

Older people's experiences of sight loss in care homes

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Dr Lizzie Ward and Laura Banks are based in the Social Science and Policy Research Centre, at the University of Brighton. The Centre is particularly focused on community-engaged and participative forms of research that develop knowledge and understanding based in the experience of marginalised and disadvantaged individuals and communities. It is committed to making new knowledge available to help shape future directions in policy and service provision.

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1. Executive Summary

1.1 Background and context

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. The impact of sight loss on physical and psychosocial well-being and older people's quality of life are not well acknowledged in policy or practice settings. There are currently no statutory requirements for care homes specifically relating to visual impairment. Although needs relating to sight loss relate to the requirement to provide person-centred care, there is no particular mention of visual impairment within the Care Quality Commission (CQC) guidance and eye health indicators are not included in their assessment criteria for care homes.

This study aims to begin to address the gap in evidence by giving a voice to older care home residents with sight loss as well as exploring the perspectives of their relatives and care staff. In particular, it explores questions around how residents with sight loss experience support (or lack of support), how daily routines and the physical environment of the setting contribute (or not) to well-being for residents with sight loss, which aspects of practices within the setting are valued and considered helpful, and how relationships can support living well with sight loss within 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. An extensive review of research on sight loss in care homes was undertaken as part of this study. It has been written up separately to accompany this main report (see Banks and Ward 2016).

1.2 Overview of the research

The research aims were:

- To contribute to improved standards of care and practice in residential care for older people living with sight loss.
- To generate understanding of living in care homes from the lived experiences of older people with sight loss;
- To gather the views of older people with sight loss, family members, friends and care home staff on good practice in residential care;
- To produce understanding about good standards of care and practice for older people with sight loss living in care homes and to make recommendations for an agenda for action.

This project adopted an approach based in the principles of co-production and involved Visually Impaired (VI) people in several ways. As a qualitative piece of research it focused on the lived experiences of older people living with sight loss in care homes. VI older people were also involved in an advisory capacity as members of an 'Experts by Experience' panel (EEP). The panel met six times over the course of the project and worked with the researchers on developing the research methods and in the analysis and interpretation of the research data. This included developing questions to use in the research interviews, approaches to recruitment and ethical aspects of the interview process. Panel members also offered insight drawing on their experiences of acquired sight loss and their knowledge of care homes. The researchers also worked with a Project Advisory Group (PAG) which included stakeholders from the sight loss and care sectors and VI members of staff from TPT. The PAG offered specialist guidance on the sight loss sector and ensured that a range of different perspectives were captured in the research process.

1.3 Methodology

The research was carried out in seven care homes (six residential care homes and one nursing home). The majority of the homes were in the charitable sector, and there was one run by a local authority and one in the private sector.

Forty participants took part in semi-structured interviews. These included:

- Twenty-one care home residents who were aged between 63 and 98, thirteen were women and eight were men.
- Ten members of care home staff.
- Nine relatives of care home residents.

The interviews explored:

- Resident's 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 home.
- The use of adaptations and assistive technologies.

1.4 Key themes from the interviews

- The importance of awareness of sight loss amongst staff, particularly agency staff.
- Having adequate staffing levels and staff time to provide emotional and social support.
- The need for support with becoming familiar with the care home for new residents and for negotiating the care home environment.
- Insufficient support from outside, especially lack of input from rehabilitation workers and lack of perceived support associated with registration.
- The importance of volunteers to help engage in activities and go out but difficulty in accessing volunteers.
- The importance of friendships, company and conversation but social interactions can require facilitation by staff.
- A reliance on family and friends to provide support and difficulties where help from family and friends is not available.
- The sense of loss related to sight loss and loss of activity, depression and lack of emotional support.
- The added financial costs related to sight loss, for example, transport and equipment.

- Difficulties with accessing or finding out about equipment which might help to address the issues of living with sight loss.

1.5 Summary of findings

- Complexity of needs within care homes. In addition to visual impairment residents were experiencing other health conditions including hearing loss, memory loss and confusion, and mobility difficulties. They clearly had emotional needs and some experienced poor mental health and depression.
- Challenges of living within a care home. Many spoke about the transition of moving in to the care home and the adjustments of living in a communal environment with less personal space. The extent to which residents were supported with orientation and the physical environment varied.
- A number of things were identified that positively contributed to a resident's quality of life which included:
 - i. Greater awareness about what it means to live with sight loss, particularly from staff, but also other residents.
 - ii. Support from others: family, befrienders, and staff. Relationships with others are crucial in counteracting feelings of isolation. Many residents talked about wanting more time to just talk with staff and highlighted the importance of having company.
 - iii. More knowledge of aids and adaptations, and technology that could help residents maintain their interests or develop new ones.
 - iv. Better connections with local external organisations such as sight loss societies and rehabilitation services.
- Person-centred care and properly executed care plans should be able to pick up on issues, such as changes to existing eye conditions or the development of sight problems. But this would depend on staff having awareness and training about picking up the signs of sight loss. Residents, relatives and staff all raised issues in relation to adequate training and awareness of the impact of having sight loss and the need for more training was identified in most homes in the study.
- The wider context of the care sector and the issues of staff recruitment and retention, increased costs, less public funding for

social care inevitably impacts on staff time available to do anything beyond basic care tasks.

1.6 Conclusions and recommendations

Care home staff awareness of sight loss

Staff recognised the need for more awareness and training on visual impairment but were not aware of any existing training or where to find training resources. The identified need for visual awareness training of care home staff coupled with evidence that residents do not always like to ask for help increases the possibility that deterioration in vision will go undetected. There needs to be greater awareness and understanding of sight loss so that residents who develop sight problems after moving into the home receive diagnosis and treatment where appropriate. There needs to be greater awareness and understanding of the impacts of sight loss so that residents with sight loss receive better support including facilitation with social interaction and communication in daily living activities.

Multiple health conditions and complex needs

All of the residents in the study were living with other health conditions and problems. It was clear that residents' sight loss calls attention to a lot of the 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 home settings. Small basic things, such as introducing yourself when entering the room of the person with sight loss or telling people that their food is being placed in front of them, can make a big difference at an individual level.

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. This adds to a sense of frustration, anxiety and distress particularly in what might be quite traumatic circumstances, such as adjusting to sudden sight loss.

Aids and assistive technology

There is a lack of knowledge within homes about aids and assistive 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. Many people may be unfamiliar with technology and lack confidence to use devices, and giving residents opportunities to try them out would be beneficial.

Befriending and support

People in care homes may be amongst the most marginalised within society. Assumptions that once people are living in a care home they no longer require social support and services may prevent care home residents' access to 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.

Understanding experiences of sight loss through co-production

Hearing the voices of older people 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. The PAG drew together a wide range of professional and personal experiences from people working in the sight loss and care sectors. Members provided valuable contextual information which contributed to the interpretation of the data and ways in which the research could impact on changing practice.

Recommendations

There is a clear need for training in sight loss awareness for staff in care homes. Care home managers expressed a preference for in-house training and the development of the 'Looking Out for Sight' visual awareness training by Wiltshire Sight, commissioned by TPT, could help to address the lack of sight loss awareness in care homes.

Support through local sight loss societies would help with the social isolation residents with sight loss experience. Local societies have expertise to offer advice and support about aids and technology to care home residents.

Improving practice in care homes will need a stronger regulatory framework for training and standards in relation to sight loss. Organisations who work with people with sensory loss could work together strategically to influence statutory bodies.

Co-produced research has an important role to play in generating knowledge and understanding about the experiences of VI people. This project has highlighted good practice for the sight loss sector in how to do this. For example, it shows how time and resources are required for co-production to work effectively and in ethically sound ways which do not result in tokenism.

2. Introduction

2.1 Background and context

The main causes of sight loss are age-related. Yet the impact of sight loss on physical and psychosocial well-being and older people's quality of life are not well acknowledged in policy or practice settings. The Royal National Institute of Blind People (RNIB) reports that a number of factors disproportionately impact on older people with sight loss, such as inequality in accessing sight saving treatments, access barriers to technology and lack of support in using it. This is compounded by pressure from spending cuts on ophthalmology services which particularly impact on older people (RNIB 2014).

The majority of people with a visual impairment are over 65 but prevalence estimates vary from between 4% – 20% of people in this age group (Horowitz, 2004). One study has estimated that 1.6 to 2.2 million older people have experienced sight loss, with around 50% of these having a moderate to severe visual impairment (Charles, 2007 p.199). Clearly, the risks of sight loss rise significantly for people over 65 with advanced age: Jacobs (2012 p.313) estimates that those over 85 are twice as likely to have a visual impairment as those aged 70, whilst Joule (2009 p.2) estimates that approximately 20% (1 in 5) of those over 75 are living with sight loss, rising to 50% (1 in 2) of those over 90.

