



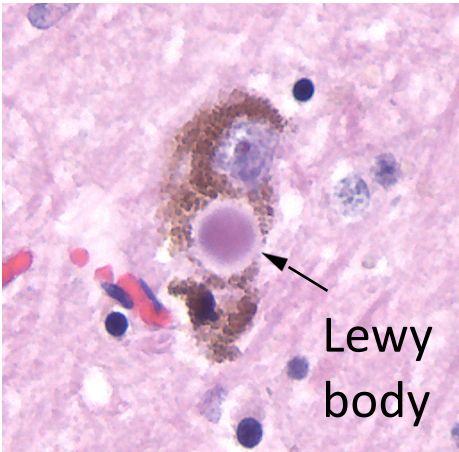
A plain English guide

Conditions caused by Lewy bodies

Have you, or someone you care for, been diagnosed with LBD?

This guide describes what Lewy bodies are, what they cause, lists symptoms which may be experienced, lists the different diagnoses given as a result and provides brief information about management and treatment. It ends with some advice about support.

What are Lewy bodies?



Lewy bodies are tiny abnormal protein deposits in different parts of the brain.

They can be identified using a DaTSCAN after the injection of a very small dose of a special radioactive substance. Lewy bodies were identified by Frederic Lewy in the early 1900s, about a century after James Parkinson published his first paper about the disease that was later given his name. Since then, other protein deposits have been discovered.

At least 10 -15% of people with dementia have LBD but Lewy body Dementia is still relatively unknown.

Parkinson's Disease is widely recognised and is commonly diagnosed as a distinct disease, with no acknowledgement of the presence of Lewy bodies.

All protein deposits cause a wide variety of symptoms, depending on where they are deposited on the brain and the brain regions that are affected.

No two people will experience identical symptoms or the same speed of deterioration.

What symptoms do Lewy bodies cause?

Lewy bodies, and other protein deposits, block neural pathways and stop messages from the brain providing information. Lewy bodies are toxic and eventually they kill cells in the brain.

Symptoms can be caused by damage in a particular region of the brain, or by affecting brain networks accessing more distant brain regions.

The position of the damage determines the type of symptoms experienced; some are cognitive, and some are physical. There are no barriers in the brain to restrict the locations of Lewy bodies to specific areas, so most people will experience a mixture of symptoms.

The deposits usually build up and may spread during the progression of the disorder, adding extra symptoms

The following lists – and they are not definitive, there are more symptoms – show the wide range of symptoms within the Lewy body disorder spectrum.

For example:

- information processing, perception and language problems are associated with Lewy bodies on the surface of the brain;
- inattentiveness and difficulties in problem-solving, with deposits at the front;
- hallucinations and visual illusions, with deposits at the back;
- anxiety and other emotions, with deposits below the brain surface;
- memory loss and loss of a sense of direction, with deposits deep in the brain;

- movement difficulties – a.k.a. Parkinson's – with deposits in the midbrain, above the brain stem;
- loss of smell, with deposits in the lower part of the brain, near the nasal cavity;
- sleep disorders and symptoms affecting bodily functions, with deposits in the brain stem.
 - REM sleep disorder is a core symptom where people act out their dreams and may shout or kick out while asleep. It often predates an LBD diagnosis by many years.

It is important to realise that the symptoms listed below, affecting bodily functions, can also be caused by Lewy bodies. They should be mentioned at appointments with a GP or Consultant and/or at LBD clinic appointments, to avoid concerns that another condition is developing in addition to LBD:

- urinary incontinence;
- constipation;
- swallowing and speech problems;
- sexual dysfunction;
- poor temperature regulation;
- cardiac symptoms;
- backache;
- loss of balance;
- a sudden drop in blood pressure.

Fluctuations

LBD is characterised by fluctuating cognition with pronounced variations in attention and alertness. Fluctuations also affect physical abilities: standing, walking, using cutlery etc.

