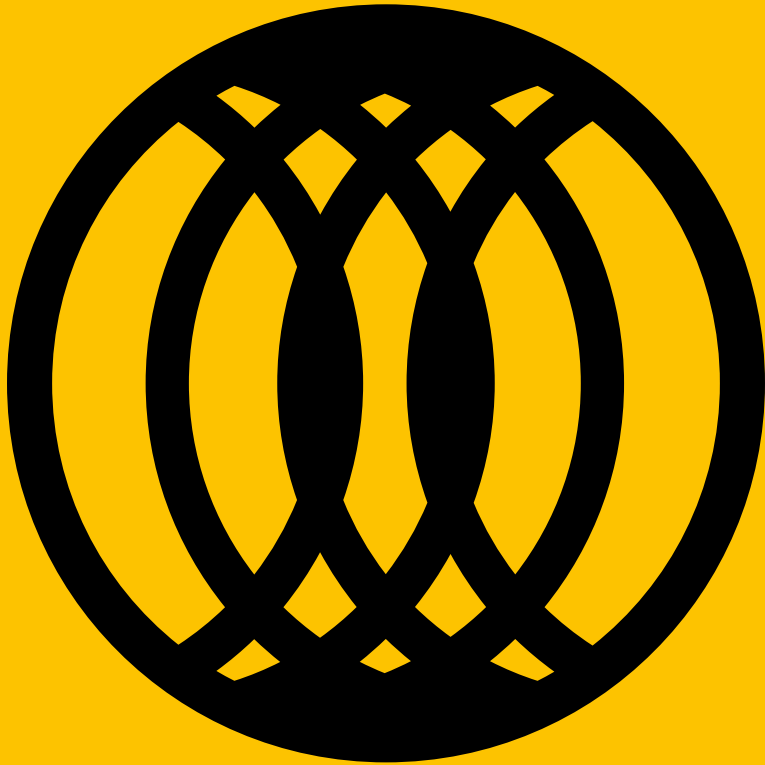


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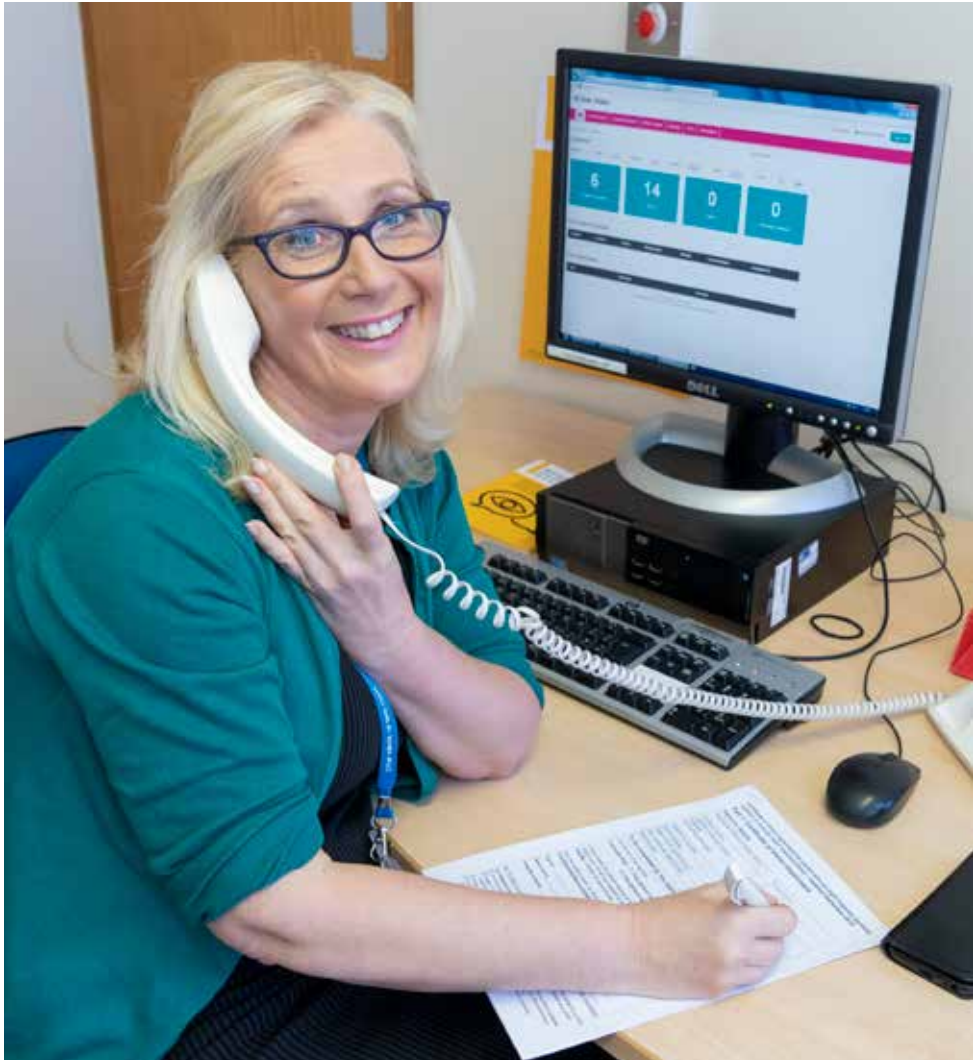
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RNIB's Understanding series

