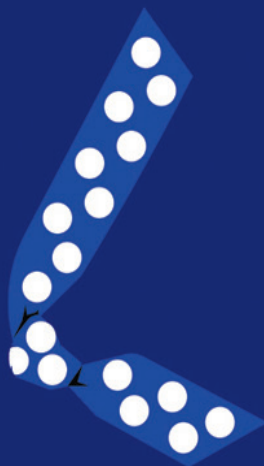


The Lewy Body Society

Registered charity number 1114579



Information about Lewy Body Dementia

The more people who know, the fewer people who suffer.

In loving memory of

**Joe Cannon
Princess Millicent Medvied
Catherine (Kit) Rayner**

Table of contents

Chapters

Introduction	p3
<hr/>	
Part One:	Overview p5
	Types of LBD p7
	Causes and risk factors p9
	Symptoms p10
	Diagnosis p16
	Treatment p20
<hr/>	
Part Two:	Advice for patients and carers p26
	Research - the way forward p33
<hr/>	
Part Three:	Resources p34
<hr/>	
Medical Alert Card	p50



Introduction

Lewy body dementia (LBD) is a complex, challenging and common brain disorder. It is complex because it affects many parts of the brain in ways that scientists are trying to understand more fully. It is challenging because its many possible symptoms make it difficult for the patient to do everyday tasks that once came easily and difficult also for a doctor to diagnose.

Although less known than Alzheimer's and Parkinson's diseases, LBD is not a rare disorder. It has been called: "the most common disease you've never heard of". It accounts for about 15 - 20% of all dementia cases. Approximately 125,000 people in the United Kingdom suffer from its disabling effects upon their ability to think and act. Taking into account families and/or other carers who have to deal 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 struggle from day to day to get an accurate diagnosis, find the best treatment and manage the disease at home.

There are two types of LBD: dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). The difference between them is essentially the timing of the major symptoms, which will be explained on pages 7 and 8. In this booklet the term LBD will be used unless something pertains particularly to either DLB or PDD. With the passage of time, people with DLB or PDD tend to develop similar symptoms.

This booklet is meant to help people with LBD, their families and healthcare professionals learn more about the disease and find ways and resources to help them cope with it. 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 and their carers. A list of resources can be found on page 34.



Overview

Dementia is 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.

LBD is caused by abnormal deposits of a protein called alpha-synuclein in the brain. These deposits are called Lewy bodies, after Dr Friederich 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% 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 disease, 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 or other rarer disorders. Early LBD symptoms are often confused with similar symptoms typical of other dementias.

It can occur alone (dementia with Lewy bodies) or along with Alzheimer's or Parkinson's diseases.

Who is affected by LBD?

LBD typically begins at the age of 50 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 it can range from 2-20 years. How quickly the disease progresses varies greatly from person to person, depending on overall health, age and severity of symptoms.

In the early stages of LBD, usually before a diagnosis is made, symptoms can be mild and people may be able to function fairly normally. As the disease advances people with LBD require increasing amounts of help as their ability to think and move declines. In the late stage of the disease they may have to depend entirely on others for assistance and care and can 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 hopefully will 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 neurons, 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).



Types of Lewy body dementia

Early Parkinson's disease is characterised as a movement disorder whilst dementia with Lewy bodies initially presents as a cognitive condition. When cognitive symptoms appear within a year of movement problems, it is considered to be DLB. In Parkinson's disease dementia the cognitive symptoms develop more than a year after the onset of movement problems.

Dementia with Lewy bodies

DLB initially appears 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;
- REM sleep behaviour disorder in which people physically act out their dreams;
- 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 disease dementia

This type of dementia starts as a movement disorder, with symptoms such as slowed movement, muscle stiffness, tremor or a shuffling walk. These symptoms generally lead to a diagnosis of Parkinson's disease. Cognitive symptoms of dementia and changes in mood and behaviour may arise later on.

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.

Parkinson's progress

When Betty retired as a school dinner lady she devoted her time to her family, especially her three granddaughters. 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.



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 neurons in the brain which produce two vital neurotransmitters, which are 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, sleep and mood.

Research has shown that age is the greatest risk factor. As previously stated, most people who develop LBD are over the age of 50.

Other known risk factors include:

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 normally considered to be a genetic disease.

A genetic association has been suggested in a small percentage of families in which someone has LBD but in most cases the cause is unknown.

