

A patient guide to radiotherapy to the brain

This leaflet is for people who have been recommended to receive radiotherapy to the brain. It will highlight the important details that you will have already discussed with your doctor. This leaflet is intended to be a guide as details and side effects of treatment will vary from one person to another. Please note this information leaflet does discuss brain cancer specifically and it is important to note that not all brain tumours are cancers.

What is radiotherapy?

Radiotherapy uses high energy X-rays. The aim of radiotherapy is to slow down or stop tumour growth. Radiotherapy is similar to having a scan, it is painless, and you will not see or feel anything. You will have to lie still for a few minutes.

Radiotherapy treatment is sometimes called external beam radiotherapy and is carried out on a machine called a linear accelerator.

Treatment is normally given in short daily treatment sessions, Monday to Friday. The number of treatment sessions you will have will depend on your condition. Your doctor will discuss this with you in more detail.

Unfortunately, some healthy cells within the treated area can also be affected, resulting in some side effects. The side effects will be discussed at a later point in this leaflet.

The treatment will not make you radioactive so it is safe to be around children and other people after your treatment.

We are a teaching hospital and have student radiographers in the department every day, who are supervised by trained staff. Your radiotherapy is delivered by radiographers, both male and female.

Why do I need radiotherapy?

Radiotherapy can be used as the main treatment for cancer or it can be used after surgery. This is to target any smaller cancer cells that may have been missed during surgery.

It can be used in conjunction with chemotherapy tablets depending on the tumour type.

What are the benefits of radiotherapy?

For most patients the benefit of radiotherapy will be to potentially cure or improve the control or symptoms of your cancer. Your doctor will discuss this with you in more detail at your first appointment in clinic.

Are there any alternative treatments to radiotherapy?

Cancer may also be treated with surgery and or/chemotherapy. It may be that you receive a combination of these treatments and your doctor will discuss your options with you.

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Pacemakers

It is important that you inform your doctor or a radiographer if you have a pacemaker. Radiation may affect your pacemaker so checks will need to be organised through your treatment.

Pregnancy

It is extremely important that you are not pregnant or become pregnant during your course of radiotherapy. Even a small amount of radiation may harm an unborn foetus (baby) so it is very important to let the radiographers know immediately if you think there is even a small possibility that you may be pregnant, before being exposed to any radiation on the CT scanner or treatment machine.

What happens before my radiotherapy begins?

Radiotherapy treatment needs to be carefully planned. You will be sent an appointment to attend the CT scanner in Radiotherapy, The Cancer Centre, Queen Elizabeth Hospital Birmingham. At this first appointment a mask will be made which you will also need to wear each day for treatment. This mask ensures you are always lying in the same position for treatment and that the treatment is targeted to the correct area. At this appointment you will also have a computed tomography planning scan (CT scan).

This CT scan enables your radiotherapy treatment to be planned and the scan needs to be carried out regardless of any other scans you may have had recently. The appointment usually lasts approximately 60 minutes.

Making the mask involves warming a sheet of plastic so that it softens and becomes flexible. The plastic is then gently draped over your head and moulded to you. The mask then needs to stay in position for about ten minutes whilst it hardens and sets.

The plastic is warm and feels like having a warm flannel over your face. The mask needs to be a close fit, but has small holes in it so that you can breathe easily.

During your CT scan contrast (dye) may be injected into one of your veins. The contrast is used to make it easier for the doctor to plan your radiotherapy.

Before this injection is done the radiographers will ask you some questions. If you have ever had a reaction to contrast before then please let them know.

Once your scan procedure is complete, you will be given an appointment for your first radiotherapy treatment. There will be a time delay between your CT planning scan and the start of your radiotherapy treatment because your treatment now needs to be planned and this can be a complex process involving your doctor and a team of other professionals.

The routine hours of the radiotherapy department are between 08:00–18:00. If you have a need for a certain appointment on a specific day, it is best to ask at the earliest available opportunity once you have started radiotherapy to avoid disappointment. It may not always be possible to accommodate all patient requests as we are a very busy department, with approximately 250–300 patients on treatment each day.

If you require hospital transport for your radiotherapy treatment please discuss this with the radiographers at your CT scan.

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What happens when I arrive for my first treatment appointment?

Your treatment will be carried out on a machine called a linear accelerator.

On your first day of treatment, you can go directly to your allocated treatment room. If you are unsure where it is, please ask at the reception desk in the Radiotherapy department or any member of staff. Place your appointment card in the box outside the room so that the radiographers know that you have arrived and then take a seat in the waiting area.

