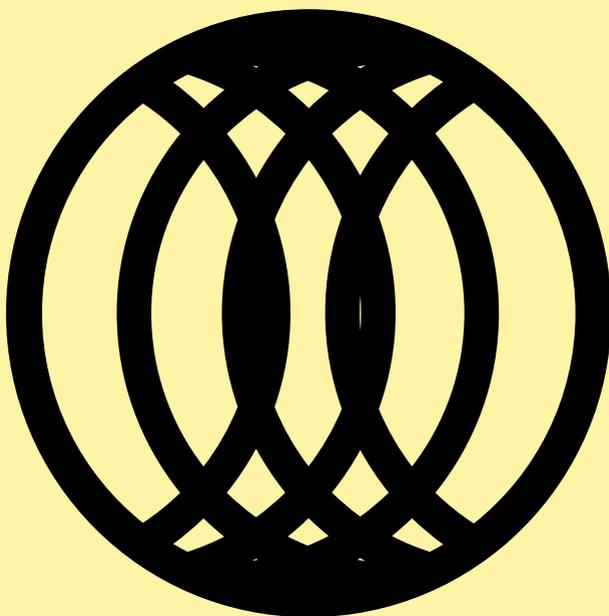


Understanding

Nystagmus



Supporting people
with sight loss



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Contact us

We're here to answer any questions you have about your child's or your own eye condition or treatment. If you need further information about nystagmus, then our Helpline is there for you.

Just give us a call on **0303 123 9999** or email us at **helpline@rnib.org.uk** and we'll be happy to speak with you.

RNIB's Understanding series

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

The series covers a range of eye conditions, and is available in audio, print and braille formats.

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What is nystagmus?

Nystagmus is a condition of uncontrolled eye movement. If you have nystagmus, your eyes move constantly. This can be in a side to side, an up and down, or a circular motion, or a combination of these. This uncontrolled movement can affect how clearly you can see. Most people with nystagmus have reduced vision.

It's thought that nystagmus affects between one and two in 1,000 people.



What causes nystagmus?

Different parts of the brain are involved in seeing. Some parts deal with processing visual information from the eyes; other parts control eye movements or gaze (the direction a person is looking). Nystagmus can develop if any of these parts don't develop properly or are damaged in later life by inflammation in the brain, a stroke or a head injury. Very occasionally, certain medications or alcohol may cause nystagmus.

What are the different types of nystagmus?

There are two main types of nystagmus: one which appears in the first few months of life called “infantile nystagmus” or “congenital nystagmus”; and another which develops later in life which is usually called “acquired nystagmus”.

Infantile or congenital nystagmus

Infantile or congenital nystagmus is also sometimes known as “early onset nystagmus”. It is usually diagnosed in very young children, soon after they’re born or sometimes in the first few months of their life. This type of nystagmus can be caused either by a problem with the eyes themselves or by a problem with the parts of the brain which control eye movements. But sometimes children develop nystagmus without these problems.

The way the brain and eyes work together is known as the visual system. All babies are born without fully developed visual systems. In the first few years of life, our vision develops through our eyes and brain being stimulated by what we see. If a baby is born with an eye condition which affects how well they can see, then their visual system may not have a chance to develop normally.

Some eye conditions which can cause reduced vision in children include:

- congenital cataracts
- ocular albinism
- retinal dystrophies, such as cone dystrophy or congenital stationary night blindness
- optic nerve conditions, such as optic nerve coloboma or hypoplasia
- aniridia.

These conditions can lead to nystagmus. The more an eye condition affects a child's sight, the worse their nystagmus is likely to be.

Nystagmus can also occur in children with other medical conditions, such as learning disabilities like Down's syndrome, or neurological conditions such as cerebral palsy.

However, many children with nystagmus don't have any eye, brain or other health problems. The nystagmus happens for no known reason and a cause can't be found – this is called “idiopathic infantile nystagmus”.

Acquired nystagmus

Nystagmus that develops later, in adults, is called “acquired nystagmus”. Anything that damages the parts of the brain that control eye movements can result in acquired nystagmus.

Acquired nystagmus is usually a sign of another underlying condition such as stroke, multiple sclerosis, brain tumour, head injury or the effects of a drug.



Describing eye movements in nystagmus

Neurologists (hospital doctors dealing with brain and nerve problems) and ophthalmologists (hospital eye doctors) sometimes classify nystagmus by describing how eyes move. For example, “jerk nystagmus” is where eye movement is quick in one direction and slow in another, and “pendular nystagmus” is slow movement in all directions. The direction of nystagmus can also be described as vertical, horizontal or circular.

