



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

Managing hallucinations and changes in visual perception in Lewy body dementia

Hallucinations and changes in visual perception i.e. how the brain sees the world, happen when the brain misunderstands the information it is receiving. This can be a common problem in Lewy body dementia which often affects the parts of the brain that help interpret what we see.

What are visual perceptual changes?

For some people with dementia, the brain misinterprets information from their senses which can lead to a misunderstanding of the world around them. Changes in 'visual perception' can be caused by changes in the brain and/or in someone's eyesight. Regular eye tests should be carried out to address any eye conditions that make seeing things more difficult.

Visual perceptual changes can make things hard to recognise and judging distances may become difficult. People may find patterns difficult to interpret and carpets or changes in flooring can be hard to navigate, leading to problems in moving around or increasing the risk of falls. Other problems can include difficulty in recognising objects, misperceiving reflections in mirrors and not recognising the home environment. Sometimes people may not recognise familiar people or faces. In Lewy body dementia this may be due to what is called 'misidentification' and can lead to 'Capgras syndrome', where the person thinks someone has been replaced by an imposter.

Problems with recognising familiar places or people may however be linked to short term memory difficulties or 'time-shifting' i.e. relying on longer term memories from an earlier time in life.

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. These are often more vivid than changes in perception, often recur and can feel very real.

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

Visual hallucinations may happen several times during the day but are usually more common in the evening or at night. This may be due to dimmer lighting or shadows caused by changing light. Also when people are tired it can be harder for the brain to process things.

The most common visual hallucinations are of people or animals which may be quite well formed, colourful and three-dimensional. They can also appear at the side of a person's vision, known as 'passage hallucinations' and some people describe feeling there is someone nearby, called 'presence hallucinations'.

For some people, hallucinations are not worrying and may not even be referred to. 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 harm.

Treatment

Research has shown that some people with Lewy body dementia who experience hallucinations have benefited from cholinesterase inhibitors such as 'Donepezil' or 'Rivastigmine'. These medications are also used in Alzheimer's disease and can help with the cognitive symptoms of Lewy body dementia such as concentration and memory problems. These are usually most effective in early or moderate phases but do not help everyone.

It's also important to note that some Parkinson's medications given for movement problems can cause or worsen hallucinations.

Approximately 50% of people with Lewy body dementia will have an adverse reaction to medications known as antipsychotics, which are used to treat hallucinations. Only certain types, known as atypical antipsychotics, should be used with extreme caution.

Some new treatments/medications for reducing hallucinations which have been approved for use in other conditions are being tested and research is being carried out.

If there is a sudden change in behaviour and hallucinations increase, check for any underlying physical causes such as an infection, constipation or dehydration which may be causing a 'delirium'. Delirium can lead to increased confusion, disorientation or difficulty with concentration and can mimic some of the symptoms of Lewy body dementia. Delirium is treatable and medical advice should be sought.

You should request regular reviews of medication as getting the balance of treatments right can make a significant difference.

“ We found by eliminating one medicine and increasing the dose of another markedly improved the condition. ”

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 and may be quite unsettling and even distressing or frightening at times.

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. ”

Useful tips for managing hallucinations

Remember your condition affects the way your brain interprets the information it receives from your eyes. It's as if your 'eyes are playing tricks on you'.

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

- Take a moment to tell yourself that what's happening is not real and remember it's just a symptom of your condition.
- If you are not sure if what you see is 'real', try the following:
 - Ask someone you trust if they see what you are seeing – if they don't, it's not there.
 - Close your eyes and open them again to see if what you are seeing is still there.
 - If it's in the room try going over to check if it is there by touching it **or** if it is a person ask a question and see if they respond.
- Do an activity and engage with something that you know is real. This can help you focus on something different and distract you from the hallucination.
 - Try going into a different room – make yourself a cup of tea or have a snack.
 - Try doing something that you enjoy, like working on a hobby, playing with a pet, watching a show, or playing a favourite game.
 - Try using a different sense to the one the hallucination is engaging. For example, if you're having visual hallucinations, then you could listen to and/or sing along to music.
- Remember to ask for help from your carer or a friend – they can offer reassurance.

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 general 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 they have found helpful:

- Calmly talk through the hallucination with the person you care for. Ask if it is frightening and offer reassurance.
- Let them know you can't see the same as them but that you realise it feels very real.
- If the person has some insight into the condition, try saying: 'Do you think your condition is making your eyes play tricks on you?'
- Encourage the person to take a deep breath and tell themselves this is not happening or not real.
- Offer distraction by diverting attention to another item within view or changing the subject.
- Suggest going into another room or doing an activity such as making a cup of tea, having a snack, playing a game.
- Try an activity which requires using a different sense such as listening to music or singing.
- Offer comfort and support through the use of touch, hand massage or relaxation techniques.
- Check the environment for things that may be misinterpreted such as coats or clothes hanging up, cushions, mirrors and ensure that lighting is adequate – particularly 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 someone about hallucinations or changes in visual perception, you can call the **Admiral Nurse Dementia Helpline free of charge on 0800 888 6678**.



**The
Lewy Body
Society**



DementiaUK
Helping families face dementia

Admiral Nurse Dementia Helpline

Call our Dementia Helpline for free on **0800 888 6678**

Send an email to **helpline@dementiauk.org**

A: Unity House, Westwood Park, Wigan WN3 4HE

T: 01942 914000 **E:** info@lewybody.org

Visit www.lewybody.org and sign up for our newsletter



Member of the Association
of Medical Research Charities