



# Dementia and sensory loss: Sight loss

---

## Key messages

- Sight loss is very common among older people, and yet it can be missed as the symptoms may be misinterpreted as resulting from dementia.
- It is important to understand the signs and symptoms of sight loss and ensure that older people have regular eye examinations.
- There are many ways in which communication can be improved with people with sight loss and dementia.
- Make the most of what sight a person has: ensure the correct and clean glasses are worn for the activities undertaken.
- Environmental improvements, specialist equipment and technology can support people with sight loss and dementia to be more independent.

*'When I got a dementia diagnosis people knew I was having problems, so were quite understanding and looked at how they could help. Not so with this sight problem. Other people can't see anything wrong... [RNIB] offered suggestions and little ways of stopping falling. I started to cry, just with relief that I'd got help for the first time.'*

Agnes Houston, talking at a seminar on dementia and sight loss (see Dementia and Sight Loss Interest Group 2009)

## How common is sight loss?

The older you are, the more likely you are to live with sight loss. Around 1 in 9 people over the age of 60 are living with sight loss – and by the age of 85 this has increased to around 1 in 3 people (Access Economics 2009).

At least 123,000 people in the UK have both dementia and serious sight loss (RNIB 2012). Most are over 65, and among everyone of that age normal ageing of the eye will, to some extent, reduce their vision. Health conditions that lead to sight loss are largely age-related. Almost everyone aged over 80 will have (or have had) a cataract. As the population ages, an increasing number of people will experience both dementia and sight loss.

Sight loss among people with dementia may be caused by:

- an eye condition, such as a cataract
- another health condition, such as a stroke
- normal ageing of the eye
- the dementia itself.

## The impact of sight loss and dementia

When a person has dementia and sight loss, many routine things – such as getting out and about, communicating, day-to-day living – become more difficult than if the person only had one of these conditions. Dementia combined with sight loss can lead to:

- profound disorientation and isolation
- an increased risk of falls
- difficulties moving between light and dark spaces

- difficulties learning to use new equipment
- less independence
- misperception and misidentification of people, articles and activities
- anxiety and worry for carers and relatives.

(for more on this, see Lawrence et al 2008)

Making the most of someone's sight, ensuring that communication is effective and taking steps to adapt the environment and support orientation – these are all vital ways to help support the independence, confidence and wellbeing of a person with dementia.

## Visual misinterpretations and hallucinations

A common problem for people with dementia is misinterpreting visually what they are seeing. For example, they may see a face in a patterned curtain, or see a shadow on the floor, but interpret it as a hole in the ground. Simple adjustments to lighting or décor may be able to stop this from occurring.

Sight loss can increase the risk of someone with dementia experiencing hallucinations. It is important however to understand that people with sight loss can experience visual hallucinations commonly called **Charles Bonnet syndrome** (CBS). This is a common condition among people who have lost their sight. It causes people who have lost a lot of vision to see things that aren't really there, known as visual hallucinations. It can be distressing, but the hallucinations are usually not permanent. Many people experience hallucinations for a year to 18 months before they become a lot less frequent. It would therefore be important to know when supporting

## Sight loss

someone with sight loss and dementia whether they had experienced sight loss-related hallucinations in the past.

People with certain types of dementia, such as dementia with Lewy bodies, Parkinson's disease dementia and Alzheimer's disease may also experience hallucinations caused by the dementia, but still have healthy eyes. So having a sight test can help to rule this out.

The Alzheimer's Society have produced a factsheet on this topic, called **Sight, perception and hallucinations in dementia**.

### Improving verbal communication

When speaking with someone with sight loss and dementia, there are many things that we can do to help the communication – and avoid frustration and confusion.

Consider the following suggestions:

- Use the person's name when addressing them; this way they know you are talking to them.
- Introduce yourself when you approach a person with sight loss, using voice and, when appropriate, touch to let the person know you are there and who you are.
- Say what you are going to do before you do it and as you are doing it.
- Tell the person when you are moving away or leaving the room.
- Use words and phrases that have meaning for the person, for example, saying something is 'over there' is not useful if the person cannot see. Use references that are familiar such as, 'I am

leaving the juice on the table on your left where you normally have your drinks.'

