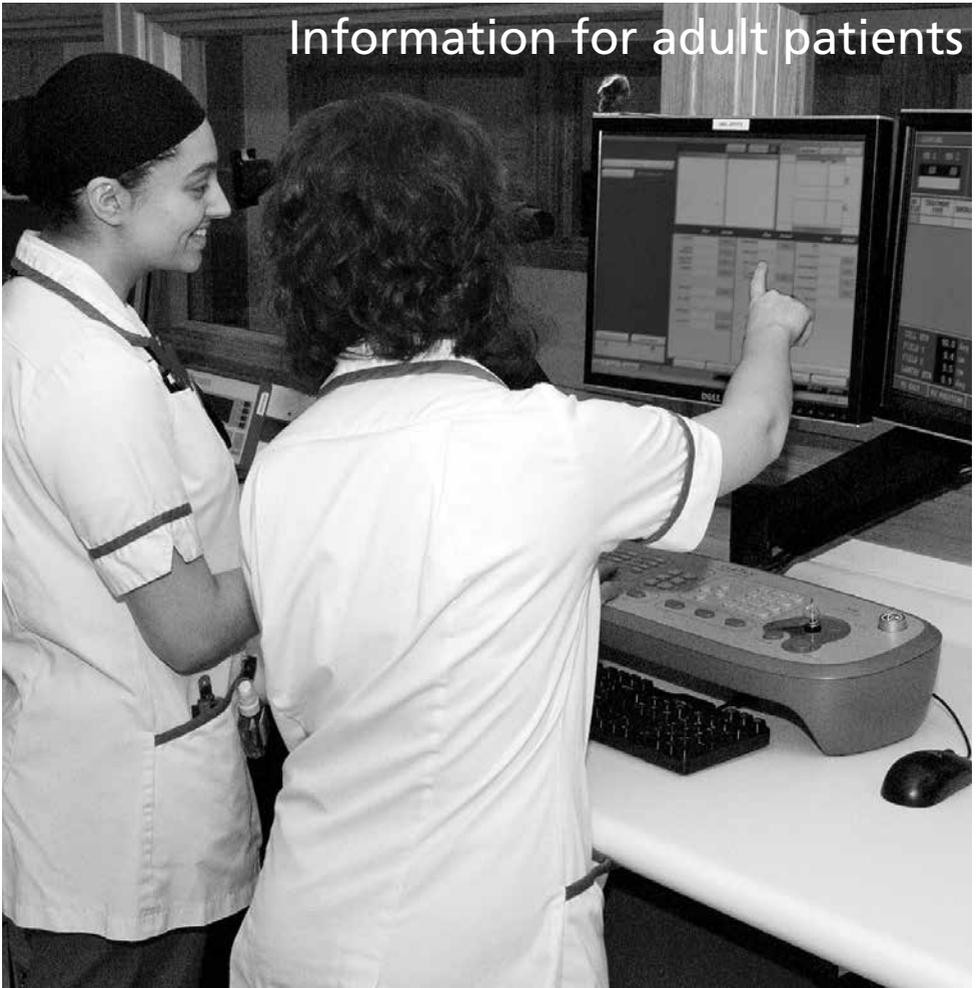


The Radiotherapy Department
**Radiotherapy to the
Brain and Spinal Cord**
(Whole Central Nervous System)

Information for adult patients



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. The 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 the use of high energy X-rays to treat tumours. It works by damaging tumour cells in a way that may stop them from growing or cause them to die.

The radiotherapy treatment is given in small daily doses called "fractions", usually delivered 5 days per week for around 6 weeks. 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 consultant will discuss this with you in more detail.

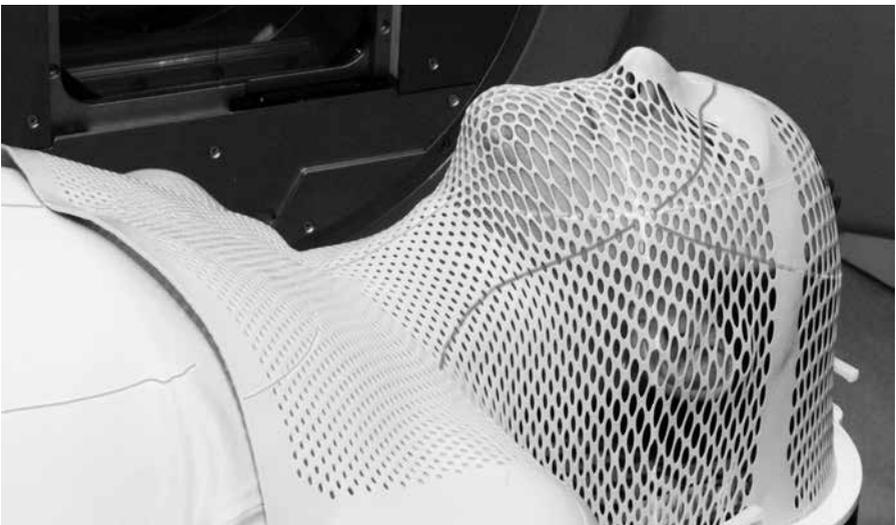
Why do I need whole CNS radiotherapy?

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 consultant whether alternative options for treatment are available and suitable for you.

Preparing for your radiotherapy

Before you come for your whole CNS radiotherapy we will need to prepare you for the treatment.

