

Proton beam therapy

Proton beam therapy for base of skull chordoma

What is chordoma?

Chordoma is a slow growing cancer, arising from a group of cells (known as the notochord), which usually disappear before birth, but can persist in some people.

What is proton beam therapy (PBT)?

PBT is a form of radiotherapy. Radiotherapy works by damaging dividing cells in our bodies. Because cancer cells are not able to repair themselves as efficiently as normal cells, more cancer cells should be destroyed. However, a small proportion of normal cells will also be damaged, leading to side-effects. PBT is as effective as standard radiotherapy at treating the tumour, but because it affects less healthy tissue there are generally fewer long-term side effects.

Short-term side effects

Most side effects experienced generally settle within 4 to 6 weeks after completing PBT.

Common side effects (more than 1 in 10):

- Tiredness.
- Nausea (feeling like you need to be sick).
- Blocked ears – your ears may seem fuller, or your hearing is less clear.
- Tinnitus – a ringing or buzzing sound in one or both ears.
- Headache – this may be similar to the headache you experienced when you first had some symptoms.
- Sore mouth/throat – your mouth and/or throat may become sore and inflamed during treatment and may develop white patches (mucositis). Some people may get ulcers, particularly on the roof of the mouth while some may have pain on swallowing.
- Loss of appetite – this can be caused by painful swallowing, nausea and vomiting, and changes to taste, and may lead to temporary weight loss.
- Hair loss/thinning – this can occur in limited areas where the beams enter.
- Taste changes – you may lose your sense of taste and find everything tastes the same.



Uncommon side effects (less than 1 in 10):

- Vomiting (being sick).
- Skin redness, dryness – changes to skin where the beams enter.
- Worsening tumour related symptoms – some symptoms may temporarily worsen from what they were before treatment.
- Seizures (fits or epilepsy) – can cause changes in movements, behaviour, or level of consciousness.
- Nasal discharge – this may be crusty or blood-stained.

Long term side effects

These can develop months to years after treatment and may be permanent and irreversible.

Common side effects (more than 1 in 10):

- Pituitary underactivity – radiotherapy can reduce the production of hormones by the pituitary gland, which is a small gland at the base of the skull. Medications may be required to replace the hormones.
- Hearing loss – your hearing may become less clear, or you may develop tinnitus.
- Short term memory or other cognitive impairment – this is usually mild (at most) and usually does not significantly impact day-to-day living.

Uncommon side effects (less than around 1 in 20):

- Permanent skin changes and/or hair loss/thinning.
- Radiation damage (radiation necrosis) to healthy brain tissue – damage to part of the brain such as the temporal lobe seen on a scan after treatment can sometimes cause seizures, needing anti-epileptic medication.
- Sometimes very important normal cells can be temporarily or permanently damaged, even with the very best efforts to prevent this. This can cause:
 - **loss of vision** – including complete and permanent loss of vision in one or both eyes.
 - **spinal cord injury** – this may cause weakness or loss of sensation in the arms and/or legs, or loss of control of bladder or bowel.
 - **brainstem injury** – this can affect a number of functions such as balance, co-ordination, speech, breathing, swallowing, movement and sleep patterns, and can rarely be life-threatening.

If you experience any of these symptoms, you must inform your local skull base team and local oncologist immediately for medical advice as sometimes these symptoms can be reversed with prompt treatment.

- Increased risk of stroke – this may occur many months or years after treatment. Minimise your risk with healthy eating, moderate alcohol intake, and not smoking.
- Radiotherapy-related second tumours – there is a small chance you may develop another tumour due to your radiotherapy treatment in the future.

Can I continue to drive?

Following your diagnosis you must inform DVLA, who will advise whether you can continue driving. While awaiting advice from DVLA, you should not drive.

Contacts

If you have any concerns or questions, please contact:

Neuro-oncology specialist radiographers **0161 918 7235 / 07584 443706 / 07825 078614**

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