Accurate information regarding prevalence of sight loss in care homes is not available because of inconsistency in the frequency of eye care examinations and recording. It is highly likely that the prevalence of sight loss in care homes is, however, higher than among the older population at large (Charles, 2007). A US study found that the rate of visual impairment in nursing homes was 13-16 times higher than in the general population (Tielsch et al., 1995). In the UK, RNIB (2010) estimates that over half of older care home residents have some form of sight loss which could impact on quality of life. 50% of the older care home population amounts to around 145,500 people out of a population of 291,000 residents aged 65+ living in care homes in England and Wales (according to 2011 census figures). The figures also show that more than half (59%) of the care home population is aged 85 or over,

amounting to 16% of the total 85+ population in England and Wales (ONS, 2014b).

The study reported here was primarily based in London. 2011 Census data (ONS, 2014a) shows 22,454 older people were living in care homes in London. Interestingly, although London had a relatively low starting point, between 2001 and 2011 it experienced the greatest increase (out of all regions in England and Wales) in the number of older care home residents (+ 9.4%). Therefore it appears there is a growing need for residential care in the capital.

Local authority run care homes have significantly declined in number since 1990 (Banks et al., 2006). In 1990, the independent sector (private and not-for-profit) accounted for 61% of all care home provision for older people. This figure rose to 91% by 2010, (approximately 60% in England), although still mostly funded by local authorities (Forder and Allan, 2011). Within this mixed economy of care home provision, statutory regulation, primarily monitored by the Care Quality Commission (CQC), is the mechanism for control over care home standards. There are, however, no statutory requirements for care homes specifically relating to visual impairment. Although needs relating to sight loss relate to the requirement to provide person-centred care, there is no particular mention of visual impairment within the CQC guidance (even though other conditions such as dementia are noted) (CQC, 2016). It has been argued though that the CQC should incorporate eye health indicators into their assessment criteria for care homes (Watson and Bamford, 2012).

In Wales, however, the Welsh Government Eye Health Care Delivery Plan includes a range of actions aimed at preventing sight loss which include work with the Care and Social Services Inspectorate Wales to ensure good quality eyesight care is promoted in residential care settings (RNIB, 2014). In Scotland, the 'See Hear' strategic framework (APS Group Scotland, 2014) recognises the importance of raising awareness around sight (and hearing) loss. The National Institute for Health and Care Excellence (NICE) have also included 'recognition of sensory impairment' as one of the elements (quality statement 4) of their quality standard 50 on 'mental wellbeing of older people in care homes' (NICE, 2013). According to this guidance, care home staff should

recognise sight related needs of residents and record these as part of their care plan. However, these guidelines are non-mandatory and a previous TPT study with Skills for Care found there is a lack of evidence on the extent to which guidelines are incorporated into practice (Burtney et al., 2014).

Research among older people in care homes can be particularly challenging for a number of methodological and ethical reasons (Hall et al., 2009; Help the Aged, 2007; Maas et al., 2002). There is therefore a dearth of literature relating to the experiences of older care home residents in general (Lee, 2000, Szczepura et al., 2008), not only specific to issues relating to visual impairment. Quantitative studies of older people using large scale surveys are often restricted to private households (e.g. Zimdars et al., 2012) and qualitative studies concerning sight loss tend to focus on older people living in the community (Nyman et al., 2012). Furthermore, studies concerned with quality of life and well-being of care home residents often fail to consider the relevance of sight loss (Bradshaw et al., 2012). Therefore, the issue of sight loss in care homes, particularly from the perspective of older care home residents themselves, is an under-researched area which the study reported here attempts to address.

An extensive review of research on sight loss in care homes was undertaken as part of this study. It has been written up separately to accompany this main report (see Banks and Ward 2016). It is beyond the scope of this project to explore all of the issues raised in the accompanying literature review in depth, such as those concerning multiple health conditions. However, the study reported here aims to begin to address the gap by giving a voice to older care home residents with sight loss as well as exploring the perspectives of their relatives and care staff. In particular, it explores questions around how residents with sight loss experience support (or lack of support), how daily routines and the physical environment of the setting contribute (or not) to well-being for residents with sight loss, which aspects of practices within the setting are valued and considered helpful, and how relationships can support living well with sight loss within residential care. Our broader aims and objectives are outlined in the following section.

2.2 Aims and Objectives of the Research

Primary aim:

To contribute to improved standards of care and practice in residential care for older people living with sight loss.

Objectives:

To generate understanding of living in care homes from the lived experiences of older people with sight loss;

To gather the views of older people with sight loss, family members, friends and care home staff on good practice in residential care;

To produce understanding about good standards of care and practice for older people with sight loss living in care homes and to make recommendations for an agenda for action.

3. Methodology

3.1 Research approach: co-production

There is growing recognition of the importance of involving people who receive services in dialogue about the design and delivery of services, both through research and other forms of involvement. In relation to social care the concept of ‘personalisation’ reflects a shift towards individualised ‘person-centred’ care in which there is an expectation that the person receiving care is fully involved in decisions regarding their care (Carr 2010). In a review of the evidence in relation to older people with high support needs, Sharif et al. (2012) report that user involvement results in ‘better quality in both policy and service development and also has benefits for everyone involved in social care provision including practitioners and carers’. Whilst user-involvement has been gaining ground within health services over the past 25 years it has more recently been adopted more broadly through the concept of co-production within government policy agendas across health and social care services. Co-production has been defined and interpreted in different ways but it generally refers to the intention and the practice of opening up decision-making to those who receive or who are affected by services. The National Advisory Group on Co-production defines it thus:

‘Co-production involves people who use services being consulted, included and working together from the start to the end of any project that affects them. When co-production works best, people who use services and carers are valued by organisations as equal partners, can share power and have influence over decisions made’ (Think Local, Act Personal, 2014).

Across the spectrum of health and social care organisations there is a need to develop capacity to respond to the call for greater involvement of service users in wider aspects of organisations’ functions and services. Approaches grounded in disability studies, emancipatory research, as well as those within critical gerontology, support giving voice to marginalised experiences in research. This position recognises the need to value disabled people’s experiences of living in disabling environments and their expertise based on their own experience of living with disabling conditions. In relation to the sight loss sector specifically,

previous work commissioned by TPT has reported a lack of involvement of visually impaired (VI) people within research projects (Duckett et al. 2010). The same study found that VI people understood the value of their own experiences in finding solutions to the problems they face and the importance of sharing knowledge by, and for, VI people in building solidarity and a sense of belonging. Clearly people's experiences of living with sight loss can provide a vital part of our understanding.

This project adopted an approach based on the principles of co-production and involved VI people in several ways. Through the empirical work the researchers gathered evidence from older people living with sight loss in care homes as research participants which are detailed in the findings.

3.2 Experts by Experience Panel

The researchers also worked with a group of VI older people who were recruited to be members of an 'Experts by Experience' panel (EEP). The EEP met six times over the course of the project and worked with the researchers on developing the research methods and the analysis and interpretation of the research data. The first meeting focused on developing questions to use in the interviews with care home residents, relatives and care home staff, approaches to recruitment and ethical aspects of the interview process. Subsequent meetings focused on discussing the themes that were emerging from the research interviews and interpreting the data. Members of the EEP offered insight drawing on their experiences of acquired sight loss and their knowledge of care homes. They also offered comments on the draft report and suggestions for the dissemination and communication of findings. In accordance with good practice on user involvement in research and the University of Brighton user involvement policy, the panel members were offered payment in recognition of their time and travel expenses.

3.3 Project Advisory Group

The researchers also worked with a Project Advisory Group (PAG) to develop and support the research. Members of the PAG included

stakeholders from the sight loss and care sectors and VI members of staff from TPT. The PAG met with the researchers four times during the project and offered specialist guidance on the sight loss sector and ensured that a range of different perspectives were captured in the research process.

The report reflects on the co-production approach and the experiences of involvement in the EEP and PAG in the final chapter.

3.4 Fieldwork

Sampling and recruitment

A stratified purposive sampling method was chosen in order to minimise bias and with the aim of achieving a varied sample, increasing representativeness and therefore maximising the potential for the transferability of findings (Graff, 2012). The following steps were taken:

- Residential and nursing care homes accommodating older people were identified through the CQC database. Only those meeting all standards in the most recent assessment (307 care homes and 363 nursing homes) were selected. The reason for this was because a primary aim was to identify examples of good practice and for ethical reasons it was felt important to avoid being a burden on homes which were experiencing difficulties.
- Homes were categorised according to London sub-regions (i.e. North, East, South, West and Central). The boroughs with the greatest number of residential care homes within each (i.e. Barnet, Brent, Croydon, Waltham Forest and Lambeth) were chosen.
- From this sub-sample of 94 residential and 55 nursing homes, those with at least 20 residents were selected, leaving a list of 86 homes in total. A letter or email explaining about the research study was sent to the manager of each of these homes. In addition, four 'specialist' sight loss care homes outside of London were invited to take part for comparative purposes.
- Managers were followed up by letter and/ or email and telephone calls. Thirty-five managers (39%) declined to take part, mostly stating they did not have 'eligible' residents, i.e. older people with sight loss

who had capacity to give informed consent. Twenty-seven managers (30%) did not respond and were unobtainable. The remaining managers initially agreed to help by passing information on to residents but the majority of these did not subsequently respond and were unobtainable.

