

# A guide to Lewy body dementia



**The Lewy Body Society**

Shining a light on Lewy body dementia

A registered charity in England & Wales (1114579) and Scotland (SC047044)

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## Introduction

Lewy body dementia (LBD) is one of several types of dementia. It is a complex, challenging and common brain disorder which affects many parts of the brain in ways that scientists are still trying to understand. As with other forms of dementia, its symptoms make it difficult for the patient to do everyday tasks that once came easily.

Although less well-known than Alzheimer's and Parkinson's diseases, LBD is not a rare disorder. It is often described as 'the most common disease you've never heard of', yet it accounts for about 15-20 per cent of all people with dementia. Approximately 125,000 people in the United Kingdom live with its disabling effects upon their ability to think and act. Taking into account families and other carers of those living with the disease, it probably affects the lives of at least half a million people in the UK.

As researchers seek better ways to treat LBD – and ultimately to find a cure – people with LBD and their families often struggle with delay in receiving an accurate diagnosis, accessing the best advice about supportive treatments and managing the disease at home.

This guide mainly uses the term Lewy body dementia. You may sometimes see other terms used as there are two sub-types of LBD: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). They are also sometimes collectively referred to as Lewy body disease.

The difference between them is essentially the timing of some of the major symptoms, which is explained on pages 10 and 13. In this guide the term Lewy body dementia (LBD) will be used unless something pertains particularly to either DLB or PDD.

This guide is intended to help people with LBD, their families and carers and healthcare professionals to learn more about the disease and the impact it has. It explains what is known about the different types of LBD and how they are diagnosed. Most importantly, it describes how to treat and manage this difficult disease, with practical advice both for people with LBD, their families and carers.



### About the Lewy Body Society

The Lewy Body Society, established in June 2006 in the UK, was the first charity in Europe exclusively concerned with Lewy body dementia. Our mission is to fund clinical research to improve the diagnosis and treatment of the disease. We also raise awareness of Lewy body dementia amongst the general public and those in the medical professions and decision-making positions, and we provide information resources for patients and carers.

This 2019 edition of the guide is a revised version of one of our most popular resources. It is available free to individuals and those requiring bulk copies should contact us. We would like to thank everyone who has donated to the Lewy Body Society or completed fundraising events. We have such a strong network of supporters, many of whom have been personally affected by the disease, and by enabling us to produce this guide they are directly helping others.

You can keep up to date with our work by visiting our website at [www.lewybody.org](http://www.lewybody.org), following us on Facebook [www.facebook.com/lewybodysociety](https://www.facebook.com/lewybodysociety) or on twitter at [www.twitter.com/lbsorg](https://www.twitter.com/lbsorg).



## Overview

Dementia is defined as a loss of thinking abilities sufficient to interfere with a person's capacity to perform daily activities such as household tasks, personal care and handling finances. How we support people living with dementia is a growing issue in society. It is estimated that 1 million people in the UK will have dementia by 2025 and this will increase to 2 million by 2050.\*

Lewy body dementia (LBD) is caused by abnormal deposits of a protein called alpha-synuclein in the brain. These deposits are called Lewy bodies, after Dr Friedrich Lewy, who first discovered them under the microscope in 1912. They affect brain cell function, leading to problems with thinking, movement, behaviour and mood.

LBD is believed to be the second most common cause of age-related dementia after Alzheimer's disease, which accounts for approximately 60 per cent of all diagnoses of dementia. The common perception that Alzheimer's is the only type of dementia is therefore far from correct.

Dementia includes a range of neurodegenerative diseases including dementia with Lewy bodies, vascular dementia, fronto-temporal dementia (Pick's disease) and the dementia associated with Parkinson's disease. It can also be caused by a stroke, vitamin deficiency, alcohol abuse, traumatic brain injury or other rarer disorders. Early LBD symptoms are often confused with similar symptoms typical of other dementias.

### Who is affected by LBD?

LBD typically begins around the age of 60 or older, although sometimes younger people develop it. It appears to affect slightly more men than women.

It is a progressive disease, which means that symptoms start slowly and worsen over time. The average time between diagnosis and death is 5-7 years but can range from 2-20 years. How quickly the disease progresses varies greatly from person to person and depends on a number of factors such as overall health, age and severity of symptoms.

\* Prince, M et al (2014) Dementia UK: Updated Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society



In the early stages of LBD, often before a diagnosis is made, symptoms are usually mild and people may be able to function fairly normally. As the disease advances, people with LBD require increasing amounts of support as their ability to think and move declines. In the later stages of the disease people become very dependent on others for assistance with dressing, eating, moving and general care. Towards the end of life they may become bedridden.


Some LBD symptoms may respond to treatments for a period of time. A cure for the disease has not yet been found. Research has improved understanding of this complicated condition and advances in science will hopefully lead to better diagnosis, improved care and new treatments.

### **What are Lewy bodies?**

Lewy bodies are made of a protein called alpha-synuclein. In a healthy brain alpha-synuclein has a number of important functions, especially at the synapses (nerve cells) where brain cells communicate with each other. In LBD this protein forms into clumps inside of neurones, making them less effective. Eventually the cells die. Lewy bodies also affect certain chemicals which regulate brain function. The result is widespread damage and decline in the brain's proper functioning.

The areas of the brain affected by LBD are:

- the cerebral cortex, which controls many functions, including information processing, perception, thought and language;
- the limbic cortex, which has a major role in controlling emotions and behaviour;
- the hippocampus, which is essential to the formation of new memories;
- the midbrain, including the substantia nigra, which is involved in movement;
- parts of the brain stem important in regulating sleep and maintaining alertness;
- regions in the brain important to recognising smells (olfactory pathways).



LBD is the second most common form of age-related neurodegenerative dementia

To find out more please visit our website at [lewybody.org](http://lewybody.org)

## Types of Lewy body dementia

As mentioned in the introduction, there are two types of Lewy body dementia: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). Both variants typically cause both movement problems and cognitive symptoms. The distinction, and therefore which diagnosis a person receives, depends on the order in which symptoms are observed and how closely together. Over time, people with DLB and PDD tend to develop similar symptoms.

### Dementia with Lewy bodies

Dementia with Lewy bodies (DLB) initially presents as a cognitive condition. If someone does not have movement problems, or develops them around the same time as developing cognitive symptoms (within a year), they are diagnosed with DLB.

DLB may initially appear as a decline in cognitive skills which resembles Alzheimer's disease. Over time, however, distinctive symptoms develop which suggest DLB. These may include:

- visual hallucinations;
- fluctuations in cognitive ability, attention and alertness;
- slowed movement, difficulty walking or rigidity (parkinsonism);
- sensitivity to medications used to treat hallucinations;
- Rapid Eye Movement (REM) sleep behaviour disorder;
- more difficulty with executive function than memory. Executive function means performing complex mental activities such as multi-tasking, problem solving, spatial awareness and analytical thinking.

### **Not so sweet dreams**

In his mid-60s Bruce started having some mild confusion and vivid dreams that he physically acted out by thrashing and even falling out of bed. His neurologist diagnosed REM sleep disorder and mild cognitive changes.

