Establishing the optimal point for engagement on the sight loss journey

Service user perspective

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Action for blind people

Part of RNIB Group

Contents

1. Introduction

In 2013, Action for Blind People (Action) conducted research into the experiences of blind and partially sighted people before, during and after their sight loss diagnosis. Action's staff had received anecdotal evidence that some people newly diagnosed with sight loss were not receiving sufficient information and support at, and directly after, the point of diagnosis.

This report provides an overview of our findings, and a crucial insight into the support requirements of people at various stages of the sight loss journey.

1.1 Aims

Our aims were to establish:

1. The information, advice and support that would be beneficial to service users at various points throughout the sight loss journey.
2. The long and short term benefits of providing information shortly after diagnosis.
3. Action's role within this.
4. The role that people who are going through, or have been through sight loss, can play in support provision.

1.2 Sampling and methodology

Research was conducted by Action's Early Reach Strategic Network through a combination of telephone and internet surveys. The survey was sent to approximately 1360 people who are blind or partially sighted. In total we had 166 respondents.

Of the respondents, four in ten were educated to degree level or higher. Seven in ten were in employment at the time of losing their sight, however, at the time of research three quarters of respondents were out of work. Ages ranged from young people to pensioners, although the majority fell into the 41 to 60 age bracket (40%) or the 61 to 80 age bracket (35%) which is commensurate with Action's age demographic.

The survey questions were determined as a result of five focus groups. These were conducted with blind and partially sighted people across the country to discuss whether there is an optimal point for engagement on the sight loss journey from the perspective of the service user.

2. Key findings

- 86% of respondents feel they would have benefited from having information about sight loss between their visit to the GP/optician and the hospital appointment.
- Only 15% of respondents felt prepared for their first eye clinic appointment.
- Over 90% of respondents feel they would have benefited from talking to someone after diagnosis who could explain their situation in simple terms. Of those, 81% wanted to speak to someone within two weeks of diagnosis.
- One in five respondents experienced feelings of grief, anger, panic and shock when they found out they were losing their sight.
- 66% of respondents would have liked to have been given the option of counselling.

3. The journey

3.1 Pre-diagnosis

67% of respondents stated that they visited the optician upon realising there were potential problems with their vision. However, when asked whether they were referred to the eye hospital by the optician or the GP, nearly 62% of respondents stated that they were referred by the GP which is in line with current referral procedure.

Of the remaining 38% who did not indicate they had been referred by the GP, some were unable to recall how they had been referred to the eye clinic whilst others were admitted as an emergency self referral when they noticed sudden loss of vision.

These findings indicate that GPs are the main referral route for people into the eye clinic. This raises crucial questions about the role GPs play in preparing and/or supporting patients during their sight loss journey. This issue is particularly pertinent, bearing in mind that GPs receive hospital reports on their patients and therefore have significant involvement in ongoing condition management.

Our research indicates that the role of the optician is also important in early sight loss experience. With 67% of respondents stating that the optician is their first point of contact when they notice problems with their vision, there is a clear need for opticians to be well equipped and informed about services that can provide patients with support outside of their clinical needs.

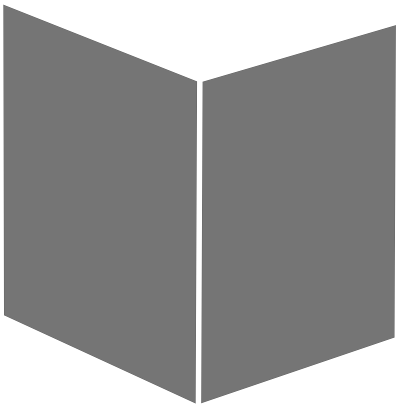
Photograph (above) of a woman wearing glasses. Snellen's in the background.

During the focus groups, respondents described the range of emotions they felt at the stage between seeing the GP/optician and their appointment at the hospital. A list of possible emotional responses was compiled and included in the quantitative research.

Nearly half of all respondents (44%) were fearful when they realised they had developed problems with their sight, partly because they didn't yet know the full extent of their sight loss. Over 34% experienced feelings of anger and frustration and 29% felt distressed/depressed. One in five felt grief even before they had been diagnosed.

These findings clearly demonstrate the need for structured support in the intervening period between patients finding out they have potential problems with their sight, and their condition being formally diagnosed at the eye clinic. Failure to provide that support could lead to heightened anxiety, or worse: as one respondent put it "I felt suicidal, I just wanted to die."

