

Nystagmus Information Pack



Part 2. Infantile nystagmus

INFANTILE NYSTAGMUS

What are the causes of infantile nystagmus?

Infantile nystagmus can be caused by a problem with the eye or with the visual pathway, the nerves between the eyes and the parts of the brain used for seeing.

A person with infantile nystagmus may have other eye conditions that also affect their vision, for example:

- cataract (cloudiness of the lens inside the eye)
- glaucoma (pressure within the eye that is too high, which can damage the structures within the eye)
- albinism (an inherited condition characterised by a lack of coloured pigment in some parts of the body)
- a condition affecting the retina (the light sensitive layer at the back of the eye)

These eye conditions can lower the amount of visual stimulus the eye and the brain receive and can contribute to the individual's overall reduced level of vision.

Recent research has been investigating the genetic causes of infantile nystagmus. The gene FRMD7 has been associated with infantile nystagmus. A genetic test may be offered to help diagnose this type of nystagmus, reducing the amount of additional diagnostic tests needed to exclude other eye conditions and diseases.

Up to 50% of people with infantile nystagmus do not have a detectable eye, brain or other health problem and are therefore diagnosed with 'infantile idiopathic nystagmus'. Idiopathic means 'of no known cause'.



The
University
Of
Sheffield.



British and Irish Orthoptic Society



Nystagmus Network

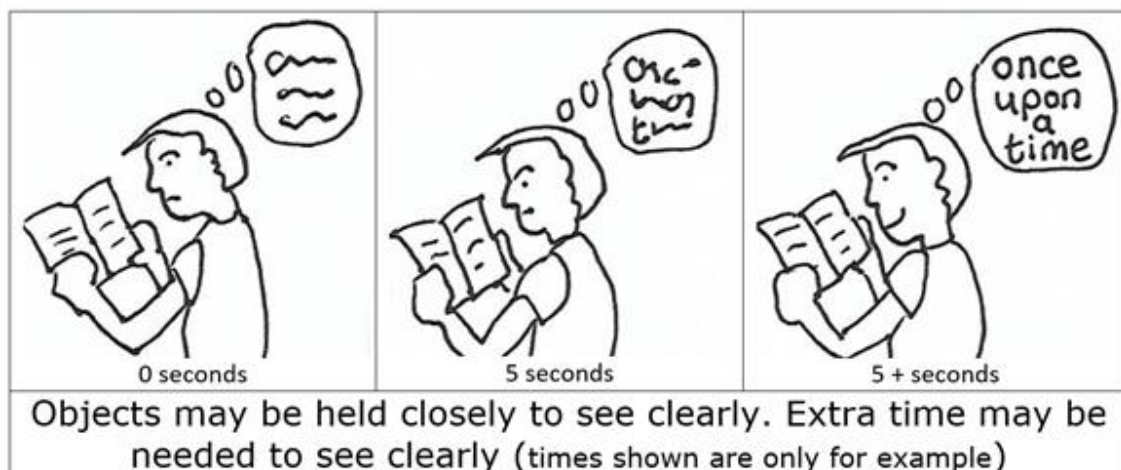
This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

What effect can infantile nystagmus have?

If a person has infantile nystagmus, they usually do not see the world constantly moving (oscillopsia) because their brain has adapted to their eye movement. His or her level of vision is typically reduced compared to someone without nystagmus. However, some people may notice oscillopsia at times, for example when looking in a certain direction or in some lighting conditions. Every person's nystagmus is different and the impact of infantile nystagmus on an individual varies greatly. Some people will have additional eye conditions, as well as their nystagmus, which additionally reduce their vision.

Commonly nystagmus causes vision to be reduced when measured using clinical vision tests, but it can also cause other problems that may be less easy to measure. For example, nystagmus can lead to:

- needing more time to see and react to things



- difficulty focussing on something once located
- difficulty seeing movement or judging distances

