

This factsheet was produced by **Sarcoma UK**, the only charity in the UK focusing on all types of sarcoma cancer.

Our mission is to amplify awareness, inspire involvement, and fund ground-breaking research to transform the lives of everyone affected by sarcoma.



Proton beam therapy

What is radiotherapy?

What is PBT?

Which sarcoma patients might benefit from proton beam therapy?

What are the benefits of PBT?

Is everyone with sarcoma eligible for PBT?

Are there any side effects from this treatment?

How can I access this treatment?

Do I have to pay anything towards having this treatment abroad?

Who pays for this treatment?

Further information

Certain types of sarcoma can be treated using a type of radiotherapy called proton beam therapy (PBT). This therapy is not currently available in the UK. Proton beam therapy services are expected to start in the UK in 2018. NHS commissioned services will be initially delivered at The Christie Hospital in Manchester and later also at University College London Hospital.

Since 2008 the NHS has been paying for selected sarcoma patients to have proton beam treatment in the USA or Europe. They will continue to do so until both UK sites are fully operational. This factsheet explains more about PBT including who is eligible for this treatment and how you can access this treatment overseas.

What is radiotherapy?

Radiotherapy is a type of cancer treatment that uses high-energy radiation beams to destroy cancer cells. It can be used to treat both bone and soft tissue sarcomas before, after or instead of surgery. When used before surgery it aims to reduce the size of the tumour, or treat the margins of the tumour to make surgery more effective. In some cases, radiotherapy is used after surgery. In this case, the aim is to kill off any local cancer cells which may remain in the area of the tumour.

What is PBT?

Proton beam therapy is a different type of radiotherapy that uses high-energy proton beams rather than high-energy radiation beams to deliver a dose of radiotherapy. It can be used to treat different types of cancer including some types of sarcoma.

Which sarcoma patients might benefit from proton beam therapy?

Children or young people can benefit from PBT as radiation can sometimes damage their developing organs. Radiotherapy delivered to healthy tissue in children and teenagers can sometimes result in long term 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
- Small increased risk of developing a second cancer

Adults with sarcoma in parts of the body which are hard to treat could also benefit from PBT. These areas include:

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

The accuracy of PBT means a higher dose of radiation can be given to a specific area, reducing radiation dose to the normal surrounding tissues.

What are the benefits of PBT?

The main advantage of PBT is in reducing long-term side-effects of radiotherapy rather than improving survival or cure. X-ray radiotherapy destroys cancerous cells but it can also damage the surrounding tissue. This can lead to short term side effects such as nausea. If the radiotherapy treatment is delivered near to vital organs it can damage them and change the way they work in the long term. For example, if the bowel is affected it can lead to diarrhoea and if the bladder is affected it can lead to a frequent need to urinate. Your doctor and radiotherapy team will spend time planning your treatment to try and minimise the dose that is received to these vital areas.

Proton beam therapy uses beams of protons that also destroy cancer cells. The difference with PBT is that the beams of protons can be made to stop just after they hit the cancerous cells. This results in much less damage to surrounding tissue or vital organs near the tumour as the radiation is delivered precisely to the area where it is needed. This is particularly useful when treating cancers in locations near vital structures such as the spine, head and neck.

Is everyone with sarcoma eligible for PBT?

For most patients there is no strong evidence that PBT is better than x-ray radiotherapy in treating sarcoma. For a lot of sarcoma patients x-ray radiotherapy may be just as or more effective to treat their type of cancer. PBT uses highly specialised and expensive equipment so it is important to prioritise this treatment for people who will most benefit from it.

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. Current research is taking place to find out how best to use PBT.

Are there any side effects from this treatment?

The side effects of proton therapy depend on the part of the body being treated and the size of the tumour. After treatment, you may experience tiredness and skin problems. These include redness, irritation, swelling, dryness, or blistering and peeling. Your treating team will discuss which side effects you are mostly likely to experience.

PBT has only been commissioned in the UK since 2008. Doctors do not yet know if there are any long-term side-effects you could experience from having this fairly new treatment.

How can I access this treatment?

If your doctor feels that proton beam therapy may be suitable for you, they will submit a referral form to a panel of specialist doctors. The panel will decide whether you are suitable for proton beam therapy, for example, is the treatment likely to be more beneficial than x-ray radiotherapy. They will also check to see whether you meet certain criteria such as that you are fit to travel. If appropriate then, the panel will confirm to your doctor that a referral to an overseas proton centre can be made.

This referral is coordinated by the National Specialised Commissioning Team (NSCT) Proton Overseas Programme. The NSCT plans and monitors services for people with rare conditions, including sarcoma.

Do I have to pay anything towards having 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 and refreshments.

Who pays for this treatment?

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

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 There you will find helpful guides for both adults and parents of children receiving PBT.



supportline@sarcoma.org.uk

This factsheet was reviewed by the Proton Beam Therapy Team at The Christie, Manchester. Special thanks to:
Dr Catherine Coyle, Sarcoma Clinical Lead
Fiona Lewis, Proton Beam Therapy Project Manager
Charlotte Smith, Specialist Radiographer



Version 1 • Published: August 2016 • Review: August 2018

This factsheet has been produced by the Information and Support Team at Sarcoma UK. It has been reviewed by Sarcoma UK's Information Review Panel which includes healthcare professionals and people affected by sarcoma.

References to the source of information used to write this factsheet and an acknowledgement of the members of the Information Review Panel who reviewed the booklet are available from Sarcoma UK – info@sarcoma.org.uk

Sarcoma UK makes every reasonable effort to ensure that the information we provide is up-to-date, accurate and unbiased. We hope this factsheet adds to the medical advice you have received and helps you make informed decisions about your care and treatment. Please speak to a member of your care team if you are worried about any medical issues.

Sarcoma UK does not necessarily endorse the services provided by the organisations listed in our publications.



The bone & soft tissue cancer charity



sarcoma.org.uk



020 7250 8271



info@sarcoma.org.uk



@Sarcoma_UK



[uk.sarcoma](https://www.facebook.com/uk.sarcoma)



49-51 East Road,
London N1 6AH

**We rely solely on your donations to keep producing these factsheets.
Any donation is welcome**

Online:
sarcoma.org.uk

By Text:
Text SAUK00 £10 to 70070

By phone:
020 7250 8271

By cheque:
payable to 'Sarcoma UK'
and send to: Sarcoma UK,
49-51 East Road,
London, N1 6AH