

# Patients with severe sight loss

## Emotional support and counselling

**T**he importance of emotional support and counselling for people with severe sight loss, especially in the early stages, is increasingly recognised as an integral part of eyecare services. This article looks at the evidence for this, discusses what emotional support actually is, and suggests ways in which you can develop your practice to help people come to terms with their sight loss and their changed lives.

Readers of *OT* will be familiar with the demographics and the anticipated increase in people with serious sight loss. According to current estimates, one in 12 people over 60 are registered blind or partially sighted, and the number increases to one in five by the age of 75<sup>1</sup>. Over 80% of people with sight loss are over 60 years old and more than 12% of people over 75 have corrected visual acuity of less than 6/18. By 2036, there may be well over a million people in this age group. In addition, large numbers of older people have reduced vision, which makes daily living extremely difficult, but is not severe enough to make them eligible for registration.

The National Eye Care Steering Group report (2004)<sup>2</sup> points out that two-thirds of people with sight loss will have an additional disability. Hearing loss or difficulty in walking, for example, add to the sum of disabilities which can greatly reduce a person's self-confidence and make many aspects of life harder. Older people may have supportive family and friends, but often they will be increasingly isolated. Familiar people move away and it becomes more difficult to make new contacts. Some will be caring for a partner who has their own difficulties, for example dementia. Many will be living alone after the death of a spouse.

Partially obscured in these facts and figures are the individual human lives you encounter in your daily practice. Patients look to you not only for an accurate prescription, an understandable explanation of their eye condition and the help available, but also for some sympathy or comfort if they are facing visual impairment. Many will appreciate your understanding as much as, or more than, the precise skills, training and experience you bring to your work.

### What is emotional support and counselling?

The simple answer is that emotional support is everything we do when we are there for someone who is going through a hard time in their lives. When we offer time and attentive listening, when we don't judge but occasionally make

constructive suggestions, we are providing emotional support. If we allow the person to articulate their feelings and to know that we do not consider them weak, silly or inadequate, we are also letting them know they are not alone, and allowing them 'space' to work out their own solutions.

The word 'counselling' is often used day-to-day in a general sense, but in this article it is used to describe the more formal psychological therapy provided by a qualified professional. Counselling provides a non-judgmental, confidential setting which can enable clients to gain perspective and a better understanding of their situation, and to develop more effective ways of dealing with potential problems. Counselling may be face-to-face, by telephone, individual or in groups.

We all need emotional support at times in our lives, especially times of transition or difficulty and most of us will turn to friends, family, colleagues and, on occasion, to professionals such as optometrists. Not everyone needs counselling, however serious the life event, but it can be helpful if more time and assistance are needed than the informal network can provide.

### Why emotional support in optometric practice?

Severe visual impairment is many people's greatest fear. It conjures up images of dependence and helplessness, even loneliness and abandonment. When facing recently diagnosed or deteriorating sight loss, many people will need to express their feelings, fears and anxieties. Bottled up or ignored, these feelings do not go away, but can worsen and prevent the patient from taking constructive action. From your point of view, the patient may appear distracted, distressed, angry, disbelieving or stoical and minimising the impact of what is happening.

Optometrists know the distress and sometimes turmoil caused by a diagnosis of severe sight loss. Sometimes you have to be the bearer of bad news, or the professional who finally confirms the patient's worst suspicions. Not only the patient, but often their family and friends



will be involved.

Sight loss is often likened to bereavement and, as with any major loss in life, people need to grieve before they can move on. This process is often helped by timely support from family, friends and professionals. It is natural to hope against hope that vision will be restored and reactions may vary greatly when people realise this will not happen. Some people will go into a period of denial, not accepting that the loss is permanent, while others may become depressed or extremely angry. Anger can spill on to the optometrist, perhaps in the form of blame. Family and friends also need time to adjust to what this means for themselves, as well as for the visually impaired person.

### Older people and sight loss

The majority of people facing visual impairment are approaching, or well into, retirement. Severe sight loss will usually have a different, possibly less obviously dramatic, impact on their lives than it has on children or people of working age. Nonetheless, the consequences can be very serious and far-reaching.

There is substantial evidence to show that rates of depression are at least twice as high among older visually impaired people than in the general population<sup>3</sup>. People with depression have been found to be 64% less likely to use any rehabilitation services. In addition, the person's subjective experience of sight loss, together with social support, appears to be much more important than the actual severity of the sight loss as measured in clinical practice<sup>4</sup>. This may be due to a number of factors including attitudes of others, societal discrimination and difficulty in accessing appropriate support and services.

It is often assumed that older people will not wish to talk about their feelings,

but this is absolutely incorrect<sup>5</sup>. Telephone based emotional support and counselling provided by the Macular Disease Society, the RNIB and local voluntary agencies for visually impaired people have a consistently high level of demand, which cannot always be met with available resources.

