

Supporting A Child With Nystagmus

Information for patients, relatives and carers

① For more information, please contact:
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This is an information leaflet for parents and guardians of children diagnosed with nystagmus.

Contents	Page
What is nystagmus?.....	2
How can I support my child with nystagmus?.....	2
How do I talk to my child about their nystagmus?	3
What is an eye clinic liaison officer (ECLO)?.....	3
What is a qualified teacher of the visually impaired? (QTVI)	4
What local and national charities are available?.....	4
Tell us what you think of this leaflet.....	5
Patient Advice and Liaison Service (PALS).....	6
Teaching, training and research.....	6
Leaflets in alternative languages or formats.....	6

What is nystagmus?

Nystagmus is an eye condition where the eyes appear to wobble or flicker side to side or up and down, or a bit of both. It is caused by an abnormal functioning of the part of the brain that controls eye movements or underlying eye conditions. It occurs in one in 1,000 people in the UK. Although it is a lifelong condition, the impact it can have on an individual's vision varies greatly. Nystagmus cannot be corrected by glasses or contact lenses. Unfortunately, there is currently no cure for nystagmus.

How can I support my child with nystagmus?

Every child with nystagmus will vary in what they can see. Quality and clarity of vision is not necessarily related to the amount or speed of the nystagmus. Not all strategies will work for every child. Support can be both practical and emotional.

Low visual aids (LVA)

York and Scarborough Teaching Hospital NHS Foundation Trust has a LVA service for children. An appointment can be made with one of our opticians to discuss and try different magnifiers and telescopes for both home and school. These can be loaned out. Please ask your orthoptist about this service to see if your child may benefit.

Large / giant / audio print books

Large print refers to generally font size 16 to 18. Giant is anything greater. Enlarged print books can be purchased online from many websites such as Custom Eyes at Guide Dogs and The Large Print Book Shop. Many eBook readers let you enlarge the font to a size that suits you. You can access free eBooks online via Oxford Owls Home readers and Seeing Ear. The RNIB Bookshare has a wide variety of educational resources including eBooks, tactile images and music stave notations available. The service is available through the child's school gaining membership, this is free to do. The RNIB also have over 25,000 audio books available for download, on a CD, or on a USB stick.

Technology

The BBC 'My Web My Way' website provides step by step guides to adjust a computer or web browser to best suit your child. This includes changing the font, magnifying the screen, making the cursor and text larger as well as making your computer speak text aloud. Some children struggle with brightness, your computer, tablet, or phone will have a brightness setting which can be adjusted.

Tinted glasses

Some children with nystagmus also suffer from light sensitivity. They may benefit from tinted glasses, wearing sunglasses, or a peaked hat.

Surgery

Some children with nystagmus may have a 'null point' and turn their head to use this 'null point'. The null point is the eye position where the nystagmus is either absent or less noticeable, giving your child better vision. Your child may tilt or turn their head without realising to use the 'null point'. Not every person has a 'null point' and it can change as children get older. If your child must turn or tilt their head a lot to use the 'null point' we may consider surgery to their eye muscles to correct this.

How do I talk to my child about their nystagmus?

When and how you talk to your child about their nystagmus is a personal decision. It is helpful to get your child used to talking about their sight, especially for when they start school so they can answer any questions from their peers and feel confident in asking for help if required because of their vision. We recommend looking at the Nystagmus Network leaflet called 'Wobbly Eyes' available on the Nystagmus Network website for guidance on how to discuss nystagmus with your child.

What is an eye clinic liaison officer (ECLO)?

An ECLO works closely with hospital staff to provide practical and emotional support to patients and their families. They are based within the Eye Department. The service offers information about any aspects of sight loss, including managing reduced vision, financial benefits, certification and registration of a visual impairment, and the local and national community support options. Please ask your orthoptist for more information about the service or contact our ECLO directly on 01904 721858.

What is a qualified teacher of the visually impaired? (QTVI)

A QTVI is a specialist teacher who provides advice and support to children who are visually impaired. They are employed by the Local Authority. Not every child with nystagmus will be classified as visually impaired and therefore require a QTVI. QTVIs hold a specialist qualification allowing them to provide direct support to babies and children with vision impairments and their parents in the home to support early development and learning through play and to promote parental confidence. At school a QTVI will provide information and advice to school staff to ensure your child has access to the curriculum and that they are appropriately supported within the classroom and school environment. In York and the surrounding areas, a referral to the QTVI team must be made via the orthoptist or ophthalmologist that your child sees with your consent. We work together to ensure your child is best supported. If you feel your child may benefit from a QTVI and they have not yet been referred, please discuss this with us.

What local and national charities are available?

Wilberforce Trust / Club Wilber

Club Wilber is the children's section of The Wilberforce Trust charity. They are based in York and will provide support to children with visual impairment, their siblings and families from across Yorkshire aged 0 to 25 years. They host events which are all tailored to be friendly for those with visual impairment such as bowling, boat trips, Easter egg hunt, pizza making, farm trips and many more. They also provide free sensory sessions fortnightly for babies and children with fibre optic lights, musical toys, bubble machines etc. Free to attend. Please see www.wilberforcetrust.org.uk for more information.

Royal National Institute of Blind People (RNIB)

National charity providing support for parents and children with visual impairment. They provide advice on a wide variety of topics such as how to create a safe and fulfilling play environment for your child and accessing adapted books. They organise social events for children and young adults aged 0 to 25 years as well as parent sessions. They also provide a service where your child can receive a letter from Santa in their preferred format e.g. Braille, or large font. Please see www.RNIB.org.uk for more information.

Nystagmus Network

The largest national charity dedicated just to nystagmus. They provide many booklets free to be downloaded from their website which cover topics such as 'an introduction to nystagmus', 'nystagmus and education' and 'nystagmus and driving'. Please see www.nystagmusnetwork.org for more information.

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact: Eye Clinic, The York Hospital, Ophthalmology, telephone 01904 726749.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Leaflets in alternative languages or formats

Please telephone or email if you require this information in a different language or format, for example Braille, large print or audio.

如果你要求本資 不同的 或 式提供 , 電或發電

Jeżeli niniejsze informacje potrzebne są w innym języku lub formacie, należy zadzwonić lub wysłać wiadomość e-mail

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Owner:	Gemma Kane, Specialist Orthoptist
Date first issued:	November 2022
Review Date:	November 2025
Version:	1 (issued November 2022)
Approved by:	CG6 Ophthalmology Governance Group – November 2022
Document Reference:	PIL 1573 v1

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