- Five residential care homes and one nursing home from three out of the five boroughs were recruited to take part in the study. One residential care home outside of London was also recruited. The response rate was therefore 8%. One of these care homes was privately run, one local authority run and the others were run by charitable organisations.

Participants

Forty interviewees took part in the research including:

21 residents aged between 63 and 98 (with an average age of 87), including 13 women (62%) and 8 men. Participants had a range of eye conditions including Age-related Macular Degeneration (AMD), glaucoma, cataracts and stroke related sight loss. Two participants had experienced eye conditions since their youth, which had worsened in older age. All others had acquired sight loss in older age. Most of the residents identified as White British, and five as Jewish;

10 members of staff including five managers, one deputy manager, one activities coordinator and three care workers. Four staff members (40%) were non-white;

9 relatives of older care home residents with sight loss. These included six women and three men (four daughters, two sons, one son-in-law, one niece and one cousin). Most relatives were in their 60s. The oldest was 78.

Analysis

Thematic coding was conducted with the assistance of NVivo10 software. Transcripts were firstly organised into the following categories (which related to the key subject areas covered in the interview

schedule) by adding headings to each section and 'auto-coding' in NVivo:

- Background/ demographic information
- Eye condition
- Living in a care home
- Support from care home staff
- Support from outside the home
- Adaptations/ assistive technologies

A selection of these sections was shared with EEP members for comment and discussion as described above. Detailed line by line, inductive thematic coding was then carried out. A total of 83 'parent' codes (which mostly fit within the above categories) and a further 35 'child' (sub-codes) were identified. Through this process, the aim was to draw out key themes and messages which appear to be particularly significant to participants. These are outlined and discussed in the next chapter.

4. The personal contexts of older people in this study

The main aim of this study was to gather older people's perspectives and generate understanding on the lived experiences of sight loss within care homes. The findings start with an exploration of the personal contexts of the residents who took part in the study. The names of the people who took part have been changed but their own words are used in the quotations.

The residents in this study share similar characteristics reported in previous research in care homes that has found that people who move into care homes have complex needs and may experience a range of health issues. There was a diversity of experiences within the sample across a range of factors, such as different types and degrees of visual impairment, the amount of time people had lived with visual impairment, and how long people had been living in the care home when they were interviewed. To gain an understanding of their individual backgrounds the interviews explored their personal circumstances, their eyesight problems and other health conditions, how they came to be living in the care home and what it feels like adapting to living with visual impairment in the setting of a care home. Their ages and complexity of care needs were in many ways typical of what is known about care home populations.

The majority of the interviewees were in their 80s and 90s. For most, visual impairment was one aspect of their lives and many were also living with other long-term health conditions and disabilities. Almost all experienced mobility difficulties, and some had little mobility and were wheelchair users. The types of eye condition that were reported were again typically related to ageing, Age-related Macular Degeneration (AMD), glaucoma, and cataracts, and some residents had more than one eye condition as well as hearing loss. Some residents had experienced visual impairment as a result of another health condition, such as stroke, Parkinson's disease and giant cell arteritis.

The degree of visual impairment varied amongst the interviewees as did the ways in which they spoke about the impacts of sight loss. The

majority had a diagnosed eye condition prior to moving into the home and for many their visual impairment was an important contributory factor in the decision to move into the home. This had often followed a crisis in health, such as a stroke or a serious fall, and recognition that the person could no longer manage everyday activities within their own home. To illustrate the transition into the home and how this was experienced, it is helpful to consider some examples in detail.

4.1 Hannah's story

Hannah, who was 92, had recently moved into the home when she was interviewed. She came to live there following a series of falls and decided that she could not manage living on her own. She is from the local area and has been very active in the local community. She already knew people who lived in the home. She has AMD and cataracts and a number of other health problems. Following a stay in hospital after her last fall, her family felt she would be safer moving into a home and she recognised it had become difficult to manage tasks in her own home:

“I have fallen five times so I feel, that made me feel a bit sorry for myself, but I tried to do different cooking, even, what can I give you as an example, even boiling an egg, you put water in the saucepan, you boil the egg and then I found that my hand was shaking when I went to empty the water away and I, at some point I went to make myself a cup of tea and I made it with a teabag, and I was holding the cup by the handle and went to pour the water in and misjudged and it went over my hand, 'cos I didn't see where I was putting it.”

Hannah also experienced hallucinations due to Charles Bonnet Syndrome, and she explained that this had improved since moving into the home:

“But of course since my falls I really am rather nervous, I shake quite a lot, I get upset because of that, but the hallucinations haven't been so bad since I've been here.”

It was early days in the care home for Hannah and she described how she was trying to adjust to accepting help:

“Sometimes I press the wrong button and then I have to shout to somebody to show me what I've done wrong. So, and it makes you a little depressed I must admit, and what shall I say, no I'm not going to use the word 'frustrated' because that isn't quite true, but it makes you feel, well it makes me feel inadequate and there are so many things that I find difficult. I mean I know I can stand up and get that but if somebody offers me their hands to help me up I'm trying to take them, whereas I feel I shouldn't have to, and then I get a little bit upset.”

4.2 Edna's story

Edna was 89 and widowed. She had been living in the home for 18 months. Like Hannah, Edna had had a series of falls and the last one had broken her hip. She had cataracts but also had other health conditions that had influenced her move into care.

“I knew I wouldn't be able to manage at home while I was in (hospital) and I went home the end of January but I had completely lost confidence. I was terrified of falling, I never minded being on my own if I was fit but I wasn't and then I developed my heart problems and I realised I wasn't going to be able to manage any longer at home.”

Edna described how life is very different now and the process of moving into the home which had not been easy:

“Well, it's different. I mean, I've always been a very independent lady, I've always run my home and brought up two children, everything, those things didn't worry me at all. When I came here, I'm getting a bit used to it now, but the fact that I've got nothing to do, no responsibility, it's a different sort of life. Added to which when you've had a whole house to yourself and you're now, I mean, it's a nice room, it's not tiny, but I'm always scratching round for space to put things because there's some things. We're encouraged to bring things from home to make it as much like home but it's very difficult to decide what to bring and what not and I've emptied out, haven't sold it, I've let it, and that was a very traumatic time, I wouldn't wish that on anybody.”

4.3 Elsie's story

Elsie was 84 and had glaucoma for a number of years but almost a year before had had a stroke which had affected her sight. She also had some hearing loss and physical weakness from the stroke. She described how the stroke had left her with very little vision and how difficult and traumatic that had been:

“I can't even remember the stroke, you know, all I know that I had the stroke and that I couldn't see afterwards, you know. So I, it was like a big shock, it was like a blow to me because I, it's, it was, it was, well, one of the worst things I've ever really had to take, and I've had some nasty things happen, but this is the worst... they said to me that I'd have to be registered blind, you know, and I think that was the biggest shock, you know the realisation that, I knew I had the glaucoma and that came, and only last January I had cataracts operations on both eyes.”

She moved into the home from hospital. She has children who she could have lived with but she was really adamant that she didn't want to do this as she felt it would be a burden on them.

“But I will come to, come to terms with it. It's very, very hard when...I've lived quite an independent life, I lost my husband seven years ago, and I was living alone and that, and, but as I say, I've got a family but it's not, I feel I'd be too much of a burden if I went to live with them because they've got their own families, and their own families must come first mustn't they? And I just don't want to be...I'd be too much, I think I'd be too much trouble for them. It's like a 24 hour job, isn't it, looking after someone?”

Elsie found the process of adjusting to her new circumstances very difficult, and described how she was trying to learn how to live without sight:

“It's just, I think it's learning to be sightless, you know? It's, you have, it's like learning anything, you've got to teach yourself how to do it. It's like I do, like, in here I'm finding my way around I can find the toilet on my own and I don't take any chances, I have to be sure that I know where I'm going. I'm, I have lost a lot of sense of directions, you know, whether they go that way, and go that...I've gone the opposite way.”

Elsie missed her own home and the things she used to do like going shopping, knitting and reading:

“And I do miss, I do miss, miss me own life and doing the things you do, just even the, your cooking and everything, I wouldn’t be able to cook now I don’t think, because I’d be too frightened. I don’t go out, I’ve not gone out on my own at all since, because I was, I’d be frightened of having an accident, you know, and that would be worse wouldn’t it? So I don’t take any chances, I don’t go, I don’t go out.”

4.4 Adjusting to changes

Hannah, Edna and Elsie’s stories illustrate the emotional and psychological challenges of coming to terms with sight loss and with moving into residential care. Others who had gone through similar difficulties with the transition into residential care were able to reflect more positively on the adjustment. Jenny, who was 83, who had lost her sight completely and very suddenly described it as “devastating it was absolutely ghastly. I really thought I wasn’t going to pull through, I felt so dreadful. ... when I first came, God, yes, I was so down.” But now she had been living in the home for almost a year she felt that considering her situation and that she has no family who could help, it was the best move she could have made.

