

Nystagmus Information Pack



Part 7.

Information from people with nystagmus and their families.

Information about nystagmus for families, teachers and other professionals.

Example information sheets and letters.

INFORMATION FROM PEOPLE WITH NYSTAGMUS AND THEIR FAMILIES.

The following are common suggestions from people with nystagmus and their families:

When talking about nystagmus, for example at the eye clinic,

1. Take care in the choice of words when you are talking about or explaining nystagmus and other eye conditions – it will be a shock. Don't say a child can't see when they are actually visually impaired.
2. Avoid negativity – "can't be", "can't do" and "won't be" are viewed as unhelpful. Be honest yet positive.
3. Avoid difficult terminology – or use the useful terminology part of this guide to support understanding.

Ways to help improve the eye clinic experience:

1. If you need additional information from the eye clinic before your appointment, contact them to ask.
2. Think about questions that may be asked at eye clinic appointments in advance. This allows time to think about the questions and have discussions with others, e.g. teachers. Example questions are found later in this part of the pack.
3. Knowing in advance what is expected to happen at an appointment, including what the different eye care



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

professionals do and how long the appointment is expected to last. See part 4 of the pack.

4. Make sure you have directions to the department. Contact the eye clinic if these are required and haven't been provided.
5. Sometimes it is possible to see the same person at eye clinic appointments. If you feel this would be beneficial, you can ask at the eye clinic.
6. Sometimes it is possible to request a morning or an afternoon appointment. To find out whether this is possible, you can ask at the eye clinic.
7. Avoiding lots of medical terminology. Clinicians try to use non-medical words to explain eye conditions, but if you are unsure what something means, always ask.
8. Information (in an accessible format) about nystagmus and any other relevant eye conditions may be provided, if it isn't you can ask at the eye clinic. This may be a leaflet about nystagmus or it may be where you can find additional support and information.
9. Some parents find it helpful to have a letter explaining what nystagmus is and what that means for their child, that they can give to others, e.g. school teachers or nursery workers. See example letters below.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

Pre-eye clinic appointment questions for patients and families:

Many patients and their families find it useful to think about the questions that may be asked at the eye clinic in advance, to help them prepare and gather information. Example questions that might be asked are below:

1. Do you notice the eyes wobble? When did you first notice this?
2. Has anyone else noticed any eye problems, for example other family members or school?
3. Do you/they hold objects very close to eyes to see?
4. Do you/they turn your/their head to the side, up/down or tilt your/their head when looking in the distance? Do you have any photographs demonstrating this?
5. Do you/they ever bob or shake your/their head?
6. Do you/they appear sensitive to light? Do you/they screw their eyes in bright light or rub their eyes a lot?
7. Do you/they have difficulty seeing in the dark/in bright light? Do you/they appear clumsy or not able to see as well in darker rooms or in bright sunshine?
8. Do you/they notice the world wobbling? If so, when does this happen?



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

9. Does the wobble of the eyes change, for example when looking far away or when looking in a certain position?
10. Do you notice one eye turning? If yes, the orthoptist will ask questions that are more detailed about the eye turning.
11. Is there a history in the family of eyes that wobble or other eye conditions e.g. albinism, retinal diseases, or poor vision? If yes, the orthoptist and ophthalmologist will ask questions that are more detailed about the family history.
12. How is your/their general health?
13. Do you/they take any medications? If so, what are they and what are they for?
14. Have you/they had any treatment for your eyes in the past? If so, the orthoptist and ophthalmologist would ask questions that are more detailed about this.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

INFORMATION FOR TEACHERS AND OTHER PROFESSIONALS

This pack contains information about nystagmus. Useful contacts and sources of information are also provided.

Recommendations for teachers and other professionals who may be in contact with children with nystagmus:

These guidelines should be used discreetly and with acknowledgment that each pupil is an individual whose sight will vary.