These changes can switch on and off for a few minutes or for longer periods. They are not simply caused by tiredness.

Improvements in both can be linked to incentives, such as the presence of visitors or a strong motivation to move to another room.

Patients attending a medical appointment usually stay alert and perform better than normal, so it may be helpful for carers to have a written report of their concerns to give to the clinician.

Diagnoses

For many people, it can take more than one consultation to reach a diagnosis. Often people are given a different dementia diagnosis first, before being re-diagnosed with a cognitive Lewy body disorder. Other people may have a diagnosis of Mixed Dementia – with LBD co-existing with Alzheimer's or Vascular Dementia.

A diagnosis of LBD may follow a DaTSCAN, but it is more likely to be given following an observation of symptoms.

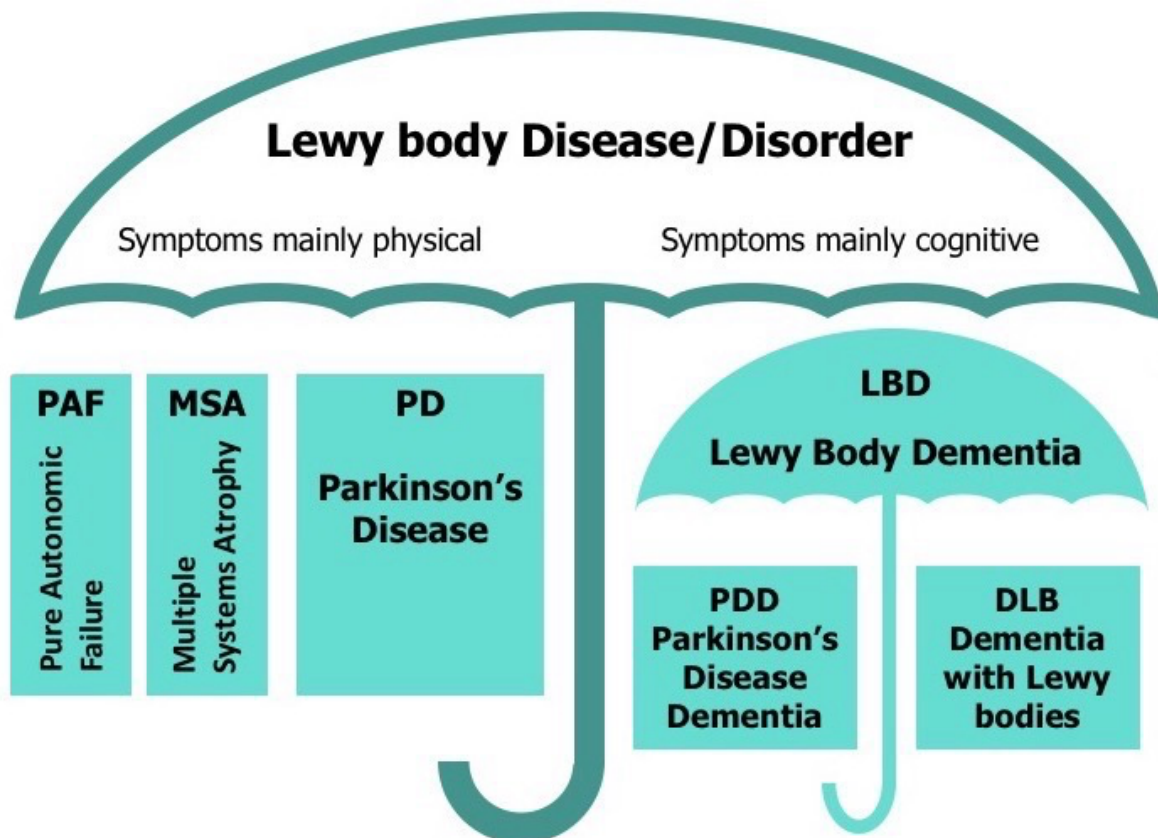
Lewy body Disease/Disorder is an umbrella term that covers cognitive and physical disorders.