- Talk directly to the person, not a companion or relative.
- Ask the person where you are most likely to be seen and heard, given their particular sight condition.

Remember that many people with sight loss will not pick up on non-verbal communication, for example your facial expressions will be lost to them or they might not be able to follow when you are making a joke.

### Improving written information

Written information can pose problems for people who cannot read standard print. Quite often, the solution involves reading everything out to the person, but this can be embarrassing and frustrating and, with confidential information, not always appropriate.

You need to know how each individual prefers to read written information and record this on their care plan and patient record. They might prefer large or clear print, audio CD or Braille.

Some basic suggestions include:

- Use font size 14 or over for written information.
- Organise copies of general information on services the person uses (or may need) in their preferred format. Your local sight loss society can tell you how to find local suppliers of large print, audio or Braille. For information on getting

individual documents transcribed and bulk transcription, go to the RNIB website [here](#).

- Produce personal information in the individual's preferred format. For large print, you could use a bold black marker pen but do not utilise block capitals, as people with some sight use the shape of words to assist with reading. Computers can enlarge the font size in electronic documents and audio versions can be made on dictaphones.
- Use large print and clear, recognisable, images on all noticeboards and signs.
- Consider purchasing a talking noticeboard and using it for daily information. These techniques will work for some people with dementia but not others, so support the individual to work out the best solutions for them.
- Ensure people are referred to a low vision clinic to get help to use simple magnifiers and to vision rehabilitation services for information and help to find ways to manage daily life. Your GP or social services team can provide information about local services.

For more information, a good resource on this is *Seeing it from their side: A guide to recognising and supporting sight loss in your care home*.

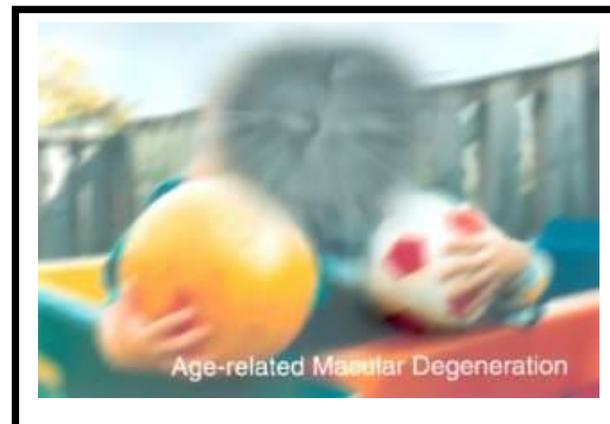
## Seeing it from their side...

Look at the pictures below. Try to imagine interpreting the world while having dementia and one of these eye conditions.

### 1. Normal vision



### 2. Age-related macular degeneration



## Sight loss

### 3. Cataracts



### 4. Glaucoma



### 5. Diabetic retinopathy



## Make the most of existing sight

Wearing the wrong spectacles is a recipe for confusion, mistakes, slips and trips. Many older people have different pairs of glasses for reading or eating, watching TV or walking around. It is easy not to remember which pair of glasses is for which task.

Some suggestions for making it easier include:

- Mark spectacle frames with the person's name and what they are for.
- Encourage wearers to use dissimilar looking glasses for different tasks (red for reading, green for walking in the garden).
- To help with identification, take photos of the person wearing the glasses and doing the task

they are intended to help with, for example eating lunch or walking around. Don't just keep the photos in personal care records – make them visible to everyone who cares for that person.

- Ensure that glasses are clean by implementing a daily cleaning regime.
- Make sure frames fit correctly and make sure frames are fitted by an optometrist, dispensing optician or someone with the relevant experience.
- Label spectacle cases. Match the colour of cases to the spectacles but use bright coloured contrasting cases.
- Use chains or other devices to hold and secure glasses around the neck so they cannot be easily misplaced.

## Regular eye tests

Even if a person's vision seems OK, an eye test can detect problems they don't know they have – and save their sight. RNIB recommends that people over 70 should have a full eye examination every year. Sight tests are free to those over 60. In Scotland people over 60 are seen annually.

