

A woman with shoulder-length brown hair and bangs is shown from the chest up. She is wearing a light-colored, long-sleeved button-down shirt and a grey scarf with white polka dots. Her hands are clasped together in front of her, and she has a thoughtful or concerned expression on her face. The background is a bright, out-of-focus window. In the bottom right corner, a portion of a blue patterned cup is visible.

Hanging by a thread

**Maintaining vital eye clinic
support for people diagnosed
as losing their sight**

Introduction

Every day 100 people in the UK start to lose their sight. For some people, it is a gradual process. For others, it happens overnight. For all, it is life changing and can have a huge emotional, psychological and financial impact.

The effect of sight loss can be profound, with people reporting a sense of loss, doubt and confusion over their future.

“Because the cause of my sight loss was not easily identifiable there were a lot of unanswerable questions and uncertainty. It was not clear if the loss was permanent, temporary or would partially or fully recover or deteriorate. It was very much wait and see and hope for the best. Because I had no definite diagnosis I was left in limbo and did not know what would happen.

I could not see fine details and small print so could not do my job as a primary teacher. I needed to learn how to manage the symptoms and thought there must be ways of overcoming the barriers so I could return to work. I feared for my job and future. I went home where I became steadily anxious and frightened for my job.

I then heard of an ECLO. The next time I was in the hospital I dropped in and I spoke to a very nice lady. She gave me some information so I knew where to access help when I was ready. She also got me seen at the Low Vision Clinic there and then and I was given a magnifier which then enabled me to read letters and other important things. Three years later the magnifier is my lifeline and I can't be without it. For the first time in months I had hope and a way of enabling me to do things independently without having to rely on others and that was thanks to the ECLO”

Amy

“For the first time in months I had hope and a way of enabling me to do things independently”



Eye clinics are full to capacity, and demand for services is set to increase. Over 80 per cent of recently surveyed ophthalmologists and ophthalmic staff across England told RNIB that their eye department has insufficient capacity to meet current demand (1). Medical staff are under huge strain to diagnose and treat patients and do not have the time they would like to discuss with patients how to manage their eye condition and what support is available.

Worryingly nearly a quarter of blind and partially sighted people (23 per cent) leave the eye clinic not knowing, or unsure of, the name or nature of their eye condition (2). This can cause distress and confusion for patients. Luckily for some, help is at hand. Across England there are established support services for patients, known as Eye Clinic Liaison Officers (ECLOs), vision support officers or sight loss advisers.

However, we are very concerned that in many areas funding for ECLOs is under threat which could imminently remove this vital support from patients at their greatest time of need.

Short term and complex funding arrangements mean that many essential ECLO services are hanging by a thread. When this breaks, vital support for patients disappears and they are left to fall into a black hole.

As of February 2014, half of the ECLO services which RNIB and Action for Blind People are contracted to deliver did not have guaranteed funding past April 2014. Of the remaining half, four out of five ECLOs were employed on contracts due to end in 2015. This means that 9 out of 10 ECLO posts have extremely uncertain futures.

This is only the tip of the iceberg. RNIB and Action are only contracted to deliver one in four of the ECLO services in England. The remaining services are provided by other organisations. Many of these contracts are also reliant on insecure funding.



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RNIB is urgently calling for funders to:

- 1. ensure ECLO posts that are at risk of ending in 2014 receive the urgent funding they need to continue**
- 2. create and implement long term plans that include sustainable funding for this vital service.**

“It is eminently obvious to all of us that the service provided by the ECLO post is invaluable to patients. Withdrawal of this will have seriously adverse effects on the care of patients with sight loss and also on the ‘patient experience’ which is an important part of the ethos of the NHS and indeed our Trust. Sight loss in some instances is incredibly distressing for patients and the psychosocial and emotional support networks that the ECLO is an expert in providing are totally essential.

I would state categorically that the ECLO post must remain in order to maintain ethical care of our patients. The ECLO may not give you sight but will put in place supportive networks that will let you live a decent quality of life.”

