

Deep brain stimulation for Parkinson's disease

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

November 2003



Corporate member of
Plain English Campaign.
Committed to clearer communication.

197

Deep brain stimulation for Parkinson's disease
Understanding NICE guidance – information for people considering the procedure, and for the public

Issue date: November 2003

To order copies

Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0349. A version in Welsh and English is also available, reference number N0350. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0350. 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 N0348.

National Institute for Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

Website: www.nice.org.uk

ISBN: 1-84257-422-1

Published by the National Institute for Clinical Excellence
November 2003

Typeset by Icon Design, Eton
Printed by Abba Litho Sales Limited, London

© National Institute for Clinical Excellence, November 2003. All rights reserved. This material may be freely reproduced for educational and not-for-profit purposes within the NHS. No reproduction by or for commercial organisations is allowed without the express written permission of the National Institute for Clinical Excellence.

Contents

About this information	4
About deep brain stimulation	5
What has NICE decided?	8
What the decision means for you	9
Further information	10

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 deep brain stimulation 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 deep brain stimulation is safe enough and works well enough for it to be used routinely for the treatment of Parkinson's disease.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of deep brain stimulation and how well it works
- asked experts for their opinion
- 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 deep brain stimulation

Deep brain stimulation can be used to treat some people with Parkinson's disease. Parkinson's disease causes shaking (tremor), rigidity of the muscles, and difficulties with starting and stopping some movements. The usual treatment is with drugs. Although the drugs usually work well at first, they do not help everyone. Also, people sometimes start having serious unwanted effects after they have been taking the drugs for a few years. Sometimes people have big swings in the symptoms of the disease (often called the on-off syndrome).

When drug treatment is not suitable for a patient, an operation on the brain may sometimes be possible. Experts think between 1 and 10 of every 100 people with Parkinson's disease could be helped by an operation. There are several types of operation for Parkinson's disease. Some involve destroying a part of the brain involved in controlling movement of the body.

Deep brain stimulation involves a different type of operation. Fine needles are inserted into the brain through the skull to locate the part of the brain to be stimulated, which may be in a slightly different position in each patient. A wire (called an electrode) is then inserted into this part of the brain. This is usually carried out under local anaesthetic.

Under general anaesthetic, the wire is then run under the patient's skin to a small machine called an implantable pulse generator, which is placed under the skin on his or her chest (a bit like a heart pacemaker). The pulse generator sends tiny electrical currents through the wire to the brain, and this reduces the problems caused by Parkinson's disease.

How well it works

What the studies said

The studies NICE looked at showed that deep brain stimulation improves the symptoms of Parkinson's disease, and makes it easier for patients to get around.

What the experts said

The experts agreed that deep brain stimulation works well soon after the operation, but said that not much is known about how well it works in the long term. One expert said it is important to consider carefully whether the operation is suitable for each patient individually, because it may not help everyone with Parkinson's disease.

Risks and possible problems

What the studies said

The operation to insert the electrode for deep brain stimulation can cause problems, and these include bleeding in the brain (a stroke), confusion, or problems with speech or sight. In two of the largest studies done so far, about three of every 100 patients who had deep brain stimulation had a stroke.

What the experts said

The experts felt that deep brain stimulation was safe as long as it was performed by a multidisciplinary team (a team of doctors and other health professionals with a range of different skills), working in a hospital department called a neuroscience unit. The team should include a doctor who specialises in treating diseases that affect the nerves (a neurologist), a brain surgeon (also called a neurosurgeon) and psychologists.

What has NICE decided?

NICE has considered the evidence on deep brain stimulation. It has recommended that when doctors use it for people with Parkinson's disease, 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.

NICE has also said that patients should be treated by a multidisciplinary team, and that patients should only be offered deep brain stimulation when drug treatment is no longer working.

A study, called PDSurg, is being done on deep brain stimulation at the moment. NICE has recommended that doctors should consider including patients in the study, with their permission.

What the decision means for you

Your doctor may have offered you deep brain stimulation. NICE has considered this procedure 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 deep brain stimulation before you agree to it. Your doctor should discuss the benefits and risks with you. Some of these benefits and risks may be described in this booklet.

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 deep brain stimulation is on the NICE website (www.nice.org.uk/IPG019guidance), or you can order a copy from the website or by telephoning the NHS Response Line on 0870 1555 455 and quoting reference number N0348. 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 is NHS Direct (telephone 0845 46 47), or NHS Direct Online (www.nhsdirect.nhs.uk).

Date: November 2003



*National Institute for
Clinical Excellence*

**National Institute for
Clinical Excellence**

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk