



Managing delusions and misidentification in Lewy body dementia



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People with Lewy body dementia can experience delusions (false beliefs) which may include delusions of 'misidentification' i.e. not recognising someone or something. These symptoms are more common in Lewy body dementia than in other dementias.

What are delusions?

Delusions are ideas or false beliefs that are not based on reality. These are often based on hallucinations or misperceptions (seeing things that are not there) but they may occur independently. They can be very distressing and make someone feel suspicious, scared, or accuse others of trying to harm them. These beliefs are hard to change by reasoning, although in Lewy body dementia insight and delusions can fluctuate.

What is a delusion of misidentification?

Delusions of misidentification occur in approximately 20% of people with Lewy body dementia.

There are two main types - 'Capgras syndrome' and 'clonal pluralisation'.

In Capgras syndrome the person believes someone close to them, like a partner or family member, has been replaced by an identical-looking imposter.

One type of Capgras known as 'Fregoli syndrome' is named after an Italian impersonator who was renowned for being a 'quick-change' artist. People with Fregoli syndrome may see a familiar face in different places, making them think they are being followed.

Clonal pluralisation is less common but is where someone believes there are multiple copies of themselves, other people or objects.

These symptoms happen because Lewy bodies (abnormal clumps of protein in the brain) affect how the brain processes and interprets information. This causes difficulties in both the:

- Visual processing system - leading to distorted sensory information
- Frontal brain - leading to faulty interpretation of information.

As a result the person may struggle to distinguish whether information is true or false. They may recognise someone's face but not know who they are. This contrasts with a syndrome called 'prosopagnosia', in which the person doesn't recognise someone's face but may know who they are.

What is 'Capgras'?

This syndrome is named after Joseph Capgras, a French psychiatrist who described the disorder in a woman who believed 'doubles' had taken the place of people she knew.

Capgras syndrome usually involves the person or people who are most familiar not being recognised and the belief they have been replaced by an imposter or double. There may be multiple versions of the imposter; a 'good' version who can be trusted; or a 'bad' version who is untrustworthy. This can be especially difficult for a partner who is the main carer if the person with dementia becomes suspicious or refuses to accept who they are. It can make the person with dementia feel frightened, and lead to them resisting their friends' and family's attempts to care for them. In some cases it can lead to the person being abusive or aggressive. For some people with Capgras syndrome, even animals and inanimate objects such as chairs can be seen as imposters.

Treatment

Medications known as cholinesterase inhibitors such as 'Donepezil' or 'Rivastigmine' can be used to help reduce the impact of delusional symptoms, including Capgras. These medications aim to improve the cognitive symptoms of Lewy body dementia, such as concentration and memory problems, and can also improve understanding or insight. These are usually most effective in early or moderate phases of dementia but unfortunately 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.

Although antipsychotic medication can be used to treat delusions or hallucinations, approximately 50% of people with Lewy body dementia can have an adverse reaction to these medications. If delusions are very distressing certain types, known as 'atypical' antipsychotics, may be used to help reduce distress. As these drugs can be quite sedating and/or increase confusion, small doses should be given and monitored.

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 is treatable and medical advice should be sought as soon as possible.

Medications should be regularly reviewed as getting the balance of treatments right makes a significant difference. Some medications used for Parkinson's symptoms can make delusions worse so this should be monitored carefully.

How to manage delusions

Recognising how best to respond to someone who is experiencing delusions of misidentification and reducing their distress wherever possible is a vital part of treatment.

Some practical tips informed by the direct experience of family carers are provided overleaf:

Tips for carers

1. **Don't argue or correct** the delusion—it can make things worse.
2. **Reassure and validate feelings:** let the person know they are safe.
3. **Show you're on their side**, even if they don't recognise you.
4. If insight is retained, explain their brain is interpreting things differently.
5. If you are feeling stressed, **take a break** and return later.
6. **Encourage recognition:**
 - Wear familiar clothes
 - Speak as you enter the room as the person may recognise your voice.
 - Call from another room first
7. Use **distraction:** change the topic, go for a walk, make tea, listen to music
8. Keep a diary to spot **patterns or triggers**.
9. Try to manage your own **expectations** – good days and bad days happen.
10. **Look after yourself** – take breaks and accept help.
11. Seek **advice** from doctors about medication.
12. If safety is a concern, remove yourself and call for help.



Summary

Delusions and misidentification can be a particularly difficult symptom for people with Lewy body dementia and their families. These are fixed ideas or false beliefs that are not based on reality and may lead to the person feeling scared or mistrusting of those around them. Capgras syndrome is a 'delusion of misidentification' where someone familiar is not recognised and seen as an imposter.

These symptoms are caused by changes in the brain which can fluctuate during the day and are not deliberate.

As a family member or friend, look out for signs which may indicate someone is not recognising you properly – such as being more secretive or looking at you suspiciously.

If you would like to talk to someone about delusions or Capgras, you can call **Dementia UK's Helpline on 0800 888 6678** or [email helpline@dementiauk.org](mailto: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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