NHS
Oxford University Hospitals
NHS Foundation Trust

Radiotherapy to the Brain and Spinal Cord

(WHOLE CENTRAL NERVOUS SYSTEM)

Information for adult patients

The Radiotherapy Department

You have been given this leaflet as your doctor has recommended that you have radiotherapy to your brain and spinal cord (whole central nervous system). This name is usually shortened to whole CNS radiotherapy. This leaflet will give you more detail about the radiotherapy treatment, specifically about the type of treatment planned for you and how you can help yourself during and after treatment.

This leaflet has been written as a general 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. Your family members and friends may also find it helpful to read.

We will also give you our **General Radiotherapy Leaflet** which will explain what radiotherapy treatment involves, common side effects and some general information about the department.

What is radiotherapy?

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

The radiotherapy treatment is given in small daily doses called “fractions”, usually delivered 5 days per week for 25-33 treatments. The number of fractions will depend on which course of treatment you will be having. Your individual treatment will be based on your condition and tumour type. Your clinical oncologist (the doctor who will oversee your radiotherapy) will discuss this with you in more detail.

Why do I need whole CNS radiotherapy?

Whole CNS radiotherapy involves treating the whole brain and spinal cord for a number of different tumour types. After discussing your case, your team of doctors (surgeons, oncologists and radiologists) have recommended whole CNS radiotherapy as a suitable treatment option. You can discuss with your clinical oncologist whether alternative options for treatment are available and suitable for you.

Depending on the type of tumour you have, you may also require a course of chemotherapy after your radiotherapy finishes.

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 will 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 and upper spine still during the radiotherapy, to make sure the treatment is delivered accurately to the area your doctor has planned to treat.

To make the mask, the radiographer will warm a flat piece of plastic until soft and then lay it on your head and shoulders so that it can be shaped to fit your face and upper body exactly. There are holes in the plastic so that 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, not on your skin.

The process of making the mask is not painful but 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 Mould Room appointment lasts approximately half an hour.

After the mask is made, usually on the same day, the next step is to for you to have a planning CT scan whilst wearing the mask and lying on a special mattress to keep you in the correct position for treatment. This scan will provide accurate information for the radiotherapy team to be able to plan your treatment.

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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 radiographers at the CT scanner will draw small marks on the skin on your chest and pelvis with felt pen. In order to make these marks permanent, you will be given four small tattoo dots (no bigger than a pin head). They are used to place you in the correct position for treatment every day.

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 a couch in the same position you were in for the planning CT scan, lying on your back on the mattress and wearing your mask. The radiographers will move the couch and the treatment machine into position. They will line up your treatment accurately using lights and lasers. The treatment machine may come close to you but it will not touch you. Your treatment will be specific to you and may not be like the treatment of a fellow patient.

When you are in the correct position, the radiographers will leave the room to start your treatment. They will return to the treatment room between treatment beams to adjust the treatment machine. You will have to lie still but can breathe normally. The team will be watching you on cameras from outside. If you want them to come back in just raise your hand. The machine makes a buzzing noise when it is switched on but you will not see or feel anything different during the treatment.

Your treatment appointment may take up to 40 minutes, but most of this time is spent making sure you are in the correct position before the treatment is delivered.

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Clinical 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 and assess any side effects from your treatment and assess your overall wellbeing. For this appointment, you may be required to have a weekly blood test to closely monitor your bone-marrow function. The therapeutic radiographers will advise you when and where to go to get your blood taken.

A few weeks after your treatment has finished you will be reviewed by your clinical oncologist or a member of their team. Radiotherapy takes time to work and so it is at this appointment that 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.

Possible short term side effects

Radiotherapy treatment is painless. However, there are some side effects associated with radiotherapy and you may notice one or more of them gradually developing over the course of treatment. They may take a number of weeks to wear off.

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 and fatigue

You may feel a build-up of tiredness during your whole CNS radiotherapy. 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. This can continue for a few weeks after your 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 fatigue 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

Unfortunately, patients undergoing this type of radiotherapy treatment generally lose all of the hair on their head and on areas of the chest and abdomen where the radiation passes through. This will usually occur around the third week of your radiotherapy treatment.

Any hair re-growth usually starts 4-5 months after you have finished treatment. It is unlikely you will have significant 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.

Nausea/Diarrohea

You may experience nausea and diarrohea as a result of the radiation beam passing through part of your intestine. The neuro-oncology team will advise you on how to cope with this and may prescribe medications to help.

