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|---------|--|--|--|------|
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# The need to see beyond the eyes

#### by Daniel Williams

#### Outline:

This article discusses the problems visually impaired people experience when visiting eye care practitioners and considers what reasonable adjustments should be made to better serve such patients. Written by a qualified sight loss rehabilitation assistant who is himself visually impaired, it provides a unique perspective on this topic.



#### About the author:

Daniel Williams is the founder of Visualise Training and Consultancy, a highly experienced trainer, and qualified sight loss rehabilitation assistant and Eye Clinic Liaison Officer (ECLO). As he himself is certified as severely sight impaired due to retinitis pigmentosa (diagnosed at 8 years old by an optometrist at Specsavers in Bath), he can offer compelling and educational insights into sight loss to inspire

dispensing opticians and optometrists to become more competent at understanding, supporting and communicating with their patients living with low vision.

Daniel is passionate about equality and diversity and giving everyone equal opportunities. He works with a range of private, public sector and voluntary organisations offering training, workplace needs assessments and web accessibility audits, enabling companies to become disability confident.

Daniel is an ambitious and determined individual with a wide variety of skills within the disability sector drawing upon personal and professional experiences. He has worked with a range of organisations including public, private and educational. A proud supporter of the Prince's Trust where he sits on Business Launch panels and considers business plans to enable young people to obtain support from the Trust to start their business. He is also an active member/volunteer for the RNIB, participating in their steering group, looking at the challenges of getting blind and partially sighted people back into work; this consists of spring-boarding ideas, implementing policies, and advising the government on the best way of doing this. For more information please visit: www.visualisetrainingandconsultancy.co.uk.

Katie (an active woman in her fifties living in England) became worried when her vision started to deteriorate. After cutting her finger whilst preparing vegetables, falling when outside, scalding herself whilst making coffee and struggling to read print, see text on her computer at work or watch television, she concluded that she needed help.

She made an appointment with her usual optometrist in the hope that her prescription needed changing. During the examination, the optometrist noted macular changes (extensive dry age-related macular degeneration [AMD]) and an OCT scan undertaken in practice identified an epiretinal membrane that could be contributing to her distorted vision. During her sight test, she informed the optometrist that she'd had several falls, was struggling to recognise faces, was feeling lonely and low in her mood and didn't have any help at home. He referred her to an ophthalmologist.

After waiting for several weeks, Katie received a call from the Hospital Eye Service saying they'd written to her regarding her appointment and that unfortunately she had missed it; Katie was unaware of the appointment. Due to Katie's vision level, she is unable to read small print and therefore missed her appointment slot. The Hospital Eye Service rebooked her appointment while she was on the phone and, one month later, she finally attended her appointment. Under the Equality Act 2010, service providers have a duty to make reasonable adjustments to ensure a person with a disability is not put at a severe disadvantage. A reasonable adjustment in this situation would have been to provide letters in large print or to call the patient to inform them of their appointment.

Her ophthalmologist diagnosed macular degeneration and she was asked to come back in three months' time for further monitoring. Katie was devastated by the news and extremely emotional. She broke down in tears saying that she feels so alone and doesn't have any help or support at home.

Unfortunately, she didn't meet an Eye Clinic Liaison Officer (ECLO) who could have provided emotional and practical support, information and referrals to services that can enable and empower people with sight loss. ECLOs are usually based within eye clinics; however, not every Hospital Eye Service currently has coverage and, even if they do, not every patient is referred to one.

Following her appointment Katie went home feeling devastated with her diagnosis and not knowing what to do next. She lives alone with no support network so continues to feel lonely, isolated and is struggling with everyday tasks such as cooking – she regularly burns herself and overpours her hot drinks. When she is out and about, she regularly misjudges steps and kerbs causing her to fall.

Katie's retinal specialist explained that due to her sight loss, she would be eligible to be certified as sight impaired. A Certificate of Vision Impairment – CVI (formerly BD8) – was completed and sent to Katie's local social services department. He explained some of the benefits of being certified which are:

- Concessionary travel card
- Skipping the queues at Disneyland
- Disabled persons railcard
- VAT exemption on specialist aids or appliances i.e. video/optical magnification

Katie waited 2 weeks to be called by the social services contact centre to assess her needs. At this point, she was placed on a waiting list to receive support from a Vision Rehabilitation Worker. During the call she was asked if she was happy to be registered on the local authority database of people with sight loss. After a further three months, a Vision Rehabilitation Worker eventually contacted Katie in order to carry out a home visit and assessment of her needs. Rehabilitation Workers provide home assessments looking at an individual's skills of getting around safely, cooking safely in the home, white cane training, lighting in the home and functional low vision therapy. They work with people to provide them with the confidence and skills to become independent following their sight loss.

