

## **Understanding NICE guidance**

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**Information for people who use NHS services**

# **Treatment of spasticity in cerebral palsy by selective dorsal rhizotomy**

*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 selective dorsal rhizotomy (shortened here to SDR) can be used to treat people with spasticity because of cerebral palsy 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 patients and their parents or carers to decide whether to agree (consent) to it or not. It does not describe spasticity, cerebral palsy 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.

Interventional procedures guidance makes recommendations on the safety of a procedure and how well it works. 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.



## What has NICE said?

Evidence suggests that this procedure is safe, but there are uncertainties about how well it works.

If a doctor wants to use SDR for spasticity in cerebral palsy, he or she should make sure that extra steps are taken to explain the uncertainty about how well it works, the potential risks and the fact that the procedure cannot be reversed. Doctors should also explain that patients will need extensive physiotherapy and rehabilitation after the procedure. This should happen before the patient (or their parents) agrees (or doesn't agree) to the procedure. The patient or parents should be given this leaflet and other written information as part of this discussion.

A team of specialists should work together to ensure the right patients are chosen for this procedure. This team should include a physiotherapist, a paediatrician, an orthopaedic surgeon and a neurosurgeon.

There should also be special arrangements for monitoring what happens to patients after the procedure.

### Other comments from NICE

The patient's ability to walk may not be improved even if the spasticity is reduced. It is important that patients are chosen carefully for this procedure.

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

## Selective dorsal rhizotomy

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

Cerebral palsy is a permanent brain disorder that affects parts of the brain that control muscle tension, particularly in the legs. Normally, information from the muscles goes to the brain, which then sends back instructions telling the muscles to contract. Spasticity (too much muscle tension) is thought to occur because too much information is sent from the muscles to the brain. The aim of SDR is to reduce spasticity by reducing the amount of information sent to the brain.

SDR is a major surgical procedure on the backbone (spine). A cut is made along the lower back near to the spine. The nerves that send information from the muscles in the legs to the brain are cut. The nerves that make the muscles contract are not cut.

After the procedure patients need long-term physiotherapy and may have to learn to walk again.

Other treatment options for spasticity include drugs (baclofen, botulinum toxin), use of surgical appliances, physiotherapy, electrical stimulation and tenotomy (cutting of tendons).

## What does this mean for me?

If your doctor has offered you or your child SDR for spasticity in cerebral palsy, 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 that I (or my child) might get?
- How good are the 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 I (or my child) need after the operation?
- What happens if something goes wrong?
- What may happen if I don't (or my child doesn'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 five studies on this procedure.

### How well does the procedure work?

Three studies showed that SDR and physiotherapy together produced a greater improvement in overall muscle function than physiotherapy alone (4% improvement with physiotherapy; 8% improvement with SDR plus physiotherapy).

In another study neither SDR, injection of botulinum toxin, nor rehabilitation therapy increased walking speed at 20 months compared with baseline. Patients who had SDR showed a temporary reduction in walking speed at 3 months.

In another study, improvement in motor function was similar with SDR and orthopaedic surgery in children.

Other studies in children found that SDR significantly decreased muscle spasticity at 4 years, and improved walking at 12 months in children who were largely immobile before treatment.

The expert advisers said that the role of SDR in improving spasticity in cerebral palsy is controversial. They also said that reducing spasticity did not always help patients to walk or move better.

## Risks and possible problems

Severe pain after surgery and unpleasant feelings in the skin were common problems: 58% and 40% of 250 children who had SDR had these problems respectively. Twenty percent of children had constipation and 5% to 10% had urine retention. Other less common but serious complications were narrowing of the airways (5%) and pneumonia (1%). In addition, 40% of patients continued to experience increased spasticity during times of stress months, or even years, after SDR.

The expert advisers said that the adverse effects of SDR include problems with the bowels or bladder, weakness in the legs, dislocation of joints, progression of spinal curvature, and abnormal sensations in the skin. Other theoretical risks are paralysis, dividing the wrong nerves, too little muscle tone, weight gain and death.

## More information about spasticity in cerebral palsy

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/IPG195](http://www.nice.org.uk/IPG195)*

*You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1141).*