Dementia and sight loss
The growing problem

The forgotten factor
Why sight loss should be made visible in dementia care

Taking action on sight loss and dementia
Ways of raising awareness and improving services
Dementia affects one person in 20 aged over 65 and one person in five over 80. It is predicted that by 2050 there will be over 1.8 million people in the UK with dementia (Alzheimer’s Society, 2004). The demographics of sight loss present a similar pattern, with incidence rates increasing markedly in the over 80 age group and a corresponding increase related to the ageing population.

Although we have these separate statistics, we do not have firm figures for the actual incidence of dementia with sight loss. A recent study published by Thomas Pocklington Trust (February 2007) estimates that 2.5 per cent of people over 75 have both conditions, based on an analysis of available statistics. Despite the lack of reliable figures it is clear that dementia and sight loss is a significant issue for sight loss professionals and care providers. This article aims to highlight some key issues for practice.

Dementia
The National Service Framework for Older People gives the following definition of dementia “…clinical syndrome characterised by a widespread loss of mental function, with the following features:

- Memory loss
- Language impairment
- Disorientation (not knowing the time or place)
- Change in personality
- Self-neglect
- Behaviour which is out of character”

(National Service Framework for Older People, 2001)

The progression of dementia is generally considered to follow a three-phase model. In the initial phase, the person is likely to be forgetful about things that have just happened. People will forget where they are or what they did five minutes ago, but long-term memory is usually unaffected.

In the middle or moderate phase of the disease confusion becomes more apparent, with the person showing greater forgetfulness and possibly mood changes. They may also become anxious and aggressive and develop paranoia directed towards family or carers. Difficulties with sequencing actions mean that daily living activities can become difficult or impossible without assistance. The person may also wander and be restless.
The final phase of dementia is characterised by greater withdrawal, as communication becomes more difficult. The person will often lose the ability to remember even close family members. Physical systems may be affected, with the person becoming increasingly frail, probably incontinent and very likely bed-bound. Even in this final phase of the disease, long-term memory is likely to be retained.

**Alzheimer’s disease**

Alzheimer’s disease accounts for about 55 per cent of all diagnosed dementia. There is a rare variant of Alzheimer’s disease called Posterior Cortical Atrophy (PCA). This condition directly affects visual processing, even when general aspects of cognitive functioning are less severely affected in what is in effect the early phase of dementia. Alzheimer’s disease can also cause difficulties with saccadic eye movements, affecting reading ability even in people who retain full visual acuity – though over time the progressive development of aphasia will affect reading ability regardless of specific difficulties with visual processing.

**Vascular dementia**

20 per cent of diagnosed dementia is of the vascular or arteriosclerotic type. It is caused by transient ischaemic attacks, or sometimes a series of acute cerebrovascular accidents or, less commonly, a single major stroke. This type of dementia can also give rise to problems with visual processing. The exact nature of these will depend on the extent of neural damage and the specific regions of the brain that are affected.

**Dementia with Lewy Bodies**

This form of dementia affects approximately 130,000 people in the UK and represents about 15 per cent of diagnosed dementia. A particular characteristic of Lewy Body dementia is that it is known to cause visual hallucinations. This symptom can help to diagnose this particular type of dementia, which can be difficult to differentiate from Alzheimer’s disease. Dementia with Lewy Bodies can also cause difficulties with initiating movement and physical rigidity (extrapyramidal symptoms), very similar to Parkinson’s Disease.

**Dementia diagnosis**

It is important that people who exhibit symptoms of dementia get a proper examination and diagnosis. This can eliminate treatable health issues that can cause dementia-like symptoms. For example:

- Over-use of medication or inappropriate prescription drugs
- Depression and anxiety
- Untreated infections

If dementia is diagnosed, then at least knowing what to expect can help the person with dementia, their family and carers. But there is a degree of complexity here that is acknowledged by Cheston and Bender (1999), who contend: “The process of making a diagnosis of dementia is a difficult one, and relies too heavily on the unfounded assumption that there is a straightforward link between neurological damage, cognitive change and symptomatic behaviour”. If we also consider the individual variables that sight loss brings, then it is clear that we are dealing with potentially complex and highly individual situations.

