

The needs of frail older people with sight loss

This publication summarises the findings from research commissioned by Thomas Pocklington Trust and conducted by Northumbria University's Professor Mima Cattan, formerly of Leeds Metropolitan University. Co-investigators were Dr Skye Hughes and Dr Fiona Fylan. Research associates were Dr Nicola Kimes and Gianfranco Giuntoli of Leeds Metropolitan University.

The research explored the specific needs and aspirations of frail older people with sight loss.

Summary findings

- Some older people struggled to retain a 'will to live' in the face of increasing sight loss and physical frailty.
- Frail older people needed help and support to come to terms with their sight loss, as changes occurred in their condition and to maintain general well-being, but the support varied.
- Feelings of isolation were not uncommon. Difficulties did not just relate to tasks but to social activities and communication. Interviewees also talked about 'not feeling welcome' by other residents.
- Sight loss was often compounded by other functional problems, and most experienced mobility problems.
- To maintain their well-being, older people needed practical as well as emotional support. Whilst practical support was provided, emotional support was rarely offered proactively. Older people were mostly dependent on family members or close friends for emotional support.

Introduction

People today are living longer and the fastest growing section of the population is the 'oldest old'. The oldest old, in particular women, are more likely to live in care homes due to frailty, illness, disability and an increasing dependence on others for everyday care.

Sight loss increases among older people and significantly so among the oldest old. Despite this, there has been a lack of information about frail visually impaired older people's experiences and expectations of ageing or about what addresses the needs of frail older people with sight loss in the care home setting.

The research team conducted a literature review, in-depth interviews with 24 frail older people living in care homes and sheltered housing schemes, and interviews with a manager and two wardens.

Research evidence to date

The literature review indicates that among very old people, sight loss compounds the physical and psychosocial impacts of ageing. Feelings of hopelessness and loss can act as triggers for low morale and a sense of bereavement and depression. Sight loss can also severely affect quality of life by limiting social interaction and independence in older people, leading to increased feelings of social isolation and loneliness. Many visually impaired older people are afraid to go outside, and stop doing things they enjoyed. Several studies have found a lack of awareness of the impact of sight loss resulting in inadequate health and social care provision. Often, older people with sight loss are treated as a single group, with services failing to understand that individuals have diverse needs at different stages of their sight loss. Lack of appropriate information is a major concern. Very few studies have investigated what information older people with sight loss need. There is an assumption that their information needs are the same as for sighted people. The literature emphasises a lack of research on their specific information and care needs, whilst other studies have shown the importance of targeted interventions to improve their quality of life.

Living with sight loss

Older people reported that the onset of sight loss led to reduced mobility and everyday activities. Not being able to perform regular day to day tasks or carrying on activities they as individuals had enjoyed in the past was frustrating. However, many showed a strong desire to maintain their independence by trying to do as much as they could for themselves, and a will to keep engaged in the activities they valued.

Their sight loss was often compounded by other functional problems: most interviewees experienced mobility problems. Although they did not necessarily attribute these problems to their sight loss, they gave examples of how being visually impaired impacted on mobility, for example an increased risk of falls. Loss of balance was sometimes attributed to 'dizziness', which they associated with medication they were taking rather than sight loss. In some cases, experiencing several falls had been the trigger for moving into sheltered housing or a care home.

Difficulties did not just relate to tasks, but to social activities and communication. Not being able to see faces was sometimes given as a reason for not socialising, and communication was described as exhausting, difficult and occasionally embarrassing, resulting in withdrawal from social activities. Visually impaired older people's emotional health was also affected. Many talked about feeling 'down' and 'depressed'.

Although older people used various strategies to cope with their sight loss and declining health, they mostly coped by reappraising what was happening to them and their feelings associated with their sight loss, because they knew their eyesight would not get better. A few also used 'problem solving' coping skills.

Feelings of isolation were not uncommon. Often this was linked to the difficulties of communication, but interviewees also talked about 'not feeling welcome' by other residents.

