

## **The experiences and needs of people with dementia and serious visual impairment: a qualitative study**

**This publication summarises findings from a series of case studies of older people affected by severe sight loss and dementia, their family carers and the professionals with whom they have contact. The studies were conducted by Vanessa Lawrence, Joanna Murray, Professor Sube Banerjee and Dr Dominic ffytche, King's College London.**

### **Introduction**

Dementia is one of the most common and serious disorders of later life, affecting 5% of people over 65. Although sight loss affects many people with dementia, this is the first study to explore the impact of the two conditions on the lives of older people and their carers. The study had three aims:

- To investigate the perceived impact of serious visual impairments and dementia on the daily living and quality of life of older people with both conditions and with family carers
- To explore needs for support, coping strategies and pathways to care
- To develop recommendations for improving access to appropriate support.

This was an entirely qualitative research study, which used a case study approach. Fifty-two in-depth interviews were conducted with:

- Older adults with both dementia and serious visual impairment
- Family carers
- Care professionals who work with them.

Six core themes emerged from the research: disorientation, loss of independence, accepting multiple losses, risk of isolation, hallucinations, and challenges to services. Recommendations are made for how services can better meet the needs of this population.

## Background

Dementia is one of the most common and serious disorders of later life with a prevalence of 5% in people aged over 65. Research indicates that more than 12% of people over 75 have sight loss. Evidence suggests higher rates of sight loss among older people with dementia,<sup>1</sup> yet there is a striking absence of formal research within this population.

Like dementia, sight loss is considered to be an extraordinary traumatic disability that has a huge impact on the identity of the individual.<sup>2</sup> The combination of dementia and severe sight loss is likely to be an overwhelming experience for the individual and their family, profoundly affecting emotional, psychological, financial, social and practical aspects of life. The increased disorientation and impaired learning associated with visual impairment may increase confusion in the person with dementia. Similarly, the increased likelihood of depression and social isolation may contribute to cognitive dysfunction, while the frustration and fear that frequently accompany sight loss may exacerbate challenging behaviours.<sup>3</sup> Uhlmann *et al.*<sup>4</sup> concluded that sight loss may be an unrecognised contributor to the decline of cognitive function, the ability of people with dementia to live independently and their admission to nursing homes.

Difficulties in detection and diagnosis of sight loss may be compounded by the presence of dementia, as ophthalmological examination requires a high level of patient co-operation. People with dementia may also be less able to communicate complaints of poor vision.<sup>5</sup> Conversely, visual impairment may mask the early clinical signs of cognitive impairment such as misplacing things and getting lost. The combination of sight loss and dementia is also likely to complicate management. Dementia impairs the ability to use compensatory mechanisms to cope with sight loss and low vision rehabilitation services lack guidelines on how best to work

<sup>1</sup> Pham T, Kifley A, Mitchell P, Wang JJ (2006) *Relation of age-related macular degeneration and cognitive impairment in an older population*, Gerontology 52, 353-358; Uhlmann RF, Larson EB, Koepsell TD, Rees EB, Duckert LG (1991) *Visual impairment and cognitive dysfunction in Alzheimer's disease*, Journal of General Internal Medicine 6, 126-132.

<sup>2</sup> Horowitz A (2004) *The prevalence and consequences of vision impairment in later life*, Topics in Geriatric Rehabilitation 20, 185-195.

<sup>3</sup> Noell-Waggoner E (2002) *Light: an essential intervention for Alzheimer's disease*, Alzheimer's Care Quarterly 3, 343-352.

<sup>4</sup> Uhlmann *et al.* (1991).

<sup>5</sup> Koch JM, Datta G, Makhdoom S, Grosberg GT (2005) *Unmet visual needs of Alzheimer's disease patients in long-term care facilities*, Journal of the American Medical Directors Association 6, 233-237.

with people who have dementia. Successful adjustment to vision loss has been related to a number of physical and psychosocial factors,<sup>6</sup> yet it is uncertain how cognitive impairments may affect this process. The implications of memory loss and sight loss appear inextricably related, and are difficult to disentangle; this may have contributed to the dearth of research in this area. However, the high co-morbidity and impact on quality of life demand that we explore the experiences and needs of this growing population.

