



## The experiences and needs of people with dementia and serious visual impairment: a qualitative study

**This publication presents findings from a series of case studies of older people affected by severe sight loss and dementia, their family carers and the professionals with whom they have contact. The studies were conducted by Vanessa Lawrence, Joanna Murray, Professor Sube Banerjee and Dr Dominic ffytche, King's College London.**

Dementia is one of the most common and serious disorders of later life, affecting 5% of people over 65. Although sight loss affects many people with dementia, this is the first study to explore the impact of both conditions on the lives of older people and their carers. The research found:

- The two conditions together led to a profound sense of disorientation and sense of isolation
- Sight loss professionals felt they were not equipped to work with people who had mental health needs, while dementia professionals felt the needs created by sight loss risked being overlooked in mental health services
- Increased co-ordination between mental health and sensory impairment teams would help in identifying individuals' abilities and needs for support.

## Background

The research team carried out a series of case studies, involving interviews with 17 older people with sight loss and dementia, 17 family carers and 18 care professionals who worked with them. The older people were asked about their daily lives, activities enjoyed, the impact of their conditions on their own life, and the help they received and needed. Their carers were asked for their opinions on these areas of their relative's lives, the impact on their own lives and the help they received and needed. Interviews with care professionals focused on their assessment of the older person's quality of life and support needs, and a general discussion about their experiences of working with this client group. Interviews lasted about an hour and were tape-recorded and transcribed for analysis. The findings on the challenges faced by older adults, family carers and care professionals; recommendations of ways to help them; and recommendations for further research, are summarised below.

### What challenges did older adults, family carers and care professionals face?

- **Older adults experienced an increased sense of disorientation**

The experience of joint sight loss and dementia created a profound sense of disorientation in older adults. Many had difficulty recalling the time and their surroundings, and were unable to locate themselves using visual cues. This often provoked distress, which led occasionally to agitated and aggressive behaviour.

- **Older adults were highly vulnerable to isolation**

Older adults experienced loneliness and isolation. The combination of sight and memory loss restricted participation in hobbies and social groups. Many were able to cope with one-to-one interaction only and were dependent on their carers for stimulation. Telephones represented a lifeline and huge value was attached to regular contact with paid carers and volunteers. Crossroads Carers were repeatedly praised for providing care that was tailored to the needs of the individual. Limited resources restricted opportunities for one-to-one contact in care homes. Older adults with sight loss and dementia enjoyed spending time with others who had similar conditions.

- **Concerns about safety threatened older adults' independence**  
 The combination of being unable to compensate for poor memory with visual cues, and being unable to compensate for poor sight by learning new skills, profoundly impaired older adults' ability to manage independently. Denial or lack of insight into their cognitive difficulties increased their vulnerability. Concerns about safety often prompted family members to place limits upon their relatives' activities, which often led to conflict in their relationship. Care professionals, who complained of insufficient time and/or expertise, often felt obliged to adopt a cautious approach that prioritised the reduction of risk, rather than promoting independence.
- **Older adults struggled to accept the multiple losses**  
 Acceptance was an important coping strategy that influenced older adults' satisfaction with their life, their willingness to give up particular activities and the ease with which they asked for and accepted help. However, dementia and sight loss represented a substantial threat to the individual's identity, and some reacted by denying their difficulties. The common view among family carers and professionals was that experiencing one form of loss increased the difficulty of accepting a second.
- **Visual hallucinations were common and disruptive**  
 Visual hallucinations were common, and profoundly increased older adults' disorientation and distress. Family members were uncertain how best to manage them. Many learned to adopt a non-confrontational approach and to provide reassurance. Exploring hallucinations sometimes helped older adults make sense of their experience.
- **Family caregivers faced exceptional demands**  
 Many older adults were wholly dependent on their relative for orientation and stimulation, as well as their everyday care. Carers were often physically exhausted, but found it difficult to leave the older person for even short periods of time.
- **Challenges for sight loss services**  
 Sight loss professionals expressed concern about the behavioural problems associated with dementia. It was felt that restless and disruptive behaviour threatened to monopolise staff time and upset other group members and residents. Sight loss professionals uniformly criticised their training for failing to equip them with the expertise to work with clients with concurrent mental health problems.

- **Minimal significance attached to sight loss**

Dementia care professionals described their work as holistic in meeting multiple needs and expressed less concern about working with older adults with both conditions. Few felt that sight loss had a significant effect on the way they worked with clients.

- **Lack of joint working**

There was little evidence of joint working between mental health and sensory impairment teams. Vision rehabilitation workers attributed this partly to the misconception that sight loss could be managed in isolation, and they identified the need to communicate their role to other professionals.

## **What should be done to help older adults, family carers and care professionals?**

- **Promoting the individual's confidence in their environment**

Informal and formal carers need to provide clear, regular communication to promote the individual's sense of orientation and confidence in their environment. Techniques such as reality orientation and validation therapy may help to raise older adults' awareness of external reality.

- **Reducing loneliness and isolation**

Older adults would benefit from more one-to-one contact with paid carers and volunteers, especially if more time could be devoted to maintaining valued pastimes. It is vital that care homes appreciate the value of one-to-one contact for this client group.

- **Managing threats to independence**

Older adults 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. Providing older adults with an acceptable rationale, such as the risk of falling, may help them to come to terms with these limitations.

- **Managing visual hallucinations**

Family members need guidance on managing hallucinations in the older person. This might include reassurance and non-confrontation, full explanation and distraction techniques.

- **Supporting family carers**  
 The exceptional demands placed on informal carers may necessitate extra respite resources such as night carers and more sessions at day centres. Family carers also require ready access to information and advice. Fact sheets, of the type produced by the Alzheimer's Society and Royal National Institute for the Blind, would be helpful, and could be distributed by vision rehabilitation workers, mental health professionals and GPs.
- **Services required to meet dual needs**  
 More services are needed that are capable of meeting both sight-related and dementia-related needs. Day centres that provide a stable environment, clear verbal instructions from staff, transport to and from the centre, activities tailored to cognitive abilities, and an opportunity to spend time with peers with similar conditions, would benefit older adults with dementia and serious visual impairment.
- **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. Current and past carers could serve a valuable role in educating professionals on how best to manage the unique challenges posed by the co-existence of the two conditions.
- **Awareness of sight-related needs**  
 It is important that service providers and staff within dementia care recognise that sight loss creates needs that require extra time and attention from staff, especially if individuals are to be supported in a way that promotes rather than undermines their autonomy.
- **Value of joint working**  
 There is a need for increased co-ordination between mental health and sensory impairment teams. Appropriate sharing of information and transfer of skills would facilitate a more accurate assessment of risk, which would help care professionals to identify individuals' abilities and needs for support.
- **Complex needs require additional resources**  
 Service providers need to acknowledge that assessing and responding to the complex needs of these clients requires extra time and resources.

## Recommendations for future work

Research is needed in the following areas:

- Identifying the prevalence of visual impairment in dementia among older people in care homes and in the community.
- Evaluating techniques such as reality orientation and validation therapy with older adults who have concurrent dementia and sight loss.
- Exploring whether counselling and support could be used to help older adults develop more adaptive coping strategies.
- Identifying the best ways to manage visual hallucinations in older adults with combined cognitive and visual loss.

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## How to obtain further information

A short report, in the form of an Occasional Paper, entitled *The experiences and needs of people with dementia and serious visual impairment: a qualitative study*, by Vanessa Lawrence, Joanna Murray, Dominic ffytche and Sube Banerjee is available from:

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Copies of this research findings report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

## Background on Pocklington

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £700,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcomes as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.

*In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.*



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