# Being There

## Developing understanding of the essential role of the Eye Clinic Liaison Officer in Wales

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Of course only with the dedication and hard work of Eye Clinic Liaison Officers is this publication made possible. A huge thank you for the fantastic work you do, day after day.

The reality is that patients only come into contact with ECLOs because they have been diagnosed with a sight-threatening condition. Through featuring their difficult, yet inspiring, stories in this publication we hope to help secure the future of the service for everyone who needs it.

# Foreword

In Wales, although the best efforts of all those involved in eye care services have produced some real benefits, some people each year will inevitably experience sight loss. As the case studies demonstrate, being told that you are losing your sight is life changing. This report demonstrates what third sector organisations can bring to improve care by supporting people at a time of distress, linking people with community, education and social services, acting as an advocate and ensuring people know their rights.

Eye Clinic Liaison Officers (ECLOs) help people to navigate the upsetting and sometimes complex journey once a diagnosis is given to ensure seamless, individual and practical support to facilitate the best patient experience and outcomes.

Really good patient care requires everyone to work together to provide seamless services across health and social care. By using patients’ stories, this report showcases how ECLOs do that every day in some of the busiest hospital clinics around Wales. ECLOs deliver the principals of prudence, partnership, integration and collaboration.

It is clear that ECLOs support blind and partially sighted people by connecting patients with the practical and emotional support they need to deal with sight loss and enable them to lead a full and independent life. Therefore, I would encourage everyone to embrace their local ECLO service and consider, each step of the way, whether their input would improve the care you can provide to your patients or clients.

Dr Andrew Goodall

Director General of Health and Social

Services/Chief Executive, NHS Wales

# Introduction

The stories you will read here are all real life case studies of people supported by the Eye Clinic Liaison Officer (ECLO) service in Wales. Some details have been changed to protect the identity of the individuals. Together these personal experiences illustrate the range of difficulties faced by people with sight loss on a daily basis; difficulties that for many, without the help of their ECLO, would have remained unresolved.

So many people are simply unaware of the support and services available to help them.

As Consultant Ophthalmologist David Laws explains, ECLOs “fulfil a role that has been needed for years. Patients complained that if their vision deteriorated there was little coordination between the clinic and community services; the ECLO smoothes this path out”.

ECLOs support patients who are often struggling to find their way through a frightening and complex sight loss journey. ECLOs have up to date knowledge of local provision, the time to connect with patients and understand their needs, and the training and experience to provide essential emotional support. With information and support from an ECLO, patients are more able to make informed choices about their health care and their lives beyond the eye clinic.

Senior Sensory Officer Tracy Martin-Smith explains “ECLOs are the liaison between the patients in the eye clinic, local authorities, and third sector”.

Through the personal experiences of our patients, shared here in this publication, you will come to understand how important it is for people to be able to read; for pleasure, for independence and to maintain a sense of control and dignity. You will see how expensive and difficult it can be for people to travel, and how the personal and financial cost of sight loss can be so high. You will see how hard it can be to find a way through bureaucratic processes, how utterly bewildering a consultation can feel, and how terribly distressing the diagnosis of a sight condition can be.

You will also begin to see the very real difference which can be made by an ECLO who has the time to listen, to understand, inform, advise, and support. The difference ECLOs are able to make is dependent on availability of a range of vital community, health and statutory support services. These services include rehabilitation support, mobility training, low vision services, local blind societies, social and peer support groups, national charities, welfare rights services, employment support and services for children and young people. The ECLO is the link to these, a friendly and accessible walking, talking signpost, directing patients from the clinic to the services they need.

The stories you will read here evidence how important these services are to blind and partially sighted people and the very real difference they make. Working positively in partnership to complement and connect the health, social care and third sectors is vital for the ECLO service to achieve its aims, for blind and partially sighted people to get the support they need to remain as healthy and independent as possible, for as long as possible. The stories here also illustrate that without the ECLO many people would not have found these services so quickly, if at all.

For more information about your local ECLO service please contact the ECLO Service Manager for Wales at RNIB Cymru on 029 2082 8500.

