

PATIENT INFORMATION**NYSTAGMUS**

WHAT IS NYSTAGMUS?

Nystagmus is a form of visual impairment. It is not painful and is characterised by an involuntary movement of the eyes, which often reduces vision. This movement is usually side-to-side but can be up and down. It may be noticeable at all times or only when the patient is tired or under stress. People with this condition may be partially sighted; some are registered blind and most encounter some difficulties in everyday life, both practical and social.

When Nystagmus occurs during the first six months of life this is called congenital Nystagmus. The condition may also develop later in life when it is termed acquired Nystagmus.

Nystagmus may be inherited or as a result of a sensory problem. In some cases, it occurs for no known reason. It can develop in later life, sometimes as a result of an accident or a range of illnesses, especially those affecting the motor system.

HOW COMMON IS NYSTAGMUS?

Current data estimates that between 1 in 1000 to 1 in 2000 people have Nystagmus but there are no accurate figures available.

IS THERE A CURE?

There is no known cure. It is involuntary eye movement, which cannot be corrected by wearing spectacles or contact lenses. However, if the patient is found to be longsighted, short-sighted or have astigmatism along with having Nystagmus then glasses may help the patient see more clearly.

GENERAL ADVICE

Nystagmus affects different people in different ways. While there are general patterns, good advice for one person may be inappropriate or even bad for another, especially where other eye problems are present. Vision can often vary during the day and is likely to be affected by emotional and physical factors such as stress, tiredness and nervousness.

HEAD POSITION

Many sufferers adopt a head turn or tilt in order to use the area of vision where the eye movement is decreased and the vision increased. A child with Nystagmus may turn their head to one side to make best use of their vision. They should be allowed to do this.

GOOD LIGHTING

This can improve the contrast of reading print. However, a small number of patients may be light sensitive so ask advice.

PRINT SIZE

Large print material should be available as this can help reading. Also holding books very close can help. Reading speed may be reduced because of the extra time required to scan words.

POSITIONING

- i. In the home - it may help to move certain things such as the television in order to optimise their vision and use of head posture.
- ii. Classroom - where they sit in the room may have an effect on how they see, by changing this it could improve their comfort and optimise their vision. Ask advice about how to help.

BALANCE

This may be affected due to poor depth perception, making people seem a little slower/clumsier than normal.

CONTACT INFORMATION

Nystagmus Network
6 Lancaster Gardens
Kingston upon Thames
KT2 5NL
Tel: 01427 718093
e-mail: info@nystagmusnet.org

Royal National Institute for the blind
Grimaldi Building,
154a Pentonville Road,
London,
N1 9JE
Tel: 0303 123 9999
Email: helpline@rnib.org.uk

Sight Concern
The Bradbury Centre,
2 Sansome Walk,
Worcester
WR1 1LH
Tel: 01905 723245

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.