



Best practice for providing social care and support to people living with concurrent sight loss and dementia: professional perspectives

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Abstract

Purpose: Approximately 100,000 people in the UK aged 75 and over have concurrent dementia and sight loss, but current understanding of their experiences, needs and preferences is limited. This paper reports on a research project that explored the provision of social care and support for older people with both conditions.

Design and Methodology: The project was a collaboration between the universities of York, Worcester, Bournemouth and Cambridge, supported by the Thomas Pocklington Trust and the Housing and Dementia Research Consortium. Data for this paper were drawn from focus groups held in 2013 involving 47 professionals across the dementia, sight loss and housing sectors.

Findings: Thematic analysis identified five main barriers to providing high quality, cost-effective social care and support: time constraints; financial limitations; insufficient professional knowledge; a lack of joint working; and inconsistency of services. The requirements of dementia and sight loss often conflict, which can limit the usefulness of equipment, aids and adaptations. Support and information needs to address individual needs and preferences.

Research Limitations/Implications: Unless professionals consider dementia and sight loss together, they are unlikely to think about the impact of both conditions and the potential of their own services to provide effective support for individuals and their informal carers. Failing to consider both conditions together can also limit the availability and accessibility of social care and support services. This paper is based on input from a small sample of self-selecting professionals across 3 geographical regions of England. More research is needed in this area.

Practical Implications: There are growing numbers of people living with concurrent dementia and sight loss, many of whom wish to remain living in their own homes. There is limited awareness of the experiences and needs of this group and limited provision of appropriate services aids/adaptations. A range of measures should be implemented in order to support independence and wellbeing for people living with both conditions and their family carers. These include increased awareness, improved assessment, more training and greater joint working.

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3 *Social Implications:* People living with dementia or sight loss are at high risk of social isolation,
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5 increasingly so for those with both conditions. Services that take an inclusive approach to both
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7 conditions can provide crucial opportunities for social interaction. Extra care housing has the
8
9 potential to provide a supportive, community-based environment that can help residents to maintain
10
11 social contact.

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13 *Originality:* This paper adds much-needed evidence to the limited existing literature, and reflects the
14
15 views of diverse professionals across housing, health and social care. The conclusions drawn can help
16
17 to inform the development of appropriate services.
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20 21 22 **Introduction**

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24 It is estimated that 850,000 people are currently living with dementia in the UK, a figure that is
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26 predicted to rise to over one million people by 2025 (Alzheimer's Society, 2014). Approximately two
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28 million people are living with serious sight loss; one in ten people aged 75 and over have a significant
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30 visual impairment, rising to one in three aged 90 and over (Evans *et al.*, 2004). Trigg and Jones (2005)
31
32 estimate that around 100,000 people in the UK aged 75 and over have concurrent dementia and
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34 sight loss, although the actual figure is likely to be higher due to under-diagnosis of both conditions.
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39 A long-standing aspiration of the Government is to support a greater proportion of older people to
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41 live independently in their own homes (Communities and Local Government, 2008; Cabinet Office,
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43 2010), and policy has emphasised the need to move from institutional models of care towards
44
45 enabling people to receive care and support in a diversity of settings. This overarching aim of
46
47 supporting independent living coincides with parallel policy objectives to support people with
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49 dementia – and other chronic conditions – in their own homes, and also to facilitate greater choice
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51 for people at the end of their lives through the delivery of care and support in domestic settings
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53 (Department of Health, 2008; Department of Health, 2009). The specific challenges of providing care
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55 and support in different settings, as well as the role of services specifically addressing the housing
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3 and support needs of complex groups such as people with concurrent dementia and sight loss,
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5 therefore need to be recognised and addressed.
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10 However, current understanding of how social care and support can best meet the needs of the
11
12 growing number of people experiencing concurrent dementia and sight loss remains limited and the
13
14 evidence base in this area is small. This is largely because the two conditions are rarely considered
15
16 together, with both research and practice often focusing on one condition or the other. Where both
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18 conditions are considered together, the tendency is to address them in the context of care being
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20 provided in a care home setting, or ways to adapt the physical environment (Haywood, 2007;
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22 Goodman and Watson, 2010). Consequently, there is a gap in knowledge regarding the impact of the
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24 concurrent conditions, especially when people live in other housing settings.
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29 In order to address this, the 'Developing social care practice in different housing settings' research
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31 project was commissioned and funded by the National Institute of Health Research (NIHR) School for
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33 Social Care Research (SSCR). The project ran from 2012 to 2014 with the overall aim of exploring how
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35 best to provide care and support for adults living with sight loss and dementia. The key areas of
36
37 interest for the project were the social care needs of people with dementia and sight loss and their
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39 carers, current models of social care and support, and the barriers and facilitators to providing high
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41 quality, cost-effective social care and support.
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44 45 46 **Methods**

