

## **Emotional Support to People with Sight Loss**

**This publication summarises the findings from research conducted by the University of Reading, which was commissioned and funded by Thomas Pocklington Trust. Based at the Institute of Health Sciences, the principal investigators were Professors Margot A Gosney and Christina R Victor, and the post-doctoral research fellow was Dr Samuel R Nyman.**

Adjustment to acquired sight loss can be challenging in many ways, not least emotionally. Thomas Pocklington Trust commissioned and funded a research team at the University of Reading to assess evidence of needs for emotional support among people with sight loss and the most effective ways of meeting those needs. To identify this evidence, a series of systematic literature reviews was conducted, along with a scoping survey to ascertain the extent of available provision of counselling for people with sight loss in the UK, and interviews with people with sight loss. The key findings of the project are outlined below.

- Sight loss was described by some as devastating, and was linked with an increased need for emotional support.
- If a person with sight loss feels that they have good support from family and friends, then they are more likely to adjust well emotionally to sight loss and are less likely to report symptoms of depression.

- Whilst there is robust evidence that people with sight loss need emotional support, there is comparatively very little evidence on how to provide that support effectively.
- Further research is now required to determine effective ways of providing support in response to emotional needs, including the contributions of professional counselling, other psychological therapies, and more informal means of support such as peer groups and befriending schemes. Such research could provide evidence to inform the provision of a range of emotional support services that at present are not available locally to everyone with sight loss in the UK.

## **Introduction**

Acquired sight loss can be devastating. A person's whole way of life may dramatically change, for instance they may well have to curtail or relinquish activities they pursued as a sighted person, and their independence may be diminished. It is widely understood that such changes may have a negative emotional impact. To identify the evidence, Thomas Pocklington Trust commissioned a project to research the needs of people with sight loss for emotional support and the responses to those needs. The research aimed to update the existing evidence base by building on a previous literature review and highlighting areas for future research. The research team used systematic literature reviews of published and unpublished literature to accumulate the evidence from previous studies, a scoping survey of counselling services for people with sight loss in the UK, and interviews with people with sight loss. A systematic literature review investigates a clearly defined research question, using a systematic and explicit strategy to identify, include, and critically appraise research.

## **The need for emotional support**

The risk of depression is raised in older people with sight loss. Working age adults and older people with sight loss are more likely to report a reduction in mental health, quality of life, and social functioning. The evidence for a higher prevalence of symptoms of anxiety in people with sight loss was mixed, as was the prevalence of depressive symptoms in working age adults. From qualitative studies, emotional adjustment to sight loss appears to follow a cycle through stages similar to those described in the context of bereavement. Participants reported initial feelings of panic and distress, followed by devastation and depression, and finally acceptance of sight loss. Reports of depression were felt in connection with the loss of independence and in particular no longer being able to drive. In the qualitative studies reviewed, there was no evidence that perceptions of support from family and friends diminished in either age group with sight loss. This is important because the perception that family and friends provide good support appears to help prevent the onset of depression while adjusting to acquired sight loss.

In the interviews conducted by the research team social support, in the form of encouragement to accept and adjust to sight loss, and practical assistance were particularly appreciated. In contrast to the qualitative studies, some participants reported difficulties in their social relationships including fewer contacts after unemployment and the loss of friendships with sighted people who could not cope with them becoming blind. The social contact and support from peers with sight loss that was coordinated by voluntary organisations was appreciated, particularly by those feeling depressed and/or lonely.

In the published literature reviewed, the experience of loneliness among people with sight loss was under researched along with the emotional reaction to complex visual hallucinations in older people with sight loss.

## **Interventions to meet emotional support needs**

There was comparatively little published evaluation of interventions. Most of these studies were published pilot studies by academic researchers and client satisfaction studies by voluntary organisations. Two American randomised control trials suggested the value of training in self-management (information about their eye condition, making use of low vision aids, anticipation of common challenges, and explaining to sighted people their visual impairment) and problem-solving (how to come up with practical solutions to problems). Both those interventions prevented the onset of depression in the short-term. Further research is required to find out how to provide these interventions and how to achieve long-term benefits effectively.

The interviews conducted by the research team suggested that practical and mobility support provided by rehabilitation officers and by others close to the person with sight loss (family, friends, neighbours, etc.) was important to participants. However, the literature reviewed suggested that rehabilitation provided only a small factor in improving emotional well-being and reducing the risk of depression. Rather than indirectly addressing emotional support needs through rehabilitation, direct support through training in self-management or problem-solving may be more effective in helping people cope with the emotional impact of acquired sight loss. The interviews conducted by the research team suggested that counselling and group-based courses, which provide both information and peer support, were perceived as very helpful. Research is needed to evaluate the cost-effectiveness of, and effective methods for, providing these interventions.

## Conclusions

This project has updated available evidence to suggest that working-age adults and older people with sight loss are at an increased risk of requiring emotional support. Research attention now needs to be given to how people with sight loss want emotional support to be provided and to the effectiveness of different approaches to providing that support. Research findings could make the case for the provision of emotional support services that at present are not available locally to everyone with sight loss in the UK.

## Authors

The principal investigators for this research were Professors Margot A Gosney and Christina R Victor, of the Institute of Health Sciences, University of Reading. Thomas Pocklington Trust commissioned and funded the research, which funded the appointment of Dr Samuel R Nyman as post-doctoral research fellow.

## How to obtain further information

A short report, in the form of an 'Occasional Paper' entitled *Emotional Support to People with Sight Loss* by the research team is available from:

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## Background on Pocklington

Thomas Pocklington Trust is a leading provider of housing, care and support services for people with sight loss in the UK. Each year we also fund a programme of 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, resource centres and volunteer-based community support services.

We strive to improve continuously the quality standards in our operational centres to meet the changing needs and expectations of our current and future service users. We are proud to be an Investor in People and a Positive about Disability organisation.

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, and improving and developing service outcomes as well as focusing on public health issues.

*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



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