

# Sight loss, dementia and meaningful activity

## Introduction

It is increasingly recognised that people with dementia often have other health conditions that will make their lives additionally challenging. For many people, one of these conditions is sight loss.

Thomas Pocklington Trust has funded a number of research projects to explore the difficulties people with dementia and sight loss face and how their quality of life can be enhanced. Supporting people to continue engaging in activities that they value ('meaningful activities') when they have both conditions is important but can be challenging to family and professional carers. This paper presents the findings of a multi-method scoping study led by Alison Dawson from the University of Stirling to open up discussion around meaningful activity for people with dementia and sight loss. It found that:

- In the academic literature, what is understood by meaningful activity changes, depending on whether the focus is on people with sight loss or on those with dementia;
- 90% of survey respondents who had supported an individual with both sight loss and dementia felt that this introduced unique challenges that were not present when an individual had either condition alone;
- There is a lack of awareness of existing resources, but 97% of respondents felt they needed further guidance, with face-to-face training being the preferred method.

## Background

The effects of having both sight loss and dementia are likely to be more severe than those resulting from either dementia or sight loss alone. When combined, they can increase the risk of confusion, disorientation, isolation and loss of independence (see Pocklington Occasional Paper 16). Recent research for Pocklington has explored how to design and adapt homes for people with sight loss and dementia so that they are as supportive as possible (see Pocklington Research Findings 42). The current scoping study was a response to practical

questions asked by family and professional carers on how to involve people with sight loss and dementia in activities in order to maintain quality of life.

The study methods were a review of existing peer-reviewed academic and 'grey' literatures, interviews with ten expert informants and analysis of responses to an on-line survey.

Elsewhere, others have referred to 'personally valued', 'perceived purposeful' or 'valued discretionary' activities, but the term 'meaningful activity' appears to be used most frequently and is used here. Defining exactly what constitutes meaningful activity has proved problematic.

### **What is the significance of meaningful activity for people with dementia and sight loss?**

Engaging in meaningful activity has been linked with better outcomes for individuals with dementia, including slower functional decline, fewer behavioural symptoms and less reliance on medication. Losing access to meaningful activity has been linked to depressive symptoms and distress.

Many people find it difficult to adjust to sight loss in later life. Deterioration in vision has been linked to significant activity limitation, even where the activities in question are less dependent on sight. It is imperative to consider the needs of individuals who have both dementia and sight loss in relation to meaningful activity in order to provide high quality care.

### **What does existing literature tell us?**

The first phase of the study consisted of a rapid literature review. A systematic search found twenty-five articles that described or reviewed research studies related to people with sight loss and/or people with dementia and focused on meaningful activity. These were reviewed and evaluated by the research team.

The most striking result of the literature review was that none of the twenty-five papers related to the needs of individuals with both dementia and sight loss, with regard to meaningful activity.

The types of activity discussed in the literature in relation to dementia or sight loss included:

- Movement based, with specific purpose e.g. household chores, gardening
- Activities designed to produce a tangible end product, e.g. knitting, pottery, cooking
- Movement based, without other purpose, e.g. walking in the garden, yoga or tai chi exercises
- Music-related, e.g. singing, playing an instrument

The types of outcome discussed as resulting from meaningful activity included those related to: emotional health; engagement; function; service use; and cognition.

## **How is meaningful activity interpreted in the academic literature?**

There was consensus that to count as 'best practice', meaningful activity needs to be constructed on strong, person-centred foundations rather than on biomedical priorities and perspectives. This suggests that 'meaningful activity' is seen across academic disciplines and professional groups as activity that meets the needs and goals of the person who is being supported to engage in it, as they are understood from the perspective of that individual.

Studies by Cohen (2006) and Harmer and Orrell (2008), in particular, highlight that for many people positive outcomes are more important in determining whether an activity is meaningful than the form or 'quality' of the activity.

A recurring theme suggested by research participants with dementia or sight loss was that activity is meaningful if it allows someone to feel that they are making a contribution, for example to their family or wider community. Critically, this perspective was rarely included in publications which focused on carer and professional reflections.

Within the literature relating to dementia, the emphasis was on the roles of professionals or family support networks in diagnosing, assessing and/or facilitating engagement in meaningful activity. In contrast, the sight loss literature suggested that people with sight loss are more likely to be encouraged to use peer support, share mutual experiences and gain self-confidence for individual motivation to engage with meaningful activities.

## **Are there any negative outcomes from meaningful activity?**

Few studies provided significant discussion of negative outcomes associated with engaging in, or supporting someone to engage in, activity. A notable exception was provided by Roland and Chappell (2015), who found that while family carers identified significant benefits for those they cared for from participating in meaningful activity outside the home, they often also viewed participation as stressful, anxiety-inducing and difficult both for those they cared for and for themselves as carers.

