

## Information for Patients

# Nystagmus

## What is nystagmus?

Nystagmus is an uncontrollable eye movement disorder of the eyes, either side to side, up and down, in circles, or a combination of these. It affects around 1 in 1000 people. Each person is different as is their nystagmus, their investigation, and treatment.

## What causes nystagmus?

For many people with nystagmus, there are no related health issues or other eye conditions, so their nystagmus is idiopathic (no known cause). Nystagmus can be caused by a problem with your eyes, or the pathway connecting your eyes to your brain. You can be born with nystagmus (congenital) or develop it later (acquired).

Some more common causes of nystagmus are:

- Congenital cataracts
- Ocular albinism
- Retinal dystrophies
- Optic nerve conditions
- Aniridia

Some nystagmus can be inherited, meaning it is genetically passed on from a member of your family. However, in many cases, the causes of nystagmus are unknown.

## What do things look like with nystagmus?

If you are born with nystagmus your visual development may be delayed in early infancy. Most people with nystagmus will struggle to see well compared to others and often take a little bit longer to see things. This happens because the image coming into your eyes 'slips' on and off the retina (back of your eye) due to the constant movement, so it has less time to make an image clear. This can make it difficult to view fast moving objects which is something you will learn to be aware of.

Some patients perceive things as shaking (oscillopsia) which is more common if your nystagmus is acquired. However, if your nystagmus is present from infancy this is rare. People with nystagmus can find bright lights uncomfortable (photophobia).

Your diagnosis of nystagmus may be a surprise, but there are lots of resources and people to help you make some changes to make things easier for you.

## What do I look like with nystagmus?

Some people may notice your eyes 'wobble'. The intensity of this can be made worse by factors such as stress, concentration, illness and tiredness. The appearance of your nystagmus may vary throughout the course of your childhood.

Some people with nystagmus move their head in a certain position to help with their nystagmus (compensatory head posture or CHP), so you or your friends and family may notice this.

You may need to wear glasses or contact lenses to help with your nystagmus. Often, people with nystagmus find their vision better when reading/ looking at things closely—this is a good thing to do. You may use visual aids, such as magnifiers, to help see things clearer.

## What can be done to help my nystagmus?

There is currently no cure for nystagmus. There are various therapies and treatments used to maximise the vision of patients with nystagmus. Treatments options are not the same for everybody with nystagmus. The options that are available for you will be discussed at your hospital appointment.

## Who will I see at the Eye Hospital?

In order to tell whether you have nystagmus, diagnose it and find a possible cause for it, you will have a number of different investigations, on more than one visit.

You may see an **Orthoptist**. They will ask questions to help them gather information about your nystagmus. They will then do some tests to assess your vision, eye movements and carefully document your nystagmus.

You may see an **Optometrist**. They will be able to check whether you need glasses or changes to your glasses. They may also assess you for visual aids.

You may see a **Vision Scientist** and have Electrodiagnostic testing. This can investigate how well the signals get from your eyes to your brain, which might tell us what causes your nystagmus.

You may see an **Ophthalmologist**. This is the 'Eye Doctor' who will perform certain checks to help diagnose the type of nystagmus you have, check the health of your eyes and discuss your diagnosis with you.

You may see an **ECLO** (Eye Clinic Liaison Officer). They will be able to give you further support about your diagnosis and be able to signpost you to helpful resources.

You may see the **Genetics Team**. This may involve genetic counselling to see if there is a link between your family's genetics and your nystagmus.

You may see a **Paediatrician** or **Neurologist**. This may be when further investigation is indicated.

## Useful Links:

ECLO, Laura Ross (Manchester Royal Eye Hospital) – (0161) 701 4258 08.30am – 4.30pm

Nystagmus Network –[www.nystagmusnetwork.org](http://www.nystagmusnetwork.org)

R.N.I.B [www.rnib.org.uk](http://www.rnib.org.uk)

IN-vision - <https://in-vision.org.uk/>

Nystagmus Information Pack - The University of Sheffield

[www.sheffield.ac.uk/health-sciences/our-research/themes/eye-movement/nystagmus-information](http://www.sheffield.ac.uk/health-sciences/our-research/themes/eye-movement/nystagmus-information)

If you require any further information please contact us on:

 **(0161) 701 4882 Monday – Friday 8.00am –4.30pm**

 **[mft.orthoptic.enquires@nhs.net](mailto:mft.orthoptic.enquires@nhs.net)**