Research findings
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Thomas Pocklington Trust
Housing and support for
people with sight loss

AS LIFE GOES ON – A closer look at how support services respond to the changing needs of people with sight loss

Previous Pocklington-funded research has shown that the support needs of people with sight loss increase over time but that the support available is failing to keep pace. A more detailed follow-up study confirms that the changing needs of people with sight loss are still not being met.

Key findings:

The picture emerging from the follow-up study found that:

- Despite deteriorating sight and other difficulties in their lives, the majority of participants were coping reasonably well.
- People were often dependent on informal networks of support, and for many of them this was unreliable, leaving them vulnerable as their support needs and options changed.
- Little had changed in terms of contact with clinical services – there was still a lack of follow-up after diagnosis, leaving people coping alone or fearing abandonment.
- The introduction of Eye Clinic Liaison Officers (ECLOs) into hospitals was a potentially significant improvement. However, this development was undermined because long-standing patients were not being directed to them and many others who would potentially benefit from the service had long since been discharged from clinical eye care.

- A smaller group of participants was not coping well with their deteriorating sight and other changes in their lives. They had already shown a clear need for emotional, and sometimes practical, support at the time of the first study. In the meantime their emotional support needs had intensified, their quality of life had drastically diminished and their outlook was even less optimistic, but they were still not accessing adequate support.

Background:

In 2007 Pocklington funded a study of the changing needs of people with long-standing sight loss. It found that life events, ageing and deteriorating health all intensified the emotional and practical difficulties caused by sight loss. People's support needs increased, whether or not their vision was deteriorating, but these ongoing needs did not receive an adequate response. Support services focussed on providing support when sight loss was diagnosed - a short-term approach that excluded those with the greatest need and failed to make best use of rehabilitation to help people stay independent.

In 2010 a follow-up study investigated how the support needs and circumstances of participants had changed since their first interview. By focusing on just the three years since the original study, it presented a more detailed picture of the changes affecting those who took part in the study. The personal accounts of 21 of the original 37 participants revealed an ongoing deterioration in quality of life and a continuing lack of access to support.

Characteristics of the study participants

- The follow-up sample was made up of 13 women and 8 men, with a mean age of 72. 48% of participants lived alone.
- Twenty of the 21 participants were White British; the two non-white participants in the original study declined to take part in the follow-up.
- Participants came from a mix of rural and urban areas across North West England and North Wales.

- Sixteen of the 21 participants were retired; none were in paid employment.
- As in the original study, the most common cause of visual impairment was Age-related Macular Degeneration (AMD).
- The majority of participants were registered either Sight Impaired (7) or Severely Sight Impaired (11).

What the follow-up study found

Life changes and deteriorating health intensify the needs caused by sight loss:

While the visual health of most of those who took part had deteriorated over the three years, it was the changes to their general health that had the biggest impact on their lives. For some, ongoing or new chronic health problems combined with sight loss limited mobility, and this, together with an increasing inability to carry out such daily tasks as reading, cooking and shopping, eroded their quality of life.

Other life changes such as bereavement and redundancy created particular needs for emotional support. The 2007 study had already noted these support needs, yet no-one in the follow-up study reported having received any counselling or one-to-one emotional support. Although such services were available in the area studied, people did not always know about them or did not think they needed "counselling". This highlights a need for emotional support to be flexible and less stigmatising, and for people to be made aware of its existence and value.

Being with people is not enough to prevent loneliness:

Some of those most badly affected by loneliness did not live alone, but were in apparently supportive relationships. However, even when they were physically in the room with loved ones they could be emotionally cut off, unable to join in social activities such as watching television or looking through family photos. Previous studies have shown that loneliness makes adapting to sight loss harder and depression more likely, and so finding ways to draw people into shared activities is vital.

Dependency alters the quality of relationships:

Increased dependency caused, for instance, by children taking charge of a parent's activities can damage relationships. People coped best if they retained some level of control, for example a visually impaired person might write a shopping list for others to use.

Clinical care – not enough follow-up:

As in the original study, after initial support provided at the time of diagnosis, most services left it up to the individual to look for support – and not everyone was offered support at the time of diagnosis. This created a fear of leaving the system. Others who had already been discharged were upset that no attempt was being made to do more for them.

Access to support – still inadequate:

The first study confirmed that access to the right support could make an enormous difference to the way people coped with sight loss. But three years on, people still found it difficult to access local authority Social Services. Long waiting times, not knowing who to contact, limited follow-up and contact time and lack of resources were common problems. Only two of those surveyed were well-supported by social services but in both cases, this was because of “unofficial” contact. Either they personally knew a particular social care practitioner or they were given support for something other than their sight loss, e.g. a temporary physical impairment.

This inequality reflects a lack of recognition at policy level of the impacts of sight loss. The initial contact provided when a person is first registered is inadequate and the expectation that people will make contact again if they require more or continuing support is not working. People did not recognise that their sight was worsening or did not have the personal resources to pursue support, or simply did not know who to contact. At the very least, an annual mail-out to everyone registered, containing current contact details and an invitation to get in touch if their needs had changed could encourage people to seek help if it was needed.

Just as in the original study, most people coped by relying on a network of informal support which could be unreliable and gave people less control over their lives. One participant had not been able to shop at the supermarket for three weeks because the friend who usually took her had been ill. Paid practical support that is available on a flexible and ad hoc basis is needed.

