

Sight loss and dementia:

Developing effective services

Sarah Buchanan

Thomas Pocklington Trust

Clive Evers

Alzheimer's Society



The Dementia and Sight
Loss Interest Group

A growing population

Prevalence of Sight Loss

- 2 million people in the UK
- self define as having a sight problem or difficulty seeing
- Of these, 1.7 million are aged over 65 years (RNIB, 2006)
- 356,000 also have serious hearing loss and are defined as 'deafblind' (Sense 2010)
- 1 in 10 people aged over 75 years has significant visual impairment
- 1 in 3 people aged over 90 years has significant visual impairment.

Prevalence of Dementia

- 750,000 people in the UK have a diagnosis of dementia
- This figure is forecast to increase to 1,735,087 by 2051
- 1 in 20 people aged over 65 years has a form of dementia
- 1 in 5 people aged over 80 years has a form of dementia.

<2% UK people aged <75 have both dementia & sight loss = 100,000

Sight loss caused by dementia

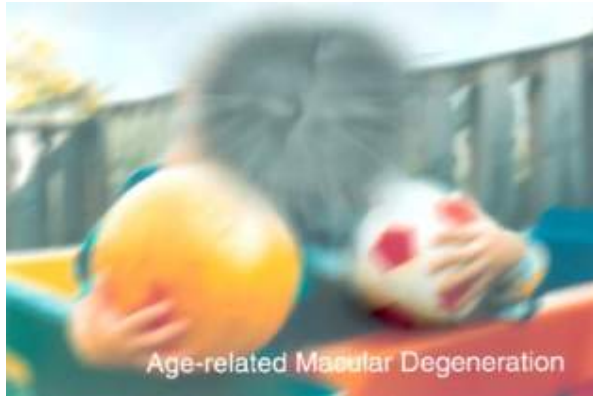
- Dementia may affect the way people perceive and process visual information
- Some dementias have a direct impact on vision:
 - Alzheimer's disease
 - Dementia related to Parkinson's disease
 - Lewy body dementia
 - Posterior Cortical Atrophy
 - Vascular dementia

Sight loss caused by eye conditions

Most eye conditions are age related and include:

- Macular degeneration, the most common cause of sight loss: loss of central vision
- Cataract: blurred or cloudy vision, made worse by glare
- Glaucoma: blank areas of vision; tunnel vision
- Retinitis pigmentosa: gradual and progressive sight loss, made worse by glare
- Diabetic retinopathy: loss of areas of vision, may lead to total loss of vision.

Eye conditions



Age-related macular Degeneration



Normal Vision



Glaucoma



Cataract



Diabetic Retinopathy

Other causes of sight loss

- Effects of medication: such as blurred vision
- Stroke: including loss of segments of visual field, sometimes unnoticed by the person but sometimes causing serious loss of vision

Personal experiences

- **Graham Doggett** has posterior cortical atrophy(PCA)
He says “ You fall over and do allsorts of funny things. If I go to the loo, there’s a good chance I’ll go into the women’s because of the stylised signs. There are so many mirrors I’ll think there are lots of other people in the room.”
- **Agnes Houston** was diagnosed with dementia four years ago and later developed vision problems that affect her perception. Agnes said “I was having fluctuations in my sight and weird experiences. I began to fall and injure myself and people thought I had a drink problem.”
- **Liz Graham** helps to care for her father who already had an inherited eye disorder called retinitis pigmentosa when he developed vascular dementia. Liz says “My father had a guide dog but was gradually unable to remember commands. He has lost the capacity to visualise the layout of the house in his mind which means that he cannot find his way around even to get to the toilet.”

Research into dementia and sight loss

The experiences and needs of people with dementia and serious visual impairment: a qualitative study by Vanessa Lawrence, Joanna Murray, Dominic ffytche and Sube Bannerjee. Thomas Pocklington Trust, 2008

Case studies and interviews of 17 older people with sight loss and dementia, 17 family carers and 18 care professionals.

Six core themes emerged from the analysis:

- Disorientation,
- Loss of independence,
- Accepting multiple losses,
- Risk of isolation,
- Hallucinations
- Challenges to services

•Increased sense of disorientation:

Many had difficulty recalling the time and their surroundings and were often unable to locate themselves in using visual clues. This often provoked distress occasionally leading to agitated and aggressive behaviour.

•Loss of independence

Combination of being unable to compensate for poor memory and poor sight impaired older adults ability to manage independently. Concerns about safety prompted family carers and professionals to adopt an approach of minimising risk rather than encouraging independence.

