

Autonomic (involuntary function) 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 autonomic (involuntary) nervous system. This system automatically regulates many bodily functions including bladder and bowel function, temperature regulation and heart rhythm. Some autonomic changes are so frequently seen as part of Lewy body disease that they are included in the diagnostic criteria. However, they can occur for other reasons. Often there are changes due to ageing, or there may be some other underlying medical condition. It is important to seek medical advice if concerned.

Changes in autonomic function can occur early in the disease and change with time. Not everyone with Lewy body disease will experience all symptoms, but the following are often reported.

Bladder function

Difficulty urinating can occur (in men this may be mistaken for prostate problems). Nocturnal polyuria is the need to repeatedly urinate at night (20 times is not uncommon). This disturbs the sleep of the person and partner, but is not regarded by them as incontinence.

Bowel function

Constipation or urgency can occur. These and an inability to attend to personal hygiene can result in socially distressing situations. Bloating and nausea are other common gastro-intestinal symptoms.

Sexual function

Changes in intimate relationships can occur early in the disease process. Impotence appears to be more common than hypersexuality.

Temperature dysregulation

Loss of the ability to automatically regulate body temperature is common. This can result in shivering or perspiring regardless of the ambient temperature.

Cardiac symptoms

Irregularities in heart rhythm such as atrial fibrillation can occur. Cardiac symptoms require specialist cardiac assessment. Other symptoms include orthostatic hypotension and syncope or fainting. Associated with an inability to control blood pressure, they can result in falls, dizziness, drowsiness and even unconsciousness for short periods.

Recognising autonomic changes

The autonomic deficits associated with Lewy body disease can be difficult to assess and treat - particularly if taken in isolation in early stages of the disease. It is always important to seek medical advice if there are changes to normal function.

Some of these autonomic changes can be distressing, embarrassing or difficult to manage for the carer. Often the person experiencing them appears to 'take it in their stride'. This apparent acceptance may be related to their dementia and their inability to regulate their social behaviour. It may help medical and allied health practitioners if someone who knows them well can, with their agreement, attend consultations or provide information during any assessment process.

Managing autonomic changes

Autonomic changes associated with Lewy body disease require medical assessment and treatment. They can add to the burden of the disease and to carer stress. Over time people usually develop strategies to cope with each issue. On the next page are some tips for more challenging situations.

Managing autonomic changes

As well as medications for the cognitive and motor symptoms of Lewy body disease, medications for cardiac or urinary symptoms are frequently prescribed by treating specialists.

- When new medications are prescribed or doses altered, monitor the person closely and report any observed changes in their condition to the prescribing doctor.
- Discuss the use of a pill dispensing system (such as a Webster pack) to reduce confusion.
- Monitor or control the medication regime as appropriate.
- Limit the number of doctors and pharmacists prescribing and dispensing medications.

Nocturnal polyuria can lead to sleep deprivation, frustration and carer burn out. It is complicated by the risk of falls, orthostatic hypotension and visuospatial deficits. It can be seen as a ‘behaviour of concern’ as it is distressing for the person and, unfortunately, the use of aids is often rejected. Assessment and advice from the Australian Continence Foundation (visit continence.org.au or call **1800 33 00 66**), reassurance and ‘trial’ use of incontinence aids can be of great benefit.

- Accept that the person feels the need to urinate even if it is only minutes after the last time.
- Consider bathroom modifications early and install non-slip floors and coloured toilet seats.
- Leave a night light on.
- Encourage independence by modifying night wear and not assisting the return to bed.
- Discuss and use aids, such as continence pads and washable pants, as a choice for a good night’s sleep rather than a necessity.
- Consider ‘spillpruf’ bottles or condom drainage for men.

Changes in bowel habits combined with cognitive and physical deficits can result in behaviour that is viewed as socially unacceptable. Assessment by a continence nurse and a management program may assist.

- Use a high fibre diet and work to an established bowel routine if possible.
- Accept that assistance with personal hygiene may be required and carry wipes, spare clothes and plastic bags in case of accidents.
- Plan ahead when travelling – know where public toilets and toilets for the disabled are located. Avoiding freeways and peak hour traffic can be a help.

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 lbd.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**