



Oxford University Hospitals
NHS Foundation Trust

Radical radiotherapy for primary brain tumours

Information for patients



The Radiotherapy Department

Introduction

This leaflet is for people who have been recommended treatment with radiotherapy to the brain.

The **General Radiotherapy Leaflet** will explain what having the treatment involves, common side effects and some general information about the department. This leaflet, **Radical radiotherapy for primary brain tumours** will provide more detail, specific to the type of treatment planned for you and how you can help yourself during and following treatment.

It is intended as a guide because the timing and effects of treatment may vary from one person to another. This leaflet will highlight the key points of the discussions you will have had with your doctor and treatment team. Family members and friends may also find it helpful.

What is radiotherapy treatment

Radiotherapy is used to treat brain tumours with x-rays. The radiotherapy machines target the radiation at a specific area of tumour, destroying the tumour cells or slowing down their growth with the aim of causing as little damage as possible to the surrounding normal brain cells in the area. It is painless.

The treatment is given in small doses called “fractions”. The number of fractions you receive will depend on the course of treatment you will be having. Your individual treatment will be based on your condition and tumour type. Your clinical oncologist (the doctor that will oversee your radiotherapy) will discuss this with you in more detail.

Radical radiotherapy

The aim of the radiotherapy is to control the growth of the tumour. This type of radiotherapy is called **radical** treatment.

The treatment will be given daily for 15 to 33 fractions; your doctor will tell you how many treatments you will have. Each fraction will last for about 10 to 15 minutes. You will be able to go home after every fraction.

It may be combined with chemotherapy, a tablet taken daily called **temozolomide**. If this is the case then your clinical oncologist and specialist nurse will advise you further on how this is taken and possible side effects. If you are having chemotherapy you will also be asked to have a weekly blood test during your treatment. A member of your treatment team will advise you how to do this.

The Oncology Team will see you weekly to assess you for any possible side effects from treatment and to assess your overall wellbeing.

Radiotherapy planning

Before you start your course of radiotherapy, you will be asked to attend the radiotherapy department for your radiotherapy planning appointment so the team can begin to prepare your treatment. At the planning appointment you will go to the mould room, where we make a plastic mask for you. The mask is individually made to fit you and needs to be worn at each stage of your radiotherapy planning and treatment. The mask will keep your head still during the radiotherapy treatments to make sure that the treatment is delivered accurately to the area that the doctor has planned to treat.

To make the mask, the therapeutic radiographer will warm a flat piece of plastic until soft and then lay it onto your head so that it shapes to your face exactly. It may be a little warm but this process isn't uncomfortable. There are holes in the plastic so you can breathe comfortably. Once the plastic has cooled and hardened

(which takes a few minutes) the radiographer takes it off. The mask is then ready to be used. Any marks to guide the therapeutic radiographer can be drawn on the mask.

If you have a beard or moustache, we will ask you to shave it off before you come, as the hairs can interfere with making the mask.

The mask



You will then have a “planning CT scan”. This scan will provide accurate information for your radiotherapy team so that they can plan your treatment.

During this scan, you may need to have an injection of contrast (a type of dye) to help show up the tumour more clearly. If you have ever had an allergic reaction to dye given during a scan before, please let the radiographer know when you come to this appointment.

The planning CT scanner



How is the treatment prepared?

Before your radiotherapy can begin, we need to produce an individual treatment plan for you. This makes sure that the area needing treatment is accurately defined and that other unaffected tissues are avoided as much as possible.

Our medical physicists will then use this information to design your individual treatment plan.

Coming for your treatment

On the first day of your treatment, the therapeutic radiographer will collect you from the waiting room. there will be an opportunity for discussion before your treatment starts. We would encourage you to let us know about any particular problems or worries you are experiencing so that we can best support you.

During your treatment you will lie on your back on the treatment couch, wearing your mask. The therapeutic radiographers will move the couch and the treatment machine into position. They will use lights, lasers and X-ray equipment to position you accurately. Your treatment will be specific to you and may not be like the treatment of a fellow patient. The treatment machine may come close to you but it will not touch you.