**The Royal College of Ophthalmologists recommends that ECLOs are part of a minimum service team.** For example, when commissioning age-related macular degeneration (AMD) services, the Royal College believes it is important that support services are offered at time of diagnosis ‘to maximize the chances of patients adjusting to their sight loss with minimal trauma’. [Boyce, 2011]

# Oliver: Needing an advocate

Oliver is an active 74 year old retiree who has a long term diagnosis of cataracts. He lives with his wife, for whom he is also a carer, in rural Wales. As a carer he relies on his car to carry out essential tasks such as the food shopping and picking up prescriptions.

Although Oliver has not driven at night for some time, he has recently experienced deterioration in his vision which means that he no longer meets the required standard to drive at all. This news was devastating for Oliver and his wife. Hopeful for a speedy solution Oliver was placed on the cataract waiting list.

When Oliver finally received his appointment letter he was shocked to find that the operation was to take place at a hospital 60 miles from home. Moving his operation to a closer hospital would have meant being placed at the bottom of the waiting list, a time delay Oliver was anxious to avoid.

Having no family locally and very little spare money to cover the cost of a taxi Oliver felt he was caught in a Catch 22. He had actively pursued a range of alternative travel options but was met with refusals. For example, the hospital transport scheme denied his request as the scheduled surgery did not fall within their agreed transport times for that hospital. Oliver found himself feeling very stressed and didn’t know where to turn.

Thankfully the clinic receptionist knew that their ECLO would be able to support Oliver and made a referral. All contact between Oliver and the ECLO took place over the telephone which was very convenient for Oliver. The ECLO reassured Oliver that he would do everything he could to find a solution. Oliver was happy for the ECLO to act as his advocate as he no longer felt able to deal with the increasingly stressful situation alone.

The ECLO spoke to a range of transport services and outlined Oliver’s difficult situation. The ECLO used his knowledge of Oliver’s situation and his professional relationships to liaise with these services. With perseverance, he was able to secure a one-off transport arrangement to get Oliver to and from his operation, avoiding a cancellation.

Oliver was delighted with the outcome. He was relieved of a great deal of stress and could look forward to getting back to normal life.

# Barry: Feeling overwhelmed

Barry is in his 50s and lives with his wife. He has recently been diagnosed with wet macular degeneration and is undergoing treatment. He was told by his consultant that it is likely he will lose his sight over the next 15 years. Barry, understandably, reacted to this news with extreme distress.

The nursing team in the eye clinic felt that Barry could benefit greatly from speaking to an ECLO because ECLOs are trained in providing emotional support. Having received a referral for Barry from the nurse, the ECLO called him at home. Barry then came into the clinic later that same day to meet the ECLO, signalling his urgent need for information and support.

This meeting lasted for over an hour and a half. This amount of time would have been very difficult for clinic staff to commit at short notice away from their other patients.

The ECLO listened to Barry’s concerns about how devastating he expected the impact of his eye condition to be. They also discussed some of the other things going on in his life, such as being on long term sick leave from his job. In this face-to-face meeting the ECLO observed how Barry was feeling through his body language; Barry regularly put his head in his hands and had to pause to calm down.

The benefits of the time spent talking to the ECLO were immediate. Barry realised whilst talking that he had been focusing on a worst case scenario. He hadn’t spoken in detail with his family about these things for fear of upsetting them. Barry was eager for all information to be provided straight away. Barry felt able to ask questions and talk through his feelings without the risk of shocking or upsetting the ECLO.

The ECLO was able to give Barry a full outline of the support available both locally and nationally. He was informed about employment advice services, rehabilitation officers, the Wales Low Vision Service, and about relevant accessible IT software. Information about further emotional support options, including the RNIB telephone counselling service, was also shared.

Barry was very appreciative of the time spent and thanked the ECLO for her support. Through the course of the conversation Barry realised he didn’t need to make any hasty or potentially life changing decisions. This significantly reduced his feelings of stress and anxiety.

**From the research:** Qualitative studies indicate that emotionally adapting to sight loss can follow a similar pattern as bereavement in the sense of initial feelings of panic, followed by depression and finally acceptance. [Emerson and Robertson, 2011.]