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.

Contact us

We're here to answer any questions you have about your eye condition or treatment. If you need further information about cataracts or on coping with changes in your vision, then our Helpline is here for you.

RNIB Helpline
0303 123 9999
helpline@rnib.org.uk

Or say, "Alexa, call RNIB Helpline"
to an Alexa-enabled device.

What is nystagmus?

Nystagmus is a condition which causes uncontrolled eye movement. If you have nystagmus these movements cause your eyes to move constantly (sometimes described as wobble). This can be in a side to side, an up and down, a circular motion, or a combination of these. This uncontrolled movement can affect how clearly you can see. Many people with nystagmus have reduced vision.

It's thought that nystagmus affects around two in 1,000 people.



What causes nystagmus?

Different areas of our brain are involved in seeing. Some areas process visual information from our eyes; other parts control eye movements or gaze (the direction a person is looking). Nystagmus can be present if any of these areas don't develop properly in early life, or are damaged later in 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:

- Infantile or congenital nystagmus which appears in the first few months of life and
- Acquired nystagmus which develops later in life.



Infantile or congenital nystagmus

Infantile or congenital nystagmus is also known as early onset nystagmus or infantile nystagmus syndrome (INS). It is usually diagnosed in very young children, in the first few months of their life. This type of nystagmus can be associated with another eye condition or with a problem with the parts of the brain which control eye movements. Sometimes children develop nystagmus without any of these issues.

The way the brain and eyes work together is known as the visual system. When a baby is born, it's visual system is not fully developed. 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 is affecting how well they can see, their visual system may not develop normally. The following are examples of eye conditions that a baby may be born with:

- congenital cataracts
- ocular albinism
- retinal dystrophies, such as cone dystrophy, congenital stationary night blindness, or Leber congenital amaurosis
- 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 learning disabilities and other medical conditions, such as Down's syndrome, or neurological conditions such as cerebral palsy.

However, many children with nystagmus don't have any problem with their eye, brain or health. When a cause for the nystagmus can't be found, it's called idiopathic infantile nystagmus or idiopathic nystagmus syndrome. Some of these children may have a faulty gene known to cause nystagmus.

Further information on conditions that can lead to nystagmus can be found further on in this booklet.

Acquired nystagmus

Nystagmus that develops later, mostly in adults, is called acquired nystagmus. Anything that damages the areas 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 certain prescribed or recreational drugs.

Describing eye movements in nystagmus

Neurologists (hospital doctors diagnosing and treating brain and nerve problems) and ophthalmologists (hospital eye doctors) sometimes classify nystagmus by describing how eyes move. For example:

- **jerk nystagmus** – eye movement is quick in one direction and slow in another.
- **pendular nystagmus** – slow eye movement in all directions.
- **mixed nystagmus** – both jerk and pendular eye movements.



The direction of nystagmus can also be described as vertical, horizontal or torsional (circular) or a combination of these.

Nystagmus may also be described depending on whether the eye movements change when looking in different directions of gaze, or whether they worsen when one eye is covered.