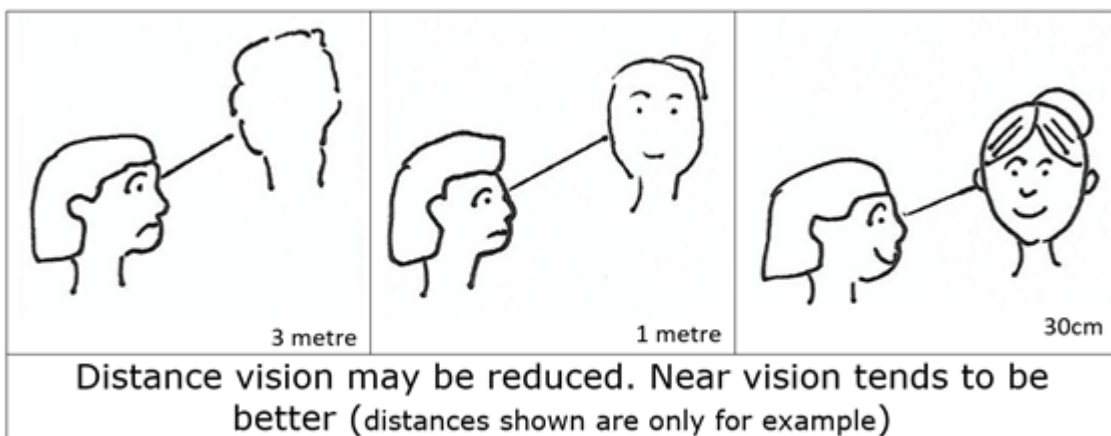


The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

- needing more time to complete reading or writing tasks
- difficulty dealing with visually crowded scenes
- difficulty seeing in bright or poor light
- reduced peripheral vision (field of vision) and depth perception
- some balance problems, particularly in unfamiliar environments



A big factor to consider is the variability of nystagmus. It can worsen when a person is tired, hungry, in different lighting, anxious, feeling unwell, stressed, excited or using some medications. This variability means the effect of the nystagmus on vision also varies. For example, if the nystagmus is worse when the person is tired and unwell, their vision will also be worse.

Living with infantile nystagmus

Lots of people with infantile nystagmus adapt by holding their head in positions that help them see more clearly. This often



The University Of Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

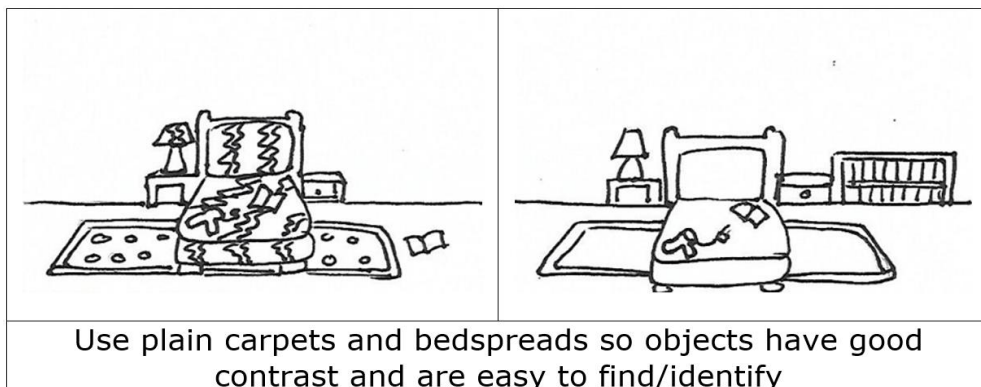
reduces the amount the eyes wobble and is called the 'null point'. Some people may shake their head or nod to compensate for their nystagmus.

Objects, images and printed material may be held at specific distances, directions or very close to the eyes. This shouldn't be discouraged as this is usually done to achieve better vision.

Children with nystagmus may take a little longer to take their first steps or ride a bicycle without stabilisers. Adaptations can be made to support individuals with nystagmus, suggestions include:

Using colour and contrast

- Increasing the contrast between doorways, handles and stairs



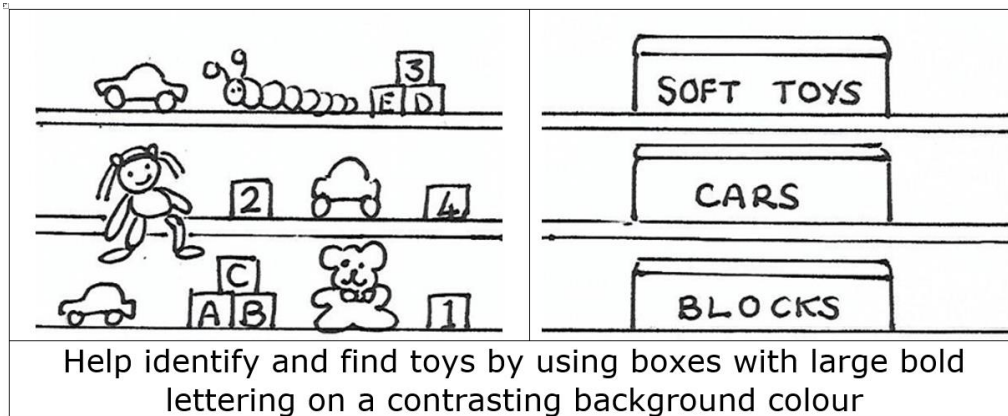
- Using different colours and contrast on computer screens and on reading materials



The
University
Of
Sheffield.