Many also described the ways in which they had adapted or tried to come to terms with their sight loss like Anne, who was 92 and developed AMD in her 80s. She had been living in the care home for almost 3 years and was generally very happy there. She was determined to remain as active as she could as she explained “the main thing is to look upon it as a challenge and want to overcome as best one can, I go out and about and I go on buses, I mean I’m comparatively speaking quite, you know, active I suppose.”

In contrast, for many the capacity to keep active and involved in things depended not only on a sense of confidence but also the extent to which other health issues impacted on daily life. Peter, who was 84, had lived with visual impairment all his life and had lived a full and very independent life. As he had got older he had developed other health problems which affected his mobility:

“I’ve had trouble with my feet for quite a long while and they’ve just got worse and worse and ulcers on my feet and I became housebound. It’s a bit more than difficult! It’s impossible. I’ve got this (walking frame), when I was in hospital for a while, when my feet were bad, and they were trying to get me up and walking again and using the frame and wanted me to take a frame home with me and what’s the use of a frame to me at home? Without someone to guide me, I haven’t got a clue where I’m going, I can’t use a frame and a stick as well.”

4.5 Multiple health conditions

Many of the participants had mobility difficulties of varying degrees due to conditions like osteoporosis and arthritis, and around a third used wheelchairs. Whilst some talked about their sight loss as the most significant health challenge they faced, for others it was just one aspect. Philip, who was 86, had lived with Parkinson’s disease for over 30 years and he described how his sight problems were “part and parcel of the overall problem.” Like Anne, he focused more on what he was able to do rather than not do.

“Yeah, I regard it as a sequence to the Parkinson condition and my sight is not good but it’s not great and you learn to live with these things, there are people in the home much worse off than I am and they serve as a marker and I’m lucky to be able to maintain as full a life as I can. But it isn’t easy, I get peaks and troughs ... but anything that requires me to use my hands I’m handicapped, that’s the one big problem.”

Many participants also experienced hearing loss of different degrees. For some like Angela, who was 92 and had lost sight in one eye, hearing loss impacted more on her capacity to communicate and remain involved with others.

“But that (sight loss) troubles me less than not hearing so well, because I don’t hear very well now, a lot less than when I came here sixteen months ago. I’m not troubled by my eyes so much as my hearing. You see, people don’t, people don’t, unless they’ve been hard of hearing, last year I realised I was taking a lot more in at the lunch table, for instance, and people don’t slow down, they start, if you say, if you just go a little slower I can understand, I can catch on to them, and I say, but

they say, "Oh, certainly", then they start off and then they go, "La, la, la, la, la", you know, and you've lost the point, so you drop out."

Given the extent and complexity of needs, the care and support that participants received was fundamental to their quality of life and well-being. The next chapter reports on a number of key issues around care and support that were explored in interviews with residents, relatives and members of staff.

5. Care and Support

5.1 Eye health within the home: reviews and checks

All the participants (including staff and relatives) were asked about how eye health is reviewed for residents. Some residents were already under the care of eye clinics and they continued to go for appointments since moving into the home. Staff were asked how eye health was checked and reviewed. All of the homes had contact with local opticians who would come into the home to provide eye tests. The regularity of these varied between homes. One home had a policy of arranging checks for new residents when they moved in. In other homes, staff described opticians visiting and how residents were supported in eye care and follow up appointments:

“Well, they have regular check-ups by the visiting optician, obviously if they’ve got any concerns they flag it up, we contact the doctor’s, the doctor’s does the referral to the necessary people, and we take them to their appointments and have them monitored, and obviously, you know, when they have eye drops, we ensure that they get their eye drops at the right time, and obviously they’re administered properly, they’re stored properly.” (Frances, support worker)

But there was some evidence of barriers to monitoring and checking on people’s sight, partly through the idea or perception that ‘nothing can be done’, on the part of the resident or their relatives. An example of this was Nell who was 95 and had had AMD for some years. She also had arthritis which severely limited her mobility, had experienced a number of mini-strokes and had hearing loss. She had lived in the home for three years and her daughter, Julie, said that her sight had got worse over that period. Nell had been under the care of the local eye clinic and had received treatment but she had made the decision not to continue treatment:

“I just gave up going to them. I let it, I wrote and said I didn’t want anymore. It didn’t really help and it, it was a hell of an ordeal to be there waiting. I mean they’re very nice people and everything, but obviously you have to wait in a queue and take up my daughter’s time taking me,

although she did very willingly. But I mean it's a bit of a carry on if you don't see much advantage."

This appeared to indicate that the staff no longer monitored any changes or further deterioration as Julie, her daughter, explained:

"It was mum who decided there was no point in carrying on with the hospital, so nobody now checks her eyes."

The idea that there was little point in attending eye clinic was echoed by Norman, whose mother was aged 101, has dry AMD and no longer goes for check-ups:

"No, because it's too far gone, she's too old to operate and anyway, it's the dry form of macular degeneration, it's not the wet form where you can get operated on, and anyway, I quite understand why the National Health Service wouldn't waste time on someone of that age! It's hard, it's awful but you know, you can see where they come from unfortunately."

Acceptance of the situation were echoed in other interviews with residents and the idea that "there's nothing that you can do, you've just got to live with what you've got" possibly reflected a generational attitude towards adversity. Connie, who was 92, typified this when she explained that although she noticed her sight had got worse lately she would not mention it to the staff:

Interviewer: "Do you think they (staff) understand your sight problems and help?"

Connie: "Probably not all because it's only the last six or eight weeks that it's been quite so... quite so bad."

Interviewer: "So do you talk to them or do they ask you about how your sight's changed or how would they sort of find out about the changes?"

Connie: "I don't think, I don't think it, no, I don't know. I don't, well it's difficult to say anything about my sight without grumbling and I don't, I'm not a grumbler, I sort of accept things as they are."

Staff also reported difficulty in sometimes getting residents to have eye checks or go to appointments, as Luke a care worker explained:

“Sometimes you taking them to go for eye checks is another thing, you might take them there, you know, getting there, the optician will want to do the checks, they will refuse.... So these are some of the challenges because you know that they need to do this check but it gets to a point, there are several occasions you go out for appointments with clients and you come back with nothing, they won't, it's just a journey you go without achieving anything, you go because if they refuse there is nothing you can do.”

Others reported that eye checks had continued. Rachel, whose father has cataracts, explained how he was continuing to receive treatment since moving into the home.

“And he's had the, he had the cataract done since he's been here, so he's under (hospital care), so he's been back there and they've checked his eyesight. And he wants to keep to our regular optician, and our optician said he'll either send someone along or we can take dad to the shop, so yes.”

This suggests there may be some variability in terms of different eye conditions, the extent to which they are understood as 'treatable' and people's individual feelings about going to appointments and seeking help.

5.2 Rehabilitation

Many of the residents were registered either sight impaired or severely sight impaired although few understood what this meant in terms of accessing support. Most had been registered before coming to live in the care home. Some residents had received rehabilitation services in the past but not since moving into the home. None of the five homes in the study routinely had specialist input from rehabilitation services, such as a Rehabilitation Officer - Visual Impairment (ROVI). One member of staff, Jackie, thought this type of specialist help could be very useful when people were having mobility problems and needing to transition from using a stick to a walking frame.

“I think mobility’s a big, is a big thing and obviously some residents use a stick, some will have walking frames, I think it would be prudent if they had the facility of a ROVI.”

Elsie, who came to live in the home following a stroke, had received some rehabilitation support, although this appeared to relate more to her stroke than her sight loss. Judy, the manager of the home commented:

Judy: “In the beginning when Elsie first came here the rehab people were involved with her, yeah, because of the degree of the stroke that she had had but then she reached her sort of, as they saw, her full potential and they withdrew.”

Interviewer: “So how do you think that support helped her?”

Judy: “Well I think in the beginning it gave her a lot of confidence, you know, from when she came from the hospital and it was a new environment, everything was new, she was coming to terms with her sight loss, I think that really did help her.”

In the same home, Frances a support worker explained that they had in the past received support but this was no longer the case:

“We used to have the rehabilitation team coming in, and they used to do that. Partially sighted, I’ve not seen it, to be honest, but we don’t have it now. Possibly you might get it in the community now, where they go in and, say, teach them how to make their own drinks and cook their own food and things like that, you know, these sensors and alarms and... No, we don’t, because I think their attitude is, I can understand they’re more focused on the outside people living on their own, whereas 24-hour care where they’ve got people round them.”

This indicates that registration and any subsequent rehabilitation support may be geared more towards people living in the community rather than in care homes. It also suggests that cuts in public sector services are likely to impact on local authority priorities in relation to rehabilitation services.