Living in supported accommodation with sight loss

Sight loss was usually not the main reason for moving into sheltered housing or a care home and few had regrets about their decision. The move was seen as a pragmatic solution to increasing difficulties in managing on their own. Positive aspects of living in sheltered housing or a care home included a sense of security, easier lifestyle

and less isolation. The concession to having security and help as they became increasingly frail, was that it became necessary to fit into an institutionalised routine, for example with mealtimes and medication. Despite accepting some institutional limitations, frail visually impaired older people had a desire for flexible and individualised services. Many older people felt that their personal preferences were often not taken into account. The interviews with care staff suggest that few are trained to work with visually impaired older people and some do not even see it as a priority. This was also reflected in the assessment and review of residents' care needs.

Frail older people needed help and support to come to terms with their sight loss, as changes occurred in their condition and to maintain their general well-being. The support they received, however, varied.

Service provision for frail older people with sight loss

Older people are rarely offered advice, help or support on how to live with their condition once their eye condition has been diagnosed, leaving them in a 'state of limbo'.

Care providers suggested that a general lack of effective coordination between services and the absence of timely, accessible information were the main causes of older people not receiving the information and support they required. There was a perception that 'old' age occasionally presented a barrier to receiving treatment or care, suggesting that covert ageism still occurs.

Aids and resources available to help with everyday life varied substantially, reflecting an ad hoc approach to identifying needs and acquiring tools. Often items had been purchased before the move, but other sources included family, charities and social services. Cost and lack of confidence with technology were barriers to accessing aids, but it was also unclear how much support or advice people had received to use such tools.

To maintain general well-being, older people needed practical as well as emotional support. Whilst practical support was provided, emotional support appeared to be rarely offered proactively. Older people were mostly dependent on family members or close friends for emotional support. With increasing adversity of sight loss and physical frailty some older people struggled to retain a 'will to live' without both practical and emotional support to stay motivated.

Conclusions

This study showed that:

- Frail older people frequently lacked information, help and support after diagnosis of eye problems.
- Provision of information and devices to support independence lacked a systematic approach and often did not address the needs and preferences of the individual.
- Visually impaired older people showed a strong desire to maintain a certain degree of independence. This was manifested both in their wish to try to do as much self care as they could, and to keep engaged in the activities they valued and enjoyed.
- Overall, living in shelter housing/care homes had a positive impact on visually impaired older people's quality of life because it gave them a sense of security.
- However, the ability to engage in activities they enjoyed before they moved into a communal living setting or before they lost their sight also played a significant role.
- Family members and friends were often the most important sources of support and practical help to engage with these activities, whereas care staff were mainly seen as a source of help and support for everyday chores or in case of health crises.

Recommendations for research

Research is needed to:

- investigate experiences and needs of very frail visually impaired older people with multiple health problems, and end of life support needs.
- explore experiences of loneliness and social isolation among visually impaired older people living in supported accommodation.
- compare experiences and needs of frail older people with sight loss in different housing settings, including those living in their own homes.
- compare experiences of frail older people with and without sight loss.
- explore benefits of problem solving coping strategies.
- explore and identify practical and emotional support solutions to retain a life worth living.

Recommendations for policy and practice

- Sheltered housing schemes and care homes need to ensure that support is equitable and both practical and emotional support are provided.
- Programmes of awareness raising and training regarding these experiences and needs should be implemented across the care sector.
- Communal living institutions should develop strategies to deal with discrimination by staff and other residents against residents with sight loss (and other impairments).
- Assessment and monitoring systems must be sensitive to the individual needs, interests and activities of older people with sight loss before moving into supported accommodation.
- Services for older people with sight loss need to be better coordinated with information shared and communicated between organisations and institutions.
- Frail older people living in sheltered housing and care homes should have support for regular access to eye tests, and to access help after diagnosis, and followed up. The primary care team could have a central role.

Authors

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How to obtain further information

A short report, in the form of an 'Occasional Paper', entitled *The needs of frail older people with sight loss*, by Dr Mima Cattan and Gianfranco Giuntoli, is available from:

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Copies of this 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 a leading provider of housing, care and support services for people with sight loss in the UK. Each year we also fund a programme of 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, resource centres and volunteer-based community support services.

We strive to improve continuously the quality standards in our operational centres to meet the changing needs and expectations of our current and future service users. We are proud to be an Investor in People and a Positive about Disability organisation.

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, and improving and developing service outcomes as well as focusing on public health issues.

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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