

Understanding NICE guidance

Information for people who use NHS services

Reconstructive surgery to stabilise the hip joint in proximal focal femoral deficiency (PFFD)

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 reconstructive surgery to stabilise the hip joint can be used in the NHS to treat children with proximal focal femoral deficiency (PFFD). 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 parents or carers whose children have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe PFFD or the procedure in detail – a member of your child's healthcare team should also give you full information and advice about these. The leaflet includes some questions you may want to ask your child's doctor to help you reach a decision.

What has NICE said?

There is not much good evidence about how well this procedure works or how safe it is. If a doctor wants to use this procedure for PFFD, they should make sure that extra steps are taken to explain the uncertainty about how well it works and how safe it is. They should explain that more procedures may be needed, even following a successful operation, and the final result may not be a fully functioning limb. This should happen before the child's parent or carer agrees (or doesn't agree) to the procedure. The child's parent or carer should be given this leaflet and other written information as part of the discussion. There should also be special arrangements for monitoring what happens to the child after the procedure.

NICE has also said that this procedure should only be done in hospitals that specialise in limb reconstruction, by surgeons with specialist knowledge of infants' hip problems and with expertise in leg lengthening procedures.

Reconstructive surgery to stabilise the hip joint in PFFD

This procedure may not be the only possible treatment for PFFD.

Your healthcare team should talk to you about whether it is suitable for your child and about any other treatment options available.

The medical name for this procedure is 'Combined bony and soft tissue reconstruction for hip joint stabilisation in proximal focal femoral deficiency (PFFD)'.

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

Children are sometimes born with defects of the hip joint, the thigh bone, and possibly other lower limb abnormalities, called proximal femoral focal deficiency, often shortened to PFFD. The treatment options depend on the severity of the PFFD. If the PFFD is severe, amputating part of the leg and fitting a false limb (prosthesis) may be the best option. For other patients with relatively mild PFFD, surgical treatment, aiming to produce as functional a leg as possible, may be appropriate. This may involve a corrective operation on the hip joint.

The procedure is carried out with the patient under a general anaesthetic. There are several variations possible. Normally a cut is made on the outside of the thigh and the muscles and tendons are moved aside. This enables the surgeon to access the bones of the hip and pelvis. The surgeon then corrects the deformity of the hip and thigh bone as much as possible. After the procedure, a plaster cast may be used while the bones are healing.

The initial operation may be combined with other procedures (at the same time or at a later date) to lengthen the leg, and treat other problems such as poor knee function.

What does this mean for me?

If your child's doctor has offered reconstructive surgery to stabilise the hip joint to treat your child's PFFD, 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 child's doctor should fully explain what is involved in having the procedure and discuss the possible benefits and risks with you. They should explain that your child might need more procedures and the final result may not be a fully functioning limb. 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 child's doctor before making your decision.

NICE has also decided that more information is needed about this procedure. Your child's doctor may ask you if details of your child's procedure can be used to help collect more information about this procedure. Your child's doctor will 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 child's chances of getting those benefits? Could having the procedure make my child 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 my child need after the operation?
- 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 two studies on this procedure.

How well does the procedure work?

A study of 14 patients reported success in 9 patients (in terms of improved walking or gait, range of leg movement, severity of dislocation and leg length difference). The study followed the patients' progress for 17 years and at the end, the leg length difference was between 1 and 20 cm, with the average difference being 11.5 cm. This study reported that 6 patients needed more than one lengthening procedure.

Another study of 3 patients reported that the procedure was successful in all 3 patients. This study reported that all 3 patients were scheduled to have more than one lengthening procedure.

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

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 the aims of the procedure are to have a working limb and a reduced need for further procedures. The advisers also said that for some patients, amputating part of the limb and fitting a prosthesis might give a better result than this procedure.

Risks and possible problems

In the study of 14 patients, problems reported were bone inflammation in 6 patients, fracture in 1 and pain from failure to heal in another patient.

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 are severe hip and knee stiffness, hip dislocation, joint deformity, bone problems, infection, nerve or blood vessel damage, poor limb function and permanent shortening of the leg.

More information about PFFD

Your local patient advice and liaison service (usually known as PALS) may also be able to give you further information 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. 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 'combined bony and soft tissue reconstruction for hip joint stabilisation in proximal focal femoral deficiency (PFFD)'. This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/IPG297

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1851). 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.