## Methodology

The authors undertook 19 case studies comprising in-depth individual interviews with:

- (a) 17 people with dementia and serious visual impairment
- (b) 17 family carers of the above
- (c) 18 care professionals who have contact with them.

Purposive sampling was used to select participants with a diverse range of characteristics,<sup>7</sup> e.g. different levels of severity in the two conditions, living in different settings. Participants were recruited via services for older adults with dementia and services for older adults with sight loss. This included Community Mental Health Teams for older adults, voluntary organisations and statutory health and social care services. Care professionals in these settings were enlisted to help identify suitable participants. An invitation letter, including an information sheet, SAE and reply slip was then sent out to the registered informal carer, which was followed by a phone call, at which time further information was given and interviews scheduled. Individuals recruited via dementia services were screened for concurrent sight loss, and vice versa. The 'MMSE-Blind',<sup>8</sup> the 'Short Form of the Informant Questionnaire of Cognitive Decline in the Elderly' and the 'Clinical Dementia Rating Scale'<sup>9</sup> were used to gain an indication of the level of cognitive impairment (see Table 1). The level of visual impairment was assessed using the 'Snellen Chart' and the 'Seeing Severity Scale' (see Table 2). Each older adult was asked to identify a family member or friend who represented their primary source of support, as well as a care professional who they thought

<sup>6</sup> Davis C, Lovie-Kitchin B, Thompson B (1995) *Psychosocial adjustment to age-related macular degeneration*, Journal of Visual Impairment and Blindness Jan-Feb, 16-27.

<sup>7</sup> Patton MQ (1990) *Qualitative Evaluation and Research Methods* (2nd edition), SAGE: Newbury Park.

<sup>8</sup> Reischies FM, Geiselman B (1997) *Age-related cognitive decline and vision impairment affecting the detection of dementia syndrome in old age*, British Journal of Psychiatry 171, 449-451.

<sup>9</sup> Morris JC (1993) *The Clinical Dementia Rating (CDR): Current version and scoring rules*, Neurology 43, 2412-2414.

knew them well. Recruitment continued until no significant new themes emerged from analysis of the interviews.

Data from these case studies were supplemented with additional interviews with formal carers, who were recruited on the basis of the role they played in older adults' care, e.g. we purposefully recruited rehabilitation workers within sensory impairment teams as they are the first point of contact for many older adults with sight loss. Although these care professionals were not necessarily nominated by a specific older adult, they all had experience of working with older adults with both visual impairment and dementia. This enabled us to explore a diverse range of perspectives.

**Table 1:** Summary of measures of dementia

MMSE-Blind		Informant Questionnaire of Cognitive Decline in the Elderly (Short Form)		Clinical Dementia Rating Scale	
Measure	Number	Measure	Number	Measure	Number
0-18	15	A bit worse	8	Very mild dementia	5
		Much worse	9	Mild dementia	7
19-22	4	Missing (no informal carer available)	2	Moderate dementia	2
				Severe dementia	5

**Table 2:** Summary of measures of visual impairment

Snellen Chart <sup>10</sup>		Seeing Severity Scale	
<6/60	13	S2 – Cannot see the shapes of the furniture in the room	2
6/60	2	S4 – Cannot see well enough to recognise a friend who is an arm's length away	2
6/36	1	S5 – Cannot see well enough to read a newspaper headline	3
6/24	2	S6 – Cannot see well enough to read a large print book	3
6/18	1	S7 – Cannot see well enough to recognise a friend across a room	1
		S8 – Cannot see well enough to recognise a friend across a road	4
		S9 – Has difficulty reading ordinary newspaper print	4

<sup>10</sup> Measure of bilateral corrected acuity

The interview guide was generated from the literature and was revised iteratively, incorporating themes emerging from the analysis of the interviews as the fieldwork progressed. Initial interviews explored the individual's daily life, health and social wellbeing, relationships, support received and how things could be improved. Interviews were held with staff at their place of work or another agreed venue; older people and their supporters were seen in their own homes. Interviews lasted around one hour and were tape-recorded and transcribed verbatim. A thematic analysis was then undertaken on the data. Two researchers independently scrutinised and coded the transcripts; data were separated into meaningful fragments and emerging themes were identified and labelled. The researchers compared their coding strategies and attempted to reach consensus. An iterative coding procedure was followed in which the initial coding frame was extended to include new themes as they were identified in subsequent interviews. The qualitative data analysis software N-VIVO<sup>11</sup> was used to process the transcripts and enable the researchers to identify, code and retrieve concepts systematically. An advisory panel was convened that included representatives of sight loss and dementia organisations and leading academics in both fields. These meetings provided an opportunity to gain feedback on emerging themes and to discuss the implications.