Dipak Parmar, Consultant Ophthalmic Surgeon.



Impact of sight loss

Sight is the sense that people fear losing most. This was true for 89 per cent of people asked to choose between the five senses (3).

Sight loss can impact on all aspects of a person’s life, including independence and wellbeing. For many it creates a fear of becoming dependent on carers and spouses. Nearly half of blind and partially sighted people feel moderately or completely cut off from people and things around them (4).

Sight loss can also lead some to give up work. Over a quarter (27 per cent) of registered blind and partially sighted people report that the main reason for leaving their last job was the onset of sight loss or deterioration of their sight (5). Many might have been able to continue in employment if they had received the right information and support at the time of sight loss.

Nearly half of blind and partially sighted people feel moderately or completely cut off from people and things around them.



“[If it wasn’t for my ECLO] I would probably have given up working and gone on to benefits.” Rachel



Being there

An ECLO plays an essential role in providing recently diagnosed people with the practical and emotional support needed to understand their eye condition and adapt to living with sight loss and maintain independence.

They work closely with medical and nursing staff in the eye clinic and local authority sensory teams, and offer time to patients and carers following a consultation with the ophthalmologist.

ECLOs receive professional training, in most cases through the Eye Clinic Support Studies Course accredited by City University London and run by RNIB. This equips ECLOs to competently address the emotional and practical needs of people experiencing sight loss. RNIB also runs networking events, including Eye Clinic Staff seminars, for professionals to meet other early intervention support workers, and share best practice in a peer support environment.

The Royal College of Nursing (RCN) classifies an ECLO as an Allied Health Professional and recognises them as a “Health Care Assistant”, acknowledging the importance of the role within a hospital setting.

ECLOs are an important part of an eye clinic team



The Royal College of Nursing (RCN) classifies an ECLO as an Allied Health Professional Member and recognises them as a “Health Care Assistant”.

and can help to fulfil unmet need. An ECLO can:

- **support patients to comply with eye treatments and to manage their condition independently. For example supporting glaucoma patients to understand the importance of taking their eye drops every day to prevent avoidable sight loss**
- **process Certificates of Visual Impairment (CVI), so that patients are referred onto social care in a timely manner to receive the care and support needed**
- **provide emotional support and advice to distressed and vulnerable patients**
- **advise on falls prevention**
- **provide a personal service, sensitive to the physical and emotional needs of the patient**
- **signpost and refer onto local and national services**
- **promote independence and reduce isolation through providing information and advice.**

Saving money, saving time

In eye clinics across England ophthalmologists and ophthalmic nurses are under enormous pressure to diagnose and treat an ever growing number of patients. Whilst they are able to provide some basic information and advice, they often do not have time to provide the level of support that an individual may need.

Patients can be left to struggle to get the information and support to either manage their condition and maintain what sight they have or to adapt to living with sight loss.

ECLO services are widely valued and respected by eye clinics, social care services, and Clinical Commissioning Groups (CCGs) and we applaud commissioners and clinics that have taken the steps to employ an ECLO.

Patients can be left to struggle to get the information and support they need.

“The development of training, funding and roll out of the Eye Clinic Liaison Officer programme has been the single most positive step in health and social care integration in recent years. The resulting emotional, practical and financial help and the important signposting to self help has transformed the lives of the many people with either recent onset or established visual impairment and disability. ECLOs are available throughout the week in the many eye clinics around the country to provide timely assistance to both patients and to clinicians alike. When the latter are unable to further improve an individual’s sight or support their needs for linkage with rehabilitation and other quality of life services.”

**Andy Cassels-Brown, Consultant Ophthalmic Surgeon/
Community Eye Health.**

Good for patients

Being told that you may lose your sight is invariably distressing and patients need the time to ask questions not just about their eye condition and any treatment, but also to talk about the emotional impact and practical implications of sight loss.

A survey of patients who have had contact with ECLO services in London, the South East and Wales found that patients valued the service for providing them with information (6).

