

Congenital nystagmus

Ophthalmology / Orthoptic Service

Information for patients and carers

• Home • Community • Hospital
Caring for you

What is congenital nystagmus?

Congenital nystagmus is a condition of the eyes. It causes them to move or wobble / flicker without control. The movements can be:

- side to side
- up and down
- rotary
- a combination

What causes it?

Different parts of the brain are responsible for how we see information from the eyes and how our eyes move.

Congenital nystagmus can happen when these areas do not develop normally in early life.

Infantile / congenital nystagmus

This type is usually diagnosed in very young children, usually in the first few months of their life.

It can be linked to a problem with the eyes or with parts of the brain that control eye movements.

Some eye conditions can be linked with nystagmus, including:

- cataracts present at birth
- cone dystrophy
- congenital stationary night blindness
- Leber congenital amaurosis
- optic nerve coloboma
- hypoplasia aniridia

All babies are born with vision that is still developing. In the first few years of life, sight develops through our eyes and brain being stimulated by what we see.

If a baby is born with an eye condition, normal development may be affected.

Congenital nystagmus can also occur in children with conditions such as:

- Down's syndrome
- cerebral palsy

However, many children with nystagmus do not have any other health problems.

Sometimes children develop nystagmus without any of these problems. This is called idiopathic nystagmus.

Symptoms

Problems linked to infantile nystagmus often improve during childhood. Giving children plenty of visual stimulation in early years can help.

However, some people with nystagmus can have:

- reduced vision
- difficulty reading different text sizes
- sensitivity to light
- discomfort in brighter conditions
- poor depth perception, balance and coordination

Children and adults with nystagmus do not usually see the world as constantly moving. The brain adapts to their eye movements.

Some people can move their head into a position which can slow down eye movements and improve vision. This is known as their 'null point'.

How is it tested?

Nystagmus is often picked up between 6 weeks and 3 months old.

If it is suspected, your child will be referred to an ophthalmologist. They will carry out a detailed eye examination.

Further tests may be needed, such as electro-diagnostic tests and scans to check for any abnormalities.

Can it be treated?

There is currently no cure for nystagmus. However, some of the underlying causes may be treatable.

Support available

A Qualified Teacher of the Visually Impaired (QTVI) is a specialist teacher who provides:

- advice
- support
- training for children who meet the criteria for this service

This support can continue from nursery into primary school and higher education.

How can school help?

Schools can support children by providing:

- large print textbooks
- large format exercise books
- printed materials
- whiteboards
- exam papers with larger text
- simplified diagrams printed on coloured paper if needed

Contacts and further information

Orthoptic Team

Phone: 01925 662772

Contact the team directly if you have any concerns about your care or changes in your condition.

RNIB

<https://www.rnib.org.uk/>

Nystagmus Network

<https://nystagmusnetwork.org/>

IN-vision

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