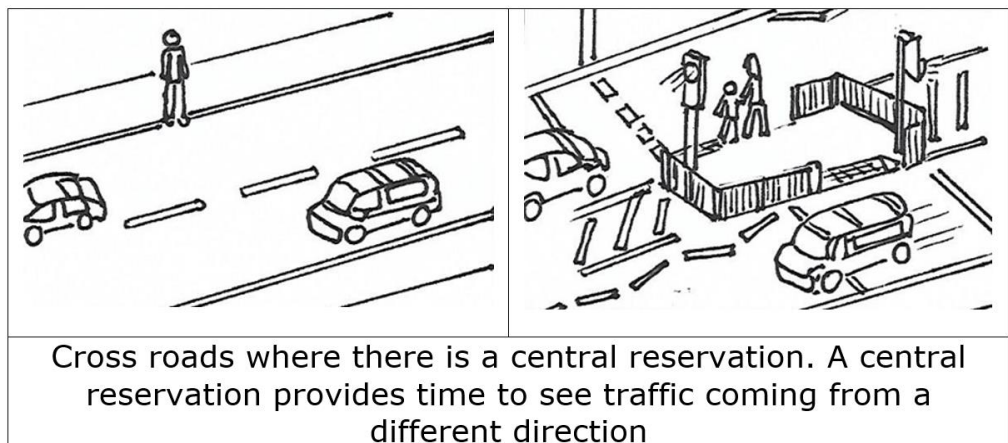


This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.



Navigation and mobility

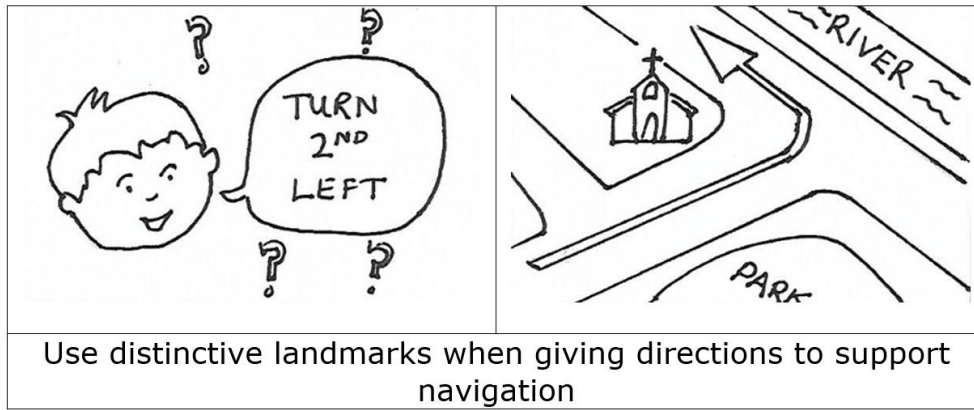
- Practising walking to school or work to increase familiarity and confidence with specific routes and to know where it is safe to cross roads to gain more independence. Practise during quieter times of day to build confidence.



The University Of Sheffield.



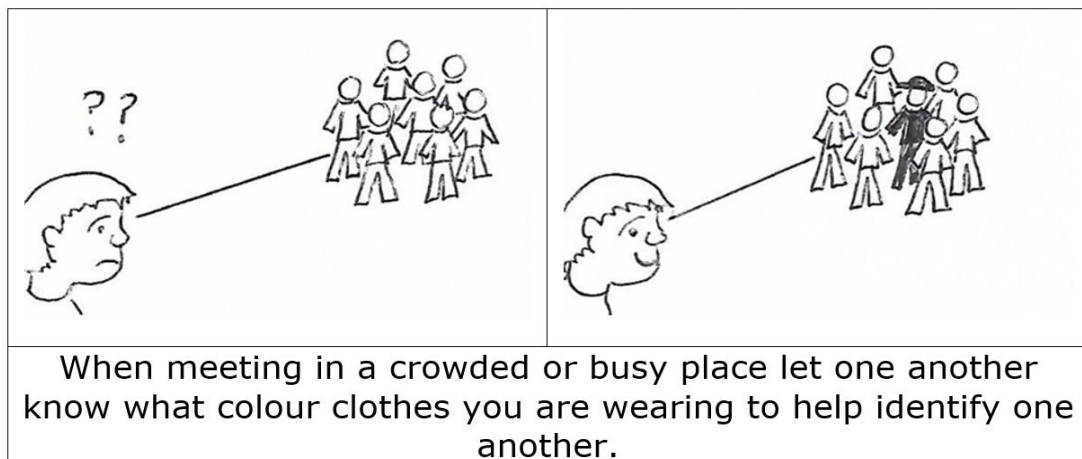
This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.



- Orientation and mobility training, if required, should be provided by a suitably qualified practitioner. This is often accessed through your local social services team or sensory impairment team. This training helps teach safe, efficient and effective travel skills to people of all ages.

Socialising

- When meeting in a crowded or busy place let one another know what colour clothes you are wearing to help identify one another. Well-lit environments are important.



