

# Neuropsychiatric (behavioural) changes in Lewy body disease

This help sheet describes how Lewy body disease can cause changes in a person's neuropsychiatric abilities (when behaviour is affected). It describes common changes and strategies that may help.

- Lewy body disease is a neurodegenerative disease of ageing that causes gradual brain damage.
- It includes three overlapping disorders: dementia with Lewy bodies, Parkinson's disease and Parkinson's disease dementia.
- Lewy body disease causes changes in neuropsychiatric abilities (when someone's behaviour is affected).

## Neuropsychiatric changes

Lewy body disease can have a significant impact on someone's behaviour.

Some changes are recognised as common signs and symptoms, used to diagnose and treat the condition. Other changes are rare.

Managing and treating neuropsychiatric symptoms is complex. It requires thorough assessment, preferably by a geriatrician, neurologist or a psychiatrist specialising in cognitive functioning.

**Important:** People with Lewy body disease can have severe adverse reactions to antipsychotic medications. Hospital accident and emergency departments and all treating doctors should be made aware of the diagnosis and the potential for adverse drug reactions.

Some common neuropsychiatric changes are described below.

### **Visual hallucinations**

Persistent and vivid visual hallucinations can occur in people living with Lewy body disease, particularly in dementia with Lewy bodies.

Hallucinations can be mild and non-threatening, but responses can range from indifference to concern and, in extreme cases, terror. Often the hallucinations are of family members, but they can be of other people or animals, including spiders and snakes.

Following hallucinations, a person can often rationally interpret and discuss their experience.

### **Delusions and hallucinations**

Delusions (where the person believes something that is false) can be less frequent but disturbing for the person and those around them. Occasionally people associate their delusions with their hallucinations.

As well as visual, delusions can be auditory (noise), olfactory (smell) or tactile (touch). For instance, a person may believe that they can see and hear a stranger (hallucinations) who is living in the room upstairs (delusion).

The common pattern of delusions is what is called 'persecutory', where the person believes that things are being done against their wishes (for example, having their possessions stolen, being administered poisons instead of medication).

Delusions may be directed against loved ones, such as claims of infidelity or the belief that a loved one has been replaced by an identical impostor (known as Capgras delusion).

### **Apathy, anxiety and depression**

Apathy, anxiety and depression are all common and can all occur at the same time. The person may lose interest in their world and the people around them or become increasingly anxious in social situations.

Changes should be assessed by a medical specialist, to see whether counselling or medication can help.

### **Rapid eye movement (REM) sleep behaviour disorder**

REM sleep behaviour disorder (RBD) is thought to be a core feature of Lewy body disease. Normally, during dream sleep the brain ‘paralyses’ the body so that dreams are not enacted. However, in over half of all people living with Lewy body disease, this brain function is lost, and the person can occasionally act out their dreams. This can sometimes result in injuries to themselves or their sleeping partner.

RBD can occur many years before cognitive symptoms develop. It is potentially an early sign of Lewy body disease.

### **Somatic (physical symptoms) disorders**

Somatic disorders are when a person has a significant focus on physical symptoms (pain, weakness, shortness of breath), which can cause distress and problems functioning. The person’s physical experiences cannot be medically explained.

### **Tips for managing behavioural changes**

Below are tips and ideas about ways to support someone impacted by changes in neuropsychiatric behaviour:

#### **Hallucinations**

Hallucinations may frighten the person experiencing them. They can increase in frequency because of extra stress, such as an acute hospital admission.

How to help:

- Try to improve lighting and remove ‘clutter’ from environments where hallucinations are frequently occurring.
- If the person is distressed and has some degree of insight, you can reassure them that they are safe and discuss the hallucination for what it is.
- Try to avoid confrontation; hallucinations and delusions feel very real to the person experiencing them. Seek strategies to redirect the person’s focus to something reassuring and familiar, such as photos of family.

If the person is receiving treatment in hospital:

- Alert hospital emergency departments and treating staff to the possibility of severe adverse reactions to antipsychotic medication, which is sometimes prescribed for hallucinations.

### **Apathy, anxiety, and depression**

Apathy, anxiety, and depression are difficult to differentiate and require skilled medical assessment.

How to help:

- Seek specialist medical assessment and advice, because these conditions can be treated.
- A range of non-drug treatments (for example, counselling, exercise) and drug treatments (anti-depressants, anxiolytics) can often improve the person's quality of life.
- Help the person maintain an active and involved lifestyle.

### **Getting help**

If changes in behaviour are distressing the person, or you would like help or advice, contact:

- National Dementia Helpline: **1800 100 500**
- Dementia Behavioural Management Advisory Service: **1800 699 799**.

## Additional reading and resources

- Dementia Australia has developed a suite of help sheets about Lewy body disease  
Visit: [\*\*dementia.org.au/help-sheets\*\*](https://dementia.org.au/help-sheets)
- Dementia Australia library service  
Visit: [\*\*dementia.org.au/library\*\*](https://dementia.org.au/library)
- Dementia Australia support  
Visit: [\*\*dementia.org.au/support\*\*](https://dementia.org.au/support)
- Parkinson's Australia  
Visit: [\*\*parkinsons.org.au\*\*](https://parkinsons.org.au)

### Further information

Dementia Australia offers support, information, education and counselling.

**National Dementia Helpline: 1800 100 500**

**For language assistance: 131 450**

**Visit our website: [\*\*dementia.org.au\*\*](https://dementia.org.au)**