



**Nystagmus** *Network*

# Nystagmus booklet for teachers

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The Nystagmus Network is a registered charity in England & Wales - 803440



# Introduction

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

This information booklet is part of an information pack created by the Nystagmus Network to help teachers become better informed about nystagmus in children.

The Nystagmus Network is the oldest charity in the UK providing support and information about nystagmus and visual impairment. The charity was established in 1985 and has been at the forefront in supporting people affected by the condition whilst also promoting a better understanding of nystagmus. 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. It also contains practical advice for teachers to enable them to help children reach their potential in the school environment.

If a student's parent would like information about nystagmus a teacher can direct them towards the Nystagmus Network. The charity has extensive information produced specifically for parents.

If teachers would like more information about nystagmus, they can contact

us directly. The charity also has representatives who can give advice on supporting a student with the condition, including strategies to overcome various common challenges reported by other educational professionals.

## "How do I contact the Nystagmus Network?"

The Nystagmus Network can be contacted by email, phone, mail and the majority of social media websites. Contact details can be found on the back of this booklet. The charity can provide teachers with further advice on supporting a child with nystagmus.



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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 them at school.

Nystagmus is a complex eye condition characterised by involuntary movements of the eye where they appear to wobble or flicker from side to side or up and down. Many children with nystagmus have what is called a null point, the position where their eyesight is at its best. This means they often 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 1 in 1,000 people in the UK and is the most common form of visual impairment in school aged children.

Although nystagmus is not usually a degenerative condition, it can seriously impair a child's access to learning. However, it does not affect the intellect and children can, with support, achieve their full potential in the classroom and on the sports field.

The impact of nystagmus varies greatly from person to person where some are just a little short sighted and have difficulty focusing while others are registered sight impaired. The majority of children with nystagmus have poor distance vision and glasses or contact lenses cannot correct this.

However, they may wear glasses to correct long or short sight and astigmatism. Some

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



children may have impaired colour vision due to other eye conditions. Most children with nystagmus will experience some degree of light sensitivity.

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

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

Depth and distance perception are compromised by nystagmus, which means that some children will have difficulty with mobility, appear uncoordinated and find ball sports challenging. Depth and distance perception are compromised by nystagmus, which means that some children will have difficulty with mobility, appear uncoordinated and find ball sports challenging.

## Social impacts of nystagmus

Nystagmus also brings social and emotional challenges as well as limiting vision. Holding eye contact and reading facial expressions is challenging and can make social interaction awkward. This can easily be mistaken for shyness, rudeness or inattention. In addition, nystagmus can cause frustration that can in turn lead to behaviour issues. Having unusual eye movements and perhaps a head turn or nod can be just as damaging to a child as poor vision because their condition makes them stand out in a crowd.

The social and emotional impact inside and outside the classroom needs to be taken into account at school as a child with a lot of eye movement or a marked head turn is often vulnerable to teasing and bullying by their peers. Any bullying needs to be addressed quickly so that it does not cause further damage to a child's self-esteem. Difficulties with social interaction due to nystagmus can sometimes be mistaken for ADHD or Dyspraxia.

# The effects of nystagmus

Nystagmus can have a variety of different effects on a child with nystagmus which can have an impact on them at school.

It is important that students with nystagmus get 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 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 which then leads to their response times being slower.
- Switching focus - It is particularly difficult to change focus repeatedly so copying from the board to an exercise book will be much more challenging.
- Visual fields - The null point indicates a reduced field of vision. A student with a null point to the right will see less well to the left, so will not necessarily see friends, teachers, activities in that gaze direction.
- Mobility - Children with nystagmus have difficulties 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 corridors and on stairs.

“What does my student mean when they talk about their null point and needing to sit in a certain position?”

The null point is a direction of gaze where the eyes move least and it is the position where vision is at its clearest for a child. The direction a student's head is pointing may suggest they are looking out of the window when in fact they are looking intently at the teacher or white-board as this is the position where their vision is at its best.

# How to support children with nystagmus?

There are various strategies which a teacher can implement in the classroom to help a child with nystagmus.

To ensure that 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 to access large print and modified versions of all school textbooks. Additional support can include:

- 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, are useful when reading books while dome magnifiers are useful in maths.
- Technology - Students will learn quickly to adapt screens to meet their needs and having their own handheld device will avoid difficulties seeing the board and switching focus.





- Extra time - Students with nystagmus are entitled to 25% extra time in school and public assessments to compensate for the extra time needed to read the questions.
- Sporting challenges - Many sports are a problem for students with nystagmus due to reduced hand eye coordination, problems with depth perception, difficulty in seeing fast moving objects and limited distance vision.
- Education & Health Care Plans - Children with nystagmus whose visual impairment compromises their access to the full school curriculum are entitled to assessment for an Education and Health Care Plan, particularly if they are registered sight impaired or severely sight impaired.
- Encouraging responses - As children with nystagmus have problems recognising facial expressions, teachers can help by saying the child's name to get their attention before instructing them.
- Potential behavioural problems - It is not always easy to separate difficult behaviour and personality issues from problems caused by nystagmus, especially in a young child. Bad tempers can be the result of frustration at not being able to see to complete a task quickly enough. Headaches and tiredness can be due to over-exertion at reading and reluctance to join in may be due to fear of teasing.



# Educational stories

Children who have nystagmus all have different experiences of their time at school. Students with nystagmus need your continued support for as long as they are at school.



"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!"

"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 best I could support their child in class."