An eye test will assess short and long sight and check eye health. It will identify eye conditions that may cause sight loss without early treatment. Eye examinations are especially important for people with dementia as the symptoms of dementia may mask the symptoms of sight loss, and so may mean that steps to improve sight, independence, wellbeing and cognitive function are missed.

Here is a simple checklist for sight loss. Does the person find it difficult to:

- recognise people?
- need more light to do tasks?
- have difficulty in bright lights or when lights dazzle?
- find things?
- locate food on a plate?
- use their spectacles? (or perhaps they say often, 'I need new glasses')

If two or more of these apply, an eye examination should be arranged. Even if someone over 70 has none of these issues, they should still have an eye test once a year.

## Eye examinations at home

If the person with dementia cannot get to the opticians due to difficulties leaving the house, they are entitled to an eye examination at home. Not all optometrists will do home visits but the person's GP or your local clinical commissioning group should be able to tell you which local optometrists provide eye examinations at home. People who are 60 or over qualify for a free NHS eye examination and will not have to pay anything for an eye test at home.

The Thomas Pocklington Trust website has information on ['Would you or someone you know benefit from a home eye test?'](#)

## Sight loss

Some people also qualify for support with the cost of glasses. For more information call the RNIB helpline on 0303 123 9999.

## Cataracts and dementia

One condition a sight examination may identify is cataracts. Cataracts are a very common eye condition in older people. Most people with cataracts are over the age of 60 and they become more common as people age. Having dementia does not preclude someone from eye surgery and in fact there may be benefits for someone with dementia having a cataract identified and treated early.

The **Dementia and Sight Loss Interest Group** (see below for more information on this group) has developed a **factsheet** that explains:

- what a cataract is and its effect on vision
- how to tell if you or someone you care for has a cataract
- cataract surgery and the difference it can make to a person's quality of life
- how to prepare for surgery
- how to help someone with dementia cope with surgery
- what happens after surgery.

## Low vision services

Low vision services can help people make the most of their remaining sight. Specialist optometrists are able to assess someone's vision and provide them with a

magnifier. They can also give advice on lighting and reading techniques. Most low vision services are based in hospitals and someone will have to be referred to them through their ophthalmologist or GP. If a person is unable to get to the hospital, a low vision assessment should be made available at home.

When a person is registered as sight impaired or severely sight impaired, they should be offered an assessment by their local social services. Even if the person is not registered but has poor sight, it should still be possible for them to have an assessment by their local social services.

Vision rehabilitation services can also make a real difference to someone with poor sight. These services are mostly offered through local social services, and some may be provided by a voluntary organisation. A vision rehabilitation officer gives advice on using a symbol or mobility cane, staying safe by adapting a person's environment, and help to stay confident when getting out and about.

Most people with sight problems use both their low vision service and their rehabilitation service. In some parts of the country these services may be integrated. RNIB or your local society for people with poor sight should be able to let you know the arrangements for your area.

## Adapt the environment

Make the environment work to make the most of everyone's sight. Consider these tips below:

- Provide good, even, internal and external lighting.
- Use clear and uncluttered interior design.
- Use contrasting colours for floors, walls and furniture.

- Use bathroom fittings that contrast with floors and walls.
- Use tablecloths and mats that contrast with crockery.
- Mark the beginning and ends of stairs and steps, using different textures or colours.

To summarise this even more simply, remember these three principles:

- Make things bigger (such as using clocks and watches with large numbers).
- Make things brighter (by using good lighting).
- Make things bolder (use contrasting backgrounds).

Or think about it this way: is it easier to find dark chocolate in a brown box or a white box? Is it easier to find white towels or blue towels in an all-white bathroom?

To find out more, go to this factsheet from RNIB Scotland and the Scottish Government: [Environmental tips to help a people with dementia and sight loss](#) and the RNIB and Thomas Pocklington Trust resource (2012) [Make the most of your sight: Improve the lighting in your home](#). The section on [Dementia friendly environments](#) in the Dementia Gateway also has lots of relevant content.

## Equipment and technology

There are many specialist gadgets available to support everyday living: large and clear faced clocks and watches, talking clocks and watches, easy-to-use remote controls for TVs, big button phones, landline phones with pictures

for speed dials, talking labels to stick onto anything and everything.