You will need to wear a close-fitting plastic treatment mask as shown in the photograph below. This mask is individually made to fit you and needs to be worn at each stage of your radiotherapy planning and treatment. It will keep your head and upper spine steady during the radiotherapy, to make sure the treatment is delivered accurately to the area your doctor has planned to treat.



Your first appointment will be a 'planning appointment'. You will be taken to the Mould Room where we will make the plastic mask for you. The radiographer making your mask will talk you through the process and any concerns you may have.

To make the mask the radiographer will warm a plastic sheet 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. The plastic will be warm and a little damp but this process is not uncomfortable. It is then allowed to set; this takes about ten minutes.

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 doctor to be able to 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 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 all the area needing treatment is included and that the other organs are avoided as much as possible.

The neuro-oncologists and neuro-radiologists will look at your planning CT scan to define the exact area to be treated and areas to be avoided. Our physicist will then use this information to design your individual treatment plan.

Coming for your treatment

On the first day of your treatment, the treatment radiographer will collect you from the waiting room and have a discussion with you before the treatment starts. They will confirm the details of the treatment with you again and you will have the opportunity to ask any final questions you may have.

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 the 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.

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 have to lie still but can breathe normally. The radiographers will be watching you on cameras from outside. If you want them to come back in just raise your hand. You will not see or feel anything 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.

Clinical review during and after treatment

You will normally be seen on a Tuesday afternoon every week by your oncology consultant or the specialist radiographer looking after you. They will check how you are coping with the treatment and monitor any side effects. For this appointment, you will be required to have a weekly blood test to closely monitor your bone-marrow function. The treatment 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 asked to return to the Outpatient Clinic to be reviewed by your oncology consultant or a member of their team. Radiotherapy takes time to work and so it is at this appointment that your doctor will assess you and discuss your progress and any continuing side effects.

Side effects of whole CNS radiotherapy

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.

- **Tiredness**

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

- **Skin reaction**

Most people develop a skin reaction in the area being treated. The area may become red, dry, sensitive or begin to peel. Please refer to the general Radiotherapy leaflet, which will tell you how to care for the skin in this area.

- **Hair loss**

Loss of hair is a problem common to nearly all radiotherapy treatments to the head. The extent of hair loss varies from

person to person, but will occur all over the head and on areas of the torso and abdomen where the radiation passes through.

Any hair re-growth usually starts four to five months after the radiotherapy and, while it is unlikely that you will have significant permanent hair loss, some areas may always be thin or patchy.

If you feel conscious about your hair loss we can arrange for you to be fitted with a wig on prescription. The specialist nurse or radiographer can help you to arrange this.

Further information can be found in the MacMillan Leaflet "Coping with Hair Loss" which we can give to you at any time.

- **Nausea**

You may experience nausea and vomiting 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. They will give you some anti-sickness medication to take an hour before treatment each day.

- **Sore throat**

You may experience a sore throat and difficulty swallowing 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 (or 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.

Possible long term side effects

Long term side effects can occur many months to years after radiotherapy has finished. These later side effects are hard to predict and unfortunately, if they do occur, they can sometimes be permanent. We carefully plan the treatment to avoid the surrounding areas around the tumour as much as possible. This reduces the chance of these side effects developing, which are generally very rare.

- **Hormone changes**

Sometimes the radiotherapy treatment can cover a gland at the front of your brain between your eyes, called the pituitary gland. This gland 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 thyroid gland lies in front of the spinal treatment field and may be affected by the radiation. This can cause cysts or low thyroid hormone levels, which will be monitored annually.

- **Fertility issues**

The radiotherapy may affect female fertility, as treatment covers part of your lower spine. This means that the ovaries in your pelvis are likely to receive very low doses of radiation, which can affect future fertility. Your consultant will discuss this with you before you start radiotherapy treatment and will explain potential options to preserve your fertility.

The radiotherapy treatment should not affect male fertility, as the testes are far enough away from the lower spine to be spared.

- **Short term memory**

Some people find that following cranial radiotherapy their short term memory is not as good as it was in the past. We can refer you for assessment and guidance if this affects you.

- **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.

Driving

If you have a brain tumour or pituitary 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 either by phone or in writing:

Tel: **0300 790 6806**

Address:

Drivers Medical Group

DVLA

Swansea

SA6 7JL

Full details and advice are also available on the website at:
www.gov.uk/contact-the-dvla

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 Radiographer

Tel: 01865 235 465 – please ask to bleep 5087

(Monday to Friday, 9.00am to 5.00pm)

Neuro Nurse Practitioner team

Tel: 01865 234 372

(Monday to Friday, 9.00am to 5.00pm – answer machine available outside of hours)

Alternatively, outside of these hours, please contact:

Oxford Triage Assessment team

Tel: 01865 572 192

Helpful websites

The Brain Tumour Charity

Website: www.thebraintumourcharity.org

Support and Information Line: 0808 800 0004

Email: support@thebraintumourcharity.org

Macmillan Cancer Support

Website: www.macmillan.org.uk

Tel: 0207 840 7840

Maggie's Centre – Oxford

Churchill Hospital, Old Road, Headington, Oxford OX3 7LE

Tel: 01865 751882

Email oxford@maggiescentres.org

Information Prescription Service

Website: www.nhs.uk/ipg/Pages/IPStart.aspx

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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www.ouh.nhs.uk/information

