



**The Lewy Body Society**

Shining a light on Lewy body dementia



**DementiaUK**

Helping families face dementia

## Understanding Lewy body dementia



### Introduction to Lewy body dementia (LBD)

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

Lewy body dementia is a progressive, challenging condition, which is thought to be the cause for 10-15% of people with dementia.

In the early stages, it is often mistaken for Alzheimer's disease and 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 Lewy bodies can build up in many parts of the brain but particularly in the areas responsible for thought, movement, visual perception and those regulating sleep and alertness.

Lewy bodies are present in people who have Parkinson's disease, 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 DLB (dementia with Lewy bodies), cognitive changes happen first, or at the same time as physical changes. This includes: changes in thinking, difficulties with visual perception (ie, spatial awareness, misinterpreting visual information) memory loss, (managing everyday tasks etc.), and problems with sleep. These symptoms tend to occur at least one year before, or at the same time as, problems with movement.

In PDD (Parkinson's disease dementia), physical changes happen first. This includes difficulties with movement (Parkinsonism), such as: tremor, rigidity or slowness. These symptoms are experienced first;



at least one year or more before cognitive changes.

## What are the symptoms of Lewy body dementia?

Lewy body dementia symptoms are complex and may differ slightly depending on whether it is PDD or DLB. Not everyone will experience the same symptoms at any time. However the most common or core symptoms include:

- difficulty with organising, planning and carrying out everyday tasks, such as handling money, using a phone or computer, using household appliances such as a kettle or washing machine etc.
- difficulty with remembering events or names of familiar people (this may be more pronounced in later stages)
- recurring visual hallucinations – seeing things that are not there (these can 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
- slowed movement, difficulty walking, shuffling or appearing rigid – ‘freezing’ (as in Parkinson’s disease).
- 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’ in LBD; a common delusion being ‘Capgras’ syndrome, in which the person believes that a friend or relation has been replaced by an imposter. Other common themes are feeling as though someone is watching them, or ‘out to get them’. These can be linked with hallucinations, for instance seeing people in their home
- apathy – where someone appears to be indifferent or lacks initiative – this can occur independently from depression
- depression – persistent low mood and feelings of hopelessness which can result in poor sleep, appetite and loss of interest in previous activities
- anxiety – intense feelings of fear or unease which can result in a racing heart, sweating and panic attacks

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

- low blood pressure (dizziness) on standing up
- urinary incontinence – particularly at night
- constipation
- swallowing problems
- impaired sense of smell
- increased salivation or ‘drooling’
- excessive sweating
- problems with speech and/or saying specific words

## Assessment

It is important for someone with LBD to get an accurate diagnosis so they get the right treatment and support.

Your GP should refer you to a memory or dementia service and/or a movement disorder/Parkinson’s service (neurologist). Where you are assessed may depend on which symptoms appear first.

The diagnosis process should include assessing the person’s physical health, and asking questions about symptoms from

the person, and a family member, wherever possible.

The person carrying out the assessment should ask questions about changes in memory, ability to carry out usual activities, changes in behaviour and mood, alertness, seeing things and sleep patterns. A short cognitive assessment may be carried out which examines visual/spatial abilities as well as memory, plus an assessment of motor function ie, presence of tremor, problems with gait (how they walk) and rigidity.

If the diagnosis is not clear following this assessment, a scan may be required to measure dopamine levels, which are usually low in LBD. This is called a SPECT scan (single photon emission computed tomography) or a DaTSCAN. This involves having an injection of a radioactive substance, which helps show how much dopamine is being transported in the brain.

## Treatment

People with LBD may be offered medication, as well as other treatments, to help with their symptoms. These will not stop or reverse the course of the disease, but can improve the quality of life for them and their families and carers.

Some of the medications used to treat Alzheimer's disease can help with the cognitive symptoms of LBD and can help reduce distressing hallucinations, concentration and memory problems. These are usually most effective in early or moderate phases, but do not help everyone.

Importantly, many people with LBD are particularly sensitive to medications known as antipsychotics, which are used to treat hallucinations. Only certain types, known as atypical antipsychotics, should be used, 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 your GP or specialist as soon as possible.

Other treatments focus on symptom control and include: physiotherapy, occupational therapy, counselling, groups, cognitive stimulation therapy, music and activities.

### Managing Lewy body dementia – practical things you can do:

#### Getting the correct diagnosis and treatment

It is important to get the correct diagnosis of LBD, as the subsequent treatment and management need close monitoring.

If you think there has been a misdiagnosis or the condition has changed, ask for further assessment. This may need to be from either a neurologist for motor symptoms (physical symptoms) or a dementia specialist (old age psychiatrist) for cognitive or psychological symptoms.

Please see the Sources of support section on page 11 for the Dementia UK leaflet on Getting a diagnosis.

Getting a diagnosis can have a significant impact on the person and family members. Seek support from local services and ensure you talk to someone about the changes you are going through. Peer and social support groups can be very helpful for sharing experiences and getting mutual support (see Sources of support for our leaflet on The emotional impact of receiving a diagnosis of dementia).

