#### Podcast: What is an Eye Clinic Liaison Officer?

D: Hello and welcome to this RNIB podcast. My name is David Watkins and I am the Visibly Better coordinator for RNIB Cymru. Today we’re going to talk about a fantastic support service for people with sight loss particularly those who have been recently diagnosed. Ruth Rhydderach is an Eye Clinic Liaison Officer otherwise known as ECLO, at the University Hospital of Wales, and she is going to talk about the services she provides within the eye health clinic in the largest hospital in Wales. Hello, Ruth, and welcome; thank you for joining us today. Can you tell us more about your role?

R: Hi Dave, thanks for having me. Well, my role is one that is about providing information and support for people and I’m based in the eye clinic, but that doesn’t mean I just deal with eye clinic patients. I work in the eye clinic 9-5, Monday to Friday, so I am available for anybody who comes here. So you are going to find two words to describe what I do, the information and support and that information is about services, it’s about people’s eye conditions and the treatment they receive, it’s about things like registration and then the support is practical support. Sometimes that can be as simple as guiding someone to the clinic or sitting with them while they’re having their appointment, so that someone has an extra pair of ears to listen so they get all the information or it’s emotional support, which is really, really important because obviously coming for hospital appointments can be really stressful and often we’re giving them a lot of information and lots of news and things that they need to understand. Yeah, two words, information and support would probably sum it up nicely.

D: What did you do before you became an ECLO and how long have you been an ECLO for now, Ruth?

R: Originally way back when I was a young spring chicken I trained as a nurse. I worked on a medical admissions unit and a medical ward, but I moved around. Did quite a few different other things, most recently working one-to-one as a support for a patient who had MS. I then worked in my last job in an advocacy role for people with dementia, but I’ve done all sorts of other bits and pieces including a little stint working for ESTIN doing stuff with schools and sort of standards around education. So it’s a real, real mixed bag of bits and pieces, but I’ve been working as an ECLO now for six and a half years and it’s been a huge learning curve because I knew nothing about eyes, nothing about eye clinics and nothing about eye services, but I’ve learned a phenomenal amount from my colleagues in the eye clinic and in other services and I do think some of the background I had in all of the other jobs I had gave me lots of skills that came to this job with me. So I would have never thought that I could be an ECLO. I didn’t even know what you needed to be good at, but I think I’ve got those skills from lots of different places and I’ve learnt a lot here from the doctors and nurses and other people.

D: That’s fab. I just want to know how did the role of the ECLOs around the country come about and why were they needed?

R: Well, I think originally there was a bit of a perception that ECLO’s would be there when patients received a diagnosis of an eye condition, but I think what we have realised is, is that it’s more that we’re there often when patients need us because what was found was that often patients come to eye clinics and they get a phenomenal amount of information. They’re often started with new treatments; that might be injections, that might be drops, that might be having laser. You know it might be a whole heap of things. They might be expecting to come in for surgery, they might in the initial period be given some really complicated difficult news that they’ve got an eye condition or they might be a parent of a child who is told that their child has an eye condition and sometimes they can't give really straight answers about that. You can sort of say what’s likely to happen, but most of the times you can’t tell people what’s going to happen.

