

Understanding NICE guidance

Information for people who use NHS services

Treating nystagmus by horizontal eye muscle disconnection/reconnection surgery

NICE 'interventional procedures guidance' advises the NHS on when and how new procedures can be used in clinical practice.

This leaflet is about when and how horizontal eye muscle disconnection/reconnection surgery can be used in the NHS to treat some people with nystagmus. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

Interventional procedures guidance makes recommendations on the safety of a procedure and how well it works. An interventional procedure is a test, treatment or surgery that involves a cut or puncture of the skin, or an endoscope to look inside the body, or energy sources such as X-rays, heat or ultrasound. The guidance does not cover whether or not the NHS should fund a procedure. Decisions about funding are taken by local NHS bodies (primary care trusts and hospital trusts) after considering how well the procedure works and whether it represents value for money for the NHS.

NICE has produced this guidance because the procedure is quite new. This means that there is not a lot of information yet about how well it works, how safe it is and which patients will benefit most from it.

This leaflet is written to help people who have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe nystagmus or the procedure in detail – a member of your healthcare team should also give you full information and advice about these. The leaflet includes some questions you may want to ask your doctor to help you reach a decision.

What has NICE said?

Although there is evidence to say that this procedure is safe, there is little evidence about how well it works. If a doctor wants to use horizontal eye muscle disconnection/reconnection surgery for nystagmus, they should make sure that extra steps are taken to explain the uncertainty about how well it works, as well as the potential risks of the procedure. This should happen before the patient or carer agrees (or doesn't agree) to the procedure. The patient should be given this leaflet and other information as part of the discussion. There should also be special arrangements for monitoring what happens to the patient after the procedure. Ophthalmologists who are experienced in the management of eye movement disorders should decide which patients should have this procedure.

NICE has encouraged further collection of data, including information on quality of life, and may review the procedure if more evidence becomes available.

This procedure may not be the only possible treatment for nystagmus. Your healthcare team should talk to you about whether it is suitable for you and about any other treatment options available.

Treating nystagmus by horizontal eye muscle disconnection/reconnection surgery

The medical name for this procedure is 'Tenotomy of horizontal eye muscles for nystagmus (with reattachment at their original insertions)'. The procedure is not described in detail here – please talk to your surgeon for a full description.

Nystagmus is persistent, rapid, involuntary eye movement (most commonly from side to side), which usually impairs vision. Nystagmus may be present at birth, caused by defects in the eye or the visual pathway from the eye to the brain. Children with eye disorders or multiple disabilities may have it. Later in life nystagmus may be a symptom of conditions such as stroke, multiple sclerosis or head injury. There is no cure. Glasses or contact lenses may improve sight but will not correct nystagmus.

In this procedure, the patient is under a general anaesthetic. The conjunctiva (the membrane covering the eyeball) is cut and the horizontal eye muscles (which move the eye from side to side) are cut and reattached at the same place. The aims of the procedure are to slow the eye's involuntary movements and improve vision, although how the surgery helps is not entirely known.

Summary of possible benefits and risks

Some of the benefits and risks seen in the studies considered by NICE are briefly described below. NICE looked at four studies on this procedure.

How well does the procedure work?

A study of ten adults measured the amount of fine detail they could see after having the procedure. After a year it was better in nine patients and worse in one. A study of nine patients with infantile nystagmus measured

What does this mean for me?

If your ophthalmologist has offered you horizontal eye muscle disconnection/reconnection surgery for nystagmus, he or she should tell you that NICE has decided that although the procedure is safe there isn't much evidence about how well it works. This does not mean that the procedure should not be done, but that your ophthalmologist should fully explain what is involved in having the procedure and discuss the possible benefits and risks. You should only be asked if you want to agree to this procedure after this discussion. You should be given information, including this leaflet, and have the opportunity to discuss it with your ophthalmologist before you decide.

NICE has also decided that more information is needed about this procedure. Your ophthalmologist may ask you if details of your procedure can be used to help collect more information about this procedure. Your ophthalmologist will give you more information about this.

You may want to ask the questions below

- What does the procedure involve?
- What are the benefits I might get?
- How good are my chances of getting those benefits? Could having the procedure make me feel worse?
- Are there alternative procedures?
- What are the risks of the procedure?
- Are the risks minor or serious? How likely are they to happen?
- What care will I need after the operation?
- What happens if something goes wrong?
- What may happen if I don't have the procedure?

the same thing. After a year, eight patients had better potential to see fine detail but in one it was no different. The time during which the eye was still (a positive outcome) had also increased in all nine patients, and all of them had less vertical movement of their eyes.

In another study two children's eye movement was measured in the same way. One child's potential to see fine detail had increased by 8% after a year and in the other it had increased by 36% after 6 months. Three studies with a total of 24 adults and children who had the procedure measured their ability to see lines of letters of decreasing size on a chart. Fifteen patients could see at least a few letters more 6 weeks or more after the procedure. Three had no change. In a study of five patients, all were able to focus more quickly on an object 1 year after the procedure.

As well as looking at these studies, NICE also asked expert advisers for their views. These advisers are clinical specialists in this field of medicine. They said that the main success factors are how good the vision is in both eyes

You might decide to have this procedure, to have a different procedure, or not to have a procedure at all.

using contact lenses or glasses, reduction in nystagmus, ability to see depth or distance, eye movement, ability to see in everyday life, quality of life, how the patient's eyes appear, and how they hold their head.

Risks and possible problems

No problems with the procedure have been reported.

As well as looking at these studies, NICE also asked expert advisers for their views. These advisers are clinical specialists in this field of medicine. The advisers said that problems could include damage to the retina (the light-sensitive area at the back of the eye) or tearing the eyeball, infection, and the eye muscles not being aligned properly, resulting in redness, swelling, double vision, squint or loss of vision, which could mean a need for further surgery. One expert adviser had read of one patient developing a conjunctival cyst after the procedure.

More information about nystagmus

Your local patient advice and liaison service (usually known as PALS) may also be able to give you further information and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider how well an interventional procedure works and how safe it is, and ask the opinions of expert advisers. Interventional procedures guidance applies to the whole of the NHS in England, Wales, Scotland and Northern Ireland. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet is about 'Tenotomy of horizontal eye muscles for nystagmus (with reattachment at their original insertions)'.

This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/11PG299

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1868 for the standard print version and N1877 for the large print version). The NICE website has a facility called Browsealoud which gives you the option to access our guidance via a screen reader service. The software allows your computer to read aloud our website content. Click on the Browsealoud logo on the NICE website to access it.

We encourage voluntary organisations, NHS organisations and clinicians to use text from this booklet in their own information about this procedure.