“If dementia is diagnosed, then at least knowing what to expect can help the person with dementia, their family and carers”
However, it is possible to draw out some broad principles that we can apply to working more effectively with people who have sight loss and dementia. Fundamentally we have three possible situations:

- A person whose visual functioning is affected by brain changes caused by the dementia, but who does not have a separate eye condition
- A person with dementia who does not have impairment of the brain functions associated with vision but has an external eye condition such as macular degeneration or cataract
- A person who has a combination of the above.

People in any of these situations will experience functional difficulties because of their combined disability. Mendez, Cherrier, and Meadows (1996) in Bakkar (2003) state: “People with dementia often experience a number of changes in visual abilities because of neurological impairments, including problems with depth perception, glare and visual misinterpretations, which are exacerbated by visual disorders.” More specific effects of dementia on visual function can include:

- Agitation caused by visually complex situations because of difficulties in processing images against their background
- Visual hallucinations that may be similar to Charles Bonnet Syndrome but may be more complex, with the sufferer unable to show insight into the unreality of what they perceive. It is also possible that someone could be experiencing CBS because of a sight loss condition and then develop dementia
- Impairment of object recognition and identification
- The processing of the visual input to brain regions that help us take action can be affected by dementia, as can the feedback system that controls how and where we direct our visual attention. This type of processing deficit may cause difficulties with navigation, even in those who retain high levels of visual acuity
- Shadows can cause confusion and visual misinterpretations. Similarly, patterns on wallpaper, tiles, etc can be perceived as frightening or threatening objects. Photographs may be misinterpreted as real people
- Even if someone with dementia does not have serious sight loss, memory impairment may cause them to forget to wear their glasses or to use an outdated prescription.

### Practical implications

Before discussing some specific issues for practice in relation to dementia and sight loss it is useful to consider a broader practice perspective. In November 2007 the National Institute for Clinical Excellence and the Social Care Institute for Excellence issued a joint guidance document on the health and social care of people with dementia. The document states. “Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia. Care plans should address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills, and minimise the need for support.” The guidance also highlights the following key issues for practice:
- consistent and stable staffing
- retaining a familiar environment
- minimising relocations
- flexibility to accommodate fluctuating abilities
- assessment and care-planning advice regarding ADLs, and ADL skill training from an occupational therapist
- environmental modifications to aid independent functioning, including assistive technology, with advice from an occupational therapist and/or clinical psychologist
- physical exercise, with assessment and advice from a physiotherapist when needed
- support for people to go at their own pace and participate in activities they enjoy.

“Well-designed environments can promote the independence of people with sight loss”

The above clearly gives a policy context that stresses the importance of maintaining independence and attempts to ensure quality and consistency of care. Furthermore it is entirely consistent with the ethos of rehabilitation practice in relation to sight loss. What then of more specific practice in relation to dementia and sight loss.

The right physical environment

Well-designed environments can promote the independence of people with sight loss. However, it is all too often the case that poor lighting, contrast and environmental design simply act to further disable us.

A good starting point is therefore to ensure that the environment for the person with dementia has adequate illumination and that critical surfaces exhibit sufficient contrast. These principles are well understood in the sight loss community but still remarkably unknown in the wider world of residential care and sheltered housing. Combating the widespread ignorance of these simple measures in itself is likely to improve independence and quality of life for people with dementia and sight loss.

The misinterpretation of environmental features is likely to be reduced if lighting and contrast are optimised. The trick is to retain visual elements that maintain interest and promote engagement whilst reducing visual clutter. For example a few objects that contrast with their background and have meaning for the person may be more beneficial than lots of ornaments jumbled on a mantelpiece or shelf.
A simple, uncluttered and small-scale environment is visually easier to navigate and may help to reduce confusion. On occasions, actually reducing contrast can sometimes be useful. For example, it might help to camouflage an external doorway while emphasising adjacent internal doors. This might help to reduce the inclination for someone to want to wander outdoors.

