Changes in perception and hallucinations in dementia
We understand the world through our five main senses:

- hearing
- sight
- smell
- taste
- touch

These senses collect information and send it to the brain, which uses it to make sense of the world around us.

For some people living with dementia, their brain misinterprets the information from their senses. This is known as ‘changes in perception’ and leads to them misunderstanding the world around them or experiencing reality differently from other people. In rarer cases, the person may also experience hallucinations.

Changes in perception can also happen because of physical changes in the brain or the sensory organs, such as the eyes or ears – for example, people’s vision and hearing often get worse as they get older. Certain types of dementia – such as posterior cortical atrophy (PCA), a rarer form of dementia that mainly affects younger people under the age of 65 – can also cause changes in vision.

Changes in perception include:

- misperceptions
- misidentifications
- visuospatial difficulties

Who do changes in perception affect?

Changes in perception – and less commonly, hallucinations – can affect anyone who has physical changes to their sensory organs, their brain, or both. They are more common in people with dementia as they may experience changes to their sensory organs (eg their eyes) as well as damage to certain areas of the brain.

For example, if there is damage to the occipital lobe (the rear part of the brain), which is responsible for processing visual information, the person may have difficulty making sense of what they see around them.

Changes in vision are more prevalent in certain types of dementia, even if the eyes themselves are healthy.
These include:

- Lewy body dementia, which can cause visual hallucinations
- Alzheimer’s disease, which can cause loss of peripheral (side) vision
- Vascular dementia – this often results from a stroke, and can cause difficulties such as double vision, blurred vision, or partial or total loss of sight in one or both eyes
- Posterior cortical atrophy (PCA)

It is helpful for the person with dementia and their family to be told what form of dementia has been diagnosed – if it is a type that is known to cause changes in perception and visual disturbances, this can help them understand why these changes are happening, make allowances for them and develop coping strategies.

Changes in perception can also affect people who have sight or hearing problems caused by physical issues with the eyes or ears, delirium caused by an infection, or side effects from medication, as well as those who overuse alcohol or take illegal drugs.
What are misperceptions, misidentification and visuospatial difficulties?

Misperceptions happen when a person sees one thing as something else. For example, they may see a reflection in a window and believe there is an intruder in their home.

Misidentification happens when the person has problems identifying particular objects or people. For example, they may mistake their daughter for their wife.

Visuospatial difficulties happen when the brain has trouble processing information about 3D objects. For example, they might misjudge depth, speeds or distances, which could affect their driving and their ability to move around safely.

What are hallucinations?

Hallucinations are sensory experiences that appear real to the person but are created by their mind, without any external cause, leading to them experiencing something that is not really happening.

Hallucinations may involve any of the senses, but the most common are visual and auditory hallucinations, where the person sees or hears something that is not there. Common examples of hallucinations include hearing sounds or voices that are not real, or seeing something that isn’t actually there – such as a person, animal or object.

Signs of changes in perception

It can be difficult to know when a person with dementia is experiencing perceptual difficulties or hallucinations. Signs that this might be happening include:

- saying or doing things that suggest they see or hear things that you can’t
- bumping into things or having frequent trips and falls, as though they are struggling to see the objects around them
- not recognising where they are
- displaying changes in behaviour that may indicate fear or distress
• becoming more socially isolated
• reacting to, or looking startled by, things that you can’t see
• muttering under their breath, or speaking as if they are responding to something you cannot hear
• plucking or picking at their skin as if they itch
• reaching for items but missing them, or putting things down in the wrong place, eg putting a cup down but missing the table
• trying to pick things up out of thin air
Practical tips for preventing perceptual difficulties

Ways to avoid visual misperceptions

- Take the person for regular eye tests
- If they wear glasses, make sure they’re clean and fit properly
- Cover mirrors or turn them around to face the wall. People with dementia may misinterpret reflections as other people in the house
- Move other objects that could be mistaken for a person, such as coat stands, dressing gowns or coats hung on doors
- Prevent reflections from windows with blinds or curtains
- Avoid busy patterns on carpets or tiles, and if possible, try to avoid changes in the levels of the floor, such as from thick carpet to wooden floor, which might be difficult for a person with dementia to see
- Make sure rooms are well lit
- Use contrasting colours to help the person, such as block coloured plates to help food stand out; brightly coloured towels that are easier to see when hanging on a towel rail against the wall; or a coloured toilet seat that stands out from the rest of the bathroom. People with dementia often find it easier to see blue than red
- If the person drives, it is essential that they inform the DVLA (DVA in Northern Ireland) of their dementia diagnosis. If they are allowed to continue to drive, try to go out in the car with them on a regular basis to check whether they are safe to drive — for example, if they are judging speeds and distances correctly
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Ways to avoid auditory (hearing) misperceptions

