# 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.

## Acknowledgements

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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((or)8( )] TJET

## 1.2 Overview of the research

- 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

### 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 residentsôaccess 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 óLooking Out for Sightôvisual awareness training by Wiltshire Sight, commissioned by TPT, could help to address the lack of sight loss awareness in care homes.

# 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 peopleôs 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% ï 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 Governmen

## 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 w 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 peopleôs 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 óExperts by Experienceô 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 0 0 -3(ac 63)] TJE

# 4. The personal contexts of older people in this study

The main aim of this study was to gather older peopleôs perspectives majority had a diagnosed eye condition prior to moving into the home and for many their visual impairment was an important contributory

## ( O V L H ¶ V 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:

ñI canôt even remember the stroke, you know, all I know that I had the stroke and that I couldnôt see afterwards, you know. So I, it was like a big shock, it was like a blow to me because I, itôs, it was, it was, well, one of the worst things Iôve ever really had to take, and Iôve had some nasty things happen, but this is the worsté they said to me that Iôd 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.ò

She moved into the home from hospital. She has children who she could have lived with but she was really adamant that she didnôt want to do this as she felt it would be a burden on them.

ñBut I will come to, come to terms with it. Itôs very, very hard whené Iôve lived quite an independent life, I lost my husband seven years ago, and I was living alone and that, and, but as I say, Iôve got a family but itôs not, I feel Iôd be too much of a burden if I went to live with them because theyôve got their own families, and their own families must come first mustnôt they? And I just donôt want to beé Iôd be too much, I think Iôd be too much trouble for them. Itôs like a 24 hour job, isnôt it, looking after someone?ò

Els

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

ñAnd I do miss, I do miss, miss me own life and doing the things you do, just even the, your cooking and everything, I wouldnôt be able to cook now I donôt think, because Iôd be too frightened. I donôt go out, Iôve not gone out on my own at all since, because I was, Iôd be frightened of having an accident, you know, and that would be worse wouldnôt it? So I donôt take any chances, I donôt go, I donôt go out.ò

## 4.4 Adjusting to changes

Hannah, Edna and Elsieôs 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 ñIôve had trouble with my feet for quite a long while and theyôve just got worse and worse and ulcers on my feet and I became housebound. Itôs a bit more than difficult! Itôs impossible. Iôve 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 whatôs the use of a frame to me at home? Without someone to guide me, I havenôt got a clue where Iôm going, I canôt use a frame and a stick as well.ò

## 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 Parkinsonôs disease for over 30 years and he described how his sight problems were ñpart and parcel of the overall problem.ò Like Anne, he focused more on what he was able to do rather than not do.

ñYeah, I regard it as a sequence of the Parkinson condition and my sight ™v,’ ~á €& is not good but itôs 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 Iôm lucky to be able to main(t)-3(T20504<004404700036<002C>09-,h9-01 1 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.ò

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 keys 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 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.”

ñI think mobilityôs 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.ò

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: ñIn 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.ò

Interviewer: ñSo how do you think that support helped her?ò

Judy: ñ

## 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 residentsôcare concerned about, we can always phone up or meet with them or ask, yes.ò

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 ñalways in such a rushò, whereas Julie thought it was a sensitivity issue and that more general awareness was needed, and she felt that:

ñI'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.ò

She gave the example of staff not introducing themselves when they entered her motherôs room:

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

This was an issue that was raised in other homes. Bertôs son had made his own sign for the door of his fatherôs room which read in large letters ñRemember Bert cannot see, please say who you are!ò

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:

ñTime 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

the carers, they are all nice, I

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

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:

ñWe donõt, we donõt. Weõve never been able to find anybody to do it. I mean even, I mean at the moment weõre actually, weõve got Specsavers that are dealing, and weõve, yeah, weõve not been able to source any kind of training on that. We have for hearing but we havenõt for sight.ò

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:

ñYes, 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.ò

## 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

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: ñShe has difficulty even getting the telly on now sometimes. If she p ñIôd like to see a lot more visually impaired people involved with email, with, well, with computers, theyôre not that difficult. Itôs confidence, itôs a big problem, a very, very big problem, with so many.ò

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:

ñShe's been using that DAISY machine for a very long time, é 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.ò

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

# 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 ñIôm always hoping thereôs gonna be somebody in the foyer that will walk me but if there isnôt, I try with my stick but, I say, sometimes I miss the bit. If I donôt quite hit the bit right, you know, I hear the bang because I canôt help it, I go straight into perhaps a wall or a door.ò

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

Elsie: ñI can find the toilet on my own and I donôt take any chances, I have to be sure that I know where Iôm going. Iôm, I have lost a lot of sense of directions, you know, whether they go that way, and go thaté Iôve gone the opposite way, seems like Iôve losté I seem to have lost sense of direction.ò

Anne: ñIn the shower, thatôs right, the showerôs a bit... Iôm always biffing myself there, always frightened to biff myself, I feel I should get... And I say, well the shower isnôt very big and that is true, itôs easy to clobber yourself on the taps and bits and bobs.ò

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:

ñWell itôs all on one level, isnôt it? If I go out that door and turn left, Iôm in the, in where they serve the food up, you see, and if I go further in, itôs a lounge, like, a sun lounge, windows all the way round and, you know, and televisions and record players and God knows what else. Iôve got no difficulty at all. If I went outside, Iôd like to hold onto somebody or something thatôs firm.ò

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:

ñYeah, 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

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:

ñWe 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, weôll get telecare involved and weôll have the mat for them so when they step on it, it will buzz and weôll know that one has to go in quickly because weôll know that apart from the sight they are frail and they are at risk of a fall.ò

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 ñrabbit warren of corridorsò and how her mother reacted:

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ñI 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.ò

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:

ñAnother thing thatôs sort of aggrieves me, they say people smile at me and I donôt smile back, I donôt see them. And they must think óOh heôs a miserable old whateverôò

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:

ñFor 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.ò

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

ñWhen a new resident comes in we do try and buddy them up with somebody of a similar, you know if theyôre chatty and that kind of thing we do try and do that.ò

activities within the care homes and the extent to which residents with sight loss took part in activities. Residentsô 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 didnôt 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:

ñYes, they have a plan for the whole week and when I go I read it to him and he makes sure he knows whatôs going on and thereôs always something every morning, every afternoon, three times a day thereôs always something on, so thereôs quite... But obviously a lot of it is no good to him because if he canôt see it, you know, a lot of things, Bingo and things like that, he canôt do.ò

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: ñThere 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 donôt know if Iôve done it right, you know, but I do have a go.ò

Connie: ñYou feel, when youôve had an active life you feel terribly frustrated that you canôt see to do things, you canôt use your brain.ò

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

Interviewer: ñSo you donôt really join in with activities?ò

Sonya: ñOne or two but not many because I canôt do it properly and it upsets me.ò

Norman: ñI 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.ò

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 peopleôs interests going which took account of the personôs 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: ñIt was a big loss for her because she was an avid reader, she said sheôd never had a book out of her hand, so itôs a completely different way of life for her, yeah, itôx m 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

x 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,

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 ódoingô

## 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 óimaginative engagementô 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 ócritical friendô 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

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 -rac(k)-3(n)T1 0 y(ed)9(p)9(oor)-3(hav)14(y(ed)9( )-6-igh[ 0 1 291.65 lo024 54t)-2(ex

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