Nystagmus and education

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

This booklet provides an overview on education and nystagmus with information on choosing a school and the services which an educational setting should provide.

This is an information booklet for parents of children with the eye condition nystagmus. It is part of a “Parents Pack” created by the Nystagmus Network to help parents become better informed about their child’s condition.

The Nystagmus Network is the oldest charity in the UK providing support and information about the eye condition nystagmus. The charity was established in 1985 and has been at the forefront in supporting people who are 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 particular booklet focuses on education and nystagmus. It contains practical experiences of other parents, advice on choosing a school for a child who has nystagmus and the support services a parent should expect from a school in England.

The additional booklets in the “Parents Pack” cover a variety of subjects, including what the condition is, diagnosis, social implications and how a parent can support a child with nystagmus. It is hoped that these documents will empower both the child and their parents to ensure they are well equipped to cope with the condition and to overcome any problems they may encounter due to nystagmus.

The Nystagmus Network is available to be contacted by anyone affected by nystagmus, their family or anyone involved in supporting someone with the condition. The charity has a variety of documents that can be easily downloaded on a variety of subjects relating to nystagmus.

“How do I contact the Nystagmus Network?”

The Nystagmus Network is available to be contacted by email, phone, mail and the majority of social media websites. These contact details can be found on the back of this booklet and the charity can provide a family with further advice on living with nystagmus.
How do I choose a school?

Choosing a school is an important decision that parents who have a child with nystagmus must make.

When a child is diagnosed with a visual impairment, most parents are concerned about the impact this may have on their education. The majority of children with nystagmus learn to read and write alongside their peers in mainstream schools, although they may need support to access the full curriculum. Fortunately, there is a lot of help available to them within the educational system in England.

Children coming into an education setting with a recognised visual impairment, such as nystagmus, are automatically entitled to some level of support. Teachers are required to provide adapted materials and the child will be allocated additional time to complete assessments and tests. Government legislation in the form of the Children and Families Act 2014 provides for SEN Support in England. For a child with vision impairment, the SEND Code of Practice says a qualified teacher of children with vision impairment (QTVI) should be involved.

When a baby is diagnosed with nystagmus, their parents should be put in touch with the sensory impairment team. If this does not happen, parents can contact them directly where they will be able to discuss their child’s education. Your Local Authority publishes a Local Offer online which gives details of all the support and resources expected to be available to them.

“I was nervous when he started school, but the teachers were amazing and made me feel at ease after his first day.”
Choosing a school for a child is a very important decision for a parent, regardless of whether they have nystagmus or not. To help make this decision, parents can do their own research by looking through potential school websites, prospectuses, exam results such as SATS and GCSEs, and Ofsted reports. For children with nystagmus it is important that parents review the SEND (Special Educational Needs and Disabilities) school information report to see what kind of support the school offers for children with visual impairment. Parents are also advised to speak with the school SENCo (Special Educational Needs Coordinator) as they are an individual the child may have regular contact with.

When a child is not making expected progress, despite SEN Support, parents should consider an EHC plan. An EHC plan is a legal document that describes a child or young person’s special educational, health and social care needs and provision. An EHC plan should be focused on the outcomes a child is expected to achieve.

The plan must be reviewed at least once a year and this is a chance for everyone involved in supporting a child to check how well they are progressing and whether anything needs to be changed. At the end of the review the local authority may make changes to the plan, end it or leave it unchanged. An EHC plan runs from birth to age twenty five or the local authority decides that a child no longer needs the plan to help them in their education.
Who is a QTVI?

A Qualified Teacher of the Visually Impaired (QTVI) is a specialist teacher who provides advice and support to children who are visually impaired. QTVIs hold a specialist mandatory qualification (MQ) which is based on a wide range of learning outcomes set out in a national specification.

In a child’s early years, QTVIs provide direct support to babies and young children with vision impairment and their parents in the home to support early development and learning through play and to promote parental confidence.

At school a QTVI will assess a child’s vision and provide information and advice to the school about the implications specific eye conditions, like nystagmus, can have on an individual’s learning.

The QTVI will also give advice and training to school staff to ensure that a child with nystagmus has access to the curriculum, and that they are appropriately supported within the classroom and school environment. One of the main roles of a QTVI is to work in partnership with schools to ensure that the needs of a child are fully met.

“Once my child’s teacher understood that nystagmus could lead to some social issues, he felt much better supported.”

If a teacher or a school is unfamiliar with nystagmus they may sometimes confuse a child’s behaviour related to their nystagmus, with that associated with another disorder. The social and emotional aspects of the condition need to be understood by a child’s teachers so that any issues that may arise can be dealt with accordingly.

QTVIs are employed by the Local Authority and will be available to help a child with nystagmus during their time in full time education.
Is there support for children at school?

Every school in the UK must provide an adequate level of support for a child affected by nystagmus. This can include practical, emotional and social support.

There are many initiatives that a school can provide for a child with nystagmus to help them during lessons. Most of these will be suggested by the QTVI but a parent may find that suggesting some of the following will help a child in school:

- **Printed materials** - Every child with nystagmus will have a different preference when it comes to printed materials. Most can read enlarged print, provided it is an original print out and not simply something that has been blown up on the photocopier such as to A3 size.

- **Large print text books** - Schools can subscribe to a catalogue of large print versions of all text books related to the national curriculum in both a print and digital format.

- **Large format exercise books** - For writing a school can provide books with bold, wide lines and bold graph paper.
• **Computer screens** - Children with nystagmus become adept at adjusting screen brightness, colour and contrast to enable them to read text and see detailed images.

• **Whiteboards** - The colour and thickness of the pen a teacher uses to write on a whiteboard can have a significant impact on how well a child with nystagmus can read it. If there is a bright artificial light or sunlight shining on to the board this will make it more difficult for a child to read. Interactive whiteboards tend to get very busy and full of icons and many schools are using technology to mirror what is on the whiteboard onto an iPad or tablet for the VI child at his or her desk.

• **Exam papers** - As well as being entitled to extra time in all public assessments and examinations, a school can request adapted examination papers with text in a larger font size and simplified diagrams, printed on the colour of paper a child prefers.

Support services available to children continue as they transition into secondary education. Children with an EHC Plan in place will have this transfer to their new school where it will be reviewed and updated according to their secondary education. An EHC Plan does not cover university, but universities are similarly well set-up for the visually impaired, where there is support and funding available for equipment.
Every child with nystagmus who attends school has their own story. Some have encountered problems which they have overcome while others have been very well supported by the 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!”

“Add a diagnosis experience. Add a diagnosis experience. Add a diagnosis experience. Add a diagnosis experience. Add a diagnosis experience. Add a diagnosis experience.”

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