Everyday gadgets – such as one-touch can openers or bendy chopping boards – can also be just the thing to make life easier. Good lighting is good for everyone. Lights above working surfaces and bathroom mirrors make everyday tasks easier and safer. Reading lamps can make the difference between reading the paper and losing touch with the world.

Specialist services for people with sight loss can also be beneficial for people with dementia:

- talking newspapers
- audio books
- audio descriptions on TV programmes and films
- tactile and large print games as well as games and puzzles, printed or for computers and notebooks
- braille and large print music
- RNIB telephone befriending groups
- audio tours and services at museums, galleries and heritage sites.

To find out more about each of these services, start with the RNIB website, and the information on [Living with sight loss](#).

To find out more about specialist products, start with the RNIB's [shop](#).

## Accessible activities

People with sight loss and dementia can often feel isolated because they can be excluded from everyday activities. It is important that activities are made accessible.

This may involve just thinking about the needs of a person with sight loss and dementia and doing some practical things to help, such as remembering to explain what you are going to do, or remembering that the person can't read the noticeboard to know what is going on and coming up with an alternative way of communicating these notices. Or it may mean buying in things such as talking newspapers and other items described above.

Finding out how someone's previous interests can still be supported and made accessible is also important and RNIB, Action for Blind People and local sight loss charities can offer support with this. Sight loss with dementia increases anxiety about risks – but it is important to work out how to make much-loved activities accessible rather than ruling them out.

Gardening, for example, is an enjoyable hobby for many people with sight loss and dementia and sight loss need not stop someone from undertaking this. There are a number of custom-made gardening tools, techniques and methods that can make gardening easier. **Thrive**, the gardening organisation for people with disabilities, can offer support and advice for people who wish to garden.

The way in which support is offered to people with sight loss is so important too. Support activities that have clear scent, sound, touch or movement, for example baking, gardening or hand massage. In unfamiliar places, find or

create audio descriptions. And wherever you are, describe what is going on and who is involved.

In the example below, Hilary Dyce explains how she has tried different things to support her mother (who has Alzheimer's disease and an eye condition) to continue to do activities she enjoys.

'I'd like to...tell you about some of the things we have been doing to compensate for Mum's difficulties – things that do not require her to 'see':

- playing talking CDs: favourites are stories she knew and loved when she was younger, ranging from 'Winnie the Pooh' to 'Under Milk Wood'; she speaks or sings along to some of the words in songs and poems
- 'watching' DVDs of favourite operas and ballets with dad: she may not see the picture well, but we think the music creates a picture in her mind's eye
- reading poetry to her: she was very good at memorising poems in her young days and, until recently, could fill in the ends of lines in her favourite ones and we would both enjoy that
- giving her a manicure: she has always had lovely, well cared-for hands and nails and this is something tactile and physical that she appreciates – we always finish by using a lovely lavender-scented hand cream

- finding interesting objects for her to hold on to: her favourite little teddy bear, the soft wool socks I gave her for her birthday last month or just a hand to squeeze.’

(from the 2010 Dementia and Sight Loss Interest Group conference, ‘Personal story from Hilary Dyce’ is available on the [Dementia and Sight Loss Interest Group microsite](#)).

## Support with orientation

‘Guiding’ refers to how support is offered to a person with sight loss to help them move around, indoors or outdoors. Here are some tips:

- Always ask people how they would like to be guided – don’t assume you know.
- Don’t hold the person’s arm unless you need to because of other mobility issues. Invite them to hold your arm, at the elbow with your arm by your side.
- While you’re walking, keep talking to the person, telling them where you’re going and what to be aware of (for example, when you’re going up and down steps).
- Always look back when you’re going through doorways to make sure the person is in the right position and is not going to walk into the frame.
- When someone wants to sit down, inform them that you’re going to put their hand on the back of a chair so they can feel that and let them

manoeuvre into the chair independently. Offer further verbal guidance if it looks as if they may miss the chair but do not push or pull them into the chair, as this can cause distress.

- Always ensure that other care staff are informed of the person’s wishes – record them in care plans and give verbal updates.

To find out more and watch useful videos on guiding people with sight loss, you can look [here](#) at the RNIB’s website.

