

See differently

Statement Summary: impact of the of research on Post stroke visual impairment carried out by Prof Fiona Rowe since 2013 at The University of Liverpool

Mrs Stevie Johnson

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This statement was written after the respondent consented to be interviewed by Research Impact Officer Selina Wallis, this was then transcribed and summarised and returned to the respondent for corroboration of fact and to give an opportunity to add any omitted details

The main part of my role is taken up with the development, training and CPD for members of staff called Eye Clinic Liaison Officers (ECLO's). They work in NHS departments and they are there to provide practical and emotional support and onward referral to a very wide range of organisations for those effected by sight loss. This came about because a number of years ago there were various pieces of research that people effected by sight loss - whilst appreciative of the excellent care they got in eye clinics - were not receiving emotional support and not being told about the range of support services and organisations that were available to them outside of the hospital. They were falling in that gap between health and social care. So ECLO's are employed in eye clinics to provide that listening ear, that emotional support and that link to the support that's available outside the hospital.

I've been with RNIB for 12 years and before that I was an Orthoptist and Low Vision therapist. So my background is 20 years of clinical work before I joined the third sector. From my point of view, Fiona is my main "go-to" stroke person. There are a significant amount of people that have vision problems as a result of their stroke and it's been mainly about raising awareness within my organisation, Fiona has spoken at a couple of our conferences, we share the VISION resources, she's also come

and spoken to our ECLO's in the past, we've written a good practice guide on stroke.

Fiona and I met up a year ago because we wanted to share her VISION resources with our ECLO's - we have a pan-organisation email network and we plan very soon to share those resources in that way, which is an additional audience of around 400 people that will be made aware of those resources (now shared- March 2019). The way we've used them is to raise awareness and to reinforce the needs of stroke patients, with regards to access to support, so I think I would say that if we didn't have access to any of Fiona's resources, it's quite possible that ECLO's would not see so many patients that had had strokes, stroke survivors wouldn't have resources specific to them, and possibly wouldn't know that they were even there, people would slip through the net.

I rely on all of Fiona's work, her statistics; her resources are my go-to place for information about vision problems after stroke. This week I've been running the ECLO training course, which is accredited by City University, and I use her research stats when we are talking about the effects of stroke on sight.

If people are not made aware of the services available, if you have a stroke patient whose vision problems are not assessed, they won't be made aware of the support available, or not referred for rehabilitation with their local sensory team. We know people are much more likely to be depressed, isolated, at greater risk of falling and sustaining further injury, less likely to remain independent and stay in their own homes {without support}. People who are friends, families and carers are affected emotionally as well, as their lives are turned upside down, people are completely unaware of the help that's available through the sensory teams, through rehab, and that includes things like communication, daily living skills, mobility training, all of those support services are there for them, they just don't know they're there.

Fiona is who I think about straight away when we talk about a raised awareness of vision problems after stroke, and with my Orthoptic head on now, her research, nobody else has done it, there's nobody else that pops into my mind when I think about it, she's almost like a one woman crusade out there, to get that message out, her work has been incredibly important in that regard and Internationally as well. Sometimes when you look at stroke guidance you can see there are pages and pages on swallowing and mobility assessment and speech, and vision has often seemed to be missed. As an orthoptist it used to make me very cross when I saw someone post-stroke, a year, eighteen months post-stroke

having their first visual assessment and they were wondering why their rehab had ground to a halt! It used to make me very cross!

There's also a postcode lottery, in some hospitals you will have a very active stroke unit that works very closely with their eye department, in others that simply doesn't happen, and so people won't even have their sight loss identified. I think there are also a lot of common misconceptions that if someone's post stroke they're somehow unable to be screened, and actually what you need is someone with the right experience and understanding {to screen}., I left my eye department twelve years ago and for the ten years prior to that we had been bidding every year for ten years to have an Orthoptist on the stroke ward to do screening, and every year we were turned down.

Fiona's work has changed the way I operate, I am banging the drum for stroke a lot of the time, and it's been a neglected form of sight loss.

SJohnson