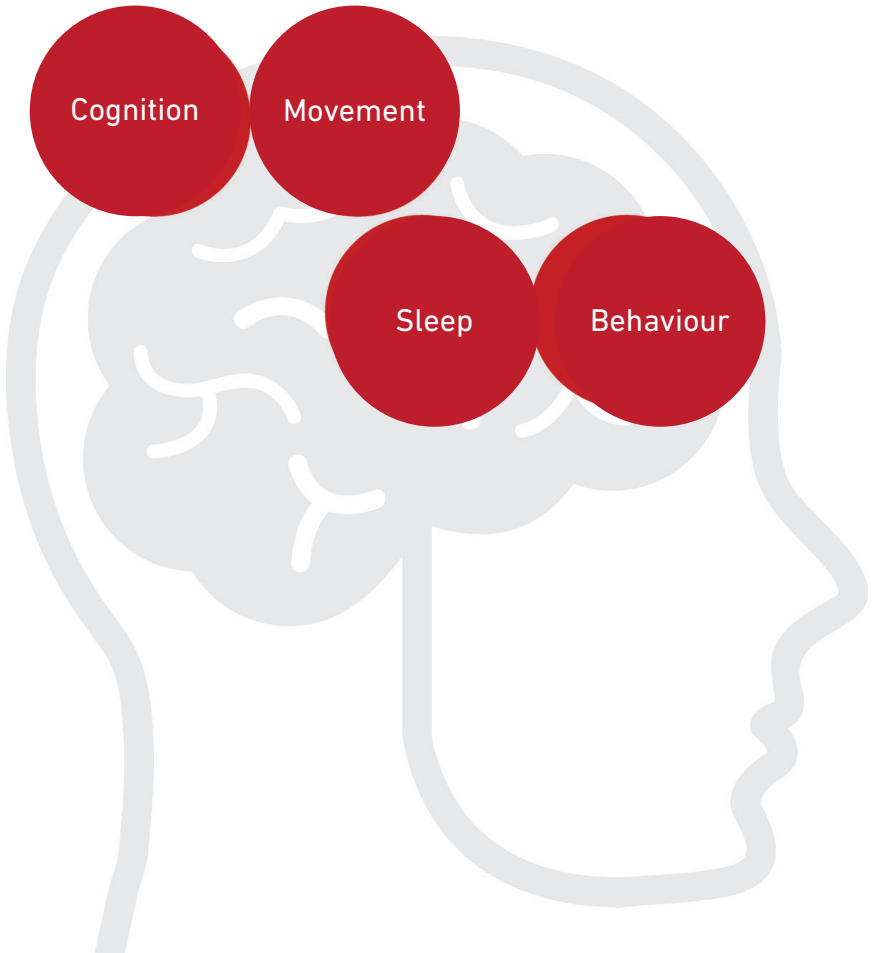
At this time a genetic test to predict accurately a predisposition to LBD has not been developed but future genetic research should reveal more information about causes and risks.

No specific lifestyle factor has yet been 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 might reduce the risk of age-related dementia. What's good for a person's heart is also good for the brain.

Symptoms

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

The most common symptoms include changes in;



Cognitive symptoms

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

Dementia

Dementia is a primary symptom of LBD. It usually includes problems with visual and spatial perception, such as judging distance and depth or misidentifying 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 movie. This roller coaster of cognitive states is one of the particularly difficult symptoms a carer must deal with. 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% 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 one of most frustrating and upsetting things that carers have to cope with. Like the fluctuations of consciousness, they rarely occur in the presence of a doctor. If the carer can bear doing it and it doesn't upset the person with LBD even further, an unobtrusively made video of that person experiencing a hallucination can be useful to a doctor who has not witnessed it.

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 tremor of Parkinson's is often not present in the early stages of LBD, as it is with Parkinson's disease. Many people are misdiagnosed as having Parkinson's. This can be very unfortunate as some of the drugs used to treat Parkinson's 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 for 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 discreetly taken video could be very useful for a doctor in making an accurate diagnosis. 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 one's sleep, violent movements or falling out of the bed. REM sleep behaviour disorder appears in some people years before other LBD symptoms.
- **Excessive daytime sleeping**, such as sleeping for more than 2 hours during the day despite getting 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.