- Latent nystagmus occurs when one eye is covered.
- Manifest-latent nystagmus is when the eye movements are always present but worsen when one eye is covered.
- Manifest nystagmus is where the eye movements are always present and do not worsen when one eye is covered.

Children who develop an inward turning squint (esotropia) at a young age may develop these types of nystagmus. Usually, treating the squint can help to reduce these types of nystagmus.

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.

Infantile nystagmus can be described as:

- Idiopathic infantile nystagmus, which is where nystagmus occurs on its own without any underlying eye conditions.
- Sensory defect infantile nystagmus which is where nystagmus is associated with an underlying eye condition such as albinism, cataract, or retinal dystrophies.

Some people with infantile nystagmus may be able to read most sizes of print without help, while others may have a significantly reduced level of vision, which tends to be more common when nystagmus is associated with an eye condition. 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.

"It takes me longer to read things and register people or objects, because my eyes take longer to focus. I think I will miss things that are around me, such as steps or objects, so worry that I might knock something over." – **Sarah Bailey**

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 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, often seen when a child is asked to read at a distance or watch television.

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 or position



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. For example, if a child has a face turn to the left, their eyes will be gazing to the right. Therefore, sitting on the left side of the classroom will be best for them so that everything is to the right of them on the side of their gaze.

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

People with nystagmus may have poor depth perception. They may find judging distances and depth difficult. This can cause difficulties when playing ball sports as it can be tricky to judge distance and speed. Balance and coordination can also be affected which sometimes mistakenly causes people to appear clumsy.

“I find it difficult to judge the distance between an object in the near distance and the medium distance. As an example, the distance between two gate posts. This becomes even more challenging if the objects are moving. Guiding a boat to the shore is really difficult, to judge the distance between the boat and the shore.”

– Brian Butcher

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 early on. Nystagmus itself does not cause pain, however some people with nystagmus have another eye condition that causes them to be sensitive to light and this can cause some discomfort, particularly in brighter light environments.

The vision problems, associated with infantile nystagmus, tend to improve through childhood. 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 schoolwork, they may start to have problems with eye strain, which can lead to headaches. If you have nystagmus and find that your eyes feel tired and achy, especially when you're doing detailed visual tasks, it can be helpful to have regular breaks, wear any glasses that you have been prescribed for that task and use any aids and adaptations which you find useful.

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 information.

Acquired nystagmus

If you develop nystagmus later 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, oscillopsia may be a short-term condition that might get better. However, some people have oscillopsia for the long term, which can cause problems with how well they can see as well as them feeling unbalanced.

Further information can be found on Nystagmus Network's website nystagmusnetwork.org

How is nystagmus investigated?

The tests that a person might have will depend on the type of nystagmus, their age, and the possible cause of the nystagmus. The priority will be to find out if there is a condition involving the eye, brain or nerves which may be causing the nystagmus.

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. An optometrist (optician), orthoptist, or doctor can detect nystagmus during an examination.



Checking for underlying conditions

As nystagmus can be the first sign of a serious condition affecting the eye or the brain, it's vital that a person with signs of nystagmus is seen by an ophthalmologist or a neurologist as soon as it's first noticed.

For infantile nystagmus, this will usually involve a detailed examination of the eye to check for any eye conditions, and to look for any refractive error (glasses prescription). Your child may need special tests called 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, a brain scan might be carried out to check for any problems.

If there is an underlying eye condition, monitoring at the eye clinic might be suggested, and this may mean seeing various eye health professionals.

- The ophthalmologist is the specialist eye doctor who is responsible for your overall eye health and any treatment necessary.

- An orthoptist specialises in assessing eye movements and assessing the way the two eyes work together (binocular vision). They usually measure the levels of vision (visual acuity).
- An optometrist specialises in prescribing glasses (refraction) and contact lenses.
- A low vision professional specialises in low vision aids.
- In some cases, genetic testing may also be carried out.

Measuring vision

The eye clinic can investigate vision in different ways. Various tests can be used to assess how well people see detail, faint edges, peripheral (side) vision, depth and colour. These tests can be adapted for children of different ages. Vision in people with nystagmus is often better when both eyes are open. When vision is measured it is often tested one eye at a time with the other eye covered. This can lead to a poorer level of vision being measured than is the case with both eyes. When vision is tested in people with nystagmus it should be measured with both eyes open, and allowing them to use any compensatory head position naturally adopted to find their null zone.



