NHS
Royal Berkshire
NHS Foundation Trust

Radiotherapy to the brain

Information for patients beginning radiotherapy treatment

What happens next?

In the clinic today, you and your doctor agreed that you are going to have radiotherapy treatment for your cancer. This booklet discusses what you can expect during and after your treatment and gives some general advice and information.

You will be given time to discuss any concerns with the radiographer (a person trained to give radiotherapy) at your planning appointment.

Brain tumours and driving

Once you have been diagnosed with a brain tumour **you must not drive** and you **must** inform the DVLA of your diagnosis. The DVLA can be contacted by telephone on 0300 123 0883. Full details and advice are also available on the DVLA website www.gov.uk/brain-tumour-and-driving. For further information please ask your clinical nurse specialist.

Pregnancy

Patients with childbearing capacity must not be pregnant or become pregnant at any time during a course of radiotherapy as radiation can be harmful to the unborn child. It is important to let the radiographers know if you have missed a period or suspect that you may be pregnant, before you are exposed to any radiation. Patients with childbearing capacity will be asked to confirm their pregnancy status prior to planning the radiotherapy and again on the first day of radiotherapy treatment. This applies to all those with childbearing capacity between the ages of 10-56 years and is a legal requirement.

Planning treatment

You will be contacted by telephone to arrange an appointment for a CT scan, which forms part of the planning of your radiotherapy treatment and can take up to an hour. Please tell us if:

- You have not had a blood test taken in the last 6 weeks as we may require you to take one prior to the planning scan date.
- You have any problems with travel or appointment times – we will do our best to help you.

If you have not been called by the Radiotherapy Planning Department within a week of today's appointment, then you can contact us on 0118 322 7872, or email: **radiotherapy.planning@nhs.net**, Monday-Friday, 8.30am-4.30pm.

What are the benefits of radiotherapy?

The benefits of radiotherapy are due to its effect against cancer in the area being treated. Radiotherapy uses high energy X-rays to kill cancer cells. Our bodies are made up of different cells, and all cells have the ability to divide and grow. Radiation damages cells ability to multiply and affects cancer cells more than normal cells as they divide more rapidly and are less effective at repair.

When recommending radiotherapy, your doctor will have taken into account the risks and benefits of the treatment. Although there are risks and side effects, it is felt that the advantages for you outweigh the disadvantages.

Radiotherapy for cancerous brain tumours

Depending on the results of your surgery or biopsy, your oncologist (specialist cancer doctor) will discuss with you the number of treatments you need. Your treatment will be given daily, Monday-Friday.

Chemotherapy

Your oncologist may recommend combination therapy. This is radiotherapy alongside chemotherapy.

Chemotherapy is the use of drugs to treat cancer cells. If your doctor feels you might benefit from this treatment, he or she will discuss this with you. Your clinical nurse specialist will arrange a 'Pre-Chemo Assessment to explain the regime and potential side effects.

This will be further supported by written information for you to take home and read.

Patient identification

The hospital has a policy to ensure the correct patient is identified for their scan or treatment each time they attend an appointment. This will be done by our staff asking you to confirm your full name, your date of birth and the first line of your address. You may be asked this by different staff members, so please bear with us, but we take great care to ensure the correct patient identification checks are undertaken.

Your planning appointment

At the start of your planning appointment you will have a chat with the radiographers who will explain what is going to happen and answer any of your questions.

Your appointment is divided into two halves on the same day. For the first half we make a mask for your treatment, and in the second half you have a CT scan which helps us plan your treatment.

Mask-making appointment

It is very important that you keep still during the radiotherapy and to help with this we make a mask that helps keep you in place for your radiotherapy planning and treatment.

At your planning appointment you will meet our specialist mask-making team, who will explain what is going to happen and answer any of your questions. They will then get you to lie down on the couch on your back and begin making your mask.

The mask begins as a flat piece of plastic with lots of holes in it. This is placed in warm water and stretched over the head and face. It then cools and sets into a personalised mask with plenty of air holes. This takes about eight minutes.

For more information on the mask-making process please ask for the ‘Making your radiotherapy mask’ leaflet.

CT scan

The CT scan takes place in the Radiotherapy Department and the scan itself takes only a few minutes. You will be wearing your mask during the scan and once you are positioned correctly on the bed, we will take a few measurements and put some marks on the mask. We will then let you know that we are leaving the room to start the scan but we are able to see you throughout the whole procedure. The scan takes two to three minutes. It does not hurt and it is very important that you stay very still during the scan. The radiographers are watching you throughout the whole procedure so if you did need them you only need to raise a hand and they can come straight in. Once the scan is finished, we will come back in and remove the mask.

Contrast (dye) injection

The doctor may have asked for you to have an injection of contrast for the scan. Not everyone will have this but for some patients it is helpful, acting like a dye, to show more detail in the head and neck area.

