Being there when it matters

Every eye department in the UK to have access to a sight loss adviser

RNIB Supporting people with sight loss
Acknowledgements

Thank you to Ian, Jennifer, Julie, Hayley, Keith, Lynette, Peter, Hadi and Vanessa for taking the time to share their stories and experiences and supporting the aims of this report. I would also like to thank Fay Sadro for her support in collecting and developing the case studies, and to Fazilet Hadi, Steve Winyard, Clara Eaglen, Fiona Austin, Philippa Simkiss and Stevie Johnson for their expertise and input.

Tara Chattaway
RNIB Campaigns Team, November 2014
Foreword

RNIB is a membership organisation and we have been told unmistakably by blind and partially sighted people that support at time of sight loss matters.

“Being there when it matters” sets out the huge impact that losing sight can have. The stories of Ian, Jennifer, Julie, Hayley, Keith, Lynette and Peter set out the emotional and practical impact that sight loss has had upon their lives. It is imperative that someone is there to provide information, advice and emotional support and to refer onto other services at this difficult time.

Sight loss advisers are ideally placed to provide excellent support to patients and are an indispensible member of an eye clinic team.

RNIB would like to see every eye department in the UK have access to a sight loss adviser. I am pleased to be able to present this report which clearly sets out the importance of sight loss advisers.

Together we need to ensure that no one is left to face sight loss on their own.

Lesley-Anne Alexander CBE
RNIB Chief Executive
Introduction

Every 15 minutes someone in the UK is told that they are losing or have permanently lost their sight. They will be left to face one of the most difficult questions of their lives – “what now?”

The questions for each person may vary, but the feelings of anxiety, devastation and loss are universal.

The loss of sight can have a profound impact. Everyday activities such as making a cup of tea, reading, cooking, shopping and using the internet become a challenge. Not being able to drive can lead to people feeling lost and isolated. New skills and strategies have to be learnt to be able get around the home safely, to go outside, cross roads and avoid hazards. For many people there is the additional fear of how they will be able to continue with work.

The answer for many people to the question “what now” can mean loss of independence, isolation and loneliness. It needn’t be this way, but without early support many people struggle to adapt to sight loss.

“When I think about the help that I received – what would I have done if I had been left on my own? You can’t pick up a telephone book to look up the number, you can’t look at your computer because you can’t see it – so what do you do? You are totally isolated until you get the help to get on with things.” Julie

Facing sight loss alone

RNIB believes that nobody should be left to face sight loss on their own. Every eye department in the UK must have access to a dedicated sight loss adviser. These professionals, also known as Eye Clinic Liaison Officers (ECLOs) or Vision Support Officers, provide vital emotional and practical support to help patients and their families to understand their diagnosis and put them in touch with key services.
Sight loss advisers are based in the eye department and are an integral member of the team, freeing up ophthalmologists time to diagnose and treat patients.

“The ECLO service is like having a consultant in a non-clinical capacity specialising in providing emotional support and identifying how a patient can get practical help – it’s an essential service for any eye clinic.” Hadi Zambarakji, Consultant Ophthalmic Surgeon

They do not just make practical sense by supporting people at an emotionally difficult time in their life, but they also make financial sense. A sight loss adviser service can deliver a financial return to health and social care budgets of £10.57 for every one pound invested [1].

A recent survey has found that 94 per cent of the public would expect to be referred to a sight loss adviser if they found that they were losing their sight [2].

**Funding and coverage**

RNIB intelligence suggests that only 30 per cent of eye clinics in the UK currently have some kind of qualified support role in place. This simply is not good enough.

We are also extremely concerned that where a sight loss adviser is available the funding is often precarious; many posts are only funded on a year on year basis [3].

**RNIB is calling for:**

- Every eye department in the UK to have access to a sight loss adviser.
- Sight loss advisers to be recognised as an essential part of the team in every eye department.
- Sight loss advisers to be funded on a permanent basis, there must be an end to annual contracts.
Impact of sight loss

Sight loss can affect all aspects of a person's life. Not only is sight the sense that people fear losing the most, but the public also fear blindness more than developing other long term conditions such as Alzheimer's and heart disease [2].