- 1.** Encourage the student to explain his/her visual needs; however, continual and undue attention to these should be avoided.
- 2.** Allow books/objects to be held close to the eyes, the head tilted and any other body posture adopted if this enhances vision.
- 3.** Provide the pupil with his own book/worksheet. Sharing is impossible.
- 4.** Enlarging material will often help.
- 5.** Wall displays for reference should be placed at eye level and where the pupil can stand close to it (not above a filing cabinet/table).
- 6.** Ask the pupil where they would prefer to sit. It is often facing and near to the board. They should not sit to one side unless specifically chosen by the child. They should be offered positions close to demonstrations during activities.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

- 7.** Store visual aids such as magnifiers, line trackers and coloured overlays, in easily accessible places so that the student can use them when they decide an aid will be helpful.
- 8.** Allow the use of prescribed tinted glasses, cap, hat, or eyeshade to reduce the effects of glare. Consider if the lighting is too bright or shining directly at the child.
- 9.** Whilst glare should be avoided, good lighting is essential. The light should be behind the student and directed onto the object being viewed. Matte surfaces for walls, boards, and paper prevent light reflection and glare.
- 10.** Use strong colour contrast between letters/figures/lines and background. Black text on yellow paper or coloured spectrum on words is often preferred.
- 11.** Read aloud when writing on the board and describing diagrams.
- 12.** When reading it is helpful to place a piece of dark card under the line of words, or to use a finger to indicate their place on the page.
- 13.** Allow more 'time to see'. This includes having more time to complete tasks and to examine materials/objects.
- 14.** Exercise books with matte paper, different colours, and well-spaced lines should be made available.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

15. In ball games, it may be difficult for the student to follow a fast moving ball if they have nystagmus, poor vision or strabismus (misaligned eyes).

EXAMPLE LETTERS ABOUT NYSTAGMUS

Grateful acknowledgment is made to the Nystagmus Network (U.K.) and the American Nystagmus Network (U.S.A.) for permission to use these texts, with minor revisions.

The following is an example of a letter that may be sent to a teacher of a student with nystagmus from an eye care professional:

Dear Mr/Mrs _____

[Child's name] has a complex eye condition called nystagmus. This means that the eyes make involuntary, repetitive movements all the time. There is no cure. Glasses or contact lenses may be worn to correct short-sightedness, long-sightedness or astigmatism and may reduce the nystagmus to some extent.

The effects of nystagmus vary, but often it reduces:

- an individual's distance vision and near vision
- the ability to continue to focus on something once located
- the ability to see movement or judge distances and the time to react to these changes
- the ability to deal with clutter or crowding

All of these things mean longer is needed to complete visual tasks such as reading and writing. Although, near vision is usually better than distance vision.



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

A QTVI can advise on the font size that will be beneficial for near reading and when reading from the board. The use of visual aids and technology to enlarge text and sensory breaks should be encouraged.

People with nystagmus may hold their head in a certain position to reduce the eye movement and achieve better vision. This is a compensatory head posture and should not be corrected or misinterpreted as being naughty, not facing the teacher or cheating from another's work.

Vision becomes worse when the person is tired, under stress, anxious, hungry or in unfamiliar surroundings. At such times increased eye "wobble" will be noticeable and vision will reduce.

Students with nystagmus usually manage very well at school. However teachers should be aware that they will need more time with reading and writing tasks and may need extra help. BIG, BOLD, BRIGHT, and contrasting stationary are the guiding principles.

If you would like to find out more about nystagmus, you can visit the Nystagmus Network website: <http://nystagmusnetwork.org/>



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.

The following is an example of a letter that may be sent to a teacher of a student with nystagmus from a parent:

Dear Teacher:

[Child's name] has a complex eye condition called nystagmus. This means that the eyes make involuntary movements all the time.

There is no cure for nystagmus. Glasses or contact lenses may be worn to correct short-sightedness/long-sightedness or astigmatism and may reduce the nystagmus to some extent.

The effects vary, but most individuals with nystagmus also have other, sensory, deficits that lead to poor vision. However, near vision is usually better than distance vision.

People with nystagmus may hold their head in a certain position to reduce the eye movement and achieve better vision. This is a compensatory head posture and should not be corrected or misinterpreted as being naughty, not facing the teacher or cheating from another's work.

Vision becomes worse when the person is tired, under stress, anxious, hungry or in strange surroundings. At such times increased eye "wobble" will be noticeable and vision will reduce.

Students with nystagmus usually manage very well at school. However teachers should be aware that they will need more time with reading and writing tasks and may need extra help. BIG, BOLD, BRIGHT, and contrasting stationary are the guiding principles.

If you would like to find out more about nystagmus, you can visit the Nystagmus Network website: <http://nystagmusnetwork.org/>



The
University
Of
Sheffield.



This Nystagmus Information Pack has been developed by the Academic Unit of Ophthalmology and Orthoptics, University of Sheffield with funding from Nystagmus Network and the University of Sheffield.