



A Patient's Journey: Living With Sight Loss

Background

In the UK, there are over 2 million people living with sight loss, with 340,000 registered blind or partially sighted¹. With growing waiting lists for low vision clinics in secondary care, there comes a need for locally commissioned, specialist low vision support in primary care.

Within this LOCSU case study, we look at a couple of patient journeys and consider how access to low vision support within primary care has improved their experience.

Norma's Journey

Patient Profile

Name Norma

Age 80 years

Eye Condition(s) Right – Dry Age-related Macular Degeneration. Left – Wet Age-related Macular Degeneration

Hobbies Reading, watching TV and socialising

It had been over six years since Norma attended for a sight test. She recalled at her last sight test, that it was discovered that she had wet AMD in the left eye and was promptly referred to secondary care for treatment. What followed was three years of intravitreal injections in the left eye, and little to no improvement in sight over the years. Norma was discharged from the Macular clinic in 2019, and another three years on, she booked herself a sight test.

She was examined and no significant change in distance prescription was found, however stronger near vision glasses were recommended. With corrected visual acuity of RE 6/15, LE 6/60, she was advised to immediately stop driving and to inform the DVLA of her eye condition as soon as possible. Understandably, this left her frustrated and distressed; Norma lived alone and relied on driving to do her weekly shop and attend hospital appointments. Further frustration was caused following a recommendation of being referred to the regional low vision clinic, but with no way of getting there, Norma declined.

¹ RNIB. Key Statistics about Sight Loss. RNIB; 2021



What Was Done?

Fortunately, Norma lived in an area that had a primary care-centred low vision pathway commissioned. The optometrist was able to provide reassurance and an alternative local choice of provider, at a practice closer to home. Norma was delighted to hear this, consented to referral and the referral was promptly actioned.

Two weeks later Norma received a phone call from the low vision practitioner, asking her a few screening questions for her assessment that was arranged 4 days later. Apprehensive but curious, Norma attended her low vision assessment at a local opticians. The optometrist took their time to explain Norma's diagnosis and together explored Norma's sight loss and its effect on her daily activities such as cooking, writing a shopping list and watching TV. Appropriate working distances and magnifiers for a variety of tasks were demonstrated, along with good task lighting, explaining how contrast is enhanced, enabling higher rates of fluency when reading. Norma was still coming to terms with not being able to drive, but having discussed further with the low vision optometrist, she was more certain that this was the right decision.

Further support options were recommended, and being impressed with the detailed and in depth support she has received thus far, Norma consented to a referral. Within a few weeks, Norma was contacted by the Eye Clinic Liaison Officer (ECLO) who explored non-optical aids and additional sensory support options available to her, to maintain her independence including a needs assessment by a Vision Rehabilitation Specialist (VRS). The ECLO signposted Norma to the Macular Society and other third sector charities for further support, and an opportunity to meet local like-minded people who can share their experiences of living with sight loss.

Three months later, a follow up phone call was undertaken by the low vision optometrist. Norma was delighted to hear from her low vision specialist again. She reported that since her visit, with the right support, she had found a new zest for life. She was using her magnifiers daily when reading and had recently spoken to the VRS, in which a number of priorities for training and support were explored and in the process of being delivered. A home assessment by the VRS had been completed and she was undergoing mobility training enabling her to cross the road and find her way to the local shops safely. Moreover, she had made some new friends at the monthly sight loss support group, and feeling confident, she was able to put herself forward and speak openly about her sight loss to inspire others to seek the support that they needed to live independently.

Peter's Journey

Patient Profile

Name Peter

Age 74 years

Eye Condition(s) Bilateral Optic Neuropathy secondary to uncontrolled Giant Cell Arteritis and high intraocular pressure

Hobbies Sailing, reading



Scared and anxious about the rapid onset of his sight loss, Peter was struggling to adapt to his new way of life. It was only when he attended with his wife for her sight test at the local opticians, wearing dark glasses and using a long cane, that Stephanie Cairns, Specialist Low Vision Optometrist, noted that he was using it incorrectly. Recognising that Peter needed support to help him get the most out of his sight, Stephanie offered a low vision assessment at the practice.

At the low vision assessment, Peter recalled that he had been certified as Severely Sight Impaired (SSI) a few weeks ago, but the certificate had yet to arrive. He had also been in touch with the ECLO team with little success and had not heard from the sensory team either. Despite the unwavering support from his wife, Peter felt lonely and depressed, isolated from the world he once knew.

Stephanie was able to establish his level of vision and noted the significant visual field loss in both eyes, especially in the inferior field. She recommended new reading glasses, to replace the previous varifocals worn, along with a stand magnifier, enabling Peter to use his superior field of vision, and achieving N6 vision. Lighting advice was provided along with glare management techniques. Following the low vision assessment, a fast-track referral was completed and sent to the local Rehabilitation team explaining the functional difficulties that Peter was having, as well as signposting by Stephanie to a counselling service and a local sight loss charity.

Speaking to Peter about his experience, he states:

“Living with sight loss has been a rocky road so far, I am still bumping into things every day. I didn’t get any help at all for a long while following diagnosis, I was completely in the dark. My local opticians have been absolutely brilliant. They were able to assess my remaining sight and make helpful suggestions and referrals to organisations that we did not know existed before. Thank you!”

Outcomes

In both cases, a collaborative approach by low vision primary care practitioners was undertaken, involving a variety of multidisciplinary teams all with the goal of ultimately improving quality of life and increasing active participation in society.

Both Norma and Peter had initially felt extremely anxious about the whole process, but speaking to the local practitioner and having had prompt access to care, made the experience less daunting. They were pleased with the service, care, and attention they had received and felt that their needs had been addressed. Norma was able to live independently with her sight loss and Peter was feeling optimistic for his future, something he previously thought was not possible.



In Summary

Improved access to low vision support within primary care is beneficial to patients. With increased patient choice and access, a primary care based low vision service provides a clear communication pathway and process involving multi-disciplinary teams across health and social care.

The LOCSU low vision pathway offers an integrated pathway, complementary to the services delivered within the hospital, bringing support to the heart of the community, delivered within primary care. The pathway embraces the whole practice team and encourages collaborative working between multidisciplinary teams keeping the patient's needs at the forefront. It is set out to provide timely and flexible access to care closer to home, whilst alleviating pressures on secondary care. Widespread commissioning of the pathway will ensure equitable access and service support, no matter what stage the patient is at in their sight loss journey.

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