You can maybe give them a name for what’s wrong, sometimes not and you might give them a plan about what’s going to happen like you’re going to need this treatment for this period of time or we need to do this operation or you need to take these drops or whatever, but it’s often a whole heap of information at a time when people are feeling pretty vulnerable and frightened and often that doesn’t just happen once. So they might get told sometime this is the name for what’s wrong with you, for example, you’ve got wet AMD and then they get a whole load of information about the treatment and then maybe a year later someone sits them down and goes well, your treatment is not working anymore now. So you need to have some magnifiers or you need to be registered and this information is quite loaded, it’s quite emotional because it impacts. I mean I’ve just been writing a presentation this morning for our new junior doctors: eye clinic patients are not just a pair of eyes because it’s not just one bit of their body. It affects their whole life and often patients were getting all this information, but they then went away not really understanding, their lives were impacted because their sight didn’t maybe work as well as it used to and they felt very vulnerable, very confused and were really struggling. Another thing that used to happen in the past would be that registration was seen as a last chance saloon, we’ve tried everything, hasn’t worked, you can’t see anymore, sign this bit of paper, bye now, off you go and all those sorts of scenarios. It was just felt that we could do better than that. We could actually offer these patients more than that and that really mattered. So the ECLO service was kind of born out of that and it’s really grown into a service that isn’t just at the point of someone’s diagnosis whatever that may be. Often there isn’t a point of diagnosis, the patient has lots of different diagnoses, for want of a better word; you know different bits of news. It’s when the patient needs us and yeah, sometimes that is a diagnosis point. Sometimes it’s like with a small child it’s in a very difficult point for parents when they have been worried that something’s not right and then someone sits them down and says, yes there is a problem, but often it’s just when somebody needs that extra bit of help. That extra bit of guidance and support and I suppose the thing to remember in this is that I’m not a doctor, I can’t operate on people’s eyes. I know my limitations, I’m not going to try, but equally they don’t know all about the services, they don’t know about the information and often they haven’t got the time. You’ve got a clinic with x number of patients outside your room, Mrs Jones is sitting in your room crying because she’s upset and you don’t quite know what to do with that situation, which is where an ECLO would kick in. You could spend time with her, I always joke with my patients I’m not on a meter; you can stay with me for as long as you need and we’ll talk things through and as well they can come back to me at their leisure. So that means with that service they are given the time they need and we can give them the information at the pace that they can deal with.

So I think it was born out of that desire to make sure that patients weren’t left high and dry. That they were supported and that we have acknowledged the fact that sight loss doesn’t just impact on whether they need drops or injections, it impacts on every aspect of their lives.

D: What ages of people do you support and is there a typical experience for people using the service?

R: Well, I talk to people of all ages, not all ECLOs do. Often that’s not because they don’t want to it’s just because the clinics they work in only cater to either adults or children, but because I’m based in the University of Wales we also have the Noah’s Ark Children’s Hospital here, which has an eye clinic. So I see patients from nought basically to I think I have seen a 104-year-old, but I wouldn’t bank on that being my eldest, but my youngest wasn’t even a day old. I actually went to see that little baby on the postnatal ward when she wasn’t even 24 hours old. So any age, obviously a lot of my patients are older because as you age you’re more likely to suffer from conditions like age-related macular degeneration, which affects your sight and comes as you get older, but I see patients of working age, I see teenagers, little ones. So today is a Friday in clinic and I’ve seen a little baby that wasn’t quite one and she was very lovely, but she needed registering and I’ve just been sorting out a registration for a gentleman in his eighties. So it’s really, really, really variable.

I wouldn’t say there’s a typical experience, everybody is very, very different in where they are at, what they need, what’s important to them, but I suppose the one thing that often I come across is the fact people will say, well I don’t know what I don’t know because you sort of say to them, right well what do we need to do and they are like I don’t even know where to start. I don’t know what’s available, I don’t know what questions to ask, I don’t know what it is actually that I need and then you kind of take a step back and go okay, well what’s worrying you the most, what bothers you the most and that often then gives you a place to start. So if I was going to say is there something typical that’s the only typical I find. It seems no matter whether you’re a parent with a little one or whether you’re in your eighties, it’s that kind of finding a starting point. When I started this job I had not a clue. Didn’t know anything about eyes, I always try and liken it a little bit to that. I also connect to a recent experience that I had with a family member where I was sat in an out-patient’s appointment and was introduced to the equivalent of me.

Totally different service, but I was sat there and I was like, oh okay, the girl said to me, she said, “Well, what do you want to know?” I said, “I don’t know, I don’t know what I do know or what I don’t know,” and I think that’s really typical of us. Until we’re confronted with a situation we don’t know where we want to start, but we all have that desire to try and make the situation better, easier, less difficult than it is and I think if you can start from that point with whoever and it’s their start point then because if you say to them where do you want to go, what’s your worry, what’s the thing that bothers you most, you won’t go far wrong, but yeah, that would what I would say is the most typical experience for my patients.

D: What type of services do you link into?