Of the 17 older adults interviewed, 11 were female and six male; one lived with family, three lived in sheltered accommodation, four lived alone, four lived with their spouse, three lived in a nursing home, and two lived in residential care for people with sight loss. Tables 1 and 2 summarise the descriptors of dementia and sight loss for the sample. The relationships of the informal carer to the older adult were: three wives, nine daughters, one son, one daughter-in-law, one sister, one cousin, and one friend. Care professionals included community psychiatric nurse, occupational therapist (community mental health team); consultant psychologist (memory clinic); support worker (carer respite service), nurse, deputy manager (nursing home for the elderly mentally infirm); rehabilitation worker, team manager (sensory impairment team); activities co-ordinator, deputy manager (residential unit for people with sight loss); group leader, service co-ordinator, director (voluntary organisation for people with sight loss).

<sup>11</sup> QSR International (2002) *N-Vivo*. QSR International Pty Ltd: Victoria, Australia.

## Findings

Six core themes emerged from the analysis: disorientation, loss of independence, accepting multiple losses, risk of isolation, hallucinations, and challenges to services. Each theme is supported by data from interviews with the older adults, informal carers and formal carers.

### Disorientation

#### Unable to orientate self using memory or visual cues

In the early stages of dementia, individuals' attempts to remain orientated in time were undermined by their inability to see the clock or read the date on the newspaper. Subsequently, many became unable to navigate their surroundings as they could neither observe nor recall the layout. Some older adults simply could not remember where they were, and frustration was replaced by fear. Care professionals considered the disorientation within this group to be more immediate and pronounced than in individuals with dementia alone, as they lacked the visual cues to anchor them to the here and now.

If you've got an awareness you've got a memory problem, [you can't do] a lot of the things people who have got normal sight would do which is to scan the environment for cues as to what they were trying to do. So the common instance we get ... people walking into a room and don't remember why they have gone there but presumably if you would scan that room and work out what the cue could be, why you are there, you might get some recollection. If you can't see what ... if you can't see the environment, how are you going to cue yourself?

Consultant Clinical Psychologist, Memory Clinic

#### Increased demands on informal carers

This profound sense of disorientation frequently led to anxiety and distress. Many older adults feared being on their own and this was exacerbated by their difficulty in recalling where their carer was, how long they had been absent and when they would be back. This placed huge demands on informal carers. Some found it difficult to leave the older person for even short periods of time, and stress and exhaustion were commonplace.

Because sometimes when you've had a bad night and you are getting up the next day and you are having to run the house and he is calling you in every minute that you leave the room, he can't understand why you have to go and wash up or you have to go and clean the floor.

Clarence's wife

Many care professionals recognised the exceptional intensity of these demands. One suggested extra resources should be committed to meeting them.

I am very coloured by the people I've been working with and the problems of orientation and the constant calling out and the demands on the carers and I think that if that can be recognised by social services and perhaps in those circumstances these people need more support because it's so constant, it's all the time, it's throughout the night, they are constantly, constantly called, they get tired and whereas night sitters are not normally put in at all, I mean it's way beyond the budget, but there are certain circumstances where that would help.

Community Psychiatric Nurse, Community Mental Health Team for Older Adults

### **Promoting individuals' confidence in their environment**

Family members adopted various strategies to help orientate the older person. Providing large-scale reminders or clocks was a common technique that appeared helpful in the early stages of the dementia. Carers also stressed the value of a familiar environment and were reluctant to disrupt the older person unnecessarily.

We can't take her home for Christmas, we've tried that, taking her home for family activities and she is confused and she gets anxious and wants to come back, because now this is sort of secure for her.