The treatment machine



When you are in the correct position, the therapeutic radiographers will leave the room to start your treatment. The machine makes a buzzing noise when it is switched on. You will have to lie still and breathe normally. The team will be watching you on cameras from outside the treatment room. If you want them to come back in just raise your hand. You will not see or feel anything during the treatment and it isn't painful.

Chemotherapy

If you are taking chemotherapy at the same time as your radiotherapy, you will see your doctor or nurse specialist on the first day of your radiotherapy treatment. They will give you your chemotherapy tablets to take at home along with some other medications which help with some of the chemotherapy side effects. You will be given a week's worth of chemotherapy at a time so that your team can monitor you closely

Possible short term side effects

Radiotherapy treatment is painless. However, there are some side effects which are associated with radiotherapy and you may notice one or more of them gradually developing over the course of treatment.

If anything is worrying you, however small, during your treatment, please tell your therapeutic radiographer or nurse specialist, either at your visit or by phoning the radiotherapy department.

Tiredness (fatigue)

You may feel a build up of tiredness during your radiotherapy treatment and for a few weeks after the treatment has finished. This can often be made worse by a combination of other things, such as recovering from surgery, chemotherapy or other medications and travelling for hospital appointments. Patients often notice that this tiredness worsens and is at its most severe at around 6 to 8 weeks after finishing the treatment.

Fatigue is the most common side effect of radiotherapy. You can help yourself by keeping well hydrated and taking frequent rest. We encourage you to maintain a healthy, balanced diet and continue with your usual activities and light exercise if you are able. Please do tell us if you are experiencing tiredness or any other side effects. It will help us to provide you with the correct advice and support.

Skin reaction

Radiotherapy may cause the skin around the area being treated to become red, itchy and dry. Your treatment team can advise you on where this is likely to happen as they skin reaction can differ from person to person.

If you have had surgery to this area less than 6 weeks ago and your wound has not completely healed, we advise that you do not use any skincare products on this area at all.

If you have had surgery to this area more than 6 weeks ago and your wound is completely healed, you may wish to gently apply a moisturiser on this area to relieve the dryness or itching caused by your radiotherapy. We do not recommend you use any other skincare products on this area.

During your radiotherapy and until 3 months after your radiotherapy has finished:

Wash your hair with your normal shampoo and lukewarm water. DO NOT use hair dye or any styling products such as hairspray and avoid excessive heat from styling equipment such as hairdryers.

During your radiotherapy and in the future:

The skin in the area receiving radiotherapy will always be more sensitive to the sun, even many years after your treatment has finished. We recommend that you wear a hat or cover up in the sun and/or use a high factor sunscreen on the area. Do not apply sunscreen if you have had surgery in this area less than 6 months ago or if your surgical wound has not completely healed.

If you are taking chemotherapy alongside your radiotherapy treatment, the skin all over your body will be extremely sensitive to the sun. We recommend you use high factor sunscreen all over your body and stay out of the sun where possible during the course of your treatment.

It is very important that if you notice any discharge, swelling or redness at the site of your surgical wound, you tell your treatment team as soon as possible.

Hair loss

It is likely that you may lose some hair close to the area that is receiving the radiotherapy treatment.

Your doctor or therapeutic radiographer will explain where to expect some hair loss. Hair loss occurs approximately half way through treatment. Any hair re-growth usually starts 4-5 months after you have finished treatment. You may have small areas of permanent hair loss, although hair regrowth after treatment may be patchy or a different colour or texture to the hair that was there before.

Your nurse or therapeutic radiographer can give you information on how to cope with hair loss after radiotherapy. You may wish to arrange to wear a wig and your team can help to organise this. Your team can also talk you through other options such as headscarves which you may like to consider.

Wigs

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Irritation of ears and eyes

Radiotherapy to the brain may cause irritation of the ears or eyes as a result of the x-ray beams passing through these sensitive tissues. As a result you may experience itching of the ear canal or temporary reduction in your hearing. This can sometimes last a few months after your treatment. One or both eyes may become dry or itchy and occasionally become inflamed during the course of the radiotherapy. Your clinical oncology or specialist therapeutic radiographer will explain whether this is likely to happen and give you advise on managing these side effects.