The emotional and psychological impact of sight loss is profound. Depression is significantly higher amongst people with sight problems [4] and feelings of wellbeing are significantly lower when compared to people without sight loss [5].

Losing sight can result in people being unnecessarily forced into early retirement from paid employment. The employment rate for blind and partially sighted people is consistently below that of the general population [6].

There is also an increased cost associated with sight loss as people have to pay for a wide range of additional goods and services including visual aids, transport and domestic help.

Family and friends are also impacted upon as they too have to adapt and may need to take upon additional responsibilities.

“I had to depend on my wife and kids to sight guide me. I couldn’t go out on my own. That’s not right.” Peter

Ian's story

Ian from Ayrshire shares the moment he was diagnosed and the impact that losing his sight had on him and his family

Ian was diagnosed with Ischemic Retinopathy in May 2011. He lost his sight suddenly and was diagnosed within two weeks. Before his diagnosis he was self employed as a private hire driver.
“After a few seconds, well it felt like a lifetime, whilst he [the ophthalmologist] was talking to me, I couldn’t make out anything that he was saying. I had a million things running through my head at the time. I remember coming back to myself, I remember squeezing my wife’s hand and saying it will be fine, everything will be okay. I don’t know why I said that, deep down in my heart I knew it wasn’t.”

After the diagnosis there wasn’t any practical or emotional support or information available for Ian or his family.

“I walked down the corridor towards the reception desk, there was nobody there to say ‘Hi, come on let’s have a coffee and sit down and chat – this is where we go to from here’. There was nothing like that. I just felt at that particular point we were both alone. My wife and I felt alone.

There were things we wanted to ask, my wife is a nurse and she wanted to ask ‘nursey’ questions and I wanted to ask practical questions, about my situation. I felt quite let down; a great big health service and they don’t have support on site to help with the impact of what has just happened. When there is no one there to talk to you about it – you just have to go home.”

He had to give up his job, and his wife was given extended compassionate leave to be able to provide support and for them both to come to terms with Ian losing his sight. It had a huge impact on the family.

Ian and his wife struggled to find the information and support they needed. As it happened Ian used to drive a lady who worked for RNIB, and when she heard what had happened she contacted him. RNIB were about to launch a vision support service and Ian was their first client.
Nowhere to turn

Unfortunately Ian’s story is typical of many people who have not had the opportunity to speak to a sight loss adviser.

When Jennifer lost her sight suddenly she didn’t have anywhere to turn to for support and advice. She didn’t know what the questions were that she was supposed to ask, let alone any of the answers. It is vital that people receive early support and have the opportunity to talk through their situation and start to identify what support they may require.

Information and support is more than just providing a leaflet with a telephone number, or a list of organisations. It is about helping patients to understand what questions they can ask and what options are available to them.

Jennifer’s story

Jennifer is 26 lives in Manchester and was diagnosed with Idiopathic Intercranial Hypertension (IIH) in 2011

Jennifer lost her eyesight two weeks before she graduated with a Masters degree in forensic science.

“It just kept getting worse and worse. I was told that the vision that I had, which wasn’t even light perception, was the vision that I would have for the rest of my life.”

Any information that Jennifer received when she left hospital “was from a friend of a friend of a friend. There wasn’t anyone that said come here and talk to me, or here is a phone number to talk to someone... It was never anything definite. I felt that there was nothing that I could get help with.”
“I didn’t go out on my own for over a year because I didn’t have mobility training. I couldn’t go out on my own; it was totally unsafe because of my sight. I only ever went out if there was someone else there with me. I was apprehensive taking a step off of the curb or walking around. I think that it really knocked my confidence because I always had to be with someone. I was really independent before.”

Even communicating with friends was difficult, “I would get a text and mum would read it out, and then I would have to tell her what to reply. You don’t always want to relay to your mum what you want to say. I wouldn’t have needed someone to read my texts before; it was frustrating that someone needed to do that now.”