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48 The project drew on four main sources of data: a scoping literature review to assess current
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50 knowledge of the area; interviews with people with dementia and sight loss and their carers; focus
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52 groups with professionals who work with people with dementia and sight loss; and the costs of
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54 providing care and support in different housing settings. While the overall project findings
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56 synthesise all of the data (NIHR SSCR, 2015), this article concentrates on the focus groups with
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3 professionals in order to explore best practice in support this client group. The views expressed in
4
5 this paper are those of the authors and not necessarily those of the NIHR SSCR or the Department of
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7 Health.
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11 The three project teams were each responsible for recruiting professionals and practitioners in their
12
13 own geographical area (North of England, the Midlands and South of England) and organising and
14
15 conducting focus groups. The initial goal was for a total of 30 professionals to be recruited to three
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17 focus groups in each area, but for practical reasons several professionals took part in one-to-one
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19 interviews instead.
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22 Overall, nine focus groups and 12 individual interviews were conducted between July and November
23
24 2013, involving a total of 47 professionals. While the original target of engaging 90 professionals
25
26 proved unachievable, those who participated provided a good representation of job roles across the
27
28 three key specialisms of health, housing and social care, including Dementia Advisors, Rehabilitation
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30 Officers for people with visual impairment, Housing Scheme Managers and Social Workers. Six
31
32 participants also mentioned family experience of dementia and/or sight problems which enabled
33
34 them to offer both personal and professional perspectives. The smaller groups and individual
35
36 interviews allowed areas to be explored in greater detail and ensured that all participants were able
37
38 to voice their opinions, rather than potentially being overshadowed as part of a larger group. The
39
40 smaller sample size was therefore not felt to have a significant impact on the findings from this work.
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46 Based on the findings from the literature review, a common semi-structured schedule was adopted
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48 across all three research sites to cover the following main areas: the experiences of people with
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50 dementia and sight loss who use services; the current care and support that services provide for this
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52 group; relevant organisational policies and procedures; experiences of the internal and external built
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54 environment; experiences of the social environment and social interaction; facilitators and barriers to
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56 providing and accessing services.
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5 All participants were given full information about the study and provided written consent. The focus
6
7 groups and individual interviews were audio recorded and transcribed. Analysis of all transcripts was
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9 conducted by the ADS project team using the NVivo 10 software package. A coding framework was
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11 developed based on the main areas of interest within the project: Social care needs of people with
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13 dementia and sight loss; Social care needs of carers; Current models of social care and support;
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15 Barriers to providing high quality, cost-effective social care and support; Facilitators for providing
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17 high quality, cost-effective social care and support. Within these five key areas the analysis was
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19 inductive, with sub-themes emerging from the content of the transcripts. Where possible, the
20
21 analysis focused on findings relating to people with concurrent dementia and sight loss, although it
22
23 was recognised that comments relating to the individual conditions were also relevant to this study.
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25 Approval for the research was given by the Social Care Research Ethics Committee.
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31 Findings

