

LEWY BODY DEMENTIA

What is Dementia?

Dementia is the umbrella term for a number of diseases and causes of problems with thinking and memory that are severe enough to make managing day to day life more difficult to achieve. Signs and Symptoms can vary considerably but may include memory loss, poor concentration, difficulties with planning and organising, and disorientation problems.

What is Lewy Body Dementia?

- People with Lewy Body dementia are likely to experience symptoms similar to Parkinsons Disease such as rigid muscles, slow movement, trouble walking, and tremors.
- When the brain cells are examined under a microscope, they contain structures containing protein called Lewy Bodies. These structures affect the regions of the brain that are specifically responsible for thinking and movement.
- People who have Lewy Bodies in their brains also have plaques and tangles associated with Alzheimer's Disease, so they also experience cognitive decline.
- Lewy Body can only be fully diagnosed at a postmortem. A diagnosis may be made based on the symptoms the person with dementia presents with.

Dementia with Lewy Bodies and Parkinson's Disease Dementia

- Parkinson's Disease Dementia and Dementia with Lewy Bodies are the two most common dementias connected with Parkinsons Disease.
- Parkinsons Disease Dementia is a continuation of Parkinson's Disease.
- Dementia with Lewy Bodies is caused by an increase of a protein called Alpha-synuclein protein, causing disturbance in function.
- Both cause problems with thinking, behaviour, and movement but in Dementia with Lewy Bodies the thinking and behaviour problems come first. In Parkinson's related dementia the movement problems come first as the dementia is a continuation of the Parkinson's disease process.

What you might see with Lewy Body Dementia

- Cognitive problems, like those with Alzheimer's Disease including increased confusion, poor focus/ concentration, problems with visual-spatial relations. Memory loss, and loss of motivation may not always occur early on.
- Symptoms may progress more rapidly than in Alzheimer's Disease, lasting an average of seven years from diagnosis.
- Sleep issues including Rapid Eye Movement (REM) sleep disturbances that cause people to physically act out their dreams while asleep, causing them to possibly punch, kick, shout or scream in their sleep.
- Drowsiness during the day or long periods of vacant staring into space.
- Movement disorders like Parkinson's Disease such as slower movement, rigidity of muscles, tremor and shuffling walking causing increased falls risk.
- Visual hallucinations are often one of the first symptoms noted, with people seeing shapes, animals and people that aren't there. Other hallucinations involving sounds, smells, or touch may also be present.
- Lewy bodies can sometimes affect parts of the brain associated with vision. This leaves a person's ability to process and respond to visual information altered. It can lead to a loss of vision, not because they have an eyesight problem – but because they have a problem with perception.
- Inability to regulate body functions can occur due to the diseases' effect on how well the automatic nervous system is working causing blood pressure to drop when the person stands up, dizziness, increased falls, loss of bladder control, and constipation.
- People with Lewy Body dementia may be more sensitive to the drugs that are helpful in treating dementia. The anti-psychotic drugs used to treat hallucinations may cause serious side effects making treatment difficult. Also, anti-Parkinson's medications can make psychotic symptoms worse, making it hard to treat those symptoms. These issues make drug therapy a very careful "balancing act".

Things you can do that may help.

- **Make sure your GP is involved in the care.** Some Parkinson's medications may increase the dementia effects, so it may be necessary to think about the "balancing act" of managing symptoms. Monitor any changes you see after medication changes and discuss these with your GP or specialist.
- **Contact your local Dementia NZ affiliate for support.** The team at Dementia New Zealand are always happy to help with a listening ear and support.
- **The following things may help sleep disturbances:**
 - o Consult your GP re treating any underlying conditions such as depression, sleep apnoea or restless leg syndrome. Medication reviews and considering Melatonin use are also things to talk with the doctor about.
 - o Establish a workable routine that minimises daytime sleeps, has a peaceful unwind time in the evenings and ensures you only go to bed when sleepy.
 - o Ensure your bedroom is a peaceful place, conducive to sleep.
 - o Avoid caffeine in the afternoon and evening.
 - o Avoid smoking.
 - o Avoid excessive drinking.
 - o Increase physical exercise – but don't exercise too close to bedtime.
- **Responding to hallucinations - hearing, seeing, smelling, and feeling things that are not there.**
 - o Check the environment and make changes as necessary. e.g. if the lighting causes shadows that trigger a hallucination, change the lighting.
 - o Maintain routines so that there are not too many surprises.
 - o Be Truthful.
 - o Don't deny their experience – it is very real to them.
 - o If the hallucination is happy, it's OK to ignore it.
 - o If the hallucination is distressing the person may be agitated so exercise caution. Write down what happened so that you can discuss this with the doctor. It is helpful to be able to tell the doctor if here are any triggers, what the person is seeing and how they respond to that, also duration and frequency.
 - o Validate any feelings they may have about what they are experiencing.
 - o Offer reassurance.
 - o Divert to something else.
- **Responding to delusional thinking - Strongly held false beliefs that the person with dementia thinks are real. Paranoia is a type of delusion where the person feels that others are out to harm them in some way.**
 - o It's not easy – but try not to take offence if you are accused of something that is false.
 - o It's not helpful to argue or try and convince the person.
 - o Listen to what is troubling them. Let them know that you care.
 - o Check things out whether the beliefs are true or false- don't just assume.
 - o Validate any feelings that are brought out due to the false thinking.
 - o Consider that the person with dementia may have confused the past with the present. It may have occurred in the past.
 - o Keep to a regular routine as much as possible.
 - o Look for the reason behind the delusion. E.g. Accusations that someone has stolen something are likely because they have lost it. Check that things haven't been misplaced. On that front – have regular places for things that get easily lost such as wallets & keys.
 - o Offer reassurance.
 - o Divert to another activity – move to a different room, go into the garden, or go for a walk.
 - o Turn off the TV if the programme is violent or upsetting.
 - o Explain to others that the delusional thinking is occurring because of their dementia.

Other useful articles

- [National Institute of Aging - Lewy Body Dementia](#)
- [NHS - Dementia with Lewy Bodies](#)
- [Dementia Australia - Lewy Body Dementias](#)
- [John Hopkins Medicine - Lewy Body Dementia](#)

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