When it is time for your treatment, a radiographer will talk to you before your treatment and explain the procedure. This also gives you an opportunity to ask any further questions you may have regarding the treatment, side effects and appointment times.

When you enter the treatment room you will be asked to remove the same clothing as in the CT scanner and lie down in the same position. The radiographers will place the mask onto your face and ensure it fits correctly. The mask needs to be a close fit to ensure accuracy but this should not be painful. The radiographers will then move the treatment couch closer to the radiotherapy treatment machine.

When you are in the correct position, the treatment machine will move around you but does not touch you at any point during your treatment. The radiographers will inform you when they are leaving the room to commence treatment and you will hear an alarm sound, which is part of the safety procedure. The radiographers will operate the machine from the control area and they can hear and see you at all times. If you need assistance just call out or raise your hand. For your own safety, please do not try to get off the bed as it is raised up off the floor.

At the start of treatment, the machine will move around you to take a scan. This scan is assessed to ensure that you are in the correct position for treatment each day. It allows the radiographers to make millimetre adjustments to your position to ensure that the treatment is as accurate as possible.

When the machine switches on, you may hear some noises such as buzzing and bleeping. This is normal and they are the noises that the machine makes whilst delivering the treatment. When the radiotherapy has finished please remain in position until the radiographers enter the treatment room and tell you that everything is finished. This is for your safety.

Your first treatment appointment normally takes around 20 minutes.



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What happens at my other treatment appointments?

After your first treatment, the appointments are normally quicker because on the first day additional checks and measurements are performed.

When you arrive please put your appointment card in the box outside your treatment room. Appointments usually take around 15–20 minutes.

CCTV monitors

The treatment rooms are monitored during your preparation for treatment, positioning and treatment delivery by television cameras. This is part of ensuring the accuracy of your treatment and your safety and wellbeing in the rooms at all times. We assure you that the camera image feed is live and it is not possible to make a recording.

The images are viewable on screens situated in the machine control areas. The control areas are only accessible by authorised radiotherapy staff, some who may not be directly involved with your care at that time.

If you have any concerns about your privacy or dignity that you have not already discussed then please do not hesitate to highlight your concerns during the information discussion with the radiographers at your first treatment appointment.

Is there anything that I need to do whilst receiving my radiotherapy treatment course?

Whilst receiving radiotherapy treatment it is important to make sure that you keep hydrated and drink plenty of fluids, especially if you are also receiving chemotherapy, as it helps to reduce toxins that build up in your system.

If you are diabetic, please ensure you bring your insulin and some food each time you attend in case there are any delays.

We also recommend you bring any medication you are required to take regularly, for example steroids, anti-epileptic drugs or painkillers.

Will I see a doctor during my treatment course?

During your course of treatment you will be monitored by your treatment radiographers and you will be seen by your doctor or one of their team in the radiotherapy clinic. The treatment radiographers will let you know when this is. Please be aware that your treatment appointment time will be made to coincide with the clinic so that you do not have to make two visits in one day. Please make sure you tell your doctor or their team of any side effects or problems that you may be having.

If you need any repeat medication that you have been given from your consultant, you should mention this during your clinic appointment. A list of current medications may be useful to bring to this clinic consultation.

Are there any side effects?

Your doctor will have explained any potential side effects when you were consented for your treatment.

The most common side effects often occur during the course of radiotherapy treatment and may continue for a few weeks after treatment has finished. Side effects which occur six months or

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longer after treatment has finished are called long-term side effects.

If you have any questions about side effects, please ask any member of the treatment team.

What are the possible early (acute) side effects?

These side effects are usually mild and normally start to occur approximately two weeks into the treatment and be at their worst at completion of radiotherapy. They should gradually improve in the weeks after your radiotherapy has finished and should have settled by the time you attend your post-radiotherapy follow-up appointment.

Steroids and anti-seizure medication may have to be frequently adjusted during your treatment to manage these symptoms. Your doctor will discuss this with you.

Tiredness: Radiotherapy can make you feel tired. This can be partly because of the travelling involved in attending hospital every day, as well as the treatment. This may continue for a few weeks after you have finished your treatment. It is important to allow yourself enough extra time to rest.

Skin: Your skin may become pink, itchy and sore, particularly on or behind the ears. The radiographers will provide you with advice about how to reduce any possible skin reactions and what to do if you find that your skin is sore. In the sun, keep these areas shaded as the sun will worsen the reaction. It is important that you do not use sun cream in these areas, but instead, wear a hat if possible.