### What can optometrists do?

The answer is – a great deal. Optometrists and other practice or clinic staff are often in a key position in the patient's journey to provide initial support and to signpost to appropriate support services. No-one in optometry needs to be reminded of the pressures of clinic lists or busy private practices. Patients can be late for appointments and inarticulate or unsure when answering questions, especially if they feel frightened or intimidated. However, even in a short appointment, the optometrist can listen to the patient's initial concerns and make constructive suggestions about the next steps.

### Listening, signposting and counselling services

As well as the optometrist, other staff, including dispensing opticians, optical assistants and receptionists, according to their own work demands, may be able to provide more time and support when necessary. Some might be interested in a basic listening skills or introduction to counselling course. This would be a valuable addition to any practice, as well as giving the staff an opportunity to develop additional skills. Training ranges from one-day workshops to one-year part-time courses leading to nationally recognised qualifications.

A small but significant number of patients who experience sight loss need professional counselling support over a period of time. GP practices often provide generic counselling or have information about local and national services. In some areas, there are well-developed and highly professional volunteer counselling services. Referral systems may already be in place with local Community Mental Health Teams (CMHT) or GP services. Counsellors will probably not be familiar with sight loss issues and services, but will be able to support people whose visual impairment has triggered other issues.

### Simple information

Most people with severe sight loss will have been seen in the hospital eye clinic, but often leave feeling confused and uncertain of what they have been told<sup>6</sup>. Many will return to their own optometrist, and this is the opportunity to help them by ensuring that information about eye conditions in straightforward language is available. This will not only help the patient, but also their family and friends. Many of the national voluntary organisations such as the RNIB, the

Macular Disease Society and the International Glaucoma Association publish this kind of information.

Information even if it is only a few essential contact telephone numbers for the local rehabilitation worker, social services, the local voluntary society, as well as national organisations is key to helping the patient make vital contacts and to move on. Some organisations provide telephone support and counselling, and local voluntary organisations often offer peer support and information.

### A new opportunity for optometrists

Optometrists are now in a new and uniquely useful position to enable their patients to access local social services for timely assistance through the Low Vision Leaflet (LVL)<sup>7</sup>. It has been shown time and time again that early support promotes independence, increased confidence and vital adaptations to life with poor sight.

There are three stages to the new registration and referral process, but from the optometrist's point of view, the most important document is the LVL, a document of self-referral issued by optometrists and dispensing opticians to people with uncorrectable sight loss. All you or the practice/clinic staff have to do is give the LVL to the patient and explain that this is an opportunity to contact social services for help. The patient completes the form and sends it off themselves. It is a simple process, and a unique chance to help patients.

LVLs can be obtained from your local social services sensory team impairment team. You can offer the LVL to any patient who you have identified with significant sight problems and who feels that support would be helpful<sup>8</sup>.

### Rehabilitation and social services

Rehabilitation workers, or officers, are specialists, trained to work with visually impaired people to help them achieve maximum independence and come to terms with their sight loss. They are employed by many social services departments and sometimes by voluntary organisations for people with sight loss.

Rehabilitation work is largely based on what the person can see, not what they cannot. The emphasis is on working with people to enable them to make the maximum use of their remaining sight to do what they need and wish to do in life. This is often referred to as the functional approach to low vision.

### Low vision integrated services

The numbers of people attending the practice with sight loss must be expected to increase with the increasing proportion of people aged over 60. Taking this into account, along with the guidance from the

National Eye Care Services Steering Group report, there will be an increasing demand for the delivery of low vision services integrated with rehabilitation services. Now is the time for optometrists to review what they offer people with low vision and take the opportunity to develop this area of their practice and skills.

### Inter-professional working

From the patient's perspective, the more linked, or integrated the service, the more they are helped and the more sense it all makes to them. Currently, the person facing sight loss usually has to cope with a range of discrete services, each helping with one part of their lives, but not connecting or linking in a way which necessarily comes together for them. It is often left to the patient to connect the different services to make some integrated sense in their individual lives, at a time of great anxiety when it is most difficult to do so.

The more joined-up and supportive the services, the more patients can benefit and move through the trauma of sight loss to lead independent and fulfilled lives.

### About the author

Sheena McBride is Early Intervention Projects Officer for the RNIB Service Development Department.

### Acknowledgement

Image by courtesy of Keeler.

### References

1. ADSS (Association of Directors of Social Services) (2002), Progress in sight; National standards of social care of visually impaired adults.
2. NHS Modernisation Agency (2004) National Eye Care Services Steering Group First Report.
3. Burmedi, Becker *et al* (2002) Emotional and social consequences of age related low vision. *Visual Impairment Research* Vol 4: 1.
4. Horowitz, Brennan *et al* (2003) Depression, disability and rehabilitation among vision impaired elders. Lighthouse International.
5. Nelson A (1999) The individual support needs of older people with serious sight loss. RNIB.
6. McBride S (2000) Patients talking, hospital outpatient eye services: the sight impaired users' view, and McBride S (2001) Patients talking 2. The eye clinic journey experienced by blind and partially sighted adults: A quantitative study.
7. The LVL has replaced the LVI (Letter of Visual Impairment).
8. See [www.sightlossmatters.com](http://www.sightlossmatters.com) for further information about the new certification system.