

**Nystagmus** *Network*®

# Nystagmus booklet for teachers

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The Nystagmus Network is a registered charity  
in England and Wales, number 1180450.  
To make a donation, please visit [CAF Donate](#).  
Thank you

Even though nystagmus is the most common form of vision impairment seen in school aged children, you may not have had a child with nystagmus in your class before. Even if you have, no two cases of nystagmus are ever quite the same.

The Nystagmus Network is here to help you understand their needs and provide support.

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# Introduction

This booklet provides an introduction to nystagmus and the impact the condition can have on a child and their education.

The Nystagmus Network is a UK registered charity providing support and information about the eye condition, nystagmus. The charity was established in 1984. We support people living with nystagmus and the professionals working with them. We also promote a better understanding of the condition. Through the charity's extensive involvement in research we are moving closer to finding effective treatments.

This booklet focuses on what nystagmus is and how it affects a child's vision and their access to learning. It also contains practical advice for teachers to enable them to help children make expected progress at school.

The Nystagmus Network works closely with QTVIs (Qualified Teachers of Visually Impaired children and young people) and VIEW, the national body for QTVIs. We also provide telephone support and free to download information for parents via our website.

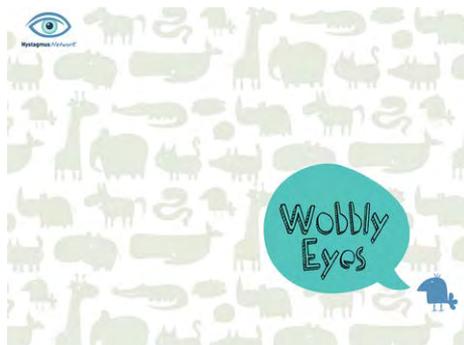
**If you would like more information or training on nystagmus and how it affects access to learning, please contact us.**

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# What is nystagmus?

If a teacher has a child with nystagmus in their class it can make a real difference if they understand the impact the condition can have on their access to learning.

Nystagmus is a complex eye condition characterised by involuntary movements of the eye, where they appear to wobble or flicker from side to side, up and down or round and round. Some children with nystagmus have a null point, the position where their eyesight is at its best. This means they need to turn their heads at an angle to see.

Nystagmus is caused by abnormal functioning of the part of the brain which regulates eye movement and positioning. It has an incidence rate of at least 1 in 1,000 people in the UK and is the most common form of visual impairment in school aged children.

Nystagmus can seriously impair a child's vision. It does not affect the ability to learn, but it does impact the way they access learning. Children can and do, with the right support, make expected progress and go on to achieve their full potential in the classroom and on the sports field.

The impact of nystagmus varies greatly from one child to another. Some are just a little short sighted and have difficulty focusing. Others are registered sight impaired or severely sight impaired. The majority of children with nystagmus have poor distance vision. Glasses or contact lenses can help, but do not correct the nystagmus.

**“My nystagmus never really caused me any problems, but when I started school lots of people asked why my eyes were moving. At first I found this difficult, but the school really supported me.”**



Children with nystagmus may wear glasses to correct long or short sight and astigmatism. Some may have impaired colour vision due to other eye conditions. Most children with nystagmus experience a degree of light sensitivity and the eyes need to be protected from sun and artificial light.

Despite the nystagmus causing eye movements, most children with the condition see a stable image. The amount of eye movement is not necessarily related to how well or badly they can see. A child may need to get very close to a document when reading. This may look uncomfortable, but it is normal. Sharing books or screens is not possible.

Although some students with nystagmus may be able to read normal sized print, they will need adapted materials for sustained periods. Reading can be very tiring because of all the additional time and effort involved in focusing, so large, clear print is helpful. Children with nystagmus also find that their vision changes throughout the day. It will worsen when they are tired, stressed, unwell or hungry.

Depth and distance perception and peripheral vision are compromised by nystagmus, which means that some children have difficulty with mobility, appear uncoordinated and find ball sports challenging. Clearly marked courts, larger, brighter coloured balls or balls with sounds can help.

## Social impacts of nystagmus

Nystagmus brings social and emotional challenges as well as limiting vision. Holding eye contact and reading facial expressions is difficult, making social interaction awkward. This can easily be mistaken for shyness, rudeness or inattention. Nystagmus can cause frustration which can, in turn, lead to behavioural issues. Having unusual eye movements and perhaps a head turn or nod can be just as problematic for a child as poor vision, because their condition makes them stand out from their peers. This can make children with nystagmus vulnerable to teasing and bullying. Any bullying needs to be reported early and addressed quickly so that it does not cause further damage to the child's self-esteem. Difficulties with social interaction due to nystagmus can sometimes be mistaken for ADHD or Dyspraxia. Please beware of potential misinterpretations and falsely labelling a child.

