

Activity, sight loss and dementia: what works?

Dementia and sight loss

At least 100,000 people in the UK have dementia and serious sight loss. Most are over 65, and among everyone of that age normal ageing of the eye will, to some extent, reduce their vision. 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 cataract
- another health condition, such as stroke
- normal ageing of the eye
- the dementia itself.

Meaningful activities: opportunities and challenges

Activity helps maintain a person's sense of self-worth and gives purpose and enjoyment to the day and improves quality of life.

Dementia care and services for people with sight loss may have different approaches to developing meaningful activities and improving quality of life. Too often the symptoms of one condition conceal the other and a focus on dementia can mean that steps to make the most of sight are ignored and a focus on sight loss may not recognise the impact of dementia.

Research shows that people who have sight loss and dementia are likely to be more confused, disoriented and isolated than a person with one condition. (Ref 1) At the same time paid and family carers may restrict activity because they fear increased risks.

“Dad loved his workshop but his poor sight and confusion meant we were too worried to let him use it. We started to lock it – and that made him so angry. Now we have worked out that when he helps with jobs in the house and garden he is safer than we thought – and he is happier.”

Take steps to make the most of everyone's sight

- Support people to wear the correct (and clean) glasses, including support for regular eye examinations
- Address sight loss in care and support plans
- Provide good, even internal and external lighting
- Use clear and uncluttered interior design.



Ideas for making activities accessible

- Talking newspapers bring the news alive, audio books make reading possible; film and TV audio description is widely available; and audio labels can help identify things
- Good lighting makes everyday activities more accessible (and safer)
- Technologies that address sight loss can aid recognition: such as talking labels, big button controls, clocks with large numbers
- Tactile and large print games are readily available and make the most of all senses.
- Try new approaches to engage people
- Support activities that have clear scents, sounds, touch or movement – baking, gardening, hand massage
- In unfamiliar places, find or create audio descriptions
- Wherever you are, describe what is going on and who is involved.



Share your experience of good practice

Professionals, carers and people with dementia and sight loss are looking for ideas and experiences of how to support meaningful activity. Share yours!

Use and extend resources from specialist organisations such as:

- **Alzheimer's Society:** Visit www.alzheimers.org.uk and see the Alzheimer's Society book of activities, by Sally Knocker, 2003.
- **SCIE Dementia Gateway:** Visit www.scie.org.uk/publications/dementia/active/resources.asp
- **RNIB:** Visit www.rnib.org.uk for practical support, information and advice, an online shop for equipment and information about regional resource centres.
- **Thomas Pocklington Trust:** Visit www.pocklington-trust.org.uk for housing and lighting good practice guides.
- **Macular Disease Society:** Visit www.maculardisease.org for information about the most common cause of sight loss among older people in the UK.
- **Tell your colleagues** about how common sight loss with dementia is and share ideas about practical steps to respond.

References

1. Thomas Pocklington Trust, Research. Findings Number 19, November 2008. "The experiences and needs of people with dementia and serious visual impairment: a qualitative study." Kings College London Institute of Psychiatry

“Music has been important to me. Memory problems, confusion and my sight loss meant I couldn't find what I wanted to listen to and music was lost. Talking labels changed all that – I can choose the music I want to listen to.”

The information in this poster was produced by the Dementia and Sight Loss Interest Group (DaSLIG) formed of the Alzheimer's Society, Macular Degeneration Society, RNIB, Arup, and the Thomas Pocklington Trust.

Visit www.vision2020uk.org.uk to find out more.

Supporting people with sight loss and dementia in care homes

There are nearly two million people in the UK living with sight loss. Although it can affect anyone at any time losing our sight becomes increasingly likely as we get older. (1)

Sight loss affects one in five people over 75 and one in two people over 90. Thus over half of care home residents will have a degree of sight loss.

Two thirds of care home residents have dementia; many will also have other conditions such as sight loss.

Five common causes of sight loss

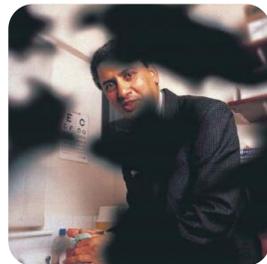
- age-related macular degeneration
- diabetic retinopathy
- glaucoma
- cataract
- refractive error.

It's possible to have more than one condition. For details see www.rnib.org.uk

The photos below show how different eye conditions may affect someone's vision



age-related macular degeneration



diabetic retinopathy



glaucoma



cataract

Other causes of sight loss

- **Stroke:** visual problems after a stroke are common. The most common effect is called hemianopia where a loss of sight in one side of the visual field occurs.
- **Dementia:** affects the way we perceive and process information from our eyes and some forms of dementia, such as Posterior Cortical Atrophy (PCA) and Dementia with Lewy Bodies, create apparent sight loss. Additionally sight loss or dementia can cause visual hallucinations.

Identification of sight loss in care home residents

Does the person find it difficult to:

- recognise people?
- be in bright light, low light or both?
- find things?
- locate food on a plate?
- use their spectacles, perhaps saying "I need new glasses".