Behavioural and mood symptoms

Changes in behaviour and mood may occur. These changes may include:

- **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.
- **Apathy** - This is 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** - This is intense apprehension and uncertainty or fear about particular events or situations. Anxiety can also be just general and non-specific.
- **Agitation** - Examples of restlessness are pacing, hand-wringing, inability to settle down, irritability or repetition of words or phrases.
- **Delusions** - These are 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.
- **Paranoia** - When someone is paranoid they have 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

Because its early symptoms resemble those of Alzheimer's and Parkinson's diseases or common mental health or movement disorders, dementia with Lewy bodies 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 is 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. This also allows them to build a support team to help them stay independent as long as possible and maximise quality of life. It is important to allow time to adjust to the diagnosis. Discussing it can help focus on a treatment plan.

How is LBD diagnosed?

Unfortunately, many physicians and other healthcare professionals are not yet familiar with LBD, which means that a patient may have to see more than one doctor before they receive a diagnosis. The first step is to visit a general practitioner, who can refer the patient to a local memory clinic or other service.

Memory clinics and services vary widely in the way they operate but generally the person will be seen by a specialist doctor – a neurologist, an old age psychiatrist or a geriatrician - either in a clinic or at home (depending on location). 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 the person's memory problems affect other members of the family. Sometimes a diagnosis can be made at the end of the assessment but it is also possible that further tests may be suggested.



It is important for the patient to be accompanied to the clinic by a carer, close friend or relation. It is always very helpful for anyone to have another pair of ears at any consultation or assessment. 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.

Tests used to diagnose LBD

- Medical tests can help rule out other diseases and vitamin or hormonal deficiencies which can cause dementia.
- Neuropsychological tests are used to assess memory and other cognitive functions and can help identify affected regions of the brain.
- 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 definitely 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 scan) and SPECT scans have shown promise in detecting the differences between Alzheimer's disease and dementia with Lewy bodies. These methods may help diagnose certain features of the disease, such as a deficiency in dopamine, a hormone which regulates, amongst other things, movement and emotional responses. Research is also being made into the use of a lumbar puncture (spinal tap) to measure proteins in the spinal fluid that might distinguish dementia with Lewy bodies from Alzheimer's and other brain disorders.

What are the possible outcomes of the assessment?

- There is no evidence at this time of a serious memory problem but that another assessment should be made in 6 or 12 months time if the problem gets worse; or
- The results of the tests suggest one of the conditions which affect cells in the brain in older people such as Lewy body disease.

The patient will be provided with written information about the condition and discuss the next steps to be taken.

A specialist doctor such as old age psychiatrist, neurologist or geriatrician 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;
- a community psychiatric nurse to help patients and their families deal with the difficult emotions they must cope with.

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

The role of palliative care

Many people associate palliative care with end of life issues and that is certainly the mission of the hospice movement. But the role of palliative care is to improve a person's quality of life at any stage of disease and make the patient as comfortable as possible. The aim is to relieve troubling symptoms, assist with medication, offer emotional support and coordinate care. Support can be given to the patient and carer by nurses, social workers, physical therapists, dieticians and pharmacists as well as doctors. Information about obtaining palliative care is offered by the National Council for Palliative Care, Dementia UK, the National Health Service, Carers UK and other organisations and agencies listed in the Resources section at the back of this booklet.

Treatment

Whilst there is yet no cure for LBD, there are drugs and other treatments available to treat LBD symptoms. They cannot stop or reverse the course of the disease but for some people they can slow the progress. It is essential to work with a knowledgeable healthcare professional because many medications make symptoms worse or can even have life-threatening side effects. Potential benefit must be carefully weighed against possible harmful or dangerous side effects. Some of the drugs used to help with motor problems can exacerbate cognitive problems and vice versa. Many people with LBD are highly sensitive to any sort of medication so drug treatment is not really an option for them. Some symptoms, however, may sometimes be improved with non-drug treatment.

Cognitive symptoms

Some of the medications used to treat Alzheimer's disease (**cholinesterase inhibitors**) can sometimes help with the cognitive symptoms of LBD. 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.

Motor symptoms

Some people's movement problems can be helped by 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.

Some people with LBD benefit from physical therapy and this is an option which the memory clinic team will probably recommend if appropriate.



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 increased 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 add to the carer's burden.