32 *The social care needs of people with dementia and sight loss*

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34 There was widespread recognition by professionals that receiving a diagnosis of dementia and/or
35
36 sight loss can be difficult and traumatic for the individuals concerned, making the post-diagnostic
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38 phase a key period where support is required. However, many acknowledged that this element of
39
40 service provision is often inadequate or non-existent:
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44 “There isn’t any follow-up support currently for people who have dementia and sight loss in
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46 [this area]” (Sight loss professional).
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50 Providing appropriate care and support can also be complicated by the fact that many people have
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52 other conditions that also need to be addressed, and these may be equally important for the
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54 individual as dementia or sight loss. Co-morbidities mentioned by the professionals included hearing
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3 loss, reduced mobility, learning difficulties, diabetes, depression and heart conditions, all of which
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5 need to be taken into account when professionals are addressing the needs on an individual.
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9 One key issue raised by many professionals was the importance of the order in which people develop
10 dementia and sight loss. People who develop dementia first or get both conditions close together
11
12 may have different needs from people who have been able to adapt to having a visual impairment
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14 first and establish appropriate coping strategies:
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18 “Say you've been visually impaired for a long, long time, you will yourself have all sorts of
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20 things that you've put in place when you were able to do that” (Housing professional)
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24 Professionals observed that people can encounter a number of difficulties as a result of either
25
26 condition, which can result in loss of confidence and independence. Isolation and loneliness can also
27
28 become an issue for people without appropriate support networks or for those who feel more
29
30 comfortable and in control in their home environment. This was seen as being especially relevant for
31
32 people who live alone. As a result, many professionals felt that their role should involve trying to
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34 maintain people’s functionality where possible, as well as encouraging social interaction in a way that
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36 addresses the interests and preferences of the individual.
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39 40 41 ***The social care needs of family carers*** 42

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44 Many professionals who participated in this study appreciated that a diagnosis of dementia often has
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46 substantial implications, not just for the individual but also for their informal carer and wider family.
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48 It can be difficult for some carers to ask for the help and support that they need, even when caring
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50 becomes stressful and detrimental to their own health and wellbeing. Sometimes this can be due to
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52 the expectations that carers have of themselves, or what they feel other people expect from them:
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56 “Sons and daughters are expected to do all sorts and actually they carry on doing it but at
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58 risk to themselves.” (Housing professional)
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5 The professionals who took part in this research felt that not enough support is available for carers,
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7 with post-diagnostic support again being a key area where appropriate information is required at the
8
9 right time:

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11 “If you don’t judge it properly, so you’re giving someone a factsheet on challenging
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13 behaviours or aggressive behaviour along with incontinence, you’re not helping anyone.”

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15 (Dementia professional)

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20 It was also acknowledged that even when dedicated carer support is available, it may not meet
21
22 everyone’s needs as different people want different things:

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25 “She didn’t want to go and share, you know, horror stories of, you know, what they’ve had to
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27 deal with in the middle of the night and, you know, she wanted to go and do something nice
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29 and forget about all that.” (Sight loss professional)

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33 Support provided for carers should be offered in a way that can be adapted to respect individual
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35 needs and preferences. An important first step is for professionals to recognise the caring role and to
36
37 value the experience that the carers have.

