

Older people's experiences of sight loss in care homes

This publication summarises findings from research commissioned by Thomas Pocklington Trust to investigate the experiences of older people with sight loss in care homes. The research was carried out by Dr Lizzie Ward and Laura Banks from the University of Brighton.

Summary findings

- Residents in care homes often have complex needs and as well as visual impairment may also have other health issues such as hearing loss, memory loss and confusion, mobility difficulties, poor mental health and depression.
- The transition of moving into a care home can be difficult. Adjusting to a new environment when living with sight loss requires support.
- Residents' quality of life is positively affected by:
 - I. Greater awareness about what it means to live with sight loss, particularly from staff but also amongst other residents.
 - II. Support from others: family, befrienders, and staff. Relationships with others are crucial in counteracting feelings of isolation. Having time to talk with staff and having company is vital.
 - III. More knowledge about available aids and technology is needed to help residents with sight loss maintain their interests or develop new ones.
 - IV. Better connections with local external organisations such as sight loss societies and rehabilitation services.
- Staff need to be given training on the signs of sight loss to ensure person-centred care and appropriate care plans for residents are provided.
- Greater awareness about the impact of sight loss is needed and most care homes identified the need for more training on this.



Background

It is estimated that as many as half of the 400,000 older people who live in care homes have some form of sight loss (RNIB, 2014). Although there is a growing body of research into the issues of sight loss in older age, there remains little which focuses explicitly on the perspectives of older people with sight loss who are living in residential care.

This project was commissioned by Thomas Pocklington Trust (TPT) to address the evidence gap by focusing on the lived experiences of older people with sight loss and their everyday needs within care homes. TPT was particularly interested in understanding co-production approaches to involve VI people in the research process.

Research aims

The study aimed to understand what it is like to live in a care home with a visual impairment and to hear the views of older visually impaired people. The study also gathered the views of family members and care home staff. The overall aim was to help improve care and practice in care homes.

Research methods

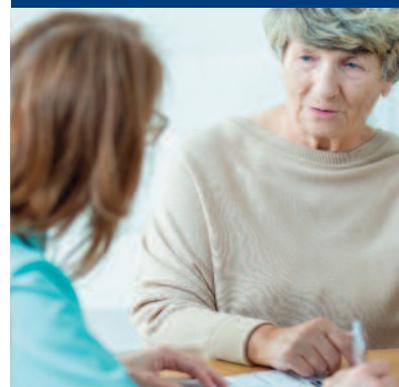
This in-depth qualitative study was carried out in six residential care homes and one nursing home. The project worked collaboratively with people with sight loss in the design and delivery of the research, based on the principles of co-production. The researchers worked with an 'Experts by Experience Panel' (EEP) of older people with sight loss who contributed knowledge and expertise based on their own experiences and offered guidance and advice to the researchers. The researchers also worked with a Project Advisory Group (PAG) which included people with visual impairment, key stakeholders from the sight loss and care sectors and TPT staff.

Forty interviewees took part in the research including:

21 residents aged between 63 and 98, consisting of 13 women and 8 men. Participants had a range of eye conditions including Age-related Macular Degeneration (AMD), glaucoma, cataracts and stroke-related sight loss.

10 members of staff consisting of five managers, one deputy manager, one activities coordinator and three care workers.

9 relatives of older aged care home residents with sight loss.



The interviews explored:

- Residents' personal backgrounds, including their eye conditions.
- Experiences of moving into a care home.
- The types of support available from care home staff.
- The types of support from outside the care home.
- The use of aids and assistive technologies

Findings

Care home staff awareness of visual impairment

Staff in this study recognised the need for more awareness of and training on visual impairment. Only one home in the sample had offered carers training using simulator specs. Others had reported it would be useful to have training but were not aware of any existing training or where to find training resources.

The identified need for visual awareness training for care home staff, coupled with evidence that residents do not always like to ask for help, increases the possibility that any deterioration in residents' vision will go undetected. Residents need to be routinely asked about their vision with simple proactive questions which should be included in regular care plans. There also needs to be greater awareness within care homes of rehabilitation and support services that residents could access.

Multiple health conditions and complex needs

All of the residents in the study were living with visual impairment as well as other health conditions and problems. It is not always possible to separate issues to do with sight loss from other disabilities and multiple health conditions. But clearly sight loss calls attention to a lot of other problems, particularly around social interaction and isolation. Increased understanding and awareness about the particular impact of sight loss on social interactions and relationships would improve people's quality of life within care homes. There are very specific things which could make a big difference. Some of these are very basic, such as introducing yourself when entering the room of a person with sight loss, telling people that their food is being placed in front of them and providing accessible information to let people know about activities.

"I do think they're (staff) not always as conscious as they might be of people's sight disability."