Some doctors may prescribe drugs such as **clonazepam**, a powerful drug which is used to control seizures and panic attacks for REM sleep disorders and Restless Leg Syndrome but they can have dangerous and unpleasant side effects such as dizziness, unsteadiness and increased cognitive problems. Stimulants are sometimes prescribed for people with excessive daytime sleepiness and sleep medications are sometimes prescribed for insomnia.

It is very important to note that drug treatment for sleep disorders in people with LBD has not been extensively investigated. They can worsen LBD 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.

Behavioural and mood problems – approach with caution

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 challenging 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 behavioural problems to suddenly grow worse and increase 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 20, 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 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 better quality of life despite her dementia.



Hallucinations and delusions are among the biggest problems for carers and family members. They can be frightening to both the person experiencing them and anyone watching someone in the midst of a 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.

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.

Antidepressants can be used to treat depression and anxiety, which often occur with LBD. Two types of antidepressants, selective serotonin reuptake inhibitors (paroxetine and fluoxetine) and serotonin and norepinephrine reuptake inhibitors (venlafaxine), are sometimes well tolerated by people with LBD.

- 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 contribute to behavioural problems.
- Carefully consider treating with medications if necessary and watch for side effects.

Caution about antipsychotic medications

Sometimes a doctor will prescribe antipsychotic medications to treat severe LBD-related behavioural symptoms in order to improve the quality of life and safety both of the person with LBD and the carer. 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.

This is the same dilemma as with Parkinson's drugs which help with movement but exacerbate cognitive problems. Again, the risks associated with the medication must be weighed against the risk of physical harm which may result from untreated behavioural problems.

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 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.**



If surgery is planned and the person with LBD is told to stop taking all medications beforehand, the person's 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.

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. Here are some things to consider:

- If you are still working, consult with your employer, union or local Citizens' Advice Bureau (CAB) 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.
- 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 at www.gov.uk/government/publications/make-a-lasting-power-of-attorney (in Scotland www.publicguardian-scotland.gov.uk and in Northern Ireland www.nidirect.gov.uk/managing-your-affairs-and-enduring-power-of-attorney). Perhaps you or a friend can fill them out and take them to a CAB 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.
- If there is a continuing care retirement community in your area you may want to consider moving into it. 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 LBD

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 him about LBD and how it differs from Alzheimer's;
- 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.

Materials are available for free from the **Lewy Body Society** (www.lewybody.org). There are downloadable leaflets on the website and hard copies are available on request.

Prepare for emergencies

Sometimes people with LBD may experience sudden declines in functioning or unpredictable behaviours that can result in visits to the 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 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 airplane journey begins with the instruction to put your own oxygen mask on before helping someone else.

All carers need time away from their responsibilities in order to maintain their own well-being. Learn to accept help when it's offered and be willing to ask family and friends for help. 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.

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 or counselors 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.
- Find online resources for older children and teenagers so they can learn about dementia and LBD.
- 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, but not all of, their lives.



Research—the way forward

LBD is of increasing interest 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 disease's underlying biology, genetics and environmental risk factors. There is also research into identifying biomarkers (biological indicators of disease) and improving screening tests to aid diagnosis.

Scientists hope that new knowledge about LBD will one day lead to more effective treatments and even ways to cure and prevent the disorder. 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 medications that are not otherwise available. Find out more about clinical trials by looking at the Dementias and Neurodegeneration website at www.crn.nihr.ac.uk/dementia.

To date there have been very few treatment trials in Lewy body dementia but hopefully this situation will improve as new agents become available.

Supporting research is a primary objective of the Lewy Body Society.

Resources

CHARITIES

Unless indicated, 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: 0131 473 2385

email: info@lewybody.org

Founded in 2006, the Lewy Body Society is the only 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.

The Society is run solely by an operations team of volunteers. There are no paid employees and no actual headquarters. Hudson House is a service which provides an address and forwards mail and phone calls to the relevant member of the team at a fraction of the cost of rent and salaries. This way the Society is able to put at least 95% of all donations directly into research and awareness raising.

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 (www.parkinsons.org.uk/dementia) and through a partnership arrangement answers Helpline call for the Lewy Body Society.

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. They provide a booklet on dementia with Lewy bodies (www.alzheimersresearchuk.org/wp-content/uploads/2015/01/What-is-dementia-with-Lewy-bodies.pdf). Alzheimer's Research UK also administers grants funded by the Lewy Body Society.

Dementia UK

www.dementiauk.org

phone: 0845 257 9406

email: direct@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 (www.dementiauk.org/what-we-do/admiral-nurses), specialist dementia nurses who provide practical and emotional support to family/carers of people with dementia.

