



The Clatterbridge
Cancer Centre
NHS Foundation Trust

Proton beam therapy to the eye

Radiotherapy



A guide for patients and carers

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This booklet is for patients who are going to receive proton beam therapy to the eye. This will provide you with general information about what will happen before, during and after your treatment. If you still have any questions, please ask.

Your consultant ophthalmologist has advised you to have a course of proton therapy. Once we receive your referral data, we will arrange suitable appointment dates. The Patient Coordinator will write to you to confirm the appointments and to arrange accommodation, if it is required.

When these details are finalised and you are satisfied with them, the Patient Coordinator will:

- Inform your consultant ophthalmologist of these dates
- Write to you confirming your appointments and give you details of your accommodation, if required. This will include information on how to find The National Centre for Eye Proton Therapy at Clatterbridge Cancer Centre – Wirral and, if necessary, the directions to your hotel. Please note, accommodation is only provided if you live too far away from the centre to travel daily

Unless you have any queries in the meantime, the next step will be your simulation visit.

What is the simulation?

The best way to think of the simulation is to consider it as a 'test run' or 'mock-up' but without having the actual treatment. It helps to prepare you for your treatment. It also provides all the information we need to plan your treatment accurately.



What happens during simulation?

Your simulation session will be divided into three parts:

1. Making your mouth piece and mask
2. Preparation for your treatment programme including taking various measurements
3. A consultation with a clinical oncologist

The first two stages take place in the treatment room and the third normally takes place in a consultation room.

When you arrive for simulation, you will be asked to confirm your name and date of birth to verify your identity.

If there is a possibility that you might be pregnant, please inform the radiographer as soon as you arrive as there may be some risk to your unborn child.

Why is a mouth piece and mask necessary?

Your treatment takes place over several days and we need to make sure that you are in exactly the same position for each treatment.

To help us reproduce the same position each time we use:

- A mouthpiece which is attached to a frame
- A plastic mask which covers the top part of your face

How are the mouthpiece and mask made?

The mouthpiece and mask are made with you seated in the treatment chair. The mouthpiece is made first.

A three-sided frame is attached to the treatment chair, rather like an upside down 'U', which fits around your head. When you are seated comfortably, the radiographer will place a small amount of soft, green dental compound onto a tab on the frame and then ask you to bite onto it with your front teeth only. After about two minutes the dental compound will become firm and you will be able to open your mouth and relax. The radiographer will remove the frame from around your head.

After making the mouthpiece, we will then make your mask. We do this by warming a sheet of meshed plastic in a hot water bath to soften it. The head frame, with your newly moulded mouthpiece attached, is put back into position on the treatment chair. You will be asked to reposition your head and teeth into the head frame and mouth-bite.

When you are in a comfortable position, the radiographer will quickly mould the sheet of warmed meshed plastic to fit over the bridge of your nose and around your eyes and forehead, **do not worry about breathing because the mask will not cover your nostrils or mouth.** The meshed plastic will not stick to your face or hair. The plastic takes just a couple of minutes to set to the shape of your face. When it is ready, the radiographer will ask you to release your bite from the mouth-bite, lean back and relax. The mask and head frame are removed and assembled.



What happens during my treatment programme preparation?

The procedure for this stage will depend upon whether you have:

- A growth in your iris
- Clips placed surgically on the back of your eye

If you have a growth in or around your iris (the coloured part of your eye):

If you have a growth in or around your iris, the area we need to treat is usually visible. This simplifies the preparation of your treatment programme. After your mask is made, we will take some photographs of your eye. We use these photographs to plan your treatment. We then turn the treatment chair around and move you into the treatment position and we will ask you to gaze at a red light. The simulation process will take about half an hour.

If you have had clips placed at the back of your eye:

Before your visit to The National Centre for Eye Proton Therapy, your ophthalmologist will have placed about four very tiny marker clips onto your eye. These clips are quite harmless and are there to mark the boundary of your treatment area. These clips allow us to build up a three-dimensional image of your eye and plan the best treatment. The first thing we will do is sit you in the treatment chair and position it as it will be for treatment. We will then ask you to look in the direction of a small red light while we take a set of X-ray images. If your vision is good enough in your treatment

eye, we will ask you to use that eye to look at a red light. Your healthy eye will be covered up with a pad. If we feel your vision in the treatment eye is not good enough, we will use your healthy eye instead. **Your healthy eye will not be exposed to any proton radiation.** The light position will be altered and another set of X-rays will be taken. This process is repeated four or five times. The information is then transferred to a 'planning computer' to enable us to build up a model of your eye and produce the treatment plan.