(Kate, relative)

Meaningful activities

There is a need to think about what meaningful activity means for people with sight loss and who are likely to also have other health conditions. Activities that are focused on 'doing' or making things might be difficult or problematic for people with sight loss if these activities are not accessible for them. This adds to their sense of frustration, anxiety and distress in what might be quite traumatic circumstances, such as adjusting to sudden sight loss. There needs to be a sensitive balance between providing generic activities and those that are personalised and help people find meaning in their lives.

Aids and assistive technology

There was a lack of knowledge within homes about aids and technology that might help residents with sight loss. Residents who used aids had found and funded these themselves, so a better general understanding about what exists would benefit more residents. People may be unfamiliar with technology and lack confidence to use devices, and bringing devices into homes and giving residents an opportunity to try them out would be beneficial.

Befriending and support

People in care homes may be amongst the most marginalised within society. There are assumptions that once people are living in a care home they no longer need the social support and services that may be available to older people living in the community. Greater links with the wider community, particularly with local organisations with specialist knowledge on sight loss, could be really beneficial for care home residents and potentially provide vital support services, such as befriending.

“Company is, I think, an essential. To have someone, even if it’s just someone to chat.”

(Peter, resident)

Understanding experiences of sight loss through co-production

Hearing the voices of older people through this research demonstrates the emotional, psychological and practical dimensions of living with sight loss in a care home. It is a powerful way of helping care providers and practitioners understand what living with sight loss is like within the setting of a care home.

The Experts by Experience Panel contributed personal experiences and knowledge, and worked with the researchers on the design of the research and on the analysis and interpretation of the data. Panel members provided insightful discussions of the data and raised important questions about what participants had said. For example, they asked why care home staff did not consider the possibility that people with sight loss could be a resource for other residents with sight loss and how the sharing of experience and knowledge could be facilitated by care home staff. They reinforced the importance of seeing beyond the current circumstances of an older person and recognising the person's whole life and experience in helping them settle into a new life within the care home. They stressed the importance of social interaction and emotional support for older people living with sight loss.

The Project Advisory Group (PAG) drew together a wide range of professional and personal experiences from people working in the sight loss and care sectors. Meetings provided a forum for discussing the design of the research, recruitment strategies and the findings from the research. Members provided valuable contextual information which contributed to the interpretation of the data and ways in which the research could impact on changing practice. Members of the PAG reflected that meetings produced some good networking and cross-sector discussion and, in the current context, partnership working would be vital to improve practice in care homes.



Conclusions and recommendations

There is a clear need for training in visual awareness for staff in care homes and care home managers expressed a preference for in-house training. The use of a screening tool, such as the Eyes Right Toolkit, and visual awareness training could help to address the lack of awareness in care homes about living with sight loss.

The range of support available through local sight loss societies could help alleviate the social isolation residents with sight loss experience. For example, local sight loss societies have expertise in how to get registered as sight impaired and the benefits of this, aids and technology that can help address the impacts of sight loss, and can signpost to other services. Local sight loss societies can also provide care homes with volunteers to help residents engage in activities and to act as a 'champion' for individual residents, particularly those with no family.

Improving practice in care homes will need a stronger regulatory framework for training and standards in relation to visual impairment. A range of organisations that support people with sight loss and people with sensory loss could work together at a strategic level to influence policy makers in order to improve practice in care homes.

Co-produced research has an important role to play in generating knowledge and understanding about the experiences of visually impaired people. This project has highlighted good practice in how to do this in social research, which could be built upon by the sight loss sector. For example, it showed how time and resources are required for co-production to work effectively and in ethically sound ways which do not result in tokenism. The outcome is research that has been shaped in partnership with the people whose needs it was intended to address and consequently research findings that are very relevant to their lives.

“So I think, even at a good care home, you still need champions. It’s like going to hospital, you know, if you go into hospital, you need people there to champion you.”
(Julie, relative)

Authors and terms

Dr Lizzie Ward and Laura Banks, School of Applied Social Science, University of Brighton.

In this publication, the terms 'visual impairment' and 'sight loss' are used interchangeably.

How to obtain further information

The full research report, 'Older people's experiences of sight loss in care homes', is downloadable from www.pocklington-trust.org.uk or on request from:

Thomas Pocklington Trust
Entrance D, BMA House
Tavistock Square
London, WC1H 9LG

Telephone: 020 8995 0880

Email: research@pocklington-trust.org.uk

Web: www.pocklington-trust.org.uk

About Thomas Pocklington Trust

Thomas Pocklington Trust is a national charity dedicated to delivering positive change for people with sight loss.

Research is central to Pocklington's work. The research we fund supports independent living and identifies barriers and opportunities in areas such as employment, housing and technology.

We work in partnership and share our knowledge widely to enable change. We provide evidence, key information and guidance for policymakers, service planners, professionals and people with sight loss.



for people with sight loss

Tavistock House South,
Tavistock Square,
London WC1H 9LG

Tel: 020 8995 0880

Email: research@pocklington-trust.org.uk

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