be quite vivid. This can happen early on in the condition. They might also experience difficulty in judging distances and movements, which can cause them to fall over for no apparent reason.

“Occasionally, my mum is very confused when I first arrive, then improves and becomes more lucid by the end of the visit.”

Barbara, whose mum has dementia with Lewy bodies

The condition can also cause someone to experience episodes of confusion, which can change a lot from hour to hour or over weeks or months.

Some people may also develop Parkinson’s-type symptoms, such as slowness of movement, stiffness and tremor. In some cases, a person’s heart rate and blood pressure can also be affected.

What causes dementia with Lewy bodies?

Lewy bodies are tiny protein deposits that develop inside some nerve cells in the brain, causing these cells to die. The loss of these cells causes dementia. It’s not yet understood why Lewy bodies occur in the brain and how they cause this damage.

Dementia with Lewy bodies shares similarities with Alzheimer’s and Parkinson’s. It’s progressive, so the symptoms will get worse over time.

Dementia is age related, so it’s rare that someone under the age of 65 will develop dementia.

How is dementia with Lewy bodies diagnosed?

A specialist will diagnose dementia with Lewy bodies based on someone’s symptoms, their medical history and the results of an examination.

There is no specific blood test for this condition, but tests on memory and thinking will help confirm what the problem is. In some cases, a specialist may request a brain scan to determine what kind of dementia a person has.

What can be done to help?

Medication

There isn’t a cure or specific treatment for dementia with Lewy bodies at the moment, but there are medications that some people may find effective.

Recent research suggests that some people may benefit from dementia medications called cholinesterase inhibitors. But it’s important to note that not all cholinesterase inhibitors are licensed for use in the UK.

Some people may respond well to Parkinson’s medication, especially if they have Parkinson’s-type symptoms such as stiffness or rigidity. However, some side effects of these drugs can make the symptoms of dementia worse, especially confusion.

Since hallucinations and delusions may often be associated with this condition, some doctors may recommend the use of antipsychotic (also known as ‘neuroleptic’) medications. In general, these medications should be avoided, because they may make problems with movement worse. But in some cases, if behavioural symptoms are becoming especially problematic, very low doses of these medications may have to be used. If this medication is prescribed, the healthcare professionals in charge of a person’s care should monitor the situation carefully.

If you have any questions about medication, speak to your GP, specialist or Parkinson’s nurse (if you have one) for more advice and information.

Support from professionals

Using medication to treat dementia can be helpful. But it’s also useful for people to get treatment from a wide range of healthcare professionals, such as physiotherapists, occupational therapists, dietitians and speech and language therapists. They can help the person with dementia and those supporting them.

You can be referred to these health professionals through your GP, specialist or Parkinson’s nurse. In some areas, you may be able to refer yourself at your local hospital or community health clinic.

Legal matters

If you have been diagnosed with early stage dementia, you may want to make some important decisions about things like your finances or 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. You may want to make a legal agreement, such as a Power of Attorney.

For more information and advice, you can 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 on page 6.

Find out more: Parkinson's UK has information that can help you think about and put plans in place for the future. See our booklet *Preparing for end of life: a practical guide*.

Caring for someone with dementia

If someone becomes less able because of their dementia, it might be necessary for their family or friends to start helping with things such as shopping, housework or cooking. If this is the case, the person with dementia may be able to apply for Attendance Allowance or Disability Living Allowance, which will help provide some financial support.

Find out more: see our information sheets *Attendance Allowance* and *Disability Living Allowance*.

If you are in a position where you are dedicating a lot of time caring for a loved one, you may be able to claim Carer's Allowance.

Find out more: see our information sheet *Carer's Allowance* and our booklet *The Carer's guide*.

Accessing local support services

It might be useful to consider support services such as day care, respite or home care. If you're caring for someone with dementia, these services can give you a chance to have time to yourself.

Parkinson's UK information and support workers can help you access local support services. Go to parkinsons.org.uk/isw or contact our helpline for more details about information and support workers in your area.

Local groups

Parkinson's UK has local groups that can offer invaluable support to anyone affected by Parkinson's and dementia. Go to parkinsons.org.uk/localgroups or contact our helpline for more details.

The Alzheimer's Society has local branches that offer support to everyone affected by dementia. These groups often provide various activities for people with dementia and also run carers' groups, which can help you meet other people in similar circumstances. See the 'More information and support' section on page 5 for contact details.

Practical advice

If you are caring for someone with dementia, there are some practical things you can do that can help reduce their agitation or confusion and make life a bit easier:

- 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.
- Encourage someone with dementia to keep engaging and interacting with people. Hobbies are also a great way to keep memory and thinking as active as possible.

Helping with communication

Difficulties with communication can be upsetting and frustrating for the person with dementia and for those around them. But there are some basic things you can do to make life a little bit 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 are saying, and give them plenty of encouragement.
- If they have difficulty finding the right word 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 are right – it's infuriating 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.

“My wife's clarity of mind can vary drastically. But when she has a good spell, these times are of great value to me.”

David, whose wife has dementia with Lewy bodies

Using body language

- Someone with dementia will read your body language. Agitated movements or a tense facial expression may upset them, and can make communication more difficult.
- Be calm and still while you communicate. This shows them that you are 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 is a great pressure valve. 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 responding with a flat contradiction.
- 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 help carers to remain close to their loved ones, or for the person with dementia to 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 is important to bear in mind that communication can be affected by other factors in addition to 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 at once
- 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

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

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 workers

Our information and support workers can also provide details and links to local services. They provide support for anyone affected by Parkinson's.

For details of the local information and support worker in your area, contact our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk**. You can also find out more on our website at **parkinsons.org.uk/isw**

Our helpline

Contact 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**

Local groups

Support is available through Parkinson's UK local groups. Visit **parkinsons.org.uk/localtoyou** or call our helpline for details of your nearest meeting.

Online forum

Speak to others in a similar situation through our online discussion forum at **parkinsons.org.uk/forum**

The Alzheimer's Society

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

020 7423 3500
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

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
advice@carersuk.org
www.carersuk.org

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

Dr Iracema Leroi, Consultant Psychiatrist for the Elderly and Honorary Senior Lecturer with a special interest in mental health in Parkinson's, University of Manchester

Prof David J Burn, Professor of Movement Disorders, Neurology and Honorary Consultant Neurologist, Clinical Ageing Research Unit, Newcastle University

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**



Dementia with Lewy bodies (FS33/2011)

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 May 2011. 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