38 39 40 41 42 ***Current models of social care and support***

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44 While current models of care and support tend to focus on dementia and sight loss separately, most
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46 professionals felt that their own services would not specifically exclude people with concurrent
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48 conditions. However, there are often limitations in terms of who can be supported and how, meaning
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50 that individual needs are not always addressed. Although existing services are varied, there was a
51
52 strong consensus about the need to provide practical support for people with dementia and/or sight
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54 loss:
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3 “Our main aim is to promote their independence and not do it for them, but support them to
4
5 do it themselves” (Sight loss professional)
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10 However, professionals reported being constrained by time, which can impact on the quality of care
11
12 provided and their ability to support individuals. Continuity of care was seen as being important
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14 because it can help professionals and clients to develop a rapport, but in reality this is not always
15
16 possible, especially when the client has relatively high care needs:
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18 “If [the client has] got complex care needs, and they need maybe four visits a day, they might
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20 even need two people at a time to go in, the chances of getting those same two people for
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22 the four visits or even for that visit throughout the seven days of the week, it just isn’t going
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24 to happen.” (Social care professional)
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29 Professionals also commented on the importance of social activities for people with dementia and
30
31 sight loss, but opportunities for people with both conditions were perceived to be more limited.
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33 Overall, it was felt to be easier for services aimed at people with dementia to cope with the addition
34
35 of sight loss, than for sight loss services to be able to support people who also have dementia.
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37 Offering service users choice and variety and making them aware of what is available were felt to be
38
39 important factors in terms of ensuring that social care and support was appropriate and useful for
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41 individuals.
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46 There was some feeling that extra care housing or housing with care schemes, where people live in
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48 their own homes within a larger scheme and have access to a range of communal facilities, can be
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50 good for people with dementia and sight loss because they provide personal care and domestic
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52 support options on-site. Similarly, social activities can be easier to access in such schemes as they are
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54 generally held on-site:
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3 “They’ve all got communal areas and garden access as well that they can go together, and
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5 there’s also activities that do take place within the communal areas.” (Housing professional)
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10 Many professionals referred to a wide range of equipment and aids that are available to people with
11
12 dementia and/or sight loss. While the aim of these aids was to support people to remain living in
13
14 their own homes and maximise independence, some professionals suggested that the focus was on
15
16 keeping people safe rather than improving quality of life. It can also be difficult to access some
17
18 equipment because there are “all sorts of financial assessments and hoops to jump through” (Sight
19
20 loss professional). Introducing new equipment can be a challenge, particularly for people with
21
22 dementia, unless it is done sufficiently early in the disease to become established as part of normal
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24 routines.
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29 Although it was recognised that some equipment could be suitable for people with both dementia
30
31 and sight loss, in many cases there appeared to be differences between the two conditions and their
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33 symptoms that can limit the usefulness of some equipment. For example, many aids to support
34
35 people living with dementia have a visual component such as an image rather than a word, which
36
37 could make them challenging to use for someone with a visual impairment who may find clearly
38
39 defined letters easier to decipher. Conversely, by modifying some equipment to make it more
40
41 appropriate for people with a visual impairment, it can become unfamiliar to someone with
42
43 dementia and therefore difficult to use. One example of this is a talking clock, which can look “like a
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45 cube, or it looks like a box with a circle on the top” (Sight loss professional) rather than actually being
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47 recognisable as a clock. Professionals also discussed adaptations to the physical environment, and felt
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49 that improved lighting and using contrasting colours were appropriate for people with both
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51 conditions.
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57 ***Barriers to providing high quality, cost-effective social care and support***
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3 Professionals felt that low levels of diagnosis of both dementia and sight loss are a significant barrier
4 to people accessing appropriate services in a timely manner. Diagnosis can also be more challenging
5 if a person already has one condition, both in terms of using appropriate diagnostic tools and
6 individuals being able to accurately describe their symptoms. In addition, some people may not
7 necessarily seek a diagnosis due to personal or family reasons, and fear and stigma around
8 conditions such as dementia:
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15 “The personal feelings people feel, all that psychological stuff of fear of loss, scared, what’s
16 going to happen to me, you know, I’ve heard about this dementia thing, it’s awful.” (Sight
17 loss professional)
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22 Time constraints and financial constraints can result in professionals becoming focused on meeting
23 targets and can restrict what they are able to implement to meet individual needs and preferences.
24 Professionals often focus on their own area of expertise rather than considering dementia and sight
25 loss together, and awareness of the interaction between conditions is also lacking:
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31 “A lot of [symptoms] sometimes [are] put down to the dementia, when actually it might be,
32 some of it might be the sight loss.” (Sight loss professional).
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38 The professionals across all three specialist areas of service provision in this study recognised their
39 own lack of knowledge and expressed a willingness to learn, but felt that there was insufficient
40 training for both conditions. A professional’s ability to do their job can be limited by not having
41 enough information about the whole picture, either in terms of an individual’s situation or the
42 services that are available relating to other conditions. This lack of knowledge can also mean that
43 professionals do not always know who to refer to or which services are appropriate. Sharing
44 information between professionals and services was therefore recognised as an important part of
45 improving care provision.
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54 “If we work together, we’ve got our specialism and you’ve got your specialism, and surely
55 that’s going to help people with dementia and sight loss?” (Sight loss professional)
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5 Despite this recognition, there was reported to be a general lack of joint working, with professionals
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7 focusing on their own areas rather than trying to work together to meet the wider needs of the
8
9 individual. When efforts were made to work together, they were often hindered by practical barriers
10
11 such as incompatible information systems.
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15 Although the professionals discussed how services can provide opportunities to socialise, they
16
17 tended to be aimed at people with either dementia or sight loss, rather than both conditions
18
19 together. People with dementia and/or sight loss can have trouble accessing services, not least
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21 because they may be unaware of what is available. Similarly, professionals may not know about
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23 individuals who would benefit from their services, creating a mutual lack of awareness.
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29 Even when services are known about, some have access criteria which can limit opportunities to
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31 attend, especially if someone's condition changes. There can also be a problem with stigma amongst
32
33 services, family, friends and the wider community, which can affect participation:
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35 "As soon as you mention dementia to [services] they shut down. They say 'no, we can't
36
37 support someone with dementia.'" (Dementia professional)
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41 Transport was raised as a recurring issue preventing people from accessing services, especially in
42
43 more rural areas, with many services being unable to provide their own transport. In addition, costs
44
45 can become a barrier for some people, and having to pay for transport on top of the service itself
46
47 may affect whether people are able to access services. Financial issues can also affect whether
48
49 people have equipment and housing adaptations put in place, as public knowledge of funding
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51 options tends to be low. Similarly, many professionals do not have sufficient information about
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53 funding to point clients in the right direction. While personal budgets and direct payments can be
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3 used and may provide a more personalised solution to social care and support, it was felt that their
4
5 management could be problematic for people with dementia and sight loss:
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7 “In principle it sounds great, but you have got to have somebody that is on the ball to
8
9 manage that.” (Sight loss professional)
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14 It could be argued that this highlights stigma and lack of imagination among professionals when it
15
16 comes to assessing the suitability of services for people with dementia and their family carers.
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18 19 20 ***Facilitators for providing high quality, cost-effective social care and support*** 21