Teresa's daughter

Some carers had to provide an ongoing commentary on where they were and what was happening. Specialist sight loss professionals similarly identified clear verbal communication and stability as fundamental to their approach. Cognitive impairments limited the amount of rehabilitation work that could be undertaken with older adults with sight loss, as clients needed to think through a process to complete it safely. Staff were aware that older adults may find it distressing to be given instructions that they may struggle to understand. Thus, rehabilitation workers focused primarily on tailoring the environment to maximise visual input, using colour and contrast and the best possible lighting. It was felt that attending to individuals' sensory needs reduced feelings of disorientation and helplessness, making it less likely that distress would be manifested in anxious, restless or disruptive behaviour.

**(Her needs) are to feel comfortable, not to feel frustrated, not to feel anxious. For her wellbeing to be constant, her feelings of wellbeing to be constant so that she is not agitated and she is not thrown in her mind that she would need to wander off and go to somewhere that perhaps she lived as a child or something like that ... have the same group of people, even regardless who she thinks they are.**

CP18, Director, voluntary organisation for people with sight loss

Although mental health professionals recognised the importance of a familiar environment, many acknowledged that staff in dementia services might lack sufficient time and expertise to provide the reassurance that sight loss demands.

## Loss of independence

### Increased risk and impaired judgement

There was a consensus among carers that the combination of being unable to compensate for poor memory with visual cues, and being unable to compensate for poor sight with cognitive strategies, profoundly impaired older adults' ability to manage their own cooking, shopping, finances, medication, etc. Although this evoked frustration and occasionally anxiety in the older person, carers were alert to the risks, fearing that the older person might leave the cooker on, neglect to eat, let strangers into the house, get lost on the way to the local shops and so on. Carers felt that the risks associated with sight loss were amplified by the co-existence of a

poor memory and, to an even greater extent, by impaired judgement. Denial or lack of insight in the older person increased their vulnerability.

**The neighbours were worried about her because she was really an accident waiting to happen because she couldn't see properly, but was still insisting on going out, getting on the bus, doing all sorts of things.**

Teresa's daughter

### **Constraints imposed on independence**

Worries about safety prompted carers to limit their relative's activities. The older person's readiness to accept these constraints seemed to increase the possibility of their continuing to live alone. Some older adults rationalised these restrictions in terms of poor mobility, physical frailty or sight loss, which enabled them to normalise their situation in the context of old age. However, this sometimes provoked conflict in the caregiving relationship, particularly when limitations were placed on valued activities and roles. One participant was extremely angry with his wife for forbidding his use of particular tools in his workshop.

**Interviewer: It sounds like you get a lot of enjoyment from the workshop?**

**Participant: I do, it's more than enjoyment, I would be thoroughly miserable if I was kept out of it. Well it would bust our marriage up I think if that happened...**

Robert

Family carers were distressed by the apparent unwillingness of the older adult to accept their advice. Some considered care professionals better placed to impose limitations of this sort, believing that the older person would be more receptive to their advice and that it would alleviate pressure on their relationship.

He won't be told by anybody in this house that you know perhaps he should ... He says how can you tell me what to do, you are not an expert and we sort of say well it's sort of common sense but it doesn't wash really.

Donald's daughter

### **Balancing risk against independence**

Informal carers identified loss of independence as the greatest threat to their relatives' emotional wellbeing. Where possible, many provided intense support that enabled the older person to continue with daily living activities. Carers advocated a non-confrontational approach and were keen to promote their relatives' autonomy in everyday matters.

When mum wants to do something we don't stop her. You have just got to let her do it, let her realise that she can't do it and then pick up the pieces from there ... she's got this thing about brushing her teeth, it don't matter, even if she's brushed them that much that her gums ... if she gets this inkling that she wants to go and brush her teeth then you've got to let her.

May's daughter-in-law

Care professionals stated that their priorities were to promote their clients' independence and safety. However, they were highly mindful of the increased level of risk in this group and of the inherent conflict in these aims.

It would be irresponsible for example if somebody has memory problems to do mobility training, it depends obviously, but if someone is not going to remember that they have to stop at the edge of the road before they cross you're not going to continue with mobility training, you know why on earth would you do that, to put people more at risk to then go out and hurt themselves.

Team Manager, Sensory Impairment Team

However, there was also residual concern that services and professionals should not withdraw from allowing individuals to take some risks. Care homes were criticised for seemingly adopting this approach.

