

Selective peripheral denervation for cervical dystonia

Understanding NICE guidance –
information for people considering the
procedure, and for the public

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (NICE) has issued to the NHS on a procedure called selective peripheral denervation. It is not a complete description of what is involved in the procedure – the patient's healthcare team should describe it in detail.

NICE has looked at whether selective peripheral denervation for cervical dystonia is safe enough and works well enough for it to be used routinely.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of selective peripheral denervation and how well it works
- asked experts for their opinions
- asked the views of the organisations that speak for the healthcare professionals and the patients and carers who will be affected by this guidance.

This guidance is part of NICE's work on 'interventional procedures' (see 'Further information' on page 10).

About selective peripheral denervation of cervical dystonia

In cervical dystonia, the muscles in the neck spasm and tighten. The tightening may happen all the time or it may come and go, and can occur at any age. Depending on the specific muscles affected, the head gets pulled backwards, forwards or to the side as a result. When the neck is pulled backwards, it's known as retrocollis. When it's pulled forwards, it's known as anterocollis. And when the head is pulled sideways, it's known as torticollis. What causes cervical dystonia is unknown, but in children, it's sometimes linked to abnormalities of the spine or the shape of the head.

The standard treatments for cervical dystonia are physiotherapy (using movement and exercise to try to ease the condition), medicines to help with the spasms, injections of botulinum toxin to try to stop the muscles from spasming temporarily, and surgery on the brain.

Selective peripheral denervation is surgery that involves cutting through the nerves that control the muscles. By cutting off the nerve supply, the tightening should stop in the muscles. The operation is done through an opening made in the skin. Sometimes the muscles are cut during the operation.

How well it works

What the studies said

In two studies that followed what happened in people who had selective peripheral denervation, the results were said to be good to excellent in most people. (This was the case in 228 out of 260 people in one study, and in 182 out of 207 people in the other study.) But the reports of these studies were not clear about the timings of the check-ups after the operation or how the results had been measured, which means that these results have to be treated with caution.

What the experts said

One expert said that the overall results from the operation should be better if doctors consider carefully which patients to offer it to, so it's not offered to someone for whom it's not likely to be suitable.

Risks and possible problems

What the studies said

In one study of 260 patients who had the operation, the problems reported were:

- an occasional twitching pain in the neck – three people had this
- one person had an abscess in the throat (an abscess is a pus-filled swelling)
- a swelling in the neck for a short time – a few people had this (the actual number wasn't given in the report)
- pins and needles or a feeling of tightness or fullness in the neck – a few people had this (the actual number wasn't given in the report).

What the experts said

The experts said that patients might have problems swallowing after they'd had the operation. And like all operations, there would be a chance of infection or bleeding.

What has NICE decided?

NICE has considered the evidence on selective peripheral denervation. It has recommended that when doctors use it for people with cervical dystonia, they should be sure that:

- the patient understands what is involved and agrees (consents) to the treatment, and
- the results of the procedure are monitored.

Selective peripheral denervation should be carried out in specialist neurosurgical units (which have specialist facilities for carrying out operations on the nervous system). And patients should be cared for by a team of health professionals linked to the unit.

Finally, the operation should be offered to a patient only if the medicines or injections don't work or have stopped working.

Other comments from NICE

NICE has commented that in the studies, nearly all the patients noticed some loss of feeling after they'd had selective peripheral denervation.

In general, the studies followed what happened in patients for a long time after their operation, so any long-term effects and problems were likely to have shown up in the results.

What the decision means for you

Your doctor may have offered you selective peripheral denervation because the medicines or injections normally used aren't helping your cervical dystonia. NICE has considered selective peripheral denervation because it is relatively new. NICE has decided that the procedure is safe enough and works well enough for use in the NHS. Nonetheless, you should understand the benefits and risks of selective peripheral denervation before you agree to it. Your doctor should discuss the benefits and risks with you. Some of these may be described above.

Further information

You have the right to be fully informed and to share in decision-making about the treatment you receive. You may want to discuss this guidance with the doctors and nurses looking after you.

You can visit the NICE website (www.nice.org.uk) for further information about the National Institute for Clinical Excellence and the Interventional Procedures Programme. A copy of the full guidance on selective peripheral denervation of cervical dystonia is on the NICE website (www.nice.org.uk/IPG080guidance), or you can order a copy from the website or by telephoning the NHS Response Line on 0870 1555 455 and quoting reference number N0662. The evidence that NICE considered in developing this guidance is also available from the NICE website.

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