Nystagmus Information Pack

Part 5. Treatment options and long-term outcomes

TREATMENT OPTIONS

The decision on which treatment is best suited for your or your child's nystagmus is often decided following a range of clinical investigations and a discussion between you and your ophthalmologist.

Whilst there is no treatment at present that can cure nystagmus, treatment often aims to reduce the nystagmus. Many of the conditions or features associated with nystagmus can be treated and these typically aim to improve vision and/or reduce the nystagmus. Sometimes an improvement in vision may lead to a reduction in the nystagmus.

GLASSES AND CONTACT LENSES

To correct refractive error:

Nystagmus cannot be cured by glasses or contact lenses. However, if the person with nystagmus has refractive error (is long or short sighted, or has astigmatism), using glasses or contact lenses to correct the refractive error makes the image they are looking at more in focus and improves their vision. This is particularly important during childhood as the visual system is developing at this time and having the image of the world made as clear as possible is vital for visual development.

Contact lenses offer the same optical correction as glasses, though as they move with the eyes they are sometimes preferred to glasses. Important factors to consider when deciding between glasses and contact lenses include age, ability to care for contact lenses, head posture and additional low vision

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aids. The optometrist and ophthalmologist can discuss the contact lens options, which may include hard and soft contact lenses. Hard lenses may be better suited to some people with nystagmus. Research into the use of contact lenses in nystagmus is ongoing.

Filters and tints:

Glasses and contact lenses can also incorporate filters and tints to try and reduce the effect of bright light and glare. For some people with nystagmus filters or tints can help make them more comfortable, for example if they are very sensitive to bright sunlight. Increased comfort may also be associated with reduced nystagmus and improved vision in some people. The optometrist and ophthalmologist can discuss whether filters or tints are appropriate.

ORTHOPTIC TREATMENTS

Amblyopia treatment - if amblyopia (lazy eye) is present in a child, in addition to nystagmus, amblyopia treatment may be offered. Amblyopia is only treatable in childhood and is undertaken by the orthoptist. Treatment typically involves covering the better seeing eye with a patch or using atropine eye drops into the better seeing eye (to make it blurred). Amblyopia treatment may be undertaken in combination with glasses (or contact lenses), which are required to focus the image the eyes are seeing.

Amblyopia treatment aims to improve the vision in the weaker 'lazy' eye and regular appointments with the orthoptist are required during this treatment.

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Prisms – if nystagmus improves when objects are held very close (dampens on convergence), sometimes prisms can be trialed to simulate this close position. This treatment is not usually a long-term option, but may be offered by the orthoptist or may be used prior to discussing other treatment options, such as eye muscle surgery.

Adaptations

- **Head posture -** a head posture may be used to reduce the nystagmus and achieve better vision. It may change for different visual tasks and different distances. It is important for others to understand the visual benefit of using a head posture, to prevent it being misunderstood as not concentrating.
- **Close reading distance -** some types of nystagmus decrease when objects are held very close (dampens on convergence). This typically leads to improved vision and should therefore not be discouraged.

VISUAL AIDS

A range of visual aids and strategies are available to help with near and distance viewing tasks in nystagmus. These include magnifiers, binoculars and monoculars, which are often assessed in a low vision clinic; as well as lighting, glare and contrast. Members of your eye care team can discuss low vision clinical input.

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PHARMACEUTICAL TREATMENTS

The aim of pharmacologic treatment (medicines or drugs) is to improve vision by reducing nystagmus without adversely affecting normal eye movements. Gabapentin and Memantine have been found to reduce the intensity of nystagmus leading to improved vision in some adults with infantile idiopathic nystagmus. Drug trials investigating the effects of these drugs are ongoing. Both Gabapentin and Memantine can be used in some types of acquired nystagmus. The ophthalmologist can discuss drug treatment options with you, as they have side effects.

BOTULINUM TOXIN (BT)

The visual symptom of oscillopsia is often very disturbing. Oscillopsia typically occurs in acquired nystagmus, but can occur in infantile nystagmus at times. In some cases patients with acquired nystagmus may be offered Botulinum Toxin to reduce the nystagmus and oscillopsia in one eye, with the other eye covered by a patch. This option is not suitable for all, but would typically be considered in people with significant oscillopsia or wheelchair users.