Describing nystagmus like this can help give the doctor an idea of what the underlying cause might be. If you are unclear about how your child’s or your own nystagmus has been described, you can ask the ophthalmologist to explain it.

What are the effects of nystagmus on sight?

If you have nystagmus, your eyes are always moving, although it may not always be obvious to you or others. The way that nystagmus affects vision varies from person to person; however, it doesn't lead to total loss of sight.

Infantile nystagmus

How your vision is affected if you have infantile nystagmus varies a lot, and can often depend on the underlying cause of your nystagmus. Some people may be able to read most sizes of print without help, while others may have a significantly reduced level of vision. Most people with nystagmus have some useful vision and normally nystagmus doesn't get worse with age.

Your vision can vary in quality when you have nystagmus, depending on which direction you're looking in or whether you're looking at something far away or close up. Your vision can also vary depending on how you're feeling.

The more stressful or tiring you find a situation, the worse your vision can become because these situations can cause eye movements to increase. Your vision may also become worse when you're feeling unwell, or if you're anxious or upset.

Having nystagmus may mean that you need longer to see or read things. The constant movement of your eyes means that you have less time to focus on what is in front of you, for example printed text.

The effects of nystagmus may improve when your head is held in a particular position, which can help you to see things better. This is known as the "null zone". This is often the direction of your gaze where your eye movements are slowest and most stable. Slowing or making eye movements more stable may mean your vision becomes clearer. Children with infantile nystagmus often find their null zone naturally. Parents or teachers may notice that a child tilts their head to one side, or looks at things sideways.

If you're a parent of a child with nystagmus, it can be helpful to tell teachers that your child should be allowed to adopt the head posture that gives them the best vision and that it does no harm if they hold their head in an unusual way. Your child may also prefer to sit on a particular side of the television or board at school based on their null zone.

Some people with nystagmus also find that nodding their head helps to improve their vision.

Nystagmus can cause poor depth perception and people with the condition may find it difficult to judge distances and height. For children, this may cause difficulties when playing ball sports at school as it can be difficult to judge distance and speed. Balance and coordination can be affected too which sometimes mistakenly causes people to appear clumsy.

Children and adults with infantile nystagmus won't normally have the sensation that the world is constantly moving because their brain would have adapted to their eye movements. Babies and young children with

infantile nystagmus don't experience any pain from the condition. The vision problems that infantile nystagmus cause tend to improve through the early years, until a child's vision stabilizes around the age of five or six. Giving children plenty of visual stimulation in the early years can help them make best use of the vision they have.

As a child gets older, and uses their vision more for reading and school work, they may start to have problems with eye strain, which can lead to headaches. If you have nystagmus and find that your eyes feel fatigued and achy, especially when you're doing detailed visual tasks, it can be helpful to make sure that you have regular breaks and use any aids and adaptations which you find handy.

Having a low vision assessment will help people with nystagmus find aids or adaptations to make the most of their vision. This may help to prevent eye strain and headaches. You can find more information about low vision assessments further on in this publication.



Acquired nystagmus

If you develop nystagmus later on in life, you may experience a constant awareness of the world moving around you, or in front of you. This is known as oscillopsia.

As the nystagmus is new, your brain has not adapted to the unexpected eye movements and so it sees the world moving. This is very disabling and can make things very difficult to see, as well as sometimes making you feel sick and dizzy.

Depending on what has caused your acquired nystagmus, it may be a short term condition that might get better. However, some people have the condition for the long term which can cause problems with how well they can see as well as being disorientating.

How is nystagmus investigated?

Many cases of infantile nystagmus are picked up between six weeks and three months of a baby's life, as this is the stage at which their eyes start to seek focus. Normally, parents or another caregiver will notice that the baby's eyes are unable to fixate on or follow an object, or they appear to be moving all the time. Sometimes, a health visitor may be the first to notice a problem.

As acquired nystagmus sometimes causes symptoms of oscillopsia, it can often be obvious that there is a problem. An optometrist can also detect nystagmus during an eye examination.

Because nystagmus can be the first sign of a serious condition affecting the eye or the brain, it is vital that the person with the signs is seen by an ophthalmologist or a neurologist as soon as they are first noticed. The tests that a person might have will depend on the type of nystagmus, their age, and the possible cause of the nystagmus. The first priority will be to find out if there is an eye or neurological condition which may be causing the nystagmus.

