Neuropsychiatric (behavioural) changes in Lewy body disease

Lewy body disease is a common neurodegenerative disease of ageing that is considered to be a spectrum disease. The disorders in the spectrum are: dementia with Lewy bodies, Parkinson’s disease and Parkinson’s disease dementia.

Lewy body disease can have a significant impact on a person’s behaviour. Some changes are so common that they are recognised as part of the diagnostic criteria, while others are rare.

The management and treatment of these neuropsychiatric symptoms is complex and requires thorough assessment, preferably by a geriatrician or a psychiatrist specialising in the treatment of older people.

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.

**Visual hallucinations**

Well formed, persistent and vivid visual hallucinations are a feature of Lewy body disease, particularly dementia with Lewy bodies. Hallucinations can be benign and non-threatening, but responses can range from indifference to concern and, in extreme cases, sheer terror. Often the hallucinations are of family members. They can also be of other people or animals including spiders and snakes.

After the event, those having hallucinations are often able to rationally interpret and discuss their experience.

**Apathy and depression**

Apathy is a common presentation. The person loses interest in their world and the people around them although they can ‘rise to the occasion’ and be engaged for short periods of time. Depression can also occur. It is a more complex illness which requires specialist assessment and management.

**Delusions and hallucinations in other modalities**

Delusions, where the person holds a belief that is false, are less frequent but disturbing behaviours. Occasionally people associate their delusions with their hallucinations. As well as visual, these 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).

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

REM sleep behaviour disorder is thought to be a core feature of Lewy body disease. It occurs when the brain is unable to paralyse the body during dreams. The person ‘acts out’ their dreams sometimes resulting in injuries to themselves or their sleeping partners. As it can occur many years before the development of cognitive symptoms, REM sleep behavior is a potential “predictor” of Lewy body disease.

There are a few less common but highly complex neuropsychiatric disturbances classified as somatic disorders where the person has physical complaints that cannot be medically explained.

On the next page are some tips for managing behavioural changes.
Managing neuropsychiatric or behavioural changes

Hallucinations may create fear in the person experiencing them or just be accepted. Additional stress such as an acute hospital admission may increase the frequency of the hallucinations.

• Discuss the hallucination for what it is and reassure the person that they are safe if they are distressed.
• Advocate for the person and alert treating staff to the possibility of severe adverse reactions to antipsychotic medication, which is sometimes prescribed for hallucinations.

Apathy and depression can be difficult to differentiate and require skilled medical assessment. Apathy is a common feature of Lewy body disease. It is often associated with increased lethargy and described as a ‘fog’. Depression is more complex, but both conditions can be treated.

• Seek specialist medical assessment.
• Recognise that the cholinesterase inhibitors (drugs prescribed for Alzheimer’s disease) often ‘lift the fog’ for people with Lewy body disease and improve their quality of life.
• Maintain an active, involved lifestyle.

Active dreams or rapid eye movement (REM) sleep behaviour disorder may be a feature of a person’s behaviour many years before any other sign is evident. Couples often accept this as the norm for their relationship and put strategies in place to enable both people to get a good night’s rest.

• Describe any sleep disturbances to assessing doctors as it may assist with diagnosis and management.
• Adopt strategies that minimise the risk of harm – such as separate beds, limited use of bedside tables, lamps and the like. Lock balcony doors and exit doors as necessary.

Get help

• If the behaviour is disconcerting to the person, or the carer is having difficulty coping, contact the Dementia Australia National Dementia Helpline 1800 100 500 or the Dementia Behavioural Management Advisory Service 1800 699 799 to discuss ways of managing behavioural changes.

The other neuropsychiatric or behavioural changes, although possibly distressing, are fortunately not common. In most instances these changes are a direct result of the disease process although changes in the environment may exacerbate some behaviours.

Resources

Parkinson’s Australia is the peak body for advocacy and support of people with Parkinson’s disease. Visit parkinsons.org.au or call 1800 644 189.
US Lewy Body Dementia Association visit lbda.org
UK Lewy Body Society visit lewybody.co.uk

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on 1800 100 500, or visit our website at dementia.org.au

For language assistance phone the Translating and Interpreting Service on 131 450

This publication provides a general summary only of the subject matter covered. People should seek professional advice about their specific case. Dementia Australia is not liable for any error or omission in this publication.

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Reviewed 2019