Hair loss: Wherever a beam of radiation enters or exits your head there will be some hair loss. It normally grows back after the radiotherapy but can appear slightly thinner. Hair loss can be particularly distressing for people and wig referrals are available on the NHS. Some people prefer to get a wig from their own hair stylist or wear hats or head scarves.

Headaches and nausea: Radiotherapy can cause the brain to swell slightly and this pressure within the head can cause headaches, nausea/sickness and changes to vision or limb weakness. If you experience any of these whilst on treatment, medications can be prescribed to help control them (dexamethasone).

Seizures or fits (epilepsy): You may have already experienced these but the radiotherapy can cause them to return or the frequency to increase, again due to the swelling within the brain. There are medications which will help, and if you are concerned about this, talk to your key worker or doctor.

Cognitive function: Brain radiotherapy can sometimes reduce the brain's ability to process information (brain function). This means that you may find it temporarily more difficult to remember things, learn things, solve problems and make decisions.

Please let the radiographers know if you are experiencing any side effects as they may be able to help. There is no need to struggle with them.

What are the possible long-term side effects?

Hormone imbalance: There is a gland within the brain called the pituitary gland. This controls many of the hormones within our bodies. The pituitary gland is sensitive to radiation so if it is in or near the part of the brain that receives treatment, it can be affected. This can lead to changes in your normal hormone levels that can affect other body functions. You will be monitored closely by

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the radiotherapy doctors when you attend for follow-up appointments after radiotherapy has finished. If you are having any problems, let one of the team know.

Tiredness/lethargy: Even if you have not experienced any tiredness during your radiotherapy, after treatment has finished there may be a period of time when you feel particularly sleepy or that you feel you do not have the energy to do anything. This can last for six weeks or longer. This duration of tiredness can cause people to worry as it does not seem to settle down but this is quite a normal reaction to the treatment and will eventually settle down.

Cognitive brain function: Radiotherapy can sometimes have a long term impact upon the brain's ability to process information. Modern radiotherapy is more precise and severe problems are very rare. Problems that could be encountered include difficulty remembering things, learning new things, solving problems and making decisions.

Other disabilities: Long-term damage to the brain from radiotherapy is rare. When it does occur it may simply become apparent as changes on brain scans, which are part of your routine monitoring, without any associated symptoms. However, occasionally the changes will be associated with disability. This is because a specific part of the brain sending signals to your body is not working effectively. The precise disability will depend upon the location within the brain that has been affected. Severe problems are very rare and the risk has to be balanced against a growing tumour, which often causes such disability sooner.

Stroke: Radiotherapy may cause long-term damage to blood vessels. Long-term follow-up studies have shown that patients receiving radiotherapy to the brain in the region of the major blood vessels are at an increased risk of stroke decades later. However, the precise relationship remains poorly understood as many of these patients had also undergone complex surgery.

Cataracts: These are cloudy patches that develop in the lens of the eye due to radiation. Radiotherapy treatment is planned to keep the doses to the lens of the eye to an absolute minimum. However, sometimes this is not achievable and the radiation can lead to cataracts. Fortunately, surgery to remove a cataract is very straightforward and very successful.

Skin: The skin in the area that has been treated will always be more sensitive to the sun, even in the future. Take care when it is sunny and cover up exposed skin with a hat or sun cream (SPF 30 at least).

Radiation-induced tumours: Radiotherapy can cause cancer and there is a very small risk of a secondary cancer developing in the area that has been treated. However, because the risk of this happening is so small, the benefit of your radiotherapy treatment far outweighs this risk. Your doctor will discuss this with you.

Skin care during your radiotherapy

During your radiotherapy and for a while afterwards, you may develop a skin reaction in the area being treated. You may notice the following symptoms:

- Your skin gradually becoming pinker or darker, depending on your skin colour
- The skin may feel dry or tight, and sore
- A rash may also appear and feel itchy
- A skin reaction may appear at any time but usually begins around 10 days after starting treatment
- Having chemotherapy alongside radiotherapy can make your skin reaction worse

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- Smoking can make your skin reaction worse – if you need help to stop, please ask for advice

How can I help myself?

Moisturising your skin can help if your skin becomes dry and itchy. You may use your normal moisturiser. Apply any cream sparingly, gently smooth it on and avoid rubbing the skin.

