

Understanding NICE guidance

Information for people who use NHS services

Treatment of twin-to-twin transfusion syndrome with intrauterine laser ablation

NICE 'interventional procedures guidance' advises the NHS on when and how new surgical procedures or procedures that use electromagnetic radiation (such as X-rays, lasers and gamma rays) can be used.

This leaflet is about when and how intrauterine laser ablation (laser surgery inside the womb) can be used to treat twin-to-twin transfusion syndrome (abbreviated here to TTTS) in the NHS in England, Wales, Scotland and Northern Ireland. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

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 parents who have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe TTTS or intrauterine laser ablation 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.

Interventional procedures guidance makes recommendations on the safety of a procedure and how well it works. 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.

What has NICE said?

This procedure can be offered routinely as a treatment option for TTTS provided that doctors are sure that:

- the parents understand that there is a risk that one or both of the babies may not survive the procedure, and that there is also a risk of neurological problems
- the parents agree to the procedure
- the results of the procedure are monitored.

The procedure should only be carried out in specialist centres by a team of suitable experts.

There are still uncertainties about which stage of TTTS this procedure is most suitable for.

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

Intrauterine laser ablation

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

In about 70% of identical twin pregnancies, both babies share the same placenta. This means that they also share the same blood supply. In these pregnancies there is a risk of twin-to-twin transfusion syndrome (TTTS), which happens in about 15% of cases. In TTTS, one twin gets too little blood and too little amniotic fluid and cannot grow very well. The other twin gets too much blood and too much amniotic fluid, which causes heart and circulation problems. This twin often squashes the other twin against the wall of the womb.

Up to 80% of babies die if TTTS is not treated. The babies who live are likely to have heart or kidney problems, and about 15% have serious neurological problems, such as cerebral palsy.

In laser ablation, a laser beam is used to seal off some of the blood vessels in the placenta so that both babies receive a more equal supply of blood. After the laser surgery, the excess amniotic fluid is removed so that both babies have an equal volume. This is called amnioreduction.

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 one review of 10 studies and another six studies.

How well does the procedure work?

Laser ablation improved the survival of babies with TTTS.

Ten studies, involving a total of 981 pregnancies, were reviewed. In one study, at least one baby survived in 11 out of 18 pregnancies; in another, at least one baby survived in 79 out of 95 pregnancies.

Another study compared laser ablation with amnioreduction alone, and showed that the chance of one baby surviving was higher after laser ablation. In this study, at least one baby survived in 55 out of 72 pregnancies after laser ablation, compared with 36 out of 70 pregnancies after amnioreduction alone.

Two studies looked at long-term neurological problems. One found that neurological problems were found in 10 out of 167 and 10 out of 89 twins treated with laser ablation, who were then followed up for 22 and 38 months respectively. Babies treated with laser ablation were more likely to be free of neurological problems at 6 months than those who had been treated with amnioreduction.

Laser ablation increased the age at which the babies were born to 33 weeks, compared with 29 weeks in pregnancies treated with amnioreduction (two studies looked at this).

One study reported that TTTS came back after laser ablation in 14 out of 101 pregnancies.

The expert advisers are not yet sure whether laser ablation reduces neurological problems. They are not sure how many blood vessels need to be treated, or how best to treat TTTS in the early stages.

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

What does this mean for me?

NICE has said that this procedure is safe enough and works well enough for use in the NHS. If your doctor thinks that intrauterine laser ablation is a suitable treatment option, he or she should still make sure you understand the benefits and risks before asking you to agree to it.

You may want to ask the questions below

- What does the procedure involve?
- Could having the procedure make the situation worse?
- What could happen if I don't have the procedure?
- 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 be necessary after the operation?
- What happens if something goes wrong?
- What may happen if I don't have the procedure?
- Could one or both of my babies die?

Risks and possible problems

The most common problem for the mother was early rupture of the membranes, which happened in 49 out of 175 women. In 6 out of the 49 women, this happened within 3 weeks of the procedure. Placental abruption (where the placenta detaches from the wall of the uterus) happened in 3 out of the 175 women. Twelve of the 175 women miscarried. The risk of miscarriage after laser ablation was similar to that with amnioreduction. In another study, miscarriage occurred in 1 out of 69 pregnancies after laser ablation, compared with 2 out of 68 pregnancies in the amnioreduction group.

Other problems reported were leaking of amniotic fluid and vaginal bleeding.

The expert advisers said that other risks of laser ablation are infection and death of one or both of the babies. There is also a risk that the TTTS will not be cured. The expert advisers also said that there is a risk of the mother dying, although this risk has been reduced as the technique has been improved.

More information about twin-to-twin transfusion syndrome

NHS Direct online (www.nhsdirect.nhs.uk) may be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further advice 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. 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 and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/IPG198

You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1165).