Two years later Bruce's confusion had progressed to dementia.

He was no longer able to live on his own in his home. His neurologist referred him for neuropsychological testing and based on the results changed the diagnosis to dementia with Lewy bodies.



## Parkinson's progress

When Betty retired as a school dinner lady she devoted her time to her family, especially her three grand-daughters. At the age of 73 Betty developed a mild tremor in one hand, cramped handwriting, a shuffling gait and a stooped posture. She was diagnosed with Parkinson's disease. Her family became alarmed when she started having hallucinations three years later. She became confused and had problems with visual-spatial orientation. She was then diagnosed with Parkinson's disease dementia.

LBD accounts for  
15-20% of all cases  
of dementia

### Parkinson's disease dementia

Parkinson's disease is characterised as a movement disorder, with symptoms such as slowed movement, muscle stiffness, tremor or a shuffling walk. Cognitive symptoms of dementia and changes in mood and behaviour may arise later.

If someone has movement problems caused by Parkinson's disease for more than year before cognitive symptoms develop, the person is considered to have Parkinson's disease dementia.

Not all people with Parkinson's disease develop dementia and it is difficult to predict who will. Being diagnosed with Parkinson's late in life, however, is a risk factor for PDD.

### Comparison with Alzheimer's disease

The most common form of dementia, affecting around 60 per cent of patients, is Alzheimer's disease. The main differences between it and Lewy body dementia are that patients with Alzheimer's disease are much more likely to have memory impairment and typically face a less severe loss of executive function in the early stages of the disease.

In contrast, people with LBD are more likely to have psychiatric symptoms and hallucinations, the parkinsonian symptoms outlined above and fluctuations in cognitive function.





## **Causes and risk factors**

The precise cause of LBD is still unknown but scientists are learning more about its biology and genetics. They know, for example, that an accumulation of Lewy bodies is associated with a loss of certain neurones in the brain that produce two vital neurotransmitters (chemicals that act as messengers between brain cells). One of these messengers, acetylcholine, is essential for memory and learning. The other, dopamine, plays an important role in regulating behaviour, cognition, motivation, movement, sleep and mood.

Known risk factors include:

### **Age**

Research has shown that age is the greatest risk factor. Most people who develop LBD are over the age of 60.

### **Diseases and health conditions**

Parkinson's disease and REM sleep disorders are linked to a higher risk of LBD.

### **Genetics**

Whilst having a family member with LBD may increase a person's risk, LBD is not 'inherited' directly through a particular gene. At this time a genetic test to predict accurately a predisposition to LBD has not been developed but future genetic research could reveal more information about causes and risks.

### **Lifestyle**

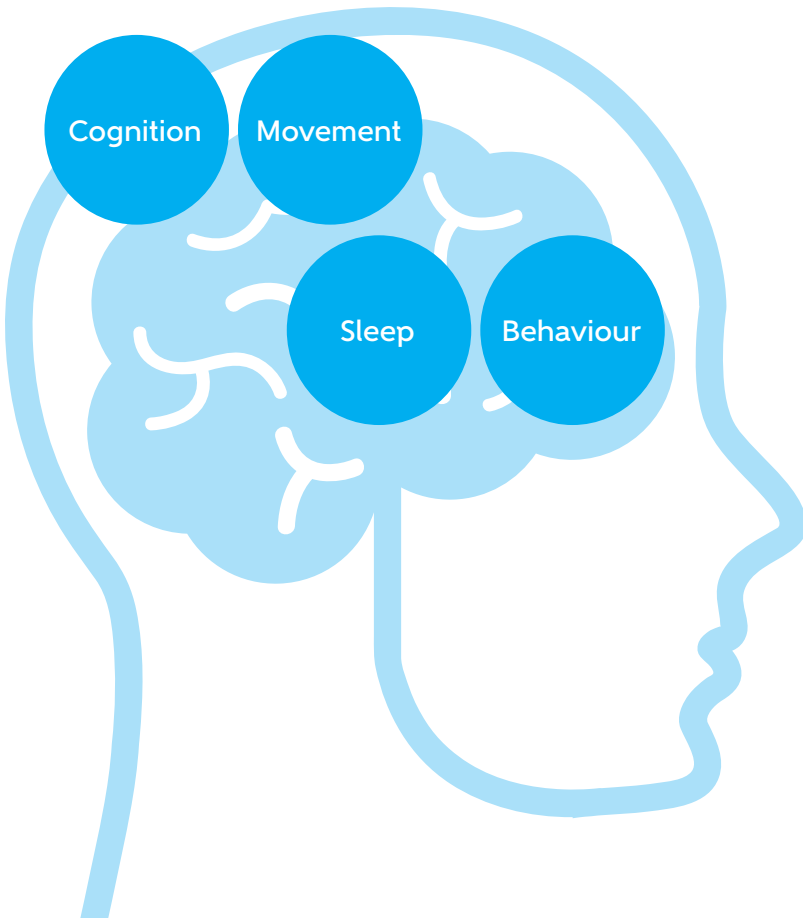
No lifestyle factor has yet been specifically proven to increase the risk of developing LBD. Some studies, however, suggest that a lifestyle which includes regular exercise, mental stimulation and a healthy diet can reduce the risk of age-related dementia.

Unlike Alzheimer's,  
symptoms are both  
mental and motor

## Symptoms

People with LBD may not have every symptom discussed in this guide and the severity of the symptoms varies from person to person. Any sudden or major change in functional ability or behaviour should be discussed with a doctor.

The most common symptoms include changes in these areas:



## COGNITIVE SYMPTOMS

LBD causes changes in the ability to think. These changes may include:

### Dementia

Dementia is the primary symptom of LBD. It usually includes problems with executive function, making the more complex activities of daily living more difficult, and visual and spatial perception, such as judging distance and depth or identifying people or objects. Dementia also affects a person's ability to multi-task, solve problems or reason. Unlike Alzheimer's disease, memory problems may not be evident at first but often arise as the disease progresses. Dementia can also account for changes in mood and behaviour, loss of initiative and inhibitions, confusion about time and place and difficulty comprehending language and numbers.

### Fluctuations in states of consciousness

These are unpredictable changes in concentration, attentiveness, alertness and wakefulness. These changes may be from day to day or even from hour to hour. A person with LBD might stare blankly into space for periods of time or seem drowsy and lethargic and spend a lot of time sleeping. Their flow of ideas may be disorganised, unclear, illogical or random. Speech may be "word salad". But other times the person will be alert, able to carry on a lucid conversation, laugh at a joke or even follow a film. This roller coaster of cognitive states is one of the particularly difficult symptoms faced by carers. Although they are a common occurrence, they do not often happen in the presence of a healthcare professional, which can add to the difficulty of making an accurate diagnosis.

### Hallucinations

About 80 per cent of people with LBD experience visual hallucinations, often in the early stages of the disease. They are typically realistic and detailed. Some people get pleasant ones: visions of children or animals or even an orchestra playing at the foot of their bed!

But others, unfortunately, have terrifying hallucinations and being in their own world, are unable to express what they see. This is another of the frustrating and upsetting things that carers have to cope with. Like the fluctuations of consciousness, they rarely occur in the presence of a doctor.

