

# Understanding Lewy body dementia



Lewy body dementia is an umbrella term for two different types of dementia: dementia with Lewy bodies and Parkinson's disease dementia.

Lewy body dementia is a progressive, challenging condition, which is thought to account for 15-20% of cases of dementia. It is more common in people over the age of 65 but also accounts for around 10% of cases of young onset dementia (where symptoms develop before the age of 65).

In the early stages, Lewy body dementia is often mistaken for Alzheimer's disease, which means it can be misdiagnosed. However, it differs from Alzheimer's in that it can particularly affect the person's movement (Parkinsonism), and can cause hallucinations, delusions, changes in alertness and sleep disturbances.

### What causes Lewy body dementia?

Lewy body dementia is caused by abnormal clumps of protein (called Lewy bodies) gathering inside brain cells. These can build up in many parts of the brain but particularly in the areas responsible for thought, movement, visual perception, sleep and alertness.

Lewy bodies are present in people who have Parkinson's, usually in the areas of the brain responsible for movement. Not everyone with Parkinson's will develop dementia, but the risk increases the longer someone lives with the condition.

The main difference between the two types of Lewy body dementia is when certain symptoms first occur. In dementia with Lewy bodies, cognitive changes happen first. These include:

- changes in thinking
- difficulties with visual perception (eg spatial awareness, misinterpreting visual information)



- managing everyday tasks
- staying alert
- memory loss

These symptoms tend to occur at least one year before, or at the same time as, the person develops problems with movement.

In Parkinson's disease dementia, physical changes happen first. This includes difficulties with movement (Parkinsonism) such as tremors, rigidity or slowness. These symptoms are experienced one year or more before the cognitive changes.

### **What are the symptoms of Lewy body dementia?**

Lewy body dementia symptoms are complex and may differ slightly depending on whether a person has dementia with Lewy bodies or Parkinson's disease dementia. Not everyone will experience all of the symptoms or develop them at the same time. However, the most common or 'core' symptoms include:

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- difficulty with organising, planning and carrying out everyday tasks, such as handling money, using a phone or computer and using household appliances
- memory problems (these may be more pronounced in later stages)
- recurring visual hallucinations – seeing things that are not there, usually people or animals. These may be pleasant or upsetting
- disturbed sleep – known as rapid eye movement (REM) sleep disorder, in which people are restless and can experience intense dreams or nightmares
- sudden changes and fluctuations in alertness – people may stare blankly into space for periods of time, seem drowsy and lethargic and spend a lot of time sleeping. As the condition progresses, periods of unresponsiveness may occur in some people
- slowed movement, difficulty walking, shuffling or appearing rigid, ‘freezing’ (as in Parkinson’s)
- tremors – usually in the hands, particularly during movement
- problems with balance and being prone to falls

Other psychological symptoms can include (although will not be experienced by everyone):

- delusions – a fixed belief about something that is not true. These often have a ‘theme’ – for example, some people experience Capgras syndrome, where they believe that a family member or friend has been replaced by an imposter. Please see Sources of support on p18 for more information. Other common themes are feeling as though someone is watching them or ‘out to get them’. These can be linked to hallucinations – for instance, they may believe they can see people in their home

- depression – persistent low mood and feelings of hopelessness which can result in poor sleep and appetite and loss of interest in previous activities
- apathy – where someone appears to be indifferent or lacks motivation. This can occur independently of depression
- anxiety – intense feelings of fear or unease which can result in symptoms including a racing heart, sweating and panic attacks

Other physical symptoms can include (although will not be experienced by everyone):

- low blood pressure on standing up – known as ‘orthostatic or postural hypotension’
- bladder sensitivity – particularly at night
- constipation
- swallowing problems
- impaired sense of smell
- increased salivation or drooling
- excessive sweating
- softer speech and/or problems saying specific words

### **Assessing and diagnosing Lewy body dementia**

It is important for someone with Lewy body dementia to get an accurate diagnosis so they receive the right treatment and support. The GP should refer the person to a memory or dementia service and/or a movement disorder/ Parkinson’s service or specialist (neurologist). This may depend on which symptoms appear first.

