

Nystagmus

The medical term is:

Nystagmus (pronounced *ni-stag-muss*).

It is often known as:

Jerky eyes, or wobbly eyes.

Nystagmus is when your eyes move rapidly by themselves. The movement can be side to side, up and down or in a circular motion. Nystagmus comes from the Greek word "nustagmos" which was used to describe the wobbly head movements of someone who was either sleepy or who had drunk too much!

How you see the world

People with nystagmus usually don't see as clearly as normal. 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.



Figure 1: Checking eyes with a slit lamp

How the world sees you

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

Is it common?

- About 1 in 1,500 people have nystagmus.
- It's not that rare!

Why did I get it?

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



many people we don't know what causes their nystagmus.

What causes 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) or 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 can the doctor tell?

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

Your doctor will ask you many questions such as when the nystagmus was first seen and if any of your relatives has ever had nystagmus or any other eye problem. Drops will be put into your eye and the eye doctor will look into your eyes to see if there is anything unusual. They may use a head set or a slit lamp (see figure 1 above) which shines light through the pupil of the eye, to examine the back of your eyes. Not all problems show up this way, so you may need further tests,

eye movement recordings (like on figure 2 below) and electrodiagnostics.

For eye movement recordings you view a screen while a video tracker takes very detailed recordings of your nystagmus. This can help us decide whether you have the nystagmus associated with a squint, if it is a nystagmus with no known cause/associated with other eye problems, or nystagmus associated with a problem with the pathway connecting the eye to the brain. If you are going to have treatment, e.g. medicine or surgery, eye movement recordings can help us decide what is most suitable and be used to assess how you respond.



Figure 2: Recording eye movements

In electrodiagnostics, small wires are gently stuck to the skin of your eyelid or the back of your head, and you look at a flashing computer screen. The tiny electrical signals which take the visual message from the back of your eye to your brain are measured. This helps show how the back of your eye and your brain are dealing with vision

information and can help identify the cause of vision problems.

Getting it sorted

Nystagmus cannot be cured but glasses and contact lenses might help improve your vision. Medicine can sometimes help, but this will need to be discussed with your doctor. 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 correct nystagmus.

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.

Your view: James

Hey there!

I'm James. I have congenital nystagmus (I've had it since birth). I run a website all about nystagmus (www.nystagmus.co.uk) which I decided to build when I was 14. On the site I've documented my own experiences of nystagmus and provide a forum for discussion.

I think I've led a relatively normal life – I play squash, the piano and the tenor saxophone. I like to go fishing and have a strong interest in computers.

So as you can see, nystagmus hasn't ruined my life and it shouldn't ruin anyone else's either. However, it does help to learn as much as you can about nystagmus so you can explain it to others and ask for help when you need it.

Information online

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.

Website: www.nystagmusnet.org

Email: info@nystagmusnet.org



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more information about your rights
under the NHS constitution, visit
www.nhs.uk/choiceinthenhs

**Moorfields Eye Hospital NHS
Foundation Trust**
City Road, London EC1V 2PD
Phone: 020 7253 3411
www.moorfields.nhs.uk

Moorfields Direct telephone helpline

Phone: 020 7566 2345
Monday-Friday, 8.30am-9pm
Saturday, 9am-5pm
Information and advice on eye
conditions and treatments from
experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)

Phone: 020 7566 2324/ 020 7566 2325
Email: moorfields.pals@nhs.net
Moorfields' PALS team provides
confidential advice and support to help
you with any concerns you may have
about the care we provide, guiding you
through the different services available
at Moorfields. The PALS team can also
advise you on how to make a complaint.

Your right to treatment within 18 weeks

Under the NHS constitution, all patients
have the right to begin consultant-led
treatment within 18 weeks of being
referred by their GP. Moorfields is
committed to fulfilling this right, but if
you feel that we have failed to do so,
please contact our patient advice and
liaison service (PALS) who will be able
to advise you further (see above). For

