

Treating brain tumours with photodynamic therapy

NICE 'HealthTech guidance' advises the NHS on when and how new procedures can be used in clinical practice.

This leaflet is about when and how photodynamic therapy (often shortened to PDT) can be used in the NHS to treat people with brain tumours. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

This HealthTech 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.

NICE has produced this guidance because 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 people who have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe brain tumours 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. Some sources of further information and support are on page 7.

What has NICE said?

Currently there is not enough good quality evidence to be certain about how well this procedure works or how safe it is. For this reason, NICE has said that this procedure should only be carried out as part of a research study (also called a clinical trial). The research should look at the type of tumour being treated, the length of time that patients survive after treatment and their quality of life.

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

Photodynamic therapy

The medical name for this procedure is 'photodynamic therapy for brain tumours'.

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

If a brain tumour, also known as a glioma, starts from inside the brain it is called a primary tumour. If it has spread from cancer cells in another part of the body it is called a secondary tumour or a metastatic tumour. Depending on where it is in the brain, the tumour can cause a range of symptoms, including weakness in the limbs, problems with vision and difficulty in speaking. If the tumour puts pressure on the brain it can lead to headaches, nausea and vomiting, and drowsiness.

Brain tumours are usually treated with radiotherapy, chemotherapy, surgery, or a combination of these methods, depending on the type of tumour and where it is in the brain. Photodynamic therapy (PDT) can be carried out at the same time as surgery to remove as much of the tumour as possible. A drug called a 'photosensitising agent' is injected into the patient's vein before the operation (or occasionally it may be injected directly into the tumour during surgery). 'Photosensitising' means that the drug does not become active until it comes into contact

with light. During the operation, a special light from a laser is shone on the area, causing the photosensitising agent to become active and destroy only the tumour cells.

After having PDT, patients need to stay away from bright light, including direct sunlight, for several weeks to avoid damage to the skin.

What does this mean for me?

Your doctor can only offer you this procedure as part of a research study (also called a clinical trial). NICE has recommended that some details should be collected about every patient who has this procedure in the UK. Your doctor may ask you if details of your procedure can be used to help collect more information about this procedure. Your doctor will give you more information about this.

You may want to ask the questions below

- What does the procedure involve?
- What are the benefits I might get?
- How good are my chances of getting those benefits? Could having the procedure make me feel 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 need after the operation?
- What happens if something goes wrong?
- What may happen if I don'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 six studies on this procedure.

How well does the procedure work?

In a study of 27 patients with newly diagnosed glioblastoma (a common and aggressive type of primary brain tumour), 13 patients who had PDT as well as surgery survived for an average of 52.8 weeks, compared with 14 patients who had surgery alone who survived for an average of 24.1 weeks. This study also used a health score to measure the effect of the procedure (with 0 meaning death and 100 being perfect health) and found that patients who had PDT after surgery improved from 60 to 80 points, compared with patients who had surgery alone, whose score stayed at 70 points.

In a study of 26 patients who had severe glioblastoma that had returned after treatment, patients who had PDT after surgery survived for an average of 8.5 months, with their tumour beginning to grow again 6 months after treatment.

A study of 112 patients who had PDT after surgery reported average survival times of 30 weeks for patients with primary brain tumours and 24 weeks for patients with secondary tumours. Another study of 136 patients who had PDT after surgery reported average survival times of 76.5 months (6.4 years) for patients with a type of primary brain tumour known as an anaplastic astrocytoma, and 14.3 months (1.2 years) for patients with a rapidly growing form of brain tumour known as a glioblastoma multiforme. This study found that the length of time patients survived was not related to the location of the tumour in the brain.

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 aim of the procedure is to remove as much of the tumour as possible and to increase the length of time patients survive without symptoms.

Risks and possible problems

In one of the studies, 3 out of 112 (3%) patients died after the operation. Four out of 112 (4%) patients had deep vein thrombosis (formation of a blood clot in a vein), 4 out of 112 (4%) patients developed an infection, and 1 out of 112 (1%) patients had a leak of cerebrospinal fluid (fluid from the brain). In the study of 26 patients, 1 patient had temporary oedema (swelling due to accumulation of fluid) in the area where the operation had been done. In three of the studies between 2% and 8% of patients developed sunburn after they exposed their skin to light following the treatment.

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 problems may include swelling and increased pressure in the brain, sensitivity of the skin to light and allergic reactions. Other possible problems are damage to normal blood vessels in the brain, stroke and an increase in the risk posed by further treatment to the brain.

More information about brain tumours

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.

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. This 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 'photodynamic therapy for brain tumours'. This leaflet and the full guidance aimed at healthcare professionals are available at www.nice.org.uk/HTG184

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1828).

We encourage voluntary organisations, NHS organisations and clinicians to use text from this booklet in their own information about this procedure.

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