- **On average, 94 of every 100 people supported by an ECLO said they came away aware of services available to them when they leave the hospital.**

- **77 said they understand more about their eye condition.**
- **66 said that they understand the role they will have to play in their own treatment.**

“Speaking to the ECLO takes the worry out of your already worried mind. When you want to know anything, she’s there. If she doesn’t know the answer to your question, she points you in the right direction. She’s worth her weight in gold.”

Dennis



Good for commissioners

A recent review of evidence on the link between falls and sight loss found that almost half (47 per cent) of all falls sustained by blind and partially sighted people could be directly attributed to their sight loss (7).

On average, the estimated medical cost of falls nationally is £269million. Of the total cost of treating all accidental falls in the UK, 21 per cent was spent on the population with sight loss (8).

ECLOs are able to refer patients onto fall clinics within the hospital and to social care support services which may be able to provide information and advice on avoiding falls in the home.

They are also able to help patients to avoid future sight loss through helping them to understand and comply with managing their condition. Many glaucoma patients have to take eye drops every day for the rest of their life and attend regular follow up appointments. By not taking eye drops correctly, patients are at high risk of further sight loss (9).

Patients at high risk of non-adherence often have complex needs and chaotic lifestyles. It is estimated that approximately one in four patients do not comply with glaucoma medication (10).

In some eye clinics, St Helens, Merseyside for example, ECLOs act as glaucoma educators. They provide practical support to high risk glaucoma patients and follow up the support with home visiting staff. This approach has shown signs of success in developing awareness and supporting compliance.

Almost half of all falls sustained by blind and partially sighted people could be directly attributed to their sight loss.

The benefits of such networks are recognised by recent glaucoma treatment guidance produced by the College of Optometrists and Royal College of Ophthalmologists (11): “Services need to be in place to support patients who have suffered significant visual loss from glaucoma and patients who find it difficult to administer eye drops themselves.”

Minimising falls and improving compliance to medication are just two ways that ECLOs can help maximise commissioner’s investment in patient care.

Good for ophthalmology departments

Ophthalmology departments in England are under enormous pressure. During 2011-2012 the number of outpatient appointments for ophthalmology totalled 6.8 million, making it the third largest hospital service in terms of attendances (12).

This demand on ophthalmology services will continue as the number of people with sight loss is set to increase. There are 1.86 million people in the UK living with sight loss. By 2020 this number is predicted to increase by 22 per cent and will double to almost four million people by the year 2050 (13). The increase can be attributed chiefly to an ageing population; over 80 per cent of sight loss occurs in people aged over 60 years.

A sample survey of 35 ophthalmologists working in clinics with an ECLO found that they helped to contribute to a saving in clinical time with patients and an improvement in staff efficiency. Two of the 35 ophthalmologists reported an estimated 10 minute saving of their own time per patient, when they were able to refer onto an ECLO. Nearly all of those surveyed agreed that the ECLO service increased clinical staff efficiency by reducing time spent with distressed patients (14).

A joint survey of medical retinal consultants by The Royal College of Ophthalmologists and the Macular Society found that 69.4 per cent thought that support staff shortages were a barrier to good or excellent services (15).

NICE quality standard for glaucoma 2011 recommends that patients should be offered the opportunity to discuss their diagnosis, prognosis and treatment, and are provided with relevant information in an accessible format at initial and subsequent visits (16).

ECLOs are ideally placed to provide this information and support to patients to manage their condition.

Nearly all of those surveyed agreed that the ECLO service increased clinical staff efficiency.



Good for local authorities

Once diagnosed as blind or partially sighted, many people require support from their local authority to learn new skills to adapt to their sight loss and live independently in their own home.

When someone's sight deteriorates significantly they should receive a Certificate of Visual Impairment (CVI). A copy of the certificate is sent to the local authority which should offer rehabilitation to provide blind and partially sighted people with the skills, training and confidence needed to live independently.

