



Sight loss advisers

Supporting patients and eye departments



Supporting people
with sight loss

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Tara Chattaway and Holly Heath

RNIB Policy and Campaigns Team, May 2015

Foreword

Ophthalmologists across the UK strive to provide high quality services for patients. Fortunately, with improvements in treatments they are able to successfully preserve or restore vision in the majority of patients they treat. Occasionally, patients suffer from conditions that mean medical intervention may be unable to prevent sight loss.

Telling patients that they are losing their sight is very challenging and at this difficult time they need considerable support and practical information. This specific expertise is where a sight loss adviser can play a vital role. Whilst there is no substitute for a properly informed discussion between the patient and his or her clinician, a sight loss adviser enhances the service by having the time to offer practical information and emotional support.

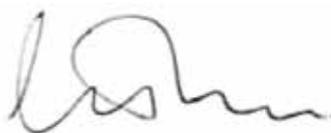
This report sets out powerful accounts from ophthalmologists showing how a sight loss adviser can be integral to the running of an eye clinic and the difference that the service makes to patient care.

From my own experience, I have recently worked with a 29 year old patient who developed rapid loss of vision in his left eye, followed a few weeks later by the same thing happening to his right eye. It took time to make a firm diagnosis and this was an extremely difficult time for the patient. He was anxious and uncertain about the future for his vision, his job, his family finances and his life in general.



The support he received through the sight loss adviser service was immeasurable. Several meetings were required in order to identify his particular needs and to ensure he was receiving tailored emotional, financial and practical support.

Sight loss advisers provide a valuable service in the running of any busy eye department and RNIB's ambition for every eye department in the UK to have access to a sight loss adviser will benefit patients at a time when they are most vulnerable.

A handwritten signature in black ink, appearing to read 'Carrie MacEwen', written in a cursive style.

Professor Carrie MacEwen, MB ChB, MD, FRCS, FRCOphth, FFSEM
President of the Royal College of Ophthalmologists

Introduction

Year on year ophthalmology continues to have the second highest number of outpatient attendances of any specialty, placing enormous pressure on ophthalmologists, ophthalmic nurses and other medical staff to diagnose and treat patients [1].

The demand for eye services and pressure on the medical profession is only set to increase with an ageing population. **There are almost two million people in the UK living with sight loss and by 2020 this is predicted to increase by 22 per cent, and is set to double to almost four million by 2050 [2].** This undoubtedly has an impact on ophthalmology services; in less than a decade there has been a staggering 45 per cent increase in the number of ophthalmic appointments [1].

This incredible increase in demand and the subsequent rise in appointments means that over stretched staff can struggle to find the time to provide the level of support to patients that is required. As a result patients can leave the clinic feeling overwhelmed about what a future with sight loss might mean, without the emotional support, practical information and advice that they need.

The loss of sight can have a devastating impact upon every aspect of a person's life, and can affect everyday activities such as reading, driving, and work. People have to learn new coping skills and strategies, it is therefore vital that all patients have access to high quality and timely support at this extremely distressing time.

Sight loss advisers providing an integrated approach

Many eye departments across the UK have introduced an integrated solution by establishing a sight loss adviser service. In England, Wales, Northern Ireland and the Isle of Man the role is known as an Eye Clinic/Care Liaison Officer (ECLO) and in Scotland a Vision Support Officer (VSO).

Sight loss advisers are trained non-clinical staff working within the eye department providing patients and their families with vital quality emotional and practical support. They help patients to understand their diagnosis and connect them with key services. They empower patients to self-manage their condition, help people to live independently and make informed choices about their care. The service is an essential part of any eye department.

“It is not a consultant ophthalmologist who can tell a patient what exactly is available through their local social services, what their rights are in detail, about Access to Work and various other benefits. My gut feeling is that it is a really, really important service and if it wasn’t present then people would be floundering.”

Professor Marcela Votruba

Eye departments are increasingly seeing the benefit of having a sight loss adviser as part of a core service provision for patients. RNIB intelligence suggests that only 30 per cent of eye departments in the UK currently have access to a qualified sight loss adviser. There is an urgent need for all eye departments in the UK to benefit from this invaluable support service.