R: Well, there’s lots of services out there and most of them would come under the umbrella of something to do with sensory needs or visual impairment, but if it’s something outside of that box that’s absolutely fine, but most people that I would deal with initially would be referred to their local sensory team. So every local authority has a team that supports people with sight loss, hearing loss or both. Obviously most of my service users have sight loss, but quite a lot of them have sight loss and hearing loss because they are older and that comes with the territory and sometimes genetic conditions, which means they do have both. So that’s the first port of call because then they can get an assessment, a visual impairment assessment and can be referred then to their rehab officer for visual impairment who can do some work with them around independence, mobility those sorts of things. Here in Wales we have the Low Vision Service Wales, which is based in the community.

So instead of having to come to a hospital to be assessed for your low vision aids that can be done with an accredited optometrist in the community, really good service, free service, easy to access, self-referral, doesn’t have to have a letter from a doctor or anybody else and they can access really good quality prescribed magnifiers, lighting, all sorts of bits and bobs to help with reading and day to day tasks. So they are my biggies, they are the two that I would say I refer to day in and day out. When I deal with children I would refer to the qualified teacher for visual impairment. So education services are really important for children and we refer to the education team from Booth, so they get a specialist qualified teacher that can support parents to promote development, assist with some placements in nurseries and schools and things and they support the parents all the way through. So when the children go to school they guide and direct the schools with regards to what adaptations need making to support those children. So that’s my biggie with children, but then you get onto the whole big wide world of things that are out there, which are provided by charity third sector organisations.

So you’ve got local blind societies that they used to be called. So places like Sight Cymru, Sight Life, which are local organisations to me. So I’ve got a pretty good knowledge of what’s available locally, which sounds simple, but when you work in the University Hospital of Wales instead of covering maybe one or two local authorities, I think last year I dealt with about 14 or 15 because my patients come from so far away. So it’s trying to have that knowledge base of either what’s available locally or who can I send you to locally, who can tell you all about that. So I’ve got other colleagues in other hospitals, in other health boards that I can pass people to. So there’s local societies that can provide support with companionship to keep people from being isolated, they can provide groups, they can provide activities, they do support around using technology. So a whole heap of different stuff and then there are organisations like Blind Veterans, which support obviously a specific category of my patients.

So people that have been in the forces in the past who have now lost their sight can get help from them and there’s quite a few organisations like that, that are quite specific in who they’ll deal with. Again, it’s about having that kind of knowledge base and that’s the whole kind of point of me. I don’t do the job of these organisations, I just get the people to them and then you have organisations that are more specific for children and families. Some of these are condition specific. So for adults you might have the Macular Society, but also they deal with young people with macular conditions. You might have organisations like Retina UK that deals with things that are retinal dystrophy kind of conditions. So there’s very specific ones, but then there’s much broader brush ones as well. There’s one for glaucoma, there’s things like Sense and UCAN and UCAN helps young people through the performing arts. So there’s a whole heap of different services out there, I don’t know about every single one of them, but I know quite a lot of them. My colleagues know quite a lot and we share information and I think it’s just trying to tailor the referrals to these places so they meet the needs of the patient.

So if the patient is telling you that they’re having difficulty with, for example, isolation you might refer them to your local society or you might refer them to say Age Connect who can set up a befriending and shopping support for them, for example. So it’s kind of tailoring it to what they actually need. If you’ve got a mum, I’ve had a lot of mums coming to me and their little one has just been diagnosed with sight loss and what we try and do is use RNIB Connect to maybe put them in touch with other parents who have walked the walk a little bit before. So not that if you’ve been through it you can tell someone else necessarily how to do it because we’re all different, but for parents often it’s really valuable to meet other people that have been there before because they know the right arguments to have with professionals or the right things to fight for or even just the emotional impact of your child having something like that. So I use loads of those different services, RNIB services, local services and just try and work out a plan for each patient and what suits them best, but also they might come to me three or four times. They don’t just come once and then vanish.

They might come back once and we sort out some low vision aids, they might come back a few months later and they are maybe struggling in a different way. So we set them up with something else maybe with a RNIB Connect talk and support sort of group and other times they may be struggling to use their mobile phone so we get them a bit of help with someone who can teach them. So it’s kind of knowing what’s out there and then getting it to your patient and making sure it’s okay.

D: What I want to know is, is do you have some real-life examples of people you have supported of retirement age and of a younger age?