However, RNIB is concerned that:

- **20 per cent of people say they do not recall receiving any visit from social services in the year after they registered as blind or partially sighted.**
- **In the year after registration, less than a quarter (23 per cent) of people who lost their sight said that they were offered mobility training to help them get around independently (17).**

ECLOs are able to support the CVI process, ensuring that they are completed and forwarded onto social care service departments in a timely manner. Information from ECLOs can help local authorities to prioritise the most urgent cases.

A survey of consultant ophthalmologists found that 96 per cent agreed that an Eye Clinic Liaison Officer is beneficial for them as well as for patients in relation to CVIs (18).



Information from ECLOs can help local authorities to prioritise the most urgent cases.

Hanging by a thread

ECLOs provide a service of enormous value to people facing sight loss and to hard pressed eye clinic staff. However, in far too many areas of the country this service is hanging by a thread. Its value is not properly recognised by commissioners of health and social care services, with ECLO posts typically funded on a short-term basis often from three or four different budgets. This needs to change and RNIB and Action for Blind People are calling for:



- **An urgent response from funders to ensure that existing ECLO posts are supported throughout 2014/15. The service is just too important to lose.**
- **Dialogue between clinical commissioning groups, hospital trusts and local authorities to put in place longer term funding plans. An ECLO service should be a central part of every hospital eye department and needs to be built into all commissioning decisions.**

References

- (1) Eaglen, C, Saving money, losing sight. RNIB campaign report. November 2013
- (2) Douglas et al, 2008. Network 1000: Access to information, services and support for people with visual impairment. Visual Impairment Centre for Teaching and Research, University of Birmingham. Full report
- (3) nfpSynergy, Charity Awareness Monitor, March 2011
- (4) Source: Pey, Nzegwu and Dooley, 2006. Functionality and the needs of blind and partially sighted adults in the UK: An interim report. Guide Dogs. Full report
- (5) 2009. Network 1000: Visually impaired people's access to employment. Visual Impairment Centre for Teaching and Research, University of Birmingham. Full report

- (6) RNIB and Action for Blind People patient questionnaires at ECLO locations in Wales and London and the South East between 2011 and 2013. Sample for questions was between 208 and 225 patient responses.
- (7) Boyce, T. et al 2013. Projecting number of falls related to visual impairment. British Journal of Healthcare Management. Vol 19 226-229
- (8) Boyce, T. et al 2013. Projecting number of falls related to visual impairment. British Journal of Healthcare Management. Vol 19 226-229
- (9) NHS-Right Care (February 2013)
<http://www.rightcare.nhs.uk/index.php/2013/02/document-of-the-week-18th-feb-commissioning-better-eye-care/>
- (10) SCHWARTZ, G.F. (2005) Compliance and Persistency in Glaucoma Follow-up Treatment. Current Opinion in Ophthalmology: 16 (2): 114-121
- (11) Commissioning better eye care. Clinical commissioning guidance from The College of Optometrists and The Royal College of Ophthalmologists. 21 March 2013
- (12) Hospital Episode Statistics: Outpatient, treatment speciality by attendance type: England 2011/2012, Health & Social Care Information Centre <http://www.ic.nhs.uk/searchcatalogue?productid=10254&q=%22hospital+outpatient+activity%22&topics=0%2fhospital+care&sort=Relevance&size=10&page=1#top>
- (13) Access Economics 2009. Future Sight Loss UK 1: Economic Impact of Partial Sight and Blindness in the UK adult population. RNIB
- (14) Johnston A 2010 ECLO Impact Report. London. RNIB
- (15) The Royal College of Ophthalmologists and Macular Society, September 2013, AMD Services Survey 2013 Report
- (16) NICE Quality Standards Programme Cost impact and commissioning assessment: quality standard for glaucoma March 2011 (updated March 2012)
- (17) Douglas et al, 2008. Network 1000: Access to information, services and support for people with visual impairment. Visual Impairment Centre for Teaching and Research, University of Birmingham. Full report
- (18) The Royal College of Ophthalmologists. Summary of Certificate of Vision Impairment Survey December 2012

Further information

For more information and to find out whether a service is hanging by a thread in your area, please contact RNIB

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