Sore throat/Reflux

You may experience a sore throat, difficulty swallowing or acid reflux as a result of the radiation beam passing through part of your oesophagus (gullet). The neuro-oncology team will advise you on how to cope with this. They may give you some medication to help ease this.

Bone marrow function

The radiotherapy may affect the function of your bone marrow. This means you may become anaemic or your body may not be able to fight off infection. Your blood will be closely monitored with weekly blood tests throughout your radiotherapy. Your doctor will let you know if your bone marrow is affected and whether you require some medication or a blood transfusion.

Seizures or fits

There is a slight increased risk of a seizure (also sometimes called a fit) after your treatment, although this is usually only a problem if you have had seizures in the past. Your doctor or specialist radiographer will discuss the likelihood of having a seizure with you and what to do if this happens.

A seizure can take different forms. You might notice that one part of your body starts twitching or jerking or you may loose consciousness and start shaking.

Usually, a seizure will only last a few minutes. However, if:

- the seizure lasts more than 5 minutes and shows no sign of slowing down
- the seizure is unusual in some way or if it is your first seizure
- you having trouble breathing afterwards
- you have been injured or are in pain
- recovery is different than 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.

Hormone changes

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 that your body needs (thyroid, adrenal and ovarian or testicular hormones). Your blood levels will be monitored yearly as necessary and you may be given medication to help with the production of these hormones.

In addition, the radiotherapy treatment beam has to pass near the thyroid gland which may be affected by the radiation. This can cause cysts or low thyroid hormone levels, which will be monitored annually and may be managed with medication.

Fertility issues

Whole CNS radiotherapy involves treating the whole spine.

People with ovaries: As the ovaries are close to the lower spine, they are likely to receive low doses of radiation, which may affect future fertility. Your clinical oncologist will discuss this with you before you start radiotherapy treatment and will explain potential options to preserve your fertility.

People with testes: As the testes are far enough away from the lower spine, they are not affected and therefore whole CNS radiotherapy does not affect fertility.

If you require chemotherapy after your radiotherapy, your fertility may be affected by the chemotherapy. Your clinical oncologist will discuss this with you and will explain potential options to preserve your fertility.

Memory loss and lack of concentration

Some people find that following cranial radiotherapy their short term memory is not as good as it was in the past. Your clinical oncologist can support you and may refer you to a neuropsychologist for additional support and advice.

A further brain tumour

There is a rare 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 every 100) and, if it was to happen, would usually develop at least 10-20 years after radiotherapy treatment has been completed.

Other side effects:

There is also a low risk of patients developing long-term side effects such as cataracts, hearing loss and tinnitus. Your radiation oncologists will explain these risks to you.

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.

After treatment

4-6 weeks after your treatment has finished you will be asked to return to be reviewed by your clinical oncologist.

Radiotherapy takes time to work so it is at this appointment that the clinical oncologist 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 and you drive any type of vehicle, you must contact the DVLA and inform them of your diagnosis. Depending on the type of tumour you have, you may have to stop driving for a certain length of time. The DVLA also has strict guidelines if you have suffered from seizures (fits) either before, during, or after your 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**
Monday to Friday, 8am - 5:30pm
Saturday 8am - 1pm

By post:

Driver's Medical Enquiries
DVLA
Swansea
SA99 1TU

Mobility:

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

How to contact us

If you have any queries during your radiotherapy treatment, please contact us by telephone, or speak with us when you come for treatment.

Neuro-Oncology Specialist Therapeutic Radiographer

Tel: **01865 235 465**
Monday to Friday, 8:00am - 6:30pm

Brain Tumour Senior Nurse Specialists (Oxford)

Tel **01865 234 372**
Monday to Friday 9:00am - 5:00pm – answer machine available outside of these hours.

Email: **neuro-oncologyanp@nhs.net**

Brain Tumour Senior Nurse Specialist (Buckinghamshire)

Tel: **01296 316 097**

Brain Tumour Senior Nurse Specialist (Swindon)

Tel: **01793 604 786**

Alternatively, outside of these hours, please contact:

Oxford Triage Assessment Team (24 hour helpline)

Tel: **01865 572 192**

Helpful websites

The Brain Tumour Charity

Website: **www.thebraintumourcharity.org**

Support & Information Helpline: **0808 8000 004**
Monday to Friday 9am - 5pm

Email: **support@thebraintumourcharity.org**

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.

Author: Neuro-Oncology Team
April 2022
Review: April 2025
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 65452