5.3 Support from staff

The interviews with all participants explored how care plans are used in the home to gather information on the ways in which residents' care needs are assessed and the extent to which sight loss is taken into account in the assessment of needs. Generally, from the interviews with staff, there appeared to be consistent practice of involving the residents and relatives in the care plan where possible. Joanne, explained the practice in the home where she is the registered manager:

“It’s personalised, it’s so individual because no one is ever the same, even so we do try and personalise the care plans and tailor to that person and ... also do an activities care plan for them that we can follow but a lot of the information comes from either one, the resident themselves to the families ... the residents have to be involved in their care plans. Because that’s where they get the information from, they also sign the care plans that they agree with what’s in it and what we’re doing and how we’re doing it and what goals we can achieve and so forth.”

However, from the perspectives of the relatives and residents a mixed picture emerged as there appeared to be a lack of clarity and understanding regarding care plans. In some cases relatives did not feel they had been involved in the care plan and there appeared to be a lack of communication between staff and relatives. Kate explained in her mother’s home staff did not appear to have the time to talk in detail about her mother’s care:

“I have to say they don't communicate very well, I don't, again, I don't think they have the time, I don't get to hear things, not at all, so I mean I have to ask, you know, 'how is she getting on', and then they tend to be a bit kind of glib, 'oh she's fine, she's fine', you know. And I'm sure she is but, you know, it's just you'd like something a bit more, I don't know, I feel like they're noting her really and they're tracking her or not, I don't think they are.”

In contrast, Rachel, whose father was in a different home to Kate’s mother, felt fully informed and involved:

“We had a meeting after his six-week review here, and I think we covered a few of the things then, and if there’s anything that we’re

concerned about, we can always phone up or meet with them or ask, yes.”

The interviews with residents and relatives explored in some detail the types of support offered by staff and the extent to which understanding of sight loss contributed to the support offered. The main difficulties that repeatedly came up were a lack of awareness of what having sight loss meant and the amount of time staff had available to provide support beyond basic care.

5.4 Staff awareness and understanding of sight loss

It was notable that the responses from the relatives were more critical of staff than those from the residents who appeared less willing to criticise staff. In this interview, Nell and her daughter, Julie, understood the staff approach differently. Nell thought the problem was the staff were “always in such a rush”, whereas Julie thought it was a sensitivity issue and that more general awareness was needed, and she felt that:

“I'm not terribly sure whether the staff have had training specifically around people with sight loss, because I don't think they always necessarily understand what that means.”

She gave the example of staff not introducing themselves when they entered her mother's room:

“That's another thing about understanding what it is when you can't see, that people could usefully introduce who they are.”

This was an issue that was raised in other homes. Bert's son had made his own sign for the door of his father's room which read in large letters “Remember Bert cannot see, please say who you are!”

Kate explained that the combination of time needed to fully support people and general awareness of ageing and living with disabilities like sight loss were essential for someone like her mum who was 98 and very limited in what she could do:

“Time that is required for someone of this age with this kind of disability, just isn't there I'm afraid. I do think they're not always as conscious as

they might be of people's sight disability. It's just that awareness that they can't see, that when you're a sighted person that sense is so taken for granted that it's hard even to imagine what the difficulties are for somebody who's not only coping with growing older and frailer and less agile, less able, to also lose that sense, which actually is so important if you think you're just sitting most of the day when you're that age, you can't watch television, you can't knit, you can't read, you, what, your ability to do anything is so small, so small."

In contrast, many of the residents had lots of positive things to say about the support they received from staff. Generally staff were described as very caring, kind and patient. Elsie, for example, spoke highly and warmly about her carers:

"They're very, very good to me, they're very helpful. I mean they tell me every, you know, even to sitting down, turning round and sitting down and making sure that I'm, I don't fall, you know, they've been very good. ... I mean like the nurses and the staff here, they, well, they, they're like friends, they're very good to me and I don't think they've been able to have done so much, because they have been good, they have been good, and been very patient, so they put themselves out, they're very, they're very good."

In another home, Emily, 95, described the staff as very helpful commenting that:

"I don't know really whether they know a lot about sight loss but they seem to look after us quite well on the whole. I mean I'm sure all these people must have a lot of patience to deal with somebody who can't see, because you're so slow about everything, that's the thing isn't it when you can't see what you're doing."

Although residents thought highly of the care staff many commented that they always seem very busy and this made them reluctant to ask for more help or support, particularly around emotional support. Anne typified this:

"You can only say nothing but praise of them, they were unfailingly kind and polite and nice and helpful but they're pushed lately, I mean they're rushing around like I don't know what. They're all nice, I mean you know,

the carers, they are all nice, I mean they don't sit down for half an hour to chat but I chat. They chat and then they go, excuse me, I must get on, which is fair enough but they are good."

The importance of continuity and relationships between staff and residents was apparent in residents' feelings about agency staff which indicated that the issues around awareness and time were compounded. This was expressed by Sonya, Jenny and Rosa who were all residents of different homes.

Interviewer: "Do you think they understand about your sight problems?"

Sonya: "One or two do, the others are a complete loss and they just sort of, you know, they come from, they're agency staff and that's not good at all."

Interviewer: "So in what ways is it not good?"

Sonya: "I'd rather have one person all the time or at least twice a week. They just, I mean, they always supply somebody but they don't understand what's going on. They never have time because they're agency people, they just do the work very quickly and get out, that doesn't help me."

Jenny: "But we get a lot of agency staff and I would have thought that they were told but they're inclined to put your meal in front of you, not always say, so unless you are aware, and sometimes the person who sits next to me will say, "Jenny, your lunch is there."

Rosa: "So when somebody comes in, until they speak I don't always know who it is. We have a lot of agency people and that is distressing."

In many homes, staff recognised the importance of good relationships with residents in being able to deliver personalised or person-centred care. Judy, a registered manager described it like this:

"It's about, you know, people really do know these residents inside out, you know they, because there's this sort of continuity, people are here, we have a key worker system whereby the staff when they're here, although you know, there are occasions when they do have to move off

of their unit but they work on the same unit so they get to know those group of clients so well.”

As some of the findings reported here demonstrated, the aspiration for building good relationships between staff and residents can be challenged by available staff time and resources.

5.5 Staff training

Staff were asked about training around sight loss which might address the basic issues around communication and awareness. Fiona, who was the registered manager in one home, said it was difficult to find training on sight issues:

“We don’t, we don’t. We’ve never been able to find anybody to do it. I mean even, I mean at the moment we’re actually, we’ve got Specsavers that are dealing, and we’ve, yeah, we’ve not been able to source any kind of training on that. We have for hearing but we haven’t for sight.”

Only one home had specific training on sight loss which the manager had organised herself by borrowing simulation spectacles (sim specs). In the other homes managers and other staff agreed more specialist training on sight loss would be welcomed, typified by Anita, a deputy manager:

“Yes, to, the same way like you have dementia and hearing loss, making all the staff more aware of what it is all about and then how do these people feel because we hear a lot about dementia awareness and hearing loss and I have never heard about sight loss in care homes.”

5.6 Support from outside the home

The interviews explored other sources of support that were available for residents. Mainly this was from family members and occasionally from friends. Thirteen of the residents depended heavily on relatives, some of whom would visit daily or several times of week. The support offered was both practical and emotional. Relatives and residents described the kinds of help received which included: correspondence, paperwork, banking, shopping (clothes, shoes, toiletries), sorting and tidying clothes,

taking to appointments, and maintaining the person's sense of who they are, their connections to the outside world and their relationships with others.

Julie explained that although her mother was getting her basic care needs met in the home she felt she needed to advocate on her mother's behalf and described it like this:

"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."

Many residents spoke about staff not having the time to sit and talk, and having visits from family members were often a vital source of social interaction, as Kate describes about her mother:

"I think contact with other people is so important, I think the isolation is the most difficult thing to cope with, that's the hardest thing, having someone spend time with you ... is pretty important really. You know, she lives for the visits from me and the odd friend and grandchildren who come through, yeah, that sort of sustains her really."

Janet described how her mother missed the kind of everyday activities, like going shopping, for which she now needed help. She described this as needing help 'to live more':

"I think what she really... what she would really like is, you know, somebody that could really help her live more, or just help do things, other than me, help do her things, do things like taking her to get a pair of trousers and telling her what colour trousers they are and, you know, it's more that sort of thing that she misses."

This type of extra support was lacking for people who either had no family, or family that lived at a distance, or had no close relationship with family. Jenny, for example, who was widowed, explained what this meant for her:

"You see, a lot of people, if they've got family, have got people that can do this but I just haven't got any family here and we have been told that we're not to take the girls' time up by getting the shopping for us."

Because if you've got your own family, I suppose they should support you but I just haven't got not anybody at hand so."