**You see them being herded about, put in wheelchairs even though they can walk but it's safer for the nursing home to put them in a wheelchair and push them from a to b and to pad them so they don't need to take them to the toilet because it's more difficult and it's more distressing for them.**

CP5, Senior Occupational Therapist, Community Mental Health Team for Older Adults

One deputy manager of a home for people with dementia recognised the importance of supporting clients with sight loss and dementia to be as independent as possible, but regretted that constraints on time and staffing meant that some clients were fed by staff rather than being encouraged and supported to eat on their own. Some vision rehabilitation workers feared that they might assume an overcautious approach as a consequence of lacking the expertise to assess dementia-related risks. Community mental health professionals were more confident in undertaking a holistic risk assessment, yet acknowledged that this was complex and time consuming.

Assistive technology was often cited as a valuable method of orienting older adults and preserving their independence and safety. A huge number of devices were mentioned, including wandering alarms, memo reminders, alarms that were activated when the gas was turned on but not ignited, and cookers that turn off automatically.

**Like a medication box, a prompt if people have to take their medication throughout the day or at various times, that gadget might enable them to live at home for the next six months, a year, with a little bit of support going in here and there and how wonderful that is. And also Careline as well, you know, the telephone dependence that people use, [name of borough] are very keen to push that because I think that also enables people to live as independently as they can for as long as they can in the community and I just think that that works very, very well.**

Team Manager, Sensory Impairment Team

## Accepting multiple losses

Acceptance was an important coping strategy that influenced older adults' satisfaction with their life, their willingness to relinquish particular activities and the ease with which they asked for and accepted help. Older adults frequently advocated acceptance as essential to adapting to the changes in their lives.

**I just don't let it worry me. You know, you can't do so you can't do it. You've got to accept it. You get by ... I mean I'm quite content with the level of life I'm at. And so it's no good aspiring to something I can't cope with.**

Mary

However, many family carers spoke about the older person's reluctance to admit their difficulties, and their unwillingness to accept advice or support. Family members were conscious that the multiple losses represented a huge threat to self-esteem.

**Every day really, there was another thing that he couldn't do any more and in the end he just was feeling totally useless. I mean he used to do all the garden and then you know he would still want to do that even though he couldn't see and he would like plant plants one day and the next day he thought they were weeds and was pulling them up and things like that you know, it's really sad. And planting bulbs all upside down, but he was just so desperate to still lead as normal a life as possible.**

Donald's daughter

Professionals in a range of capacities shared the view that experiencing one form of loss increased the difficulty of accepting a second.

## Risk of isolation

### Dependence on others for stimulation

Combined sight loss and dementia has a destructive effect on an individual's ability to enjoy hobbies and interests. Older adults complained that sight loss prevented them from enjoying country walks, painting, knitting, reading, doing jigsaw puzzles, watching television, etc.

**I can't read my Bible any more, I was a reader in this diocese for 20 years and I can't even read my own Bible ... and that hurts, believe you me, that hurts.**

Andrew

Poor memory compounded their difficulties and often prevented the use of compensatory strategies such as talking books. Informal carers explained that they 'accessorised everything big', including jigsaw puzzles, books and sheet music, but the older person's poor concentration negated their efforts after a time. Carers and older adults consistently identified listening to music as a continuing pleasure. However, only people with mild dementia managed to operate tapes, CDs and radios. The implications of this were far-reaching: the loss of enjoyable and relaxing activities, loss of identity, and increased emotional dependency on others.

**I know that obviously they can't give him one-on-one care, but you see if he's left alone he has no way of entertaining himself because you know, unless he's listening to the TV like he is now, he has no way of entertaining himself. Because he can't see to read and he forgets anyway where he is.**

Clarence's wife

This increased the burden on family members to provide stimulation and entertainment. The deputy manager of a home for people with dementia and a deputy manager of a home for people with sight loss both identified this as a challenge to their service since individuals with both conditions might not gain from activities targeted at the wider group.