The cognitive disorders are Lewy Body Dementia (LBD), which is another umbrella term that covers Parkinson's Disease Dementia (PDD) and Dementia with Lewy Bodies (DLB).

The physical disorders are Parkinson's Disease (PD), Multiple Systems Atrophy (MSA) and Pure Autonomic Failure (PAF).



This diagram may help:



The symptoms of PD, MSA and PAF are mainly physical but some of the cognitive symptoms listed above are likely to develop. Similarly, the symptoms of LBD are likely to include some physical impairments.

The dementia diagnosis you receive usually depends on the major symptoms first experienced.

For example:

- **If the problems began with cognitive impairments** that interfere with activities of daily living, the diagnosis will be LBD or DLB. Parkinson's related problems such as slowed movements, balance, or a mild tremor, usually follow within a year, but the delay may be longer. Some people do not experience movement problems.
- **If the problems began with movement impairment** the diagnosis will be Parkinson's Disease Dementia.

All these diagnoses usually include problems of confusion, sleepiness, hallucinations, delusions and anxiety.

A significant difference between LBD and other dementias is that in LBD people retain an awareness of their condition.

Receiving a diagnosis can be a source of relief, as the symptoms can start to make sense.

A second diagnosis

It is common to receive a second diagnosis, when the deposits spread, within the LBD spectrum (often Parkinson's and LBD) in spite of the fact that many of the symptoms are, to some degree, shared by all the diagnoses.

This may be due to the lack of awareness of LBD amongst clinicians or, in some cases, the need for a new diagnosis for a referral to a different consultant.

A second diagnosis is often added after death for morbidity statistics.

A second diagnosis can mean that you can access the extra help and support that you and the person you are caring for need.

Management and treatment

There will be many different medical professionals involved in treating and managing this complex condition, based on symptoms. A Neurologist or Psychiatrist may make the diagnosis, with the GP managing the ongoing care. Specialised support may be needed from Neuro-physiotherapists, Occupational Therapists, Speech and Language Therapists, and Continence Nurses amongst others. Support from Social Services will probably be required at different stages.

Medications

Medications may be recommended by consultants or a GP. They need to be considered carefully as they can have positive impacts on some symptoms and negative impacts on others. A medication's benefits and dosages will need to be monitored carefully.

Exercise

There is [anecdotal evidence](#)¹ that energetic activity may alleviate symptoms for a while. All physical activity is beneficial and is likely to raise a feeling of wellbeing, for both people with a diagnosis and their carers. However, some people are restricted in movement; just do what you can.

Mindfulness & relaxation

Making time to relax during the day is equally important for both people with a diagnosis and their carers. Making mindfulness, or other relaxation techniques, a shared part of your day can reduce the need for anxiety medications.

It can be challenging to coordinate the different services and options. It's essential to have help from medical professionals, however it can also be helpful to have support and advice from other carers with similar experiences.

Advice and support

Receiving a diagnosis of a Lewy body disorder is likely to have a profound effect on both the person with the condition and the people around them.

If you have received a second diagnosis nothing new or unexpected has happened. The progression of the disorder, adding extra symptoms, has led to the second diagnosis.

Our advice is to pause, take a few slow breaths and smile.

You may feel in need of some extra support. We believe some of the most meaningful support can come from other people with similar experiences.

Connect with a Lewy Buddy

Join our support network to connect with 'Buddies' in similar situations, for phone calls, video calls and possibly local meet-ups. [Buddy Directory](#)²

Join our Facebook community

Our Facebook group is an informal place to connect with a community of people affected by a cognitive Lewy body disorder across the UK. [Buddy Support on Facebook](#)³

¹ See 'What worked for me' <https://www.lbsnuk.org/posts/what-worked-for-me-reversing-symptoms-with-rapid-cycling>

² See <https://www.lbsnuk.org/join.html>

³ See <https://www.facebook.com/groups/lbsnuk>