Botulinum Toxin wears off after approximately 3 months, so if successful, may need to be repeated. Possible side effects include a drooping eyelid and double vision, but these are often temporary.

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SURGERY

Surgery can be performed on the muscles around the eyes (extraocular muscles) by an ophthalmologist specialising in extraocular muscle surgery. Surgery is not suitable in every case, so the ophthalmologist can discuss whether surgery may be appropriate.

Surgery - to reduce a head posture

If a person with nystagmus uses a significant head posture, surgery on the extraocular muscles may be offered to try and reduce the size of the head posture. The aim of surgery is to reduce the size of the head posture whilst maintaining the reduced nystagmus effect; but without disturbing the ability of the eyes to move or work together as a pair. Surgery would typically be considered if the head posture was large and either very uncomfortable to maintain or it was causing other visual problems.

Surgery - to reduce nystagmus

Surgery cannot cure nystagmus. There are some surgical procedures on the extraocular muscles that specifically aim to reduce infantile nystagmus, but they are less well established.

Research is ongoing to investigate the effectiveness of 'tenotomy of horizontal eye muscles'. This surgery cuts the extraocular muscles that move the eyes horizontally, removes them from the eye and then reattaches them back onto the eye at the same

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place. This procedure has been considered safe by NICE (National Institute for Health and Clinical Excellence), yet limited information is available about the outcomes from this procedure at present.

The Sinskey procedure has been reported in the USA but is not currently offered in the UK, as it is not considered safe or effective. This surgery permanently removes some of the extraocular muscles that attach to the eye.

LONG-TERM OUTCOMES

The long-term outcome of treatment for nystagmus depends on the cause of the nystagmus and any other associated eye or brain problems. Every person with nystagmus is an individual, so not all outcomes will be the same, even if the nystagmus looks very similar.

Infantile nystagmus is not a progressive condition and does not typically worsen with age. Children with infantile nystagmus can have improvements in their vision as they grow and adapt. In addition, adaptations to nystagmus often continue to develop over time.

The outcome of treatment for acquired nystagmus is often linked to the condition causing the nystagmus. For example, in a person with stable multiple sclerosis, their nystagmus and oscillopsia may remain stable; however in a person with progressive and worsening multiple sclerosis, their nystagmus and oscillopsia may worsen.

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Vision may worsen in some of the eye conditions associated with nystagmus. The need for glasses may also change over time. It is therefore important that people with nystagmus attend an eye clinic or optometrist for regular sight tests.

Registration of visual impairment

Some people with nystagmus will have reduced levels of vision that meet the criteria to enable them to be certified as sight impaired (SI) or severely sight impaired (SSI), if they choose to be. These certifications of sight impairment are completed by an ophthalmologist and are based on measurements of vision using a clinical vision chart and a visual field testing machine. Other factors affecting vision such as the ability to see a varying levels of contrast can also be considered.

If a visual impairment certification is made, your local council have a duty to contact you to offer registration and to see if you need help with day to day tasks. Registration of visual impairment is not the same as certification and it is carried out by your local council rather than an ophthalmologist. Registration involves two stages:

- Stage 1 - Certification as sight impaired or severely sight impaired by an ophthalmologist (vision meets required criteria). The form is completed by the individual and the ophthalmologist, and signed by the ophthalmologist. This allows the person to be registered with local social services as visually impaired, if they wish to be.
- Stage 2 - Local social services team contact the person (or their family) to invite them to register as sight impaired or

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severely sight impaired. They will discuss the purpose and benefits of registration, although it is not compulsory. In some areas registration may be undertaken by telephone contact or by post. Social workers, care managers, rehabilitation workers or assessment workers carry out the registration visit and initial assessment.

Local authorities cannot register people without their consent. You don't have to be registered to receive vision rehabilitation support through your council's sensory impairment team, but in some areas funding for equipment may require registration.

The sensory impairment team aims to provide support and help for you to live as independently as possible. Examples of support that may be offered with daily living skills:

1. Moving round the home safely and learning new strategies
2. A low vision service
3. Mobility training
4. Accessing transport and concessionary passes
5. Accessing technology for communication
6. Signposting to a disability support officer to help with seeking vocational and employment opportunities.

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