Older blind and partially sighted people are three times more likely to experience depression than those with good vision. [Evans, Fletcher and Wormald, 2007]

A survey of individuals registered blind and partially sighted in the past eight years reveals that only 15 per cent of them were offered any form of emotional support in the year after registration. [Douglas, Pavey and Corcoran, 2007]

#### Views from professionals: Garry Merrell, Dual Sensory Loss CMO for City & County of Swansea Sensory Services Team, explains that: “Prior to [the ECLO] being in post, once diagnosed [patients] would have left with limited information, not knowing if any support was available and possibly feeling quite alone and lost.”

# Arthur: Help throughout his journey

Arthur is 71 years old and lives in his own 3 bedroom house with his wife. He has wet macular degeneration and has been receiving treatment for this for the last three years.

Arthur first met the ECLO two years ago, by chance, during a routine visit to the eye clinic. Arthur said he was managing everything OK but, during the conversation, the ECLO identified additional support which he was unaware of. Arthur wasn’t claiming Attendance Allowance, to which he was entitled, because he mistakenly thought this was a means tested benefit. He was also having difficulty reading and wasn’t aware of the free Wales Low Vision Service.

The ECLO and Arthur had a long chat about these different services and Arthur agreed to be referred for a Low Vision Service assessment and for an RNIB welfare benefits check. As a result Arthur was awarded Attendance Allowance, making a real difference to the family income. He was also provided with a free reading aid which he found extremely useful.

A couple of years later Arthur again sought the support of the ECLO. Arthur’s vision was getting noticeably worse and reading was becoming increasingly difficult. Desperate to improve his quality of life, and to maintain some independence, Arthur and his wife were considering buying an expensive video magnifier.

The ECLO arranged for a home demonstration of the magnifier, and following this Arthur was able to rent the machine on a trial basis. This allowed him time to see whether it was the right equipment for him without having to spend thousands of pounds.

Arthur contacted the ECLO to say that this had absolutely been the right course of action. The magnifier was making a huge difference and he had decided it would be well worth the investment.

Around the same time the ECLO also reminded Arthur about the local rehabilitation service, explaining that a rehabilitation officer could carry out a home assessment. The service could provide further advice and equipment to assist with other everyday needs.

Arthur and his wife were both grateful for the assistance they had received. They found it comforting to know they could contact the ECLO or their rehabilitation officer for help at any time.

Without the ECLO making the referral Arthur would not have received the support of the rehabilitation officer. This is because he was not registered as sight impaired and would not have come to the notice of the local social service department.

#### Views from professionals: Professor Marcela Votruba (Consultant Ophthalmologist, University Hospital Wales, Cardiff) explains that one of the main groups of patients she refers to the ECLO service is those who have not yet met the criteria for certification and registration.

With regards to unregistered patients Professor Votruba says: “If we didn’t have an ECLO service these people would find it really, really hard to get the information they need.”

This is echoed by Tracy Martin-Smith, Senior Sensory Officer for Pembrokeshire County Council, who explains that “[without an ECLO service] non-registered patients may miss out on information.”

# Katie: What’s important to her

Katie is an outgoing 7 year old who lives at home with her family. Katie has a diagnosis of Nystagmus and she receives additional support at school. Katie’s mum was referred to the ECLO by Katie’s consultant as she had expressed some worries about Katie not being able to take part in activities outside of school.

ECLOs receive specialised training to engage with and support children and their families, and so are well placed to help in situations like these.

Using simple questions such as ‘what would you most like’ and ‘how would you like me to help you’ the ECLO was able to find out more about Katie’s worries. The ECLO gave Katie a chance to talk about her situation and how she was feeling in her own words.

Katie was upset about not always being able to join in with activities with her friends. The ECLO was keen for Katie’s opportunities not to be limited as a result of her condition.

Drawing upon her knowledge of local services the ECLO was able to signpost Katie and her mum to a range of community and sports groups offering opportunities for children with sight problems. These contacts were all new to mum who said she would look through the information and follow things up.

Soon after this meeting the ECLO received a telephone call from Katie’s family thanking her for providing all these contacts. Mum had been able to find a range of after school activities suitable for Katie. Mum shared that Katie was really happy that she had now found a hobby which wasn’t limited by her sight condition.