Other side effects

You may have already experienced **headaches, nausea, and changes to your vision or limb weakness**, and you may have been given a course of dexamethasone (steroid) tablets to help these symptoms. However, the radiotherapy may cause some of these symptoms to return or to become worse. This is because radiotherapy can cause some temporary swelling of the brain.

If you experience these side effects during treatment then please tell your therapeutic radiographer or contact the oncology triage service outside of radiotherapy department opening hours. They may arrange for you to see a doctor. Your medication may need to be adjusted to control these symptoms during your treatment.

Seizures or fits

Radiotherapy can cause some swelling of the brain as the treatment works. If you have already experienced a seizure as a result of your brain tumour, radiotherapy may cause the return or increased frequency of seizures, even if they are being controlled by medication. If you have never had a seizure before, the swelling caused by radiotherapy may trigger one to happen. Your doctor, nurse or therapeutic radiographer can tell you if this is likely to happen.

Usually a seizure will last a few minutes and does not need emergency help. However, if:

- the seizure lasts more than five minutes without any sign of slowing down,
- the seizure is unusual in some way, or if it's your first seizure
- you have trouble breathing afterwards,
- you are injured / in pain or,
- recovery is different from usual,

then call for emergency help – DIAL 999.

It maybe helpful if you or someone with you is able to tell the doctors what you were doing just before the seizure began, what happened during the seizure, how long it lasted, and how quickly you recovered afterwards. You may wish to make family and friends aware that you may experience a seizure and let them know when they should call for emergency help.

Psychological Wellbeing

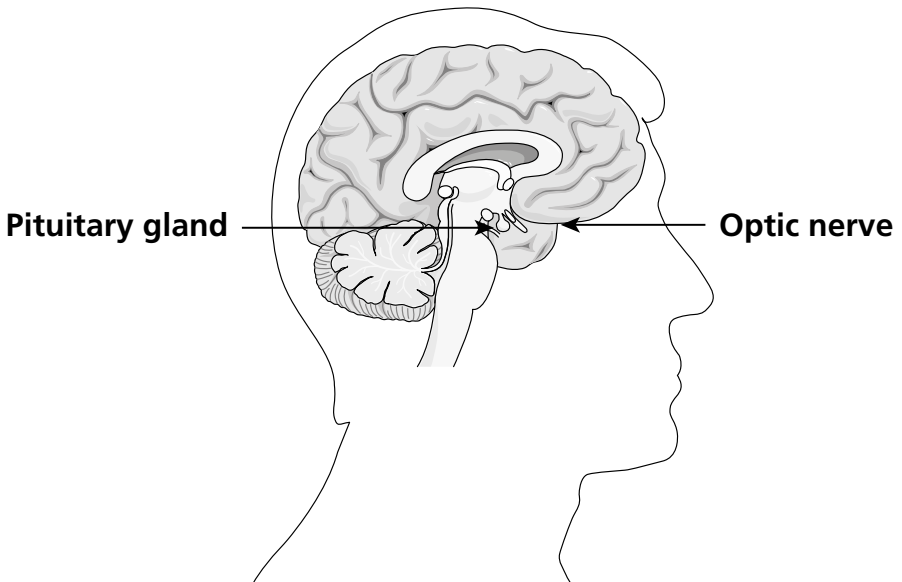
The radiotherapy team are here to support you with the psychological and emotional impact of your diagnosis and treatment.

A member of the team would be happy to chat to you about your emotional wellbeing at any time.

A list of resources to help support you and your family can be found at the end of this leaflet.

Possible long term side effects

Long term side effects can occur many months or years after radiotherapy has finished. These late side effects are hard to predict and unfortunately, if they do occur, they can sometimes be permanent. We carefully plan your treatment to ensure the healthy tissue surrounding your tumour receive as little radiation as possible. This reduces the chance of these side effects developing, which are generally very rare.



Memory loss and lack of concentration

You may have already been experiencing these symptoms and have found ways of coping with them. Your doctor, nurse or therapeutic radiographer can support you through this and may refer to a neuropsychologist for additional support and advice.

