

Understanding NICE guidance

Information for people who use NHS services

Treating wet age-related macular degeneration by rotating the macula and repositioning it on the eye

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 surgery to rotate and then reposition the macula can be used in the NHS to treat people with wet age-related macular degeneration (AMD). 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.

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 wet AMD 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. Some sources of further information and support are on the back page.

What has NICE said?

Evidence shows that this procedure does not work in all patients, and that there is potential for serious problems as a result of the operation. If a doctor wants to use this procedure, they should make sure that extra steps are taken to explain the uncertainties about how well the procedure works and how safe it is. They should also explain the alternative treatments available to the patient. This should happen before the patient 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.

Other comments from NICE

Before surgery is offered, most patients with wet AMD are treated with drugs called anti-vascular endothelial growth factor agents, which block the growth of blood vessels in the eye. Evidence suggests if a patient does not respond to drug treatment, it is likely that this procedure will not improve their eyesight either.

Treating wet age-related macular degeneration by rotating the macula and then repositioning it in the eye

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

The medical name for this procedure is 'macular translocation with 360° retinotomy for wet age-related macular degeneration'.

The procedure is not described in detail here – please talk to your specialist for a full description.

In the eye, the retina covers the back wall of the eyeball and is the layer of cells responsible for creating vision. Macular degeneration affects the area of the retina responsible for detailed vision (the macula). Because degeneration usually occurs in older people it is also known as 'age-related macular degeneration'. There are two types – 'dry' and 'wet'. The wet form is caused by bleeding at the back of the eye from new blood vessel growth, and the loss of vision can be quicker than the dry form.

The aim of this procedure is to improve vision by repositioning the macula so that it lies over a healthier part of the eyeball that has not been affected by new blood vessel growth. A disc of retina with the macula at its centre is detached from the eye wall, rotated slightly and then reattached.

A second operation is needed 1–2 months later. Because the retina has been rotated, vision after the procedure is also rotated. This is corrected in the second procedure, in which the eyeball is rotated in the opposite direction.

Summary of possible benefits and risks

Some of the benefits and risks seen in the studies considered by NICE are briefly described here. NICE looked at 7 studies on this procedure.

What does this mean for me?

If your doctor has offered you this procedure, he or she should tell you that NICE has decided that not all patients benefit from the procedure, and that serious complications can develop as a result of having the procedure. This does not mean that the procedure should not be done, but that your doctor should fully explain what is involved in having the procedure and discuss the possible benefits, risks and alternative treatments with you. You should only be asked if you want to agree to this procedure after this discussion has taken place. You should be given information, including this leaflet, and have the opportunity to discuss it with your doctor before making your decision.

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?

How well does the procedure work?

In a study of 25 patients treated by the procedure and 25 treated by a type of laser treatment called photodynamic therapy (PDT), eyesight improved in 7 patients in the first group when their progress was checked after 12 months. Eyesight did not improve in the PDT group. There was no difference in quality of life scores between the groups when their progress was checked after 24 months. A study of 50 patients reported improved eyesight in 33 patients, no improvement in 14 patients and worsened eyesight in 3 patients after 21 months. A study of 64 patients reported improved eyesight in 32 patients and much worsened eyesight in 7 patients after 12 months.

In a study of 12 patients who had the procedure and 12 who had a patch graft, eyesight had improved in the first group and worsened in the graft group when the patients' progress was checked after 3 years.

A study of 55 patients showed that by 12 months after the procedure, patients' reading speeds had improved from an average of 71 to 105 words per minute.

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 success factors are retinal attachment, improved vision and reading speed.

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

Risks and possible problems

In the study of 50 patients, unplanned detachment of the retina was reported in 6 of the 25 patients treated by the procedure. In studies of 90 and 64 patients, retinal detachment was reported in 19% (number of patients not stated) and 5 patients.

In the study of 24 patients, a third procedure was needed to treat 2 patients where the retina had been over-rotated. In another study, retinal slippage from the desired final position was reported in 2 of 75 eyes.

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 other possible problems include scar tissue formation in the eye, swelling or deterioration of the macula, and double vision. There may be a risk of further damage to the macula from recurrent disease.

More information about age-related macular degeneration

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as PALS) may also be able to give you further information and support. For details of all NICE guidance on AMD, including the procedure in which the affected part of the retina is repositioned using a stitch, visit our website at www.nice.org.uk

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 'macular translocation with 360° retinotomy for wet age-related macular degeneration'. This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/IPG340

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2151 for the standard print version and N2152 for the large print version). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

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