The diagnostic process should include assessing the person's physical health and asking both them and a family member, if possible, questions about their symptoms. The person carrying out the assessment should ask about:

- difficulties with memory
- their ability to carry out their usual activities
- changes in behaviour and mood
- changes in alertness
- whether they are seeing/hearing things
- their sleep patterns

A short cognitive assessment may be carried out which examines visual/spatial abilities and memory, plus an assessment of motor function eg tremors, problems with gait (how the person walks) and rigidity.

If the diagnosis is not clear following this assessment, a specific scan may be required to measure levels of the hormone dopamine, which are usually low in Lewy body dementia. This is called a SPECT scan or DaTSCAN. It involves having an injection of a special radioactive substance, usually into a vein in the arm, which helps show how much dopamine is being transported in the brain. The dose of radiation is very small and is quickly eliminated from the body.

Investigations for other symptoms may include:

- myocardial perfusion scintigraphy: used to measure blood flow to the heart and to detect any orthostatic hypotension. This involves an injection of a special radioactive substance, followed by monitoring the person's heart using electrodes (sticky pads) stuck to the chest, and a scan of their heart



- polysomnography: a study of someone's sleep that monitors brain waves and other functions to help diagnose sleep disorders including REM sleep behaviour disorder. This involves the person having electrodes stuck to their head, chest, legs and fingertips; a video camera will also monitor their activity whilst they sleep. It is usually done at a specialist sleep clinic

## Treatment

People with Lewy body dementia may be offered medication, alongside other treatments, to help with their symptoms. These will not stop or reverse the progression of the condition but may improve quality of life for them and their families and carers.

Some of the medications used to treat Alzheimer's disease may help with the cognitive symptoms of Lewy body dementia, for example by reducing distressing hallucinations and improving concentration and



memory. These are usually most effective in the early to mid stages but do not help everyone.

It is important to know that many people with Lewy body dementia are particularly sensitive to medications known as antipsychotics, which are sometimes used to treat hallucinations. Only certain types, known as atypical antipsychotics, should be used, and even then, with extreme caution.

Medications used for Parkinson's may be helpful but again, caution is required as certain medications can make hallucinations worse.

If you have any concerns about the introduction of a new medication or change in treatment or notice any side effects, it is important to discuss this with the person's GP or specialist as soon as possible.

Other treatments focus on symptom control and include:

- physiotherapy
- occupational therapy
- speech and language therapy
- counselling
- support groups
- cognitive stimulation therapy
- music therapy
- meaningful activities





## Practical tips for managing Lewy body dementia

### Getting the correct diagnosis and treatment

If someone has Lewy body dementia, a correct diagnosis is important to ensure they receive the right treatment and management and close monitoring of their condition. If you think the person has been misdiagnosed or their condition has changed, ask for further assessment. This may be with a neurologist for motor symptoms (physical symptoms) or a dementia specialist for cognitive or psychological symptoms. Please see Sources of support on p17 for our information on getting a diagnosis of dementia.

A diagnosis of dementia can have a significant emotional impact on the person with the condition and their family members, so make sure you seek support from local services. Peer and social support groups can be very helpful for sharing experiences. Please see

Sources of support on p17 for more information on the emotional impact of a dementia diagnosis.

It is important for the person with Lewy body dementia to have regular reviews of their treatment, medication and any changes in symptoms. Try keeping a diary of their symptoms for a week and share this with the professionals overseeing their care, especially if there has been a change in treatment.

### **Environment and activities**

There are a number of things you can do to simplify and improve the quality of life of someone with Lewy body dementia. These include:

- replacing or removing patterned carpets, rugs and floor tiles. Difficulties with visual perception (how we see things) are common in Lewy body dementia, and plain floors will reduce the risk of tripping and falling
- removing mirrors, which can be confusing, especially for someone experiencing hallucinations
- displaying a large, clear clock showing the day, date and time
- using a pin board or whiteboard for notes and visual reminders
- using voice reminders on the person's phone or smart speaker

Please see Sources of support on p18 for our information on making the home safe and comfortable for a person with dementia.

Keeping physically and mentally active is important, and an occupational therapist and/or physiotherapist will be able to provide specific guidance on beneficial and meaningful activities. You can ask the person's GP or specialist for a referral.