Hormone changes

Sometimes, the radiotherapy treatment beam has to pass through the pituitary gland to reach the area being treated. The pituitary gland is at the front of the brain, between the eyes and controls several hormones which your body needs (thyroid, adrenal and ovarian or testicular hormones). These may decrease as a result of your radiotherapy which may lead to irregular periods, fertility or sexual problems, constipation, tiredness or lack of energy. Your blood levels will be monitored yearly and you may be given medication to replace hormones.

Possible effects on vision

When treating a brain tumour that is close to either of your optic nerves, there is a small chance that your eyesight could be damaged. It is a less than 1% risk (less than 1 in 100 people are affected). Your radiotherapy doctor will tell you if you are at risk.

A further brain tumour

There is a chance of developing a second tumour as a result of radiotherapy treatment. This occurs in less than 1% of people treated (less than 1 in 100) and, if it was to happen, would usually develop at least 10-20 years after radiotherapy treatment has been completed.

Review during and after treatment

You will normally be seen weekly by a member of the neuro-oncology team looking after you to see how you are coping with the treatment. They will also monitor any side effects from your treatment and assess your overall well-being.

After treatment

4-6 weeks after completing your treatment you will be asked to return to the Outpatient Clinic to be reviewed by your clinical oncologist or his/ her team. Radiotherapy takes time to work and so it is at this appointment your doctor will assess your progress and how you have been feeling since your treatment finished. They will also discuss the timing of future scans, appointments and further treatment, if appropriate.

We ask that you speak with a member of the team before booking any kind of holiday or trip following your radiotherapy treatment so that you receive the appropriate advice.

Driving

If you have a brain tumour, or have had surgery to remove a tumour and you drive any type of vehicle; you must contact the DVLA and inform them of your diagnosis. The DVLA also has strict guidelines if you have suffered from seizures (fits) either before, during or after your radiotherapy treatment.

Failure to comply with these regulations is illegal and potentially dangerous; your insurance will be invalid and you may be fined up to £1,000.

The DVLA can be contacted at:

Website: www.gov.uk/contact-the-dvla

DVLA Driver's Medical Enquiries Helpline

Tel: **0300 790 6806**

By Post:

Driver's Medical Enquiries

DVLA
Swansea
SA99 1TU

Mobility:

Your radiotherapy team can help you to access the following schemes to help you get around.

- Access to work government programme – www.gov.uk/access-to-work
- Disability bus pass – apply to your local council
- Disabled persons railcard – www.disabledpersons-railcard.co.uk
- Blue parking badge – www.gov.uk/apply-blue-badge

How to contact us

If you have any queries during your radiotherapy treatment, please do not hesitate to contact us by telephone or speak to us when you come for treatment.

Neuro-Oncology Specialist Therapeutic Radiographers

Tel: **01865 235 465**

Monday to Friday, 8:00am to 6:30pm

Brain Tumour Senior Nurse Specialists (Oxford)

Tel: **01865 234 372**

Monday to Friday, 9:00am to 5:00pm – answer machine available outside of these hours.

E-mail: neuro-oncologyanp@nhs.net

Brain Tumour Senior Nurse Specialist (Buckinghamshire)

Tel: **01296 316 097**

Brain Tumour Senior Nurse Specialist (Swindon)

Tel: **01793 604 786**

Oxford Triage Assessment Unit

(24 hour helpline)

Tel: **01865 572 192**

Helpful Information

The Brain Tumour Charity

Website: www.thebraintumourcharity.org

Support & Information Helpline: **0808 8000 004**

Monday to Friday, 9am - 5pm

Email: support@thebraintumourcharity.org

Macmillan Cancer Support

Website: www.macmillan.org.uk

Support & Information Helpline: **0808 808 0000**

Monday to Friday, 9am - 8pm

Maggie's Centre at the Churchill Hospital

Located opposite the main entrance to the Cancer Centre.

No appointment needed.

Website: www.maggiescentre.org/our-centres/maggies-oxford

Tel: **01865 751 882**

Email: oxford@maggiescentres.org

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Making a difference across our hospitals

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OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