The social environment
Care and the support of carers is critical to maintaining the quality of life for people with dementia. This can be even more important when sight loss is also present. For people who live with and support someone with dementia the emotional demands are likely to be high. A separate carer’s assessment should always be offered. The carer may also benefit from advice and guidance on how best to respond to the person with dementia.

Carers should be encouraged to resist the temptation to argue or reason with the person with dementia. The thoughts and actions of someone with dementia have their own logic, which is unlikely to be changed by argument. Instead the carer should distract or deflect situations that may lead to arguments. Some excellent examples of this can be found on Alzheimer’s Outreach website.

In conclusion, it is clear that existing expertise and knowledge available in the sight loss community can do much to improve the independent functioning and quality of life of people with dementia and sight loss. It has not been possible in this short article to discuss specialist assessment and training techniques, and indeed there is still considerable need for these to be developed and disseminated. The author is compiling information and gathering field experience on this specialist area of practice, and would welcome specific requests for advice or examples of good practice.

References and resources

Occasional paper February 2007 number 11, Thomas Pocklington Trust


NICE/SCIE Guidance on Dementia: www.nice.org.uk/guidance/cg42

Alzheimer’s Outreach – an excellent American website with information about Alzheimer’s disease. Index of articles: www.zarcrom.com/users/alzheimers/t-index.html#t6

Alzheimer’s Society: www.alzheimers.org.uk

The forgotten factor – why sight loss should be made visible in dementia care

The onset of dementia can be traumatic, hugely affecting a person’s life and identity, but what happens when a serious eye condition occurs at the same time? By commissioning research into the concurrence of sight loss and dementia, Thomas Pocklington Trust has begun to unravel a complex set of consequences and expose a serious gap in dementia care. Sue Cooper of the Trust reports on the new findings.

In November 2008 the first research ever to look at the effects of combined sight loss and dementia found that the importance of sight loss was being overlooked. Sight loss makes the impact of dementia worse – increasing confusion and isolation, causing depression and adding fear and frustration that can trigger aggression. Support individuals to deal with their sight loss, said the research, and both the distress of dementia and the likelihood of disruptive behaviour could be reduced.

Yet the vital place of sight loss in the lives of people with dementia was not recognised by mental health professionals, the research found. During in-depth interviews they acknowledged that staff in dementia services might lack the time and expertise to respond adequately to visual problems. Some said they worked ‘holistically’, yet few dementia care staff felt that visual impairment would significantly affect the way they worked with clients.

“It... goes with the territory. You tend to use touch more to make sure they know you are there, but otherwise, it doesn’t make that much of a difference.”
– Community psychiatric nurse, community mental health team for older adults

Sight loss professionals, on the other hand, were recognising more cases of joint dementia and sight loss. The problem was common and growing, but they felt ill-equipped to deal with it. They had no guidelines about how to work with dementia, and when some looked for training they had no success. They were critical of mental health professionals, GPs and ophthalmologists for failing to inform them
about a person’s dementia at the point of referral. Assessments for dementia were undertaken independently of assessments for other health issues, and the results were not shared. This put their clients at risk, they said, and left them struggling to cope.

“I feel overwhelmed and out of my depth. I could probably do more [but] I don’t know who to turn to.” – Rehabilitation worker, sensory impairment team

“When I went to visit him I wasn’t able to assess whether his difficulties were because of his sight loss... I picked up that he had some memory difficulty but... it’s not my line of speciality. There was no indication whatsoever on social services’ database that this client had dementia.” – Team manager, sensory impairment team

