An introduction to nystagmus
Introduction

This booklet provides an introduction to nystagmus and the impact the condition can have on a child and their family.

This is an information booklet for parents of children with the eye condition called nystagmus. It is part of a “Parent Pack” created by the Nystagmus Network to help parents become better informed about their child’s condition.

The Nystagmus Network is the oldest charity in the UK providing support and information about the eye condition nystagmus. The charity was established in 1985 and has been at the forefront in supporting people who are affected by the condition whilst also promoting a better understanding of nystagmus. Through the charity’s extensive involvement in research we are moving closer to finding effective treatments.

This particular booklet focuses on explaining what nystagmus is and how it affects a child’s vision. It also contains practical experiences of other parents who have a child with nystagmus so that any tips they have may be passed on to others.

The additional booklets in the “Parents Pack” cover a variety of subjects, including education, diagnosis, social implications and how a parent can support a child with the nystagmus. It is hoped that these documents will empower both the child and their parents to ensure they are well equipped to cope with the condition and to overcome any problems they may encounter due to nystagmus.

The Nystagmus Network is available to be contacted by anyone affected by nystagmus, their family or anyone involved in supporting someone with the condition. The charity has a variety of documents that can be easily downloaded on a variety of subjects relating to nystagmus.

“How do I contact the Nystagmus Network?”

The Nystagmus Network is available to be contacted by email, phone, mail and the majority of social media websites. These contact details can be found on the back of this booklet and the charity can provide a family with further advice on living with nystagmus.
Nystagmus is a complex eye condition that is characterised by involuntary movements of the eye where they appear to wobble or flicker from side to side or up and down. Nystagmus is caused by abnormal functioning of the part of the brain which regulates eye movement and positioning. It has an incidence rate of 1 in 1,000 people in the UK and is regularly seen as a symptom of many other underlying conditions.

Although it is a lifelong condition, the impact nystagmus can have on an individual’s vision varies greatly. A child’s sight can continue to improve and they will learn to adapt and live with their nystagmus. Most people will have reduced distance vision, but can see fine detail if they get close enough. Nystagmus itself cannot be corrected by glasses or contact lenses, but if someone also has short or long sight they should wear glasses or lenses to correct this.

Unfortunately, there is currently no effective cure or treatment for nystagmus. However, the Nystagmus Network supports the research into finding therapies that could one day potentially have a positive impact on managing the condition. There is currently some early work on the use of drugs to reduce the amount of eye movement and there are also some surgical procedures available to change the direction of the gaze if this is very

“My natural reaction when our son was diagnosed was to blame myself. What had I done wrong during my pregnancy to make this happen? The Nystagmus Network reassured me that it wasn’t my fault.”
pronounced. In addition to these, there are many non-invasive therapies that can help reduce the symptoms of nystagmus.

The long-term future for a child’s sight in relation to their nystagmus is good as the condition does not deteriorate their vision as they get older any more than normal as a result of the aging process.

Tinted glasses or contact lenses help with light sensitivity and prescription glasses and lenses should be worn to correct short or long sight. This will mean that a child’s vision is as good as it can be.

Congenital nystagmus

The term congenital nystagmus refers to a persons whose nystagmus was present when they were born. The first few months of a baby’s life is very important for their visual development as this is when they begin to focus and learn how to hold their gaze. It is usually at this point when nystagmus is noticed by a parent or carer as it is very hard to spot the condition in a regular health check up. Common signs which parents report include noticing their child having problems following a toy and also not being able to focus on a person calling their name from the other side of a room.

Most people with nystagmus read relatively comfortably and although they have few problems with mobility new technology has had a huge impact. Although there is currently no cure for nystagmus, in recent years there has been a lot of work in developing the knowledge about the underlying problems with the visual system that can lead to nystagmus.
What is the “null point”?

Someone who is diagnosed with nystagmus will be told that some people have something called a null point. This is a position in which vision is the clearest for someone who has the condition.

When a baby with nystagmus starts to sit up it is very common for parents to notice that their child holds their head to one side and also looks at people sideways or up and down a lot. Parents may also notice that the eye movements in their child slow down when they focus on a face. If this is happening, it indicates that the child is finding their null point.

The null point is the position where vision is at its clearest and it is a child’s way of seeing things better. As a child grows up their parents can help them by encouraging them to sit in a position where they are most comfortable.

However, it is important to note that not everyone has a null point and it may also change over time. When this happens, a child will experience a slight temporary deterioration in their vision as they adjust to the new position.

A child with nystagmus may tilt their head, as this is the direction of gaze in which their eyes are most stable to help them see things better. Those children with a null point may turn or tilt their heads without actually realising they are doing it and it can come as a shock to some people whey they find out that they actually tile their head.

“Why does my baby keep looking at things sideways whenever they are trying to concentrate on something?”

A lot of people experience discomfort due to their null point because holding their head at an angle for any length of time to watch a screen or read can become uncomfortable. Therefore, it is important that parents encourage their child to take lots of breaks to avoid this.
How does nystagmus affect a child’s vision?

Nystagmus is a condition which varies greatly between individuals and while some are able to drive, others may have mobility issues and need help getting around to complete every day tasks.

Nystagmus can affect vision in many different ways, although it is very common that people with the condition may need more time to see and take in the world around them. For example, in a busy or cluttered environment such as school classroom it may take a child more time to recognise familiar faces. Computer screens with lots of icons may also be confusing at first to someone with nystagmus which is why they need to be given more time to take in their surroundings to complete a task.

Children with nystagmus sometimes find that their vision changes throughout the day. For example, it may get temporarily worse if they are tired, anxious, unwell, hungry, stressed or excited and parents may notice the amount of ‘wobble’ increases too.

People with nystagmus are sometimes more sensitive to strong light, especially sunlight where they can become dazzled and can find it very uncomfortable. If parents find that their child is light sensitive, they should shade their baby’s eyes with things such as...
sunglasses, a parasol over the buggy or peaked as these can all keep the sun off the eyes.

Depth perception can be an issue for some children with nystagmus, which is why they may start walking a little later than their peers. This is because they may find steps difficult to judge and struggle with their balance. Issues with depth perception also arise with sport as seeing and following fast moving objects can be challenging for an individual with nystagmus. However, there are many other activities, such as running and swimming which they can get involved with and enjoy.

A common question which parents have is whether their child sees the world moving because of their nystagmus. Actually, even though the eyes may be moving rapidly it is very likely that the child will see the world as still. The brain adapts very quickly to compensate for the eye movements so although some people with congenital nystagmus may occasionally have the sensation that the world is moving, most of the time this will not be the case.

As a variable condition, a parent needs to understand that their child’s vision may be very different from someone else who has nystagmus. A small child’s sight is very difficult to test and as it continues to develop in their early years doctors are unable to tell parents exactly how limited their child’s vision may be. However, parents can be assured that there are a variety of support services available.
Diagnosis stories

Every child who is diagnosed with nystagmus has a different diagnosis experience. Some parents find this a positive experience because they are able to discover why their child’s eyes are constantly moving.

“When our little girl was first diagnosed we were terrified about what the future held for her. After speaking with other mums we felt a lot more optimistic about her future.”

“We had never heard of nystagmus before and then suddenly there we were, plunged into an unknown world and an uncertain future. Meeting other parents online has been a lifeline.”

“I left the GP’s surgery with just a piece of paper and one word written on it – nystagmus. I googled it when I got home and found the Nystagmus Network. Thank goodness for them!”