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# Nystagmus

## Patient Information Leaflet

If you need this leaflet in a different language or accessible format please speak to a member of staff who can arrange it for you.

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Dacă aveți nevoie de această broșură într-o altă limbă sau într-un format accesibil, vă rog să discutați cu un membru al personalului să se ocupe de acest lucru pentru dumneavoastră

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إذا احتجت إلى هذه النشرة بلغة أخرى، أو بتيسيق يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

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## What is Nystagmus?

The medical term Nystagmus is pronounced “ni-stag-muss”.

Nystagmus is a rhythmical, repetitive and involuntary movement of the eyes. It is often known as jerky eyes or wobbly eyes.

It is usually from side to side, but sometimes up and down or in a circular motion.

Both eyes can move together or independently of each other.

A person with nystagmus has no control over this movement of the eyes.

## What causes nystagmus?

Early onset nystagmus will appear in very young babies. It can also be called congenital nystagmus. Acquired nystagmus is when the condition appears later in childhood.

The condition might be caused by a developmental problem of the eye or brain, or the pathway between the two. Sometimes the condition can be caused by a stroke or head injury.

Most children with the condition do not have any other health problems.

When the cause is unknown it is called idiopathic. Some forms of nystagmus can be inherited.

In some cases genetic testing may be discussed with your Consultant.

Where appropriate a referral to the Visual impairment (VI) team will be made and this can be done via our Eye Care Liaison Officer (ECLO).

Eligibility for sight impairment registration can be discussed with the Consultant Ophthalmologist.

## Useful websites

[www.nystagmus.co.uk](http://www.nystagmus.co.uk)

[www.nystagmusnet.org](http://www.nystagmusnet.org)

Email: [info@nystagmusnet.org](mailto:info@nystagmusnet.org)

The Nystagmus Network is a group that aims to give support and advice to sufferers, relatives, friends and professionals and to raise funds for research.

## What happens next?

Each case of nystagmus will vary in severity and symptoms and reduced vision is common.

Children with nystagmus will need extra support and time to read. But this does not mean that they are unable to read or have learning difficulties. They simply have a challenge to overcome and it will take extra effort.

Children with nystagmus may feel self-conscious.

This means it is important to build up their confidence.

### Facts

- Nystagmus is not painful, but your vision may be reduced, and some people experience headaches, eye aches or eye strain when they get older.
- Nystagmus does not get worse over time and sometimes gets better.

### There is no treatment to cure nystagmus

## What are the signs and symptoms of nystagmus?

The most obvious sign that a child or adult has nystagmus, is their eye or eyes will be moving involuntarily.

Children with nystagmus often have poorer vision and problems with balance.

But while some people with nystagmus have very poor sight, others can see really well.

Sometimes you may not see things as quickly as others.

Very occasionally, on a bad day, you may see things wobble a little.

It is also more difficult to follow fast movements.

People may be able to see your eyes moving about or 'wobbling' when they are talking to you. Other people might not even notice.

## How is nystagmus normally diagnosed?

Nystagmus is defined according to the direction of movement of the eyes, how far they move and how often.

Both eyes can move together or independently of each other.

Nystagmus is diagnosed simply by looking at the eye movements, but it is important to find out whether it has any underlying cause.

Your doctor will ask you many questions such as when the Nystagmus was first seen and if any of your relatives have ever had Nystagmus or any other eye problem.

Drops will be put into the eyes and the Orthoptist will look to see if there is anything unusual.

They may use a head set or a slit lamp which shines light through the pupil of the eye, to examine the back of the eyes.

Not all problems show up this way, so further tests may be required, such as eye movement recordings and electrodiagnostics.

## What else can cause Nystagmus?

Nystagmus can be hereditary (passed on in the family), but there are also many other reasons you may have it.

Nystagmus in early childhood may be caused by:

- a problem with your eye or along the pathway of nerves connecting your eye to your brain.
- it can occur in a wide range of childhood eye conditions such as cataract (cloudy lens of the eye).
- glaucoma (high pressure in the eye causing nerve damage).
- for abnormality of the retina or optic nerve (such as inherited conditions which affect the health of the retina or its ability to detect light) at the back of the eye.

- It can occur if you have albinism, in which there is too little pigment (colour) in the eyes and often in the skin and hair too.
- In many people there is no obvious cause.

## How is nystagmus normally treated?

There is no cure for nystagmus.

Sight problems, such as long or short-sightedness are common in people with nystagmus. Glasses will not cure the condition but can help with reduced vision.

Large print books can help and will be especially useful for children learning to read. Extra time in school tests may be needed as reading the questions may take a little longer.

There is often a 'null point' where the eye movement is reduced. This can sometimes involve holding the head at an awkward angle, but it will help improve vision.

Very rarely, surgery is needed on the muscles which move the eyes to reduce the amount you have to turn your head to see.

Surgery cannot cure nystagmus.

Medicine can sometimes help, but this will need to be discussed with your doctor.