Supporting people living with dementia and serious sight loss.

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Vision 2020 Dementia and Sight Loss Interest Group
A growing population: serious sight loss

Almost 2 million people in the UK live with serious sight loss. Most are older: around 1.7 million, are aged over 65 years.

Sight loss is largely age related. The number of people affected will rise to 2,250,000 over the next 10 years.

1 in 10 people aged over 75 years has serious sight loss.
1 in 3 people aged over 90 years has serious sight loss.
Over 100,000 people are affected

• Estimates suggest that at least 123,000 people have both dementia and serious sight loss in the UK today

• As the number of people with each condition rises so will the number of people with both conditions

• Over and above those with serious sight loss, the normal ageing of the eye means that most people with dementia are likely to need spectacles and benefit from steps to make the most of their sight.
Sight loss caused by dementia

• Dementia may affect the way people perceive and process visual information
• Some dementias have a direct impact on vision:
  Alzheimer’s disease
  Parkinsons Disease Dementia
  Dementia with Lewy Bodies
  Posterior Cortical Atrophy
  Vascular dementia.
Sight loss caused by eye conditions

The four leading causes of sight loss in the UK are

- macular degeneration
- cataract
- glaucoma
- diabetic retinopathy.
Eye conditions

Age-related macular Degeneration

Normal Vision

Cataract

Glaucoma

Diabetic Retinopathy
Other causes of sight loss

• Stroke: leading to the loss of segments of visual field which are sometimes unnoticed by the person but sometimes cause serious loss of vision

• Effects of some medication: such as blurred vision

• Refractive error - not having or wearing the correct spectacles.
The experience of sight loss and dementia

• People with dementia and sight loss:
  – experience profound disorientation and isolation
  – have an increased risk of falls
  – experience communication difficulties
  – are more likely to live in a care home than people with either dementia or sight loss
  – visual hallucinations may occur, caused by dementia or sight loss.
Hallucinations and visual misinterpretation

• People with sight loss especially those with AMD can experience visual hallucinations commonly called Charles Bonnet Syndrome.

• Sight loss increases the risk of some one with dementia experiencing hallucinations or visually misinterpreting what they are seeing.
Good Practice

• Understand the individuals sight loss - what is their sight loss condition, what can they see?
• Have they had hallucinations in the past due to their sight loss?
• Make the most of sight
• Ensure there is good lighting.
• Follow advice around hallucinations e.g. University of Sterling guide.
Eye tests and screening

- People with dementia need regular eye tests and access to routine interventions, in the same way as any other person.
- Tell the optometrist in advance that the person has dementia.
- The appointment may need to be longer and the optometrist may want to make sure the environment is more dementia friendly.
- Domiciliary tests at home (and in care homes) are available for those unable to visit an optometrist.
Cataract and Dementia

• Cataracts are very common in older people
• Cataracts can be identified through an eye examination by an optician.
• Having dementia does not exclude someone from cataract surgery.
• Early identification and treatment can be very important for someone with dementia
Improving models of care

• Models of care need to respond to both conditions, too often they may focus on one

• Assessment and care planning should include sight loss, what the person can see, coping strategies, communication and how activities and the environment can be made accessible.

• Care home inspections should address how well services meet the needs of people with both conditions.

• Regular assessment and diagnosis is essential, with steps to support follow on action and in particular spectacle wearing.
Math points:

• Think Sight!
• Ensure people with dementia have yearly eye examinations.
• Make sure people with dementia are supported to wear their glasses.
• Work to make the most of people’s vision and making your services accessible - think about lighting, contrast, environmental changes.
• Support people to have daily access to daylight, this will support with orientation around night and day.
Where can I find out more

- DaSLIG and member organisations have produced useful resources, FAQ's, Dementia and Sight Loss, Cataract and Dementia Fact Sheet.
- SCIE partnership on the Dementia Gateway website
  - New web section on sensory loss in Jan
  - New films on sensory loss and dementia
Questions - discussion

• What challenges do you face in working with people who have dementia and sight loss?
• How can we support you?
Dementia and Sight Loss: Useful links and resources

Thomas Pocklington Trust:
• Research publications: http://www.pocklington-trust.org.uk/research/publications/Dementia

RNIB:
• Information for professionals
  • www.rnib.org.org.uk/olderpeople
  • www.rnib.org.uk/professionals/socialcare/services/olderpeople/resources/Pages/dementia.aspx
• Information for people with dementia and carers.
  • http://www.rnib.org.uk/livingwithsightloss/otherconditions/Pages/dementia.aspx

Alzheimers Society:
• Sight, perception and hallucinations in dementia factsheet.

Social Care Institute of Excellence (SCIE)
• Dementia Gateway: http://www.scie.org.uk/publications/dementia/index.asp
• Includes the film: ‘The dementia environment at home’
  • http://www.scie.org.uk/socialcaretv/videoplayer.asp?v=dementiaenvironmentathome
• **Dementia and Sight Loss Interest Group:**
  - Aims to develop & promote understanding of the issues facing people affected by dementia and sight loss.
  - To join the group register at:

• **RNIB Scotland and Alzheimer Scotland**
  - Dementia and Sight Loss Information Leaflet:
  - [http://www.rnib.org.uk/professionals/socialcare/services/olderpeople/resources/pages/dementia.aspx#H2Heading2](http://www.rnib.org.uk/professionals/socialcare/services/olderpeople/resources/pages/dementia.aspx#H2Heading2)

• **College of Optometrists:**
  - Guidance on carrying out sight examinations with people with dementia or other acquired cognitive impairment

**University of Sterling**
• **10 Helpful hints for carers - Hallucinations**
• [www.dementia.stir.ac.uk/publications](http://www.dementia.stir.ac.uk/publications)
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