#### From the research: There are 488 children (aged 0-17) registered blind or partially sighted in Wales. However, it is likely that many children living with sight loss are not registered as such. There are estimated to be 1,186 children (aged 0-16) living with sight loss in Wales [RNIB, 2016].

# Wendy: Improving her everyday life

Wendy is 82 years old and lives with her husband. She has dry macular degeneration which has been getting increasingly worse. She also has poor mobility and walks with a frame.

Wendy was recently certified as severely sight impaired by her consultant. During this process Wendy was given contact details for the ECLO along with an accessible leaflet explaining the service. Some days later her sister telephoned the ECLO and asked for help for Wendy.

During their first telephone conversation Wendy told the ECLO that she was feeling isolated and out of touch because she could no longer read the local news.

Her poor mobility and poor vision also meant that she had been using taxis to get to appointments and to go food shopping as she could no longer travel independently. This cost was getting too much to afford and she hadn’t realised she might be eligible for financial help.

The ECLO outlined the services available to someone in Wendy’s situation. Wendy was pleased to hear that her two local newspapers were available as a talking newspaper free of charge.

With her ECLO’s support she was able to receive these and as a result felt connected again with her local community.

The ECLO also made a referral to Age Cymru who visited Wendy at home to help her complete an Attendance Allowance application form. This would have been impossible for her to do by herself. As a result of this support Wendy was awarded higher rate Attendance Allowance of £82.30 per week (over £4,000 per year in extra income).

Wendy agreed that it would be a good idea to have a home assessment carried out by the local rehabilitation officer. Following this Wendy was provided with a range of equipment to help her with her everyday life.

By being a part of the referral pathway in the clinic the ECLO was able to deliver timely and accessible support to Wendy, resulting in tangible improvements to her circumstances.

Wendy rang the ECLO to thank her for all her support, and for helping her to maintain her independence at home.

# Mr Williams and his daughter Eira: Supporting the whole family

Mr Williams is an active 85 year old who has macular degeneration. He lives with his wife who has dementia.

Mr Williams’ physical health had recently deteriorated and this had led to him having some serious falls. While he was an inpatient his daughter Eira contacted the ECLO service to find out if there was any support available to help him to use his iPad again, now his sight had deteriorated. The ECLO went to meet Mr Williams on the ward and chatted with him and Eira about a range of issues.

The ECLO made a referral to the RNIB technology support service to arrange for a support officer to visit Mr Williams to help him to learn to use his iPad’s accessibility functions.

Eira next got in touch seeking information about certification and registration as her dad was now eligible. They spoke about the various benefits and concessions and an information booklet was sent. Eira mentioned that there would be a wait of several months for a consultant appointment to complete the relevant paperwork.

The ECLO actively pursued the issue of this potential delay with the consultant. The consultant agreed that a long wait in this situation was inappropriate and he offered to see Mr Williams in an emergency slot.

A period of some weeks passed before Eira called the ECLO with a query regarding aids and adaptations. The ECLO told her about the local blind society’s central resource centre which displayed the different aids.

During this latest conversation it became apparent that Eira was beginning to struggle with being the main carer for her parents. The ECLO was able to offer her both emotional support and practical solutions.

One of Eira’s worries was about finding someone to sit with her mum while she took Mr Williams to his various health appointments, including eye tests. The ECLO sign-posted Eira to her local domiciliary optometrist, who would be able to provide her parents with eye tests at home. Eira was also given information about different carer support groups.

The whole family was supported emotionally and practically by the ECLO service. They had one central point of contact throughout their journey and felt able to come back to the ECLO as frequently as necessary.

#### From the research: Older people with visual impairment are much more likely to experience falls than their fully sighted counterparts. [Dhital, Pey and Stanford, 2010].

In Wales it is estimated that there are 48,546 falls a year amongst older people that are directly attributable to sight loss. Of these falls, 485 are estimated to be severe falls that require hospital admission. [RNIB, 2016]

Falls and resultant fractures in older people cost the NHS an estimated £2 billion per year. [Royal College of Physicians, 2011]

# Tara: Young, anxious and worried

Tara is a young woman in her 20s who lives with her boyfriend. She was recently diagnosed with glaucoma with complicating factors after attending eye casualty. Her level of vision had dropped suddenly resulting in immediate and total sight loss in one eye and severe deterioration of sight in the other.