When a young child is first diagnosed with nystagmus it can be difficult to know how well they can see or how much the nystagmus is affecting their sight. Some children may have other eye conditions or focussing problems (such as being long-sighted or short-sighted) which may also be affecting their sight. There are different ways in which vision can be measured in very young children to give an idea of their level of vision, although the accuracy of this will improve as a child gets older and is able to say how well they can see.

The most common test is the visual acuity test which uses a 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 relaxed and can use their null zone. Because of this, it can give a false impression of how well a person 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 or stressed in certain situations. These additional 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 day to day. This is important if these records are used to explain how you or your child are affected by nystagmus in a place of education or workplace in later life.

Genetic counselling

Infantile nystagmus can sometimes be inherited (passed on in families). How nystagmus might be passed down in families 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.

Genetic counselling can help you understand how nystagmus is passed on within your family, as well as offering you guidance and support in making any future decisions relating to your nystagmus, such as starting a family. Genetic counselling is a free service within the NHS and to access this service, you can ask your GP or ophthalmologist to refer you.

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 eye 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 to ask your eye clinic team.

How can nystagmus be managed?

Currently there's no cure for nystagmus but 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, which means they 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 **in-vision.org**.

uk about new developments in research.

Nystagmus Network is a charitable organisation that offers support and information to those with nystagmus or those supporting someone with nystagmus. They also raise awareness of nystagmus and promote and fund research into nystagmus. Further information can be found on their website **nystagmusnetwork.org**.

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

Glasses and contact lenses

Glasses and contact lenses will ensure that you, or your child, have the best vision possible. They can't correct nystagmus but can correct for any refractive (focusing) error you may have. In young children with infantile nystagmus, treatment with glasses is important to help their vision develop as fully as possible.

Contact lenses may be more helpful for some people, for example, those who have a high glasses prescription and have a null zone which is far away from the straight-ahead gaze. This is because when wearing glasses, moving your eyes to far positions of gaze will mean you are not looking through the correct central part of the glasses lens. Contact lenses move with the eye, so you are always looking through the centre and getting the best vision. Research has also looked at how the sensation of contact lenses touching the surface of the eye may help to reduce the nystagmus eye movements. Contact lenses are not suitable for everyone, your optometrist or ophthalmologist can advise you if they are appropriate for you.

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 or contrast 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, such as tinted glasses which may be useful to control glare.

Ask your ophthalmologist, optometrist, or GP about a referral to your local low vision service. There is further information on low vision on our website.

If your child has reduced vision due to nystagmus, it's helpful to attend a low vision service at least once a year. This is important as the advice and suggestions gained during 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.

"I use handheld magnifiers, my smartphone with screen magnification, invert colours, a video magnifier. I take a symbol cane out with me, in case I need people to give me extra space if my balance isn't too good, or confirm changes in depth of a space." – Sarah Bailey

Other options

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

Surgery

Surgery can't correct the nystagmus, but it can be used to change the position of the muscles that move the eye. This 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. Surgery doesn't work for everyone and it's not usually considered until a child is older and when the null zone is more stable.

Medication for acquired nystagmus

Drugs may be used in some specific cases of acquired nystagmus, for example if the nystagmus is caused by multiple sclerosis. Drugs called baclofen, memantine and gabapentin are the commonly used ones, and can sometimes help control eye movements and reduce the symptoms of oscillopsia. However, for many people the side effects of these drugs may outweigh the benefit they provide.

This type of treatment is not yet widely used to treat infantile nystagmus although research is being done to see whether similar drugs could

be used to help people with infantile nystagmus. A type of eye drop used in the treatment of glaucoma may help some people with infantile nystagmus but more research is needed.

Botulinum toxin for acquired nystagmus

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 can weaken all eye movements and not just the eye movements relating to the nystagmus, so this can cause its own problems which limits the usefulness of this treatment.

Further research is being carried out to look at whether this type of treatment 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 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 only affects the eyes is known as ocular albinism. People with albinism find they are most affected on bright sunny days and in brightly lit environments. Almost 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. More information about aniridia can be found on our website and the Aniridia Network website 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 years old, and others may begin in early childhood or be present at birth. More information can be found on our website and the Macular Society website macularsociety.org.