Admiral Nursing DIRECT

www.dementiauk.org/information-support/admiral-nursing-direct

phone: 0845 257 9406

email: direct@dementiauk.org

A telephone and email helpline run by experienced Admiral Nurses.

Age UK

www.ageuk.org.uk

phone: 0800 169 6565

email: contact@ageuk.org.uk

Age UK is the result of the merger of Age Concern and Help the Aged. It aims to improve later life for everyone through information and advice, services, campaigns, products, training and research. There is useful information on social care and support it offers its groups and a range of local services.

Alzheimer Europe

www.alzheimer-europe.org

phone: +352 29 79 70

email: info@alzheimer-europe.org

Based in Luxembourg, this is a federation of national Alzheimers' 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 Alzheimers' 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.

Care to be different

www.caretobedifferent.co.uk

phone: 01908 582231

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 Trust

www.carers.org

phone: 0844 800 4361

email: support@carers.org

Carers Trust is a charity which was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in 2012. 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 (www.carers.org/carers-services/find-your-local-service).

Dementia Care Matters

www.dementiacarematters.com

phone: 01273 242335

email: info@dementiacarematters.com

An independent team specialising in working with organisations and their staff in developing dementia care and mental health services for older people.

Dementia Challengers

www.dementiachallengers.com

email: dementiachallengers@gmail.com

A comprehensive source of information for carers compiled by carers.

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.

Elderly Accommodation Counsel (EAC)

www.eac.org.uk

phone: 0800 377 7070

email: info@firststopadvice.org.uk

A national charity that aims to help older people and their loved ones make informed choices about meeting their housing and care needs. It offers the following services:

FirstStop Advice

www.firststopcareadvice.org.uk, which provides independent, free advice and information about care and housing options in later life.

Freephone: 0800 377 7070, 9am to 5pm, Monday – Friday

Email: info@firststopadvice.org

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

phone: 0207 872 5510

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.givingvoiceuk.org/dementia

phone: 0207 378 3630

email: Campaigns@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.

Music & Memory

www.musicandmemory.org

Music and Memory is a non-profit organisation that brings personalised music into the lives of the elderly or infirm through digital music technology, thus vastly improving quality of life.

My Ageing Parent

www.myageingparent.com

email: info@myageingparent.com

An organisation set up to help children support their parents as they become older.

National Council for Palliative Care

www.ncpc.org.uk

phone: 020 7697 1520

enquiries@ncpc.org.uk

An umbrella organisation for all those in the UK dealing with and using hospice care. The Council recently issued a discussion document on palliative care for people with dementia.

Relatives & Residents Association

www.relres.org

phone: 020 7359 8136

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 (www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200343). They also provide a range of local services (www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200138).

Tourism for All

www.tourismforall.org.uk

phone: 0845 124 9971

email: info@tourismforall.org.uk

www.openbritain.net

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.

BOOKS

A Caregiver's Guide to Lewy Body Dementia
by Helen Buell Whitworth and James A. Whitworth
2010, Demos Health

Available from online retailers.

This useful book is written in everyday language and is filled with personal examples that connect to the readers' own experiences. It includes facts about the disease and caregiving tips for easy reference, a comprehensive resource guide, and a glossary of terms and acronyms. The Whitworths are founders of the US Lewy Body Dementia Association.

A Misted Mirror
by Gillian Jones
2011, Proverse Hong Kong

Available from online retailers

A novel inspired by her late husband Keith's Parkinson's disease dementia and his poetry.

Dementia Support for Family and Friends
by Dave Pustford and Rachel Thompson
2012, Jessica Kingsley Publications

Available from online retailers

Written for relatives and friends of people who suffer with dementia to help them understand the condition and cope with the impact it can have on their lives. This book looks at how the condition will affect the person and those around them as well as how best to provide support and assistance. Ms Thompson was one of the first Admiral Nurses before becoming Dementia Lead at the Royal College of Nursing. In 2014 she rejoined Dementia UK as Professional Lead of the Admiral Nurses. She is a member of the Lewy Body Society's Specialist Advisory Committee.

Dementia with Lewy Bodies and Parkinson's Disease

by Dr. J. Eric Ahlskog

2013, Oxford University Press USA

Available from online retailers

A guidebook for patients, families and clinicians working together for better outcomes of these challenging disorders.