Jenny considered herself fortunate in that she had a volunteer befriender who could take her to the bank and help with her correspondence. Other residents also benefited from volunteer befrienders which had been arranged by a local sight loss society. They commented that they had had to wait for a long time for one to be found but they were very much appreciated, as Anne describes:

"They say would you like a volunteer and you say yes and you forget all about it and then about eighteen months later! But it's a question of finding someone they think you'll, you know, match with and I've got an extremely good volunteer who comes, well when I ask her to, to sort of do a few odd jobs for me here and then, weather permitting, go out and have coffee or something."

Four residents described having contact with local sight loss support groups and one belonged to a telephone befriending scheme for people with sight loss. Some had had contact before moving into the care home and this had continued but for others this ceased once they were living in the home. This may indicate that services are focused more on people in the community and possibly an assumption that if someone is in a care home they may not need services that help with isolation. Norman explained how his mother had continued to have support after she moved into the home but thought it was generally for people living in their own homes:

"They arranged for a visitor to go and see her in her previous home and they carried on coming to see her when she moved to [the care home], so they've been, they were good but, again, it's got past the point, they're really for people that are still at home as I understand it, that's what the association is geared up for 'cos they have meetings which mum went to once or twice, the local branch."

5.6 Aids and assistive technologies

The interviews explored the use of aids and assistive technologies and the extent to which residents, relatives and staff were aware of the

availability of these. Two main issues emerged around the use of aids. Firstly, that, with a few exceptions, there was a lack of knowledge of what aids might be available or how to find out about them. Secondly, that some people who had used aids in the past were finding it more difficult to use them because of other difficulties.

Typically the aids that people talked about were magnifiers, speaking clocks, talking books and newspapers. Relatives, in particular, often commented that what the person needed was larger buttons or dials on everyday gadgets, such as radios, remote controls and telephones but were not aware that any such aids existed, as these quotes from Robert and Julie show:

Robert: “She has difficulty even getting the telly on now sometimes. If she presses the wrong button on the remote, she’s lost, she can’t get back.”

Julie: “We were trying to get a radio where you could keep, with the three channels you wanted, Radio Four, the World Service and Radio Four Extra, and the buttons, they're hopeless. I mean, so you can just now turn it on, turn it off on Radio Four, so we haven't found a radio. That would be a great boon, a very sensible, sort of clear buttons, big buttons that allowed you to get the stations you wanted.”

Other barriers to accessing aids were financial. Anne, who had been registered sight impaired for 15 years, described how she had found out about magnifiers herself and described the video magnifier as a ‘lifeline’ but at a cost of £500 recognised that this would put it beyond the reach of many people.

Peter, who had sight loss from childhood, was an exception in that he was very knowledgeable and experienced at using aids. He talked about how he used a computer for Skype and emails, and used a screen reader, Sonata radio, and a memo recording device. He belonged to various networks of blind associations and had been involved in teaching other visually impaired people how to access and use aids. He recognised that for many people, confidence was an issue:

“I’d like to see a lot more visually impaired people involved with email, with, well, with computers, they’re not that difficult. It’s confidence, it’s a big problem, a very, very big problem, with so many.”

For some of the residents it was becoming increasingly difficult to use equipment because of other health factors such as memory or hearing loss, as Kate explained about her mother:

“She’s been using that DAISY machine for a very long time, ...but I’ve noticed just recently she’s, she says ‘oh remind me how to do this’, so it’s the memory thing that is so difficult. When I went in to see her last time, she has little buttons, little raised buttons that we stick on things to sort of remind her what are the important buttons, but all, you know, her memory is just beginning to go and that’s the issue, she can’t use the telephone anymore.”

Robert explains about his mother, who is 95 and also has hearing loss:

“We got her audio books from the library, but she wears National Health hearing aids, and she has difficulty tying the technology up between these gadgets.”

Janet, whose mother is 92, reflected that the impacts of ageing make it more difficult to engage with technology:

“I think it’s very difficult when you’re that much older because if you were young and you were with it and, you know, like if you’re a young guy, or young woman in their, you know, 20s or 30s you’d be computer literate wouldn’t you and then you could have all sorts of gadgets, but when you’re her age it’s just a case of strong magnifiers, she’s had a few gadgets that have really been beyond her because she then just presses the wrong button and get... even with a radio she gets in a terrible muddle and she’s always mucking it up, her phone, she’s always mucking it up because she just presses a few buttons and then it all goes wrong and she’s mucked up the menu or whatever, so it’s kind of beyond her, I don’t know if that’s age or sight loss, a bit of both I think.”

6. Living in a care home with sight loss

The interviews generated a large amount of information about day to day living which provides insight into the particular challenges facing people with sight loss living in a care home setting. Drawing on the work by My Home Life (Help the Aged 2007), which considered factors that contribute to quality of life in care homes, the findings in this section are presented in three sections: Environment; Relationships; and Activities.

6.1 Environment

One particular difficulty for people who were significantly visually impaired before moving into the home was learning to get around a new environment. As Kate explains about her mother, who has glaucoma and AMD:

“Because she'd grown blind in her own home she had a mental picture of the place, so actually her sight was much worse I think than a lot of us realised ...in her own home she could find her way round really easily. As soon as we put her in the care home she was completely lost ...and because of her age the short-term memory is rubbish ...the first few months there were just terrible and I don't think the staff quite took that on board, the fact that the short-term memory means that even when she was told repeatedly how things worked, where they were, she just didn't hold it in her memory. You could see her just completely at sea, she hadn't a clue where anything was, you know, even just the layout of the room was a nightmare, and just learning how to, things functioned within her own, what was then very limited space.”

This clearly impacts on the person's capacity to feel 'at home' in their care home and to manage everyday tasks independently. Jenny, who was totally blind, described what it was like when she first moved in:

“If you can imagine what it's like to be in a strange place that I've never seen and I don't know anything about the place except what I now feel around and get my way around, but it was dreadful.”

She described herself as very independent and had learned to negotiate the building by herself but it still presented some difficulty:

“I’m always hoping there’s gonna be somebody in the foyer that will walk me but if there isn’t, I try with my stick but, I say, sometimes I miss the bit. If I don’t quite hit the bit right, you know, I hear the bang because I can’t help it, I go straight into perhaps a wall or a door.”

For residents like Elsie and Anne, getting lost and bumping into things created anxiety and affected their confidence:

Elsie: “I can find the toilet on my own and I don’t take any chances, I have to be sure that I know where I’m going. I’m, I have lost a lot of sense of directions, you know, whether they go that way, and go that...I’ve gone the opposite way, seems like I’ve lost... I seem to have lost sense of direction.”

Anne: “In the shower, that’s right, the shower’s a bit... I’m always biffing myself there, always frightened to biff myself, I feel I should get... And I say, well the shower isn’t very big and that is true, it’s easy to clobber yourself on the taps and bits and bobs.”

These can be mitigated through staff awareness and design. Syd had fallen badly before moving into the home and continued to have mobility difficulties. He was fearful of falling again but spoke about being able to move around the home easily:

“Well it’s all on one level, isn’t it? If I go out that door and turn left, I’m in the, in where they serve the food up, you see, and if I go further in, it’s a lounge, like, a sun lounge, windows all the way round and, you know, and televisions and record players and God knows what else. I’ve got no difficulty at all. If I went outside, I’d like to hold onto somebody or something that’s firm.”

Staff in several homes commented on how they support people to adjust to the physical environment of the home when they move in. Luke, a care worker, explained how he saw his role in this respect:

“Yeah, so most of them you find a way of making things easier for them, like walking with them, trying to make them to go the right direction then making sure their rooms, there are no, you know, obstruction while they are walking so there are lots of things we do as carers to kind of make it easier for them to live their life as much as possible.”

Staff also talked about this from the perspective of managing risk within the home, particularly in relation to falls prevention, and also used telecare sensor maps to help with this, as Luke went on to explain:

“We try as much as possible to do risk assessments in their rooms and then we also, after doing the risk assessment, those we know that are at risk of falls, we’ll get telecare involved and we’ll have the mat for them so when they step on it, it will buzz and we’ll know that one has to go in quickly because we’ll know that apart from the sight they are frail and they are at risk of a fall.”

Both staff and relatives commented about the appropriateness of design within care homes. Some relatives had visited several care homes in the process of finding the right one for their family member. They were often surprised at the lack of suitability of the physical layout for people with sight loss and how many were large Victorian houses that had been converted, and had lots of steps and corridors. Kate described one home she visited with her mother as a “rabbit warren of corridors” and how her mother reacted:

“My mother said 'I'll never cope' and I just, she said 'I'm terrified of walking down the corridors and negotiating all these bits of furniture', and then having to sort of go across quite a large landing to a lift and, she was terrified, and yet it was a very nice home actually, it would have been lovely, but totally unsuitable for somebody with sight impairment.”

One home had been refurbished 2 years before and this had taken account of disability and accessibility. The registered manager, Judy, explained that they had considered design and décor, such as flooring and rails, and had also re-designed the garden to take into account accessibility:

“I became really concerned about people with sight issues and particularly if they’re pushing a Zimmer frame as well, they would end up going down into the garden beds either side. So they had to actually, in the end, we fought and we actually got the beds, the actual pathways redone, they had to be re-lifted, dug down and re-done again.”