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 several 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.

Optic nerve or chorioretinal coloboma

Coloboma means that part of one or more structures inside an unborn baby's eye does not fully develop during pregnancy. This underdeveloped tissue can affect the retina and the choroid (the layer of tissue and blood vessels behind the retina). This is known as a chorioretinal coloboma. An optic nerve coloboma is where the optic nerve (which carries information from the eye to the brain) is affected by coloboma. Optic nerve or chorioretinal coloboma which affects both eyes can cause poor vision and nystagmus. More information about coloboma can be found on our website.

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. More information on eye conditions that people with Down's syndrome may develop can be found on the Down's Syndrome Association website at **downs-syndrome.org.uk**.

Leber congenital amaurosis (LCA)

LCA is an inherited eye condition which can cause sight loss in very early childhood. It affects the light sensitive cells in the retina at the back of the eye, causing them to stop working properly. LCA can also cause nystagmus, photophobia (light sensitivity) and slow pupil response to light. There are several different types of LCA depending on the gene that is faulty. Recently, a gene therapy treatment has become available for a fault in the RPE65 gene, providing there are still enough retinal cells working. More information on LCA can be found on Retina UK's website at **retinauk.org.uk**.

Optic nerve hypoplasia

Optic nerve hypoplasia is underdevelopment of the optic nerve. The optic nerve is a bundle of nerve fibres which carries information from your eyes to your brain. Optic nerve hypoplasia can affect central and peripheral (side) vision.



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.

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 are 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 are not registered.

For children with infantile nystagmus, having the right support at school can make a big difference. 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.

“Keira struggles to see fine detail and needs to have things enlarged in order to see them properly. She has to concentrate when trying to see things and this can make her very tired and sometimes give her headaches. Keira uses voiceover on her devices and Alexa. Technology is brilliant and really makes accessibility easier.”

– Kirsty, mum to Keira Mills

Your local authority (LA) should have at least one qualified teacher of the visually impaired (QTVI) to work with you and your child both at home and at school. A QTVI is a qualified teacher who can provide support with development, play, learning and education. At an early stage, ask your local authority to put you in contact with a QTVI. They will support you and your child as soon as a visual impairment is suspected or diagnosed.

For adults, there is a range of support available for people with sight conditions to help them into work or remain in work. Our Sight Loss Advice service can give you further advice and guidance, including information about what your rights at work are, and training and work programmes available.

Our Sight Loss Advice service can be contacted via our Helpline for more information about the support available to children and adults with sight loss.

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. Most children with nystagmus will be able to attend mainstream education.

“Eye contact is difficult and can be awkward, but I tend to use one eye to focus on looking at someone, so they have one point to focus on. It takes me longer to identify someone I know if I am meeting them, but I will have a rough idea if it might be that person by the outline features. I have become confident in saying if I wasn't sure if it was them, or making a joke out of not spotting someone.” – Sarah Bailey

The Nystagmus Network has a lot more information about living with nystagmus, from information for adults with nystagmus, social implications of living with nystagmus to support with education. They have information aimed at teachers to help explain the way nystagmus can affect someone with the condition. They also have online support groups for parents and for adults and a virtual peer to peer support group for people living with acquired nystagmus. 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 (presbyopia) 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 their ability to meet the eyesight standard set out by the DVLA. Many people with nystagmus are not able to meet this standard and so would not be able to hold a driving licence, however, 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 and safe enough to drive. This is because nystagmus may cause vision to be variable and impact things like judging distances. Your optometrist or ophthalmologist can let you know whether your sight meets DVLA sight standards.

You can find more information by visiting the DVLA website **[dvla.gov.uk](https://www.dvla.gov.uk)**.

If your sight means you are unable to hold a driving licence, you may be entitled to certain travel concessions, such as free or discounted bus or train fares. You can find out more by contacting our Sight Loss Advice service via our Helpline.



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 Counselling and Wellbeing 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 an Eye Care Liaison Officer (ECLO), who can be on hand to provide you with further practical and emotional support about your child's or your own eye condition.