22 Understanding, education and awareness of both dementia and sight loss were seen as key to
23
24 providing high quality, cost-effective social care and support. It was not considered necessary for
25
26 professionals to become experts on both conditions, but to have some knowledge of both and who
27
28 to contact regarding any issues that may arise. Joint working was valued and was known to take
29
30 place, but it varies between areas and depends on the individuals and organisations involved. Key
31
32 elements of joint working were identified including sharing examples of best practice, offering
33
34 suggestions of approaches to try, and sharing information and research that may be relevant to other
35
36 teams.
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41 The importance of receiving a timely diagnosis for both conditions was recognised, particularly
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43 because a diagnosis is often necessary in order to access medication and specialist services. While it
44
45 can be difficult to achieve, being diagnosed in a timely fashion can also facilitate planning and
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47 preparation for the future and enhance the impact of rehabilitation through a greater range of
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49 options being available and individuals having an “extra window of time when they can learn things
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51 and can cope more on their own” (Sight loss professional).
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3 The study reported here focused on people living in their own homes, and professionals suggested
4 that the housing setting could have an impact on accessing services and the quality of life for
5 individuals. For example, people living in extra care housing usually have daily contact with
6 professionals, which can make it easier for symptoms of dementia and sight loss to be recognised at
7 an earlier stage than when someone lives in the community. Many extra care housing schemes also
8 focus on providing opportunities for social interaction and community involvement. Conversely, if a
9 person with dementia and sight loss is in private housing, especially if they live alone, they may
10 require substantial support to stay at home for longer.
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23 Discussion