We will then measure the position and shape of your eyelids so that we can include them in the treatment plan if needed.

At this point, we will usually have all the information we need. You will be asked to take a seat in the waiting room for a short period while we enter the data into the computer and check that it is satisfactory for planning your treatment. Occasionally, we may need extra information. In this case, we will ask you to return with us to the treatment room so we can take another set of X-ray images. The first simulation will then be complete.

When do I talk to the doctor?

When you come for your first simulation, you will usually have a consultation with your oncology doctor who will be responsible for your care while you are with us.

If this is not possible, a consultation appointment will be arranged at the beginning of your treatment. This is your chance to ask any questions, or voice any concerns, you have about the treatment. If



you have a pacemaker, please mention this. Finally, if you have not done so already, you will be asked to sign a consent form.

What happens between my first simulation and the treatment week?

After you have had your simulation, the therapy staff will start working on your treatment plan. The planning process searches for the best way for us to treat your particular lesion. It is created with the help of a computer using all the information gathered from your first simulation.

The plan is checked several times to make sure it is the most suitable one for your treatment. It is checked both at The National Centre for Eye Proton Therapy and also by your consultant ophthalmologist. This all happens before you return for your treatment week so we are ready for your final simulation.

Why is there a final simulation and when is it?

This simulation is the final 'test' we do to ensure that your plan is correct and that can proceed with your treatment. It takes place on the Monday of the treatment week.

What happens at final simulation?

The treatment chair is positioned as it was for your first simulation and we will ask you to look through the small red light. If you have had clips inserted, we will take X-ray images to confirm that the clips are in the position predicted by our computer plan. If an area on your iris needs treatment, we will check that the light pattern covers the treatment area and that your eyelids are out of the way.

The final simulation is usually simple and quick, but we must confirm that your treatment plan is accurate. If needed, any minor adjustments will be made.

You will return home or to your accommodation after final simulation. Your treatment will commence the next day.

What happens during treatment?

When you arrive for treatment the next day, you will again be asked to confirm your name and date of birth to verify your identity.

You will have four daily sessions, from Tuesday to Friday. A therapy physicist and radiographer will be in the treatment room with you. Your treatment is set up exactly as it was during simulation, except that the radiographer will put two drops of local anaesthetic into your eye.

This will prevent your eye from blinking during treatment. An image of your eye taken from the camera in the room will be displayed on a TV screen on the control desk outside.



When we are sure that your eye is correctly positioned, the therapy physicist will leave the room whilst the radiographer stays with you. Only when the physicist is satisfied with the position of your eye on the TV monitor will the radiographer leave the room.

At this point, a clearance button is pressed and you will hear a siren. If your eye is still in the correct position, we will start the treatment, which takes about 30 seconds. You will hear a loud 'hum' during the treatment. You will not feel any discomfort.

During your treatment, both the radiographer and the physicist will watch you from the control desk outside the room. If your eye moves, the treatment will be interrupted. If necessary, changes will be made so that the treatment can continue correctly. The whole procedure, from start to finish takes about 20 minutes each day. The rest of the day is then yours. We will give you an eye pad to wear over your eye whilst the anaesthetic wears off. This can be removed after one hour.

What happens after treatment?

When you have had your last treatment on the Friday, you can return home. We will ensure that all the information about your treatment is entered into your file. After you have left, your oncology doctor will review all the reports and they will write an official discharge letter. This letter will be sent to your consultant ophthalmologist and your GP. The length of time before your follow-up appointment with your consultant ophthalmologist can vary, but it is usually between four to six weeks.

Treatment advice

During treatment:

Proton beam treatment may make your eye and eyelid red. This redness will vary from person to person according to which part of the eye receives treatment, but it can be minimised if you treat your eye and eyelids carefully.

From the first treatment day, do not use any creams, lotions or make-up on the eyelids. Wash the skin around your eye carefully and then gently pat your skin dry. Do not rub your eye or eyelid. You will be advised when to resume using products following a discussion with your radiographer at the end of your treatment.

Apply a cold compress to your eyelids for 10 minutes, several times a day. This will help to soothe the skin of your eyelids.

Keep your eyelids out of the sun especially during the summer months. We recommend wearing sunglasses.