Tara was referred to the ECLO by a clinician because of the magnitude of the diagnosis, particularly for someone so young. When the ECLO first met Tara she talked about the ECLO role and the support she could offer. Tara was visibly distressed but maintained that she was fine and coping well.

The ECLO thoughtfully reassured Tara that her feelings of anxiety were entirely normal, and that this was part of the process of coming to terms with her sight loss.

As Tara was in shock, it was important not to overwhelm her further. The ECLO gave Tara a leaflet about the service and encouraged her to get in touch when she was ready, allowing her space to process her situation. It was clear to the ECLO that Tara had anxieties, particularly about what would happen with her job.

A few weeks later Tara got in touch with the ECLO and from this point on they made rapid progress. They discussed the issue of anxiety, and thought of strategies together to help manage this, including helpful relaxation techniques. Tara planned to implement some of the strategies in her day-to-day life.

As Tara had concerns about her ability to stay in work, the ECLO discussed the support available from services such as Access to Work and the RNIB employment support team, and recommended that Tara get in touch with them.

Tara subsequently received a further diagnosis and went back to the ECLO. The ECLO was concerned that Tara didn’t have a full understanding of her eye condition, so took steps to liaise with the clinician. Between them they developed information for Tara which was easier to understand.

Increasing awareness of the condition and the treatment helped Tara to realise how important it was for her to comply to reduce risk of further sight loss.

Tara was supported at an early stage in her sight loss journey and shared that she felt reassured that the ECLO would be there to continue to support her as needed.

#### From the research: Only around 1 in 3 blind or partially sighted people are in employment [Clements and Douglas, 2009]. By way of comparison with the general population, in April 2015, 73 per cent of the UK general population were in employment [DWP, 2015].

# Mrs Gibb: Early intervention

Mrs Gibb is 86 years old and lives alone. She suffers from glaucoma which affects her peripheral vision. This means she is at risk of bumping into things, stumbling and falling. Although she receives support from her family, her wish is to stay independent for as long as she can.

Mrs Gibb’s current level of visual acuity (the clearness of her vision) is slightly above the requirement to be certified as sight impaired. Not being certified and registered as sight impaired can limit the type and amount of support a patient can receive.

Upon referral, the ECLO was able to help Mrs Gibb access crucial support services that she was eligible for, but would not have been automatically referred to without a Certificate of Visual Impairment (CVI).

Following their initial chat, the ECLO thought that Mrs Gibb might be eligible for Attendance Allowance and put her in touch with the RNIB welfare rights service for a full benefits check.

They also discussed other support and the ECLO, with permission, actively set up appointments for Mrs Gibb with her local low vision service for a low vision assessment, and with the local visual impairment team for a home assessment. Following these assessments, Mrs Gibb may receive free low vision aids, other equipment, and mobility training as appropriate to her needs. As she lives alone these will be important contributors to maintaining her independence and a good quality of life.

Being able to get out and about was very important to Mrs Gibb, so the ECLO also provided additional information regarding the Blue Badge scheme, community transport services and ambulance transport. Mrs Gibb expressed her gratitude for the ECLO’s timely support and early intervention.

#### Views from professionals: The importance of the ECLO in providing early intervention support is explained further by Garry Merrell, Dual Sensory Loss CMO for City & County of Swansea Sensory Support Team. Garry explains that “[The ECLO] plays a key role in the patient’s wellbeing immediately after diagnosis and going forward.”

Early intervention is important in all cases, but when discussing a specific case Garry describes how the link between the ECLO and the Sensory Support team can help to reduce risk to individuals: “[The ECLO] alerted the team to the immediate risk the service user was facing as a result of their sudden and severe sight loss. As a result an urgent referral was generated and we were able to provide swift intervention to support.”

# Gwen: Unaware of the support available

Gwen is a 78 year old woman who lives alone. She has macular disease and was anxious about her condition.

Gwen had voiced concerns about her deteriorating vision, in particular about the impact this was starting to have on her ability to read. Her ophthalmic Nurse referred her to the ECLO service to get information about what might be available to help Gwen.

