

Understanding

Nystagmus



RNIB

Supporting people
with sight loss



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Understanding series

Our Understanding series is designed to help you, your friends and family understand a little bit more about your eye condition.

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- Understanding cataracts
- Understanding Charles Bonnet syndrome
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About nystagmus

Nystagmus is continuous uncontrolled movement of the eyes. The movements are usually side to side but can also be up and down or rarely in a circular motion. Most people with nystagmus have reduced vision.

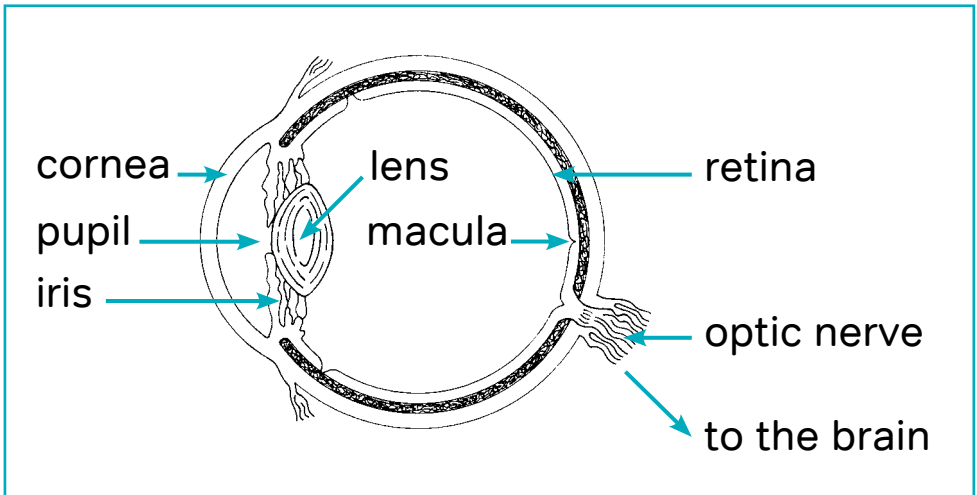
Nystagmus is a sign of a problem with the visual system or the pathways that connect the eyes to the parts of the brain that analyse vision. These parts of the brain deal with eye movement.

Some types of nystagmus happen when your eye gaze positions are extreme, when you looking far to the left, right, up or down and are a natural part of the way the eye and brain work together. Nystagmus, which happens when your eyes aren't in these positions, is usually is a sign of a problem.

There are two main types of nystagmus, one which appears in the first months of life which is called "early onset nystagmus" or "congenital nystagmus" and another which develops later in life which is usually called "acquired nystagmus". In many cases the cause of the nystagmus will not be known. It's thought that nystagmus affects between 1 in 1,000 and 1 in 2,000 people.

How your eye works

When you look at something, light passes through the front of your eye and is focused by the lens in your eye onto the retina. The information then passes along the visual pathway to the different parts of the brain that allow you to see things. Different parts of the brain send signals back to your eye to control different aspects of how the eye works. Where your eyes focus, the size of your pupil and your eye movements are constantly being controlled and adjusted to give us the best vision possible. Mostly you are unaware of your eye and brain doing this.



Causes

The eye movement seen in someone with nystagmus can also sometimes be seen in people without nystagmus. The movements used by a healthy visual system (the way the eye and the brain work together to produce sight – a tracking system) are in certain situations the same movements seen in someone with nystagmus. For example if you watch someone's eyes as they are watching a train passing, their eyes follow the train then flick back to a starting point and this is repeated over and over until the train has passed. This type of nystagmus is called “physiological nystagmus” and it is a normal part of how our eyes work.

If the visual pathways, or parts of the brain that process visual information, control eye movements or gaze, do not develop properly or is damaged in later life, then eye movements can become poorly controlled and this is called nystagmus (short for “pathological nystagmus”).

Congenital nystagmus

Congenital nystagmus simply means nystagmus that is noticed in very young children, usually soon after they're born or sometimes in the

first couple of years of their life. This type of nystagmus can be caused either by a problem with the eye itself or by a problem with the visual pathway from the eye to the brain.

All children are born with a visual system that is not fully developed. Our vision continues to develop in the first few years of life by the eye and brain being stimulated by what we see. If a child is born with an eye condition which affects vision such as cataract, glaucoma, some conditions of the retina or albinism then their visual system may not develop normally. This is because these conditions lower the amount of visual stimulation the eye and brain receive.