24 This paper adds to the limited existing literature on how services can support people with concurrent
25 dementia and sight loss. The findings reflect the views of professionals across housing, health and
26 social care, and highlight the substantial impact that dementia and sight loss often have on the lives
27 of individuals and their families. The impact can be exacerbated for people who have both conditions
28 concurrently, which can often lead to loss of confidence, reduced independence and feelings of
29 loneliness, reflecting findings from previous research (Lawrence *et al.* 2008).
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40 Professionals who took part in this study identified a range of barriers to providing services that meet
41 the often complex needs of this group. In particular, the fact that many services focus on one
42 condition or the other can significantly limit the availability and effectiveness of services for people
43 living with both dementia and sight loss. Opportunities for social interaction can also be limited,
44 particularly for those living alone, but some services that could provide this are not appropriate for
45 people with both conditions. Eligibility criteria can also be problematic, with some services for
46 people with sight loss being reluctant to support people who also have dementia.
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3 Many people with both conditions are only able to continue living at home due to high levels of
4 support from family carers. This is often a spouse but adult children also feature as an important part
5 of support networks. Many family carers also need appropriate and timely support if they are to
6 maintain a role that can be demanding and stressful.
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13 The findings presented in this paper suggest that while receiving a diagnosis of dementia and/or
14 sight loss can often be traumatic, it is important in order to access appropriate services, both for the
15 individual and their family carers. The order in which people develop dementia and sight problems
16 can have implications regarding how services are delivered, particularly where aids and adaptations
17 are being considered. Professionals also suggested that using approaches that focus on carrying out
18 tasks or meeting targets can limit the value and quality of care provided, especially when service
19 users have complex needs associated with dementia and sight loss, and often additional co-
20 morbidities.
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33 Professional awareness and knowledge of both conditions is required to enable effective service
34 provision. Many professionals specialise in either dementia or sight loss and know very little about
35 the other condition. This lack of wider knowledge is a major barrier to addressing complex needs and
36 also limits opportunities for joint working, which has previously been identified as a vital element of
37 supporting people with dementia and sight loss (Lawrence & Murray, 2010). This study also found
38 evidence to suggest that specialist settings such as extra care housing can offer some advantages
39 over general-needs housing, including regular contact with professionals and more opportunities for
40 social interaction.
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53 Overall, greater consideration is required in terms of how services are configured and provided if the
54 growing numbers of people living with dementia and sight loss, together with their family carers, are
55 to be supported to maintain a good quality of life in their own homes.
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Interpretation of findings

The overall aim for care and support for people living with both dementia and sight loss is to maximise wellbeing and preserve independence where possible. Support and information is most effective when provided in a way that can be adapted to address each individual's needs over an extended period of time as both conditions progress. This is also true for spouses and other family members who are often key to enabling people to remain living at home.

Professionals in any specialism should be provided with opportunities to improve their own knowledge of the 'other' condition and how dementia and sight loss interact; this can increase joint working and information sharing with other professionals and services in their local area.

Aids and adaptations play a key role in supporting people with dementia or sight loss to live in their own homes. They are best introduced earlier rather than later to enable them to become embedded as part of routines, and should be kept simple where possible. Having both dementia and sight loss, and often other co-morbidities, makes it particularly important to consider what works for whom and at what stage. The complex and often conflicting needs of people with both conditions make general recommendations very difficult and any solution should always be adapted to meet the needs of the individual.

Implications

In some respects, the points raised by the professionals are based on a common sense approach, as recognised by one of the participants:

“None of this is rocket science it just doesn't usually happen unless you actually think, think like a customer I suppose is what I'm saying. You know, we need to stop thinking like

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3 developers or just doing standard stuff, think what we would want when we were older and
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5 what genuinely does help older people live easier.” (Housing professional)
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9 However, it was also recognised that unless professionals have a reason to consider dementia and
10
11 sight loss together, such as working with an individual with concurrent conditions, they are unlikely
12
13 to think about the impact of both conditions and the role of their own service. This paper and similar
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15 studies therefore have a clear role in informing service development. The findings from the focus
16
17 groups and interviews as presented here form one element of the wider ‘Developing social care
18
19 practice in different housing settings’ research programme. The programme as a whole has informed
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21 a set of best practice guidelines that aim to improve care and support for adults living with sight loss
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23 and dementia in a range of housing settings (NIHR SSCR, 2015).
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