One year on
Over a year after that first report, the situation has barely changed. Despite the launch of a new National Dementia Strategy in 2009, sight loss remains largely invisible in policy and practice. No specific mention of it was made in the strategy, and two newly published studies (‘People with dementia and sight loss: a scoping study of models of care’ and ‘Visual hallucinations in sight loss and dementia’) found that this omission continues in all areas of dementia care. Researchers at the University of Bradford’s dementia and optometry divisions reviewed current policy, practice and literature and concluded that all three display a “fundamental lack of awareness of sight loss”. Frontline care workers were doing their best to deal with combined sight loss and dementia, but it was clear they were not being given the tools, the advice or the training they need.
In dementia care literature it is generally assumed that people can see. Issues related to joint dementia and sight loss are not debated, and key words such as visual impairment, optometrists, and eye care/health are not even indexed. Even where there are opportunities to highlight issues of sight loss, these are overlooked. Multi-sensory methods such as aromatherapy and music therapy are discussed, but with no mention of their particular potential value to those with sight loss.

The study looked at a range of available models of dementia care. In all of them there was a lack of attention to sight loss, but in particular the model most commonly used in the UK (the ‘enriched’ model) fails to take sight loss into account. Dementia policy pays too little attention to the physical environment to be sensitive to sight loss. Sensory solutions such as good lighting, contrasting and tactile signage and positive sounds are simply overlooked.

**What can practitioners do?**

**Dementia care professionals can:**
- recognise and promote the importance of identifying sight among people with dementia
- allow greater time and attention to support people who have sight loss and in particular to work in ways that protect their autonomy
- coordinate work with sight loss staff, and share information
- provide consistent, clear, verbal or audio instructions and information

**Optometrists can:**
- be proactive. Visit local care-homes to raise awareness of how common sight loss is and what it means. Seek out mental health professionals to share understanding of these issues and work cooperatively.

**Care service providers can:**
- understand the value of one-to-one contact for people who have sight loss and dementia
- maximise people’s vision by providing good lighting and high contrast markers
- support people with sight loss and dementia to pursue valued activities and retain their autonomy: they have a higher risk of loss of independence, and at an earlier stage than people with just one of those conditions
- give extra support to family care-givers such as extra night carers and more sessions at day centres
- acknowledge that assessing and responding to the complex needs of this population requires extra time and may need additional resources
- provide more services capable of dealing with sight loss and dementia

**Vision rehabilitation workers, mental health professionals and GPs can:**
- distribute fact sheets and audio tapes to family carers. No one organisation yet does this for the issue of combined sight loss and dementia, but information is available from the Alzheimer’s Society, Macular Disease Society, and RNIB.

**Care-home inspectors:**
- check on spectacle wearing and the uptake of eye tests
- check that service information, including notice boards, is accessible to people with sight loss
“People walk into a room and don’t remember why they have gone there. If you can’t see the environment, how are you going to cue yourself?” – consultant clinical psychologist, memory clinic

In dementia care practice the study found “persistent and pressing problems” for those with both conditions. Misdiagnosis is common, staff are unable to cope, and support that could substantially improve the lives of individuals is not provided. One care home had not had a visit from an ophthalmologist for more than a year. In others, inspectors relied on notice boards to convey information, assuming that everyone could read them. There was no evidence of them checking whether people were wearing glasses or having essential eye tests, and managers were sceptical about the value of such eye tests. Outside of care homes the stress on family carers was of an “extreme intensity”. Demands on them are constant, and conflict can flare when they try to safeguard the person with dementia by preventing them from doing things they love.

“Carers... need more support because it’s so constant, it’s all the time, it’s throughout the night. They are constantly, constantly called.” – Community psychiatric nurse, mental health team for older adults

Visual hallucinations

In another study, published in October 2009, researchers at the Institute of Psychiatry, King’s College London, suggest that dementia and sight loss may act together to cause hallucinations – and that previous studies may have overlooked this possibility. If this is the case, far more people with joint dementia and sight loss may experience hallucinations than previously predicted. The current estimate is that 30 per cent of people with both conditions will have hallucinations, but it is possible that the true figure could be anything up to 100 per cent. Since the distress of hallucinations can be the tipping point when people enter care homes, a greater understanding of what triggers them is vital. Hallucinations, sight loss and dementia occur together more frequently than was previously thought, say the researchers. Despite this they again found no evidence of initiatives, guidelines or co-ordinated working between professionals in the two fields. Routine assessments for both conditions were rare, and as a result many cases of combined sight loss and dementia are still being missed.

