

Treating bleeding-related hydrocephalus in premature babies by drainage, irrigation and breaking down blood clots

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

This leaflet is about when and how drainage, irrigation and breaking down blood clots can be used in the NHS to treat bleeding-related hydrocephalus in premature babies. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

This HealthTech 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 babies will benefit most from it.

This leaflet is written to help parents decide whether to agree (consent) to it or not. It does not describe hydrocephalus or the procedure in detail – a member of your baby's healthcare team should also give you full information and advice about these. The leaflet includes some questions you may want to ask your baby's doctor to help you reach a decision. Some sources of further information and support are on page 8.

What has NICE said?

Currently there is not enough evidence to be certain about how well this procedure works or how safe it is. For this reason, NICE has said that this procedure should only be carried out as part of a research study, sometimes called a clinical trial.

Other comments from NICE

NICE noted that bleeding-related hydrocephalus in premature babies may result in severe disability and that there are few effective treatments to prevent this. NICE considered this procedure to have the potential to be effective, but there is not enough evidence about whether it works.

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This procedure may not be the only possible treatment for bleeding-related hydrocephalus. Your baby's 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 'drainage, irrigation and fibrinolytic therapy for post-haemorrhagic hydrocephalus in preterm infants'. It is also known as 'DRIFT'.

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

Bleeding in the brain is a serious complication that can happen within a few days of birth in a small proportion of babies born prematurely. It is more common in babies born before 30 weeks of pregnancy. It can block the flow of fluid (called cerebrospinal fluid) in the cavities of the brain, leading to progressive enlargement of the head (hydrocephalus). Death or permanent brain damage may follow.

Treating bleeding-related hydrocephalus in premature babies usually involves repeatedly draining the cerebrospinal fluid and inserting a shunt (a tube), which helps to move the fluid to other parts of the body. The DRIFT procedure aims to reduce death and disability, and the need to insert a shunt. It does this by removing the blockage, reducing its harmful effects by draining excess fluid from the brain, washing out the blood, and breaking down blood clots using drugs (fibrinolytics). It is carried out with the baby under a general anaesthetic. Treatment usually lasts for up to 3 days.

What does this mean for me?

Your baby's doctor can only use this procedure as part of a research study because there is not enough evidence about how well this procedure works. Your baby's doctor will be able to give you more information about this.

You may want to ask the questions below

- What does the procedure involve?
- What are the benefits my child might get?
- How good are my chances of my child getting those benefits?
Could having the procedure make my child's condition 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 my child need after the procedure?
- What happens if something goes wrong?
- What may happen if my child doesn't have the procedure?

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 2 studies on this procedure.

How well does the procedure work?

In a study of 70 babies (34 had DRIFT and 36 had standard treatment), DRIFT did not reduce the number of deaths while in hospital or before 6 months (whichever was longer) compared with standard care. A second report from the same study, with new results for 7 additional babies, stated that 3 of the 39 babies treated by DRIFT and 5 of the 38 babies given standard care died within 2 years.

The report of 77 babies also stated that 16 of the babies treated by DRIFT and 15 of those given standard care needed a shunt inserted in their heads within 2 years of treatment. In a study of 24 babies, 6 of the 23 who survived the DRIFT procedure needed a shunt.

In the report of 77 babies, infant development scores were used to predict the likelihood of the babies having developmental problems or disabilities. Babies treated by DRIFT were significantly less likely to develop a severe mental disability at an average follow-up of 25 months than babies given standard care. DRIFT also reduced the chance of developing severely disrupted communication between the brain and the limbs, allowing them to move more normally, compared with standard care, but there was no significant difference between the groups. In the study of 24 babies, 11 of the 19 babies examined at 1 year had a disability and 4 of these babies had multiple disabilities.

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 the main success factors are a reduced need for shunt insertion and long-term improvements in mental ability and movement.

Risks and possible problems

In the report of 70 babies, 12 of the 34 treated by DRIFT and 3 of the 36 given standard care had further bleeding in the head. The bleeding did not cause any outward symptoms in most of the babies; 1 baby had a significant, temporary drop in the number of platelets (small cell fragments that help to form clots) in their blood. In the study of 24 babies, 2 had further bleeding in the head requiring medical attention: 1 was successfully treated with a clotting drug and 1 was stabilised without treatment.

The report of 70 babies stated that up to 4 blood transfusions (average 1.7) were needed in babies treated by DRIFT, compared with 0–2 (average 1.8) in babies given standard care.

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 possible problems include infection, meningitis, movement or blockage of the draining tube, and brain damage. They also said that there is a risk of further bleeding in the head when the fibrinolytic drug is injected.

More information about hydrocephalus

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 progressive enlargement of the head in babies born prematurely, 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. HealthTech 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 'drainage, irrigation and fibrinolytic therapy (DRIFT) for post-haemorrhagic hydrocephalus in preterm infants'.

This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/HTG276

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.

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