The University Of Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

- Introduce yourself or ask others to introduce themselves to you. Nystagmus affects the time to see and distance vision, therefore faces may not be recognised quickly as you approach someone.

Technology

- Static and mobile devices increasingly have accessibility options to increase the size, contrast and magnification of text to suit the needs of the user.
- Mobile devices can be tilted or have different screen covers to decrease glare and aid vision.
- Taking pictures with a mobile device, for example a picture of a signpost can be enlarged to help read it.
- Some mobile devices offer a “tap to talk” option which converts text to speech. Apps and software which convert pictures of text into speech are available.
- Using a mobile device with GPS technology to provide audio support when navigating unfamiliar environments. Smart watches can be useful for providing immediate access to directions in a familiar way.

Sport

Mainstream sports can be enjoyed or may be a challenge depending on a person's level of vision and whether they have difficulties with other aspects of their vision, for example depth and motion perception. When playing sports or being active, individuals with nystagmus may make adaptations such as using



The
University
Of
Sheffield.



British and Irish Orthoptic Society



Nystagmus Network

This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

a different head position or using colour and contrast to help them identify items more easily.

There are also lots of different sports that can be adapted for individuals with significantly impaired vision, including golf, tennis, athletics, football, judo, archery, cricket, snowsports and ten-pin bowling. There are also sports like goalball that have been developed specifically for people with visual impairment and fully sighted players wear restricted vision glasses to be able to play.

Education

Most children with infantile nystagmus attend mainstream education. Many go on to university and lead independent lives. Reduced vision due to nystagmus or needing extra time to read because of nystagmus are classed as a sensory need and additional support as part of the Special Educational Needs (SEN) support should be provided in the early education setting, school, or college. You may find it useful to ask your hospital for a letter to explain to the teacher what nystagmus means for your child and what should be put in place. Example letters are available in part 7 of this pack.

There are two important professionals you may come into contact with at school:

- The Special Educational Needs and Disabilities Coordinator (SENCO) who will work with parents to develop and implement a support plan
- Qualified Teacher of the Visually Impaired (QTVI) who is a specialist teacher who provides advice and support for



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

children who are visually impaired. The QTVI works in partnership with families and schools to ensure a child's needs are fully met.

You should be contacted by, or you can contact, your child's SENCO and together a SEN support plan should be developed. The school is responsible for keeping you up to date with the plan and your child's progress throughout the school year.

Young people aged 16 to 25 are fully involved in designing their own SEN support and provision.

As nystagmus affects children and their vision differently each SEN support plan should be tailored to the individual. Support may include:

- Extra help from a teacher or a learning support assistant
- Working with your child in smaller groups
- Having larger format books
- Making or changing materials and equipment. Teachers are required to adapt materials such as using contrasting colours for paper and whiteboard, and enlarging print if required.
- A special learning programme for your child

As nystagmus can worsen when a child is tired, anxious, unwell, hungry, stressed or excited, the need for sensory breaks should be discussed. The use of technology and other adaptations in the classroom should be discussed. For example, a child may have a screen or device displaying work from the board next to them



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

in lessons to avoid the need for them to constantly switch focus from the whiteboard to their work.

The Department for Education has released a useful guide for parents and carers describing the support system for children and young people with special educational needs and disabilities which is available at:

<https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities>

If more support is required than provided by SEN support, an Educational, Health and Care (EHC) plan can be applied for through your local authority. A request can also be made by anyone else who thinks an assessment may be necessary (including doctors, health visitors, teachers and parents). The EHC is a statutory assessment and your local authority is required to carry out the assessment in accordance with the Children and Families Act (2014). Details of the EHC are available in the Department for Education booklet detailed above.

The Independent Parental Special Education Advice (known as IPSEA) is a registered charity which provides free and independent legally based information, advice and support to parents who are thinking about or have applied to their local authority for an EHC.

www.ipsea.org.uk

The charity Nystagmus Network provides information booklets for teachers and can provide training for school staff to better



The
University
Of
Sheffield.



British and Irish Orthoptic Society



Nystagmus Network

This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

understand nystagmus and how to adapt their lesson materials to ensure they are making learning accessible to children with nystagmus.

<http://nystagmusnetwork.org>

Driving

Depending on a person's vision (measured on a clinical vision test) and their peripheral vision (visual field), some people with nystagmus may meet the legal requirements for driving. However, you must inform the DVLA if you have nystagmus.

<https://www.gov.uk/driving-eyesight-rules>

Employment

Sight loss and impaired vision are considered a disability under the Equality Act (2010). Employers are not allowed to discriminate against someone based on their disability. Practical and financial support is available to sight impaired individuals in work or starting a new job via the 'access to work' scheme. The scheme can help by providing different visual aids, equipment, support workers and travel to work.

<https://www.gov.uk/access-to-work>



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.