A core service

Eye departments that have a sight loss adviser consider the post to be “core business”. They contribute enormously to the efficient running of a department and RNIB’s latest research shows that the service can deliver a welcome financial return to health and social care budgets of £10.57 for every one pound invested [\[3\]](#).

Key ways in which a sight loss adviser can support the eye department and patients include:

Making the registration process clear

Sight loss advisers can provide valuable support with the certification and registration of patients. If a patient’s loss of sight means that they meet the criteria of sight impaired (partially sighted) or severely sight impaired (blind), in England, Wales and Northern Ireland an ophthalmologist may make the decision to issue a certificate of visual impairment (CVI) or in Scotland a BP1.

The process can be very confusing to patients, at a time when they may be feeling emotionally overwhelmed and unsure about the options available to them. Across the UK, ophthalmologists often depend on sight loss advisers to be able to help patients to understand the process and to make an informed decision about the choices and opportunities available to them. Ophthalmologists and other staff working in eye departments have identified the lack of a sight loss adviser in some eye clinics as a major barrier to certification [\[4\]](#). The support service is vital in supporting the completion and processing of the CVI.

In England, Wales and Northern Ireland receiving a CVI enables the patient to make a choice as to whether or not they would like to be registered, which can be a gateway to receiving some services and support. Patients describe the help and support received at this time as “substantially improving their lives” [\[5\]](#).

Patient support

The NHS aspires to put patients at the heart of everything it does, and having a sight loss adviser is one of the most effective ways of achieving this within an eye department. Sight loss advisers are crucial in helping to ensure that patients' social, emotional and additional care needs are not overlooked in a busy clinic. New RNIB research highlights that 90 per cent of patients that had seen a sight loss adviser felt they had received the practical support needed to help them live with sight loss [\[6\]](#).

Providing tailored advice

Sight loss advisers have a good understanding of a range of eye conditions and can provide tailored advice to patients. They are able to respond to a clinic's need, for example they can teach patients to administer eye drops for glaucoma in order to ensure compliance with treatment. Sight loss advisers can also provide reassurance to patients worried about injections in the eye or cataract surgery.

Sight loss advisers in children's clinics

The services and support needed by children with a visual impairment can be different to adults. A sight loss adviser acts as a point of contact for children and their families and can provide them with continued support and information, whilst ensuring that there is a seamless transition between health, social care and education services.

A professional service

The sight loss adviser deals with complex issues faced by patients, and works closely with ophthalmologists and nurses to ensure continuity of care. Therefore, it is important that the sight loss adviser is trained in the role, so that they can offer a high quality professional and integrated service.

Professional training is provided by RNIB's Eye Clinic Support Studies course accredited by City University London, and there are also ongoing training and development opportunities. A quality framework has been established which identifies the elements that make an effective sight loss adviser service.

Bringing health and social care together

The service can also support patients to navigate the complex health and social care system to ensure a seamless transition between services. Sight loss advisers work with local authorities and external agencies. They can identify patients' needs and refer them for mobility training, rehabilitation, counselling and other support in the community. By working with other agencies, they are able to provide a bridge between health and social care.

Ophthalmologists' viewpoints

It is not just RNIB and the wider sight loss sector promoting this vital support service. Consultant ophthalmologists from across the UK provide accounts of why a sight loss adviser is indispensable to their eye department. Eight ophthalmologists from across the UK, share how the adviser operates in their eye department and the positive benefits the service has brought to both patients and staff.

RNIB calls on ophthalmologists to explore the need for a sight loss adviser service in their eye department.

Providing practical information and emotional support

Winfried Amoaku is an Associate Professor and Consultant Ophthalmologist at Nottingham University Hospitals NHS Trust

Winfried has worked in the eye department at Nottingham for over twenty years and has felt the positive impact of having an ECLO service.

Nottingham's eye department is extremely busy and clinicians have limited time to answer patient's questions that go beyond discussing diagnosis and possible treatment. Winfried explains that the ECLO has helped address this by taking on responsibility for providing patients with quality information and emotional support.

