

Proton beam therapy (PBT) is a type of radiotherapy used to treat certain types of tumours, including some sarcomas.

A Sarcoma UK Factsheet produced by the information and support team

This factsheet explains more about PBT, including who is eligible for the treatment and why it might be beneficial for them.



What is radiotherapy?

Radiotherapy is a type of cancer treatment that uses x-ray radiation beams to destroy cancer cells. It can be used to treat bone and soft tissue sarcomas before, after or (less commonly) instead of surgery. Using x-ray radiation is sometimes called conventional radiotherapy. When used before surgery, the aim of radiotherapy is to stop the tumour spreading or growing any bigger. This can make surgery more effective. However, it is important to bear in mind that having radiotherapy before surgery can sometimes slightly increase the risk of surgical complications. In some cases, radiotherapy might be advised after surgery. In these cases, the aim is to kill off any local cancer cells which might remain in the area of the tumour. Not all patients need to have radiotherapy after surgery, and only a small number of patients would benefit from having radiotherapy by PBT rather than conventional radiotherapy.



What is proton beam therapy?

Proton beam therapy (PBT) is a form of radiotherapy which uses high energy proton beams instead of x-ray radiation beams. Radiation enters the body in a similar way to conventional radiotherapy, causing damage to the tumour and the normal tissues. However, proton beams reduce the amount of radiation reaching beyond the tumour.



What are the benefits of PBT?

The main advantage of PBT is that it can cause less long term side effects than radiotherapy, for some types of sarcoma in certain parts of the body. This is because although x-ray radiotherapy works by destroying cancerous cells, it can damage the surrounding tissues at the same time. When this surrounding tissue is in or near a sensitive part of the body – like the spinal cord, or the bowel or bladder – the damage caused by x-ray radiotherapy can lead to long term side effects. For example, if the bowel is affected by radiation this may lead to a change in bowel habits, or if the bladder is affected it may lead to

changes to how your bladder works. When proton beam therapy is used, the beams of protons which deliver the treatment can be made to stop just after they hit the cancerous cells. This means that less radiation is delivered beyond the tumour, which results in less damage to the surrounding tissue or organs.

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Who might benefit from PBT?

The main advantage of PBT is that it can deliver a more targeted use of radiotherapy than x-ray radiotherapy. This doesn't mean that it will be more or less likely to improve the chances of survival or the chances of a cure. However, there are two main groups who would benefit from PBT rather than x-ray radiotherapy.

1. Children and young people can benefit from proton beam therapy, because radiotherapy can sometimes damage their developing organs. If radiotherapy is delivered to healthy tissue in children or teenagers, it can sometimes result in long term side effects. Depending on where the sarcoma is and the radiation dose needed, these may include problems with:

- Growth
- IQ
- Development through puberty
- Hormone deficiencies
- Fertility
- A small increased risk of developing a second cancer

2. Adults with sarcoma in parts of the body which are hard to treat would also benefit from proton beam therapy, as there is a smaller radiation dose to surrounding tissues. 'Hard to treat' or sensitive areas include:

- Spine
- Base of the skull
- Head and neck region
- Pelvis

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Are there any side effects from PBT?

The side effects of proton beam therapy depend on the part of the body being treated and the size of the tumour. After treatment, like with x-ray radiotherapy, you might experience changes to your skin. These might include redness, irritation, swelling, dryness, blistering or peeling. Your treatment team will explain these in more detail and give you information on dealing with any problems you might have because of PBT. It is important to remember that proton beam therapy has only been commissioned in the UK since 2008 and is a relatively new treatment.

This means that there is less evidence available on its side effects or effects over time.



How can I access PBT?

If your doctor feels PBT might be suitable for you, they will submit a referral form to a panel of specialist doctors. This panel will then decide whether you are eligible for the treatment. If you are eligible, you'll be referred to the NHS centre at The Christie, or to an NHS commissioned overseas centre in Germany, the USA or Switzerland. Patients will continue to be referred to overseas centres until both NHS proton beam centres are fully open. This is expected to be in 2020.



Do I have to pay anything if I have this treatment abroad?

The medical costs of PBT are paid for by the NHS. The NHS will also pay for the economy class travel and accommodation costs for patients and two parents/carers for paediatric patients and one carer for teenage and adult patients. The NHS will not cover the cost of meals or refreshments.



Who pays for the treatment?

In England and Scotland, the NHS will pay for your treatment and cover your travel and accommodation costs. In Wales and Northern Ireland, your doctor will liaise with your local health board about funding for treatment, travel and accommodation costs.



What if I'm not eligible for PBT?

For most patients, there is no strong evidence that proton beam therapy is better than x-ray radiotherapy in treating sarcoma. For a lot of sarcoma patients, x-ray radiotherapy might be just as or more effective in treating their type of cancer. Your medical team will discuss your treatment options with you and explain why you are or are not being considered eligible for PBT. The current evidence suggests that proton beam therapy is unlikely to cure more people than current radiotherapy techniques. To find out which patients could benefit most and who should be offered PBT as their standard treatment, we need data from clinical trials and ongoing research.



Further information

Please speak to your doctor if you have any questions about proton beam therapy. There is also further information on the NHS England website: www.england.nhs.uk. They have a range of guides and information for adults and parents of children receiving PBT.

Talking to us



0808 801 0401



supportline@sarcoma.org.uk

Our Support Line offers practical and emotional support and advice to anyone affected by sarcoma.

- Our support line is independent & confidential.
- We believe no question is a silly question.
- We lend a listening ear.

We can point you in the right direction.