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Retrobulbar irradiation for thyroid eye disease

Understanding NICE guidance –
information for people considering
the procedure, and for the public



Ordering information

You can download the following documents from www.nice.org.uk/IPG148

- this booklet
- the full guidance on this procedure.

For printed copies of the full guidance or information for the public, phone the NHS Response Line on 0870 1555 455 and quote:

- N0949 (full guidance)
- N0950 (information for the public).

National Institute for Health and Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA
www.nice.org.uk
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About this information

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. One of NICE's roles is to produce guidance (recommendations) on whether interventional procedures are safe enough and work well enough to be used routinely in the NHS in England, Wales and Scotland.

This information describes the guidance that NICE has issued on a procedure for thyroid eye disease called retrobulbar irradiation. It is not a complete description of what is involved in the procedure – the patient's healthcare team should describe it in detail.

NICE has looked at whether retrobulbar irradiation is safe enough and works well enough for it to be used routinely for the treatment of thyroid eye disease.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of retrobulbar irradiation and how well it works
- asked experts for their opinions
- asked the views of the organisations that speak for the healthcare professionals and the patients and carers who will be affected by this guidance.

This guidance is part of NICE's work on 'interventional procedures' (see 'Further information' on page 10).

About the procedure

Thyroid eye disease affects the muscles and other tissues around the eyeball. The eye muscles become large, and fatty tissue builds up behind the eyeball. The eye starts to bulge as a result (the medical name for this is proptosis) and may feel sore or gritty and water more than usual. The person may find bright light uncomfortable, and may also get double vision.

For most people, the symptoms are mild and may be helped by steroid medicines, which help to reduce inflammation in the eye muscles and tissue.

If the condition is more severe, the person may not be able to close their eye or eyes properly, which can lead to problems. Surgery may be used to make more room for the eyeball in the eye socket. And radiation therapy is sometimes an option to reduce the inflammation in the area.

The procedure NICE has looked at is called retrobulbar irradiation. It is usually done as an outpatient procedure. The person lies on their back with their head kept still in a 'shell', and radiation is directed at the tissue behind the eyeball. The person has about 10 sessions of radiation treatment over 2 weeks.

How well the procedure works

What the studies said

One study compared people who had retrobulbar irradiation with people who went through a similar procedure but with a device that blocked the radiation entering the eye so that they were not actually given any active radiation. The 88 people in this study had mild symptoms. The physical condition of the eye improved in more of the people who had the radiation treatment than those that did not have it (52% of people who had the radiation, compared with 27% of people who did not have the radiation).

In another study that made a similar comparison, eye movement improved for 14 out of 17 patients (82%) who had the radiation treatment compared with 4 out of 15 patients (27%) who didn't have the radiation treatment. And nearly 6 months after the procedure, the patients who had the radiation treatment could point their eyes further upwards than the patients who didn't have the radiation. The radiation treatment did not seem to make any difference to eyeball bulging or swelling in the eyelids.

A third study found that, 3 months after the treatment, there were no real differences in the size of eye muscles and eyeball bulging between eyes treated with radiation and those not treated with radiation.

One study compared patients who had radiation treatment with patients who had steroid treatment. There were no differences in eyeball bulging, eyesight, or size of eye opening between the two groups of patients after treatment. Also, there were no differences between the two groups in patients' views of how they thought their eyes were working after treatment.

What the experts said

The experts said that it was hard to say how well the procedure worked because thyroid eye disease sometimes improves over time without any treatment.

Risks and possible problems with the procedure

What the studies said

Two studies followed what happened after people had retrobulbar irradiation over a long period (one study followed patients for 7 years and the other followed them for 11 years). In this time, around 1 in every 10 people in the studies developed cataracts (where the lens in the eye becomes cloudy). And around 1 in every 100 people developed retinopathy, which is where problems develop in the layer at the back of the eyeball and can affect eyesight.

In one of the studies 10 out of 197 people developed tumours, but these were not in the area treated with the radiation.

In the other study there were no head or neck cancers in 157 people during 11 years after treatment. But in this study scans showed that 53 out of 157 people who had radiation treatment developed thickened tissue or polyps (growths) around the eye cavities.

What the experts said

The experts said that it was possible that radiation treatment could make the eye problems worse in the short term. It might also make the eye or eyes dry, or cause cataracts, retinopathy (especially in people with diabetes) or cancerous changes in the area.

What has NICE decided?

NICE has considered the evidence on retrobulbar irradiation. It has said that the procedure seems to work well enough and to be safe enough to justify its use for people who can't have the other standard treatments either because they don't work or because of side effects. It has recommended that when doctors use this procedure, they should be sure that:

- the patient understands what is involved and agrees (consents) to the treatment, and
- the results of the procedure are monitored.

NICE has also said that clear arrangements should be in place so that the right doctors and healthcare professionals are involved in the decision about whether the procedure is a suitable option for a specific patient. In particular, an ophthalmologist (a doctor who specialises in eye conditions), a cancer specialist and an endocrinologist (who specialises in hormone disorders, including thyroid problems) should be involved in the decision.

What the decision means for you

Your doctor may have offered you retrobulbar irradiation. NICE has considered this procedure because it is relatively new. NICE has decided that the procedure is safe enough and works well enough for use in the NHS for people who can't have other treatments. Nonetheless, you should understand the benefits and risks of retrobulbar irradiation before you agree to it. Your doctor should discuss the benefits and risks with you. Some of these may be described above.

Further information

You have the right to be fully informed and to share in decision-making about the treatment you receive. You may want to discuss this guidance with the doctors and nurses looking after you.

The NICE website (www.nice.org.uk) has further information about NICE, the Interventional Procedures Programme and the full guidance on retrobulbar irradiation for thyroid eye disease that has been issued to the NHS. The evidence that NICE considered in developing this guidance is also available from the NICE website.

If you have access to the internet, you can find more information on thyroid disease on the NHS Direct website (www.nhsdirect.nhs.uk).

You can also phone NHS Direct on 0845 46 47.

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MidCity Place
71 High Holborn
London
WC1V 6NA

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