

Sight, perception and hallucinations in dementia

Some people with dementia may encounter problems with their sight – in some cases, this includes having hallucinations. This factsheet looks at some of the difficulties and mistakes this can cause, and suggests ways of providing support for the person. Understanding the problems they may face and giving appropriate help, support and reassurance can help people living with dementia to feel safe. This is especially important at a time when the way they perceive the world around them may be changing.

Vision and perception

The complicated process of seeing involves many different stages. Information comes through our eyes to the brain, where it is interpreted in relation to our expectations (of what will be seen), other senses, thoughts and memories. We then become aware of what has been seen (what is 'perceived'). Problems that involve both vision and perception can be referred to as 'visuoperceptual difficulties'. As there are many different stages involved in the seeing process, various different types and combinations of mistakes can occur. Common mistakes include:

- misperceptions – the person sees one thing as something else. For example, mistaking a coat hanging up for a person, or a blue coloured floor as water
- misidentifications – damage to specific parts of the brain can lead to problems identifying specific objects and people. For example, mistaking a son for a husband or brother.

It is easy to see how these mistakes may lead to the person with dementia saying or doing things that do not make sense to others. However, what they are experiencing is not a problem with thinking (it is not based on incorrect reasoning or 'delusional thinking'). Instead, it is the result of damage to the visual system.

Causes of visuoperceptual difficulties

The ageing process can bring about many difficulties, particularly those relating to sight and visuoperception. These include:

- seeing things less sharply (blurring)
- needing more time to adapt to changes in light levels (eg when going from a dark room into sunlight)
- the area in which objects are seen (the 'visual field') getting smaller, and loss of peripheral vision (being able to see things outside of the direct line of vision)
- problems with depth perception (the ability to judge the distance of or to an object and see in three dimensions)
- shadowing from small shapes floating in the visual field (known as 'floaters').

Eye conditions that can affect visuoperception include cataracts, glaucoma, macular degeneration and retinal complications from diabetes. These can all result in changes such as blurring, distortion, partial loss of visual field and, in some cases, blindness. They can also cause hallucinations known as Charles Bonnet syndrome.

Charles Bonnet syndrome occurs when people with deteriorated vision start to see things that aren't there (visual hallucinations). There are two main types of hallucination: simple repeated patterns or complex images of people, landscapes or objects. These hallucinations are caused by the person's deteriorating sight and not from any other condition.

For more information on hallucinations see 'Hallucinations in people with dementia'.

A stroke can also cause someone to have problems with their vision. They may lose the ability to see things directly ahead (central vision loss) or lose peripheral vision (visual field loss). This can happen in both eyes at the same time. They may also have problems with eye movement and how the brain processes visual signals.

Certain medications can cause or contribute to problems with vision. They include drugs for cardiovascular problems, non-steroidal anti-inflammatory drugs, antibiotics, drugs for Parkinson's disease, and eye medications.

Specific types of dementia can also damage the visual system and cause visuoperceptual difficulties. These include Alzheimer's disease, Parkinson's disease dementia, dementia with Lewy bodies and vascular dementia. Rarer forms of dementia, such as posterior cortical atrophy (PCA), can also cause visuoperceptual difficulties. For more information see factsheet 442, **Rarer causes of dementia**.

Visuoperceptual difficulties in people with dementia

The specific difficulties a person experiences will depend on the type of dementia they have. This is because each type of dementia can damage the visual system in a different way.

Difficulties may include:

- being less sensitive to differences in contrast, such as black and white, and contrast between objects and background
- being less able to detect movement
- changes to the visual field (how much you can see around the edge of your vision, while looking straight ahead)

- being less able to detect different colours. For example, a person may have problems telling the difference between blue and purple
- changes to how the pupil reacts to light
- problems directing or changing gaze
- problems with the recognition of objects, faces and colours
- losing the ability to say what has been seen
- double vision
- problems with depth perception (judging the distance of objects from the person).

Difficulties with orientation

Dementia can also cause difficulties with orientation. This can lead to:

- bumping into things
- swerving to avoid door frames
- difficulties reaching for things , such as a cup of tea or door handle
- getting lost or disorientated, even in familiar environments.

These difficulties can have a big impact on the person with dementia. They may include:

- difficulties with activities and hobbies such as reading and writing
- problems locating people or objects, even if they are in front of the person. This may be because of other visual distractions (such as patterned wallpaper) or because of a lack of contrast (for example, not seeing mashed potatoes on a white plate)

- misinterpreting reflections such as seeing an ‘intruder’ or refusing to go into a bathroom because it looks as if someone is in there
- mistaking images on the TV for real people
- having difficulty positioning themselves on a chair or on the toilet
- becoming confused or restless because the environment is visually over-stimulating (has ‘too much going on’) and is difficult to navigate. For example, a room with patterned wallpaper, bright lights or too many signs.

Difficulties with moving around

Visuoperceptual difficulties can also lead to problems moving around. Consequently, people with dementia may:

- misjudge distances and where objects are, even in familiar environments
- step too high over carpet rods or shadows because the change in colour looks like a change in level or height
- have difficulty going down stairs due to problems judging how many steps there are and where the next one is
- try to avoid shiny floors and surfaces because they appear wet or slippery.