#### Top tip

If the carer can bear doing it and it doesn't upset the person with LBD even further, a discretely made video of the person experiencing an hallucination can be useful to a doctor who has not witnessed it.

Photograph by Geordie Barrie



## MOTOR SYMPTOMS

Some people with LBD may not experience significant movement problems for several years, whilst others may experience them in the early stages of the disease. The first signs may be very mild and overlooked, such as a change of handwriting. Changes in gait might be attributed to orthopaedic problems. The hallmark resting tremor, which can occur with Parkinson's disease, is often not present in the early stages of LBD. But where it is present, people may be misdiagnosed as having Parkinson's disease. This may result in the patient being prescribed antiparkinsonian drugs, which are usually not effective and may worsen the hallucinations in a person with LBD.

Specific symptoms which resemble Parkinson's disease may include:


- muscle rigidity or stiffness;
- shuffling gait, slower movement or freezing;
- tremor or shaking, most commonly in the hands and usually when at rest;
- balance problems and subsequent falls;
- reduction in the size of a person's normal handwriting;
- reduced facial expressions;
- difficulty swallowing;
- weak voice.

## SLEEP DISORDERS

Although sleep disorders are common in people with LBD, as with changes in cognitive states and hallucinations, they are often not diagnosed because the doctor does not witness them.

Again, a discretely taken video could be very useful for a doctor in making an accurate diagnosis and keeping a sleep diary to track patterns may also help. A sleep specialist can play an important role as part of a treatment team, helping to diagnose and treat sleep disorders, which may include:

- **REM sleep behaviour disorder**, which is when a person appears to be acting out dreams. This may include vivid dreaming, talking in their sleep, violent movements or falling out of the bed. REM sleep behaviour disorder appears in some people years, or even decades, before other LBD symptoms.
- **Excessive daytime sleeping**, such as sleeping for more than two hours during the day, despite sufficient sleep the previous night.
- **Insomnia**, which includes difficulty in falling or staying asleep or waking too early.
- **Restless Leg Syndrome**, which is a condition in which a person at rest feels an urge to move their legs in order to stop unpleasant or unusual sensations in them. Walking or moving slowly may help relieve the symptoms.



Sleep disorders  
are common  
in people  
with LBD



## BEHAVIOURAL AND MOOD SYMPTOMS

Changes in behaviour and mood may occur. Symptoms may include:

- **Apathy** – a loss of interest in anything, even things the person may have previously enjoyed or have been excited about, such as events, people and social interaction.
- **Anxiety** – intense apprehension and uncertainty or fear about particular events or situations. Anxiety can also be just general and non-specific.
- **Agitation** – pacing, hand-wringing, inability to settle down, irritability or repetition of words or phrases.
- **Delusions** – strongly-held false beliefs not based on evidence or reality. A person may not be able to distinguish what they see on the television from their actual environment. Or a person may think that their spouse is having an affair or that dead people are alive and present. One type of delusion that may appear to a person with LBD is Capgras Syndrome, in which they believe that a friend or relation has been replaced by an imposter. This is another unsettling experience for which a carer must be prepared.
- **Depression** – more serious than a normal reaction to a sad event or grief, depression is a persistent feeling of sadness and inability to enjoy activities. It can affect people's eating and sleep patterns and interfere with normal daily activities.
- **Paranoia** – extreme, irrational distrust and suspicion of others. They may feel that people are stealing things from them or conspiring against them.

## OTHER LBD SYMPTOMS

People with LBD may experience significant changes in the autonomic nervous system, which regulates the involuntary actions of the heart, muscles and glands.

The person may have:

- frequent variations of body temperature;
- fluctuating and/or abnormal blood pressure;
- dizziness;
- fainting;
- sensitivity to heat and cold;
- frequent falls;
- sexual dysfunction;
- constipation;
- impaired sense of smell.

## Diagnosis

As early symptoms may be similar to those of Alzheimer's and Parkinson's diseases or common mental health or movement disorders, Lewy body dementia is often misdiagnosed or missed completely. It is often easier to make an accurate diagnosis after additional symptoms appear.

It is important to know whether a person has DLB or PDD in order to find appropriate treatment and to understand how the disease is likely to progress. DLB may progress more quickly than PDD.

Lewy bodies are present in the brains of all people with DLB and PDD. No matter how the disease begins, everyone with LBD will eventually develop similar symptoms. Whilst a diagnosis of LBD can be distressing, some people are relieved to know the reason for their troubling symptoms. An early and accurate diagnosis of LBD can enable a person to plan medical care and sort out legal and financial affairs whilst they still have the capacity to do so. This also allows them to build a support team to help them stay independent for as long as possible and maximise their quality of life. It is important to allow time to adjust to the diagnosis. Discussing it can help focus on a holistic care plan that considers all aspects of a person's physical, psychological and social wellbeing.

Early and  
accurate diagnosis  
can help with good  
quality of life



### How is LBD diagnosed?

Unfortunately, many doctors and other healthcare professionals are not yet familiar with LBD, which means that a patient may have to see more than one specialist before they receive this diagnosis. The first step is usually to visit a GP. The GP will ask a number of questions and do some blood tests to exclude other potential causes of the symptoms. If dementia is suspected a referral is made to a local memory assessment clinic or other service. This depends on the referral pathway in your area.

Memory clinics and services vary widely in the way they operate but generally the person will be seen first by a specialist doctor – usually an old age psychiatrist – either in a clinic or at home. Referral to another specialist, such as a neurologist may be required. There will be a physical examination and a medical history will be taken. The doctor will want to know about any changes in ability to perform daily tasks, manage financial affairs or cope in social situations. They will want to know if and how the person's memory problems affect other members of the family. Other tests, such as taking scans (photos) of the brain are usually required before a diagnosis can be made with certainty. There are different types of scans, but the most common are CT and MRI (more detail on scans on page 23).

Scans are usually performed at a different place than the memory clinic. The patient will then be asked to attend the memory clinic again (usually 4 to 6 weeks later but maybe longer) to discuss the results.

It is important for the patient to be accompanied to the clinic appointments by a carer, close friend or relative who knows them well and can contribute to the patient's history and description of the symptoms.


It is always very helpful to have another pair of ears at any consultation or assessment, especially at the appointment to discuss the results. The patient may feel anxious and there will be a lot of information given and received, which may be overwhelming for one person to absorb. Someone having memory problems may not be able to understand or retain the information given or be able to describe objectively symptoms or worrying behaviour. They may not remember what medications they are on and other vital facts which the accompanying person can provide. If this person is reluctant to discuss the patient in his or her presence, they can ask to speak to a member of the team privately. The more information that is given about the patient, the better chance there is of an accurate diagnosis.



### **What's going on?**

Janet, a 60-year-old executive secretary, began having trouble managing the accounting, paperwork and other responsibilities of her job. She became increasingly irritable and her daughter insisted that she see a doctor.

Janet was diagnosed with depression and other stress-related problems. She was prescribed antidepressants but her thinking and concentration problems got worse. When she could no longer function effectively at work, her doctor diagnosed Alzheimer's disease. A few months later Janet developed a tremor in her right hand. She was referred to a neurologist, who finally diagnosed Lewy body dementia.



