

# Dementia with Lewy Bodies



**DSiDC**

Dementia Services Information  
and Development Centre

# Dementia with Lewy Bodies

**Dementia with Lewy bodies (DLB) is a brain illness. It's described as a progressive illness because its symptoms get worse over time.**

People with DLB develop abnormal proteins in their brain. When these abnormal proteins build up, they cause brain cells to die. This can make thinking and remembering difficult.

DLB can make a person feel confused and cause their movements to slow down. It can also make it difficult for them to sleep and they may have visual hallucinations.

Changes are often small to start with but they will progress so that they start to affect a person's daily life.



# Symptoms

DLB can take many years to develop and people can have many different symptoms. The symptoms are not always the same for everybody – and they can appear better or worse at different times.

The areas affected by DLB include:

- › Thinking
- › Behaviour
- › Sleep
- › Movement
- › Visual hallucinations
- › Bodily functions

## Thinking

Some of the thinking and memory problems that come with DLB may appear similar to Alzheimer’s disease. These can include slower thinking and having difficulty paying attention, concentrating and making decisions. However, a person with DLB may not experience the severe memory loss associated with Alzheimer’s until later in their illness.

## Movement

People with DLB often have problems with movement and these can look similar to those seen in people with Parkinson’s Disease.

With DLB, movement often becomes slower and people may shuffle when they walk. Their muscles sometimes become stiff and rigid and they may also have tremors in their arms or legs.

Often, when a person has DLB, their handwriting becomes smaller, their voice becomes quieter and their facial expression is reduced.

## Behaviour

DLB can affect a person’s emotions. They may suffer from low mood and depression. They may also lose motivation or interest in what is going on around them.



## Sleep

Some people may have disturbed sleep. They may have vivid dreams and restless sleep, called REM Sleep Behaviour Disorder (RBD). They may speak, shout or start to “act out” their dreams. It is common for people to feel drowsy during the day.

## Visual hallucinations

A visual hallucination occurs when a person sees something that is not there. This is a common symptom and can be upsetting for the person with DLB and those close to them. People with DLB also sometimes hear or smell things that are not there.

## Bodily functions

DLB can also interfere with the way a person’s body functions. For example, it can cause constipation and bladder problems and affect sexual functions. It may also affect their body’s ability to control their temperature and blood pressure. At times, blood pressure may become low or it may drop quickly when a person stands up. This may make them feel lightheaded and it increases the risk that they might fall.



