

Managing hallucinations and changes in visual perception in Lewy body dementia



The Lewy Body Society
Shining a light on Lewy body dementia



Dementia UK
Helping families face dementia

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Changes in visual perception and hallucinations can happen when the brain misinterprets the information it receives. In Lewy body dementia, this is a common problem due to changes in the parts of the brain that help us interpret what we see.

What are visual perceptual changes?

Changes in 'visual perception' can be caused by both changes in the brain and/or problems with eyesight. Regular eye tests are important in detecting any eye conditions that can be resolved such as cataracts or deteriorating vision.

Visual perceptual changes can include:

- difficulty recognising objects or people
- trouble judging distances
- problems navigating patterns e.g. carpets or changes in flooring
- seeing reflections in mirrors as something or someone else.

This can lead to people missing steps, bumping into walls and or sitting down in the wrong place with an increased risk of falls.

Difficulty with recognising familiar places or people may also be caused by short -term memory problems, with people referring to previous experiences or mistaking people from their past.

What are hallucinations?

Hallucinations can involve any of the senses, but the most common are **visual** and **auditory** hallucinations: seeing or hearing something that is not there. Simple visual hallucinations can be momentary flashes or shapes whereas complex hallucinations are vivid, detailed images which are often recurring and can feel very real.

Approximately 70% of people with Lewy body dementia will experience complex visual hallucinations at some point during their condition.

Visual hallucinations may happen several times during the day but are usually more common in the evening or at night, when lighting is poor or the person is tired.

The most common visual hallucinations are 3-dimensional and may be of people or animals. People may also experience 'passage' hallucinations; figures or shapes at the edge of someone's vision or 'presence' hallucinations include having a sense that someone is nearby.

For some people hallucinations are not worrying and may even be a source of interest or companionship. However, for others, hallucinations can be extremely distressing especially if the person feels threatened. This may lead to delusional or paranoid ideas i.e. believing that someone or something is going to cause them harm.

Treatment

Medications known as 'cholinesterase inhibitors' such as 'Donepezil' or 'Rivastigmine' can help reduce the impact of hallucinations for some people with Lewy body dementia. These medications are also used in Alzheimer's disease and can help with the cognitive symptoms such as concentration and memory problems. These drugs are usually most effective in early or moderate phases of Lewy body dementia but do not help everyone.

People with a history of heart problems, usually need an ECG (electrocardiogram) prior to commencing these medications as they may cause abnormalities. If they are not suitable, an alternative medication called 'Memantine' may be offered. This can also be given in addition to cholinesterase inhibitors in mid or later phases of the condition.

Parkinson's medications which are given for movement problems can either cause or worsen hallucinations when at higher doses. These should be reviewed and may need reducing if hallucinations become a problem.

Approximately 50% of people with Lewy body dementia will have an adverse reaction to antipsychotic medications, used to treat hallucinations. If hallucinations are persistent and distressing, certain 'atypical antipsychotics' may be used. As these drugs can be quite sedating and/or increase confusion, small doses should be given and monitored carefully.

Research into new treatments and medications for reducing hallucinations is ongoing.

Any sudden change in behaviour or increase in hallucinations may be due to a physical cause such as an infection, constipation or dehydration. This is known as 'delirium' and can lead to increased confusion, disorientation or difficulty with

concentration. Delirium can also mimic some of the symptoms of Lewy body dementia including changes in awareness and hallucinations or can make existing symptoms worse. Delirium is treatable and medical advice should be sought as soon as possible.

Regular reviews of medication are important as getting the balance of treatments right can make a significant difference.

How to manage hallucinations

It can be difficult to know how best to respond to hallucinations in Lewy body dementia as they can feel very real, may be unsettling and even distressing or frightening at times.

It is important to ensure good lighting especially at dusk or when it's dark to reduce the chance of misperception.

Other environmental changes can also be helpful such as ensuring contrast colours on doorways, edges and light switches using coloured tape. Reducing the amount of patterns on flooring, carpets and removing large mirrors in hallways can also be tried.

For some people insight can be retained and it is possible to question or challenge the hallucination. However, if this is not possible, certain responses can be helpful in reducing distress.

Some useful tips are offered overleaf – both for the person with dementia and those supporting them.

Calmly talk through the hallucination with the person you care for. Bear in mind it is real to them.

For people with dementia

Useful tips for managing hallucinations

Remember your condition affects the way your brain interprets the information it receives from your eyes.

See below for some suggestions based on what people with Lewy body dementia have told us they found helpful:

- Remind yourself it's a symptom of your condition.
- Ask someone you trust if they see the same thing.
- Close your eyes and open them again.
- Touch the object or speak to the person you think you see.
- Distract yourself with an activity, go to another room, or listen to music.
- Ask for help from a carer or friend.

I could see there was a 'large bear' in the room. I thought about reaching out and touching it but was worried about what would happen so I shouted for my wife instead. It was a relief when she told me it wasn't real but it felt so lifelike.

For family carers/friends

Useful tips for managing hallucinations

Remember this condition affects the way the brain interprets the information it receives from the eyes and hallucinations can feel very real to the person.

As a rule it is better not to disagree or challenge what the person is seeing, try to understand how it feels for them and offer reassurance.

See below for some suggestions based on what carers have told us:

- Stay calm and talk gently. Ask if the hallucination feels frightening and offer reassurance.
- Acknowledge the person's experience. Say that you can't see it, but you know it feels real.
- If they understand their condition, try saying: "Do you think your eyes are playing tricks on you?"
- Encourage calming techniques: Take a deep breath and to remind themselves it's not real.
- Distract and redirect: Change the subject or focus on something else in view.
- Suggest an activity: Make tea, have a snack or move to another room.
- Use other senses: Listen to music or sing together.
- Offer comfort: Gentle touch, hand massage, or relaxation.
- Check the environment: Remove confusing items (coats, mirrors, cushions) and ensure good lighting, especially in the evening.

Summary

Visual hallucinations are a common symptom of Lewy body dementia, but some people may feel reluctant to admit to or talk about them. Asking the question: "Do you ever feel your eyes are playing tricks on you?" can be a useful starting point.

Remember that hallucinations might be ignored or brushed aside initially but over time can cause significant anxiety and worry.

For families/friends, being aware of any changes in behaviour that may indicate the person is experiencing hallucinations is important. This might include checking rooms constantly, looking worried or suspicious, talking to things that are not there.

If you would like to talk to a specialist dementia nurse about hallucinations or changes in visual perception, you can call

Dementia UK's Helpline on 0800 888 6678

(Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video appointment with a dementia specialist Admiral Nurse in our virtual clinics, please visit

www.dementiauk.org/book



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