Living with Dementia: A Caregiver's Journey

by Bishop Philip Weeks

2012, CreateSpace Independent Publishing Platform

Available to download online

The Most Reverend Philip Weeks is a retired bishop in the Charismatic Episcopal Church. He writes of his experience as caregiver for his wife, June, who was first diagnosed as having Alzheimer's disease in 2002 and subsequently with LBD. Without any warning or training in how to care for her, at first he did it alone. Then he tried adult day care and finally, home care with the help of care providers. The Bishop shares his failures and victories and tells how caring for his wife helped him mature into being a more loving husband and better person.

Living with Lewy Body Dementia

by Judy Towne Jennings

2012, Westbow Press

Available from online retailers

Written in 2012 by physiotherapist Judy Towne Jennings, this comprehensive guide benefits from professional and personal experience of dementia with Lewy bodies. Judy writes from personal experience of caring for her husband Dean and her many years of treating movement disorders.

Living with Lewy's: Empowering Today's Dementia Caregiver

by Amy and Gerald Throop

2010, Cando Books LLC

Over Streams and Squirrel Woods

by Alys Williams

2011, Alys Williams (Self-published)

Available from online retailers

This moving account is based on the personal diary kept by a loving daughter caring for her mother as they journeyed through the mother's struggle with LBD and eventual decline.

Telling Tales About Dementia: Experiences of Caring

Edited by Lucy Whitman

2009, Jessica Kingsley Publications

Available from online retailers

This book contains stories from thirty carers from different backgrounds and in different circumstances that share their experiences of caring for a parent, partner or friend with dementia.

Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease

by Pat Snyder

2012, CreateSpace Independent Publishing Platform

Available from online retailers.

Written by a carer, this book looks at enhancing and extending the early stage of Lewy body dementia drawing from the experiences of the writer.

Reviews of books about dementia can be found on the Dementia UK website www.dementiauk.org/information-support/books

VIDEOS AND PODCASTS

The Lewy Body Society

Has produced 3 podcasts featuring Society President, Professor Ian McKeith, who discusses the medical and scientific aspects of the disease. LBS Patron, June Brown MBE, recalls her experience of her late husband's DLB and Peter Ashley, a DLB patient, talks about living with the disease.

Alzheimer Scotland, Essential Conversations: Talking about Death and Dementia

www.essentialconversations.org.uk/index.html

A resource for health and social care professionals and family carers.

Bob And Jo's Story

www.youtube.com/watch?v=f4DWnhMcoy0

'Bob And Jo's Story' is a YouTube video from The Alzheimer's Society that supports honest conversation about changes in relationships after a diagnosis of dementia. The Alzheimer's Society offers more videos and podcasts (www.alzheimers.org.uk/multimedia).

Henry's Story

www.youtube.com/watch?v=5FWn4JB2YLU

Watch Henry's story from 'Alive inside' from the Music and Memory Project. A demonstration of the power of music and the importance of understanding someone's life story.

Naomi Feil and Gladys Wilson

www.youtube.com/watch?v=CrZXz10FcVM

This is a beautiful and moving demonstration of how to connect with someone with advanced dementia through empathy and song.

BLOGS

A Week with Mr Lewy Body

www.vblogs.com

Karen Wilson's father suffers from LBD. She has written an account of a week looking after him in order to raise awareness of all types of dementia, as well as some money for the LBS and AZUK.



Creating Life with Words: Inspiration, Love and Truth
www.kateswaffer.com

Kate Swaffer is an Australian who has dementia.

(Dementia Just Ain't) Sexy
www.dementiajustaintsexy.blogspot.co.uk

A thoughtful blog written by scriptwriter Ming Ho about the impact of dementia on those who live with it.

D4Dementia
www.d4dementia.blogspot.co.uk

A blog written by Beth Britton who is a dementia campaigner, care consultant and freelance writer.

Lewy Body Journey
www.lewybodyjourney.wordpress.com

A wife writes of her experiences of her husband's dementia with Lewy bodies.

Living Well With Lewy Body Dementia
www.ken-kenc2.blogspot.co.uk

This blog is written by Ken Clasper, who has DLB and is an ambassador for the Lewy Body Society and LBD advocate.

