

Registering as sight impaired: The piece of paper that proves it

A shorter version of this article first appeared in Nystagmus Network's Focus newsletter 102, March 2014. Please note that registering as sight impaired is an option in the UK. Other countries have different systems.

Certification & registration (a two stage process)

Certification – Ophthalmologists (hospital eye doctors) can certify people as sight impaired. They then issue you with a CVI (Certificate of Vision Impairment). The CVI forms – including explanatory notes for consultant ophthalmologists are online at

<https://www.gov.uk/government/publications/guidance-published-on-registering-a-vision-impairment-as-a-disability>

Registration – The hospital should send the CVI to your local authority who keep a register (list) of everyone with a CVI. “Are you registered?” is often the first question people ask when you’re seeking help at school, applying for DLA or Access to Work, etc. The RNIB’s website has a list of the benefits of registration at

http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/registration_benefits.aspx

A recent Facebook post led to comments about the difficulties some people with nystagmus have registering as sight impaired or severely sight impaired (“partially sighted” or “blind” as was). This reply sums up the problem: “This has annoyed me for a while. Many people with nystagmus will never drive... Yet they are still not eligible to register as partially sighted as they can read quite a way down the eye chart (with difficulty, head postures & wobbly eyes).”

NN agrees that if you can't see well enough to drive you should – if you choose – be able to register as sight impaired. Unfortunately the two stage certification and registration system was set up separately from the vision test for driving, so it's not always that simple.

Here's how certification and registration works. If you have an eye problem (like nystagmus) and a hospital eye doctor (ophthalmologist) considers your sight meets the criteria (is "bad enough") then he or she might suggest they certify you as sight impaired. You can also take the initiative and ask your ophthalmologist to certify you or your child.

Once certified as sight impaired you can go on a register kept by your local authority. The theory is that the register tells local authorities how many people with a sight problem live in their area so they can plan services accordingly.

What's the point?

Why bother getting a CVI and going on the register? At first glance, the benefits of being "registered" as it's usually known may not seem that great to everyone. They include free NHS sight tests, being able to apply for a disabled person's railcard and possible reduced entry prices to cinemas, theatres, museums, etc.

But the reality is that being registered helps open doors to support at school, PIP (Personal Independence Payment) and other state financial benefits, help at university and the Access to Work Scheme.

And sometimes just having that piece of paper (you don't usually have to show it) comes in handy in ways you can never imagine. Especially when people don't believe nystagmus is a problem.

Making your case

So, for many people with nystagmus it is worth considering registration. Yet ophthalmologists sometimes hesitate about issuing a CVI to people with nystagmus, even though the guidance to doctors gives them a lot of

discretion. Here's what the notes from the Department of Health say (see box for a link to the CVI website):

“There is no legal definition of sight impairment. The guidelines are that a person can be certified as sight impaired if they are ‘substantially and permanently handicapped by defective vision caused by congenital defect or illness or injury’.”

Most people agree that definition generally includes nystagmus. However, the guidance notes to doctors go on to say: “As a general guide, certify as sight impaired, people who have visual acuity of 6/18 Snellen or even better ...” Many of us with nystagmus do have visual acuity of 6/18 or better. That may explain the reluctance to give some people with nystagmus a CVI.

But the scientific evidence is mounting that visual acuity is an inadequate measure of the impact of nystagmus on day to day vision. So, here are some additional suggestions to back up your case for registration:

1. Nystagmus varies throughout the day, so visual acuity (VA) measured under ideal conditions is better than our real vision.
2. Our response times are slower, so we need more time to see -- see research at <http://www.ncbi.nlm.nih.gov/pubmed/24222308>
3. If you have a null zone, your vision is worse in all other gaze directions -- so your field of vision is affected.
4. Nystagmus reduces depth perception and can affect balance.
5. Cluttered, crowded, busy environments make it harder for us to see than our VA would suggest.
6. We struggle with fast moving objects, so we are at greater risk for instance in traffic than our VA would suggest.
7. We have poor contrast sensitivity.
8. Many with nystagmus are light sensitive (photophobic) – usually because of associated conditions such as albinism, achromatopsia and high myopia.
9. Although early onset nystagmus is not usually degenerative, normal changes to vision in middle age may have a greater -- and often unrecognised -- effect on us than on others.

Not everyone with nystagmus wants to register as sight impaired. But, if you do, the above list shows that nystagmus is more than just poor distance vision and that you're as entitled as anyone else with a sight problem to get a CVI.

Stuff the stigma

Over the years I have spoken to hundreds, very probably thousands, of people affected by nystagmus. Some are adults with the condition and many are anxious parents of children with flickering eyes. One issue that comes up time and again is that of stigmatising or labelling a person – a child in particular – by getting a CVI.

Pretty much without exception, nearly everyone I know who has taken the decision to apply for a CVI has been glad they did so. In fact, most say they wonder why they didn't do it sooner. In my experience there is little or no question of a CVI being a stigma or a label.

Moreover, you don't have to tell anyone that you are registered unless you choose to do so. Yes, it is a good idea to tell prospective employers, but think carefully about how you tell them, what you tell them and when you tell them.

Parents often worry that getting a CVI for their child may affect their chances of one day getting a driving licence if it turns out that their sight is better than expected. This is very unlikely. You can come off the register whenever you want. So, if you reach 17 and your vision isn't as bad as perhaps feared at diagnosis, you can de-register. You'll still need to look into whether a) you can legally see well enough to drive and b) whether you'd be safe to drive. But that's another question altogether.