Professional Awareness - sight loss still being overlooked:

Some of those surveyed clearly needed to be reassessed for registration as Sight Impaired (SI) or Severely Sight Impaired (SSI). Registration is key to accessing support, but once discharged from eye clinics, people's worsening sight may be overlooked. One participant had been registered SI for over a decade and had been discharged. Over time his sight had reduced until he could "barely see"; he felt he should be reassessed but other health problems had taken priority. Despite being in regular contact with his GP he was not referred for reassessment. This finding highlights the need for GPs to be aware of, and act on, changes in people's visual health.

Provision of information - one positive change:

Since 2007 the creation of the role of Eye Clinic Liaison Officers (ECLOs) has improved the provision of information to those newly diagnosed with sight loss. All hospitals used by participants in the follow-up study had ECLOs, yet existing patients, diagnosed years ago, were not directed to them. Eye clinic staff could help by reminding all patients, old and new, of what ECLOs offer. Some of those surveyed suggested placing volunteers alongside ECLOs to provide even more information and advice.

In general, the follow-up study found that the provision of information is still mainly ad hoc. There were examples of people only recently finding out about benefits they should have been receiving years ago. The voluntary sector is the primary source of information on sight loss and there is a need for this to be more readily available. A community facilitator, who could signpost people to appropriate services was suggested, with the role widely advertised through the local media, community groups and GPs.

The voluntary sector is vital but adds complexity:

The voluntary sector was acknowledged as playing a vital role - providing formal support and bringing people with sight loss together. Mutual support can be key to adjusting to sight loss and volunteering opportunities give people a sense of value through helping others. However, the range of organisations can be confusing and there is a particular need for information about sources of support to be better co-ordinated.

More help needed to stay independent:

Some participants in the study would clearly have benefited from vision rehabilitation support, such as mobility training and help to use low vision aids (LVAs) to carry out daily tasks. While most were using some LVAs, such as magnifiers, access to these resources was patchy and people were not automatically assessed to identify which aids would be useful. Provision of more complex assistive technology designed for specific tasks was even more variable, with some areas providing free resources and others charging what were seen by some as prohibitive costs.

Mobility aids such as guide dogs, long canes and the white symbol cane, are known to improve independence but just providing the aids is not enough. In the case of the white symbol cane, participants struggled to use it and feared that it marked them out as a vulnerable target. Help with using the canes is needed at the time of registration and also via voluntary sight loss organisations.

Work to improve public transport for people with sight loss is also needed. Buses were particularly unpopular, with reports of unhelpful drivers and buses not stopping. Training for bus drivers in raising awareness of vision impairment, and help for people with sight loss to make better use of the white symbol cane could help people get around. New technologies, such as talking bus stops could also be considered.

What could make a difference? The study recommends:

- Make it easier for people to re-access services beyond initial diagnosis and registration. Follow-ups should be routine with at least an annual mail-out to everyone who is registered as sight impaired or severely sight impaired, inviting them to get in touch for information or for reassessment if their needs have changed.
- Integrate services so that referrals between services are more systematic and provision of information more consistent and thorough.
- Create accessible community-based facilitators to direct people to services.
- Raise awareness of sight loss amongst GPs so that they look for changes in visual health, and are alert to the interaction of sight loss with other physical health conditions and of the links between sight loss and depression.
- Protect and promote support groups. Their role is crucial in helping people to adapt and cope but pressure on funding could force them to compete for resources with what might be seen as more important services.

Author

Sue Cooper
Media/PR consultant

How to obtain further information

This paper is a brief summary of the key findings of the report "Changing Needs of People with Sight Loss: Follow Up Study" by Dr Suzanne Hodge, Dr Paul Knox, Dr Jude Robinson and Dr Clare Thetford, University of Liverpool which is available from:

Thomas Pocklington Trust
Pier House
90 Strand on the Green
London W4 3NN.

The findings from the original study conducted by Clare Thetford, Jude Robinson, Paul Knox, Jignasa Mehta and David Wong from the University of Liverpool have been published as Occasional Paper number 17 and Research Findings number 20 entitled The Changing Needs of People with Sight Loss, published by Thomas Pocklington Trust and available at www.pocklington-trust.org.uk.

Background on Pocklington

Thomas Pocklington Trust is a voluntary sector organisation providing services across England which assist and enable people with sight loss to reach their potential. Our five strategic aims are:

Knowledge: we increase understanding of how to prevent avoidable sight loss, how to provide the most effective support to alleviate sight loss and how to apply this knowledge.

Empowerment: we enable people with sight loss to have control over their lives and their services.

Services: we provide services that people with sight loss need.

Housing: we help people with sight loss to get and keep a home that meets their needs.

Sustainability: we will be there for the long term future.

Research is a keystone of our 'knowledge' strategic aim. We manage a programme of research to identify and promote practical ways in which Pocklington and others can improve the lives of people with sight loss.

Our research team works with a range of partners who are recognised across the sight loss sector and in the academic world. We welcome collaborative opportunities and research proposals related to our main themes and priorities. You can find out more about Pocklington and its research programme at **www.pocklington-trust.org.uk.**

Thomas Pocklington Trust
Pier House
90 Strand on the Green
London W4 3NN

Telephone: 020 8995 0880
Email: **research@pocklington-trust.org.uk**

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 have partial sight.

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Web: www.pocklington-trust.org.uk

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