For infantile nystagmus, this will usually involve a detailed examination of the inside of the eye to check for any eye conditions. Your child may need electro-diagnostic tests to check how well the cells of the retina are working and to see if there is an eye condition affecting the retina which may be causing the nystagmus.

In cases where a neurological problem is thought to be the cause, especially in acquired nystagmus, you may need to have a brain scan to check for any problems.

If there is an underlying eye condition which is causing the nystagmus, you will normally be monitored at the eye clinic and this may mean seeing a number of different professionals.

- The ophthalmologist is the specialist eye doctor who is responsible for a patient's overall eye health and would carry out any treatments.
- An orthoptist specialises in assessing eye movements and may look at the way your eyes are moving in detail.
- An optometrist specialises in prescribing glasses and contact lenses and may also carry out low vision assessments.



Measuring vision

The eye clinic can investigate vision in a number of different ways. Different tests can be used to assess how well people see detail, faint edges, peripheral detail and colour. These tests can be adapted 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 can manage to read down quite far on this test especially if they are calm and can use their null zone. Because of this, it can give a false impression of how well you or your child can see.

The tests done at the eye clinic to measure vision are useful for the eye specialists to monitor your vision from visit to visit. However, the tests don't reflect how your vision is in everyday life where objects move, lighting changes and we can become anxious. All of these factors can make vision worse.

If your vision or your child's vision is variable, make this clear to the specialists carrying out the tests. If possible, give examples of situations when vision is worse, such as when trying to find the right platform for a train or playing ball sports. Any records of your vision or your child's vision need to reflect the fact it is variable, and that more time may be needed to see things. This helps to provide a more realistic picture of what your sight or your child's sight is like. This is important if these records are used to explain the effects of nystagmus on your child's sight to their school or to your workplace in later life.

Low vision assessment

A low vision assessment looks at ways to help people make the most of their vision. This may mean making things bigger, using brighter lighting or using colour to make things easier to see. The assessment gives people a

chance to discuss any practical problems they are having with their vision with a low vision specialist. The specialist can explore things like magnifiers, lighting, colour contrast and other adaptations that may help.

You can ask for a referral to a low vision clinic from an ophthalmologist, optician or GP. Because it's an NHS service, any aids that are found to help can be loaned for free as long as they are needed.

If your child has reduced vision due to nystagmus, it's helpful to see a low vision service at least once a year. This is important as the ideas from the assessment can be reported back to school, with time built in for your child and the staff to learn how to use any aids or equipment.

Genetic counselling

Infantile nystagmus can sometimes be inherited (passed on in families). The chance of passing on nystagmus depends on the inheritance pattern of the underlying eye condition. Idiopathic nystagmus is known to run in families and recently a genetic link for this type of nystagmus has been found.

To find out the chances of someone passing on nystagmus to the next generation, speak to an ophthalmologist. They can refer you to a clinical geneticist (a doctor who specialises in genetic conditions) who can discuss this further with you and your family.

Information from the eye clinic

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

If you're an adult with nystagmus, you may also have similar or perhaps different questions – don't be afraid to raise them with your eye clinic team.



How can nystagmus be managed?

There's no cure for nystagmus at the moment. Some of the underlying conditions which cause nystagmus may be treatable.

Researchers 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 have been clinically trialled in research studies, and therefore are not backed up by good clinical evidence. Ask your doctor about any new treatments you may hear or read about to get their advice.

IN-vision is a charitable organisation which is involved in furthering research into infantile nystagmus. They offer a lot of reliable information on their website at **in-vision.org.uk** about new developments in research.

Having nystagmus can cause reduced vision but there things which can help manage the condition and make the most of your sight.

Glasses, contact lenses and low vision aids

Glasses and contact lenses will ensure that you, or your child, have the best vision possible. They can't correct nystagmus but having clearer vision can help slow the eye movements in infantile nystagmus. In young children with infantile nystagmus, treatment with glasses is important to help their vision develop as fully as possible.

Low vision aids, such as magnifiers can help with reading. Tinted glasses may be useful to control glare. A low vision assessment will look at using these types of aids and explore which ones may help.

Other options

There are also some other options which can sometimes help to manage nystagmus. These options don't work for everyone as their suitability varies from person to person.

