



**University
Hospitals Sussex**
NHS Foundation Trust

Nystagmus

Orthoptic Department
St Richard's Hospital
Southlands Hospital

Patient information

This leaflet is intended to answer some of the questions of patients or carers of patients diagnosed with Nystagmus under the care of University Hospitals Sussex NHS Foundation Trust.

What is Nystagmus?

Nystagmus is an involuntary, usually constant eye movement (often described as wobbling or dancing eyes) which typically results in some degree of visual loss. The degree and direction of eye movement, amount of visual loss and resulting impairment varies greatly from person to person.

Are you born with nystagmus?

There are two main types of nystagmus:

- Congenital nystagmus is that which is present from birth and in young children.
- Acquired nystagmus develops later, generally in adults.

What causes nystagmus?

Nystagmus may be inherited, be idiopathic (no known cause), or be associated with a sensory problem e.g. Albinism or congenital cataract. Its direct cause is an instability in the motor system controlling the eyes.

Acquired nystagmus may be a result of an accident or a range of illnesses, especially those affecting the brain e.g. stroke or multiple sclerosis (MS).

What are the symptoms of nystagmus?

In congenital nystagmus, how much the vision is affected depends on the underlying condition. Some people will be able to read most sizes of print without help, while others may have vision that makes them eligible to be registered as sight impaired or severely sight impaired. Being registered sight impaired or severely sight impaired does not mean that you are totally without sight, or will lose all your sight in the future.

The severity of nystagmus may vary according to the direction of gaze, or how close or far away somebody is looking.

Most people with nystagmus find that their vision is variable and some people with nystagmus find that they have a particular head position that results in the slowest movement of the eyes. This is known as the 'null point'. This reduction in the movement of the nystagmus usually means the vision improves.

People with congenital nystagmus very rarely see the world constantly moving. By contrast, people who develop acquired nystagmus later in life are usually aware of constant and sometimes very disabling movement. This awareness is called oscillopsia. This is probably because their brain has not adapted to the unexpected eye movements and sees instead the world moving around.

How is nystagmus tested?

Nystagmus may be the first sign of a serious disorder of the eye or the brain. It is vital that when nystagmus first develops the child or adult is referred to an Ophthalmologist (eye specialist).

The investigations will depend on the type of nystagmus, age of the patient and the underlying cause. The ophthalmologist is responsible for the case overall and would carry out any treatments. The orthoptist specialises in assessing vision and eye movements in detail. An optometrist specialises in making sure glasses and contact lenses are correct.

How is nystagmus treated?

Nystagmus cannot be cured. Some underlying conditions may be treatable which may affect the nystagmus. Researchers around the world are looking at different aspects of nystagmus with the aim of developing treatments.

Glasses and contact lenses ensure that vision is corrected to the best possible level. They do not stop the nystagmus although having clearer vision can help slow the eye movements.

Special magnifiers called low vision aids can help with reading and tinted glasses may be useful to control glare.

Very occasionally, surgery is performed to alter the position of the muscles which move the eye. This is to reduce the amount the head has to turn to get to the null point, making it more central. However, **surgery cannot correct or cure nystagmus.**

Sometimes drugs are used in the treatment of some nystagmus. The drugs help to control the eye movements and reduce the person's awareness of the constant eye movement.

What support is there for people with nystagmus?

If their vision is affected children with con-genital nystagmus will be referred to the sensory support team who will support the child at home and through their education.

Information and support groups can also be found on the internet e.g. **Nystagmus Network website**

www.nystagmusnet.org

Email: info@nystagmusnet.org Tel: **01427 718093**

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Ref. number: 2232
Publication date: 03/2022
Review date: 03/2024

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