What to expect

What is it like to be treated with proton beam therapy?

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Both proton beam therapy centres in the UK use state-of-the-art equipment and facilities to provide the best possible care and treatment for every patient. A course of proton beam therapy is delivered in a number of radiotherapy sessions over a period of 6–8 weeks. Accommodation is provided for the whole of this period if required.

Both proton beam therapy centres have a single particle accelerator that serves up to four individual treatment rooms known as 'gantry rooms'. This name comes from the large circular piece of machinery that contains the treatment delivery system. The gantry is able to fully rotate around the patient to achieve the best angle for the proton beams. Before each treatment session, the radiotherapy team positions the patient on an advanced bed known as a 'robotic couch'. This couch allows very fine adjustments in positioning, and the radiotherapy team helps the patient adopt a position that is comfortable to remain still in.

Once in position, the radiotherapy team moves to the imaging bay, an area within the gantry room. Here they check the patient's position through a series of 2D and 3D scans. Special ProBeam software allows the radiotherapy team to make small adjustments to the position to ensure precision in treatment. When the patient's position is confirmed, the radiotherapy team will leave the treatment room to start the proton beam therapy. They constantly monitor the patient throughout the treatment using CCTV and an intercom system, so the patient isn't alone. Patients may also be able

to bring in music or audiobooks to listen to during treatment, and young patients may be able to have soft toys to help them through this short period with everyone out of the room. Very young patients may require sedation prior to treatment so that they can remain absolutely still during treatment. They will then be taken to a recovery room after the treatment until they wake up.

After the treatment has been delivered, the radiotherapy team re-enters the gantry room to help the patient out of the apparatus. Each treatment session can last anywhere between 15 and 45 minutes, with the proton beam therapy being delivered in just 1–3 minutes. Patients have 5 sessions per week (Monday–Friday) over the 6–8 week course.

Imaging

Imaging is very important throughout the whole treatment process because the size and shape of the tumour is likely to change after each radiotherapy session. In addition, imaging can ensure that the patient is in the same position for each treatment session. The radiotherapy team assesses the patient's positioning very carefully before each session to ensure the protons are still travelling to the right place. Images are also reviewed by the radiotherapy team to monitor progress throughout the entire treatment course so that if any changes are necessary, they can be made.

Review

As part of proton beam therapy, the patient has a weekly review. This review keeps the patient up to date on the progress of the treatment and the effect it is having on the

tumour. The team also reviews any side effects and any other treatment that is being given at the same time, such as chemotherapy. Patients can also expect to receive an assessment and any support required from allied health professionals. These reviews are also good opportunities to ask any questions.

What are the potential side effects of proton beam therapy?

Although proton beam therapy has been shown to reduce the side effects of conventional X-ray radiotherapy in some cancers, the treatment does still carry the risk of unwanted side effects. Some healthy tissue may still be damaged when the protons release their radiation. The exact side effects experienced depend on the dose of proton beam therapy and the area being treated. It's best to ask the healthcare team about potential side effects, as it will be different for everyone.

Short-term side effects may occur during or after treatment. These side effects are characterised by their temporary nature, so these symptoms may only be experienced during the treatment and for a few weeks afterwards. Some reported short-term side effects in the treatment of brain tumours with proton beam therapy include:

- fatigue
- headaches
- sore or dry mouth and throat
- nausea and vomiting
- hair loss

- skin redness
- loss of taste and appetite
- metallic taste
- ear congestion
- inflammation of the mucous membrane.

These are similar to the side effects experienced with conventional radiotherapy. Patients may experience some, but not necessarily all, of these side effects, and they may occur at different stages throughout the proton beam therapy treatment.

There is less information available concerning the long-term side effects of proton beam therapy simply because the treatment hasn't been around for long enough to conduct effective clinical studies. Long-term side effects are those that either continue for months or years after treatment, or have a late onset months or years after treatment. These are also known as late effects. As there is a small risk of damage to healthy tissue in proton beam therapy, this carries the concurrent risk of the long-term side effects of radiotherapy.

If there are any unusual symptoms either during or after treatment, it is important to talk with the doctor or the healthcare team immediately. Talking with the healthcare team throughout treatment is invaluable, as there may be options for managing side effects, such as anti-sickness medication, painkillers and skin creams.

Something that is also a valid side effect of radiotherapy are psychological side effects. These may include anxiety, depression, post-traumatic stress disorder, and a range of overpowering emotions such as fear, anger, guilt and

loneliness. It is perfectly normal to feel any or all of these emotional or psychological symptoms. As with any physical side effects, it is also important to talk with the healthcare team about any psychological side effects, as these can have a very serious impact on quality of life. Throughout the care pathway, patients should have ready access to health services to support them through their treatment and beyond.

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Mike, Tom, Rebecca, Charlie & Sophie