"You should realise that you're just the same as everyone else, but just happen to not see very well. Recognise that there are limitations and challenges, but don't let this stop you doing anything. Be brave, be positive and most of all believe that "you can." – **Brian Butcher**

Further help and support

RNIB Helpline

If you need someone who understands sight loss, call our Helpline on **0303 123 9999**, say "**Alexa, call RNIB Helpline**" to an Alexa-enabled device, or email **helpline@rnib.org.uk**. Our opening hours are weekdays from 8am – 8pm and Saturdays from 9am – 1pm.

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

RNIB
The Grimaldi Building
154A Pentonville Road
London N1 9JE
rnib.org.uk

Connect with others

Meet or connect with others who are blind or partially sighted online, by phone or in your community to share interests, experiences and support for each other. From book clubs and social groups to sport and volunteering, our friendly, helpful and knowledgeable team can link you up with opportunities to suit you. Visit **rnib.org.uk** connect or call **0303 123 9999**.

Sightline directory

Find services and organisations near you that support blind or partially sighted people:
sightlinedirectory.org.uk

Sight Advice FAQ

Sight Advice FAQ answers questions about living with sight loss, eye health or being newly diagnosed with a sight condition. It is produced by RNIB in partnership with many other sight loss organisations. **sightadvicefaq.org.uk**

Other useful contacts

Nystagmus Network

6 Lancaster Gardens
Kingston upon Thames,
KT2 5NL

01427 718093

info@nystagmusnet.org

nystagmusnetwork.org

IN-vision

47 Hillside Road
Marlow, Bucks SL7 3JX

info@in-vision.org.uk

in-vision.org.uk

Down's Syndrome Association

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

0333 1212 300

downs-syndrome.org.uk

info@downs-syndrome.org.uk

Albinism Fellowship

PO Box 2535 Ilford IG1 8NY

07946457979

info@albinism.org.uk

albinism.org.uk

Aniridia Network UK

22 Cornish House

Adelaide Lane

Sheffield S3 8BJ

07792867949

info@aniridia.org.uk

aniridia.org.uk

Macular Society

PO Box 1870

Andover, SP10 9AD

0300 3030 111

help@macularsociety.org

macularsociety.org

Retina UK

Wharf House

Stratford Road

Buckingham MK18 1TD

0300 111 4000

info@RetinaUK.org.uk

retinuk.org.uk

Driver and Vehicle

Licensing Agency (DVLA)

Drivers' Medical Enquiries

Swansea SA99 1TU

0300 790 6806

dvla.gov.uk

RNIB Booklet Series

About the Starting Out series

Essential information about living with sight loss.

Titles include:

- Benefits, Concessions and Registration
- Emotional Support
- Help from Social Services
- Making the Most of Your Sight

About the Confident Living Series

Information to build confidence and independence. Titles include:

- Reading
- Shopping
- Technology
- Travel

About the Understanding Series

More about your eye condition. Titles include:

- Age Related Macular Degeneration
- Cataracts
- Dry Eye
- Diabetes Related Eye Conditions including Diabetic Retinopathy
- Glaucoma
- Nystagmus
- Retinal Detachment
- Inherited Retinal Dystrophies including Retinitis Pigmentosa
- Posterior Vitreous Detachment
- Visual Hallucinations – Charles Bonnet Syndrome

For audio, print or braille versions of these booklets please contact our Helpline or visit **shop.rnib.org.uk**

For a list of information sources used in these titles and to provide feedback on the Starting Out and Confident Living Series, email **ckit@rnib.org.uk**.

We value your feedback

You can help us improve our information by letting us know what you think about it. Is this booklet useful, easy to read and understand?

- Is it detailed enough or is there anything missing?
- How could we improve it?

We would also like your views on the pictures and diagrams, are they appropriate, helpful and are there places where a diagram might have helped?

