



**University
Hospitals Sussex**
NHS Foundation Trust

Nystagmus

Orthoptic Department

Patient information

What is this information about?

This leaflet is about nystagmus.

It explains:

- what nystagmus is
- what may cause it
- how it can affect your eyes and vision
- how it is diagnosed and treated
- where you can find more information or support.

Why have I been given this leaflet?

You have been given this information because you, a family member, or someone you care for has been diagnosed with nystagmus. Reading this leaflet can help you understand more about the condition and what to expect.

What is nystagmus?

If a person has nystagmus, it means their eyes move quickly from side to side, up and down, or in circles. This happens all the time, even when the person is not trying to move them. Some people call this 'wobbly eyes' or 'dancing eyes'.

These movements are 'involuntary', which means you cannot control them. Nystagmus can make it harder to see clearly. How much a person's eyes move and in which directions is different for everybody with nystagmus. So is the amount their vision is affected.

Are people born with nystagmus?

There are two main types of nystagmus:

- **congenital (or infantile) nystagmus.** This means you are born with it or develop it as a baby.
- **acquired nystagmus.** This means it develops later in life, often in adults.

What causes nystagmus?

- Congenital nystagmus may be caused by:
 - having a family history of nystagmus. This means it is passed down (inherited) from parents.
 - by an eye problem which is present from birth such as cataracts or a lack of pigment (colouring) in the eyes caused by albinism.
 - Sometimes there is no clear cause for congenital nystagmus. When a condition has no clear cause, it is called an 'idiopathic' condition.
- Acquired nystagmus can happen because of:
 - some illnesses that affect the brain, such as a stroke or multiple sclerosis
 - an accident or head injury.

Nystagmus happens because the part of the brain that controls eye movements is not working as it should.

What are the symptoms of nystagmus and how might it affect my vision?

If you have congenital nystagmus, the amount your vision is affected depends on the underlying condition. It varies from person to person.

Some people can read most print sizes and only have mildly blurred vision.

Other people may have more severe sight problems. They may be registered as sight impaired or severely sight impaired. This does not mean they are totally blind or will lose all their sight.

How severe your nystagmus is may change depending on:

- the direction in which you are looking
- whether you are looking at things which are close to you or far away.

Sometimes people with nystagmus can have the sensation that 'the world is moving'.

- It is rare for people who are born with nystagmus to feel this
- People who get nystagmus later in life sometimes feel that things around them are moving or shaking. This is called oscillopsia. It probably happens because the brain has not adapted to the unexpected eye movements and interprets them as the world moving around.

Many people with nystagmus find that their vision varies. Turning your head to a certain position may help you see more clearly. This position is called your 'null point'. It is where your eye movements are slowest, and vision is often best.

How is nystagmus diagnosed?

If nystagmus is noticed in a child or adult, it is important to see (be referred to) an ophthalmologist (eye specialist). This is because it can be the first sign of a serious eye or brain condition.

The tests and checks that you have will give you depend on:

- your age
- the type of nystagmus
- any other health conditions you have.

You may see:

- an orthoptist, who checks how your eyes move and how well you see
- an optometrist, who checks your glasses or contact lenses are right for you.

Sometimes, you may need scans or other tests to find out the cause of your nystagmus.

Based on the test results and what the orthoptist and optometrist find, the ophthalmologist (who is responsible for your care overall) will give you any treatment that you need.

How is nystagmus treated?

There is no cure for nystagmus at the moment, but there are ways to help you make the best use of your vision.

These may include:

- glasses or contact lenses to give you the clearest vision possible
- magnifiers (low vision aids) to help you with reading
- tinted glasses or filters to reduce glare.

Sometimes:

- medicine may help control the eye movements or reduce how much you notice them
- surgery may be done to move the eye muscles slightly, so you do not need to turn your head as much to find your 'null point'.

Research is ongoing around the world to find better treatments.

What support is available?

If your child has congenital nystagmus that affects their vision they may be referred to a sensory support team. This team can help your child at home and at school.

You can also find helpful information and support on the **Nystagmus Network – Supporting people living with nystagmus** www.nystagmusnetwork.org or you can contact them by:

Phone: 01427 718093

Email: info@nystagmusnet.org

Who can I contact if I have further questions?

If you have any questions about nystagmus after you have read this information, please contact your orthoptist for advice:

St Richard's Hospital Orthoptists

01243 831499

Southlands Hospital Orthoptists

01273 446077

Sussex Eye Hospital Orthoptists

01273 664872

Princess Royal Hospital Orthoptists

01444 441881 Ext. 68305

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