In total, Katie waited over 6 months before she got the support she needed. In this time, her confidence plummeted – she barely left the house and was afraid to cook. Katie's mental health dipped, and she began to suffer from anxiety. The Rehabilitation Worker helped her to regain her confidence with getting out and about safely, training her how to use a white cane and how to cross roads safely. They also gave her strategies and equipment for cooking and making hot drinks to avoid burning herself and referred her to social groups run by the local sight loss charity, where she could get peer support and talk to other people with sight loss. Katie now participates with her local sight loss charity, attending social groups, tandem cycling and walking clubs. She is beginning to feel less isolated and is facing the future with new-found confidence.

It is the eye care professional's responsibility to have a working knowledge of pathways to support services and an awareness of what local charities, organisations and groups can offer. It is important to find out what is available for patients locally.

With social services under pressure and under-resourced, the role of the optometrist and dispensing optician has become even more important, in fact essential, for a person with sight loss. However, the referring optometrist or dispensing optician must move away from the single-track pathway that is GP referral, or just to an ophthalmologist. If a low vision patient is struggling, then an optometrist, optical assistant, receptionist or dispensing optician can refer directly into social services or local sight loss charities immediately. The patient doesn't have to be certified before these referrals are made.

In many ways, you are at the front line of eye care, and as such, need to think holistically and make swift and intelligent referrals and engage with your local sight loss provision to build relationships as we know sight loss is on the increase so we need to ensure patients don't get lost.

Some areas may have updated the Low Vision Leaflet (LVL) which enables a patient to contact social services directly. In England, you might wish to complete a *Referral of Vision Impairment (RVI)*. Another option might be to copy your referral letter or create your own letter, to your local sight loss charity, ECLO or vision impairment team in social services. The other option would be to pick up the phone and give them call. What's important is that you establish links with these sight loss professionals and local organisations and are realistic about the amount of time you can dedicate to these referrals. It is in everyone's interest, but most of all the patients, to ensure there are as few barriers as possible to getting support that's needed quickly.

If you do, people like Katie will find themselves enjoying support far more quickly, and their quality of life will be enhanced. To do this, the patient must be made aware of what provision is available, and what agencies can do to help. In addition, the quicker someone like Katie receives support, the easier it is to rehabilitate someone in this situation.

If Katie knew that support was available – such as liquid level indicators, high contrast kitchenware, mobility training, smart phone apps, special lighting and magnifiers – she could have had contact with social services earlier in her sight loss journey.

Furthermore, if Katie knew that local sight loss charities existed to provide advice, information, social clubs, support with technology, activities and resource centres, then she may not have felt so alone and could have begun to move forward in her sight loss journey quicker.

It is important to know that referrals to outside agencies can be made prior to a CVI being issued. If a patient is struggling with day-to-day tasks and needs support, they should be referred to appropriate organisations regardless of their visual acuity. Every area has a social services department, and most have a local sight loss charity that can help, so I would urge you find your local provision.

You can refer to both local and national charities and organisations to get support for your patients.

# Let's look again at the initial situation and see how earlier intervention could have really helped.

Katie goes to her local optometrist because her eyesight is getting worse. She thinks that there is a chance that she may lose considerable vision.

Her optometrist makes her an appointment with an ophthalmologist, but this time he takes a proactive approach and meets his duty of care to his patient. Referral for "confirmation of diagnosis" is not legally required prior to referral to outside agencies, so any service can and should be initiated because sight loss support services DO NOT HAVE TO WAIT for ophthalmology: A patient doesn't have to be certified as sight impaired or severely sight impaired to receive a referral to a local sight loss charity or social services.

He does the following:

- 1. Refers Katie to social services for vision rehabilitation training.
- 2. Gets in touch with a local sight loss charity who can offer practical advice and guidance ensuring Katie can access local services.

This time, with the essential signposting being done at the same time as the ophthalmologist's referral, Katie gets support before social services respond. This approach is far more proactive and allows her to enjoy a degree of autonomy.

With technology moving so quickly, there is no need for patients to struggle for so long. Even without referrals, with a little knowledge of technology, simple advice about smart phone applications or affordable hardware, can be given.

To better illustrate the above points, let's look at three case studies:

1. A woman has been diagnosed with a condition that results in a loss of vision. After adapting to her new levels of eyesight for some months, the woman, a mother of two small children, presents herself. Beyond medication and updated records, the optometrist can offer further advice and guidance. The optometrist's initial thoughts take him towards a social services

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referral, safeguarding for example. The woman feels very anxious about this, as she thinks her lack of eyesight will result in her ability to take care of her children being called into question.