R: There was a gent a while ago when I had not long started here and he was a classic ECLO patient, not that elderly, but coming up for retirement age, still working and lost his sight overnight, which is really shocking and doesn’t happen that often and he has come back and forth to the ECLO service on so many occasions for different bit and pieces. But I’m really, really proud of what we have achieved with him because he arrived here literally sat here going, what am I going to do, I’ve lost my sight, this is just you know, and the emotional support bit was the important bit then and there was lots of it. There was lots needed, but it was also a flurry of giving him information and he was here with his wife and saying, right these are the services that I think we need to get to you ASAP and that was a sensory team to get rehab, welfare rights to get his benefits sorted out because obviously he suddenly couldn’t work anymore because we offered him support, but he just really couldn’t cope with it at that point. So it was sorting out his benefits and also he had always used his mobile phone, always used his iPad. So it was getting that sorted and trying to work out which order we did things and get help to him quite quickly.

And it was really interesting because his wife came back into the clinic a few months later, I haven’t seen them since, I pinged a few emails to the wife, but nothing and I was like, oh dear, that didn’t go very well, don’t know how that’s going on and she just bounced back into the clinic about three or four months later going, “You are not going to believe what’s happened, he’s now walking with a long cane because he has had mobility training. He has had some help with this technology and I’m so pleased” she said, “We were really getting worried about our financial situation and our benefits have now been sorted and it’s just taken a weight off our minds.” And then a little while later came back again and needed a bit more emotional support because things had taken a bit of a turn for the worse and it was just having a bit of a chat with him and his wife because that’s an important thing to say, we support the family whether that’s a parent or a spouse or a child it’s not just the patient comes in and we shut the door.

We helped him get a tax rebate through Blind Person’s Tax Allowance, which got him a not insignificant sum of money back and sat one day in the hospital, we have a big concourse area where you can go for your lunch and I just sat there and someone with a white cane went past. I was like, so I kind of turned and looked and was like, oh my goodness and there he was and it was like wow. So I had gone from this chap who had sat in my office literally breaking his heart because he’s lost his sight and his wife was telling me he was now confident going out on his own with his cane. He could use his iPad again, he had his benefit sorts and that wasn’t a five minute story, that was probably two or three years, but it really sums up what we do is we meet you when you need us. You can come back whenever and we’ll sort things out. It’s not easy because he still struggles and there are times when his wife comes back to the clinic and she sits in my room and has a good cry and a good shout and then we crack on again.

So that’s kind of an example of somebody that age and then a real quickie of the littlest one I ever dealt with we registered before she was even sent home from hospital as a baby and she’s a really complicated case and mum is complicated and it’s a complicated social situation, but the vision impairment team had said from the start that their job would have been 100 times harder if they had met this child when she was maybe a year, 18 months old, which is what often used to happen in the past. They kind of got missed, they didn’t necessarily get sent to them when they were tiny and they’ve built a really good relationship that works with mum and there have been some bumpy bits of that journey, but they have said that they are so grateful that this baby came my way straight away. So when they went within weeks of birth so it’s made things a lot, lot easier and that’s always emphasised to me that it’s really important with children to get to them as quickly as we can, but also it’s really important about relationships with whoever.

Whether it’s an adult, a baby, a parent whatever, that’s what the job is about building relationships either with me or with the other professionals, with the right people.

D: That’s fab. Lastly, who is eligible for your support and how do they access it?

R: As far as eligibility you don’t need a referral from a professional or a doctor or an optician or anything. You can just find out who your local ECLO is and get their contact details online and give them a ring. If you attend an eye clinic you can just ask to be put in touch with your ECLO. If you are going to see your optician you can always say is there an ECLO locally, can I be put in touch with them? So there’s no barriers to it, you can refer a relative in if you think they’ll need help or you can ask for help yourself. So if you think you might benefit even if it then turns out we’re not the right person quite for you, we can always pass you onto the person that is the best for you to speak to.

D: Ruth Rhydderach, thank you for your time today. I think we can all agree that what you and the other ECLOs provide is such a wonderful and a much needed service. That’s the end of the podcast today and Ruth and I hope you have enjoyed listening. Thank you and bye now.