If two or more of these apply you need to have the person's vision assessed. People over 60 should have a full eye examination every year.

Improving care homes for people with sight loss

- minimise glare
- increase colour and shade contrasts
- balance light levels
- provide lighting for close work
- reduce the amount of visual information
- provide clear signage in lower case
- keep things in set places
- improve general lighting
- sight loss specific care plans and assessments.

Dementia and sight loss

Most people with dementia are over 65 and may also be living with sight loss.

Research shows that a higher proportion of residents in care homes may have both conditions.

At least 100,000 people have both dementia and serious sight loss and some research suggests that the number may be higher. (2)

Dementia combined with sight loss can lead to:

- Profound disorientation and isolation
- Increased risk of falls
- Difficulties moving between light and dark
- More visual mistakes
- Less independence (3)

Practical improvements for people with dementia and sight loss:

- Ensure that the environment makes the most of light and sight
- Support people to wear the correct (and clean) glasses, including support for regular eye examinations
- Spend time getting to know the person
- Address sight loss in care and support plans
- Ensure activities are accessible.

For details see www.alzheimers.org.uk

References/additional information:

1. Seeing it from their side: a guide to recognising and supporting sight loss in your care home. RNIB 2010. www.rnib.org.uk/professionals/healthsocialcare/Pages/care_homes.aspx
2. Hallucinations in people with dementia. www.alzheimers.org.uk/factsheet/520
3. Visuoperceptual difficulties in dementia. www.alzheimers.org.uk/factsheet/527

The information in this poster was produced by the Dementia and Sight Loss Interest Group (DaSLIG) formed of the Alzheimer's Society, Macular Degeneration Society, RNIB, Arup, and the Thomas Pocklington Trust.

Visit www.vision2020uk.org.uk to find out more.

Dementia and Sight Loss Interest Group

Dementia and Sight Loss

- 750,000 people in the UK have dementia
- Most are over 65 years old
- Around 1 in 7 of people over 65 is living with significant sight loss.
- At least 100,000, but probably more, people have both dementia and serious sight loss.

As the population ages, the number of people with both dementia and sight loss will increase. In care homes, studies indicate a higher proportion of residents may have both conditions.

“I call it brain blindness – I can’t see. There is not much wrong with my eyes, but I have Posterior Cortical Atrophy. That is a dementia with a particular effect on vision.”

People with dementia and sight loss can experience:

- Increased isolation and disorientation
- Increased risk of falls
- Less independence
- Misperception and misidentification
- Increased worry or anxiety
- Lack of accessible activities
- Visual hallucinations.

Making the most of available sight can significantly reduce the impact of these experiences.

“It’s so hard for Dad to do the things he liked to do. It’s not just the effect of macular disease and his poor central vision, but the confusion and loss of memory because of the dementia makes everything twice as difficult for him; you can see him just giving up.”

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What can professionals who work with people who have dementia or sight loss do?

- Ensure people seek early diagnoses for dementia and for vision
- Take steps to make the most of vision
- Get involved with the Dementia and Sight Loss Interest Group (DaSLIG) and work with others to:
 - Share information and experiences
 - Work collaboratively across disciplines
 - Support carers through information and advice.

About the Dementia and Sight Loss Interest Group

In 2008, Royal National Institute of Blind People (RNIB), Alzheimer’s Society and Thomas Pocklington Trust formed the Dementia and Sight Loss Interest Group as part of VISION 2020 UK. In 2010 the Macular Disease Society and Arup joined the core group.

Aim of the Dementia and Sight Loss Interest Group:

- To improve the lives of people affected by dementia and sight loss.

Objectives

- To develop and promote a better understanding of the issues facing people affected by dementia and sight loss by presenting at events and seeking publications in relevant journals
- To collate, develop and share information and good practice on microsites
- To develop shared experience, knowledge, systems and resources which improve our organisations ability to provide information on dementia and sight loss to enquirers.
- To support and influence initiatives around dementia and sight loss, such as through joint working on product development.

The Group’s focus is on issues relating to the concurrence of loss of vision and dementia. This includes issues of visual perception that may be related to dementia and issues related to eye conditions, such as cataracts, and the impact of normal ageing of the eye.

“Working with people with sight loss means I know what can be done to make the most of their sight – linking up with the dementia team brings my skills and experience to people with dementia and their carers; it’s making a real difference to independence and quality of life.”

Information and advice about dementia

- **The Alzheimer’s Society:** Visit www.alzheimers.org.uk
- **The Alzheimer’s Society book of activities**, by Sally Knocker, 2003
- **Hallucinations in people with dementia** www.alzheimers.org.uk/factsheet/520
- **Visuoperceptual difficulties in dementia** www.alzheimers.org.uk/factsheet/527

Information and advice about sight loss:

- **RNIB:** Visit www.rnib.org.uk
- **Local sight loss charities**, find yours at: www.visionary.org.uk
- **Disability equipment centres**, find yours at: www.assist-org.uk
- **Thomas Pocklington Trust:** Visit www.pocklington-trust.org.uk
- **Macular Disease Society:** Visit www.maculardegeneration.org