You may have had an injection of contrast for scans before. It involves having a cannula, which is a bendy tube, inserted into your arm or hand using a needle. The contrast (dye) is injected via this cannula. The timing of the injection is quite important and the contrast is injected just before the scan starts.

The contrast (dye) can give you a very warm feeling during and after the injection for about 20 seconds. This is often concentrated around the pelvis and groin area, spreading down the thighs. This is common and goes away quickly. It may also give you a metallic taste in the back of your throat.

If you have had an allergic reaction to contrast dye before, you must tell the radiographers before your scan.

The cannula will be removed about 15 minutes after your CT scan is finished.

After the planning appointment

Once you have completed your planning appointment, there will be a period of 2-3 weeks before your treatment begins. This is because it takes time for the team to prepare your treatment plan.

You will also be shown where to report for your first treatment appointment.

During your treatment you will be able to park for free on site by giving the radiotherapy receptionist your vehicle registration.

Your first radiotherapy treatment

On your first treatment you will have a chat with a member of the radiographer team who will be treating you. They will:

- Check your details.
- Give you a list of the first week's appointment times.
- Discuss the treatment procedure.
- Outline the potential side effects.
- Tell you which day your doctor and clinical nurse specialist will see you during the treatment.
- Answer any questions you may have.

The Berkshire Cancer Centre is a training centre, so you may meet radiography students, who may be involved with the delivery of your treatment under close supervision.

What happens during treatment?

- Radiographers operate the radiotherapy machines to give you the precise treatment prescribed by the doctor. Each time you attend the department for treatment, we need to make sure that we are treating the correct person so when you enter the treatment room, you will be asked to identify yourself by telling staff your name, date of birth and first line of your address. The staff will check this information against your radiotherapy prescription treatment sheet.
- On each treatment visit they will ask you how you are feeling and ensure that you are coping well as the treatment progresses. The radiographer will help you onto the treatment bed, put your mask on you and adjust the bed and machine to the exact positions needed. He or she will ask you to remove any clothing or jewellery, including earrings, in the area being treated.
- All the measurements for your treatment will then be set and checked.
- This preparation may take quite a bit of time and is often longer than the treatment itself. As part of this preparation, you will hear the radiographers calling out some numbers and measurements; this is how they check your position. You should breathe and swallow normally but try to stay as still as possible.
- Once the radiographers are happy with your position, the machine will then be moved to the first treatment position. The treatment machine will not touch you.
- The radiographers will leave the room, take a short scan to check your position and then start the treatment. Although you are alone in the room, the radiographers are able to see you through closed-circuit monitors. If you need a radiographer during the treatment, raise your hand clearly and a radiographer will stop the machine and come into the room.
- The machine is controlled by the radiographers outside of the treatment room and it will move around you and give you treatment from different angles. You will not feel anything during the

treatment, but you will hear a buzzing noise as the treatment is delivered.

- Every day a scan will be taken before treatment to make sure that you are in the right treatment position. These are then repeated weekly or more frequently as required.
- The total time of your first treatment will be approx 25 minutes. Subsequent treatments should take between 15 and 20 minutes.
- Once you have started your course of radiotherapy treatment, we aim to continue it without any breaks or days off.
- Staff on the radiotherapy treatment machine will give you times for your other visits on a weekly basis (usually Friday).
- Treatment is usually given Monday to Friday. Sometimes, treatment is given once over a Bank Holiday weekend.
- Due to servicing of the machines it may sometimes be necessary to treat you on a different machine. Please be assured that all the machines give the same treatment.
- **It is very important that you do not miss treatment days as this may make your treatment less effective.** If you feel you are unable to attend for any reason, please discuss the problem with a radiographer or phone your cancer nurse specialist.
- Each week, while you are having radiotherapy, you will see a doctor and clinical nurse specialist. The purpose of these visits is to support you through treatment and help with any side-effects that you may be having. If you feel you need to be seen at any other time, please speak to a radiographer who will arrange for you to be seen.

After treatment

Radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, after your treatment. You may experience some symptoms and side effects (see below). If you would like to keep your mask after your treatment has finished just ask the radiographers on your last day of treatment.

Possible side effects

Side effects and their intensity will vary from patient to patient – everyone is different and reacts differently to treatment. It is important that you let the radiographers know of any side effects that you get. Most side effects will gradually start from approximately 3-4 weeks into your treatment and may continue 6-12 weeks after treatment is completed. Not everyone will experience all of the side effects listed here. If you do experience any of the following side effects, do not worry, they are a normal reaction to treatment and are temporary. Please let staff how you are feeling so that they can help you.