This has allowed clinicians to spend more time dealing with patients' medical needs.

Winfried explains that the ECLO is adept at translating complex information into more practical explanations.



“Telling somebody they are losing their sight is devastating and there is often only so much a clinician can say during a consultation. But if the patient’s appointment is followed immediately by the ECLO giving support and referring the patient onto other relevant services, it can have a positive impact on the patient.”

“Patients can be aware that they’re taking up clinicians’ time and feel they can’t ask lots of questions. Doctors may also use medical terminology so patients can prefer explanations coming from a non-clinical perspective to reinforce what the clinician has said.”

For Winfried, patient leaflets are not a substitute for face to face contact with the ECLO. “Although there are patient information leaflets available in the eye department, sometimes it can be like reading lecture notes. It’s easier if somebody explains the different points to you. The ECLO also tailors the help they give to patients depending on their need.”

Winfried is keen to emphasise that without the service “unfortunately the support available to patients would become more haphazard. It would be dependent on time and how busy the clinics were”. Whilst the department was fortunate at one stage to have two ECLOs, there has recently been a reduction in the support service to one ECLO due to funding issues. Whilst the one ECLO can’t singlehandedly support the entire department, Winfried highlights that it is better than having no support and it is hoped that the support service will return to full capacity.

Winfried explains that while it is essential that eye clinics continually improve clinical care, patient information and emotional support is equally important. Having an ECLO is considered an essential ingredient to the smooth running of the eye department and supporting patients. Patients will often provide feedback about their experiences of the support service and are extremely positive about it. “The ECLO is a necessary part of the department.”

Delivering a high quality eye service

Praveen Patel is a Consultant Ophthalmic Surgeon at Moorfields Eye Hospital NHS Foundation Trust

Praveen has worked at Moorfields Eye Hospital for over ten years, working both at the main hospital site and satellite clinics. Praveen feels fortunate to work in a clinical service which has been supported by a continuously expanding ECLO service.

For Praveen, the benefits of the service at Moorfields are clear; it allows clinicians to concentrate on the consultation and clinical aspects of care, whilst providing patients with specialist support from people who are trained to deliver this.

The range and breadth of support available to patients can change over time. Praveen emphasises the importance of having “an individual or a team of individuals who have access to up-to-date knowledge and information. This ensures that patients are receiving quality advice, rather than relying on clinicians or information leaflets which may be out of date”.

Praveen explains that what works well at Moorfields is having an ECLO service which is accessible, both in location and time, and someone who communicates effectively with patients and can listen and identify their needs. They are also aware of very specific local solutions and support that can be offered to patients.

“The more sessions provided by an ECLO the better. It’s great having them alongside the clinic. If any questions have been initiated from the patient, they can be appropriately tackled by the ECLO or be redirected back to the clinical nurse, consultant or another doctor; so there is always that interface between staff. What works well is having someone close by who has a bit more time to answer questions.”



Whilst Praveen appreciates that unfortunately due to funding constraints and organisational issues those without an ECLO will not be able to create a support service overnight, he explains that “the need is there today as well as tomorrow, so the sooner hospitals can organise services and find how they can be supported and funded locally, the better”.

“Moorfields is fortunate as without the support service for patients, it would have a profound impact on our ability to offer a high quality service. **I would argue that provision of that kind of patient support is part of delivering any high quality eye service, whether for younger patients with sight loss due to inherited eye disease or those with AMD.** We would not want to lose any of the support available for patients here. The feedback from patients would also support this.”

Streamlining the CVI process

Martin McKibbin is a Consultant Ophthalmologist at Leeds Teaching Hospitals NHS Trust

Martin has worked at Leeds since 2001 and has seen the expansion of the eye department across several sites, with an ECLO now in place at two hospital sites.

Martin explains that one of the key benefits is that they have the time to discuss what certification means and the benefits of registration.

“Having the ECLOs take responsibility for processing CVIs has saved medical and nursing staff time. Typically, for a new patient, consultants discuss the patient's history, carry out the examination, make the diagnosis, discuss any treatment options and then finally he or she would address sight impairment certification. By this point, you would always be conscious of time and that other patients were waiting.