• Take the person for regular hearing tests
• If they wear a hearing aid, make sure it’s clean and well maintained, and that the battery is checked regularly
• Speak slowly and calmly to the person
• Face them when speaking
• Turn off background noise such as the TV and radio when speaking to them
• Try to avoid sudden loud noises, such as Christmas crackers, party poppers or fireworks as these can cause shock and fear

Ways to avoid taste misperceptions

• Take the person for regular dental check-ups. Tooth decay or gum disease can create a bad taste in the mouth, which people with dementia can misperceive as something wrong with their food
• Make sure the person follows a daily mouth care routine, with support if needed
• Check the person’s dentures, teeth and mouth for signs of soreness, infection or damage and ask whether they have any discomfort
• Be aware that people’s food and drink preferences may change when they have dementia and try to accommodate this – for example, someone may suddenly dislike milk in their tea

Ways to avoid sense of touch misperceptions

• Look out for excessive itching or plucking at the skin and try to identify a trigger
• Find out whether there has been a change in medication – itching might be a side effect
• Check if there has been a change in washing detergent
or fabric conditioner which may have triggered an allergic reaction or skin sensitivity

- Consider whether the person has an allergy to something else, such as soap or pet hair
- Assess whether the person is too hot or cold
- Check if their clothing is causing discomfort, for example if cuffs are too tight, fabric is rough or scratchy (e.g., pure wool) or seams are irritating the skin

**Ways to avoid sense of smell misperceptions**

- Investigate if anything in the house is causing a bad smell – for example, the bin, food that is off, a pet litter tray or cage etc. People with dementia can misperceive bad smells as something worse, such as a gas leak
- Encourage the person to follow a hygiene routine, with assistance if necessary
- Consider using mild washing detergents and fragrance-free toiletries – strong smells may be overwhelming
What to do if someone is experiencing perceptual difficulties and hallucinations

Changes in perception and hallucinations can feel very real to the person with dementia and can cause distress. If you believe someone is having difficulties, ask them what the matter is. Listen carefully to their response and if possible, see if you can deal with the source of their distress – for example, by drawing the curtains if they are troubled by reflections in the window.

Talk in a reassuring, slow, soothing way and explain what is happening, but try not to contradict the person as this may make them feel you are dismissing their concerns and increase their distress.

Hold the person’s hand or sit close to them and stroke their arm if they find this reassuring.

If the person wears glasses, check they are wearing the correct pair and that they are clean. If they use a hearing aid, make sure it is working and that the batteries are charged.

Check for possible physical reasons for their distress. Could they have an infection; be dehydrated or constipated; be in pain; or be experiencing side effects from prescribed medication? If you are unsure, contact the person’s GP.

Distraction techniques can sometimes help. You could suggest you both go into a different room or the garden; take them to the kitchen to make a drink; offer them a snack; change the topic of conversation; turn some music on; look at some family photos; or go out for a walk.

Where to get help and support

If the person with dementia is having episodes of distress which become more regular or worsen, make an appointment with their GP. It is helpful to keep a record of the person’s behaviour to show their GP, including:

- any triggers for the change in their behaviour
- the signs and symptoms
- what time of the day the behaviour occurred
• what, if anything, helps to reduce or stop the behaviour

The GP will be able to check for any physical causes that could be treatable, such as an infection or pain. If no cause can be found, they may be able to recommend additional strategies for managing the person’s behaviour, or you can call Dementia UK’s free Helpline or book an appointment in our clinics – please see Sources of support on p11.
Sources of support

To speak to a specialist dementia nurse about changes in perception and hallucinations or any other aspect of dementia, please call our Helpline on 0800 888 6678 (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-a-clinic-appointment

Dementia UK resources
False beliefs and delusions
dementiauk.org/false-beliefs

Tips for better communication
dementiauk.org/better-communication

Pain and dementia
dementiauk.org/pain

Making the home safe and comfortable for a person with dementia
dementiauk.org/safe-comfortable-home

Dealing with restlessness
dementiauk.org/dealing-with-restlessness

Delirium (sudden confusion)
dementiauk.org/delirium

Coping with distress
dementiauk.org/coping-with-distress

Sundowning
dementiauk.org/sundowning

Mouth care for a person with dementia
dementiauk.org/get-support/health-issues-and-advice/mouth-care-dementia
If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
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Thank you.