

Understanding NICE guidance

Information for people who use NHS services

Treating greater trochanteric pain syndrome by lengthening the iliotibial band close to the knee

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 lengthening the iliotibial band can be used in the NHS to treat people with greater trochanteric pain syndrome (one of the causes of hip pain). 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 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 greater trochanteric pain syndrome 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



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want to ask your doctor to help you reach a decision. Some sources of further information and support are on page 7.

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 (also called a clinical trial). The studies should report which patients are most suitable for the procedure, and the research should look at how well it works and quality of life.

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

Treating greater trochanteric pain syndrome by lengthening the iliotibial band close to the knee

The medical name for this procedure is ‘Distal iliotibial band lengthening for refractory greater trochanteric pain syndrome’.

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

The greater trochanter is the medical term for the bony bump on the outer side of the hip. This area may become painful due to inflammation of the fluid-filled sac (the bursa) which allows smooth movement between the bone and tendons/muscles that pass over it. The inflammation (called bursitis) is often caused by direct injury, damage to the tendon, infection, differences in leg length, or as a result of hip replacement surgery.

Current treatment options are non-surgical treatments such as rest, physiotherapy, anti-inflammatory drugs and corticosteroid injections. If

these don't help, the person may be offered surgery to remove the bursa or divide the fibrous iliotibial band where it passes over the trochanter.

The procedure is carried out with the patient under local or general anaesthesia. The aim is to lessen the pressure on the bursa. This is done by lengthening the fibrous band that runs along the outside of the thigh from the hip to the knees (called the iliotibial band). The iliotibial band is lengthened by 1.5 cm to 2 cm through a small cut made above the knee. The connective tissue is then repaired with stitches.

What does this mean for me?

Your doctor can only offer you this procedure as part of a research study, also called a clinical trial.

NICE has recommended that some details should be collected about every patient who has this procedure in the UK. Your doctor may ask you if details of your procedure can be used in this way. Your 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 I might get?
- How good are my chances of getting those benefits? Could having the procedure make me 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 I need after the operation?
- What happens if something goes wrong?
- What may happen if I don't have the procedure?

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

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 11 patients who had the procedure a patient questionnaire was used to assess hip movement and ability to function, on a scale from 0 to 100. The results showed an improvement, with the average score increasing from 61 before the procedure to 91, at an average of 43 months after the procedure.

The same study reported a reduction in pain after the procedure, with average pain scores decreasing from 83 before the procedure to 13 at an average of 43 months.

A study of 12 patients who had the procedure reported a significant increase in quality of life assessed using a questionnaire (with measures including freedom of movement, self care, everyday activities, pain and/or discomfort, and anxiety and/or depression). The average score increased from 0.26 before the procedure to 0.67 at an average of 28 months after the procedure.

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 they have doubts about how the procedure worked in theory. They said that key success factors are pain relief, patient satisfaction, hip function and quality of life.

Risks and possible problems

In the study of 11 patients, 1 patient had a seroma (a swelling caused by the build-up of clear fluid), which was treated successfully by surgical drainage.

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 in theory, loss of strength in the lower limb could be a problem.

More information about hip pain

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 greater trochanteric pain syndrome, 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. This 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 'distal iliotibial band lengthening for refractory greater trochanteric pain syndrome'. This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/HTG246

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2412). 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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