

## Understanding NICE guidance

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Information for people who use NHS services

# Lengthening of the leg bones using intramedullary distraction

*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 intramedullary distraction can be used to lengthen leg bones 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 people who have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe leg length deficiency or the procedure 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 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 over the safety of this procedure for lengthening the thigh bone (femur) or shin bone (tibia), and how well it works in lengthening the shin bone. If a doctor wants to use this procedure, he or she should make sure that extra steps are taken to explain the uncertainty and the likely benefits and potential risks of the procedure. This should happen before the patient agrees (or doesn't agree) to the procedure. The patient 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.

A number of different devices can be used, and new methods are being developed.

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

## Intramedullary distraction

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

Some people have one leg that is shorter than the other because of injury or infection. Some people are born with abnormally short legs (for example, because of hypoplasia or dysplasia). The thigh bone (femur) or the shin bone (tibia), or both, may be too short. This can cause a limp and may affect the person in their everyday life.

The device used to lengthen the bone is similar to that used to fix broken bones in position while they mend. A surgeon cuts the leg bone and fixes the two sections of the device to the two parts of the bone with locking screws. The device gently forces the two parts of the bone apart, allowing new bone to grow in the gap and gradually making the bone longer.

An alternative procedure is to use a device fixed to the outside of the leg but these devices are not always practical and cause some problems.

## 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 six studies on this procedure.

### How well does the procedure work?

The average increase in the length of the thigh bone was 46–63 mm in two studies. The lengthening happened at 0.8–1.1 mm per day.

Overall, bone lengthening did not affect the patients' ability to bend or straighten the leg.

In one study, the results of the procedure were described as 'excellent' in 75% of patients (by looking at knee movement, walking, pain and everyday activities).

Patients could bear their full body weight after about 2 months in a study of 48 patients.

The expert advisers said that the procedure is still being refined. It may be difficult to control the rate at which the bone lengthens, which may affect when and how strongly the new bone forms.

*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?

If your doctor has offered you intramedullary distraction, 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?
- What are the benefits I might get?
- How good are my chances of getting those benefits?
- 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 I need after the operation?
- What happens if something goes wrong?
- What may happen if I don't have the procedure?

## Risks and possible problems

Few studies reported on risks and possible problems. One study reported damage to the bone during the surgery in one patient and another reported damage to the nerve in the calf in 2 out of 23 patients, which resolved within 3 months.

The most common problem was pain during leg lengthening, although this varied between studies. Some patients needed a general anaesthetic during ratcheting (the actual lengthening process) and some required painkillers. In one study in which pain was measured on a scale of 0–3 (where 4 was maximum pain), pain was 1.5–2.4 during ratcheting and 1.5 during bone consolidation (the period when the new bone is forming). In two studies, none of the 30 patients needed pain relief during lengthening.

Three out of a total of 83 patients in two studies had a fracture either during lengthening or after the lengthening device was removed. Mechanical failure of parts of the device occurred in 4–16% of cases.

The expert advisers listed possible problems as poor bone formation, bone lengthening at the wrong rate (resulting in bone that is weak, or that reforms too soon), release of fat globules into the circulation (which may block blood vessels in the lungs or brain), deep vein thrombosis, breathing difficulties, and lack of movement in the ankle so that the patient has to walk on their toes.

## More information about leg length deficiency

NHS Direct online ([www.nhsdirect.nhs.uk](http://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](http://www.nice.org.uk/aboutguidance)*

*This leaflet and the full guidance aimed at healthcare professionals are available at [www.nice.org.uk/IIPG197](http://www.nice.org.uk/IIPG197)*

*You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1163).*