

Best practice in social care and support for adults with concurrent sight loss and dementia within different housing settings

KEY POINTS FROM THE RESEARCH

- The overall aim for care and support for people with dementia and sight loss should be to preserve independence and/or support interdependence where appropriate. A key principle is that of being led by the person with dementia and sight loss in all decisions and lifestyle choices as long as this remains possible in terms of the progress of the dementia.
- Early diagnosis of both conditions can help people plan and prepare and make it easier to access relevant services sooner.
- Following diagnosis people may need on-going practical support in making the necessary adjustments to their lifestyles, and emotional support for coping with feelings of loss and anxiety.
- Assessment of care and support needs must take account of both conditions, and draw on the expertise of dementia and sensory impairment practitioners.
- Practical assistance should be provided by familiar staff, with time allowed for staff to get to know the person they are helping, and allow the person to get to know them.
- Services should aim to provide more social and cognitive stimulation and enjoyable activities that are

This project aimed to further knowledge on how best to provide care and support to people living with sight loss and dementia. Given the relatively limited knowledge base, this study has considerably enhanced the evidence base.

accessible to people with dementia and sight loss.

- There should be a variety of options to meet individual carers' preferences for support.
- Assessment for aids and adaptations to the home needs to take account of both sight loss and dementia, and the individual's capacity to cope with change.
- Changes to lighting and the use of contrasting colours can be helpful to people with sight loss and dementia.
- Extra care housing schemes have the potential to offer some advantages to people living with dementia and sight loss, particularly those who live alone.

BACKGROUND

It is estimated that currently about 123,000 people (about 2 per cent of people aged over 75) have concurrent sight loss and dementia. This is likely to be an underestimate as both dementia and sight loss remain under diagnosed.

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A familiar and consistent environment is crucial for people with either condition, and this need is amplified for people living with both dementia and sight loss. People with dementia and sight loss often cannot easily adapt to new environments, or use visual cues to help with orientation and recognition of people, places and things. They are at greater risk of losing their independence, of falling, and of being socially isolated.

Research and practice often focus on dementia or sight loss, and relatively little is known about how best to provide care and support to people with both conditions. Meeting the social care and support needs of people living with concurrent sight loss and dementia presents complex challenges. This project explored how social care and support for people living with concurrent sight loss and dementia in housing settings could be improved, and aimed to address this knowledge gap.

FINDINGS

Familiarity of both people and place is essential for people with sight loss and dementia, thus remaining in a familiar environment, even one that presents certain risks would seem the preferred option.

Early diagnosis of both conditions is crucial to enable planning and preparation for the future and access to services.

Problems with eyesight are often considered secondary to cognition problems, and priority may not be given to regular eye tests, or routine interventions that could dramatically improve levels of independence and quality of life. People with dementia and sight loss need regular eye tests and access to routine interventions for eye sight problems.

Support and information should be offered at a time that is right for the individual, in an appropriate format, and in a suitable level of detail. The offer of support should be an ongoing process rather than a 'one-off', time-limited option, to enable people to come back as both conditions progress and their needs change, or as they feel ready to ask for more information or help.

Around half the people with dementia and sight loss in the study were not receiving any

formal support, and most of the rest received just a few hours of care a week from local Adult Social Care services, third sector organisations, or had made private care arrangements. Various reasons for these apparently low levels of care and support were given. Sometimes this was through choice, some felt they were coping with support they received from their partners and wider family, friends or volunteers from charities. However, most of those who were not receiving services said that they would welcome support but were unsure who to ask for help, or what services were available. Further examples of unmet need were highlighted where services were available but already oversubscribed, unsuitable to their particular circumstances or unaffordable.

Assessment of the care and support needs of people with dementia and sight loss must take account of both conditions, and draw on the expertise of dementia and sensory impairment practitioners. Practitioners in this study emphasised the need for time to be taken with assessment, allowing careful observation of how people managed in their homes, listening to the person with dementia and sight loss and reflecting on what people can and want to do, and assisting them to access services that address their preferences and needs. Carers and family should also be involved in assessment, and their knowledge of the person with dementia and sight loss recognised.

A common experience is that of one set of dementia/visual impairment needs being addressed, rather than both being taken into account. This study does not suggest there is a need for a "new" specialism, however many people with dementia and a sight loss would benefit from increased joint working, and sharing of skills and expertise by different practitioners.

Rehabilitation and sensory impairment teams need to know about local dementia services and be able to contact or refer to dementia specialists, or to services that support people with memory loss. Dementia specialists need to know about sight loss services and be able to contact and refer to them.

There are two simple principles for the provision of care and support: adequate time

and continuity. Practical assistance for people with dementia and sight loss should, where possible, be provided by familiar staff, and time should be spent to allow staff to get to know the person they are helping, and allow the person to get to know them.

Some people with dementia and sight loss spoke about being bored. Previous hobbies or daily pastimes, i.e. watching the television or reading, were difficult to maintain. Previous strategies for coping with sight loss were no longer so helpful. Many participants wanted to keep doing as much as they could, even if they were less able to do the things they used to do. Social isolation was a feature in many people's lives, although people's experience varied greatly.

Services generally should provide or support access to more social and cognitive stimulation, and enjoyable activities that are accessible to people with dementia and visual impairment.

Caring for someone with dementia and sight loss can be extremely demanding as there is a need for constant repetition, description and explanation to provide reassurance and help with orientation. Carers who participated in this study spoke about difficulties in getting a diagnosis, information needs, concerns for the future, and services that would help them as carers. There should be a variety of options to meet individual preferences for carer support, and it should be flexible enough to meet the needs of the carer as well as the person with dementia and sight loss. For many people this could include both respite and replacement care.

Most of the people interviewed had some adaptive technologies in their homes, although adaptations for mobility difficulties were more common than those to assist with sight loss or dementia. Introducing new aids and/or adaptations to the home could create difficulties, as people were not always able to understand what they were or how to use them. Sight loss aids were highly valued but sometimes very expensive. Often memory aids were not suitable to people with low vision. People did not always know what aids were available or how to get them.

ABOUT THE STUDY

This project adopted a multi-method approach. A literature review was undertaken. Twenty six people living with sight loss and dementia in a range of housing settings were interviewed, often with their family carers. Almost fifty practitioners, including dementia specialists and sensory impairment specialists, took part in discussion groups or interviews. The emerging findings were validated at a multi-disciplinary consensus building event.

This project was undertaken by a team of researchers from the University of York, the University of Worcester, Bournemouth University, and University of Cambridge. It was supported by Thomas Pocklington Trust, and the Housing and Dementia Research Consortium.

A main output of the project is a guidance document supported by a collection of supporting evidence reports, available from www.york.ac.uk/chp/expertise/housing-later-life/publications/.

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Assessment for aids and adaptations needs to take account of both sight loss and dementia, and the individual's capacity to cope with change. Aids and environmental adaptations should be introduced early to enable them to become embedded in familiar routines.

Changes to lighting and the use of contrasting colours are the key environmental changes that appear to work well for people with dementia and sight loss as they can assist people make the most of the vision they have, and reduce disorientation.

While extra care housing is a costly option it potentially offers some advantages to people living with dementia and visual impairment, particularly those living alone. The timing of a move to an extra care scheme needs to be considered, taking account of people's capacity to learn and adapt to new environments.