Jennifer believes that there needs to be someone there when you are diagnosed, even if you do not want to talk to them at that time. It is important to know that there is someone you can go to when you are ready.

“Just having somebody immediately who you are able to talk to, obviously it would have been difficult for me to say certain things to my mum and dad, because they were going through similar things to me.”

“Although it was me that lost my sight, it was also my mum that could have initially done with someone who could support her and give her more information earlier on. Initially my mum was doing things for me, that I should have been doing myself. But I think she thought that she had to do this to help me. To be told that it is okay to let me do things by myself. It is not just about the person who has lost their sight.”

A few years on and Jennifer has had mobility training and is able to go out on her own in familiar places, she has relocated and now lives with her boyfriend and she is aware of a range of technology products which can assist her. However, Jennifer feels that she would have reached this place a lot earlier on and would be further ahead if she had received information and support when she needed it.
Losing more than sight

Life after sight loss can have many uncertainties. When surveyed nine out of ten members of the public said they would lose their independence, and would be scared or anxious if they lost their sight [2].

People living with sight loss report having lower feelings of wellbeing [5]. This can be for many reasons, including giving up, sometimes unnecessarily, treasured activities and hobbies, such photography, cycling, sewing and knitting.

“I thought about my three grandchildren, if I was going to be able to see them properly again. I felt everything I did required good sight.”
Lynette Lusk

Employment

Staggeringly, 66 per cent of registered blind and partially sighted people of working age are not in employment [7]. Two-thirds of working age or employed people with sight loss experience restrictions in being able to access and fully participate in employment [5].

Job retention support and information at the point of diagnosis is an effective way to prevent the loss of existing employment, and a sight loss adviser can inform and signpost to relevant support [1].

Hayley didn’t receive any support or information when she lost her sight and her life changed completely, including having to give up a career that she had worked hard to build. She believes that there must be someone there when the ophthalmologist says those words “there is nothing further we can do.”
Hayley’s story

Hayley is 46, lives in the West Midlands and has retinitis pigmentosa

Hayley used to manage several chains of a well known pub before she lost her sight in both eyes. She had been in hospitality all her working life, kitchen and front of house prior managing a number of pubs. “I have worked all my life, I have worked really hard, I’ve worked stupid amount of hours.”

When she was diagnosed there was no support available. “It was awful; I was told I just had to accept it. I cried all the way home, and I slunk down the wall when I got home. I shut the door and lent against the wall and was like I don’t even know what I am accepting here.”

Hayley strongly believes that there must be someone there when you are told you have lost your sight and that there is nothing that can be done. “I really feel that if there had been somebody with me or an ECLO to sit down, calm me down, talk things through, tell me – advise me more than anything on the support out there. I needed a huge amount of support and it wasn’t there, it wasn’t there. I felt isolated, I couldn’t work. That was a huge thing as well, I had been in hospitality all my working life, it was just like what? This just can’t be the rest of life, it just can’t be.”

Hayley explains that since losing her sight that she has had to fight for everything, from information to receiving financial support.

When she lost sight in both of her eyes Hayley had to give up her job. Her company sent her to see an occupational therapist who found her unfit to work. “The bottom fell out of my world; it was all I had left that I was proud to have achieved by myself. I was left stuck in my flat not knowing what the future held.”

“You need continuing support, there are new questions and information that you need to know. Being told that you have lost your sight it is soul destroying, you feel useless. For somebody like me who has been in management, trained people, who takes a real pride in what I do, and then to feel totally useless, it is devastating.”
Providing emotional support

Being told that you are losing your sight can have a profound and devastating impact, as Ian, Jennifer and Hayley’s stories demonstrate. The need for high quality emotional support at the eye clinic is clear.

A recent survey found that almost half of the public would expect there to be emotional counselling available if they found out that they were going blind [2]. Worryingly only eight per cent of registered blind and partially sighted people were offered formal counselling by the eye clinic, either at the time of diagnosis or later [8].