There wasn't an incentive or enough time to get the CVI done and to provide support to the patient. As a result, I am sure that completion of the CVI was often missed in the past. **Now, where appropriate, I'll ask the ECLO to come and speak to the patient about certification and the ways in which it can help, and to provide additional information about the relevant eye condition.** The ECLO also ensures that a copy reaches adult social care or if necessary a Qualified Teacher of the Visually Impaired (QTVI); they take ownership of the process.”



In addition to freeing up clinicians' time, the ECLOs involvement in the CVI process ensures patients have access to timely support. Martin feels that "patients tend to get more of a holistic package as they also receive support and information at the point that they are first seen, rather than simply sometime later by the local authority which is essential".

Martin explains that, for the role to be most effective, the ECLO should be situated in the eye department and available on demand. "Having the immediate access to the ECLO is a great thing. Being able to walk into their office and ask for advice, or to help a patient, is wonderful. It can be frustrating when they are not there."

Martin believes that any departments that are thinking about introducing an ECLO service should "definitely go for it, and try to get somebody there every day of the week that there are clinics. If we didn't have ECLOs in Leeds, the standard of care that the department provides to people with sight loss would be diminished".

Cost effective intervention

Professor Marcela Votruba works at University Hospital of Wales, Cardiff

Marcela works in a busy retinal genetic clinic and liaises with the ECLO on a weekly basis.

Marcela explains just why an ECLO is so important when providing support to a patient: “The patient may have been told a few things by the consultant during the consultation, and they don’t remember everything. I’m not talking necessarily about medical details, but as a way of backing up information. If they have just received very bad news about being registered and they didn’t expect it, they have the opportunity to talk it through. The ECLO provides practical support and reassurance. I definitely think that it is an important addition to the service we offer and should be delivered by a trained person.”



There are two types of patients who Marcela may refer on to the ECLO. “The first might be someone who is being told that they are receiving a certificate of visual impairment that day. I try to refer them the same day. As a backup the eye department keeps a log book in the clinic of every single patient who has received a CVI. The ECLO carries out a weekly check to ensure no one has slipped through the net.”

The other group are patients who have not yet met the criteria to receive a CVI, or have been registered a long time ago, and have dropped off the radar with social services. “If we didn’t have an ECLO service these people would find it really, really hard to get the information they need.”

As well as providing this vital patient support, Marcela also describes how an ECLO can save money and time by freeing up appointments.

“I think that it is actually helping to save time in the clinics. Often when you tell someone that they need to be registered they can be really upset by the news. One way of helping with this is that you might ask the patient to come back sooner than they necessarily need to. That might not be the right use of resources.”

“So the ECLO is really helping to free up resources for new patients who need to be seen. I think that it is saving a lot of time, and is therefore cost effective for the NHS. It is actually a real cost effective intervention. And it should therefore be regarded as part of the core service.”

Marcela would encourage all eye departments to explore how an ECLO could help clinicians and patients in their clinics. “Our experience of an ECLO has been really amazing and I would certainly endorse it, as it is really valuable.”

Providing coordinated care

Sonia George is a Consultant Ophthalmologist at Royal Victoria Hospital, Belfast Health and Social Care Trust

Sonia has worked at the Royal Victoria Hospital for thirteen years and her specialist interest is Paediatric Ophthalmology, with a particular interest in children with neurological and brain injury related sight loss.

Sonia relies on the ECLO service enormously to refer children who are newly diagnosed with or have progressive sight loss. The ECLO provides critical support, information and advice to the children and their families.



“Before the support service was in place, parents of affected children would be told that they have a problem with their sight, one that was potentially incurable and at best they would be sent to the low vision clinic. Whilst the clinic is fantastic, there wasn’t anywhere for families to turn to for support, or anyone that could act as a point of contact.

It is a very devastating experience to hear that your child has a visual impairment. By referring children to the ECLO, parents are provided with emotional support and have access to all the support services available, including parent support groups, which allow them to meet other families and share experiences. I think the ECLO service is really invaluable when providing that support.”