Various tests  
can help with  
the diagnosis

### Tests used to diagnose LBD

Initial tests will be carried out in a primary care setting to consider whether the patient's symptoms are the result of physical illness, hormone deficiency or the side-effects of existing medication. If a physical illness is diagnosed and treated and the person still has symptoms, it is important that they are re-screened for dementia.

Further tests will then be carried out in secondary care.

Neuropsychological tests are used to assess memory and other cognitive functions and can help identify affected regions of the brain and types of cognitive and executive functions that are affected.

Brain imaging, such as computed tomography (CT scan) or magnetic resonance imaging (MRI), can detect brain shrinkage or structural abnormalities and help rule out other possible causes of dementia or movement symptoms. A single photon emission computed tomography (SPECT) scan can help support a diagnosis of LBD.

Unfortunately at the present time no testing or imaging can definitively diagnose LBD. It can only be confirmed by a brain autopsy after death. But a skilled and experienced specialist practitioner such as an old age psychiatrist or a neurologist can usually make a diagnosis of LBD.

Researchers are studying ways to diagnose LBD more accurately in the living brain. Positron emission tomography (PET) and SPECT scans have shown promise in detecting the differences between Alzheimer's disease and dementia with Lewy bodies. Research is also being made into the use of a lumbar puncture (spinal tap) to measure proteins in the spinal fluid that might distinguish LBD from Alzheimer's and other brain disorders.



### What are the possible outcomes of the assessment?

- There is no evidence at this time that the person has dementia.
- There is an acknowledgement that something is not quite right but the evidence does not indicate a diagnosis of dementia at the moment. In this case a further assessment is recommended in 6 to 12 months time.
- Sometimes a diagnosis of mild cognitive impairment (MCI) may be given. This is a condition in which someone's mental abilities are worse than would be expected for their age but do not interfere with daily life the way dementia does.
- A diagnosis of dementia is discussed with the person and their family/ carer. This should be done in a considerate and thoughtful way in an appropriate environment with further information provided about the condition and the next steps.



### Next steps after a diagnosis of dementia

At this point the patient may be introduced to a Dementia Navigator or Admiral Nurse who will usually be at the memory assessment clinic at the time of diagnosis. They will then visit the person with dementia and their family and/or carer in their home at a suitable time, usually within 4-8 weeks. They will provide further information about planning for the future, practical matters that the patient may need to consider, treatments and therapies.

The patient should be recorded on their GP's register as having dementia with the sub-type of Lewy body dementia also recorded. The person with dementia and their carer should be offered a review at least once a year. Although someone with dementia may have contact with lots of health and care professionals from different services (see below), the contact with their GP remains important. They provide important continuity of care as dementia progresses and can offer support with care planning which not only looks at the impact of dementia but also the impact of other long-term conditions the patient may have.

A specialist doctor such as an old age psychiatrist or a neurologist will lead the patient's care team which may also include:

- **a physiotherapist** to help with movement problems;
- **a speech therapist** to help with impaired speaking and difficulties swallowing;
- **an occupational therapist** to help with ways that the patient can perform more activities of daily life such as bathing and dressing and thus regain more independence. Occupational therapists can also address mood, sleep, apathy and motivation concerns;
- **a community psychiatric nurse** to help patients and their families deal with the difficult emotions they must cope with.

Some clinics offer arts or music therapy, which can provide meaningful activities which often relieve anxiety and improve well-being.



## Treatment


Whilst there is currently no cure for LBD, patients may be offered drugs and non-drug treatments to help with their LBD symptoms as well as general lifestyle advice. The treatments cannot stop or reverse the course of the disease but many people show benefit from the treatments that improve quality of life for them and their families and carers. It is essential to work with a knowledgeable healthcare professional who understands LBD and advises about medications that can make symptoms worse or can even have life-threatening side effects. Potential benefits must be carefully weighed against possible harmful or dangerous side effects. Some of the drugs used to help with motor problems can worsen cognitive problems and vice versa. Many people with LBD are very sensitive to medications so drug treatment may not be suitable for them. Some symptoms, however, may be improved with non-drug treatment.

Treatment in the UK is regulated by the National Institute for Health and Care Excellence (NICE). It produces guidelines, advice and quality standards for the management and treatment of all conditions. There are a number of documents relating to dementia mentioned below, including information on treatments, care pathways and promoting wellbeing. It is advisable to read these and you can always discuss them with medical professionals to ask them to explain anything that isn't clear.

## Cognitive symptoms

Some of the medications used to treat Alzheimer's disease can help with the cognitive symptoms of LBD. Recommendations have been made by NICE about the management of DLB and PDD and you may hear drugs such as memantine, donepezil or rivastigmine discussed. These drugs act on a chemical in the brain which plays an important role in memory and thinking. The drugs are most effective in the early to moderate stages of the disease but unfortunately do not work for everyone.

The treatment regime will vary depending on the severity of the disease and other factors. It may take a little time to get right and should be reviewed regularly.



Caring for someone with LBD  
is the ultimate expression of  
unconditional love

### Motor symptoms

For information on managing Parkinson's disease symptoms in people with DLB or PDD, you can refer to the NICE guidance on Parkinson's disease. You should be aware that some interventions may need to be modified for people living with dementia. Movement problems can be treated with the Parkinson's medication, carbidopa-levodopa. This drug may help improve motor symptoms in some people and make it easier for a person to walk or get out of bed. Unfortunately, the side effects of this medication can make hallucinations worse and cause serious psychiatric or behavioural problems.

If the person is struggling with motor problems (walking, balance, movement, transfers such as getting in and out of bed), they should be referred to a physical therapist or a multidisciplinary team for management and support. Cues and strategies can be taught to alleviate some problems.

### Trouble with balance

After major surgery at the age of 69, Cliff developed balance problems and later his movements became stiff. Within a year Cliff started hallucinating and suffered troubling side effects from anti-psychotic medication.

Soon after an initial diagnosis of parkinsonism, he began to have cognitive problems and was diagnosed with Lewy body dementia. His balance problems worsened, and he had many falls. With physical and occupational therapy he learned to use adaptive devices and techniques. Cliff's wife found that putting on his shoes before getting out of bed helped improve his balance. A low dose of medication for parkinsonism, prescribed by his doctor, also helped.

## Sleep disorders

Sleep problems may increase confusion and behavioural problems in people with LBD and can be very difficult for carers to cope with.

The NICE guidance on sleep problems for people living with dementia states that a personalised, multicomponent sleep management approach should be considered, which should include sleep hygiene education, exposure to daylight, exercise and appropriate activities.

Some doctors may prescribe drugs for REM sleep disorders, excessive daytime sleepiness or insomnia. The patient's doctor will discuss the options and may seek advice from specialists. It is very important to note that drug treatments for sleep disorders in people with LBD have not been extensively investigated. They can worsen other symptoms and should be only used under expert supervision.

Certain sleep problems, however, can be addressed without medications. Increasing daytime exercise or activities and avoiding lengthy or frequent naps can promote better sleep. Avoiding alcohol, caffeine and chocolate late in the day can also help with insomnia. Some over-the-counter medications may affect sleep, so it is important that all medications and supplements are reviewed by a doctor.