Send your comments to us by emailing **eyehealth@rnib.org.uk** or by writing to:

**Eye Health Information Service
RNIB
The Grimaldi Building
154A Pentonville Road
London N1 9JE**

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:

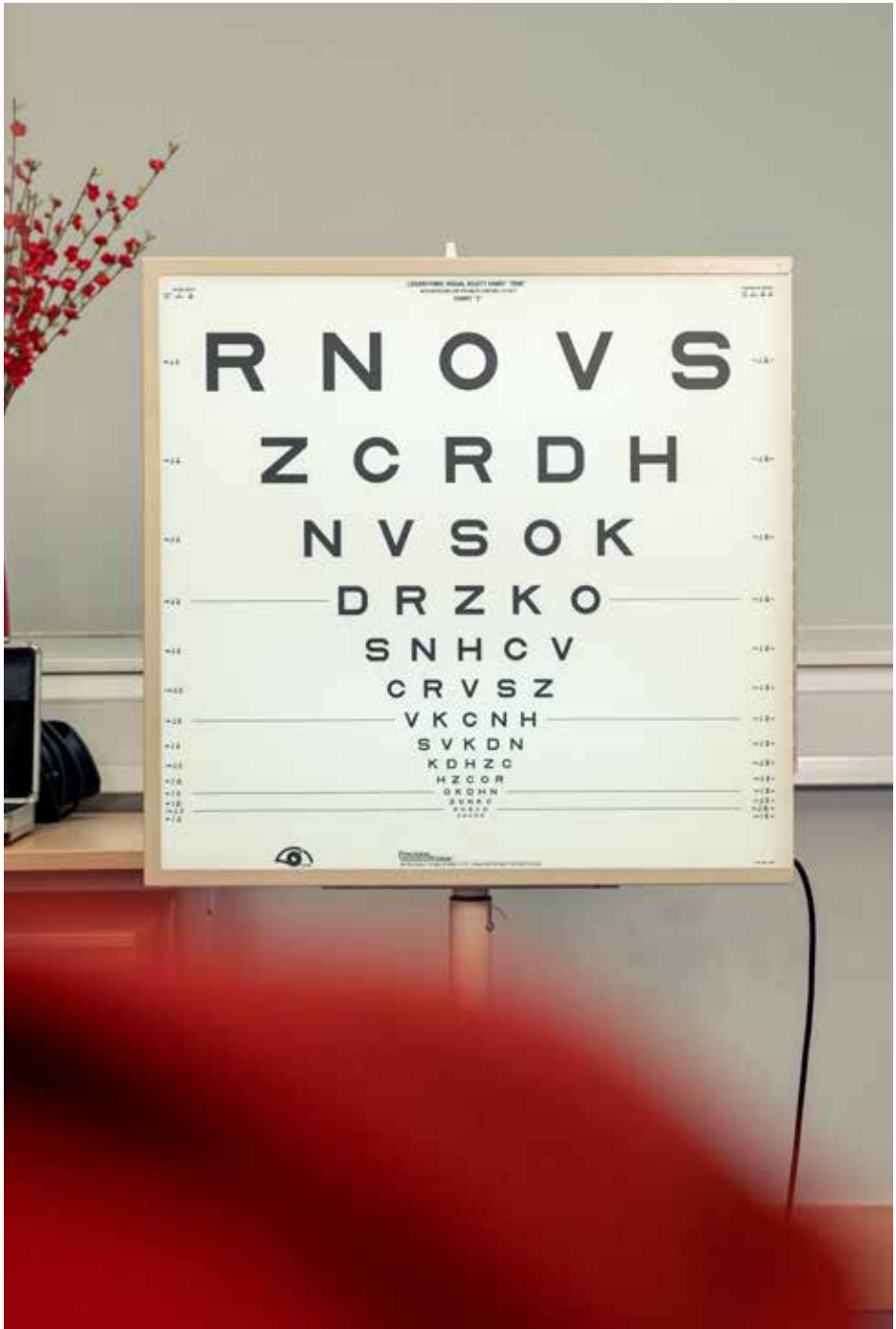
- The Royal College of Ophthalmologists' guidelines for treatment
- clinical research and studies obtained through literature reviews
- specific support groups for individual conditions
- medical textbooks
- RNIB publications and research.

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



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Sight Advice FAQ: **sightadvicefaq.org.uk**

This booklet has been produced jointly by RNIB and The Royal College of Ophthalmologists.

RNIB is a member of the Patient Information Forum (PIF) and have been certified under the PIF TICK quality mark scheme.

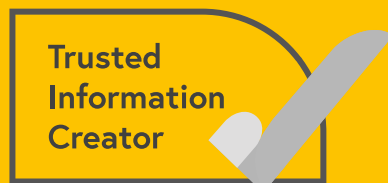
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