The ECLO helps to ensure that patients are receiving co-ordinated care; they act as a link between different bodies and professionals. Sonia explains that “they are best placed to offer ongoing support to both children and their families. It’s a matter of supporting the children as well as possible and ensuring that everyone around the child, such as the education board, and their teachers are aware of their visual needs.”

Although the majority of her work is with children, Sonia also sees adults in general clinics, many of whom are affected with glaucoma or anterior segment problems. The ECLO service has time to help patients understand and manage their eye condition by teaching people how to administer eye drops. Sonia says **“following a good chat about their treatment with the ECLO, I have seen certain patients’ compliance with glaucoma drops improve, leading to a direct improvement in their intraocular pressures – it is definitely time well spent.”**

In the setting of a busy clinic, Sonia explains that “consultants may not necessarily have the time to provide the support and instruction a patient needs whereas ECLOs can devote that much needed time to these patients. The support service has become a core part of the eye department. To have someone in the clinic with the knowledge, advice and support to give to patients and their families is vital. The ECLO has a very diverse role; it is definitely a positive thing.”

The Paediatric Ophthalmology service in the Belfast Trust where Sonia works has recently expanded the support service and introduced an ECLO dedicated solely to meeting the needs of visually impaired children.

A professional service

Zachariah Koshy is a Consultant Ophthalmologist and Vitreoretinal Surgeon at University Hospital Ayr

Zac joined the eye department in 2007, when initial discussions on setting up the support service were in motion. The service was established in 2008 and the Vision Support Officer (VSO) covered a number of clinics over two hospital sites. The service has been so successful that the need for two Vision Support Officers soon became evident.

Zac explains that he was very conscious that the provision of emotional and practical support was missing: “I was very clear that there was an unmet need, and absolutely certain that we needed to do more than just diagnose and treat; we needed to do a lot more than we had the capacity to do. The Vision Support Officer has slipped into meeting that unmet need.”

Zac also explains that having a trained, professional VSO is essential. “They need to be aware of not just all the means and methods of signposting a person who has sight loss to the right organisations and resources, but they also need to have the capacity to psychologically boost the patient, to empathise with them with the turmoil they are in right now, and to ease them through that process. I know for a fact that our VSO doesn’t just leave it with one face to face contact, but will be in touch on multiple occasions. **That kind of thing needs empathy, it needs awareness and it needs knowledge, so training is essential.**”



Once a VSO is in place, Zac highlights the importance of consultants and nurses championing the service. “The difficulty at first was to make everyone aware of the service and to consciously tap into it. We had a bit of work, to repeatedly make folks aware of the presence of the service and everything that it had to offer. The good thing of course was the people who did end up going really, really benefited from that service.”

The integration of the role has included ensuring that there are clear referral pathways and involving the VSO in departmental audit meetings.

The role that the VSO plays is invaluable in supporting the patient, Zac explains: “It has benefited the patients, for example if, when a person is told that there is not much more that can be offered to make their vision better, that is a very depressing end to the consultation. On the other hand, if we can say – ‘do you know what, there is this person who has the ways and means of finding a way to get around the problem that you have’, then it leads to a more positive narrative to that consultation.”

“Personally that is what I have found the most useful, it is really when I know that the person will benefit from that extra person speaking to them and easing them into a process of coming to terms with what is essentially a difficult bit of information to take on.”

Support in the eye department

James Talks is a Consultant Ophthalmologist at the Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust

James joined the eye department in 2000 and has witnessed the introduction and expansion of the ECLO service. There was always demand for the service and Newcastle was fortunate to receive funding for a second ECLO. The support service covers all the clinics across the department, five days a week.

