

## Proton beam therapy

# Proton beam therapy for base of skull chordoma

### What is chordoma?

Chordoma is a usually 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 will be destroyed. However, a small proportion of normal cells will also be damaged, leading to side-effects. PBT is as effective as conventional radiotherapy (X-ray radiotherapy) at treating the tumour, but because it affects less healthy tissue there are 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) and uncommonly vomiting (being 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 throat/mouth – some people get ulcers, particularly on the roof of the mouth. 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.

#### Uncommon side effects (less than 1 in 10):

- 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 impairment – this is usually at most mild and usually does not significantly impact on day-to-day living.

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

- Permanent skin changes and/or hair loss/thinning.
- Temporal lobe damage (necrosis) – damage to part of the brain known as the temporal lobe seen on a scan after treatment can sometimes cause seizures, needing anti-epileptic medication.
- 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.
- Sometimes very important normal cells can be permanently damaged, even with the very best efforts to prevent this. This can cause:
  - **Loss of vision** – including complete 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.
- Radiotherapy-related second tumours – there is a small chance you may develop another tumour due to your radiotherapy treatment over the next several decades.

## Can I continue driving?

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

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

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For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.



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