Tommy On Tour
www.tommy-on-tour-2011.blogspot.co.uk/

Based in Glasgow, Tommy Whitelaw cared for his mother who had vascular dementia. He collects the life stories of dementia carers in order to raise awareness of both dementia and caring amongst health and social care professionals.

OTHER SOURCES OF INFORMATION AND SUPPORT

CANDID (Counselling and Diagnosis in Dementia)

www.dementia.ion.ucl.ac.uk

Phone: 020 7829 8773

A service of the Dementia Research Group at the National Hospital for Neurology and Neurosurgery, providing information and support for people with dementia and their carers.

Counselling Directory

www.counselling-directory.org.uk

Phone: 0844 8030 240

The Counselling Directory was set up to connect visitors with a wealth of information including the ability to search for the most suitable counsellor or psychotherapist.

Dementia and Elderly Care News

www.dementianews.wordpress.com

An information portal to research, policy and service developments in dementia and the care of older people.

Dementia Partnerships

www.dementiapartnerships.org.uk

Provides resources for people, partnerships and networks working to improve outcomes for people living with dementia.

GOV.UK

www.dh.gov.uk/health/category/policy-areas/social-care/dementia

NHS Choices

www.nhs.uk/conditions/dementia/pages/introduction.aspx



The National Institutes of Health (USA)

These are two excellent sites all about dementia with Lewy bodies.

Medline Plus: www.nlm.nih.gov/medlineplus/lewybodydisease.html

National Institute Of Neurological Disorders And Stroke: www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm.

Disclaimer

Although the Lewy Body Society conscientiously strives to ensure that it is accurate, the information contained in this booklet 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 booklet 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 site.

Acknowledgement

The Lewy Body Society is very grateful to the U.S. National Institutes of Health, namely the National Institute on Aging and the National Institute of Neurological Disorders and Stroke for allowing the Society to base this booklet on their 2014 publication, Lewy Body Dementia: Information for Patients, Families and Professionals and adapt it for use and relevance to the U.K.

MEDICAL ALERT CARD



The Lewy Body Society

The information on this card is intended for general informational use only. It is not intended to be medical advice or to take the place of competent medical professionals who are familiar with a particular patient's situation. Each individual is advised to make an independent judgement regarding the content and the use of this information.

With many thanks to the Lewy Body Dementia Association Inc (USA) for permitting the Lewy Body Society to adapt their medical alert card for British use.

I have a disorder of the brain known as **LEWY BODY DEMENTIA (LBD)** which could make me appear confused and have difficulty moving or speaking normally.

Please call my family or my doctor

My Name: _____

Address: _____

Person to Call: _____

Address: _____

Phone: _____

GP: _____

Phone: _____

Allergies: _____

Other Medical Conditions: _____

Emergency Treatment of Psychosis in LBD

Psychotic symptoms such as visual hallucinations, or misidentifying one's spouse or home are common in LBD. The goal of addressing these symptoms is to ensure the safety of the patient and others.

1. Identify possible causes of delirium, e.g., pain, infection, metabolic stress, alcohol withdrawal.
2. Reduce or eliminate anticholinergic medications, such as OTC sleep agents and bladder-control medications, and reduce dopaminergic drugs used to treat Parkinson's disease, if clinically indicated.
3. Consult with a doctor experienced in treating LBD. Cholinesterase inhibitor drugs may improve cognition and psychiatric symptoms, although such effects are not usually immediate.
4. Antipsychotic agents may be indicated if psychotic symptoms are severe and pose a significant safety risk. AVOID traditional antipsychotic agents (e.g., haloperidol). Newer atypical antipsychotic agents (e.g., quetiapine, clozapine) should only be used with caution at the lowest dose possible, under close supervision of a doctor and should be switched to a safer medication as soon as possible.

For more information about
Lewy body dementia, please
go to www.lewybody.org

WARNING

Up to 50% of patients with LBD who are treated with any antipsychotic medication may experience severe neuroleptic sensitivity (worsening cognition, heavy sedation, increased or possibly irreversible parkinsonism, or symptoms resembling neuroleptic malignant syndrome which can be fatal)

A WORD FROM OUR PATRON

"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 more people who know, the fewer people who suffer."

June Brown MBE



The Lewy Body Society
Hudson House, 8 Albany Street, Edinburgh
EH1 3QB
Tel: 0131 473 2385
Email: info@lewybody.org
Press enquiries to lewybodypress@gmail.com

You can also find us on Facebook



Follow us on Twitter @lbsorg