If you have had local anaesthetic drops in your eye, keep your eye covered for one hour after treatment and then leave your eye uncovered if possible. If you are out in a strong wind, you may find it is more comfortable to cover your eye, but remove the pad when you are indoors.



After treatment:

Your treatment reaction will carry on for four to six weeks after your treatment has finished and you will have to take special care of your eye and eyelids during this time. Your eye and eyelids are probably going to become redder than they were during treatment. If a blister forms on your eyelid, it will heal quicker if it is left open to the air and you should avoid creams and lotions.

Continue to be careful with the skin around your eye and continue using cold compresses until the redness disappears. Once the redness fades, you may return to using creams and lotions.

Sometimes, you may find that your eyelids are stuck together when you awake in the morning. Moisten your eyelids with cotton wool and cooled boiled water. Try to be as gentle as possible.

The skin of your treated eyelid will always be more sensitive to the sun, and precautions should be taken to protect it if you are likely to be exposed to direct sunshine.

The referring ophthalmologist will want to see you approximately four to six weeks after you have completed proton beam treatment. If you have been given any eye drops, continue to use them until you see the ophthalmologist.

These are general instructions and the time periods mentioned are approximate. They will vary from person to person according to the position and size of the area treated. Any side effects will affect the treated eye only and eyelids and no other part of your body.

Will I need to return to The National Centre for Eye Proton Therapy?

No. Your GP and consultant ophthalmologist will now take over.

If you have time, we would really like to hear how you are getting on. The National Centre for Eye Proton Therapy has treated more than 3200 patients and your treatment experience will help us in the future.

Frequently asked questions

Who can I call with problems or questions?

If you have any problems during or after treatment, you can ring the proton radiographer on 0151 556 5596 from Monday to Friday between 8:30am and 5:00pm. When you come for treatment, we will give you information on who to contact in an emergency, outside of these hours.

Who treats each day and who prescribes my treatment?

A team, consisting of at least one radiographer and one physicist, will treat you each day. You will usually see the same team for the whole of your treatment week. The oncology doctor, who you will have met when you signed the consent form, prescribes your treatment.

What are the advantages of proton therapy?

A proton beam, due to its well-defined shape, allows tumours of any size, shape or position within the eye, to be treated with very



little effect on the surrounding area, thus sparing sensitive tissue. See additional information on page 15.

Why come to The National Centre for Eye Proton Therapy?

The Clatterbridge Cancer Centre NHS Foundation Trust is one of the largest specialist cancer centres in the UK and has an excellent history and reputation for treating patients with various forms of cancer. The National Centre for Eye Proton Therapy has an extremely high success rate and is also the only place in the United Kingdom that can provide this type of proton therapy.

How many times will I need to attend?

The number of visits required will depend upon your condition. Usually this will need a single visit for simulation and a full week (Monday-Friday) for the final simulation and treatment.

Where will I stay?

If you do not live locally, we will make arrangements for you to stay at one of the local hotels. During your stay, we will pay for double or twin accommodation on a room-only basis with breakfast, for yourself and a spouse/friend or relative if you would like to bring somebody with you. It is your responsibility to pay for any other meals.

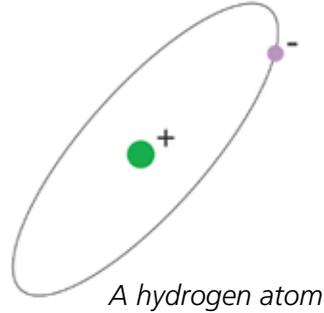
How will I get to The National Centre for Eye Proton Therapy?

There is free patient parking for anyone travelling by car. If you are staying in a hotel and do not have a car with you, we will arrange taxi transport from the hotel to the centre each day. We will pay for these journeys.

Additional information should you wish to know more

What is a proton?

A hydrogen atom consists of a proton and electron. When the atom loses an electron through 'ionisation' the remaining nucleus or proton is positively 'charged'. This enables proton beams to be focussed and accelerated by magnetic and electric fields. Protons are produced by a machine called a cyclotron.

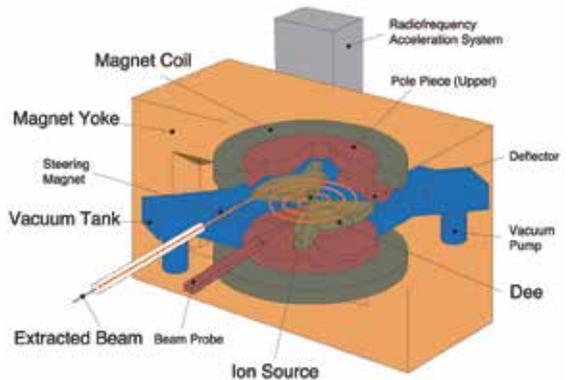


A hydrogen atom

What is a Cyclotron?