## **Value of day centres**

There was ample evidence that older adults benefited from attending day centres or lunch clubs, aimed specifically at older people with dementia or sight loss. Older adults and their relatives often praised the stimulation and activities that these centres provided. Critically, day centres also offered opportunities for social interaction. One apparent consequence of individuals' inability to pursue hobbies and interests was that they placed a greater emphasis on interaction with others. Clubs for older people with sight loss and clubs for older people with dementia demonstrated both common and specific strengths. One lunch club, which routinely served both populations, offered a useful summation of these. It recognised the importance of small groups, the necessity of transport to and from the centre, and activities that were adjusted to individuals' cognitive abilities. Older adults enjoyed meeting others with sight loss, while family carers considered it advantageous that their relatives were not the only individuals present with memory problems.

**Oh I like that, they are nice people. They are in the same position as I am really I suppose, they can't see you know ... you can laugh and talk about things and say 'oh I didn't see that' you know.**

Nell

**Oh yes she does, she really looks forward to it ... and they are all in the same position as her, they are either blind and deaf or blind and memory is going and whatever you know and they probably tend to talk a bit louder than probably some of the ladies do here you know so mum can hear them better and understand them better.**

Nell's son

## **Importance of one-to-one interaction**

Despite the benefits of day centres, it was evident that most older adults found it easier to interact on a one-to-one basis. Visual impairment made it difficult to identify when conversation was directed at them, while dementia impaired their ability to follow the pace and complexities of the discussion around them. One-to-one

interaction also enabled older adults to pursue valued hobbies and interests. Donald and his daughter both attached huge value to the two hours per week that he spent with a Crossroads carer, with whom he completed crosswords and puzzles. Carers across the sample agreed that some older adults with dementia and sight loss were at risk of becoming entirely isolated if they did not receive attention of this sort. However, care professionals were mindful of the funding implications of one-to-one care.

## Hallucinations

### Increased disorientation and distress

Over a third of the older adults experienced visual hallucinations. Three explicitly discussed the content of these hallucinations and how they made them feel. Despite insight into the hallucinations, it remained an ongoing challenge to differentiate between what was real and what was not.

**Well it is disorientating. I mean now you've hit on the key word I think that I'm suffering from. Because life can be very unsure, put it that way ... See when you have lived all your life with your sight you know that what you see is something definite or whatever the term is. But when it's an hallucination it's awfully difficult for you to say well that's silly, no it can't be.**

Donald

Four individuals with more severe cognitive impairment appeared to have a complete lack of insight into their hallucinations. Their carers described the impact as highly distressing, as they often 'saw' strangers in the house.

### Diffusing fear

Family carers expressed uncertainty about how best to deal with hallucinations, although there appeared to be an initial inclination to challenge the older person's beliefs. One daughter benefited from observing the care professionals' approach, but regretted that she had not received guidance on how to manage her mother's hallucinations at an earlier stage.

Initially my brother and I tend to think that we ought not to acknowledge that she was talking about having visitors and we'd say, 'well the door's locked, therefore nobody could have come in' ... And I suppose being confrontational really although we would obviously try to do the best thing, but we didn't really know how to handle it. But since seeing the psychiatrist and the CPN and seeing how they ask more and more questions and ask how it distresses her and that's obviously the way to handle it, but it was quite difficult for us to know what to do.

Florence's daughter

Providing older adults with a rationale for what they were seeing had mixed success. Where older adults were able to comprehend that their visions were a hallucination, exploring them seemed to help make sense of their experience and attenuate its negative impact. These explanations were most successful when given in a way that did not challenge the authenticity of their experience. Hallucinations even provided pleasure on some occasions.

**A crowd under a bridge. I quite enjoy it because I can see the people's faces when they turn around. Yes I quite enjoy it. I kept saying to myself don't be ridiculous you can't keep looking at this, you see but then I think that's rather silly because it doesn't really hurt.**

Florence

However, the majority of the older adults believed unequivocally in what they were seeing, and any suggestions that the visions were not real simply proved upsetting. Subsequently, relatives focused on comforting the individual and alleviating their anxiety. However, sometimes reassurance was not enough and it was often these events that prompted a referral to a community mental health team or a move into residential care. Hallucinations had the potential to elicit discomfort in both groups of care professionals; staff who specialised in sight loss tended to associate hallucinations with dementia, while mental health staff were wary that there might be a visual basis.

