

Understanding NICE guidance

Information for people who use NHS services

Treating malignant parotid tumours using photodynamic therapy

NICE 'interventional procedures 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 malignant parotid tumours. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence).

Interventional procedures 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 the procedure is not generally used in the NHS. 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 people who have been offered this procedure to decide whether to agree (consent) to it or not. It does not describe parotid 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 the back page.



What has NICE said?

There is not much good evidence about how well this procedure works or how safe it is. If a doctor wants to use PDT for malignant parotid tumours, they should make sure that extra steps are taken to explain the uncertainty about how well it works, as well as the uncertainty surrounding potential risks and benefits of the procedure. This should happen before the patient agrees (or doesn't agree) to the procedure. The patient should be given this leaflet and other written information as part of the discussion. There should also be special arrangements for monitoring what happens to the patient after the procedure.

NICE has said that further information on the safety of PDT and how well it works will be helpful.

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

Treating malignant parotid tumours using PDT

The medical name for this procedure is 'Interstitial photodynamic therapy for malignant parotid tumours'.

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

The parotid glands are located in front of the ears and help to produce saliva. A tumour in a parotid gland usually causes a painless swelling on the side of the face where the affected gland is. Only a small number of these tumours are cancerous (malignant).

The main treatment for parotid gland tumours is surgical removal. Radiotherapy and chemotherapy may also be used if the tumours are malignant.

PDT is a type of therapy using light. In PDT, a drug called a 'photosensitising agent' is injected into a vein. 'Photosensitising' means that the drug does not become active until it comes into contact with light. A few days later, the operation is carried out under a local or a general anaesthetic. Using image guidance, needles are inserted into the tumour, and a special laser light is shone through them. The light from the laser causes the photosensitising agent to become active and destroy the tumour cells.

After the photosensitising agent has been given, patients need to avoid sunlight because their skin can get damaged, so they need to be reintroduced to normal lighting conditions gradually over a period of approximately 2 to 3 weeks.

What does this mean for me?

If your doctor has offered you PDT for malignant parotid tumours, he or she should tell you that NICE has decided that the benefits and risks are uncertain because there is not a lot of evidence about the procedure. 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 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?

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 two studies on this procedure.

How well does the procedure work?

In one study, two patients whose parotid tumours had not responded to other treatments were treated with PDT. The study reported that it was successful in one patient who was alive and cancer-free just over 1 year after the procedure. The other patient was described as responding to treatment but no other information was given. In a second study of one patient, the patient was still alive 3 years after the procedure

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 control the growth of the tumour.

You might decide to have this procedure, to have a different procedure, or not to have a procedure at all.

Risks and possible problems

There were no problems reported that were linked to PDT.

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 possible problems could include burns, allergic reactions, nerve and blood vessel damage, bleeding and delayed healing.

More information about malignant parotid tumours

NHS Direct online (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. Interventional procedures 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 'Interstitial photodynamic therapy for malignant parotid tumours'. This leaflet and the full guidance aimed at healthcare professionals are also available at www.nice.org.uk/IPG259

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1554).

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