What’s needed?

Estimates say that at least 2.5 per cent of over 75-year-olds are likely to have dementia and significant sight loss but the researchers suggest that this is probably an underestimate. Diagnosis is difficult and joint cases are often missed. A person with dementia may not communicate their sight problem or be able to engage in standard eye tests, while a person with sight loss who misplaces things or gets lost or confused may not be picked up as having the early stages of dementia. The combination of sight loss and dementia poses a unique challenge for professionals, but as knowledge grows policy and practice can be developed.

A new model of care – one that explicitly covers the needs of people with sight loss – could be created, say the researchers, by including environmental considerations. A new model could take leads from the ‘Nightingale’ model used in Korea, combining some of its principles with those of the UK’s enriched model to create a truly sensory model of care. Greater coordination among professionals is
also needed. Assessing a person’s risk, abilities and needs can only be done accurately if mental health and sensory impairment teams share information and transfer skills. Joint training could encourage the exchange of knowledge and expertise, while vision rehabilitation staff could benefit from training in working with dementia.

“My interpretation of what might be an OK risk for someone with sight loss and memory problems is not going to be the same as another professional. By sharing that risk, people might be more empowered, rather than individual professionals saying ‘actually I’m not willing to put my name to that, I’m not willing to say that that’s a possibility’… There might be a better way round that, a skill that we aren’t party to.”
– Team manager, sensory impairment team.

“By sharing the risk, people might be more empowered, rather than individuals saying ‘actually I’m not willing to put my name to that’”

New initiatives
Since the research projects began, several charities have come together to highlight the issue of concurrent sight loss and dementia. RNIB, the Alzheimer’s Society and Thomas Pocklington Trust took a poster campaign, headed ‘Double Trouble’, to the 2009 National Dementia Congress, and a dementia and sight loss interest group has been formed. At a seminar in October (reported on page 12) this group committed itself to raise awareness and improve action on this important issue.

More information about the group appears on page 13.

Following the three studies there has been clear interest in developing effective models of care. The Bradford researchers quickly brought together over 30 organisations and staff looking for better ways to support people who have sight loss and dementia. With the support of these and other professionals it is hoped that sight loss will be integrated into caring for dementia. In the National Dementia Strategy, in the UK Vision Strategy, and in practice throughout the UK, sight loss must be made visible in dementia care.

References
The reports can be found at www.pocklington-trust.org.uk:


Bartlett, R (Division of Dementia Studies) and McKeefry, D (Division of Optometry), University of Bradford, 2009. People with dementia and sight loss: a scoping study of models of care. Thomas Pocklington Trust Research findings no. 25, October 2009.

Taking action on sight loss and dementia

A seminar bringing together people with dementia and sight loss and professionals from health and care organisations has begun to explore ways of raising awareness and improving services.

In 2008 RNIB joined forces with the Alzheimer’s Society and Thomas Pocklington Trust to create the Dementia and Sight Loss Interest Group. The group’s formation was triggered by 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 is very low.

In October 2009 the interest group held a seminar bringing together people who have dementia and vision problems with professionals from a range of voluntary and statutory organisations with an interest in the issue.

The seminar was an opportunity for professionals to hear first-hand the experiences of people with dementia and sight loss and their carers. Their stories offered an insight into the practical and emotional problems they face and highlighted the lack of a joined-up approach towards the diagnosis and care of people with this combination of conditions.

Lack of awareness
Agnes Houston, who began to experience low vision after being diagnosed with dementia, found there was little information, understanding or support available:

“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. It took 18 months, maybe longer, for someone to listen and offer help.”