These problems can make a person afraid of falling and lead to them slowing down their movements while they try to walk safely.

Tips

- Try to anticipate the situation and explain the environment. For example, if you notice someone avoiding a room with a shiny floor or surface, walk in first to show the person that it’s safe.

- Offer the person plenty of support and encouragement.
- Try not to make the person feel rushed, and allow them plenty of time.
- Slow down your own movements.

If a person with dementia is living at home with other people, it may not be clear how their visual difficulties affect them until they experience a change in environment. This may include visiting family, going out shopping or going on holiday.

How to support someone with visuoperceptual difficulties

There are many ways you can help to reduce visuoperceptual difficulties for a person with dementia. By being aware of this type of problem, you will be able to better support them.

Careful attention to eye care and visual health

- Arrange regular eye checks, and inform the optometrist of the person's dementia. This will help when arranging appointments and getting the right treatment.
- If the person wears glasses, check that they are clean and they have the right prescription. Encourage the person to wear them as and when necessary.
- Check the person is wearing the correct glasses for a specific activity, such as reading. It can help to label the glasses, the case or to have a different colour frame for different activities – for example, red frames for reading and black frames for watching television.
- Research has shown that multifocal glasses can increase the risk of falls in people when they are outside the home. Therefore, it may be useful to have separate glasses for distance (for the outside) and reading (for things up close).

- If the person has cataracts, talk to an optometrist or their GP about how to have them treated.

Environmental adaptations

An occupational therapist (OT) can offer advice on ways to maintain ability and independence with daily activities. This can include information and advice on assistive technology (devices or systems that support a person to maintain or improve their independence, safety and wellbeing, eg medication prompts or locator devices). They can also advise on adaptations and equipment for the home (eg grab rails or adapted cutlery). If an assessment from an OT would be helpful, speak to your GP, consultant or social services. For more information see factsheets 429, **Using equipment and making adaptations at home**, and 437, **Assistive technology – devices to help with everyday living**.

General tips

- Try not to make too many changes to the person's environment (eg keep furniture and other items in the same place). This can help the person feel confident and reduce their fear of tripping or falling.
- Use colour. For example, having a different colour toilet seat to the bowl (eg a black toilet seat on a white toilet). A red plate on a white tablecloth is easier to see than a white plate.
- Colour can also be used to highlight important objects and orientation points (eg the toilet door), or for camouflaging objects the person doesn't need to use (eg light switches or doors).
- Improve lighting levels around the person's home. This can reduce visual difficulties and help to prevent falls. Lighting should be even around the home and should minimise shadows – some people resist going near dark areas in corridors and rooms.
- Try to avoid 'busy' patterns (eg on the walls or floors) and changes in floor patterns or surfaces. They may be seen as an obstacle or barrier and the person may avoid walking in these areas.

- Reduce the risk of trips and falls by removing clutter and obstacles.
- Remove or replace mirrors and shiny surfaces if they cause problems.
- Close curtains or blinds at night.
- Consider assistive technology products such as automatic lights.

Practical tips

- If a person fails to recognise an object, don't draw any unnecessary attention to the mistake. Avoid asking questions that might make them feel 'put on the spot'. If appropriate, give the object to the person and explain how it is used. If they do not accept this explanation, try not to argue with them. Ignore the mistake and listen to what they are trying to say. Being corrected can undermine a person's confidence and they may become reluctant to join in conversations or activities. Therefore, it is important to focus on the emotions behind what is being said, rather than the facts or details.
- If the person struggles to recognise people, ask friends and relatives to introduce themselves. If the person doesn't recognise somebody, it can be distressing for them as well as for those around them. If this happens, try to reassure the person and find tactful ways to give them reminders or explanations.
- Try to make activities accessible for the person. For example, if the person enjoyed reading but is no longer able to, think about audiobooks instead.
- Consider adapting activities to make the most of the person's abilities, eg cooking using pre-chopped vegetables and ready-made sauces. For more information on activities and staying involved, see factsheet 521, **Staying involved and active**.
- At mealtimes, it may help to describe the food and drink, where it is on the table and where cutlery is, if appropriate.

- After you've used something, try to leave it where it was or in a familiar place, eg keys in a fruit bowl.
- Let the person know where they are, who they are with and what is going on.
- Tell the person when someone enters or leaves the room.
- If you're giving the person medication, explain what it is, what it is for and what you are doing.

Hallucinations in people with dementia

What are hallucinations?

A hallucination is an experience of something that is not really there. They can occur for all the senses, though visual hallucinations (seeing things that are not really there) are the most common type experienced by people with dementia.

Visual hallucinations can be simple (eg seeing flashing lights) or complex (eg seeing animals, people or strange situations). Less often in people with dementia, hallucinations can involve hearing, smelling, tasting or feeling things that do not really exist.