## **Who supports engaging in meaningful activity?**

The literature suggested three key sources of support in enabling people to participate in meaningful activity:

- **Allied Health Professionals (AHP)**

AHP involvement was highlighted in papers on sight loss and those on dementia, with a number of studies focusing on significant benefits for individuals from interventions introduced by occupational therapists. AHPs are able to facilitate continued or novel engagement for older people with visual impairment in the context of daily routines or employment. They can make a valued contribution to facilitating adaptation and continued participation in activities.

- **Informal or family carers**

Informal or family carers can make a key contribution to supporting participation

in activity. Phinney (2006) describes how family members can try to reduce the cognitive or physical 'demands' of the task for the individual, can guide their attempts at an activity and accompany them into the community.

- Peer support

The use and value of peer support in facilitating and supporting meaningful activity was frequently discussed in the sight loss literature. Peer support could be considered a mechanism for facilitating further meaningful activity but may also be a meaningful activity in itself, conferring social benefits and promoting a sense of connection.

## **What additional challenges are there with enabling and supporting meaningful activity in people with both sight loss and dementia?**

The academic literature tended to focus on either individuals with sight loss or those with dementia. To shed light on what additional challenges might be associated with enabling and supporting participation in meaningful activities for people with both conditions, ten semi-structured interviews were conducted with 'expert informants' holding professional roles related to the provision of meaningful activity (e.g. an occupational therapist, a vision rehabilitation worker and a dementia consultant). The interviews were used to shape a web-based questionnaire, which attracted 117 usable responses.

### **How is meaningful activity described?**

Both sets of respondents generally adopted the 'person-centred' view of meaningful activity seen in the literature. When asked to describe what meaningful activity was, survey responses often focused around the idea that the activity in question provided pleasure to the individual, or was in some manner fundamental to their identity.

*'(It is) an activity that is part of the patient's life history, interests, routine and personality. Meaningful activities are activities that help describe our identity e.g. when we first introduce ourselves to a group we would say something like: 'Hello I am John, I am a bus driver and I enjoy reading the newspaper every day.'*

*Physiotherapist / Researcher, Survey Respondent.*

In contrast to survey respondents, interview respondents reflecting on the difficulty in defining the term often drew attention to the difference between activities that had been meaningful to a person in the past and those that held meaning for them in the present. One interviewee reflected that it was often important to try and remove family and care-giver opinion from the equation, allowing the individual to adopt a 'trial and error' approach to discover what held interest and meaning for them now, rather than being exclusively tied to formerly favoured but perhaps no longer meaningful, activities.

## **What are the challenges and barriers to supporting meaningful activity?**

Both survey respondents and interviewees identified issues related to training as major barriers to facilitating meaningful activities for people with sight loss and dementia. Lack of specific training resources plus lack of available time for dedicated training led to care staff having limited understanding of people's abilities to participate in different activities and a lack of explicit awareness of how challenges in supporting activity for this group might best be addressed.

Interview and survey participants were aware of locally successful approaches for overcoming many of the training-related barriers identified. Schemes perceived as successful focused on making staff aware of small changes that can make a significant difference to those with dual sensory impairments. Understanding the impact of the physical environment can prompt supporters to adjust it according to an individual's needs, for example by providing additional task lighting or shade from direct sunlight which might cause glare.

Interviewees also reflected on the different support needs of people who had lost their sight before the onset of dementia and those for whom dementia preceded sight loss. It was noted that people often experienced the latter as more challenging because it was difficult for people with dementia to remember the changes in routine that were necessary in order to adapt to their sight loss. One interviewee reflected on the safety issues such co-occurrence could introduce:

*'Do you teach someone to adapt their normal technique to try and pour in a different way, or do you teach a new technique like put it in the microwave and boil it in the microwave, which is a lot simpler and safer, but is completely unfamiliar to him [...] He puts it in [the microwave] it goes ping and he forgets about it. [...] It's about trying to work out what is the best.'*

### ***Adam, Interviewee***

Both interviewees and survey respondents described methods that they had developed to engage individuals with varying severity of both sight loss and dementia in meaningful activity. These included, for example, providing 'sensory bags' containing items to stimulate different senses and the use of gentle physical prompts to guide people to complete tasks.

Several interviewees reflected that despite it being possible to provide or devise meaningful activities for people with dementia and sight loss, these individuals often received less encouragement and support to engage in activities due to lowered expectations that often followed a dementia diagnosis.

