

Real Patients Coming to Real Harm

A Patient Experience Story

Summary

This is a patient experience story about a patient who lives in Wales who has Age Related Macular Degeneration (AMD). She has Wet Macular Degeneration and has recently lost sight in her left eye which she feels is due to a delay in her diagnosis in primary care followed by a further delay in her referral to secondary care. She and her family were so concerned by the delay in her treatment that they paid for her to see a consultant privately. This consultant then referred her immediately to her local hospital eye clinic and her NHS consultant said that she had lost vision in her left eye and that she only has some vision in her right eye. Her private consultant said that if she had been seen earlier they could have treated her Wet Macular Degeneration, but unfortunately this was no longer possible.

However, when she was referred to the hospital, her records were mislaid and they did not send them to her GP. This has caused her to feel very worried and has meant a delay in enabling her to access services and support. She has had to contact the hospital eye clinic to ask for them to be re-sent to her GP.

She feels very distressed by her treatment and is devastated by her resulting sight loss. She feels that this has had a huge impact on her life and her mental health. At the end of her tether, she contacted her local Assembly Member who then referred her to RNIB Cymru.

She is currently receiving support but is considering raising a complaint.

Further details are included below and only include what the patient has consented to share. Patient details are anonymised.

Age: Not given

Eye condition: Age Related Macular Degeneration (AMD). She has lost sight in her left eye and has poor vision in her right eye.

Main issues: The patient feels her eye condition was not diagnosed appropriately and she has suffered loss of vision due to the delay in waiting for a referral from primary to secondary care. Due to the delay, her family paid for her to see a private consultant. When she was eventually seen in the NHS hospital eye clinic, the hospital lost her records and also didn't forward them to her GP. This has caused her considerable distress and has delayed her being able to access services and support.

Case: In July 2017, the patient went to see her local optician who she said also works in her local hospital eye clinic one day a week.

She said she went to her appointment explaining that she had a shadow over her eye and her optician said it was a sort of "dementia" of the eye.

She was given glasses and they helped for a while, but then things just got worse.

She went back to her optician but said that he was just very dismissive.

However, eight months later, in March 2018 she went back to her optician again as she felt things had got worse. She said that her optician dilated her eyes and she was diagnosed with AMD. He referred her to secondary eye care and said that she should be seen in about two weeks.

However, she didn't hear anything after the two weeks had passed and she was very concerned. She phoned the hospital and was told that she wouldn't be seen for 26 weeks.

Her family were very worried she would lose her sight, so her brother arranged for her to see a private specialist at a private hospital in her health board area. She said he was exceptionally thorough and diagnosed that she had had Wet AMD in her left eye and dry MD in the other and would refer her straight away to her local NHS hospital eye clinic.

Three weeks after this, she had an appointment at the hospital and her consultant there said that her left eye was damaged and that she had lost vision.

Her consultant completed a Certificate of Visual Impairment in September 2018 but she had not received any information following this and does not know if she is registered sight impaired or severely sight impaired (which affects her ability to access certain benefits). The only verification that she currently has regarding her sight loss is from her private consultant and the patient had to contact him to ask if he would share this with her GP. However, the patient feels it's hard for her to attend appointments and speak to the doctor as her surgery is three miles away and she can't drive and is afraid to leave the house.

She said she has been discharged from hospital as they said there is nothing they could do. She was given an emergency contact number in case her dry MD worsens or changes to wet.

Feeling very distraught, she contacted her Assembly Member who referred her to RNIB Cymru for support. This is detailed below:

Support via RNIB Cymru in Swansea: Staff arranged for a domiciliary visit by a local optician to enable her to access low vision services and have provided support with helping her access benefits. She has been referred to the Eye Care Liaison Officer (ECLO) at her hospital eye clinic. However, the ECLO has not been able to locate her files in the hospital system so has not been able to review details of her diagnosis including a copy of her Certificate of Visual Impairment.

RNIB are providing her with support in accessing services such as benefits, tax allowance, transport and any equipment she needs. They have also contacted the sensory team to carry out a sensory assessment as the patient is finding it difficult to leave the house and will only travel outside if someone is with her. Staff are advising on adaptive equipment such as electronic magnifiers and arranging for her to visit the resource centre and see the range of equipment available to help her with everyday life tasks. They are also arranging a home visit to advise on different services available and provided information on RNIB counselling services and emotional support.

Care and Repair Cymru are providing support to see if her house is safe and to advise on any adaptations. This includes improved lighting, a handrail on the stairs and grab rails in her bathroom.

Impact: She feels that her sight loss could have been avoided if her optician had diagnosed her eye condition earlier and if there hadn't been a delay in her referral to secondary care. She feels that if she hadn't been seen privately, she would still be waiting.

She says that she has some vision in her right eye but things are distorted and she can't judge depth or cross the road. She feels under-confident, housebound and completely devastated. She used to be outgoing, but now she feels she can't meet up with friends like she used to and she can't even see the inside of cupboards or saucepans, in order to cook.

Next steps: She is considering making a complaint, but at the moment she is still upset, in shock and struggling to cope with her sight loss. Also, she feels a lot of people are calling to see her to support her, so she is trying to manage this as it is taking up a lot of her time.

End of document.