



Managing delusions, misidentification and Capgras syndrome in Lewy body dementia



The Lewy Body Society

Shining a light on Lewy body dementia



DementiaUK

Helping families face dementia

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People with Lewy body dementia are more likely to experience symptoms of delusion and misidentification (ie not recognising someone or something) than those with Alzheimer's disease or vascular dementia.

'Capgras syndrome' is a 'delusion of misidentification'. It involves the person believing that a friend, spouse or other close family member has been replaced by an identical-looking imposter.

What are delusions?

Delusions are fixed ideas or false beliefs that are not based on reality. These can be experienced by some people with dementia and are often, although not always, accompanied by hallucinations or misperceptions: seeing things that are not there.

These ideas or beliefs can be very distressing and can lead to mistrust and accusations that someone or something is trying to cause harm. Often, the person's mind cannot be changed by encouraging them to see reason, although in Lewy body dementia these ideas can change or fluctuate and levels of insight may vary.

What is a 'delusion of misidentification'?


'Delusions of misidentification' can occur in approximately 20% of people with Lewy body dementia. There are two main types; Capgras syndrome and clonal pluralisation.

Capgras syndrome is where someone familiar is not recognised and the person is seen as an imposter. One type of Capgras is known as 'Fregoli syndrome' in which the person sees a familiar face or faces in a crowd or in a place where they wouldn't expect to see them and believes they are being followed.

Clonal pluralisation, which is less common, is where the person believes there are exact copies of other people or themselves.

Both types of delusion are caused by changes in different parts of the brain due to the presence of Lewy bodies, which are abnormal clumps of protein that gather inside brain cells.

Lewy bodies interfere with the wiring or messaging system in the brain and lead to visual information being misinterpreted. Both the visual processing system, which receives information and the recognition system, which helps the brain interpret what is being seen, are affected. This can lead to the person recognising someone's face but not recognising who they are.



Why are you trying to trick me?

I don't like this version of you. Where's the nice one?

I am not sure what is going on but it doesn't feel right.

Why don't you believe me? I am scared that someone is going to harm us - we need to be careful.

Who are you? What have you done with my husband?

Did you see that person watching the house? I think they have been following me.

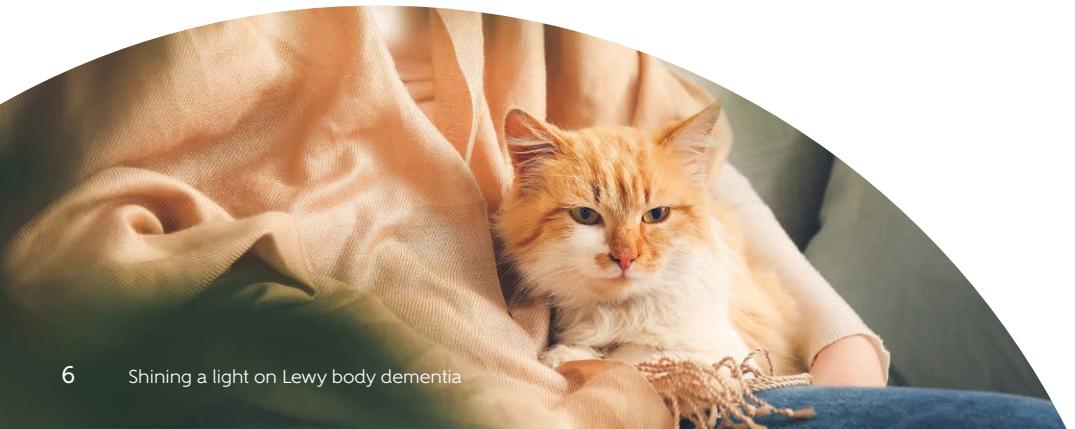
What is 'Capgras'?

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

Unfortunately, Capgras usually involves the person or people who are most familiar to the person with dementia not being recognised, and the belief they have been replaced by an imposter or double. There may be multiple versions of the imposter, who may appear as a 'good' version where the person seems more familiar and can be trusted; or a 'bad' version where the person is trying to do them harm or can't be trusted.

This can be especially difficult for a partner who is the main carer if the person with dementia becomes suspicious of them 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 may lead to the person with Lewy body dementia being abusive.

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 treat people with Lewy body dementia. They can help reduce hallucinations as well as 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 have been found to be most effective in early or moderate phases of dementia but unfortunately they do not help everyone.

Although antipsychotic medication can be used to treat delusions or hallucinations in other conditions, approximately 50% of people with Lewy body dementia can have an adverse reaction to these medications. Only certain types, known as 'atypical' antipsychotics, should be used in helping to reduce distress caused by delusions, and even then, with caution.

If there is a sudden change in a person's behaviour and delusions increase, it is important to check for possible underlying physical causes such as infection, constipation or dehydration. These can cause delirium leading to increased confusion, disorientation or difficulty with concentration, and this can mimic some of the symptoms of Lewy body dementia. Delirium is treatable and medical advice should be sought.

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

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.

Managing delusions and Capgras

It is important to accept that although delusions, including Capgras, can be very upsetting, this is part of the condition and is not personal or malicious.

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

It can be particularly difficult to know how to respond to Capgras, especially if the person who is offering support is the person who is being misidentified and therefore seen as not to be trusted.

If the person has some insight, it may be possible to question or challenge the delusion. However, if the idea seems quite fixed, care should be taken not to increase the person's distress by trying to reason or persuade them of the reality.

Keep in mind that there may not be one right approach, different approaches may work at different times.



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

Useful tips

1. Try not to correct or challenge the delusion immediately as this can add to the person's distress and increase stress and anxiety for both of you.
2. Validate the person's feelings and concerns, reassuring them they are safe and that you are there to help them.
3. Show the person you are on their side and you accept their version of reality, even if it's upsetting that they do not recognise you.
4. If the person has some insight, explain that their condition is making their brain see and interpret things differently, but this will change over time.
5. If things are not working and/or you are feeling stressed, try making an excuse and walk away or go into another room. Wait a while before returning if possible.
6. Try to encourage recognition and familiarity by:
 - Changing your outfit to one the person may recognise
 - Talking as you walk into the room: the person may recognise your voice
 - Talking to them on the phone from another room: this can help establish a connection that can be continued as you walk into the room.

7. Distraction can help with moving someone away from their delusion or false belief:
 - Change the activity or topic of conversation; say you need to do something quickly
 - Go out for walk – exercise is good for boosting self-esteem
 - Visit a friend or relative
 - Offer to make a cup of tea
 - Suggest a hobby or activity that the person enjoys
8. Try keeping a record or diary to see if there are any triggers or times of day that are worse. Remember that delusions can change over time and fluctuate due to tiredness, stress, and other factors.
9. Try to lower your expectations and be happy when things are going well, take one day at a time and accept that bad days are no one's fault.
10. Look after your own mental well-being, take regular breaks and accept offers of support from family and friends.
11. Accept, as a carer, that you are not trained but you are trying your very best and you won't always get it right.
12. Seek help and advice from the person's doctor or specialist – some medications, such as cholinesterase inhibitors, may help reduce delusions.
13. If you are worried about your own or the person's safety, remove yourself from the situation and contact a friend or family member or call the emergency services.

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 the **Admiral Nurse Dementia Helpline on 0800 888 6678** 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-an-appointment**



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