

Subthalamotomy for Parkinson's disease

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

June 2004



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Issue date: June 2004

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Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0595. A version in Welsh and English is also available, reference number N0596. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0596. The NICE interventional procedures guidance on which this information is based is available from the NICE website (www.nice.org.uk). Copies can also be obtained from the NHS Response Line, reference number N0594.

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Website: www.nice.org.uk

ISBN: 978-1-4731-8764-1

Published by the National Institute for Clinical Excellence
June 2004

Typeset by Icon Design, Eton
Print on Demand

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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 subthalamotomy for Parkinson's disease. 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 subthalamotomy is safe enough and works well enough for it to be used routinely for Parkinson's disease.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of subthalamotomy for Parkinson's disease 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 subthalamotomy for Parkinson's disease

Parkinson's disease affects the brain. Because of the effects on the brain, patients shake, find it hard to stop and start movements, and their muscles can become fixed. These things usually get worse as time goes on. Normally, people take medicines to help, but sometimes these don't help or the person has bad side effects. Some people may find that the medicines help some of the time but they don't help at other times. If the medicines aren't helping or the person has bad side effects, the doctor may discuss having an operation on the brain.

Subthalamotomy, which is the operation NICE has looked at, is one type of operation for Parkinson's disease. It involves putting very thin needles into the brain through small holes made in the skull. Heat or radiofrequency energy is sent along the needles and this is used to destroy a small part of the brain that is involved in controlling movement, called the subthalamic nucleus.

How well it works

What the studies said

Not much evidence was available on subthalamotomy and the studies only looked at a small number of patients. In two studies of a total of 32 patients, it seemed that patients experienced better movement control after the procedure.

What the experts said

The experts said that there hadn't been enough studies done on the operation to judge whether or not it worked well for people with Parkinson's disease. They said that another operation, which uses an electrical current on the subthalamic nucleus, was the operation that doctors prefer to use. This is called subthalamic electrical stimulation.

Risks and possible problems

What the studies said

The problems that affected people who had subthalamotomy included:

- problems with voluntary movements (these are the ones you think about doing rather than the ones that happen automatically)

- a worsening of the ability to learn and remember information, and of the short-term memory that deals with where things are (called the spatial working memory).

In a study that followed what happened in 66 patients, 27 patients still had these types of problems 2 weeks after their operation.

What the experts said

The experts said that possible problems following a subthalamotomy were:

- stroke
- violent uncontrollable movements in one side of the body (this is called hemiballismus)
- difficulties with speech, swallowing or walking.

One expert was concerned that the effects of the operation could not be undone, and that patients might need to keep having the operation if the effects wear off.

What has NICE decided?

NICE has decided that, if a doctor wants to carry out subthalamotomy for Parkinson's disease, he or she should make sure that the patient understands what is involved and that there are still uncertainties over the safety of the procedure and how well it works. There should be special arrangements in place so that the patient only agrees (consents) to the procedure after this discussion has taken place.

A clinical trial is currently being organised to look at subthalamotomy, among other treatments for Parkinson's disease. NICE has encouraged doctors to discuss this trial with suitable patients, with a view to them taking part in it.

NICE has recommended that the decision about whether a patient may be suitable for a subthalamotomy should be made by a team of different healthcare professionals with different areas of expertise. The operation should be discussed as an option with patients only when the medicines for Parkinson's disease have stopped having an effect.

NICE may look at the operation again if new information becomes available.

Other comments from NICE

The studies that have been reported so far have mainly involved younger people with Parkinson's disease.

What the decision means for you

If the medicines for your Parkinson's disease have stopped having an effect, your doctor may have offered you subthalamotomy. NICE has considered this procedure because it is relatively new. NICE has decided that there are uncertainties about the benefits and risks of subthalamotomy which you need to understand before you agree to it. Your doctor should discuss the benefits and risks with you. Some of these benefits and risks 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 subthalamotomy for Parkinson's disease is on the NICE website (www.nice.org.uk/IPG065guidance), or you can order a copy from the website or by telephoning the NHS Response Line on 0870 1555 455 and quoting reference number N0594. The evidence that NICE considered in developing this guidance is also available from the NICE website.

If you want more information on Parkinson's disease, a good starting point would be NHS Direct (telephone 0845 4647) or NHS Direct Online (www.nhsdirect.nhs.uk).

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