## Challenges to services

### Disruption to sight loss services

Sight loss professionals expressed concern about the behavioural problems associated with dementia. It was felt that restless and disruptive behaviour threatened to monopolise staff time and upset other group members or residents. For these reasons, care professionals were apprehensive about older adults with moderate to severe dementia joining their service. It was felt that it would be unfair to staff and the individuals themselves as their service lacked sufficient resources to attend to dementia-related needs.

**I find sometimes dementia gets to be the bigger problem than sight loss ... well basically the dementia is the disruptive bit. And the dementia is taking over, i.e. they won't get out of bed in the morning. To get them to eat breakfast is a struggle. So you're spending time because they don't remember to eat, because they don't want to eat, they don't know that they want to eat.**

Deputy Manager, Voluntary organisation for people with sight loss

However, there was evidence that each of these services had made attempts to accommodate existing members who developed cognitive impairments. One club routinely provided a service for older people with both sight loss and dementia, recognising that people with dementia gained security and comfort from the expertise of staff working with people with sight loss.

### Sight loss professionals uncomfortable with dementia

Rehabilitation staff in sensory impairment teams identified the co-existence of sight loss and dementia as a common and growing phenomenon, which represented one of the greatest challenges to their service. Many felt that their difficulties stemmed from the false expectation that sight loss could be dealt with in isolation. They criticised their training for failing to equip them with the expertise to work with clients with concurrent learning disabilities or mental health problems. Many had attempted, but failed, to find adequate skills training.

So the training out there tends to be more of an overview for memory loss issues rather than how it affects your work ... quite often I feel overwhelmed and out of my depth really that I could probably do more, um, and I don't know who to turn to. Maybe I should go and spend some time with the memory services...

Rehabilitation Worker, Sensory Impairment Team

### **Minimal significance attached to visual impairment**

Staff within dementia care identified themselves as working holistically to meet multiple needs and articulated fewer reservations about working with older adults with both conditions. Few felt that visual impairment would have a significant effect on the way they worked with clients.

It's just something that goes with the territory really and sometimes people who are profoundly deaf are ... that is far more of a headache because they can't hear what you are saying but we've got this thingy that magnifies which helps a bit. But in terms of poor sight, I mean yes you tend to use sort of touch more to make sure that they know that you are there but otherwise not really, it doesn't make that much of a difference.

Community Psychiatric Nurse, Community Mental Health Team for Older Adults

### **Value of joint working**

Rehabilitation workers criticised GPs, ophthalmologists and mental health professionals for failing to provide information about additional impairments at the point of referral.

This could place the client at risk.

When I went to visit him I wasn't initially able to assess whether his difficulties were because of his sight loss ... I picked up that he had some memory difficulty but I wasn't able to assess, because it's not my line of speciality how serious the memory difficulties were. And anyway I just, I could have just carried out the piece of work for this client, I could have just gone in, there was an issue with the gas but he knew how to turn it on, I could have just told him turn on the gas and showed him how to use the cooker, mark it up and so forth, which we usually do ... there was no indication whatsoever on social services' database that this client had dementia.

Team Manager, Sensory Impairment Team

There was little evidence of communication between mental health and sensory impairment teams; assessments were undertaken independently and information was rarely shared. One sensory impairment team manager argued that increased contact between the teams would provide a more holistic understanding of the client's capabilities and the ways in which support could be targeted to maximise their independence.

My interpretation of what might be an OK risk for someone with sight loss and memory problems is not going to be the same as another professional and you know I think by sharing that risk perhaps people might be more empowered rather than individual professionals saying 'actually I'm not willing to put my name to that, I'm not willing to say that that's a possibility'. Whereas within a group decision it's the sharing of information and sharing of knowledge, you know what level of cognitive function are we talking about, what are the possibilities? Very often we don't know, ... our possibilities are – can you make a cup of tea or not? Well you know there might be a better way round that, a skill that the CPN has developed, a way of communicating that we aren't party to.

Team Manager, Sensory Impairment Team

## Conclusions and recommendations

- **Promoting individuals' confidence in their environment**

Concurrent visual impairment and dementia create a profound sense of disorientation. This can provoke distress, which is occasionally manifested in disruptive behaviour. Informal and formal carers need to provide clear, ongoing communication that promotes individuals' confidence in their environment. Techniques such as reality orientation and validation therapy may help to raise awareness of external reality for people with both conditions.

