## 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.

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.

## USEFUL INFORMATION AND SUPPORT

**Websites:**
www.nystagmusnetwork.org

For infantile nystagmus -
www.in-vision.org.uk

**Support:**
Sensory impairment team – local councils provide a sensory impairment service that can advise and provide specialist equipment, group activities, emotional support and learning new skills.

Eye Clinic Liaison Officer (ECLO) – an ECLO is based in a hospital eye clinic and they support individuals with visual impairment to help them understand their diagnosis or eye condition. They offer help, support and advice on the emotional and practical aspects of life with a visual impairment, to both patients and their families. They help patients deal with their sight loss and maintain their independence.

Low vision support – depending on where you live, your low vision service may be provided within the hospital setting or in the community. Your eye care team will be able to advise you further and provide a referral when required.

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Bae Abertawe
Swansea Bay University Health Board

Singleton Hospital

Orthoptic Department

# Nystagmus

This leaflet gives you information that will help you understand Nystagmus including; what Nystagmus is, the cause, effects, different types, how common Nystagmus is, treatment options and long term outcomes. Support and further information is also included.

**WHAT IS NYSTAGMUS?**

Nystagmus is characterised by involuntary, repetitive, rhythmical movements of the eyes where they appear to wobble or flicker. The movement can be slow or rapid, side-to-side, up and down or circular. It is usually seen in both eyes but in rare cases, can affect only one eye.

**WHAT CAUSES NYSTAGMUS?**

Nystagmus is caused by abnormal functioning of the part of the brain or inner ear which regulates eye movement and positioning.

**HOW DOES THIS AFFECT VISION?**

Nystagmus leads to decreased vision and needing more time to try and see things. Due to the constant movement of the eyes, the eyes are not still when a person is trying to look at something. This means the image "slips" from the fovea - the area of the retina at the back of the eye, which provides the best level of vision.

As the eyes are constantly moving, the fovea has brief moments focussed on the image of interest. The brain then uses these brief glances to see, a process that takes longer and is often less clear in those who have nystagmus compared to someone whose eyes are still.

**TYPES OF NYSTAGMUS**

There are two main types of nystagmus, infantile (sometimes called congenital) and acquired. Infantile nystagmus is present at birth or within the first few months of life. Often, there are no associated causes of the nystagmus and this is termed idiopathic congenital nystagmus. However, this type of nystagmus can be associated with other illnesses such as Down's Syndrome, Leber's Congenital Amaurosis and ocular albinism which has a genetic base.

Acquired nystagmus occurs later in life and is typically associated with neurological disorders or loss of vision. Acquired nystagmus has many different causes ranging from a bang on the head or other accident to Stroke, Multiple Sclerosis and Ataxia. In some cases acquired nystagmus can come and go over time, so someone might experience oscillopsia (a visual disturbance where objects appear to constantly move) for some time and then have some time without any or with reduced symptoms.

**HOW COMMON IS NYSTAGMUS?**

Nystagmus affects 1 in 1,000 people in the general public and is the most common form of visual impairment among children. The condition can affect both males and females.

**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.

Treatment options may include; glasses and contact lenses, filters and tints, amblyopia treatment, prisms, adaptations such as head posture and close reading distance, visual aids, pharmaceutical treatments, botox and surgery.