We asked respondents how aware they were of organisations that could support them with their sight loss. Half of all respondents were not at all aware of where to turn to for help, information and advice. Less than 7% knew about organisations they could contact for support at the time. A majority of respondents (86%) said that an information pack including information about eye conditions, available support and relevant organisations would have been useful at this time.



86% of respondents feel they would have benefited from having information about sight loss between their visit to the GP/optician and the hospital appointment.

3.1.1 Registration

Nearly 62% of respondents would have found it useful to have been informed about the possibility of registration by their GP/optician before the eye clinic appointment. One of the reasons given was that people wanted to get a sense of the extent of their sight loss before they received the final diagnosis.

In another survey conducted by Action of over 280 blind and partially sighted people, just 20% had been registered. This compares to a registration rate of over 90% for Action's own service users – a clear indication that provision of registration information at, or shortly after, the point of diagnosis could be beneficial to patients.

As you would expect, opinions varied on the precise point at which registration information should be supplied. For some, the eye clinic was the appropriate place for this information, whilst others would have preferred to have been told at a later date when they'd had time to digest their situation. For those who experienced sudden loss of vision, many felt that there simply wouldn't have been time to discuss peripheral issues like registration, as healthcare professionals were focussed solely on clinical matters.

When asked about provision of information before the eye clinic appointment, 65% of people stated that they wanted information at this time, including: what to expect at the eye clinic and during the appointment; information on all suspected eye conditions; contact information for charities and organisations who can provide help; and some brief information about living with sight loss and where to find help if needed.

The question now is how well equipped GPs are to provide this kind of support to people with a suspected visual impairment, pre-diagnosis. A survey currently being conducted by the Royal College of General Practitioners (RCGP) is assessing general practitioner understanding of visual impairment and may go some way to answering this question. It is hoped that their findings may result in increased awareness of sight loss amongst GPs and subsequently, better information and support for patients.

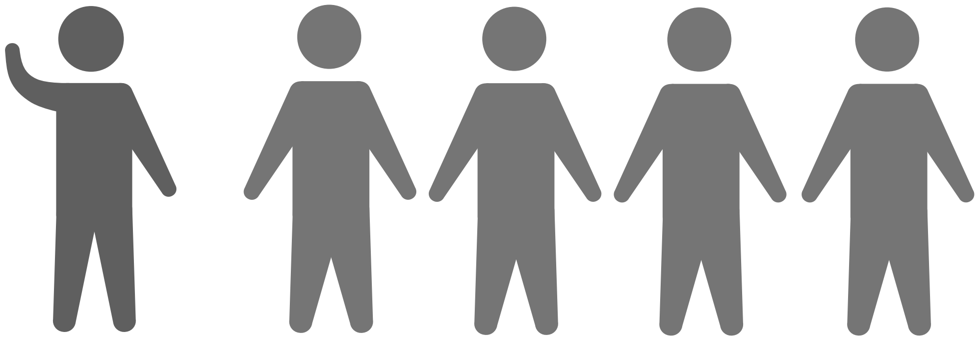
In addition to medical care from healthcare professionals, 55% of respondents said they would have liked to speak to someone who had been through a similar situation. Similarly, 51% felt that they would have benefited from speaking to a medical professional or other professionals from sight loss charities. Only 14% of respondents stated that they did not need to speak to anybody.

Our evidence clearly shows that people would find it useful and reassuring to have some information, either as an information pack, or through contact with another blind or partially sighted person or a professional at the early stage of sight loss, even before they are fully diagnosed.

The survey asked participants how prepared they felt for their appointment at the eye clinic. Only 15% felt that they were fully prepared for their appointment with 40% of respondents feeling not at all prepared – although no further comments were given as to what would constitute preparedness.

As we would expect, a high proportion of respondents (76%) confirmed that they would have welcomed contact from someone to tell them what to expect when they were waiting for an appointment. The 24% who did not feel the need for contact at this stage gave multiple reasons for their position, including: the fact that they were in denial and therefore wouldn't have been able to process such information; the fact that they were still confident about their prognosis; or they were emergency self-referrals into hospital after sudden loss of vision.

Feelings at this stage were mixed. Some people were optimistic about their prognosis and expected to make a full recovery, whilst others experienced worry, fear, frustration and grief.

