

Two new studies show dementia care fails people with sight loss

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New sensory model of care is needed, says Thomas Pocklington Trust

Sight loss charity, Thomas Pocklington Trust (1), today calls for a fresh approach to dementia care after new research confirms a lack of attention to sight loss. A sensory model of care practice should be developed, says the charity after two new studies revealed a widespread failing to acknowledge the importance of sight loss.

The first study, "[People with dementia and sight loss: a scoping study of models of care](#)," (2) exposes pressing and persistent problems in the care of those with dementia and sight loss. It finds that both the most widely used model of care, and the leading best-practice literature display "a fundamental lack of sensitivity about sight loss."

The second study, "[Visual Hallucinations in Sight Loss and Dementia](#)", (3) describes people with joint dementia and sight loss as a forgotten group, and finds that many cases are missed or misdiagnosed because of failures to assess for both conditions.

Says Dr. Angela McCullagh, Research and Development Director, Thomas Pocklington Trust, "Sight loss plays a major role in people's experience of dementia, yet it is almost entirely excluded from current models of care. A change in policy and practice is needed, where sight loss is made visible in dementia care."

The first study (Models of Care) looked at major texts, interviewed practitioners and audited care homes. It found that while front-line care workers try to respond to the problems of dementia and sight loss, neither official policy nor guidance provides the means to fully address the issue.

Eight leading models of practice were assessed. One specifically gives importance to visual cues. Of the rest, only two explicitly mention visual impairment. The most common model used in the UK (4) which is embedded in dementia policy fails to take sight loss into account.

This policy, says the study:

- Pays too little attention to the physical environment to be sensitive to joint dementia and sight loss.
- Overlooks sensory solutions that help groups of people such as good lighting, contrasting and tactile signage and positive sounds.

A new model of care - a sensory model - is needed, say the researchers (5).

In dementia care literature, it is generally assumed that people can see:

- Issues related to joint dementia and sight loss are not highlighted or debated.
- Key words that might be expected – visual impairment, lighting, optometrists, eye care/health – are not even indexed in "best practice" texts.
- Opportunities to highlight issues of sight loss are overlooked, e.g. multi-sensory methods such as aromatherapy and music therapy are discussed with no mention of their potential value to those with sight loss.

In dementia care practice:

- Sensitivity to and awareness of sight loss issues varies amongst practitioners.
- In care homes, inspectors often rely on notice boards to provide information.
- The importance of wearing spectacles, having eye examinations and taking up free NHS tests can be overlooked. One care home had not had an optometrist visit for over a year and managers were sceptical about the value of eye tests for people with dementia.

Interest in developing effective models of care is clear: the researchers quickly brought together over 30 organisations and staff looking for better ways to support people who have sight loss and dementia.

The second study (Hallucinations), carried out by researchers at the Institute of Psychiatry, King's College, London, reviewed existing literature on hallucinations in sight loss and dementia and found the three conditions occur together more frequently than previously recognised.

From their study the researchers predict that 30% of those with combined sight loss and dementia will have hallucinations - around 35,000 people in the UK. However, the study also led them to question whether previous research has overlooked the fact that sight loss and dementia may act together to cause hallucinations. In this case, some 118,000 people could be affected – 100% of those with joint dementia and sight loss. Despite this the study could find no evidence of initiatives, guidelines or co-ordinated working between professionals in the two fields. Many cases of combined sight loss and dementia are missed, says the study, as routine assessments for both conditions are rare. This means that someone with sight loss may be wrongly diagnosed with dementia or a diagnosis of dementia may be missed in someone with sight loss.

"Once again, people who have joint sight loss and dementia are missing out on a combined approach to care," says Dr. McCullagh. "The research shows a clear need for greater coordination amongst professionals. Now more research is needed both to widen our knowledge of this forgotten group and to develop professional practices that address their particular experiences."

Editors Notes:

1. Thomas Pocklington Trust is a charity which aims to improve the quality of life of people with sight loss. It is a leading provider of housing, care and support services for people with sight loss in the UK, and is a major research and development body.

2. "[People with dementia and sight loss: a scoping study of models of care](#)," was conducted by Dr. Ruth Bartlett (Division of Dementia Studies) and Dr. Declan McKeefry (Division of Optometry) at the University of Bradford. The study searched current academic literature, interviewed seven practitioners and audited working practices in four care homes for older people.

3. The research review, "[Visual Hallucinations in Sight Loss and Dementia](#)", was conducted by Joanna Murray, Dr. Dominic ffytche and Dr. Kate Briqqs at the

Institute of Psychiatry, King's College, London.

4. The enriched or dialectic model of care is embedded in UK dementia policy in the form of person-centred care.

5. A sensory model of care could combine principles from two existing models, the Nightingale-based and the enriched.

6. Dementia and serious sight loss are both common in older people, particularly among those in long-term care facilities. It is estimated that at least 2.5% of people over the age of 75 are likely to have dementia and significant sight loss. However, this is probably an underestimate given the complexities both of diagnosing dementia and vision testing someone with severe dementia.



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