Sight loss advisers can provide emotional support but they are not counsellors and may need to refer onto other relevant services. A recent RNIB study has found that a sight loss adviser service played a key role in increasing emotional wellbeing in patients [1].
Keith’s story

Keith is 78, lives in Nottingham with his wife and has wet age-related macular degeneration (AMD)

When first diagnosed with sight loss in his right eye, neither Keith nor his wife had ever heard of the condition. Keith left the hospital with no referrals, support or clear understanding of how his life might change.

“It was never explained to us how quickly you could go blind from macular degeneration. I slipped through the cracks. No one contacted me, no one talked to me, no one came to the house and I was sort of there – out on my own.”

After his diagnosis, Keith suffered from clinical depression and his life completely changed because of losing his sight.

In 2007, Keith was then diagnosed with wet AMD in his left eye. At this point, there was clinical treatment available to him on the NHS to try and save as much sight as possible. He now has around 40 per cent vision in his left eye.

It was only at Keith’s second diagnosis that he was first introduced to an ECLO. He was referred to a range of local services that have significantly improved both his physical and mental wellbeing. Meeting other people at local support groups has enabled Keith to get involved with helping others and also campaign for better services for blind and partially sighted people.

Keith feels that the ECLO role is essential; “Everyone needs access to this – the ECLO needs to have access to everyone with sight loss in the UK. You need someone to talk to, someone to explain your condition. They are able to advise you professionally.”

“I still have a tremendous quality of life, even though I’m nearly blind – and that’s because of the help and support I’ve received. It all goes back to the ECLO.”
Practical support

A sight loss adviser is able to help piece together the support and information that a patient needs. They are in the unique position to be able to follow up on patient support and check that people are receiving the help they need.

A crucial role of a sight loss adviser is the provision of quality, impartial, timely, accurate and up-to-date information. They are able to answer questions and ensure that the information is appropriate and understood by the patient. Importantly they are able to assess the readiness of the patient to receive information.

Not everyone is ready to digest information when they are diagnosed, but they do need to know that there is someone to talk to when they are ready.

“I think initially it would have been good for someone to be there to say ‘we can help you when you are ready’.” Jennifer

For Jennifer this may have been supporting her mum to understand that it is alright for her to do things on her own, providing information on what aids and adaptations may be appropriate and in time, putting her in touch with rehabilitation and employment services.

Integrated care

Sight loss advisers are embedded in the eye clinic and can provide a wide range of support. They can refer patients onto other services within the hospital such as falls and stroke clinics.

This is crucial as there is a link between sight loss and falls, almost half (47 per cent) of all falls in the population of blind and partially sighted people are directly attributable to sight loss [9] [10].

There is also a link between stroke and sight loss [11]. Julie lost her sight as a result of a stroke and received high quality support as both services worked together. She has been
able to come to terms and adapt to her sight loss, but only because of the support she has received.

“*It was not a lone journey – it was the ECLO, stroke team, and others who were there to help, support and guide me. If it wasn’t for them I would have be a blithering wreck. There are times when I still feel that I am sinking but I know that the ECLO is still there for me.*” Julie

Sight loss advisers provide valuable support with the registration and certificate of visual impairment (CVI) of patients. Certification is a gateway to a range of services and benefits. Once certified a patient is referred onto the local authority. They will then contact the individual to ask whether they would like to be registered and to carry out an assessment of their needs.

Between April 2012 and March 2013 an estimated 28,000 patients in the UK were certified as either sight impaired or severe sight impaired. However, we know that this is under representative of the number of people who have a sight condition which could be certified.

Sight loss advisers ensure the effective administration of CVIs. Over 96 per cent of ophthalmologists surveyed by the Royal College of Ophthalmologists believe sight loss advisers are beneficial to both them and patients in relation to CVIs [12].

Through supporting CVIs sight loss advisers provide a bridge between health and social care. In particular they work closely with local authorities to ensure that people access rehabilitation support.