Cognitive stimulation therapy can be helpful, particularly for people in the earlier stages of dementia. This involves taking part in activities and exercises designed to improve memory, problem-solving skills and language, and may be available via the local memory service or dementia services.

It is helpful to focus on activities the person enjoys and is capable of, with adaptations to make them more manageable if required, such as gardening, cooking, socialising, shopping and exercising – if the person has mobility problems, which are common in Parkinson's disease dementia, they could do seated exercises.

If the person is in employment, encourage them to speak to their employer about reasonable adjustments to help them continue to work, if they wish to.

If the person drives, they are legally obliged to tell the DVLA (DVA in Northern Ireland) and their insurance company about their dementia diagnosis. The changes in vision and spatial awareness associated with Lewy body dementia may impair their driving ability. However, a dementia diagnosis does not necessarily mean the person will have to stop driving straight away – they may be asked to take a driving assessment and/or issued a shorter licence with a reassessment when it expires.

See Sources of support on p17-18 for information on staying healthy with a diagnosis of dementia, employment and dementia , and driving.

### **Responding to symptoms**

Dementia can affect how someone sees and experiences the world as a result of physical changes in the brain. This may lead to the person having difficulty recognising and managing their emotions due to low mood, apathy or frustration.

Understanding that changes in emotions are part of the person's dementia can be an important first step in helping you understand and respond to them sensitively. There are practical steps you can take to help the person feel more at ease and cope with some of the more challenging symptoms.

- Focus on the person's strengths rather than on the things they have difficulty with
- Break tasks down into small parts, explaining each step as you go
- If the person experiences apathy and sudden changes in alertness, offer to do activities together if possible or seek help from someone else – they may respond to a different person more positively



- Encourage activity in the mornings or when the person is less tired
- Treatments for anxiety and/or depression may be effective for some people with dementia. Speak to your GP about options, which might include medication and/or talking therapies
- If there are any changes in physical health such as incontinence, difficulty with swallowing or constipation, speak to the person's GP

### **Hallucinations and delusions**

Seeing the person that you care for in unexplained distress can be worrying and upsetting. It is important to try to respond to any signs of hallucinations or delusions as calmly as possible.

Ask the person what is happening and listen to what they say, or look for signs in their behaviour. Try not to disagree with what they are

saying, even if you know it is not true. Sometimes going along with what they are saying, but neither agreeing nor disagreeing, is the best response.

Ask the person how they are feeling and offer comfort and reassurance if possible.

Please Sources of support on p18 for information on managing hallucinations and delusions in Lewy body dementia.

If the hallucinations or delusions are persistent and/or distressing, speak to the GP or specialist about possible treatments. Some treatments for dementia known as ‘cholinesterase inhibitors’ may help reduce hallucinations and delusions. If the person takes Parkinson’s medication, this may need reviewing as it can increase hallucinations.

Antipsychotic medication is generally not recommended but small doses of certain drugs may be tried if the person is in distress, with careful monitoring for any side effects such as severe stiffness or rigidity.

### **Sleep disturbance**

Sleep disturbance can be extremely difficult for both the person with Lewy body dementia and their family. The person with dementia may experience vivid nightmares or involuntary, jerky movements as dreams are acted out. The person may be unaware of this, or may wake up suddenly feeling frightened or distressed. This can also impact on the sleep of other people in the family, particularly the person’s spouse or partner. For some partners, sleeping separately from the person with Lewy body dementia is an option to allow the partner better quality of sleep.





Keeping the bedroom decor and lighting simple can be helpful to avoid unusual shadows or silhouettes which may be misinterpreted if the person with Lewy body dementia wakes in the night.

Good sleep hygiene techniques may ease sleep disturbance. These include:

- avoiding caffeine, alcohol and heavy meals prior to bedtime
- maintaining a regular routine, including some exercise and/or activity during the day
- reducing the frequency and length of daytime napping, if possible
- ensuring a comfortable sleeping environment, eg dark, quiet and not too hot or too cold



- providing pain relief before bed if the person is in pain or discomfort – your pharmacist can offer advice
- asking your GP for medications for specific conditions that disturb sleep, such as ‘restless leg syndrome’ (an urge to move the legs when resting)

See Sources of support on p16 for our information on managing sleep disturbance in Lewy body dementia.

