

Patient information

Proton Beam Radiotherapy

St Paul's Eye Department

Your Consultant / Doctor has advised you to have Proton Beam Radiotherapy.

What is Proton Beam Radiotherapy?

This means that your tumour will be treated with a radioactive beam of protons directed at the tumour. A special machine is used to model the beam of radiation to the exact size and shape of the tumour so as to minimise damage to the delicate tissues which surround it.

This treatment will take place in three stages:

1. An operation to sew three or four tiny metal buttons to the back of your eye around the outside of your tumour.
2. After your operation, you will be contacted by Clatterbridge Centre for Oncology Wirral, who will give you a date to attend for planning measurements and other preparations to be carried out. This will take about half a day.
3. After your planning, you will be given a date to return to Clatterbridge(Wirral site) for a five day course of treatment. Accommodation may be provided for the duration of the treatment for patients that live a long distance from Clatterbridge Hospital. The cost of the accommodation is met by the hospital, and you will be transported to and from the hospital by taxi if necessary.

What are the benefits of having Proton Beam Radiotherapy?

Proton beam radiotherapy is highly successful at destroying tumours and is particularly useful when other methods are less reliable or more complicated.

What are the risks of having Proton Beam Radiotherapy?

These may include local tumour recurrence, retinal detachment, and radiation damage to your retina and optic nerve with loss of vision. There may also be eye and eyelid irritation, dry or watery eye, and loss of your eye.

The chances of systemic tumour recurrence (spread of tumour to other parts of the body) are about the same as after removal of the eye.

Are there any alternative treatments available?

There may be other treatments available and the doctor will have discussed these with you. If you feel that you need any further information please feel free to ask your doctor or specialist ocular oncology nurse (your key worker).

What will happen if I don't have any treatment?

Your tumour may continue to grow. This might make treatment more difficult and could make your eye painful.

There may be an increased risk of tumour spread out of your eye and to other parts of your body.

What sort of anaesthetic will be given to me?

You will be given a general anaesthetic. General anaesthetic is drug induced unconsciousness. It is always provided by an anaesthetist, who is a doctor with specialist training.

Unfortunately, both local and general anaesthetic can cause side effects and complications.

Side effects are common, but are usually short-lived: they include nausea, confusion and pain. Complications are very rare, but can cause lasting injury: they include awareness, paralysis and death.

The risks of anaesthetic and surgery are lower for those who are undergoing minor surgery, and who are young, fit, active and well. For more information, please ask for a copy of the Royal College of Anaesthetists Patient Information “You and Your Anaesthetic”.

You will be given an opportunity to discuss anaesthetic options and risks before your surgery.

If you are worried about any of these risks, please speak to your Consultant or a member of their team before you are due to have this treatment.

Stage one: Getting ready for your operation

You will be admitted to the day ward the morning after your clinic appointment or, if this is not possible, a couple of weeks later. You will have some blood tests and an ECG (heart tracing). These tests are very important for you. It is better to find out about any problems as soon as possible to help prevent operations being postponed for medical reasons.

If there are any complications, our doctors will refer you to the appropriate hospital specialist or to your own family doctor (GP). You will be told if this is the case.

Interview / teaching session

You will be encouraged to ask questions and talk about your condition and operation. A qualified ophthalmic nurse will explain your care in detail using a specially designed care programme.

The day of your operation

- You will be admitted via the Theatre Assessment Unit (TAU) on the day of your operation.
- Please leave all cash and valuables at home. If you need to bring valuables into hospital, these can be sent to General Office for safekeeping. General Office is open between 8.30 and 4.30 Monday to Friday. Therefore, if you are discharged outside these times we will not be able to return your property until General Office is open. The Trust does not accept responsibility for items not handed in for safekeeping.
- You will be asked to remove jewellery - band rings can be worn but they will be taped.
- If you are on regular medication, you will be told to take this if necessary.
- You will be asked to put on a gown and disposable underwear.
- A bracelet with your personal details will be attached to your wrist.
- You will be asked to sign a consent form.
- You may be prescribed some medication to take before your \ operation by the anaesthetist. A member of the nursing staff will give this to you.
- A nurse and porters will take you to the operating theatre.
- Your dentures, glasses or hearing aid can stay with you on your journey to the operating theatre.
- When you arrive in the waiting area, a theatre nurse will check your details with you. You will then be asked to put on a disposable hat.
- The unit nurse will then leave you and you will then be taken to the anaesthetic room.

The operation

The operation to put in the location markers takes about 45 minutes.

These markers will not be visible and are usually left in place permanently after treatment is completed.

What should I expect after my operation?

- After your operation you will be kept in the theatre recovery room \ before being transferred to the in-patient ward.
- A nurse will check your pulse, blood pressure, breathing rate and wound regularly.
- The nursing staff will also advise you when you can start taking sips of water. Anaesthetics can make some people sick. If you feel sick we advise you not to drink until this feeling has passed.
- The nursing staff may offer you an injection to help this sickly feeling go away.
- Your eye may feel a little uncomfortable for a few days. You will be offered painkillers if needed.
- The stitches will dissolve so will not need to be removed.
- Your treated eye might be red and possibly a little swollen for a couple of weeks, but this should settle quickly.