It is important to have regular reviews of treatment and medication, and monitor any changes. Different drug treatments can reduce or increase different symptoms. Try keeping a diary of symptoms over a period of a week, and share this with the professionals overseeing 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 LBD.





These include:

- replacing or removing patterned carpets, rugs and curtains. Difficulties with visual perception (how we see things) are common in Lewy body dementia, and plain floors will cut down on the risk of tripping and falling
- removing mirrors, which can be confusing, especially for someone experiencing hallucinations
- getting a large, clear clock, showing the day and date. A pin board or chalkboard for notes and visual reminders is also useful

Please see Sources of support for the Dementia UK leaflet on Making

the home safe and comfortable for a person with dementia and Changes in perception and hallucinations.

Keeping physically and mentally active is important, and an occupational therapist and/or physiotherapist will be able to give specific guidance on therapeutic activities to alleviate certain symptoms.

Cognitive stimulation therapy can be helpful for people, particularly in 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 your local memory service or dementia services.

It is helpful to focus on activities the person enjoys, and adapting these to make them more manageable, such as bringing potting plants inside; helping with cooking, cleaning, and folding washing; or seated dancing or exercises.

See Sources of support for our leaflet on Staying healthy with a diagnosis of dementia.

### Responding to symptoms

Dementia can impact the way someone sees and experiences the world, due to physical changes taking place in the brain. This may lead to the person having difficulty controlling their emotions or understanding what is happening. Understanding these experiences as ‘part of the dementia’ can be an important first step in helping us respond to the person.

There are practical steps you can take to help the person feel more at ease, and to cope with some of the challenging symptoms of their dementia.

- Try to focus on activities that the person can still do, and do these together, if possible

- Apathy and sudden changes in alertness are both symptoms of LBD. These can be difficult to manage and can be upsetting for family members. It’s important to remember these symptoms are caused by the changes in the brain and are not ‘intentional’
- Any change in physical health such as incontinence, difficulty swallowing, or constipation should be reported to a GP or appropriate clinician so that specific treatment and advice can be provided

### 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 distress or unexplained behaviour as calmly as possible.

Ask the person what is happening. Listen to what they say, or observe their behaviour. Try not to disagree with what they are saying, even if you know it to not be the case. Ask them how they are feeling, and how what is happening is affecting





them, and offer comfort and reassurance if possible.

Sometimes going along with what the person is saying, but neither agreeing nor disagreeing, is the best response. If the hallucinations or delusions are persistent and/or distressing, speak to your GP or specialist about possible treatments.

## Sleep disturbance

Sleep disturbance can be extremely distressing and can have a negative impact on both the person with the diagnosis and those that care for them. REM sleep behaviour disorder, a common symptom of LBD, can include vivid nightmares or involve the person having

involuntary, jerky movements as dreams are acted out. The person may be unaware of this or may wake up suddenly feeling frightened or distressed.

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

- reducing caffeine intake, 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, ie, not too hot or

too cold, and try to reduce noise or bright lights

- providing pain relief before bed, if the person is in pain or discomfort
- asking the GP for medications for specific conditions that disturb sleep, such as ‘restless leg syndrome’

See the Sources of support section for our leaflet on Good habits for bedtime.

### Parkinsonism (motor symptoms)

The three main motor or movement disorder symptoms related to Parkinson’s include tremor, stiffness and slowness of movement. Tremor is less common in DLB (ie, 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 – urge to move legs when resting

- Swallowing – reduction in frequency, poor swallow reflex

- Speech – less fluent and quieter volume

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

Exercise is particularly important for people with Parkinson’s symptoms and can help with managing 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.

Support with maintaining independence and managing tasks may be provided by an occupational therapist and advice about speech and/or swallowing problems should be accessed from a speech and language therapist.

If you need referrals for any of the above, contact your GP and/or specialist who should advise.

## Sources of support

**For further information about Lewy body dementia see:**  
[lewybody.org](http://lewybody.org)

**For information about Parkinson's symptoms see:**  
[parkinsons.org.uk](http://parkinsons.org.uk)

## Dementia UK leaflets

**Changes in perception and hallucinations in dementia**  
[dementiauk.org/changes-in-perception](http://dementiauk.org/changes-in-perception)

**False beliefs and delusions**  
[dementiauk.org/false-beliefs](http://dementiauk.org/false-beliefs)

**Good habits for bedtime**  
[dementiauk.org/good-habits-for-bedtime](http://dementiauk.org/good-habits-for-bedtime)

**Getting a diagnosis**  
[dementiauk.org/getting-a-diagnosis](http://dementiauk.org/getting-a-diagnosis)

## Our Admiral Nurses can help

If you have any questions or concerns about dementia, you can call the dementia specialist Admiral Nurses on our Helpline for free.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Opening hours:

Monday-Friday, 9am-9pm

Saturday-Sunday, 9am-5pm

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit [dementiauk.org/donate](https://dementiauk.org/donate) or call **0300 365 5500**.

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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday – Friday, 9am – 9pm  
Saturday and Sunday, 9am – 5pm



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