Photograph by Georgie Barrie

### **Behavioural and mood problems**

Behavioural and mood problems in people with LBD can arise from hallucinations or delusions. They may also be a result of pain, illness, stress, anxiety, the inability to express frustration, fear, or feeling overwhelmed. The person may resist care or lash out verbally or physically.

Carers must try to be patient and use a variety of strategies to handle such problematic behaviours. Sometimes these can be managed by making changes in the person's environment and/or treating medical conditions. Other problems may require medication. The first step is to visit a GP to see if a medical condition unrelated to LBD is causing the problem. Injuries, fever, urinary tract or pulmonary infections, pressure ulcers (bed sores) and constipation can cause discomfort that precipitates or worsens behavioural problems and increases confusion.

Certain medications that are used to treat LBD symptoms or other diseases may also cause behavioural problems, adding to the difficulty of managing LBD. Some over-the-counter sleeping aids, strong pain medications, medications for bladder control as well as the prescription Parkinson's drugs mentioned previously on page 27, can cause confusion, agitation, hallucinations and delusions. Paradoxically, some anti-anxiety medicines can increase anxiety in people with LBD.

This is the dilemma which arises in the use of medications to treat LBD: sometimes drugs which improve some symptoms aggravate other symptoms.

Not all behaviour problems are caused by illness or medication. A person's environment – including levels of stimulation or stress, lighting, daily routines and relationships – can lead to behaviour issues. Carers can alter the home to try to minimise anxiety and stress for the person with LBD. In general, people with LBD benefit from having simple tasks, consistent schedules, regular exercise and adequate sleep. Large crowds or overly stimulating environments can increase confusion and anxiety.

A close-up photograph of a white ceramic teacup filled with a reddish-brown liquid, likely tea. The cup and its matching saucer are decorated with a vibrant pink chrysanthemum flower design. The background is softly blurred, showing hints of a patterned surface and a blue decorative element with white circles in the top left corner.

### **A peaceful routine**

Susan realised that her mother, Estelle, could not manage a lot of stimulation. Estelle easily became agitated and confused, so Susan avoided taking her to places with large crowds or with noisy environments. Susan discovered that soothing music calmed Estelle and used it to help her relax when she grew anxious and irritable. Establishing a routine with familiar faces in smaller groups has allowed Estelle to enjoy a good quality of life despite her dementia.

The management of hallucinations and delusions are among the biggest challenges for carers and family members. They can be frightening to both the person experiencing them and anyone watching someone during an hallucination. The person with LBD may not understand or accept that the hallucinations are not real and become agitated or anxious. Carers can help by responding to the fears expressed. Rather than arguing or responding factually to comments that may not be true, carers should offer sympathy and concern, which will help maintain the person's dignity and limit further tension.

Cholinesterase inhibitors may reduce hallucinations and other psychiatric symptoms in some people with LBD. But these medications can have unpleasant side effects, such as nausea and are not always effective. As cholinesterase inhibitors do not have an immediate effect on behaviour they should be considered only as part of a long-term strategy. As with all medications given to people with LBD, they should be approached cautiously and monitored closely.

Treatments for depression and anxiety have not been adequately evaluated for use in patients with Lewy body dementia, and the use of antidepressants may make other symptoms (particularly sleep problems) worse. Again, make sure to discuss all the options and possible side effects with your doctor.

### **Top tips for behavioural and mood problems**

- Rule out physical causes, like infection, pain or other medical conditions.
- Review current prescription and over-the-counter medications.
- Look for environmental or social factors that may be contributing.
  - Carefully consider treating with medications if necessary and watch for side effects.



### Seeing things

John, 58, started seeing small children outside the window who were not there. Eventually he began talking with some of these children, whom he thought were visiting the house. Fortunately for John, these hallucinations were not frightening or threatening and actually seemed to provide companionship and entertainment. His wife consulted the memory clinic and was told that since the hallucinations were not disruptive, medication was not needed. She was advised not to argue with her husband about whether or not the children were there and let him enjoy their company.

### **CAUTION about antipsychotic medications**

Sometimes a doctor will prescribe antipsychotic medications to treat severe LBD-related behavioural symptoms. In most cases this will only be for a short-time. These types of medications must be used with extreme caution because they can cause severe and dangerous side effects and increase the risk of death in people with LBD. If antipsychotics are prescribed, it is very important that they are of the newer kind, called 'atypical antipsychotics'. These medications should be used at the lowest dose possible and for the shortest time possible to control symptoms. Many LBD experts prefer quetiapine or clozapine (less common in the UK) to control difficult behavioural symptoms. Older drugs called typical (or traditional) antipsychotics, such as haloperidol, olanzapine and risperidone should not be prescribed for people with LBD. These drugs can cause dangerous or even lethal side effects.

In rare cases, a potentially deadly condition called neuroleptic malignant syndrome can occur. Symptoms include high fever, muscle rigidity and muscle tissue breakdown that can lead to kidney failure. Report these symptoms to a doctor immediately.

### **CAUTION with anti-parkinsonian drugs**

There are similar risk/benefit considerations with Parkinson's drugs which help with movement but exacerbate cognitive problems. Again, the benefit associated with the medication must be weighed against the risk of side-effects and physical harm which may result from untreated problems.





## Surgery

If surgery is planned and the person with LBD is told to stop taking all medications beforehand, their neurologist should be consulted to develop a plan for careful withdrawal. The anaesthetist should also be informed in advance to discuss medication sensitivities and risks unique to LBD. People with LBD who receive certain anaesthetics often become confused or delirious and may have a sudden, significant decline in functional abilities which may become permanent. Depending on the procedure, possible alternatives to general anaesthesia include a spinal or regional block. These methods are less likely to result in post-surgical confusion.

## Other treatment considerations

LBD affects the part of the nervous system that regulates automatic and involuntary actions like blood pressure, digestion and elimination.

One common symptom is orthostatic hypotension. This is a sudden drop in blood pressure, often upon rising too quickly to a standing position, that can cause dizziness and fainting. There are some simple measures which can be helpful in controlling this, such as rising to a standing position slowly, elevating legs, wearing elastic stockings, and, if recommended by a doctor, increasing salt and fluid intake. If these are not enough, a doctor may prescribe medication. Urinary incontinence should be treated cautiously because certain medications may adversely affect cognition. Constipation can usually be treated by exercise and changes in diet, though laxatives and stool softeners may be necessary.





## NON-DRUG TREATMENTS

### Cognitive Stimulation Therapy

CST, or 'Cognitive Stimulation Therapy', is a treatment for people with mild to moderate dementia. Group CST treatment involves 14 or more sessions of themed activities, which typically run twice weekly. Sessions aim to actively stimulate and engage people with dementia and give the social benefits of being in a group. CST groups can take place in settings including residential homes, hospitals or day centres. Each session covers a different topic and is designed to improve the mental abilities and memory of someone with dementia.