Reduced visual stimulation can affect how the control of eye movements develops in children and poor development of this can lead to nystagmus. The severity of the congenital nystagmus often depends how much of the sight is affected by the underlying condition.

Children who have learning disabilities, such as Down's syndrome, may also develop nystagmus. Nystagmus can also be caused by some inherited neurological conditions.

However, many children with nystagmus do not have any obvious eye, brain or other health problems. This type of nystagmus is called “congenital idiopathic nystagmus” or “idiopathic nystagmus”, meaning that the condition starts very early on in life and the cause is unknown. In idiopathic nystagmus the vision is also reduced.

Nystagmus isn't painful and doesn't lead to total loss of vision. Problems resulting from congenital or early onset nystagmus tend to improve until vision stabilizes around the age of five or six. Giving children plenty of stimulation in the early years does seem to help them make best use of the vision they have. The nystagmus doesn't usually get worse throughout the rest of life.

It's difficult to say which type of school is best for a child with nystagmus – each child has their own special requirements. However, most children with nystagmus go to mainstream schools. Many go on to college and most adults with nystagmus lead independent lives.

Acquired nystagmus

Nystagmus that develops later, generally in adults, is called “acquired nystagmus”. Often acquired nystagmus is a sign of another

(underlying) condition such as stroke, multiple sclerosis, brain tumour, the effect of a drug or a head injury. Anything that damages the parts of the brain that control eye movements can result in nystagmus.

Describing how your eyes move

Neurologists and ophthalmologists sometimes classify nystagmus by a description of how your eyes move. For example, “jerk nystagmus” describes nystagmus where the movement is quick in one direction and slow in another and “pendular nystagmus” describes slow movement in all directions. The direction of the nystagmus is also recorded as vertical, horizontal or circular. Direction and type of movement may vary depending on where someone looks and how calm they are feeling.

This way of classifying nystagmus can be helpful in giving your specialist an indication of what is causing the problem. If you are unclear about how your nystagmus has been described, you can ask the specialist to explain it to you.

Symptoms

Because nystagmus is a sign of so many different underlying causes, the way that vision is affected is very varied.

If you have congenital nystagmus, how much your 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 severely sight impaired (blind) or sight impaired (partially sighted). Being registered as severely sight impaired/blind does not necessarily mean that you are totally without sight, or will lose all your sight in the future.

The degree or severity of nystagmus may vary according to direction of gaze, near or distance fixation. Most people with nystagmus find that their vision is very variable. The vision tends to worsen when the eye movements or amplitude of the nystagmus increases. This is often linked to how stressful they are finding a situation. The more stressful a situation, the worse the vision can become.

Most people with nystagmus find that they have a particular head position that results in the slowest movement of their eyes which usually means their vision can improve. This is known as the “null point” where the movement or amplitude of the nystagmus is at its lowest. Some people with nystagmus also find that nodding their heads helps to improve their vision.

For reasons that are not fully understood, people with congenital nystagmus only very rarely see the world constantly moving. By contrast, people who develop nystagmus later in life (acquired nystagmus) 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. This is very disabling and early treatment is aimed at controlling this problem.

Because each case of nystagmus is individual, each person needs a detailed assessment.

Investigation

Nystagmus may be the first sign of a serious disorder of the eye or the brain and it's vital that when nystagmus first develops the child or adult is referred to an ophthalmologist (eye specialist) or a neurologist.

The investigations depend on the type of nystagmus, your age and what your doctor feels is the underlying cause. For a baby or young child with congenital nystagmus the focus of the investigations and treatment will be on maximising the child's visual development.

It's very likely that an eye clinic will monitor the condition and this may mean seeing a number of different professionals. The ophthalmologist is the specialist eye doctor who is responsible for the case overall and would carry out any treatments. An orthoptist specialises in assessing eye movements and may be used to assess in detail the way the eyes are moving. An optometrist specialises in making sure glasses and contact lenses are correct but can also carry out a low vision assessment.

Measuring vision

The eye clinic can investigate your vision in a number of different ways. Different tests are used to assess how well we see detail, faint edges, peripheral detail and colour. There are specially adapted tests for children of different ages.