- **Reducing loneliness and isolation**

Older adults experienced loneliness and isolation. The ability to pursue hobbies and interests was often impaired and one-to-one interaction was required. Telephones represented a lifeline and high value was attached to regular contact with paid carers and volunteers, especially when time was spent in maintaining valued pastimes. Crossroads Carers were repeatedly praised for providing individualised care. Limited resources restricted opportunities for one-to-one contact in care homes. It is vital that service providers appreciate the value of one-to-one contact for this client group.

- **Services required to meet dual needs**

More services are needed that are capable of meeting both sight-related and dementia-related needs. One day centre, which successfully combined specific services for dementia and sight loss, provides a useful model. Staff understood the importance of consistency and clear verbal instructions, numbers were restricted, transport was provided and activities were tailored to cognitive abilities. Older adults with sight loss and dementia also benefited from spending time with peers with similar conditions.

- **Optimising visual input**

Optimising individuals' visual input through adequate lighting and high contrast markers is imperative in this population. Assistive technology may help to orientate and protect the independence and safety of this group and alleviate some of the demands on informal carers.

- **Promoting independence**

Inability to manage activities of daily living, coupled with impaired judgement, increased the threat that dementia and sight loss individually posed to older adults' independence. Challenges to independence also appeared to occur at an earlier stage. Older adults should be allowed to exercise as much autonomy as possible and supported to pursue valued activities in a safe environment.

- **Increased demands on informal carers**

Family caregivers faced exceptional demands, as many older adults were wholly dependent on them for orientation and stimulation, as well as their everyday care. Care professionals recognised that these unrelenting demands sometimes necessitated extra respite resources such as night carers and more sessions at day centres.

- **Access to information and advice**

Family carers need ready access to information and advice. We know of no organisation that provides specialist information on the impact and management of the two conditions and available support. Fact sheets, of the type produced by the Alzheimer's Society, Macular Disease Society and Royal National Institute for the Blind, and information on audio tape could be distributed by vision rehabilitation workers, mental health professionals and GPs.

- **Limiting activities**

Family members' concerns about safety often led them to impose constraints on the older person's activities. This provoked conflict in their relationship. Care professionals are well placed to initiate discussion about the reduction of activities with older adults, and to validate the informal carer's position.

- **Managing visual hallucinations**

Care professionals should provide family members with information and advice on managing visual hallucinations, including the possibility that existing medication and concurrent infection may be contributing factors requiring medical review. Optimal management, ranging from reassurance and non-confrontation to a full explanation and distraction techniques, is currently not clear-cut and may depend on the cognitive abilities of the older adult.

- **Value of joint working**

There is a need for increased co-ordination between mental health and sensory impairment teams. Appropriate sharing of information and transfer of skills would facilitate a more accurate assessment of risk, which would help care professionals to identify individuals' abilities and needs for support.

- **Training**

Training programmes for vision rehabilitation workers should include information on working with people with dementia. Joint training of mental health and sight loss professionals would encourage the exchange of knowledge and expertise. Current and past carers could serve a valuable role in educating professionals on the unique challenges posed by the co-existence of the two conditions.

- **Awareness of sight-related needs**

Dementia care professionals often overlook the needs created by visual impairment. It is important to recognise that these needs require extra time and attention from staff, especially if individuals are to be supported in a way that promotes rather than undermines their autonomy.

- **Complex needs require additional resources**

Service providers need to acknowledge that assessing and responding to the complex needs of this population requires extra time. Thus, additional resources may be required to meet these needs adequately.

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## How to obtain further information

A summary report, in the form of a 'Research Findings', entitled *The experiences and needs of people with dementia and serious visual impairment: a qualitative study*, by Vanessa Lawrence, Joanna Murray, Dominic ffytche and Sube Banerjee is available from:

Thomas Pocklington Trust  
5 Castle Row  
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Web [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk)

Copies of this report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

## Background on Pocklington

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £700,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcomes as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.

*In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.*

## Notes

## Notes



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**Registered Charity No.** 1113729

**Company Registered No.** 5359336

Published by Thomas Pocklington Trust

ISBN 978-1-906464-04-2



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