6.2 Relationships

Relationships are central to quality of life for everybody, to sustain wellbeing, maintain connections to others and to our sense of ourselves. Within the setting of a care home there are multiple dimensions to relationships to consider. The interviews explored the impact of visual impairment on relationships within the home.

In the interviews with relatives, many expressed concern that their family member could feel isolated because of the impact of their sight loss on being able to communicate with others. This included both within the home and beyond, for example not being able to use the telephone and maintain contact with friends and relatives outside the home. Kate explains how she feels that having a lack of relationships impacts on her mother:

“But it's the isolation I think more than anything which has been so devastating. So I think she spends a lot of time in her room, pretty isolated. ...the sight thing obviously has its particular problems and I suppose it's the isolation and the boredom, the sheer boredom I think.”

Residents echoed the importance of having someone to talk to, as Peter and Anne express here:

Peter: “Company is, is, is one of the main things, as I say, company is, I think, is an essential, to have someone, even if it's just someone to chat.”

Anne: “I like company, I'm not much good in my own company and here, I've been here two and a half years and the first year was really quite dreadful because there was very few people, not many people here and fewer still who've properly got their wits about them. I don't mean to sound awful but I mean there was no-one to talk to, properly talk, you know. So it was miserable, miserable, miserable.”

Both residents and relatives talked about the difficulties of sustaining relationships within the home because of not being able to recognise people. Kate describes how her mother, who has AMD, can no longer recognise people's faces:

“I think is hard because you don't know if you've passed someone in the corridor who you were talking to yesterday, you wouldn't know that, it's just another body going by. Because of course that's one of the things you lose with macular, is the detail of someone's face, so although she can see the outline of the person she can't recognise faces, so it's sort of doubly isolating in a way, and so again, being in the home, not being able to recognise people, it takes a long time before you start to recognise voices.”

The seemingly small daily interactions of greeting are much more difficult. This can lead to a misunderstanding between residents who may think the visually impaired person is being unfriendly, as Bert, who has no vision, explains:

“Another thing that's sort of aggrieves me, they say people smile at me and I don't smile back, I don't see them. And they must think 'Oh he's a miserable old whatever'.”

The extent to which relationships between residents can be facilitated by staff, and through for example, activities which are discussed in the next section of the report, is crucial. This links to the earlier points made about staff awareness and understanding of the impact of visual impairment, as Kate explains the importance of introducing residents in communal areas and during activities:

“For people to say, you know, 'this is so-and-so, this is', it doesn't matter if they've seen each other a million times but, you know, to be aware that they don't always recognise each other. Yes, you know, if they get together just go round and say, just let's go round the room and just say who you are, so that everybody in the room is aware of who's there, 'cos otherwise you wouldn't know how many are in the room or who they are.”

One care home operated a 'buddy system' for new residents to try and foster friendships between residents. Joanne, the manager, explained how they tried to match people with similar interests:

“When a new resident comes in we do try and buddy them up with somebody of a similar, you know if they're chatty and that kind of thing we do try and do that.”

There were many examples where such friendships flourished between residents. Emily describes the friends she has made in her home:

“Yes, I get on with the others, there's [name], she sits next to us at lunchtime and we get on quite well. And there's [name] she's somebody else, she comes and sits in here and spend, you know, in the evening and have a talk so she likes to come to find somebody to talk to. Yes I find the other people are quite pleasant too, you know, quite friendly.”

These relationships were a form of support between residents who helped each other. Robert describes how his mother, who has AMD, helps other residents who have less vision than she has:

“She's a caring woman, and if she can she looks after other residents there. She can lead other people down to dinner, there's a couple of ladies on her wing, Mum will guide them down to the dining room.”

Jenny and Angela also described similar examples of those who were more able with certain tasks helping those who were less able:

Jenny: “What happens is those of us that can read or those of them that can read a little bit, we say, ‘Oh, what's on the activity list?’”

Angela described how she is able to help a fellow resident at meal times:

“Oh, he's very independent, and I sit next to him and I take care of him if his daughter's not there some lunchtimes, because I can do it without drawing attention, and he doesn't mind that because if I turn his plate round that sits off the mat or something, I can put it back while he's got the spoon in his mouth.”

6.3 Activities

Like relationships, the importance of having meaningful activity has been widely recognised as important for well-being and quality of life.

Activities are also an important means of fostering relationships between people. All of the homes that took part in the study had programmes of activities for residents. In some homes these were organised by dedicated staff and in others individual staff took on responsibility for organising specific activities. The interviews explored the role of

activities within the care homes and the extent to which residents with sight loss took part in activities. Residents' experiences varied as some took part in activities and spoke about them in positive terms, others found taking part more difficult.

Some relatives expressed concern that their family member didn't always know what activities were happening. This was particularly important if the programme of activities was only communicated on paper and compounded if the resident had memory problems. In some homes staff were more active in encouraging residents to join in by verbally reminding them on a daily basis but relatives were often key in this as well. Sandra explained that she carried out this role for her family member, but also commented that although there were always a lot of activities on offer, many were not appropriate for people with sight loss:

"Yes, they have a plan for the whole week and when I go I read it to him and he makes sure he knows what's going on and there's always something every morning, every afternoon, three times a day there's always something on, so there's quite... But obviously a lot of it is no good to him because if he can't see it, you know, a lot of things, Bingo and things like that, he can't do."

Other residents also described not being able to do the activities on offer because of their sight. Many reported that this led to feelings of frustration:

Jenny: "There is an awful lot of things that I cannot do. I do try, I go down to the craft and I have a go but that I find very frustrating because I was so good at anything with my hands and now I can only feel and I don't know if I've done it right, you know, but I do have a go."

Connie: "You feel, when you've had an active life you feel terribly frustrated that you can't see to do things, you can't use your brain."

For others, not being able to do activities increased their sense of disability and led to emotional distress:

Interviewer: "So you don't really join in with activities?"

Sonya: "One or two but not many because I can't do it properly and it upsets me."

Norman: "I think that's the problem she has, because she's, her brain is so with it, she thinks of all the things she used to do and 'oh, I wish I could do that' and consequently she does get depressed and tearful."

There was little evidence that sight loss was specifically taken into account in the organisation of activities. Some homes held quizzes and did crosswords in which clues and questions were read aloud and everyone could join in with the answers. But there was little awareness of games with raised letters or tactile numbers, such as scrabble or dominoes, which could be used for people with visual impairment.

Staff were aware, however, of the importance of trying to find things to keep residents engaged according to their individual preferences. There was acknowledgement that group activities would not appeal to everyone and finding activities that would suit each individual was challenging. In homes that had a person-centred approach staff tried to discover ways to keep people's interests going which took account of the person's changed abilities and emotional state. Judy, a registered manager, explained this could be very challenging for a resident with sight loss, as in the case of Elsie who was adjusting to life after having a stroke:

Judy: "It was a big loss for her because she was an avid reader, she said she'd never had a book out of her hand, so it's a completely different way of life for her, yeah, it's getting over that and looking at positive things that, you know, sort of individual things that can take place with the person."

Interviewer: "So how would you sort of support people with those kind of things?"

Judy: "Well I think when she first came in, you know, the staff did kind of look at what other things she could do but unfortunately she could only... she was going back to the reading and she used to do a lot of knitting which she found she couldn't do either. So then it was looking at what else did she like and she really likes music so, you know, and from then she's actually got involved in, and particularly the music and we actually have a voluntary group here once a month and she really enjoys that, and she actually gets quite a lot from that. We've been using like the laptop and things with, you know, so they can listen to what they, like

very individual things and we've done people's individual playlists on MP3 players for them and you know, we've used things like that."

7. Conclusions and recommendations

This final chapter of the report draws together a summary of the main issues and reflects on what this study contributes to understanding the experiences of older people living with sight loss in care homes.

7.1 Researching sight loss in care homes

This is a qualitative study which aimed to generate rich, in depth accounts of older people's experiences of living with sight loss in care homes. However, it is important to recognise some of the limitations of the study. The majority of residents who took part in the study were diagnosed with sight loss prior to living in a care home. Their experiences are informative on how they experienced sight loss in this setting, the extent to which their eye conditions were monitored and if any changes to their vision were picked up and followed through. A small number of residents had developed cataracts whilst living in the care home and these had been picked up and followed through. What the researchers are not able to comment on is the extent to which there were further undiagnosed sight problems within the participating homes, that is, people who developed other eye conditions and sight loss problems since moving into the home which had not been picked up by staff. During the recruitment phase of the research many of the homes initially contacted reported that they had no residents with sight loss. Given what is known about the estimates of sight loss in people aged over 70 and the age demographic within care homes this seems unlikely. The researchers adjusted the approach to ensure that the managers understood the research was not about people who had no sight but people who had with difficulties with their sight.