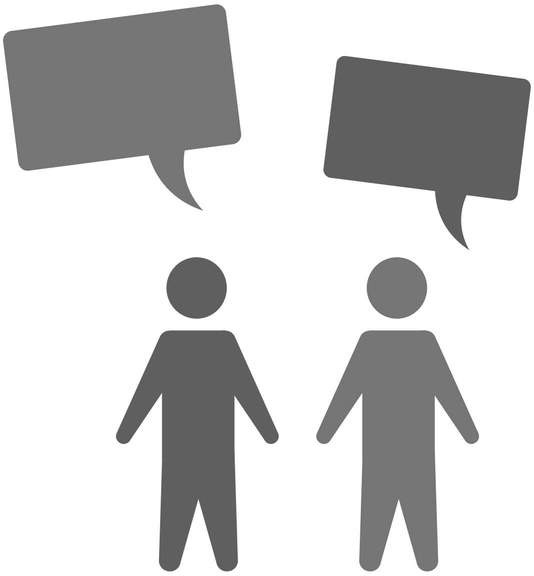


One in five respondents experienced feelings of grief, anger, panic and shock when they found out they were losing their sight.

3.2 Post-diagnosis

Our results demonstrate that a majority of people (92%) would appreciate talking to someone after diagnosis who can explain their options in simple terms.

Of those who expressed a desire to speak to someone, nearly 79% would prefer to talk to someone who had gone through a similar ordeal. Around half of respondents were keen to find out about available services and support at this stage, but only a small proportion (38%) felt that this was an appropriate time to give information to their friends and family.



92% of respondents would appreciate talking to someone after diagnosis who can explain their options in simple terms.

With regards to the timing of speaking to someone, 39% of respondents felt the need to talk to somebody at the point of diagnosis whilst 42% felt within two weeks would have been ideal. In comparison, 7% wanted contact later than a month and less than 1% indicated that they never wanted to speak to someone.

Opinions were mixed on the type of information that respondents wanted to receive. Some wanted to be given information and contact details for the appropriate organisations so they could make contact in their own time, whilst others wanted to leave their telephone number so that a sight loss organisation could contact them.

Photograph (above) of a signpost showing directions to past, present and future.

There has been substantial debate within the sector about whether counselling ought to be offered to people diagnosed with sight loss, and if so at what stage. 66% of respondents indicated that they would have liked the option to receive counselling compared to 34% who did not require counselling. In terms of the timing of receiving counselling, responses were mixed but most felt that soon after diagnosis, up to a few weeks after diagnosis was preferable.

66% of respondents would have liked to have been given the option of counselling.

3.4 UK Adult Sight Loss Pathway (2013)

Before drawing any conclusions from this report, it’s worth visiting the UK Adult Sight Loss Pathway (2013) to compare the pathway recommendations and the findings of this survey.

The framework clarifies the pathway across health and social care, enabling better partnership working and a smoother transition for the patient (UK Vision Strategy 2013). The pathway is a process map describing how the principles of best practice can be applied to service delivery for adults with sight loss so that they can enjoy:

- Early interventions to address their presenting needs, as a right.
- Visual impairment rehabilitation as an early intervention, delivered by specialist, qualified professionals.
- Interventions that help them maximise their functional vision.

In the pathway, early intervention starts post-diagnosis. While guidance notes in the UK Adult Sight Loss Pathway (2013) clearly state that intervention could be instigated at any point, the pathway does not include provision of any information pre-diagnosis.

This is in contrast to the view of 86% of our respondents who said that they would have benefited from information from a professional prior to diagnosis.

3.5 Seeing it My Way outcomes

It should be noted that the Adult Sight Loss Pathway aims to achieve the ‘Seeing it My Way’ outcomes. Seeing it My Way is a framework that describes the outcomes that blind and partially sighted people would like to have in their lives. The outcomes are underpinned by a philosophy of ‘nothing about me without me.’

Five out of ten of these outcomes include the word information, or refer to the provision of information. In addition, the supply of information is integral to the delivery of the remaining outcomes.

The findings of this report support the Seeing it My Way outcomes, which recognise the importance of people with sight loss having early access to tailored, comprehensive support and information appropriate to their needs.

4. Conclusion

The provision of relevant information is vital at all stages in the sight loss journey. Early indications of sight loss can be upsetting for many patients, so relevant information should be provided wherever possible, and especially information which prepares the patient for the next stage of the process. Patients should have a good understanding of the pathway they are on, and of what will happen at each point throughout their eye care journey.

After diagnosis, information and support is essential to reassure patients and demonstrate the breadth of options that are available to them.
In addition, information about the benefits of registration would be beneficial. Our research shows that significant numbers of people are not being registered, and therefore are missing out on the benefits they’re entitled to.

Our research shows that people prefer to receive information at different times throughout their diagnosis, so clinical staff and sight loss organisations should offer advice in a sensitive manner, recognising that some people will not be ready to process this information for some time.

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