Graham Doggett, who has memory problems, developed problems with his vision in 2002. He spoke of the difficulty of getting a diagnosis. After many fruitless visits to ophthalmologists and neurologists he and his wife and carer Susan found out about Benson’s Syndrome (posterior cortical atrophy or PCA).
Taking action on sight loss and dementia

through their own research, and he was diagnosed with this condition four years after his sight problems began. Graham said, “It was a lengthy journey, including some DIY. Professionals couldn’t give us an answer.”

**Challenges of caring**
The additional strain of caring for a person who has both dementia and sight loss was a key issue. Liz Graham helps to care for her father, who has retinitis pigmentosa and also has dementia. She explained:

“From my mum’s perspective, caring is a full-time, hands-on job. My father used to have a visual image in his mind of how the house was laid out, but he has lost that capacity now. He can’t find his way around, he can’t even find his way to the toilet. Because he is not aware of his surroundings he panics, or he will get up four or five times in the night because he doesn’t know whether it is day or night.”

Liz’s family has also found it difficult to find suitable care services. While there are specialist services available for people with dementia or people with sight loss, it was hard to identify services that met the complex needs of people with both conditions. Liz said:

“The issue for us now is how to get an appropriate level of care. Mum mostly has to cope on her own. How would it work in terms of respite? The fear is that there isn’t necessarily the capacity to deal with my father because he can’t see. We’re concerned he’ll be left in a corner, feeling frustrated, lost and upset, and this has been a restraining factor in finding somewhere.”

**Quality of life**
Another issue for Liz and her family has been finding suitable activities for her father. She explained:

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**About the Dementia and Sight Loss Interest Group**

The aims of the Dementia and Sight Loss Interest Group are:

- to develop a better understanding of the issues facing people affected by dementia and sight loss
- to support and influence initiatives around dementia and sight loss, initially at RNIB and Alzheimer’s Society
- to develop and disseminate materials, resources and tools that contribute to good practice.

The Interest 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.

For more information about the group contact Clive Evers, Alzheimer’s Society, cevers@alzheimers.org.uk or Rebecca Sheehy, RNIB, rebecca.sheehy@rnib.org.uk
“One problem we found was how to keep him interested and stimulated. Many activities and aids are focused on people with vision, such as memory books and special signage. If he could see he’d be able to interact and do more things. Listening to music has really kept him going, and it is something he can still do now. It keeps him stimulated in the moment.” Although his memory loss is less advanced, Graham faces a similar challenge:

“I can’t read and I can’t write. I’ve spent my life writing books and scientific papers, and that’s gone. So how do I keep body and mind together? Susan [Graham’s wife and carer] keeps me up to date and in the right direction. We have very good friends who, when they learned about the situation, gave us lifts and took me to concerts. I enjoy classical music, I can listen to CDs all night. If Susan goes out, on goes the music.”

“While there are specialist services available for people with dementia or people with sight loss, it was hard to identify services that met the complex needs of people with both conditions”

Priorities for action
As well as hearing from people with dementia and sight loss and their carers, seminar participants received an overview of research commissioned by Thomas Pocklington Trust in this area. With this information in mind, they went on to discuss priorities for action in four areas: information and awareness, living at home, hospitals and care homes and issues for carers. The priorities they identified included:

- raising awareness of dementia and sight loss issues, both in the dementia field and with sight loss professionals
- making more information about dementia and sight loss available to people affected by the conditions and their carers
- improving the quality of assessments for people with both conditions
- increasing the support available to carers, taking into account the additional challenges they face
- promoting practical measures, such as low vision passports, dementia champions in care homes, the development of the care workforce and the Visibly Better scheme (an accreditation scheme for housing providers).

Moving forward
The seminar provided a wealth of insight, information and ideas for the Dementia and Sight Loss Interest Group to consider and take forward. It also gained the commitment of those present to raising awareness within their sectors or organisations and promoting action on dementia and sight loss issues. Since the seminar the group has made some preliminary plans: in raising awareness it aims to focus on carers’ issues and in particular the need for prompt effective assessments of carers’ needs. Depending on the availability of funding it will consider organising an external conference in 2010 for up to 100 people.
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