Reflecting on the process of undertaking this research it is immediately clear that there are two areas that require more attention within care home settings. Firstly, greater awareness and understanding of sight loss so that residents who develop sight problems after moving into the home receive diagnosis and treatment where appropriate. Secondly, greater awareness and understanding of the impacts of sight loss so that residents with sight loss receive better support including facilitation with social interaction and communication in daily living activities. It is, however, important to acknowledge the current context facing the care

home sector. As one member of the PAG described it, “social care is shrinking budgets and escalating costs”, and the pressure on the sector to provide good care should be seen in this context.

7.2 Summary of main findings:

- Complexity of needs within care homes. In addition to visual impairment, residents were experiencing other health conditions, including hearing loss, memory and confusion, and mobility difficulties. They clearly had emotional needs, and some experienced poor mental health and depression.
- Challenges of living within a care home. Many spoke about the transition of moving into the care home and the adjustments of living in a communal environment with less personal space. The extent to which residents were supported with orientation and the physical environment varied.
- A number of things were identified that positively contributed to a resident’s quality of life, including:
 - I. Greater awareness about what it means to live with sight loss, particularly from staff, but also other residents.
 - II. Support from others: family, befrienders, and staff. Relationships with others are crucial in counteracting feelings of isolation. Many residents talked about wanting more time to just talk with staff and highlighted the importance of having company.
 - III. More knowledge of aids and adaptations, and technology that could help residents maintain their interests or develop new ones.
 - IV. Better connections with local external organisations such as sight loss societies and rehabilitation services.
- Person-centred care and properly executed care plans should be able to pick up on issues, such as changes to existing eye conditions or the development of sight problems. But this would depend on staff having awareness and training about picking up the signs of sight loss. Residents, relatives and staff all raised issues in relation to adequate training and awareness of the impact of having sight loss and the need for more training was identified in most homes in the study.

- The wider context of the care sector and the issues of staff recruitment and retention, increased costs, and less public funding for social care inevitably impacts on staff time available to do anything beyond basic care tasks.

7.3 Care home staff awareness of sight loss

Staff in this study recognised the need for more awareness and training on visual impairment. Only one home in the sample had offered 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. Some spoke in general terms that it could be difficult for staff to attend training if that meant taking them off the rota. These managers expressed a preference for in-house training.

As noted above, in the recruitment process many care home managers approached responded that they did not have any residents with sight loss. 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 deterioration in 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.

7.4 Multiple health conditions and complex needs

As already noted, all of the residents in the study were living with other health conditions and problems. This raises the question about the extent to which it is possible or even beneficial to separate issues to do with sight loss from other disabilities and multiple health conditions that people living in care homes are likely to be experiencing. However, it was clear that residents' sight loss calls attention to a lot of the other problems, particularly around social interaction and isolation. Therefore, 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 home settings.

The findings highlighted very specific things that could contribute to improved quality of life for older people with sight loss living in care homes. Some of these are very basic, such as introducing yourself when entering the room of the person with sight loss, telling people that their food is being placed in front of them and not using written sheets to let people know about activities. Although seemingly small details, these are likely to make a big difference at an individual level.

7.4 Meaningful activities

In relation to 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. As the participants expressed, this adds to their sense of frustration, anxiety and distress, particularly in what might be quite traumatic circumstances, such as adjusting to sudden sight loss. Clearly a sensitive balance is needed beyond providing generic activities and those that are personalised and help people find meaning in their lives whatever their circumstances.

7.5 Aids and assistive technology

There was also an unmet need in relation to aids and technology with a lack of knowledge within homes of what was available 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. Given there is a lack of knowledge about what devices exist, how they work and issues around confidence to use devices, ways of bringing devices into homes and giving residents an opportunity to try them out would be beneficial. This needs to take into account that people may be very unfamiliar with technology and lack confidence in using devices.

7.6 Befriending and support

The experiences of the people in this study also need to be understood within the broader context of understanding old age and the extent to which all people in care homes may be amongst the most marginalised within society. There appeared to be assumptions that once people are living in a care home they no longer needed the social support and services (however limited these may be in the current climate) 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.

7.7 Understanding experiences of sight loss through co-production

This study aimed to bring the voices of older people with sight loss to the forefront, and to involve VI people in the research process. This section reflects on the value of this approach, the challenges working in this way presents and identifies learning that can help develop future co-production and involvement of VI people in research.

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. It allows an 'imaginative engagement' with these issues and can help people to think differently and help create an awareness that could contribute to developing better practice.

Members of the EEP contributed their personal experiences and knowledge through working with the researchers on the design of the research and in the analysis and interpretation of the data. The panel were able to question the assumptions of the researchers and act as a 'critical friend' for the project. 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.

They reflected on their involvement in the project. They found the resident's stories very interesting and relevant to their own lives. One member would have liked to have done more 'hands-on' data analysis and reading of the transcripts. Another reflected that they were unsure if their contribution was adding any value to the research. Changes in personal circumstances and challenges in members' own health meant meeting together as a group proved to be difficult and this impacted on a sense of connection to the project.

The researchers adopted a flexible approach to accommodate changing circumstances to try and ensure members could participate. This included meeting with members individually, keeping in touch by phone, and providing materials in alternative formats.

The 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 care practice in care homes. The PAG also discussed the value of this type of research in the sight loss sector and the possibilities for developing research training and skills for VI people.

Learning points

- Provide clear information about the project, its aims and expectations so that those you are seeking to involve understand what their role will be and how their experience can contribute.

- Make clear what opportunities there will be for those you involve, for example, developing new skills, contributing knowledge and expertise, and social interaction.
- People can make informed and meaningful contributions when materials are inclusive and accessible.
- Innovative co-production is needed to embed genuinely inclusive processes and outcomes for people with sensory impairment and to achieve the aspirations of joined-up and person-centred care within health and social care services.
- People want to make a positive difference when they get involved. It is important to recognise this expectation and be honest about the extent that this will happen through a research project.
- Provide appropriate support and ensure people feel their contribution is valued. People may feel unsure or nervous about taking part so it is important to make it a worthwhile and rewarding experience rather than one that feels tokenistic and disempowering.
- Communication and maintaining connections to the project are vital. It is important to find ways to keep everyone informed and part of the project, particularly if there are long gaps between meetings.
- Maintaining interest and momentum can be difficult, particularly if people are facing health or personal challenges. A flexible and supportive approach is needed to accommodate any unexpected events and interruptions that may occur and have an impact on the project.
- It is important to listen to those you involve and value different perspectives; these may challenge academic and practitioner perspectives.

7.8 Recommendations

Sight awareness training

The research identified a clear need for training in sight loss awareness for staff in care homes. There is scope for TPT to further develop the Looking Out for Sight visual awareness training and toolkit, developed by Wiltshire Sight, and the role of local societies in delivering training in care homes. The researchers experienced difficulties in gaining access

to residents with sight loss in care homes and local societies may need some support or training in understanding the care home context, such as how to approach care home managers and build relationships.

Local support

Local societies are also well placed to offer advice and support to care home residents. TPT could consider developing work which fosters greater links between sight loss societies and care homes. This could be in relation to aids and assistive technologies by demonstrating devices in care homes and providing a 'try out before buying' scheme. There is also scope for befriending and developing a role of 'champion' for people with sight loss in care homes. Local societies could also share their expertise in supporting residents in care homes through the certification of visual impairment (CVI) registration process and building greater awareness of the benefits of registration, not just for individuals but also at the local authority level, to provide evidence of need.

Improving practice in care homes

The findings of this research provide further evidence on the needs of care home residents with sight loss which could be used at a strategic level to improve practice. By working with statutory bodies, such as the CQC, NICE and Skills for Care, organisations in the sight loss sector can seek to influence the regulatory framework for standards and training in relation to sight loss.

In addition to providing sight loss training and developing the work of local societies in care homes, TPT is well positioned to help care homes understand their responsibilities for meeting the needs of residents with sight loss. For example, by developing ways of using the new NHS Accessible Information directive for information provided to patients with sensory impairment, which came into operation in July 2016. Care homes that are contracted by NHS are included in this directive.

Discussions within the PAG, whose members included care providers, indicated that the pressures facing the social care sector (lack of funding, increasing costs from the introduction of the living wage, recruitment and retention issues) need to be understood in relation to improving practice. Organisations in the sight loss sector could consider how to make change happen to improve the care of people with sight

loss in this context. Suggestions from the PAG included consideration of partnership working and ways to deploy and share existing resources and knowledge.

Co-production

Co-production is recognised as an important way of involving service users in health and social care, and ensuring they have a voice in the design and delivery of services. Co-produced research has an important role to play in generating knowledge and understanding about the experiences of VI people. The co-production approach adopted in this study represents a step in the right direction. It has highlighted good practice for the sight loss sector in how to do this. For example, it shows how time and resources are required for co-production to work effectively and in ethically sound ways which do not result in tokenism.

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