•Accepting multiple losses

Acceptance was an important coping strategy that influenced older adults satisfaction with their life. However dementia and sight loss became a substantial threat to the persons' identity leading to denial. So accepting the second loss was a major problem.

•Increased risk of isolation

Many were able to cope with one to one interaction only and were dependent on their carers for stimulation. Telephone were regarded as a lifeline and huge value was attached to regular contact with paid carers and

•Visual hallucinations

Visual hallucinations were common and increased disorientation and distress. Family members were uncertain how best to manage them. Many learned to adopt a non-confrontational approach and to provide reassurance.

•Family carers faced exceptional demands

Many people with dementia and sight loss were wholly dependent on their relative/spouse/partner for orientation and stimulation as well as their everyday care.

•Challenges for sight loss services

Sight loss professionals felt that restless and disruptive behaviour by people with dementia threatened to monopolise staff time and upset other group members and residents.

•Promoting the individuals confidence in their environment.

Informal and formal carers need to provide clear, regular communication to promote the persons sense of orientation and confidence in their environment
Techniques such as reality orientation and validation therapy may help.

•Reducing loneliness and isolation

People with dementia and sight loss would benefit from more one to one contact with paid carers and volunteers especially if more time could be devoted to maintaining valued pastimes.

•Managing threats to independence

People should be supported to pursue valued activities in a safe environment.
Care professionals rather than family carers should initiate discussion about activities that are no longer considered safe.

•Managing visual hallucinations

Family members need guidance on managing hallucinations – this might include reassurance and non-confrontation, full explanation and distraction techniques.

Supporting family carers

Extra respite resources such as night carers and more sessions at day centres required. Family carers also require ready access to information and advice such as that provided by RNIB and the Alzheimer's Society.

Services required to meet dual needs

More services are needed that are capable of meeting both sight-related and dementia related needs. Day centres, activities and peer support would benefit people with dementia and sight loss.

Training

Training programmes for vision rehabilitation workers should include information on working with people with dementia. Joint training of mental health and sight loss professionals would encourage the exchange of knowledge and expertise.

Improving models of care

- Models of care need respond to both conditions, too often they may focus on one
- Sight loss should be addressed in dementia resources, and vice versa
- A sensory model of care is needed
- A network of practice could support staff in different settings and share good practice
- 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.

People with dementia and sight loss – a scoping study of models of care; Ruth Bartlett and Declan McKeefry. Thomas Pocklington Trust. 2009

Good practice tips: environment

- Improve lighting – make it brighter
- Use colour and increase contrast – walls to doors, furniture to walls
- No clutter – physical or visual
- Reduce glare – shade lamps, blinds
- Support route finding and orientation – use sound, smell, touch, colour

Good practice tips: occupation and activity

- Make enjoyed activities accessible - e.g.
 - Audio transcription, talking books
 - Tactile activities
 - Audio labels to sort and locate personal effects
 - Provide 1:1 support to explain and describe
 - Assess benefits, not just risks

Eye tests and screening

- People with dementia need regular eye tests and access to routine interventions, in the same way as any other person
- Optometrists lack experience of dementia
- Paid and family carers may not give priority to eye tests, spectacle wearing or other interventions
- Eye tests are not enough: information for paid and family carers is essential

Good practice tips: eye tests

- Domiciliary tests at home (and in care homes) for those unable to visit an optometrist
- Appointments that are longer than usual
- Information and training about sight loss and the effect of interventions is essential for carers (family and paid)

Dementia and Sight Loss interest group: raising awareness/supporting action

- The Dementia and Sight Loss interest group
 - See our web pages on www.VISION2020UK.org.uk click on
 - <http://www.vision2020uk.org.uk>)
 - Click on Interest/Workgroups & Committees
 - Register or log-in using your email address and password
 - Scroll down to "JOIN Dementia and Sight Loss Interest Group" and double click on this link

Contact details

Sarah Buchanan, Thomas Pocklington Trust

sarahb@pocklington.trust.org.uk

Clive Evers, Alzheimers Society

Cevers@alzheimers.org.uk

Rebecca Sheehy, RNIB/Pam Lacy

Rebecca.Sheehy@RNIB.org.uk

Research acknowledgements

- University of Bath
- Kings College London, Institute of Psychiatry
- University of Bradford, Dementia Studies Group and Division of Optometry



The Dementia and Sight
Loss Interest Group

Support acknowledgement:

the Dementia and Sight Loss Interest Group is grateful for the support of Ove Arup in its development activity.