Rehabilitation services provide training and guidance for people to adapt to their sight loss. They support with mobility skills both inside and outside the home to enable people to live independently.
Peter’s story

Peter didn’t receive any support or information for many years; it wasn’t until he had reached absolute crisis point when he had the opportunity to meet a sight loss adviser, and then everything changed for him.

For the first time he had someone to talk to who could refer him onto other services and provide him with the help and guidance he needed.

Peter Carling is 48, lives in Sunderland and has retinitis pigmentosa.

Peter started to lose his sight in his late teens and was told that his sight would deteriorate over time.

Peter went onto experience other health conditions and in 2004 had a major operation; “This was when it started to hit me, I was in the hospital and my sight was really bad. I didn’t have a clue where I was, how to get to the toilet. I was just sitting there, I couldn’t read books. I was listening to the radio and that was when I realised how hard things were getting.”

Once out of hospital and recovering from the operation, Peter’s sight started to get worse again and he became depressed as he increasingly became dependent on his family.

“I couldn’t cope, I just didn’t want to leave the house, I didn’t want to do anything. I think it happens to a lot of us. I hit rock bottom. Whilst you’re stuck in the house, you can’t cope and are afraid to go out of your front gate. If I did go past the front gate I would have to depend on a family member to take me out.”

Throughout all of his visits to the hospital spanning from the late 1980s until 2008 Peter wasn’t offered any support. It wasn’t until he accompanied his daughter to her eye appointment that the consultant asked Peter how he was doing, and he replied “I need help.”
The consultant immediately contacted the ECLO who spoke to Peter that morning. “This is where my life changed. I told her I couldn’t cope anymore. She asked about my mobility and I said ‘I’ve got no mobility, I’ve got nothing.’ I had no mobility at all, because I was always getting sight guided. I couldn’t go anywhere by myself. I had to be taken to places.”

“When I hit rock bottom, and I mean rock bottom, I went to the right person and she was there. She pointed me to right people as well. There was no one else to ask. Speaking to the ECLO was the best thing I ever did.”

He was put in touch with other organisations and sources of support and received mobility training and now has a guide dog. Peter has learnt how to use a computer and his confidence and self esteem has improved and he no longer feels isolated.

“Things that I couldn’t do before, I am doing now. I can go for a walk now; I have got my independence back. That is the biggest life changing thing.”

Peter is shocked to hear that there are a lot of places across the country that does not have a sight loss adviser. “How do people know where to go or what is happening? I know what it is like to have depression and the impact of sight loss. It puts pressure on your family and it is very hard.”

“When I hit rock bottom... I went to the right person and she was there. She pointed me to right people as well... Speaking to the ECLO was the best thing I ever did.”
Integral to the eye department

Sight loss advisers not only provide essential support to patients, ensuring that they receive timely information and helping to reduce isolation, but they are also indispensable to the functioning of the eye department.

Ophthalmology departments in the UK are under enormous pressure. During 2011–2012, in England alone, the number of outpatient appointments for ophthalmology totalled 6.8 million, making it the third largest hospital service in terms of attendances [13].

This demand on ophthalmology services will continue as the number of people with sight loss is set to increase.

“Consultants are incredibly dependent on the ECLO service.”
Hadi Zambarakji, Consultant Ophthalmic Surgeon

Recent research conducted with health care professionals in Wales found that sight loss advisers can reduce the number of follow up appointments as a result of the immediate and on-going support they are able to offer [1].

From the consultant’s perspective

Hadi Zambarakji is a Consultant Vitreoretinal and cataract surgeon at Barts Health, Whipps Cross University Hospital NHS Trust

The service is in huge demand at Whipps Cross because of the number of patients who need to be seen and based on the feedback from patients and their carer’s. The ECLO engages with the emotional aspects of care and provides practical support to patients and their carers. Patients simply have more information which can make a significant difference to people and their families’ lives.
Hadi and his colleagues rely upon the ECLO for a range of services including providing the patient with quality and appropriate information and advice.

