Nystagmus Information Pack



Part 3. Acquired nystagmus

ACQUIRED NYSTAGMUS

What are the causes of acquired nystagmus?

Acquired nystagmus occurs later in life and is typically associated with ocular disorders, neurological disorders and loss of vision.

Disorders affecting the eyes or trauma can cause loss of vision and acquired nystagmus, for example, a disorder of the retina (the light sensitive layer at the back of the eye).

Acquired nystagmus can occur in a wide range of neurological conditions, which are conditions that affect the brain. It is particularly common in multiple sclerosis, stroke, diseases of the vestibular system (important for balance) and brain tumours.

Head injury (which may be called traumatic brain injury) and a wide range of drugs and medications can also cause acquired nystagmus.

What effect can acquired nystagmus have?

If nystagmus is acquired and begins later in life, the brain has not adapted to the constant movement of the eyes. The world is often seen as constantly moving and this can be very disorientating and disabling. This constant movement of the world is called oscillopsia. Not all people with acquired nystagmus will have oscillopsia, but instead they may describe blurred vision.

In acquired nystagmus the type of nystagmus may be the same in each eye, but it may also differ in each eye. Some people may have acquired nystagmus affecting one eye only, yet others may have both eyes affected, possibly with a different direction or







speed of nystagmus in each eye. Every person's nystagmus is different, causing the impact of nystagmus on each person to vary greatly.

In acquired nystagmus, as well as experiencing oscillopsia, vision may be reduced, people may feel unsteady, nauseous and have problems with balance. As the nystagmus is more likely to change when the eyes are moved, these symptoms and problems may be worse when the person is trying to look around. Acquired nystagmus therefore can also lead to:

- needing more time to see and react to things
- difficulty focussing on objects once located
- difficulty judging whether objects are moving or still, and difficulty judging distances and depth
- difficulty when trying to read or write, particularly when the scene or surrounding area is busy and crowded
- difficulty seeing in bright or poor light
- reduced peripheral vision (field of vision)
- balance and mobility problems

A big factor to consider is the variability of the nystagmus. It can worsen when tired, hungry, in different lighting, anxious, feeling unwell, stressed or excited; as well as when moving the eyes. This variability means the oscillopsia and blurred vision also vary, for example, if the nystagmus is worse when the person is tired, their vision and oscillopsia will also worsen.



Living with acquired nystagmus

Some people with acquired nystagmus may be able to hold their head in positions that help them reduce the nystagmus and oscillopsia to see more clearly. Some may shake their head or nod to try and reduce their nystagmus. For others, they will be unable to reduce the nystagmus in any way.

Adaptations can be used to try and help maximise vision. These include:

Using colour and contrast

Increasing the contrast between doorways, handles and stairs



• Using different colours and contrast on computer screens and on reading materials



Navigation and mobility

 Practising walking to school or work to increase familiarity and confidence with specific routes and to know where it is safe to cross roads to gain more independence. Practise during quieter times of day to build confidence.





Orientation and mobility training, if required, should be provided by a suitably qualified practitioner, often through your local social services team or sensory impairment team. This training helps teach safe, efficient and effective travel skills to people of all ages.



Socialising

• When meeting in a crowded or busy place let one another know what colour clothes you are wearing to help identify one another. Well-lit environments are important.



 Introduce yourself or ask others to introduce themselves to you. Nystagmus affects the time to see and distance vision; therefore, faces may not be recognised quickly as you approach someone.

Technology

- Static and mobile devices increasingly have accessibility options to increase the size, contrast and magnification of text to suit the needs of the user.
- Mobile devices can be tilted or have different screen covers to decrease glare and aid vision.
- Taking pictures with a mobile device, for example a picture of a signpost can be enlarged to help read it.



- Some mobile devices offer a "tap to talk" option, which converts text to speech. Apps and software that convert pictures of text into speech are available.
- Using a mobile device with GPS technology to provide audio support when navigating unfamiliar environments. Smart watches can be useful for providing immediate access to directions in a familiar way.

Sport

Mainstream sports can be enjoyed or may be a challenge depending on a person's level of vision and whether they have difficulties with other aspects of their vision, for example depth and motion perception. When playing sports or being active, individuals with nystagmus may make adaptations such as using a different head position or using colour and contrast to help them identify items more easily.

There are also lots of different sports that can be adapted for individuals with significantly impaired vision, including golf, tennis, athletics, football, judo, archery, cricket, snowsports and ten-pin bowling. There are also sports like goalball that have been developed specifically for people with visual impairment and fully sighted players wear restricted vision glasses to be able to play.

Education

Please refer to the section on 'education' within Part 2 of the Nystagmus Information Pack.



Driving

Depending on a person's vision (measured on a clinical vision test) and their peripheral vision (visual field), some people with nystagmus may meet the legal requirements for driving. However, you must inform the DVLA if you have nystagmus.

https://www.gov.uk/driving-eyesight-rules

Employment

Sight loss and impaired vision are considered a disability under the Equality Act (2010). Employers are not allowed to discriminate against someone based on their disability. Practical and financial support is available to sight impaired individuals in work or starting a new job via the 'access to work' scheme. The scheme can help by providing different visual aids, equipment, support workers and travel to work.

https://www.gov.uk/access-to-work