The most common test is the visual acuity test which is the familiar set of letters on a chart held six metres away. Many people with nystagmus manage to read down quite far on this test especially if they are calm and can use their null point. They then feel that the result gives a false impression of how well they can see. This is because the test does not reflect well the real world where objects move, lighting changes and we can become anxious. All of these factors make vision worse.

If your vision is variable, make this clear to the specialists testing you. Give examples of situations when your vision is at its worse such as trying to find the right platform for a train if you are running late. Any official reports on your vision need to reflect the fact that your vision is variable.

Low vision assessment

This assessment looks at ways to help you make the most of your vision by choosing appropriate lighting, making adaptations, such as colour contrast, as well as using magnifiers or technology to make things easier to see. It is an ideal opportunity to discuss any practical problems you are having with your vision.

A low vision assessment helps you understand what you can see in different conditions and what resources or alternative methods you can use. It also includes practical help such as magnifiers to enable you to read.

Ideally, if you have reduced vision due to nystagmus, it's helpful to see a low vision service at least once a year. This is especially important for children and the ideas from the assessment should be reported back to school, with time built in for the child and staff to learn how to use any special equipment.

Investigating the null point

As part of any assessment the specialists will investigate and try to identify your “null point”. The null point is the position of the head that results in the slowest movement of your eyes.

This reduction in the movement or amplitude of your nystagmus usually means that you are able to see more easily. Identifying the null point for someone with nystagmus, especially in children, is very useful. Teachers may need to be told that it does no harm to hold the head in an unusual way and that a child should adopt the head posture that gives the best vision.

Genetic counselling

Several types of nystagmus can be inherited. To find out the chances of someone passing on nystagmus to the next generation, a specialist must first make an accurate diagnosis of the underlying condition. Your eye specialist can refer you to a clinical geneticist who can provide detailed information.

Information sharing

Accurate information and support, during the early years in particular, can and does make a big difference. In the worst cases, without a clear explanation of the effects of nystagmus, some children are mistakenly thought to have learning difficulties. This means that the real problems caused by their poor vision are not addressed.

With the support of teachers trained in visual impairment, an understanding school and the help of parents, most of the difficulties presented by nystagmus can be overcome. As a parent you can ask that hospital reports are sent to your child's school, using wording that can be understood by everyone.

You may have many questions that you would like your eye clinic team to answer. For example, will my vision get worse? How do I best use my vision? Can my nystagmus be treated? Thinking about the questions you want answered before your clinic appointment and writing them down is often very useful. Don't be afraid to ask for a clear explanation of things you have not understood about your or your child's nystagmus.

Treatments

Nystagmus cannot be cured. Some underlying conditions, which may affect the nystagmus, could be treatable. Researchers around the world are looking at different aspects of nystagmus with the aim of developing treatments. A lot of this work still focuses on how the eye movements are controlled and our understanding of this is far from complete. Not all the treatments you

may read about are backed up by good clinical evidence. The Nystagmus Network website nystagmusnet.org produces authoritative updates on current research work in the field.

Glasses, contact lenses and low vision aids

Glasses and contact lenses ensure that vision is corrected and that you are getting the most from your vision. They don't correct nystagmus although having clearer vision can help slow the eye movements. Low vision aids, such as magnifiers can help with reading and tinted glasses may be useful to control glare. A low vision assessment will look at using these types of devices and explore which ones may help you.

Surgery

Very occasionally, surgery is performed to alter the position of the muscles that move the eye. This is to reduce the amount your head has to turn to get to your null point, making it more comfortable to keep your head in the best position. However, surgery cannot correct or cure nystagmus. Work is being done to see if surgery to the eye muscles can correct the nystagmus itself but this research is in its early stages.

Drugs

Sometimes drugs are used in the treatment of some acquired nystagmus, for example for someone with multiple sclerosis who develops nystagmus. The drugs help to control the eye movements and reduce the person's awareness of the constant eye movement. This is a very specific type of treatment and is not yet widely used to treat congenital nystagmus. Research is being done into how drugs that affect eye movements might be used to help people with long-standing or congenital nystagmus.

Bio feedback

Researchers have explored ways of trying to reduce the nystagmus by making the patient aware of the eye movement and encouraging them to control it. These techniques rely on visual and audio signals (known as bio feedback) to the patient. One approach, Intermittent Photopic Stimulation (IPS), did not show clear improvements when trialled. There is no clear evidence that any bio feedback works but some people with nystagmus have reported good results.