Going Home

You will be discharged from hospital on the same day as your operation.

Discharge Information

Pain relief and medication

- The nursing staff will advise you about painkillers before you leave the hospital.
- Continue any oral medication prescribed by the doctors.
- A member of the nursing staff will show you how to apply antibiotic and anti-inflammatory eye drops. If necessary, a District Nurse will be asked to help you with this once you get home.
- Please wash your hands both before and after applying eye drops.
- Apply your drops at the correct times.

Your eye

For two to three weeks after the operation please:

- Avoid rubbing or pressing on your eye.
- Avoid heavy lifting (i.e. heavy shopping bags) strenuous exercise or heavy gardening.
- Avoid getting soap or shampoo in your eye whilst washing.
- Avoid eye makeup for at least two to three weeks after your operation.

If you notice any severe pain, sudden loss of vision or excessive stickiness please contact the Emergency Eye Department:

**Tel: 0151 706 3949 Text phone number: 18001 0151 706 3949
Or your local hospital.**

Stage two

You will be given an appointment to attend Clatterbridge hospital, within the next two weeks to commence the next stage of your treatment.

A two week delay is ideal as it allows any swelling around the eye to settle before the treatment planning continues.

Your first visit to Clatterbridge is for one half day and allows the staff there to take all the measurements necessary to make a protective mask needed to deliver your radiation safely at your next visit to the hospital. These preparations take about two weeks to complete and you will return home during this period.

Stage three

When you come back for your final visit to Clatterbridge you will be accommodated in a guesthouse. You will be required to stay for a period of five days.

The first day is a practice session only.

On the four remaining days you will be given your radiotherapy. You can expect to be at the hospital for about one hour each day, although the actual treatment takes only a few minutes and is painless. Once your treatment is complete you will be allowed to go home the same day.

You may be asked to attend the Royal Liverpool Hospital for a tumour biopsy, either on the last day of your proton beam treatment or a few days later. This biopsy is performed for prognostic tests.

Important

Ocular radiotherapy does not cause tiredness, hair loss or any other generalised side effects. Some patients may experience a localised skin reaction following treatment. If this is likely to be the case the staff at Clatterbridge will advise you on this matter.

During treatment and for a few weeks after, you should avoid using any creams, lotions and makeup on your eyelid.

Sometimes you may find that your eyelids are stuck together when you wake in the morning. Moisten your eyelids gently with cotton wool and cooled boiled water.

The skin of your treated eyelid will always be more sensitive to the sun, and special precautions should be taken if you are likely to be exposed to a lot of sunlight.

Getting back to normal

- Ask your doctor when you can resume driving, swimming and other sports.
- You may feel low in mood at times after you have been discharged from hospital. Sister Gillian Hebbar is available to help you and can arrange for you to see a counsellor if required. She works closely with Professor Heimann.
- If you would find it helpful, you can arrange for her to contact you at home after discharge from hospital. This might be an opportunity for you to ask her any questions you may have.

Returning to work

You can self-certify for the first seven days of sickness. Before you are discharged, a medical certificate (fit note) may be issued by your hospital doctor to cover the expected time off you will need. Any further fit notes will be supplied by your GP

Further Appointments

You will receive an appointment through the post to attend your own hospital in about two month's time.

You will be reviewed here at the Royal Liverpool Hospital about six to nine months after completion of your radiation treatment.

This delay is necessary, allowing enough time to pass so that your consultant can assess the effectiveness of your treatment. This appointment will be sent to you through the post.

If you do not receive an appointment within this time, please telephone 0151 706 3973.

Text phone number: 18001 0151 706 3973

You should be reviewed every six months for the first few years, and then once a year for the rest of your life. At first these appointments will be alternated between here and your home hospital until eventually you will be discharged from the Royal Liverpool Hospital and continue your care at home.

If at any time your consultant feels the need to send you back here for review, this can easily be arranged.

Feedback

Your feedback is important to us and helps us influence care in the future

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Clinical Nurse Specialists

- **Gillian Hebbar**
- **Gwendolyn Hachuela**
- **Shirley Varghese**

Tel: 0151 706 3976 (answer machine out of office hours)

Text phone number: 18001 0151 706 3976

Email:

gillian.hebbar@rlbuht.nhs.uk

gwendolyn.hachuela@rlbuht.nhs.uk

shirley.varghese@rlbuht.nhs.uk

Theatre Assessment Unit

Tel: 0151 706 3947

Text phone number: 18001 0151 706 3947

Mrs Jenny Pendlebury

Service Administration Manager

Tel: 0151 706 3973

Text phone number: 18001 0151 706 3973

Accredited Websites:

<http://www.looc.uk.com/>

Royal College of Anaesthetists

www.rcoa.ac.uk/patients

www.rcoa.ac.uk/sites/default/files/documents/2022-06/02-YourAnaesthetic2020web.pdf

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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