

Understanding NICE guidance

Information for people who use NHS services

Treating spasticity in cerebral palsy by cutting selected nerves in the lower spine (selective dorsal rhizotomy)

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 cutting selected nerves in the lower spine can be used in the NHS to treat people with spasticity in cerebral palsy. 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 child has been offered this procedure to decide whether to agree (consent) to it or not. It does not describe cerebral palsy 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. Some sources of further information and support are on the back page.

What has NICE said?

The evidence shows that the procedure is effective but that complications can be serious. This procedure can therefore be offered routinely as a treatment option for spasticity in cerebral palsy provided that doctors are sure that:

- the parents or carers understand what is involved and agree to the treatment, and
- the results of the procedure are monitored.

Parents or carers should be told that the procedure cannot be reversed, that walking ability and bladder function may deteriorate, and there may be later problems, such as spinal deformity. They should understand that prolonged physiotherapy and aftercare will be needed and that additional surgery may be necessary.

A healthcare team with specialist training and expertise in the management of spasticity in cerebral palsy, with access to the full range of treatment options, should decide which patients could benefit from this procedure and should carry it out. The team would normally include a physiotherapist, a paediatrician and surgeons.

NICE has encouraged further research into this procedure.

This procedure may not be the only possible treatment for muscle rigidity in cerebral palsy. Your child's healthcare team should talk to you about whether it is suitable for your child and about any other treatment options available.

Cutting selected nerves in the lower spine

The medical name for this procedure is 'Selective dorsal rhizotomy for spasticity in cerebral palsy'. The procedure is not described in detail here – please talk to your specialist for a full description.

Cerebral palsy is a brain condition that affects movement, posture and coordination. It may be seen at or around the time of birth or may not become obvious until early childhood. Some children will have lower limb spasticity, which can cause problems with walking and sitting, as well as discomfort, cramps and spasms.

Selective dorsal rhizotomy is a major surgical procedure that aims to reduce the amount of information carried by the sensory nerves. With the patient under general anaesthetic, a cut is made in the lower back and into the spinal canal to expose the spinal cord and lower nerves. Some of the sensory nerves that carry information from the muscles in the legs are cut. The nerves that make the muscles contract are not cut. After the procedure patients will need long-term physiotherapy and aftercare and may have to learn to walk again.

Other surgical procedures for spasticity include tendonotomy (cutting of tendons), neurotomy (cutting of nerves), osteotomy (cutting of bones), and tendon lengthening. Other treatment options include drugs (baclofen, botulinum toxin), use of corrective braces, physiotherapy, and electrical stimulation of the muscles or lower spinal cord.

What does this mean for me?

NICE has said that this procedure is safe enough and works well enough for use in the NHS. If your child's doctor thinks it is a suitable treatment option, he or she should still make sure you understand the benefits and risks before asking you to agree to it.

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 things 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 13 studies on this procedure.

How well does the procedure work?

A study of 142 patients reported a significantly greater improvement (reduction) in muscle tone at 1 year in 71 patients who had the procedure compared with 71 patients who had baclofen therapy. In a report of 3 studies (90 patients), patients who had the procedure plus physiotherapy were more able to move around at 9 months (1 study) and 12 months (2 studies) after the procedure (8% improvement in Gross Motor Function Measure [GMFM] score) compared with patients who had physiotherapy only (4% improvement in GMFM score).

In a study of 108 patients, GMFM score improved by 6% (5 points) at 20 months in patients who had the procedure and physiotherapy compared with 2% (2 points) in patients who had physiotherapy alone. A study of 14 patients reported that 10 had a sustained improvement 20 years after the procedure and of the 14, 9 had at least 1 further operation.

In the study of 142 patients, 94% and 96% of parents whose children were treated by the procedure or baclofen therapy respectively were satisfied with the outcome of treatment at 1 year.

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 are reduction in spasticity of the legs, reduced need for further corrective procedures, quality of life, and improvements in patients' ability to move, gait and walking, and level of independence.

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

Risks and possible problems

A study of 61 patients reported that 4 patients developed spondylolysis and spondylolisthesis (a stress fracture and slippage of part of the spinal column) in the lower back between 3 and 5 years after the procedure.

In 3 studies of 105, 98 and 30 patients, scoliosis (curvature of the spine) was reported in 55% of patients at 4 years, in 43% at 6 years, and in 50% at 21 years respectively.

In the study of 208 patients, 20 developed problems with bladder emptying, which resolved within 4 weeks in 18 patients.

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 complications of the procedure include death, worsening movement (including paralysis), wound infection, meningitis, leakage of fluid from the spine, dislocation of the hip(s), back pain, chronic pain, sensory disturbance, constipation, weakness, inflammation of the arachnoid (one of the membranes that protects the nerves in the spine) and formation of a cyst or cavity in the spinal column.

More information about cerebral palsy

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 cerebral palsy, 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. 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 'selective dorsal rhizotomy for spasticity in cerebral palsy'. This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/IPG373

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2391). 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.