Related eye conditions

It is important to remember that many children with nystagmus do not have eye, brain or other health problems. However in a small number of cases nystagmus can be related to other conditions.

Albinism

Albinism is the name given to a group of inherited conditions in which there is a lack of pigmentation (colour) in the eyes (ocular albinism) and often in the skin and hair as well. People with albinism find their greatest problems arise on sunny days and in brightly lit environments. Virtually everyone with albinism has nystagmus. To find out more about albinism visit the website for the Albinism Fellowship albinism.org.uk

Cone dystrophy

Cone dystrophies are a group of conditions that affect central vision and can cause problems with seeing in bright light, seeing detail such as watching TV, reading, writing or sewing

and seeing colours. Some cone dystrophies are inherited and some appear later in life, sometimes as late as 50. Other types may begin in early childhood or be present at birth.

Childhood (or “juvenile”) cataract

Cataract is a clouding of the lens of the eye which causes sight to become blurred or dim because light cannot pass through to the back of the eye. Some babies are born with cataracts and some develop them later in childhood. Childhood cataract may be inherited or may be caused by injury or illness. However, in most cases the cause cannot be identified. Cataracts in children can be removed by surgery, but every cataract is different. The decision to remove childhood cataracts may depend on a number of things, such as how old they are and how badly the cataracts are affecting sight. More information on cataracts in children can be found at rnib.org.uk

Down’s syndrome

Down’s syndrome is a genetic condition caused by the presence of an extra chromosome. It’s among the most common forms of learning disability. People with Down’s syndrome often have nystagmus and many also have other

eye conditions. They should have their sight checked regularly by an optometrist who has some experience of testing people with learning disability. The Down's Syndrome Association produces information on eye problems that people with Down's syndrome may develop.

Coping

It's completely natural to be upset when you or your child is diagnosed with nystagmus and it's normal to find yourself worrying about the future and how you or your child will manage with the change in vision. RNIB can help with our telephone Helpline and emotional support service. Call us on 0303 123 9999.

Having nystagmus can cause serious changes to vision but there are lots of things that you can do to make the most of your remaining vision. This may mean making things bigger, using brighter lighting or using colour to make things easier to see. Ask your ophthalmologist, optician or GP to refer you to your local low vision service, which can provide you with magnifiers to help with reading and advice on lighting to help make the most of your sight.

If your vision is impaired, it is also worth asking your specialist to help you register as “sight impaired” or “severely sight impaired”. This opens the door to expert help and some financial concessions.

Local social services should also be able to offer you information on staying safe in your home and getting out and about safely. They should also be able to offer you some practical mobility training to give you more confidence when you are out.

Our Helpline on 0303 123 9999 can give you information about low vision clinics and the help available from social services. They can also offer advice if you have any difficulties accessing these services. Our website rnib.org.uk offers lots of practical information about adapting to changes in your vision and products that make everyday tasks easier.

Useful contacts

Royal National Institute of Blind People

105 Judd Street, London WC1H 9NE
0303 123 9999 • helpline@rnib.org.uk
www.rnib.org.uk

Royal College of Ophthalmologists

18 Stephenson Way, London NW1 2HD
020 7935 0702 • www.rcophth.ac.uk

Nystagmus Network

0845 634 2630 • www.nystagmusnet.org

Albinism Fellowship

01282 771900 • www.albinism.org.uk

Down's Syndrome Association

0845 230 0372 • www.downs-syndrome.org.uk

Driver and Vehicle Licensing Agency (DVLA)

Drivers Customer Services (DCS)

Correspondence Team DVLA

Swansea SA6 7JL

0300 790 6801 • www.dvla.gov.uk



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Information sources

We do all we can to ensure that the information we supply is accurate, up to date and in line with the latest research and expertise.

The information in RNIB's Understanding series uses:

- Royal College of Ophthalmologists guidelines for treatment
- clinical research and studies obtained through literature reviews
- information published by specific support groups for individual conditions
- information from text books
- information from RNIB publications and research.

For a full list of references and information sources used in the compilation of this guide email publishing@rnib.org.uk

If you, or someone you know, is living with sight loss, we're here to help.

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

Ask RNIB is the simple, easy to use way to find the answers to your questions online – try it today at rnib.org.uk/ask

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