### Lifestyle advice

There is some evidence that keeping active through regular, appropriate exercise can help a patient with dementia to retain their abilities for longer, as well as maintaining physical health in other areas such as their heart. Other lifestyle factors, such as eating healthily, not smoking, avoiding excess alcohol and getting enough sleep, can help with the symptoms of LBD.

### Vitamins and supplements

The use of vitamins and supplements to treat LBD symptoms has not been studied extensively and is not recommended as part of standard treatment. Vitamins and supplements can be dangerous when taken with other medicines. People with LBD should tell their doctors and memory clinic team about every medication they take. They should be informed of all prescription and over-the-counter medicines, as well as vitamins and supplements.

## Advice for patients and carers

### FOR PATIENTS

Coping with a diagnosis of LBD and all that follows can be daunting. Getting support from family, friends and professionals is critical to ensuring the best possible quality of life. Creating a safe environment and preparing for the future are important too. Focus on your strengths, enjoy each day, and especially your time with family and friends. Here are some ways to live with LBD day to day.

#### Get help

Your family and close friends are likely to be aware of changes you are experiencing. You may want to tell others about your diagnosis so they can better understand the reason for these changes and learn more about LBD. For example, you could say that you have been diagnosed with a brain disorder called Lewy body dementia, which can affect thinking, movement and behaviour. You can say that you will need more help over time. By sharing your diagnosis with those closest to you, you can build a support team to help you live with LBD.

As LBD progresses, you will likely have more trouble with everyday tasks such as taking medication, paying bills, and driving. You will gradually need more assistance from family members, friends, and perhaps professional carers. Although you may be reluctant to get help, try to let others work with you so you can manage responsibilities together. Remember, LBD affects your loved ones too. You can help reduce their stress and make them feel better when you accept their assistance. It is a win-win situation. Find someone you can talk with about your diagnosis. A trusted friend or family member, a mental health professional or a spiritual advisor may be helpful.

#### Safety

The changes in thinking and movement that occur with LBD require attention to safety issues. Consider these steps:

- Subscribe to a medical alert service. They will provide a button that can be worn around your neck or wrist or clipped to your belt which you can push to summon emergency help if needed.

- Address safety issues in your home, including areas where there is a risk of falling, poor lighting, stairs, or cluttered walkways. Think about home modifications that may be needed, such as installing grab bars in the bathroom, modifying stairs with ramps or installing a stair lift.
- Contact your local fire service and ask for a home fire safety check.
- Discuss LBD and driving with your doctor and, if appropriate, have your driving skills evaluated.

### Plan for your future

There are many ways to plan ahead. This section covers some areas you may wish to consider and discuss with your family.

If you are still working, consult with your employer or trade union about planning for disability leave or retirement. LBD symptoms will eventually interfere with work performance and it is essential to plan now to obtain benefits you are entitled to. You can get advice about benefits and your rights from your local Citizens Advice service or from charities such as Age UK. Your carer should also get information and advice about benefits and rights at work, for example from Carers UK.

Advance Care Planning is the term for the discussion between you, your family and carers, and those looking after you, about the sort of care you would like in future. This might include where you would like to be looked after in future and who care professionals should speak to if you can't make decisions any more. It's your chance to record your future health and care wishes and you can ask for it to be recorded in an advance care planning form and shared with everyone involved in your care. The NHS produces a guide to Advance Care Planning, and the National Council for Palliative Care may also have useful information.

Consult with a solicitor who specialises in elder law or estate planning to help you write or update important documents, such as a will, an advanced directive and lasting powers of attorney, for when you no longer are or feel capable of managing your affairs. There are two types of powers of attorney; one for health and welfare and the other for property and financial matters. Legal Aid support is available in some cases so you should ask your solicitor if you are entitled to this. If you can't afford a solicitor, these forms are available online (there are different versions available for England and Wales, Scotland and Northern Ireland). Alternatively, you or a friend can fill them out and take them to a Citizens Advice or law centre to look over.

Check with your local council and find out about home care, Meals-on-Wheels and other services before you need them so you know whom to call when the time comes. You will usually need to have a care assessment (also known as a needs assessment) to access these services and you may have to contribute towards the cost.

If there is an extra care retirement community in your area you may want to consider this. Extra care housing allows you to maintain your independence, but there are staff on hand and services provided if you need them. Be sure to ask about the staff's experience of caring for people with LBD.

Ask your GP or memory clinic team about community groups in your area that support patients and carers with dementia. There may also be short courses that you can attend which can help you learn ways to meet the challenges of dementia successfully.

### **Find enjoyment in every day**

It is important to focus on living with LBD. Your attitude can help you enjoy daily life. Despite the many changes and adjustments, you can still have moments of humour, tenderness and gratitude with the people closest to you.

Make a list of events and activities which you love to do—then find a way to do them! Listen to music, exercise or go out for a meal or to the cinema. Enjoy time with family and friends. If you can't find pleasure in daily life, consult your doctor or memory clinic team to discuss effective ways to cope. And let your family know if you are struggling emotionally or finding life difficult, so that they can offer support.



## FOR CARERS

### Educate others about Lewy body dementia

Most people, including many healthcare professionals, are not familiar with LBD. A&E doctors and other hospital workers may not know that people with LBD are extremely sensitive to antipsychotic medications.

Carers can educate healthcare professionals and others by:

- informing hospital staff of the LBD diagnosis and of medication sensitivities, and requesting that the person's neurologist or old age psychiatrist be consulted before any drugs to control behaviour problems are given;
- sharing pamphlets and other educational materials with doctors, nurses, and other healthcare professionals who care for the person with LBD;
- writing to your MP to tell them about LBD, how it differs from other forms of dementia, and the importance of research;
- telling everyone you know about LBD, not only so that they can understand your situation but pass the information on to others. Everyone knows someone with dementia but the chances are that they equate it with Alzheimer's. They may wonder why the person they know with dementia has hallucinations or fluctuations of consciousness.

### Prepare for emergencies

Sometimes people with LBD may experience sudden declines in their ability to function or unpredictable behaviours that can result in visits to A&E.

Infections, pain or other medical conditions often cause increased confusion or behavioural problems.

Carers can prepare for emergencies by having available:

- a list of the person's medications and dosages;
- a list of the person's health conditions, including allergies to medicines or foods;
- the person's NHS or private health insurance card;
- copies of any healthcare advance directives and/or health and welfare powers of attorney;
- contact information for doctors, family members and friends.

### Adjust expectations

You will likely experience a wide range of emotions as you care for a person with LBD. Sometimes caring will feel loving and rewarding. Other times you will be angry, impatient, resentful or exhausted. You must recognise your strengths and limitations, especially in light of your past relationship with the person. Roles may change between a husband and wife or between a parent and adult children. Adjusting expectations can allow you to approach your new roles realistically and to seek help as needed.

People approach dealing with LBD differently. Some people want to learn everything possible and be prepared for every scenario, whilst others manage best by taking one day at a time. Caring for someone with LBD requires a balance. On the one hand, you should plan for the future. On the other hand, you may want to make each day count in personal ways and focus on creating enjoyable and meaningful moments. Caring for someone with LBD can be extremely frustrating but it is the ultimate expression of unconditional love.