“Before the ECLO service was available, the patients did not receive the necessary support relating to non-clinical issues and day to day practical matters. Patients are now often more comfortable with their eye condition and situation after engaging with the ECLO service. We have seen a marked impact as well as receiving positive comments from patients. This makes the consultation much easier and allows clinicians to concentrate on the clinical aspect of care.”

Hadi Zambarakji’s clinical service includes patients with retinal disease including macular degeneration and advanced diabetic eye disease. In some cases, both eyes may be involved and visual outcomes may be limited. The treatment and diagnosis of sight loss is essential, but ECLO support is equally important.

Having an ECLO support service is considered an integral running of an effective eye department. Challenges presented by the CVI and registration process, means that a well integrated ECLO service with a close working relationship with the clinical team is essential.

“The ECLO service, in my mind, is a key part of a good quality service for patients. Everyone in the UK should have access to the service.”
Sight loss advisers – saving money

The role of a sight loss adviser is essential in providing support to patients and already over-stretched eye clinics. Early intervention and support can mean that people require less intensive support at a later date and that they are able to maintain independence.

Every eye department must have access to a paid, trained and professional sight loss adviser that is embedded and works closely with medically trained nurses and consultants.

Key roles of a sight loss adviser include:

- being a contact point for patients, providing impartial, relevant and high quality information, at the right time
- providing emotional support to patients their families and carers
- advocating for patients and helping them to make their own views known. They can attend appointments and obtain accurate and independent advice and information
- working with the patient to identify what is important to them and to work towards finding a solution
- referring onto relevant services both within and external to the hospital, for example low vision, fall clinics and rehabilitation support
- supporting the certification and registration process
- monitoring and following up patient progress.

Not surprisingly a sight loss adviser saves money and contributes to the efficient running of an eye department. A sight loss adviser service can deliver a staggering financial return to health and social care budgets of £10.57 for every one pound invested [1].
From the ECLO’s perspective

Vanessa is an ECLO at York Hospital. York Blind and Partially Sighted Society are commissioned to deliver the service

Patients often don’t know what they want or need when they visit the ECLO service. Many patients are in emotional distress and just do not know what’s out there to help them.

“Part of my skill is to unpick what the fundamental issues are that the patient is facing, and how best we deal with them. What I try and help people understand is that you can still do things, you can still be independent and you can still make your own choices.”

Vanessa is regularly asked by consultants to attend patient consultations in cases where patients need additional support. She sees around 700 new patients every year, and has a vast amount of work that continues to happen with existing patients. It can be very challenging to help people accept their eye condition and most people receive some kind of emotional support. It’s important for Vanessa that people feel they can speak freely.

“I can’t change the diagnosis but it’s about finding ways to give people hope; little things can make a huge difference”. With increasing numbers of people visiting the clinic each year, there is not much time for medically trained staff to offer emotional or practical support to patients, which is where an ECLO can step in.

Patients place a lot of trust in the service at a time when they are feeling particularly vulnerable; they trust the ECLO to make good decisions for them with advice, signposting and referrals. Vanessa believes strongly that a trained professional like herself has the ability to build a strong professional relationship with eye department staff. Presenting a professionally trained service enables the staff to have confidence in the ECLO when making referrals for patients.

“I bridge that gap between consultant, patient and their access to the community; and as long as I continue to do that I think we provide a really excellent service for the patients and for the staff in the clinic.”
No one should face sight loss on their own

It is clear that sight loss can have a devastating and profound impact upon a person’s life and it is shocking that people are left to face this on their own.

The general public expect there to be a level of practical and emotional support available to people losing their sight. No one should have to return home on their own, not understanding their sight condition, not knowing what support is out there and left isolated.

Sight loss advisers are able to provide a bridge between health and social care and ensure that patients receive the support and information that they need to be independent and to learn the skills they need to adapt to losing their sight.

The service is cost effective and benefits the clinic in ensuring that patients receive the support they need resulting in clinicians being able to focus on treating and diagnosing patients.

That is why RNIB are calling for every eye department in the UK to have access to a sight loss adviser and that these vital posts are permanently funded.

We need to ensure that no one is left to face sight loss on their own.
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