### **Parkinsonism (motor or movement disorder symptoms)**

The three main motor or movement disorder symptoms related to Parkinson’s are tremor, stiffness and slowness of movement. Tremor is less common in dementia with Lewy bodies but symptoms such as ‘freezing’ (ie getting stuck) and poor balance can increase the risk of falls and cause discomfort or pain.

Other motor symptoms can include:

- muscle cramps and dystonia (painful contraction of muscles)
- restless legs
- changes in swallowing, eg reduction in frequency, poor swallow reflex
- quieter and less fluent speech

Medication used for Parkinson’s may help reduce some of the motor symptoms but needs monitoring regularly by a neurologist or Parkinson’s specialist/Parkinson’s nurse.

Exercise is particularly important for people with Parkinson’s and can help with other symptoms such as sleep problems, mood and cognitive problems. Specific exercises may be recommended for different movement problems and advice should be sought from a physiotherapist.

## Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at ➤ [dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25<sup>th</sup> December) or email ➤ [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit ➤ [dementiauk.org/book](https://dementiauk.org/book)

## Dementia UK resources

### Changes in perception and hallucinations

➤ [dementiauk.org/changes-in-perception](https://dementiauk.org/changes-in-perception)

### The emotional impact of a dementia diagnosis

➤ [dementiauk.org/emotional-impact](https://dementiauk.org/emotional-impact)

### Employment and dementia

➤ [dementiauk.org/employment](https://dementiauk.org/employment)

### False beliefs and delusions

➤ [dementiauk.org/false-beliefs](https://dementiauk.org/false-beliefs)

### Getting a diagnosis of dementia

➤ [dementiauk.org/getting-a-diagnosis-of-dementia](https://dementiauk.org/getting-a-diagnosis-of-dementia)

### Making the home safe and comfortable for a person with dementia

➤ [dementiauk.org/safe-comfortable-home](https://dementiauk.org/safe-comfortable-home)

### **Medication and dementia**

➤ [dementiauk.org/medication-management](https://dementiauk.org/medication-management)

### **Sleep and dementia**

➤ [dementiauk.org/dementia-and-sleep](https://dementiauk.org/dementia-and-sleep)

### **Staying healthy with dementia**

➤ [dementiauk.org/staying-healthy](https://dementiauk.org/staying-healthy)

### **Young onset dementia section**

➤ [dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

## **Lewy Body Society resources**

### **The Lewy Body Society**

➤ [lewybody.org](https://lewybody.org)

### **Managing delusions, misidentification and Capgras syndrome in Lewy body dementia**

➤ [lewybody.org/managing-delusions-misidentification-and-capgras-syndrome-in-lewy-body-dementia](https://lewybody.org/managing-delusions-misidentification-and-capgras-syndrome-in-lewy-body-dementia)

### **Managing hallucinations and changes in visual perception in Lewy body dementia**

➤ [lewybody.org/managing-hallucinations-and-changes-in-visual-perception-in-lewy-body-dementia](https://lewybody.org/managing-hallucinations-and-changes-in-visual-perception-in-lewy-body-dementia)

### **Managing sleep disturbance in Lewy body dementia**

➤ [dementiauk.org/wp-content/uploads/dementia-uk-lewy-body-dementia-managing-sleep-disturbance.pdf](https://dementiauk.org/wp-content/uploads/dementia-uk-lewy-body-dementia-managing-sleep-disturbance.pdf)

## Other resources

### Parkinson's UK

➤ [parkinsons.org.uk](https://parkinsons.org.uk)

### NHS: occupational therapy

➤ [nhs.uk/conditions/occupational-therapy](https://nhs.uk/conditions/occupational-therapy)

### Royal College of Speech and Language Therapists

➤ [rcslt.org/speech-and-language-therapy](https://rcslt.org/speech-and-language-therapy)



**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:

**0800 888 6678** or ➔ **helpline@dementiauk.org**

Book a virtual appointment:

➔ **dementiauk.org/book**

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit ➔ **dementiauk.org/donate**
- Scan the QR code



**Thank you.**



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Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
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