The cyclotron was one of the earlier types of particle accelerator or 'atom smashers' used in nuclear physics in the early 1930s. Within a decade, their use in diagnosis and therapy was being exploited.

The cyclotron uses a powerful magnetic field to bend the moving protons into circular paths in a vacuum tank. Twice during each orbit the protons are accelerated at electric field gaps provided

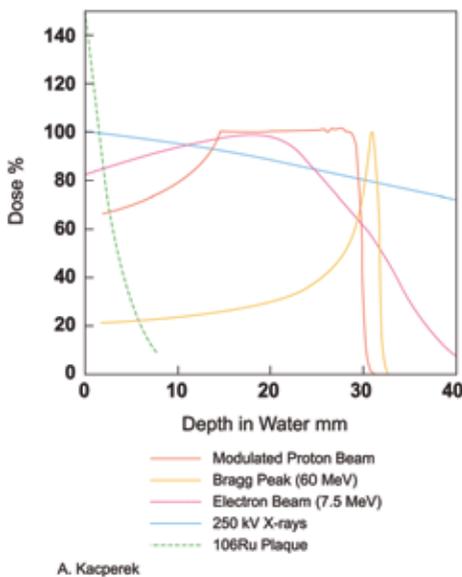


A diagram of a cyclotron



by two large electrodes called 'dees' due to their shape. Thus, the energy and orbital radius of the protons increases after each orbit, until the protons reach the edge of the magnetic field; they are then 'extracted' from the cyclotron tank by an electrostatic deflector and formed into an external beam.

The protons originate from the centre of the vacuum tank, where hydrogen gas is ionised using a PIG ion source. The cyclotron at The National Centre for Eye Proton Therapy is a 62 MeV proton machine made by Scanditronix, using an 800-ampere main magnet and a 25.7 MHz (50kV) RF supply.



How are proton beams different from other radiations?

Most therapeutic radiation doses (photons, X-rays & electrons) decrease with depth in tissue; the dose is uneven and includes normal tissue.

As shown in the picture, proton beams (Bragg peak and modulated) stop sharply at a pre-determined depth, and 'modulation' offers a flat dose over the tumour volume with much tissue sparing.

Why are proton beams used for eye therapy?

Protons, which are 'heavy' nuclear particles, are scattered very little as they travel through tissues, hence the proton beam has sharp edges or penumbra. Also, due to the remarkable phenomenon of the Bragg peak, the protons travel a fixed distance (depending on their energy) and come to an abrupt halt (in <1 mm). So the major advantage of proton beams lies in their unique physical characteristics, which allow the protons' energy to be deposited precisely where required. Thus, the sensitive parts of the eye are avoided while the tumour is fully irradiated.

What is a modulator, a range shifter and a collimator?

The peak itself is too narrow for use in radiotherapy. However, if the proton energy is modulated, using a modulator, the Bragg peak can be spread in depth. This is called the modulated or spread-out Bragg peak. The range and the amount of modulation are 'tailored' according to the shape and position of the tumour. The range shifter is an absorber, which limits the proton beam depth.

Protons travel in essentially straight lines; hence the cross-sectional area of the proton beam is also tailored to the shape of the tumour using a finely machined aperture in a disc of brass (the collimator). Wedges are sometimes used to further reduce unneeded dose.



The Clatterbridge Cancer Centre NHS Foundation Trust

www.clatterbridgecc.nhs.uk

0151 556 5000

The National Centre for Eye Proton Therapy at Clatterbridge Cancer Centre - Wirral

0151 556 5596

Macmillan Cancer Support

www.macmillan.org.uk

tel: 0800 808 0000

If you have any general enquiries prior to starting your treatment, please contact the Proton Patient Co-ordinator at **The National Centre for Eye Proton Therapy**, Monday to Friday during office hours (9am - 5pm) on 0151 556 5596.

If you have any concerns out of hours, please contact The Clatterbridge Cancer Centre Hotline on **0800 169 5555**. The Clatterbridge Cancer Centre hotline is a 24 hour seven day a week service, providing help and advice for patients experiencing problems related to their treatment. Patients, relatives or healthcare providers can call the hotline during and up to six weeks after treatment.

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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