Fatigue (chronic tiredness): Radiotherapy can make you feel very tired. Tiredness may start during your treatment and continue for a number of weeks / months after treatment. Allow extra time for a rest, for example, an afternoon nap. If possible, spread your chores out over the week. There is no reason why you shouldn't continue with your usual daily activities; just remember to take a rest in between.

Headaches: Radiotherapy may cause some swelling around the tumour at first. This can make your symptoms a little worse and some patients can experience headaches and nausea. A couple of weeks after treatment you should notice that your symptoms will start to improve. If you experience symptoms, please tell your specialist nurse or doctor. You may be advised to take a steroid called dexamethasone, as steroids help to reduce swelling.

Hair loss: You will lose your hair in the area being treated. Hair should begin to grow back a few months after the treatment is over. Hair re-growth may be a little patchy, particularly at first. Sometimes, hair grows back with a slightly different colour and texture and perhaps not as thickly as before. In the meantime, hats, wigs or hairpieces are some practical suggestions for coping with hair loss. Please ask a member of staff to discuss this with you, as there is a wig service available.
Washing your hair: Once radiotherapy has started you may wash your hair very gently with lukewarm water. Baby shampoo may be used.

Dry the hair and scalp very gently using a soft towel. Do not rub your head or use a hair dryer.

Sickness: Rarely, the treatment may make you feel nauseous or cause vomiting. To alleviate this, the oncologist will prescribe an anti-sickness tablet. If you continue to feel nauseous, please let your nurse or consultant know so we can suggest some treatment.

Skin reaction: For about two weeks after your radiotherapy treatment your scalp may become dry, itchy, red and tender. It is advisable to protect your head from both the sun and cold weather. You may want to wear a hat. You will find it more comfortable to have a hat made of natural fibres e.g. cotton or silk, while you are having the treatment.

Seizures: Some people may have seizures because of their brain tumour. If you suffer from seizures, your oncologist or GP will prescribe you anti-seizure medication. Radiotherapy can cause some temporary swelling to the brain. This can cause the seizures to return or increase in frequency. Please continue to take your prescribed medication and notify your nurse specialist.

Patients may notice mild seizures (focal seizure – affecting one part of the brain) that last a few seconds or minutes. For example, facial twitching, arm/leg twitching, staring into space or word finding difficulty. **If this happens, please contact your nurse specialist or GP. This is <u>not</u> a medical emergency but may require treatment.** Monday to Friday please contact your GP or nurse specialist. Out of hours please call NHS 111.

Sometimes, a focal seizure can spread to the whole brain (generalised tonic clonic seizure). The person will fall to the floor and shake all over. They may bite their tongue and be incontinent. The shaking normally lasts less than five minutes and stops on its own. The time a seizure lasts is from the onset of the shaking until the shaking stops. A person will appear drowsy after a seizure but they should start to slowly recover.

You need to call for emergency help and **dial 999** if any of the following occurs:

- If it is the first time someone has a generalised tonic clonic seizure.
- The generalised tonic clonic seizure lasts for more than five minutes.
- The person doesn't regain full consciousness, or has several seizures without regaining consciousness.
- The person has trouble breathing afterwards.
- The person is injured during the seizure.

Your specialist nurse or the seizure nurse specialist can give you further advice on seizure first aid.

Long-term side effects

It is possible for some types of reaction to occur months or years after the treatment has finished, although this will depend on the type of treatment you have had. Some patients may notice short-term memory loss. Other late effects will depend on the part of the brain treated. Your doctor will discuss any possible late effects with you.

Contact details

Radiotherapy Clinic: 0118 322 7890 (9am-5pm)

Neuro Oncology Nurse Specialists: 0118 322 8542

Berkshire Cancer Centre: 0118 322 7888 (9am-5pm)

Sue Ryder/Macmillan Clinical Nurse Specialist:

_____ Tel: _____

GP: Dr _____ Tel: _____

District Nurse: _____ Tel: _____

Further information

- Brainstrust charity and Brainstrust Reading brain tumour support group. Tel: 01983 292 405 www.brainstrust.org.uk
- The Brain Tumour Charity support@thebraintumourcharity.org 0808 800 0004
- www.macmillan.org.uk Call free on 0808 808 00 00 (Mon-Fri, 9am-8pm).
- The Newbury and District Cancer Care Trust for people living in West Berkshire www.newburycancercare.org.uk
- Shine cancer support for 20s 30s 40s info@shinecancersupport.co.uk
- Royal Berkshire NHS Foundation Trust PALS Team: 0118 322 8338 PALS@royalberkshire.nhs.uk
- For seizure related queries email seizure nurse Jackie.Scott@royalberkshire.nhs.uk and copy in neurooncologynurse@royalberkshire.nhs.uk

Notes

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Author: Lisa O'Sullivan, April 2015.
Revised by Allison Hopkins, Kirsten Burrell: January 2023
Next review due: January 2025