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NHS
National Institute for Health and Clinical Excellence

Septostomy for twin-to-twin transfusion syndrome (with or without amnioreduction)

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 septostomy (a procedure that involves making a hole in the membrane between twins in the womb), with or without amnioreduction (removal of amniotic fluid), 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 septostomy 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 page 7.

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?

There are still uncertainties about the safety of this procedure and how well it works. If a doctor wants to use septostomy for TTTS, he or she should explain the uncertainty and the risk that one or both of the babies may not survive the procedure, as well as the risk of neurological problems. This should happen before you agree (or don't agree) to the procedure. Parents should be given this leaflet and other written information as part of the discussion. There should also be special arrangements for monitoring what happens after the procedure.

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

There is uncertainty about the stage of TTTS for which this procedure is suitable.

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.

Septostomy with or without amnioreduction

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.

Septostomy is the creation of a small hole in the membrane between the babies using a fine, hollow needle. This allows the amniotic fluid to move from one baby to the other, so both babies have a more equal amount of amniotic fluid. The surgeon may also remove some of the amniotic fluid through the needle. This is called amnioreduction.

What does this mean for me?

If your doctor has offered you septostomy (with or without amnioreduction) for TTTS, he or she should tell you that NICE has decided that the benefits and risks are uncertain. 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 and risks 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 written 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?
- 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 procedure?
- What happens if something goes wrong?
- Could one or both of my babies die?

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 six studies on this procedure.

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

How well does the procedure work?

In one study, at least one of the babies survived in 28 out of 36 pregnancies treated with amnioreduction alone, compared with 28 out of 35 pregnancies treated with septostomy (with or without amnioreduction). In the same study, both babies survived in 18 out of the 36 pregnancies treated with amnioreduction, compared with 21 out of the 35 pregnancies treated with septostomy.

In a smaller study, both babies survived in 3 out of 7 pregnancies treated with amnioreduction, compared with 4 out of 7 pregnancies treated with septostomy. In both these groups, at least one baby survived in 6 out of 7 pregnancies. The overall survival rate was 9 out of 14 babies in the amnioreduction group, and 10 out of 14 babies in the septostomy group.

In an analysis of four small studies of septostomy (with or without amnioreduction), the overall survival rate ranged from 12 babies from 26 pregnancies, to 20 babies from 24 pregnancies. The survival rate was thought to be affected by the severity of the TTTS.

The babies' average age at delivery ranged from 27 to 31 weeks. The pregnancies treated with septostomy were longer (30–31 weeks) compared with amnioreduction alone (28–30 weeks).

The studies did not look at any neurological effects.

The expert advisers said that the best treatment for early stage TTTS is still unclear. They also said that from the studies they looked at, septostomy with amnioreduction does not have any major advantage over amnioreduction alone.

Risks and possible problems

There was not a lot of information available to say how safe septostomy is.

In the study of 35 pregnancies treated with septostomy, in two cases the membrane between the twins was damaged during the septostomy. This damage was also reported in two other studies. When this happens the babies grow together in one amniotic sac which can increase the risk of the umbilical cord becoming tangled or coming down out of the womb.

In a study of 13 pregnancies, one woman went into labour after septostomy and amnioreduction. This was thought to be caused by damage to the placenta.

One expert adviser thought that septostomy and amnioreduction is a safe procedure, and said that septostomy is often done accidentally during amnioreduction for TTTS. All the expert advisers said that there is a risk of the cord becoming tangled.

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/IPG199

You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1167).

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