Hallucinations and dementia

People with dementia are often thought to be hallucinating when in fact they are making a mistake about what they have seen (see 'Visuoperceptual mistakes'). In some specific forms of dementia, hallucinations are more common. These include dementia with Lewy bodies and Parkinson's disease dementia. People with Alzheimer's disease can also experience hallucinations.

Hallucinations in people with dementia with Lewy bodies usually take the form of brightly coloured people or animals. They often last for several minutes and can occur on a daily basis. Some people with dementia with Lewy bodies can also experience hallucinations

in other senses – for example, hearing things that aren't there (auditory hallucinations) or smelling things that aren't there (olfactory hallucinations). People with other types of dementia may also experience these types of hallucinations, as well as tactile hallucinations (sensing things that aren't there).

Supporting the person

If you suspect that a person is hallucinating, try to calmly explain what is happening. If they cannot retain this information, repeat it when they are more relaxed. If this is still not possible, don't argue with them – it will not help. Trying to convince someone that they are mistaken can lead to more distress for both you and them. Stay with the person and try to reassure them. Explain that even though you can't sense what they do, you want to know what they are experiencing. Listen carefully to what they describe. There may be some language difficulties that may explain what the person is reporting. For example, referring to green cushions as 'cabbages'.

Hallucinations may be limited to a particular setting. Gently leading someone away from where they are having the hallucinations can help make the hallucinations disappear.

It may help to distract the person, and see if this stops the hallucinations. For visual hallucinations, consider making changes to the environment, such as improving lighting levels and reducing visual clutter. In addition, make sure that the person has regular eye checks, wears the correct glasses (if needed) and that they are clean.

For auditory hallucinations, arrange to have their hearing checked. If the person wears a hearing aid, check that it is working properly and encourage them to wear it. People are less likely to hear voices that are not there when they are talking to someone real, so having company around may help.

Treatment

It is important to note that hallucinations can be caused by the side-effects of certain medications. This includes some antidepressants and drugs for Parkinson's disease, or certain illnesses (including fever, seizure, stroke, migraine and infection). If a person is experiencing hallucinations, you should consult their GP.

If the person's hallucinations involve multiple senses, seek medical help immediately, as this can be a sign of serious illness. It is also a good idea to seek medical attention if the hallucinations frighten the person or they last a long time. The same applies if the hallucinations occur often or if the person seems more confused than usual (this may be a sign of delirium).

When visiting the GP, it will help if you bring notes about:

- what the person saw or sensed
- what time of day it occurred and after what event (eg nap, meal, exercise)
- where it happened and how long it lasted
- how the person responded (eg if they were distressed) and the words they used to describe what they experienced
- medication the person is taking and the dosage (including any supplements and over-the-counter medications)
- the person's medical history, including any previous sight (or other sensory) conditions and mental health issues
- the person's use of alcohol or other recreational drugs.

Some people with dementia experiencing hallucinations respond to anti-dementia drugs, particularly people with dementia with Lewy bodies. In some situations, people with dementia may be prescribed antipsychotic medication. Antipsychotic drugs do help some people with dementia, but they can also cause side-effects and should be used with caution and be regularly reviewed. However, there are certain circumstances where antipsychotic medication can be effectively used to treat hallucinations, despite the risks. In some cases they can eliminate or reduce the intensity of psychotic symptoms, such as delusions and hallucinations, and have a calming and sedative effect. For more information, see factsheet 408, **Drugs used to relieve behavioural and psychological symptoms in dementia**.

If a person with dementia with Lewy bodies must be prescribed an antipsychotic drug, it should be done under constant supervision and regularly reviewed. People with dementia with Lewy bodies are at particular risk of severe adverse reactions to antipsychotic medication. If you have questions about the use of antipsychotic drugs speak to the GP or consultant.

Other useful organisations

Dementia and Sight Loss Interest Group

W www.vision2020uk.org.uk/interest-groups/dementia-and-sight-loss-interest-group/

Aims to develop and promote better understanding of the issues facing people affected by dementia and sight loss. Also provides materials, resources and tools that contribute to good practice.

Macular Society

PO Box 1870
Andover, Hampshire SP10 9AD

T 0300 3030 111 (helpline)
E info@macularsociety.org
W www.macularsociety.org

A national charity offering support and advice for anyone affected by central vision loss.

Royal National Institute of Blind People

105 Judd Street
London WC1H 9NE

T 0303 123 9999 (Monday to Friday
8.45am – 5.30pm)
E helpline@rnib.org.uk
W www.rnib.org.uk

A charity that offers support and advice to blind and partially sighted people in the UK.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2016. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

Factsheet 527

Last reviewed: March 2016

Next review due: March 2019

Reviewed by: Dr John Paul Taylor, Wellcome Intermediate Clinical Fellow and Honorary Consultant in Old Age Psychiatry, Institute for Ageing and Health, Newcastle University; Daniel Collerton, Consultant Clinical Psychologist, Northumberland, Tyne and Wear NHS Foundation Trust and Associate Clinical Teacher, Newcastle University; Paul Ursell, Consultant Ophthalmologist and Lead Cataract Surgeon for Epsom & St Helier University NHS Trust; College of Optometrists.

This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.



Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499