# Effects of nystagmus

Nystagmus can have a number of different effects on a child, any of which can have an impact on them at school.

Pupils with nystagmus need support at school. They should be encouraged to say when they cannot see something and to ask to sit at the front of a class or in a particular spot depending on their null point. Some of the challenges they may have at school are:

- **Slow to see** - They need more time to see what they are looking at, to process it and to respond
- **Switching focus** - It is particularly difficult to change focus repeatedly, such as when copying from the board into an exercise book
- **Visual fields** - The null point indicates a reduced field of vision, so a pupil with a null point to the right may not see objects or people to the left
- **Mobility** - Children with nystagmus struggle with fast moving ball sports as they cannot always judge distances and speeds. Because of compromised depth perception they may be at greater risk of accidents in crowded corridors and on stairs.

## **Nystagmus Awareness Day**

The Nystagmus Network raises awareness every day of the year, because we believe that the more people who know about it the better. We also celebrate national and international Nystagmus Awareness Day every year on 20 June.

Schools can take part, too.

**Find out more here**

“What does my student mean when she talks about her null point and needing to sit in a certain position?”

The null point is a direction of gaze where vision is at its clearest.

The direction a student's head is pointing may suggest they are looking out of the window when in fact they are focusing their eyes intently on the teacher, their task or the whiteboard .

# How to support children with nystagmus?

There are various strategies a teacher can implement in the classroom to support a child with nystagmus to have equal access to learning.

To ensure a student with nystagmus has equal access to the full school curriculum, despite their visual impairment, they may need adapted materials, additional time to complete tasks and the support of a teacher who understands their needs. Schools can subscribe to large print book services, such as Book Share, to access large print and modified versions of all school text and story books. Additional support includes:

- Low Vision Aids - Children can be encouraged to try a full range of magnifiers and tactile equipment. Bar magnifiers, especially if they have a coloured line in them, and slotted cards are useful when reading print whilst dome magnifiers are useful in maths.
- Technology - Students will learn quickly to adapt screens to meet their needs and having their own hand-held device will avoid difficulties seeing the board and switching focus.



- Extra time - Students with nystagmus are entitled to extra time in school and public assessments to compensate for the 'slow to see' element.
- Sporting challenges - Many students with nystagmus have reduced hand eye coordination, peripheral vision, depth and speed perception, but larger or brighter coloured balls and court markings will help.
- Education and Health Care Plans Children with nystagmus are entitled to assessment for an Education and Health Care Plan, particularly if they are registered sight impaired or severely sight impaired.
- Work sampling - Completing the key questions in an exercise rather than all of them is useful, provided the learning points are covered
- Encouraging responses - As children with nystagmus have problems seeing faces, teachers can help by saying the child's name to get their attention before addressing them.
- Inclusion - Headaches and tiredness can be due to the sheer effort of reading; reluctance to join in may be due to fear of teasing or not being able to tell when it's their turn; challenging behaviour may arise from frustration at not being able to complete tasks on time.

## Normal way of working

If your pupil with nystagmus needs adapted materials and extra time in exams and tests, these should also be available every day in the classroom.

## Time

Time out, regular breaks and extra time can help mitigate against impatience, tiredness and frustration provided this does not impact on break time and precious socialising opportunities.



**To receive regular updates, information and support from the Nystagmus Network please email [info@nystagmusnet.org](mailto:info@nystagmusnet.org) and ask to be subscribed to our teachers' newsletter**

# Stories from school

Children who have nystagmus all have different experiences at school. They all need your continued support.



"I've always loved stories, but because of my nystagmus I struggled to read when I first started school. Now I've got a degree in philosophy and I work in communications!"

"Our son gets frustrated when he can't complete a task in the time allowed. It can lead to temper tantrums and excessive tiredness. We've found that if the teacher lets him take regular time out he can cope much better."



"I had never taught anyone with nystagmus before, but I found the parents were really well informed thanks to the Nystagmus Network. I met with them or called them every week until we all felt we had a plan for how I could best support their child in class."



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The Nystagmus Network relies entirely on membership subscriptions, fundraising and donations to continue its important work, providing support and information to the nystagmus community, raising awareness and funding research.

If you have found this free document useful, please consider making a donation to the charity today through CAFDonate. Thank you.

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