The optometrist therefore gives the patient the details of Blind Mum's Connect and a small local charity that deals with the patient's specific eye condition. In one consultation, the optometrist has measured the level of eyesight, discussed the condition and symptoms, and has given the patient and her partner the opportunity to access additional support and guidance. If the non-medical referrals hadn't taken place, it is likely that the patient would have felt a spiralling sense of anxiety, resulting in diminished mental health and a breakdown in her family's structure.

- 2. A man is diagnosed with a condition that is resulting in a gradual loss of eyesight. As someone who has worked in a busy office environment for more than twenty years, he experiences anxiety and feels a mounting sense of hopelessness, asserting that he may not be able to do his job. The optometrist refers him to the RNIB for talking support and Access to Work. A few weeks later, the patient has started a course of counselling and Access to Work has assessed his workplace needs and, along with his employer, has installed screen magnification and screen reading software to allow him to continue his job. If these referrals had not have taken place, the patient may have suffered emotionally.
- 3. A patient has very little vision left. A keen sportsman and former soldier, he finds his mental health dipping, experiencing a sense of loss and motivation. The optometrist refers him to a specialist who can better deal with his symptoms. But this is only part of the story. The optometrist recognises that sport and exercise promote a positive mental state, so he refers the patient to Blind Veterans UK, British Blind Sports and the Thomas Pocklington Trust. He then gets the opportunity to exercise and socialise and, along with the clinical and surgical intervention, he soon begins to feel more positive. Six months down the line, he feels able to participate in mainstream sport and has a social life, things that most people take for granted, but are vitally important.

These three snapshots give you an idea of the power of referrals and the importance of slightly lateral thinking. However, I am acutely aware that consultations have time limitations and practices have limited resources and constraints. These factors should not get in the way of your moral and ethical duty of care you have for your patients. Therefore, it is important to consider giving certain patients more time during the consultation in order to explore choices. It can be argued that the Equality Act would support a patient's right to having a little more time with you. This said, the process takes time, so in some cases delegation would be wise and sensible. The optical technician, optical assistant, dispensing optician or receptionist could help make sure your patient has the information in a format he or she can access, and fully understand what support is available.

If a non-medical referral doesn't take place, a patient may find themselves in a hospital where an ECLO is in place. If this is the case, the patient's needs may be better understood. However, there are many hospitals who do not employ an ECLO, and therefore the opportunity for support is very limited. In fact, some hospitals have little or no clue of how to provide basic things like a sighted guide and important documents such as consent forms being in an accessible format for the patient.

https://www.youtube.com/watch?v=9V3fjCfXZyA&t=128s

So, if we were to design a utopian world, what would it look like?

Let's take two scenarios:

- 1. A totally blind person has a routine examination in order to measure eye pressure. The check complete, instead of shaking hands and saying goodbye after 10 minutes, the consultant or optometrist asks how he is feeling. The patient has an opportunity to be honest maybe they say that they are feeling low or depressed. Maybe they allude to the fact that they don't have a social life. The doctor or optometrist can make several referrals to local and national organisations in order to address the issues. This proactive approach means that the patient will have the opportunity to get proper and meaningful help, so his quality of life can be improved.
- 2. A partially sighted woman is in your examination room. As she has useful eyesight and has exhibited several worries and concerns, you give her a little more time. Your conversation reveals anxiety relating to a few daily tasks. You offer her a full explanation and demonstration of how to correctly administer eye drops, an outline of the services she may be able to access and verbally give her some advice. You provide her with literature in electronic format; snappily written, easy to read notes. As there are a number of agencies who can support her, you delegate, and a colleague makes the referrals. You encourage her to make an appointment to look at low vision aids, and in a few weeks, she is empowered by a mixture of technology, optics and knowledge.

Sometimes evesight cannot be saved. Some people may lose some. a lot or all their eyesight. Whilst life will inevitably become more challenging, in some cases much more difficult because of several factors that I won't go into here, there is no reason why a full and meaningful life cannot be enjoyed. As a medical professional, it is your instinct to preserve and save, to do what you can, to employ drugs or surgery to mend somebody's eyes. When you can't do that, you may feel you have failed, you may feel disappointed or even sad. You may even feel a complex cocktail of emotions. Your training and experience may lead you towards a sense of negativity, and you may analyse the case, internalise it and even question yourself. But there is far more you can do than save eyesight as you have the ability to change someone's life in a real and meaningful way. You can help change, mend, and save someone's life by thinking away from medicine and optics, and towards the person as a whole. Sometimes small things change lives; the opportunity to talk to someone who truly empathises and understands, the ability to read, be it in large print, audio or Braille. The chance to make a cup of tea safely, or to do the washing without fear of mixing colours. The chance to train again, to compete again, to act again, to feel like a fully functioning, important member of the family and society. Referrals can help these things happen. If everyone does their job, referrals can truly change lives.