The ECLO met Gwen in a busy clinic but they were able to have a private chat in a quiet area. Gwen was able to share her story and raise her concerns in a comfortable environment away from the bustle of the clinic.

Gwen was feeling low because she was finding that her ability to read was gradually declining and reading was something that had given her great pleasure in the past. The ECLO informed Gwen about her local low vision service and suggested she make an appointment.

While Gwen did not mention living on a low income, from the conversation the ECLO recognised that she may have been entitled to welfare benefits, and suggested she have her income reviewed by the RNIB Cymru Welfare Rights Service. Gwen agreed to this and a home visit was arranged.

During the visit it became apparent that Gwen had quite complex care needs following an accident many years before. As a result an application was made for the care component of Disability Living Allowance. Just a few weeks later Gwen was awarded the highest rate of care. As a result of this application, she was subsequently successful in claiming other entitlements that she hadn’t previously been aware of. This extra income has made a huge difference to Gwen, taking away many of her practical and financial worries.

As a result, Gwen is now able to buy better quality food, including some pre-prepared foods which are easier for her to cook independently. Gwen also has the option of taking a taxi if needed which helps with her feelings of isolation. Although Gwen was initially referred because she was having trouble reading, through talking with her the ECLO was able to identify a range of services which could help make Gwen’s life easier. This holistic approach is typical of the ECLO service.

#### From the research: A considerable number of people with a visual impairment do not claim all the benefits to which they are entitled because of lack of awareness of benefits, reluctance to identify as disabled and difficulties in the application process. [Bevan Foundation, 2012]

Disabled people, including those with a visual impairment, face additional costs in most parts of their everyday lives [O’Sullivan, 2011].

These include higher utility bills, cost of equipment to live more independently, additional food, travel, medical and clothing expenses and assistance costs [RNIB, 2012].

The direct cost of sight loss to Wales is £124 million annually. Direct costs of sight loss are based on NHS expenditure on sight loss, such as inpatient procedures, outpatient appointments and ongoing treatment [StatsWales, 2015].

The indirect cost of sight loss to Wales is estimated to be £263.2 million annually. Indirect costs of sight loss include the informal provision of care by family and friends and other indirect costs such as reduced rates of employment and the cost of specialist equipment [StatsWales, 2015].

# Linda: Dual sensory loss

Linda is a 79 year old woman who lives on her own. She has recently had cataract surgery, but since that operation she was further diagnosed with a macular hole leaving her with no useful vision in that eye. This left Linda feeling anxious and concerned.

Due to complications arising from her surgery, Linda had to make multiple visits to the eye unit. The travel involved proved difficult for her. Using a taxi was fast becoming an unaffordable expense, costing over £40 each way. Travelling by hospital transport meant that she could be out of the house for more than ten hours at a time, due to the set transport schedules. Linda had no family to help out.

In addition to the practical and financial difficulties in accessing the clinic, once there, the consultations themselves were also hard because Linda had hearing problems. Linda was feeling worried that she was missing or mishearing important information.

During one of these visits, the consultant gave Linda a leaflet about the ECLO service. Linda contacted the ECLO by telephone, and during their first conversation she explained that it was hard for her to manage some essential daily living tasks. Difficult tasks included reading the directions for microwaving food, seeing the dials on her washing machine and reading the instructions for her medication.

Having understood more about Linda’s situation the ECLO contacted social services who referred her to the older people’s team for an urgent assessment for home care. The ECLO was able to reassure Linda that she was ‘in the system’, helping to alleviate some of her worries.

The ECLO contacted the Royal Voluntary Service (RVS) and explained Linda’s situation. Following some discussion the RVS assigned a volunteer to visit Linda on a regular basis. They also provided transport to and from the hospital, and attended hospital consultations with her. Linda was comforted knowing that she wasn’t on her own.

While there is a cost for the transport provided by the RVS, it is cheaper than a taxi and has the added benefit of friendly company and someone to be with her at her clinic appointments.

#### From the research: There are estimated to be 20,282 people living in Wales with a visual and hearing impairment [RNIB, 2016].

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# For more information:

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