The options are:

Prisms

Prisms can sometimes be prescribed in spectacles. Prisms can't correct nystagmus, but can sometimes be helpful in aligning the eyes to make the null zone easier to use. They may be helpful to people whose eye movements are slower when they're looking close up. However, they don't work for everyone and they're only really suitable for people whose null zone is quite close to the straight ahead gaze.

Surgery

Very occasionally, surgery can be used to change the position of the muscles that move the eye. The surgery can't correct the nystagmus, but can be helpful in reducing the amount a person needs to turn their head to get to their null zone, making it more comfortable to keep their head in the best position. It doesn't work for everyone and it usually isn't considered until a child is older and when the null zone is more stable.

Researchers are looking at whether surgery can be used to correct the nystagmus itself, but this research is in its early stages.

Medication

Drugs may be used in some cases of acquired nystagmus, for example if the nystagmus is caused by multiple sclerosis. Drugs called baclofen and gabapentin are the most commonly used ones, and can sometimes help control eye movements and reduce the symptoms of oscillopsia.

This type of treatment is not yet widely used to treat infantile nystagmus.

Research is being done into how similar drugs could be used to help people with long-standing or infantile nystagmus.

Botulinum toxin

Botulinum toxin (Botox) injections into the eye muscles may occasionally be used to help some people who have acquired nystagmus that is caused by a neurological problem, such as multiple sclerosis. Botox weakens the eye muscles and helps to slow down the movements. The effects are only temporary, but can sometimes help to reduce the symptoms of oscillopsia in the short term. However, Botox weakens all eye movements and not just the eye movements relating to the nystagmus, so this can cause its own problems.

It's not yet clear whether this type of treatment helps everyone with nystagmus. Further research is being carried out to look at whether it can be used in people with infantile nystagmus.

Other therapies

You may hear of research into other management therapies such as acupuncture or biofeedback, which aims to reduce nystagmus through audio signals. However, it's uncertain whether any of these therapies actually work and more research is needed.



Related eye conditions

Sometimes, nystagmus is related to other conditions, including:

Albinism

Albinism is the name given to a group of inherited conditions in which there is a lack of pigmentation (colour) in the eyes and often in the skin and hair as well. Albinism which affects the eyes is known as ocular albinism. 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 at **albinism.org.uk**.

Aniridia

Aniridia is an eye condition where the iris (the coloured part of the eye) is missing or incomplete. Most aniridia is inherited and caused by a faulty gene being passed down from parent to child. Aniridia can cause poor vision and sensitivity to light. To find out more about aniridia, visit the website for the Aniridia Network at **aniridia.org.uk**.

Congenital stationary night blindness

Congenital stationary night blindness is an inherited eye condition, which causes difficulties with seeing in low light levels. Other vision problems can include short-sightedness and squint, as well as nystagmus. The vision problems are present from birth but they tend to remain stable and not become worse over time.

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. Cone dystrophies are inherited. Some types appear later in life, sometimes as late as 50, and others may begin in early childhood or be present at birth.

Childhood (or congenital) cataract

A cataract is a clouding of the lens in the eye. This causes sight to become blurred or dim because light can't pass through to the back of the eye. Some babies are born with cataracts or develop them at an early age. Childhood cataract may be inherited or may be caused by injury or illness. However, in most cases it is not known why they occur. Cataracts in children can be removed by surgery, but this depends 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 on our website **rnib.org.uk**.

Down's syndrome

Down's syndrome is a genetic condition caused by the presence of an extra chromosome. It's one of the most common causes of learning disability. As 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 disabilities. More information on eye problems that people with Down's syndrome may develop can be found on the Down's Syndrome Association website at **downs-syndrome.org.uk**.

Living with nystagmus

Although nystagmus can cause problems with your sight, with the right support at the right time, most people can lead full and independent lives.

For children with infantile nystagmus, having the right support at school can 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.

When a child is first diagnosed with an eye condition, a qualified teacher for visual impairment (QTVI) can provide support with development, play, learning and education. This support is continued from infancy into school and higher education, and other support is available when moving into employment.

Local social services can provide help to people with sight conditions with getting out and about safely and with practical adaptations around the home.

Depending on how much of a person's sight is affected by nystagmus (or an underlying eye condition if there is one) they may be eligible to be registered as sight impaired (partially sighted) or severely sight impaired (blind). An ophthalmologist would be able to tell you whether you or your child is eligible. Registration can act as a passport to help and sometimes to financial concessions, but a lot of this support is still available to people who aren't registered.