- Wash the skin gently with soap and water and gently pat dry
- Wash your hair gently with shampoo and dry gently
- Avoid rubbing the area
- Avoid/reduce shaving in the area being treated
- You may swim if your skin is not broken. Shower after swimming to wash off the chlorine and apply your moisturiser. Please stop swimming if it irritates your skin
- Avoid sun exposure and protect the area from direct sunlight. You can wear a brimmed hat and/or cover up with clothing

After your treatment has finished, your skin will continue to be more sensitive for the next 7–10 days before starting to improve. Most patients find their skin has healed about four weeks after treatment finishes. If the skin has broken, healing may take longer than this.

Be careful in the sun for at least a year after you have finished treatment. Wear a hat or use a sunscreen with a minimum UVB sun protection factor (SPF) of 50 and UVA protection, as your skin will be more sensitive.

Who do I contact if I have any questions or concerns whilst on treatment?

All our staff are here to make sure your treatment goes as smoothly as possible and to support you through this difficult period. If you have any questions about your treatment or side effects, please do not hesitate to ask your doctor or any of the radiographers for advice.

During your treatment and for up to six weeks after treatment finishes if you need urgent advice due to side effects or are feeling unwell, please contact the oncology hotline on **07789 651543**.

In the event that your call is not answered, please leave a message stating your name, hospital number and contact telephone number.

You should have a named key worker to help with advice and support regarding symptom management. If you have not been introduced to a key worker, please ask the team and they will advise.

My key worker _____

Key worker contact: 0121 371 3718

What do I need to do when I have finished my treatment?

Once you have completed your treatment, the acute side effects may continue for a few weeks even though you are no longer receiving treatment. Continue with the advice that was given to you during your radiotherapy until the side effects stop. If you are unsure of what to do, please ask a radiographer or your doctor before you finish your treatment.

You will be seen by your doctor when you have completed your treatment and this will be 4–12 weeks after the end of your radiotherapy. If you do not receive an appointment in the post within this time then please contact the secretary of your doctor who will be able to check this for you.

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Your follow-up appointments will continue for months/years after your radiotherapy treatment has finished. During these appointments it is important that you mention any side effects or problems that have occurred since completing your treatment. This enables your medical team to help manage any late side effects.

Travelling to your treatment appointments

By train

University station is the closest train station to the hospital and is only a 5-10 minute walk away. There is also a shuttle bus running from the train station to the Cancer Centre, for those patients who have difficulty walking.

By car

Car parking in Car Park D is free for patients attending for daily radiotherapy treatment. Car Park D is located directly opposite the doors to the Cancer Centre. The postcode for your satellite navigation device is B15 2GW.

If you do drive, please bring in the ticket you have taken to access the car park and the radiographers will exchange this for a prepaid one so you may exit the car park without charge.

Hospital transport

Hospital transport is only provided if you have a medical need that stops you from using private or public transport. If you need any help/advice, please contact: **Patient Transport Services** on **0800 035 6511** (Monday–Friday, 08:00–18:00).

If you use hospital transport it can mean spending many hours away from home and travelling long distances (you will be collected/returned on a schedule) therefore we recommend you use other forms of transport if you can. Please ask a member of staff for details.

Bromley Wing accommodation

Patients who live some distance away can stay in the Bromley Wing in the Queen Elizabeth Hospital. It is comfortable accommodation with meals from Monday–Friday for people who are able to look after themselves. Outside treatment times, you are free to entertain yourself, have visitors or go out. Accommodation here is free and can be arranged by contacting the Bromley Wing on **0121 371 4506**.

You may also find these organisations helpful:

Cancer Research UK

www.cancerresearchuk.org

Macmillan

www.macmillan.org.uk

Tel: **0808 8080000**

Radiotherapy contact numbers

Heritage Building, Patrick Room – Cancer Centre, Queen Elizabeth Hospital Birmingham
Information and support for people with cancer and their families.

Tel: **0121 371 3537/9**

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Oncology hotline

For urgent medical problems out-of-hours when attending for treatment and up to six weeks after radiotherapy or chemotherapy has finished. Tel: **07789 651543**

Radiotherapy treatment rooms - direct telephone numbers

Room 1: **0121 371 5703**

Room 2: **0121 371 5076**

Room 4: **0121 371 5090** (tomotherapy)

Room 5: **0121 371 5085**

Room 6: **0121 371 5098** (tomotherapy)

Room 7: **0121 371 5084**

Room 10: **0121 371 5079**

Room 11: **0121 371 5080**

Radiotherapy

Queen Elizabeth Hospital Birmingham

Mindelsohn Way, Edgbaston

Birmingham, B15 2GW

Telephone: 0121 627 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.