

Information for patients

Early Onset Nystagmus in Children

The aim of this leaflet is to explain nystagmus and how it affects children. If you have any further questions please ask the Orthoptist or Ophthalmologist involved in your child's care.

What is Early Onset Nystagmus?

This type of nystagmus occurs early in childhood, usually from birth. Nystagmus is an involuntary, uncontrollable movement of the eyes, usually from side to side, however sometimes the eyes can move up and down, or in a circular motion. This movement can vary in speed, depending on the direction the eyes are looking. Children are not aware that their eyes are moving.

What causes Early Onset Nystagmus?

Nystagmus in childhood may be inherited or be associated with another eye disorder e.g. albinism. Many children with nystagmus have no other eye or health problems. At present there is no known cure, however, it is unlikely to get worse with age and may become less noticeable.

How common is the condition?

Nystagmus is believed to affect around 1 in 1,000 individuals.

How does nystagmus affect people?

- In most cases with early onset nystagmus, the brain adapts so whatever the person is looking at appears steady despite the eyes moving, however the object may not look clear.
- Nystagmus can reduce eyesight to below average and, in some cases a child may be registered partially sighted. Generally near vision, for example reading, is better than distance vision.

- Many people with nystagmus can read very small print if it is held closer. However, books and schoolwork with enlarged print can be used to make reading easier. In some cases the use of a magnifying glass may help.
- Children may read more slowly and tire more easily because of the nystagmus, but this should not be taken as a sign of poor reading ability.
- In some cases nystagmus is helped by using a different head position e.g. turning the head to one side or lifting the head up or down to steady the nystagmus. Children do this instinctively if it helps to improve their vision.
- Most children with nystagmus attend mainstream schools.

How can the potential for vision be maximised?

- If a child is also long or short sighted then glasses should be worn to correct this.
- Don't discourage your child's tendency to get closer to objects.
- Don't discourage the use of a different head position.
- Inform teachers of your child's condition and use larger print books and magnifiers, if helpful.
- Advise teachers where a child should be sat in the classroom to best see the blackboard.
- Advise teachers to allow your child to have regular breaks/rests when reading as they may tire more easily. Nystagmus can be worse if a child is stressed, tired, anxious or unwell.
- Your Ophthalmologist can provide a supporting letter to your child's teacher if required.

A small number of children may benefit from prisms or surgery to help reduce an obvious head turn, but this does not stop the nystagmus.

Your Orthoptist or Ophthalmologist will advise as to which, if any, treatment is best suited to your child.

Further Information

Support and information is available from the Nystagmus Network. This service includes a telephone help line, meetings, talks, booklets and information leaflets.

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