## About the Dementia and Sight Loss Interest Group

The Vision 2020 UK [Dementia and Sight Loss Interest Group](#) was set up in 2008 in response to the growing realisation that, although large numbers of people with dementia also have problems with vision and visual perception, awareness of the particular difficulties faced by those affected by both conditions is very low. The group consists of Alzheimer’s Society, RNIB, Thomas Pocklington Trust, Macular Society, Guide Dogs and the Royal College of Ophthalmology.

The group’s aims are to:

- develop and promote a better understanding of the issues facing people affected by dementia and sight loss
- support and influence initiatives around dementia and sight loss
- develop and disseminate materials, resources and tools that contribute to good practice.

To date, the group has developed a range of resources including:

- a 'frequently asked questions' factsheet (find this [here](#))
- a '**Dementia and sight loss**' leaflet (RNIB Scotland and Alzheimer's Scotland)
- a factsheet on '**Dementia and cataracts**'
- a **web page** on RNIB's website on dementia and sight loss which links to specialist training available, products and other dementia websites
- presentations on dementia and sight loss (look on the Vision 2020 website [here](#))

The group supports a significant amount of research as well. The Thomas Pocklington Trust has led on this (for more information go to [www.pocklington-trust.org.uk/dementia](http://www.pocklington-trust.org.uk/dementia)).

### Further reading and resources

Access Economics (2009) *Future sight loss UK 1: Economic impact of partial sight and blindness in the UK adult population*. London: RNIB.

Alzheimer's Society (2013) *Taking part: Activities for people with dementia*. (2nd edition), London: Alzheimer's Society.

Alzheimer's Society (2012) **Sight, perception and hallucinations in dementia**. Factsheet 527. London: Alzheimer's Society.

Dementia and Sight Loss Interest Group: to find out more, go to the **Vision2020** website.

Dementia and Sight Loss Interest Group (2009) *Double trouble: Report on seminar on dementia and sight loss, October 2009*. This can be found on the microsite of the Dementia and Sight Loss Interest Group within [www.vision2020.org.uk](http://www.vision2020.org.uk)

Fisk, M. and Raynham, P. (2010) *Good housing design – lighting: A practical guide to improving lighting in existing homes*: Good practice guide no 5. London: Thomas Pocklington Trust.

Lawrence, V., Murray, J., Banerjee, S. and ffytche, D. (2008) **The experiences and needs of people with dementia and serious visual impairment: A qualitative study**. Thomas Pocklington Trust occasional paper 16. London: Thomas Pocklington Trust.

Ricability and Thomas Pocklington (2012) *Choosing energy saving light bulbs for your home*. London, Ricability and Thomas Pocklington in partnership with Which?

RNIB (2012) *Sight loss UK 2012: the latest evidence*, London: RNIB.

RNIB (2010) *Seeing it from their side: A guide to recognising and supporting sight loss in your care home*, London: RNIB.

RNIB. **Cataracts and dementia**. Factsheet. London: RNIB.

RNIB. **Meeting, greeting and guiding**. Online information. Here you find out more about how to guide a person with sight loss and watch videos on guiding people with sight loss.

RNIB and Age UK (2011) *Seeing it from their side: Adapting older people's services to support sight loss*. London: RNIB and Age UK.

RNIB Scotland and The Scottish Government. **Environmental tips to help a person with dementia and sight loss**. Factsheet. Edinburgh: RNIB Scotland, The Scottish Government.

RNIB Scotland and The Scottish Government. **Tips for communicating with people with dementia and sight loss**. Factsheet. Edinburgh: RNIB Scotland, The Scottish Government.

RNIB and Thomas Pocklington Trust (2012) *Make the most of your sight: Improve the lighting in your home*, London: RNIB and Thomas Pocklington.

## Helplines and advice

### *Working with older people*

#### *Thomas Pocklington Trust - Dementia*

Alzheimer's Society National Dementia Helpline: 0300 222 1122

Macular Society Helpline: 0300 3030 111

RNIB help line number: 0303 123 9999

Written 2014

<http://www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/sight-loss.asp>

**Social Care Institute for Excellence**

[www.scie.org.uk](http://www.scie.org.uk)

© SCIE 2014