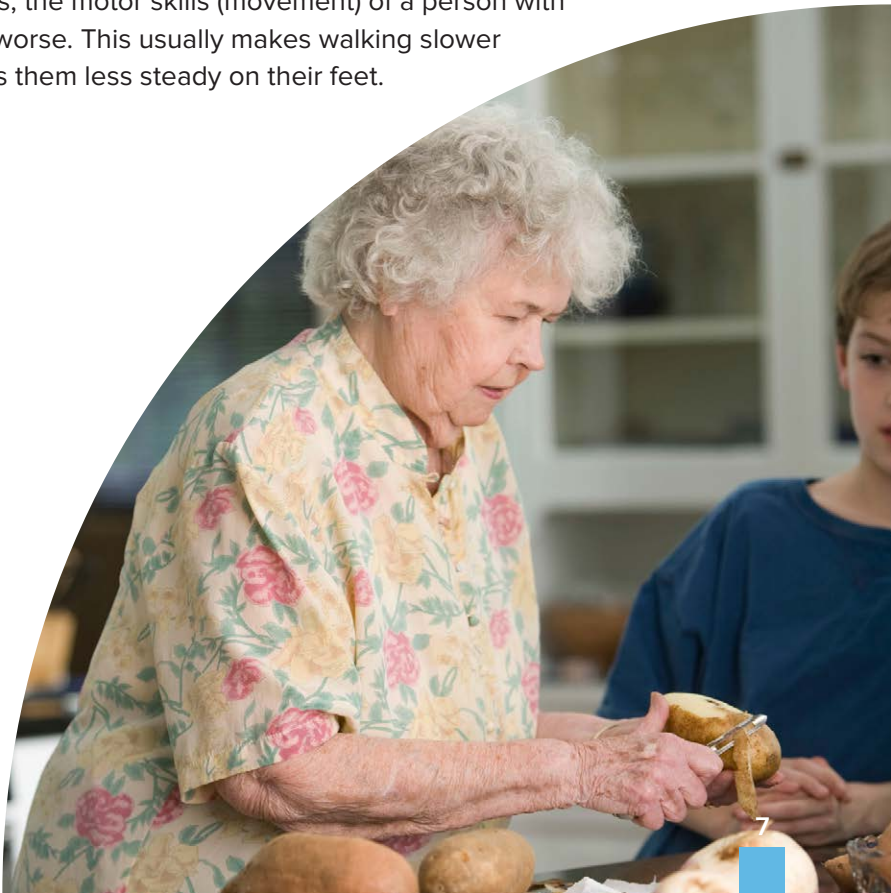


## Progression

DLB progresses over time. It is very difficult to predict how DLB will affect a person over time because it affects everyone differently. Factors that can make a difference to how it progresses include a person's general health, their attitude to life, their mood, and the amount of mental and social stimulation they receive. The level of support available can also be a factor.

Over time, some of the symptoms of DLB may become more like those of Alzheimer's disease. These include: greater problems with day-to-day memory, changes in behaviour, and increased agitation and restlessness.

Sometimes, the motor skills (movement) of a person with DLB gets worse. This usually makes walking slower and makes them less steady on their feet.



# Treatment

There are medications that can be prescribed for DLB. These do not reverse or stop the damage caused by DLB but may improve some of the symptoms.

The same medications used to treat Alzheimer's disease may help with a person's thinking and planning. They can also help to control hallucinations.

If hallucinations are causing distress and need medical treatment, your doctor may be able to suggest some options. However, many of the medications used to treat hallucinations may make movement symptoms worse and, if that happens, it is best to avoid them.

Medications normally used to treat Parkinson's disease may also help relieve some symptoms like tremors, stiffness and sleep problems.

A person's nightmares or their acting out dreams can be a health and safety issue for spouses and partners. Sometimes, it helps to change from a double bed to single beds or even to move into separate rooms.

Some medications may make the symptoms of DLB worse, particularly a group of drugs called 'antipsychotics' which are often used to treat hallucinations. Great care is needed whenever a person with DLB is prescribed anti-psychotic medication.

General health is very important for a person with DLB and any underlying health problems (like diabetes, high blood pressure and high cholesterol) need to be treated.



Changes in lifestyle can help with general brain health – even for a person with DLB. Exercise may improve mood and sleep. Having a balanced diet, not smoking, limiting alcohol intake, and sleeping well will also help.

It's important to check the hearing and vision of a person with DLB. However, some problems can be caused by brain changes and it may not be possible to correct them with glasses, a hearing aid or treatment.

Being mentally stimulated and socially active are good for all types of dementia.

Offering reassurance and support to a person with DLB can help to maintain their quality of life.



## Living well

It is important that a person with DLB, along with their carers and families, get accurate information and support after a diagnosis of DLB.

If you have diagnosis of DLB:

- › Understanding the disease will help you plan for the future.
- › Be hopeful in your outlook.
- › Be as physically active as you can.
- › Look after your mental health.
- › Be aware that infections (like chest or urinary tract infections) can cause serious complications and should be treated by a doctor as soon as possible.
- › Keep connected with your friends and family.
- › Look for supports. Consider contacting your Public Health Nurse or local Dementia Advisor.
- › Change your environment to make your life easier. For example, de-cluttering your home will make it easier to find things.
- › Live one day at a time.








## Get support

The Alzheimer Society of Ireland (ASI) provides supports for all types of dementia. For example, they provide one-to-one dementia nurse advice, online support groups and family training.

### Contact ASI on

- › Freephone Confidential National Helpline: 1800 341 341
- › Email: [helpline@alzheimer.ie](mailto:helpline@alzheimer.ie)
- › Website: [www.alzheimer.ie](http://www.alzheimer.ie)
- ›  [@alzheimersocirl](https://twitter.com/alzheimersocirl)

### For more information about DLB

- › The DSiDC provides education, training and information on best practice in dementia care. For more information visit [www.dementia.ie](http://www.dementia.ie)
- ›  [@DSiDCDementia](https://twitter.com/DSiDCDementia)
- › [www.lewybody.org](http://www.lewybody.org)
- › [www.lbda.org](http://www.lbda.org)
- › Lewy Body Ireland can be contacted via Twitter  [@lewybodyIRL](https://twitter.com/lewybodyIRL)
- › [www.understandtogether.ie](http://www.understandtogether.ie)
- › HSE helpline: 1850 24 1850

**DSiDC**

Dementia Services Information  
and Development Centre

Dementia Services Information and Development Centre  
6th Floor, Mercer's Institute for Successful Ageing  
St James's Hospital, James's Street  
Dublin 8, D08 E9P6

[www.dementia.ie](http://www.dementia.ie)