You can find more information about all the support available to children and adults with sight problems on our website rnib.org.uk or by calling our Helpline on **0303 123 9999**.



Social implications

Life with nystagmus can have its challenges, but what often helps is explaining to other people what nystagmus is, and how it affects you or your child.

The Nystagmus Network has a lot more information about living with nystagmus, from social implications to support with education. They also have information aimed at teachers which can be used to help explain the way nystagmus can affect someone with the condition. More information can be found on their website at **nystagmusnetwork.org**.

Your eyesight in the future

Infantile nystagmus will not get worse as a child gets older and goes through adulthood. Making sure that glasses are up to date will help you make the most of your sight. Normal age-related changes to people's ability to focus at around the age of 40 can make it feel like your eyesight is getting worse. For someone with nystagmus, this doesn't mean that their nystagmus is getting worse, but is a normal change that happens to everyone. At this stage, you may need a different pair of glasses to help with focusing for close work.

Driving and nystagmus

Whether someone with nystagmus is able to drive depends on whether they are able to meet the eyesight standard set out by the DVLA.

Many people with infantile nystagmus may not be able to meet this standard, but it may be possible for some. Even if a person's sight does meet the DVLA standard, they should use their personal judgement as to whether they feel confident enough to drive, because nystagmus may cause vision to be variable.

If you have developed acquired nystagmus later on in life, you are required by law to report this to the DVLA. They will then need to find out more about your condition and whether you meet basic eyesight requirements for driving. You can find more information by visiting **[rnib.org.uk/driving](https://www.rnib.org.uk/driving)**.

Coping

It's completely natural to be upset when you or your child have been diagnosed with nystagmus, and it's normal to find yourself worrying about what it means now and in the future.

It can sometimes be helpful to talk about these feelings with someone outside of your circle of friends or family. At RNIB, we can help with our telephone Helpline and our Sight Loss Counselling team. Your GP or social worker may also find a counsellor for you if you feel this might help.

Your eye clinic may also have a sight loss advisor (also known as an Eye Clinic Liaison Officer or ECLO), who can be on hand to provide you with further practical and emotional support about your child's or your own eye condition.

Further help and support

If you have questions about anything you've read in this publication, please get in touch with us.

Our Helpline is your direct line to the support, advice and services you need. Whether you want to know more about your eye condition, buy a product from our shop, join our library, find out about possible benefit entitlements, or be put in touch with a trained counsellor, we're only a call away.

It's also a way for you to join RNIB Connect, our community for anyone affected by sight loss. RNIB Connect is free to join and you'll have the chance to meet other people with similar experiences in our helpful, welcoming and supportive community.

Give us a call today to find out how we can help you.

RNIB Helpline

0303 123 9999

helpline@rnib.org.uk

We're ready to answer your call Monday to Friday 8am to 8pm and Saturday 9am to 1pm.

You can also get in touch by post or by visiting our website:

RNIB

105 Judd Street
London WC1H 9NE

rnib.org.uk

Other useful contacts

Nystagmus Network

nystagmusnetwork.org

IN-vision

47 Hillside Road
Marlow
Bucks SL7 3JX

in-vision.org.uk

Albinism Fellowship

PO Box 2535
Ilford IG1 8NY

0128 277 1900

albinism.org.uk

Aniridia Network UK

22 Cornish House
Adelaide Lane
Sheffield S3 8BJ

0779 286 7949

aniridia.org.uk

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS

0333 1212 300

downs-syndrome.org.uk

Driver and Vehicle Licensing Agency (DVLA)

Drivers' Medical Enquiries
Swansea
SA99 1TU

0300 790 6806

www.dvla.gov.uk

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4. Do you have any other comments about this publication or any aspect of your contact with RNIB?

Information sources

RNIB and The Royal College of Ophthalmologists 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.

This publication uses information from:

- The Royal College of Ophthalmologists' guidelines for treatment
- clinical research and studies obtained through literature reviews
- specific support groups for individual conditions
- medical text books
- RNIB publications and research.

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

About The Royal College of Ophthalmologists

The Royal College of Ophthalmologists champions excellence in the practice of ophthalmology and is the only professional membership body for medically qualified ophthalmologists.

The College is unable to offer direct advice to patients. If you're concerned about the health of your eyes, you should seek medical advice from your GP or ophthalmologist.

rcophth.ac.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 and easy way to find the answers to your questions online – try it today at **rnib.org.uk/ask**

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