### Care for yourself

As a carer, you play an essential role in the life of the person with LBD, so it is critical that you maintain your own health and well-being. You may be at increased risk of poor sleep, depression or illness as a result of your responsibilities. Watch for signs of physical or emotional fatigue such as irritability, withdrawal from friends and family, and changes in appetite or weight. Remember, every plane journey begins with the instruction to put your own oxygen mask on before helping someone else. No matter what you do you will probably find yourself feeling guilty. It's irrational but it goes with being a carer. Try to ignore it!

All carers need time away from their responsibilities in order to maintain their own well-being. Learn to accept help when it is offered and be willing to ask family and friends for assistance. One option is professional respite care, which is available from many organisations and agencies throughout the UK. See the Resources section for further information.

When someone asks if there is anything they can do, take the offer up. Friends or family will probably be glad to help out in your home or take the person with LBD on an outing to give you a few hours break. Don't be afraid to ask.



### Address family concerns

Not all family members may understand or accept LBD at the same time and this can create conflict. Some adult children may be supportive whilst others may deny that their parents have a problem. It can take a while to adapt to new roles and responsibilities. Occasional visitors may not see the symptoms that primary carers must cope with daily and may underestimate or minimise the causes of your stress. Professional counsellors can help with family meetings or provide guidance on how families can work together to manage LBD.



## Changing relationships

Diane's husband, Jim, was diagnosed with Lewy body dementia two years ago. Their son and daughter, who live a considerable distance away, thought that Diane was making too much of his illness. She asked them to come to a family meeting. A counsellor who specialises in geriatrics gave the children helpful educational materials and the family talked about the kind of emotional support Diane needed. As a result, they are now working together as a team.



## Helping younger people cope with LBD

Lewy body dementia affects the whole family, including children and grandchildren. They will start to notice when a person acts differently than they are used to and this may upset or frighten them. Help them understand these changes by explaining that the person they know or love, who seems to be acting strangely, has been diagnosed with a brain disorder. Give them enough information to answer questions or provide explanations without overwhelming them. You can find resources online that explain dementia in ways that are appropriate for different age groups.

Children and teenagers may feel a loss of connection with the person with LBD who has problems with attention or alertness. They may be frightened if the person says something bizarre or uncharacteristic and their feelings may be hurt if that person does not recognise them. They may also resent the attention the parent carer gives to the patient and may need to have their own special time with the parent. Look for signs of disturbance in children, such as difficulties with school, withdrawal from friendships or unhealthy behaviours. Parents may want to notify teachers that someone in the family has LBD so they can watch for signs of stress that warrant attention.

Here are some other ways parents can help children and teenagers when a family member has LBD:

- Try to keep home life as normal as possible and keep up with activities such as sports, clubs and other hobbies outside the home. Suggest ways they can engage with the relative with LBD through structured activities. For example, the young person can make a cup of tea for the person with LBD, go through photo albums with them or listen to music and sing together.
- Make time for fun. Many challenges can be faced when they are balanced with enjoyable times. Whilst LBD causes significant changes in family routines, children and teenagers will cope more effectively if the disorder becomes partly integrated into their lives, without taking over entirely.

## Research – the way forward

Lewy body dementia is of increasing interest in its own right, as well as to the Alzheimer's and Parkinson's disease research communities. It represents an important link between these other brain disorders and research into one disease often contributes to better understanding of the others. However, there are many things to learn about LBD, such as why alpha-synuclein creates Lewy bodies and what role Lewy bodies play in causing the symptoms of LBD.

Many avenues of research focus on improving understanding of LBD. Some researchers are working to identify the specific differences in the brain between dementia with Lewy bodies and Parkinson's disease dementia.

Others are looking at the underlying biology, genetics and environmental risk factors relating to the disease. There is also research into identifying biomarkers (biological indicators of disease) and improving screening tests to aid diagnosis.

### Join Dementia Research – how you can help

Scientists hope that new knowledge about LBD will one day lead to more effective treatments and even ways to cure and prevent the disease. Until then, researchers need volunteers with and without LBD for clinical studies. People with LBD who volunteer for these important studies may receive highly specialised care and access to medicines that are not otherwise available.

Join Dementia Research is a service which allows people to register their interest in participating in dementia research and be matched to suitable studies.

You can sign up by visiting:

<https://www.joindementiaresearch.nihr.ac.uk/>

Supporting research is a primary objective of the Lewy Body Society. Most of the generous donations we receive go directly towards the grants that we offer to researchers. We are a member of the Association of Medical Research Charities which helps ensure that the research we fund is rigorous, credible and independent. We have a Specialist Advisory Committee of experts which chooses which applications are successful each year. You can find out more about our research strategy and the projects we are currently funding on our website.





## Resources

All telephone numbers are in the UK and callers from abroad need to use the country code +44

### The Lewy Body Society

**www.lewybody.org**

**Phone:** 01942 914000

**Email:** [info@lewybody.org](mailto:info@lewybody.org)

**Facebook:** @LewyBodySociety

**Twitter:** @lbsorg

Founded in 2006, the Lewy Body Society was the first charity in Europe dedicated exclusively to Lewy body dementia. The charity's mission is to raise awareness of LBD amongst the general public and educate those in the medical profession and decision-making positions about all aspects of the disease and to support research into the disease.

### Admiral Nurse Dementia Helpline

**Phone:** 0800 888 6678

**Email:** [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Open Monday-Friday 9am-9pm and weekends 9am-5pm

The Admiral Nurse Dementia Helpline is a free service offering expert advice for anyone affected by dementia. The Lewy Body Society has a partnership with Dementia UK to offer the service to people affected by LBD. The nurses are highly trained and experienced and will listen to you and offer advice and support.

### Age UK

**www.ageuk.org.uk**

**Phone:** 0800 055 6112

**Email:** [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)

Age UK aims to improve later life for everyone through information and advice, services, campaigns, products, training and research. They provide useful information on social care and offer support through its groups and a range of local services.

### Alzheimer Europe

**www.alzheimer-europe.org**

**Phone:** +352 29 79 70

**Email:** [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)

Based in Luxembourg, this is a federation of national Alzheimer's societies which aims to raise awareness of Alzheimer's disease and other dementias through cooperative effort. The website also offers useful tips for carers.



### **Alzheimer Scotland**

**www.alzscot.org**

**Phone:** 0131 243 1453

**24 hour helpline:** 0808 808 3000

**Email:** info@alzscot.org

Alzheimer Scotland is the leading dementia organisation in Scotland. It campaigns for the rights of people with dementia and their families and provides an extensive range of support services.

### **Alzheimer's Disease International**

**www.alz.co.uk**

**Phone:** 020 7981 0880

**Email:** info@alz.co.uk

Alzheimer's Disease International (ADI) works locally by empowering Alzheimer's associations in each country to promote and offer care and support for people with dementia and their carers, whilst working globally to focus attention on dementia.

### **Alzheimer's Research UK**

**www.alzheimersresearchuk.org**

**Phone:** 0300 111 5555

**Email:**

enquiries@alzheimersresearchuk.org

The UK's leading research charity for dementia, dedicated to funding scientific studies to find ways to treat, cure or prevent all dementias. ARUK also provides a booklet on dementia with Lewy bodies, which is available in Welsh.