#### https://www.youtube.com/watch?v=TLWARF8AloO&t=23s

Rehabilitation, mobility, and the learning of skills is vital and with a little knowledge, you can make sure that when a patient leaves your consulting room or practice, they take more with them then a pair of glasses, they take hope and knowledge.

Visualise Training and Consultancy has developed a resource pack for professionals to make it quick and easy for optometrists and dispensing opticians to refer their patients for support.

To download your free copy, please visit

http://www.visualisetrainingandconsultancy.com/resource-packhealth-pros/

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The Visualise Seeing Beyond the Eyes CET roadshow has now empowered over 4000 optical clinicians throughout England and Scotland to deliver improved services to patients living with sight loss and refer them to local and national support services. Workshops are ongoing so book your free place with this link

https://www.eventbrite.co.uk/o/visualise-training-and-consultancyand-orbita-black-7994577028

### GOC's Enhanced CET Scheme

CET and CPD regulators require practitioners to reflect on their learning. Additional activities are required to gain CET for distance learning.

Log into your CET dashboard via iLearn. On the menu you reach you can choose either interactive or non-interactive CET for this unit of learning.

If you choose 'non-interactive', you have to pass (>60%) a ten-question multiple-choice quiz. If you choose 'interactive', you must pass the MCQ quiz and complete a further 30-minute discussion with a colleague, and upload a short summary of your discussion and reflections within 30 days. Note you must complete both tasks before your CET can be awarded. If you want the CET counted within a calendar year, make sure you submit the online record of discussion and remind your colleague to verify it online at least 2 weeks before the end of the year.

Further instructions for interactive learning are as follows:

The following steps must be completed within 30 days of completing the MCQ quiz:

- Discuss the interactive questions below with a registered colleague. Note if you are an optometrist, the colleague must also be an optometrist. If you are a dispensing optician, the colleague may be a dispensing optician, a contact lens optician or an optometrist. The discussion should be in a quiet environment where you are not interrupted for at least 30 minutes. Discuss the set questions and record a summary of the output of your discussion. Please ensure to create a paper copy of your record. Sign and date the document and keep it safely stored in case your CET is audited in future by the GOC.
- 2. In the event of an audit, we need to be able to show the GOC that the interaction has taken place in accordance with the instructions. Therefore, before you can be given points for this activity you must, within 30 days, record your answers to the set questions in the online Discussion Record and Reflection form (link provided on iLearn).
- 3. You will be asked for the GOC number, name and email address of the colleague who has completed the interaction with you, so please have those ready. Your colleague will be contacted by email (so please make sure you enter their correct email address) and will be sent a link to verify the interaction took place.
- 4. You can only be awarded interactive CET points if these steps are completed within 30 days.

The learning objectives for this article are:

- 6.1.5 Optometrists will understand the effects on vision, and the effect this has on patients' ability to carry out everyday practical tasks, and makes appropriate non-medical referrals to a range of services to minimise the impact of sight loss on the patient's life
- 2.10.1 Optometrists will have an understanding of service providers who deliver a range of services to people with sight impairment to help them make appropriate referrals and give advice to patients about access to these services
- 2.10.1 Dispensing opticians will have an understanding of service providers who deliver a range of services to people with sight impairment to help them make appropriate referrals and give advice to patients about access to these services
- 2.13.8 Optometrists will better understand the needs of patients with visual impairment and what constitutes reasonable adjustments.
- 2.13.8 Dispensing opticians will better understand the needs of patients with visual impairment and what constitutes reasonable adjustments to dispensing practice
- 6.1.1 Dispensing opticians will understand the causes of low vision, their effects on vision, and the effect this has on patients' ability to carry out everyday practical tasks

The discussion tasks for the interactive learning option are as follows:

- 1. Discuss with your colleague what local support services are available to individuals with low vision and how you can enable them to access these.
- 2. Discuss with your colleague how you could adapt your practice to ensure that you meet the needs of individuals with sight loss.
- Discuss with your colleague the personal learning outcomes you have gained from this module and how you will apply this learning to practice. Consider the following questions (you will upload these reflections to iLearn and to myGOC within 30 days of completing the quiz).
  - a. What are the main things you learned from the reading?
  - b. How will you apply this learning in your future practice?
  - c. Has this module identified any areas in which you wish to pursue further learning?