*'The biggest challenge has to be understanding; not only of the visual impairment but also of the dementia. People really understanding what it means to live with dementia; what someone is able to do; how to encourage people to participate; and an expectation that they can participate.'*

### ***Carol, Interviewee***

## What resources are being used?

Survey respondents were asked to indicate which of a list of existing resources they had accessed in their roles as carers and professionals interacting with people with both sight loss and dementia. The most widely used resources were:

- ‘Getting to Know Me’, a profile for collecting information about a person needing support (mentioned by 47% of respondents)  
[www.scottishcare.org/docs/037\\_280\\_\\_gettingtoknowme\\_1369954145.pdf](http://www.scottishcare.org/docs/037_280__gettingtoknowme_1369954145.pdf)
- ‘Living Well Through Activity in Care Homes’ toolkit (24%)  
[www.cot.co.uk/living-well-care-homes](http://www.cot.co.uk/living-well-care-homes)
- ‘Pool Activity Level’ (‘PAL’) toolkit (20%) [www.jackiepoolassociates.org/](http://www.jackiepoolassociates.org/)
- ‘Making Every Moment Count: A guide for everyday living’ (19%)  
[www.scswis.com/index.php](http://www.scswis.com/index.php)
- My Home Life resources (11%) <http://myhomelife.org.uk/resources-and-information/older-people-relatives/resources/>

Other resources included publications from national organisations e.g. NAPA, Skills for Care; websites; local workshops; bespoke toolkits; leaflets on activities of daily living e.g. from RNIB and Macular Society.

## What forms of training would people like?

Responses to the survey highlighted the importance of resources supporting care givers and professionals to maintain a person-centred focus and, concerns about the pitfalls associated with poorly designed or targeted tools.

Survey respondents identified their preferred forms of training

- 70% face-to-face;
- 47% creation of a resource using case studies;
- 32% online learning modules;
- 21% online peer support; and,
- 21% having a checklist.

The overwhelming preference for face-to-face training may reflect the complex nature of the issue. Recognising that each person has a unique pattern or severity of sight loss and set of cognitive challenges associated with their dementia, unique abilities and capacities to engage in activity and a personal perspective on what is ‘meaningful’ to them, participants were wary of prescriptive approaches or ‘one size fits all’ guidelines for facilitating meaningful activity.

*‘What it would not be is a list of things that visually impaired people can do or would find interesting. ... For me it is not about the sight problem. Fundamentally, it is about the person, what they want to do and activities in general and then getting the [user of the resource] to think about what that particular person’s sight, hearing or cognition problems are and work back to the activity.’*

**Adam, Interviewee**



## Is there a need for new guidance?

Despite the availability of existing resources, 97% of survey respondents felt they needed further guidance if they were to effectively support individuals with both sight loss and dementia to access meaningful activities.

## Conclusions and issues for further consideration

Meaningful activity is important for health and wellbeing but there is a paucity of literature relating to people with both sight loss and dementia. The literature relating to dementia suggests it is seen differently by people with dementia and their carers. For people with dementia it can be about making a contribution to their family or community.

- Is this difference one you recognise?

There is consensus among academics and professionals that meaningful activity needs to be 'person-centred' i.e. it meets the needs and goals of individuals. However, too often a lack of training and low expectations mean people with sight loss and dementia are not offered meaningful activities and so don't experience the benefits.

There is a desire for further support to be available to inform the provision of meaningful activities to people with sight loss and dementia. Face-to-face training was seen to be preferred by most people.

- Is there a way to provide this face-to-face training?
- Who should be the priority groups for training?

The next best option was a resource with case studies, which would be welcomed by many. Any resource needs to stress that provision must be person-centred, reflecting individual abilities and what is meaningful to each person. Its message must stress that 'one size doesn't fit all'.

It is important to highlight that significant numbers of survey respondents were not aware of, or did not use, existing resources. Future research should focus not only on the development of specific tools and training resources to meet perceived professional needs but also on awareness-raising and dissemination activities to ensure that the resources are widely recognised and available to those who need them.

## References

Cohen, GD (2006) Research on Creativity and Aging: The Positive Impact of the Arts on Health and Illness. *Generations*, 30 (1), pp 7-15.

Harmer, BJ and Orrell, M (2008) 'What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers', *Aging & Mental Health*, 12 (5) pp 548-558

NICE (National Institute for Health and Care Excellence) (2013) 'Mental wellbeing of older people in care homes', NICE Quality Standard 50, issued December 2013.

Phinney, A (2006) 'Family strategies for supporting involvement in meaningful activity by persons with dementia', *Journal of Family Nursing* 12 pp 80-101.

Roland, K.P. and Chappell, N.L (2015) Meaningful Activity for Persons with Dementia: Family Caregiver Perspectives. *American Journal of Alzheimer's Disease and Other Dementias*, 2015 Mar 18. pii: 1533317515576389 [E-pub ahead of print].

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### **About Thomas Pocklington Trust**

Thomas Pocklington Trust is a national charity dedicated to delivering positive change for people with sight loss.

Research is central to Pocklington's work. The research we fund supports independent living and identifies barriers and opportunities in areas such as employment, housing and technology.

We work in partnership and share our knowledge widely to enable change. We provide evidence, key information and guidance for policymakers, service planners, professionals and people with sight loss.

We would welcome your views on any of the issues raised in this paper at [research@pocklington-trust.org.uk](mailto:research@pocklington-trust.org.uk)



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