Any patient with sight loss requiring support or considering registering their sight loss has access to an ECLO who is located within the eye department. James highlights that this is vital as the service must be accessible. **“It’s like a walk in service; whichever clinic is running, if there is someone who would like some emotional support or practical advice, or to be registered, the option is there for the patient or their family to go round and talk to the ECLO.”**

James explains the invaluable support provided by the service to a patient with diabetic retinopathy. “He is of working age and registered blind and as a result of his sight loss found it extremely difficult getting to work. The patient experienced a significant loss of confidence and depression; this was recognised and he was referred to RNIB’s Emotional Support Service. The ECLO also provided advice and helped build his confidence to speak to his employers about supporting someone with sight loss. With continuing help and support, he is now managing to cope and remain in work.”



James also emphasises that there is a professional element as the knowledge required is quite complicated and specific. It includes all of the different support that is available, as well as understanding what entitlements and benefits patients may be eligible for and keeping up to date with any changes.

For James, the ECLO has significantly improved the functioning of the clinic by decreasing the amount of time clinicians spend with upset patients, while at the same time improving the quality of information given to patients.

“I would go as far as saying the sight loss adviser service is an essential part of an eye clinic. However good an eye department is, you are going to have people with sight loss, which may or may not be treatable, and they will need help. We do our medical part, but patients have to leave the clinic and live with the consequences of their sight loss. The support service is vital for patients but it also supports the doctor. I am able to finish the consultation on a more positive note – patients have access to support services. As a clinician, knowing the ECLO is there, you feel that a better job is being done for your patient.”

Support for all patients

Clare Bailey is a Consultant Ophthalmologist at University Hospitals Bristol NHS Foundation Trust

Bristol Eye Hospital developed an ECLO service in 2008 and staffing levels have increased since then. The service consists of a full-time ECLO as well as a patient support nurse who works almost full-time. They work across all departments at Bristol Eye Hospital and provide invaluable support for patients by providing information and advice, referring patients onto other services as needed, and supporting the CVI process. They also act as an advocate and help patients come to terms with their eye condition.



Clare explains that the service supports all patients, irrespective of their eye condition or degree of sight loss. “The ECLO and patient support nurse see many patients that have not received a CVI, but who need support because they are really struggling with their diagnosis, and visual symptoms.”

They help to process CVIs where needed, in a timely manner. They also provide a facilitating role to enable patients to access further support as needed. The medical and nursing teams can refer patients to the ECLO and patient support nurse, and usually one of the team is available right away during the clinic appointment. If either of them are not available, then a direct referral is made and the patient may be contacted within 24 hours.

Clare and her consultant colleagues find having an ECLO invaluable. In every room within the macular clinic area there is a clear bold sign above each desk with the name and contact details of the ECLO and patient support nurse encouraging doctors and patients to contact them as needed.

What makes a good ECLO? Clare explains that a comprehensive skill set is required. “It is vital that the service is embedded and based in the clinics; that they have good communication skills; are compassionate; have a good knowledge of support services; are well trained; and are contactable.”

“The ECLO service is now a core part of the work at Bristol Eye Hospital. This support service is an invaluable part of the care we deliver.”



Conclusion

It is clear from the ophthalmologists featured in this report that sight loss advisers contribute to the smooth running of eye departments.

They provide invaluable emotional and practical support to patients, helping them to feel more informed and confident about their condition. Patients leave the eye department with a better understanding of their sight condition, with the knowledge of what other support is out there for them and not feeling that they are on their own.

Nobody should be left to face sight loss on their own. Sight loss advisers provide a bridge between health and social care. They provide expertise in working with the patient to identify their individual needs and to refer onto appropriate support services.

As strongly conveyed by ophthalmologists, sight loss advisers can help to free up clinicians' time. This coupled with the financial return to health and social care budgets of £10.57 for every one pound invested demonstrates the clear benefits that the service can have on the cost effectiveness of running a department [\[3\]](#).

Every eye department in the UK should have access to a sight loss adviser service. RNIB is calling upon ophthalmologists to explore the need for a sight loss adviser service in their eye department.

For more information and resources about sight loss adviser services to help initiate discussions in your department please contact RNIB.

Email: campaigns@rnib.org.uk

Telephone: **020 7391 2123**

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For previous RNIB reports about sight loss advisers please see:

- RNIB. Hanging by a thread. May 2014.
- RNIB. Being there when it matters. November 2014.

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