### **Care to be different**

**www.caretobedifferent.co.uk**

**Phone:** 0161 979 0430

A specialist information resource providing practical tips and advice about NHS Continuing Healthcare. N.B. This is not a charity/statutory information service – some services incur charges.

### **Carers UK**

**www.carersuk.org**

**Phone:** 020 7378 4999

**Email:** advice@carersuk.org

**Helpline:** 0808 808 7777 open Monday and Tuesday 10am-4pm

Carers UK is the national membership organisation for carers. It provides expert advice, information and support, has local groups and an online support community, and campaigns for better support for carers.

### **Carers Trust**

**www.carers.org**

**Phone:** 0300 772 9600

**Email:** info@carers.org

Carers Trust works to improve support, services and recognition for anyone living with the challenges of unpaid caring for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. With its Network Partners, Carers Trust aims to ensure that information, advice and practical support are available to all carers across the UK. It provides a database of local carer services.

### **Dementia Journeys**

**www.dementiajourneys.com**

A forum that aims to provide a safe place for patients and carers to share their thoughts, feelings and experiences of their Dementia Journey. It attracts experts with experience of the Dementia Journey so they can share their knowledge with members and facilitate friendships through the forum. A place of peace, respect, listening, positive contributions and of course... smiles, love and laughter.

### **Dementia UK**

**www.dementiauk.org**

**Phone:** 0300 365 5500

**Email:** info@dementiauk.org

Dementia UK is a national charity committed to improving quality of life for all people affected by dementia. The charity provides Admiral Nurses, who are specialist dementia nurses who provide practical and emotional support to family/carers of people with dementia

### **FirstStop Advice**

**www.firststopcareadvice.org.uk**

**Email:** info@firststopadvice.org

Provides independent, free advice and information about care and housing options in later life.

### **Housing and Care Options**

**www.housingcare.org**

Offers comprehensive, easy to find information on all aspects of care, support and housing for older people.

### **European Parkinson's Disease Association**

**www.epda.eu.com**

**Email:** info@epda.eu.com

A federation of European PD societies throughout Europe, with its secretariat in the UK.

### **Giving Voice for People with Dementia**

**www.rcslt.org**

**Phone:** 0207 378 3630

**Email:** info@rcslt.org

The Royal College of Speech and Language Therapists (RCSLT) runs the Giving Voice for People with Dementia campaign to improve the quality of care received by people with dementia, their families and their carers. People with dementia and their carers have a range of needs in communication, safe eating and drinking, which should be met by individuals with the appropriate clinical expertise or those who have been trained by people with that expertise.

### **Life Story Network**

**www.lifestorynetwork.org.uk**

**Phone:** 0151 237 2669

**Email:** enquiries@lifestorynetwork.org.uk

Life Story Network promotes the value of using personal stories to improve the quality of life and well-being of people marginalised or made vulnerable through ill health or disability, including dementia. Life stories enable care staff to grasp who the person with dementia really is, thus enabling provision of more person-centred care.

### **Parkinson's UK**

**www.parkinsons.org.uk**

**Helpline:** 0808 800 0303

**Email:** hello@parkinsons.org.uk

As parkinsonism is a core feature of dementia with Lewy bodies, many people are misdiagnosed as having Parkinson's disease. Parkinson's UK offers support for patients and carers, including excellent advice on coping with daily activities. The charity has a range of information on Lewy body dementia – see [www.parkinsons.org.uk/dementia](http://www.parkinsons.org.uk/dementia).

### **Relatives & Residents Association**

**www.relres.org**

**Phone:** 020 7359 8136 helpline open

Monday to Friday 9:30am-1pm

**Email:** info@relres.org

The Association provides information and help both for older people in need of or living in residential care and their friends and families.

### **The Alzheimer's Society**

**www.alzheimers.org.uk**

**Phone:** 020 7423 3500

**Helpline:** 0300 222 11 22

**Email:** enquiries@alzheimers.org.uk

The Alzheimer's Society provides a wide range of information on all aspects of dementia, including caring for someone with dementia. It also provides a range of local services and groups and has a helpline and Live Online Advice service.

### **Tourism for All**

**www.tourismforall.org.uk**

**Phone:** 0845 124 9971

**Email:** info@tourismforall.org.uk

Tourism for All UK is the UK voice for accessible tourism. It is a national charity dedicated to making tourism welcoming to all, including people with dementia as well as those with mobility challenges.

### **When They Get Older**

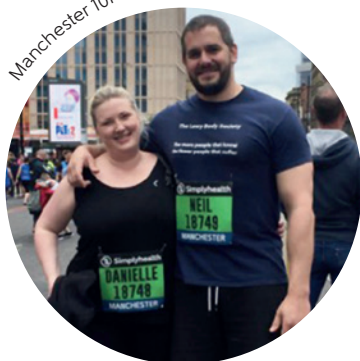
**www.whentheygetolder.co.uk**

**Email:** editor@whentheygetolder.co.uk

This is an idea-sharing website which helps family members care for their older relations.



Manchester 10K



Read about these challenges and request your own fundraising pack on our website at [www.lewybody.org](http://www.lewybody.org)

Showtime Challenge 48-Hour Musicals. Photograph by Darren Bell



**Richard Branson** @richardbran... · 12m ✓  
Incredible to read that a @VMGiving fundraiser has broken the world record for the 289-mile Enduroman Arch to Arc triathlon from London to Paris. Huge congratulations Chris [thetimes.co.uk/article/6870a3...](https://thetimes.co.uk/article/6870a3...) #readbyrichard



#### Disclaimer

Although the Lewy Body Society strives to ensure that it is accurate, the information contained in this guide should not be considered medical or professional advice. It is published as a general overview only. The Society, its agents and others involved in assembling or disseminating information are not responsible for any errors or omissions therein, or any action resulting therefrom. If you think that you or someone you know might be experiencing symptoms of Lewy body dementia, please consult your GP or another qualified medical professional immediately. You are advised to confirm any information contained in this guide or otherwise originating from the LBS with other reliable sources. The LBS cannot be held responsible for information or advice provided by organisations or publications linked to this guide.



Showtime Challenge 48-Hour Musicals. Photograph by Darren Bell

Wigan 10K

Manchester 10K

Great Glen Walk



“

I became patron of the Lewy Body Society because my husband, Robert Arnold, died of Lewy body dementia. The charity was founded so that more people become aware of this disease. The Lewy Body Society is so important because it is dedicated solely to this disease, providing information and sponsoring research. It is imperative that more research is done in the hope of prevention, better treatment, and ultimately, a cure.

”

June Brown MBE



## The Lewy Body Society

Shining a light on Lewy body dementia

**A:** Unity House, Westwood Park, Wigan WN3 4HE  
**T:** 01942 914000 **E:** [info@lewybody.org](mailto:info@lewybody.org) [www.lewybody.org](http://www.lewybody.org)

 [lewybodysociety](https://www.facebook.com/lewybodysociety)   [lbsorg](https://twitter.com/lbsorg)

**amrc**

Member of the Association  
of Medical Research Charities