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. The leaflet – Radiotherapy to the brain 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 radiation. The radiotherapy machines target the radiation at a specific area of tumour, destroying the cancer 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 will depend as to which course of treatment you will be having. Your individual treatment will be based on your condition. Your consultant 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 25 to 33 fractions for about six weeks to six and a half weeks in total. 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 oncology doctor and nurse practitioner will advise you further on the way this is taken and possible side effects.

The oncology team will see you every Tuesday afternoon to assess you for any possible side effects from treatment. We will take a blood test before the appointment.

Radiotherapy planning

At the planning appointment you will go to the “mould room”, where we make a plastic mask for you. The mask will keep your head still during the radiotherapy treatments so that the radiation is given accurately and to exactly the same area each time. To make the mask the radiographer will warm the plastic until soft and then lay it on to your head, so that it shapes to your face exactly. It feels a little like having a warm towel put onto your skin. 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 radiographers can be drawn on the mask, not on your skin.
You will then have a “planning CT scan” The doctor looking after you will use the scan to outline the tumour and the surrounding brain, so that we can highlight the exact area to be treated. We may put a small plastic needle in you hand or arm to give you a dye to help outline the tumour and blood vessels in your brain. If you ever had an allergic reaction to a dye before, then please let the radiographer know at the time of the appointment.

The planning CT scanner
Treatment

You will lie on a couch in the same position you were in for the planning CT, lying on your back and wearing the mask. The radiographers will move the couch and the treatment machine into position. 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 radiographers will leave the room to start your treatment. The machine makes a buzzing noise when it is switched on. You have to lie still and 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 treatment, but some patients experience an unusual smell.
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.

Please note that it is rare for one patient to experience all of these side effects.

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

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 having to travel to the hospital each day. Patients often notice that this tiredness worsens and is at its most severe at around six to eight weeks after finishing the treatment. Listen to your body and if necessary allow yourself extra time to rest.
**Skin reaction**

Most people develop a skin reaction in the area being treated, especially on the back. The area may become red, more dry, sensitive or begin to peel. Please refer to the Skin Care Sheet, which will tell you how to care for the skin in this area. It is usual for the skin reaction to begin two to three weeks after the beginning of a radiotherapy course.

After treatment finishes continue your skin care regime until your skin has recovered. It will last for a small number of weeks after radiotherapy is complete. The redness and soreness will go away completely, but occasionally there may be some longer term skin changes that will be discussed with you if they are likely to be significant.

Your skin is very sensitive and needs protecting from the sun or cold winds, try wearing a hat or cotton scarf. The skin in the **treated area will always be sensitive to the sun**. Therefore it is best to use a high factor sun cream factor 25+ or sun block in the future. It is very important to cover the treated area if you go out in sunshine.

**These restrictions apply to the treatment area only.**

**Hair loss**

You will lose the hair within the area of the radiotherapy treatment. Ask your radiographer or oncology doctor to show you exactly where your hair may fall out. The hair will begin to fall out usually three weeks after starting the treatment. Although we plan the radiotherapy to try and avoid permanent loss, small areas maybe permanent or patchy and thinned. Any hair growth usually starts in four to five months after the radiotherapy and full re-growth is seen by 18 months or so.

**Wigs**

Before your treatment begins the nurse practitioner will tell you how to obtain a wig including the recommended shops. There is a form to complete and unless you are exempt a prescription
charge – payable at the General Cashiers Office at the hospital. They will complete the form which can then be taken to a hospital approved supplier. Our suppliers often provide a fitting service so that the wig can be trimmed or brushed to the style you like. They will also tell you how best to look after your wig.

Wigs can feel tight and uncomfortable, as your skin will be more sensitive during and perhaps after treatment. There are towelling turbans available or perhaps a light cotton or silk scarf or soft hat will feel more comfortable.

Your hairdresser maybe able to help you find a style which will cover any hair loss or patchy area.

Further information can be found in the Macmillan Leaflet Coping with Hair Loss.

**Headaches and nausea**
You may have already experienced **headaches, nausea, and changes to your vision or limb weakness**, controlled by dexamethasone tablets (steroid). However the radiotherapy may cause some of these symptoms to return or 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 radiographer or contact the triage service if out of working hours. They may arrange for you to see a doctor. The dexamethasone which you have been prescribed may need to be adjusted to control these symptoms during your treatment.

**Seizures or fits**
You may have already been experiencing seizures or fits, which may be controlled now by an anti epileptic drug. However the radiotherapy may cause the return or increased frequency of these fits. This is because radiotherapy can cause some swelling of the brain as it works. Please continue with your prescribed medication.
Usually a fit will last a few minutes and does not need emergency help. However, if it

• lasts more than five minutes without any sign of slowing down,
• is unusual in some way,
• the person has trouble breathing afterwards,
• appears to be injured / in pain or,
• recovery is different from usual,

then call for emergency help – dial 999.

It maybe helpful to be able to tell the doctors what the person was doing just before the seizure began, what happened during the seizure, how long it lasted, and how quickly the person recovered afterwards.

Usually the side effects you have experienced may become worse for a short while after the radiotherapy has finished and slowly settle. Please do not worry as this is quite normal. During this time you should continue to follow the advice you have been given during your treatment. Continue to take any prescribed medication for the side effects until advised by your doctor.
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 can sometimes be permanent. We carefully plan the treatment to avoid the surrounding areas around the tumour as much as possible to reduce these side effects.

Memory loss and lack of concentration

You may have already been experiencing these symptoms and found ways of coping with them. Your nurse practitioner will advise and support you and may refer to a neuro psychologist.

Hormone changes

Sometimes the radiotherapy treatment can cover a gland at the front of your brain between the eyes – the pituitary gland. This gland 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 as necessary.

Review during and after treatment

You will normally be seen on Tuesday afternoons every week by a doctor or nurse practitioner looking after you to see how you are coping with the treatment and monitoring any side effects. If you are to take chemotherapy tablets you will be seen on the first day of radiotherapy and asked to collect your tablets from pharmacy. If you have any symptoms or concerns, please speak to one of the therapy radiographers when you come for treatment.
After treatment

After your treatment has finished you will be asked to return to the Outpatient Clinic to be reviewed by your oncology consultant or his/ her team. Radiotherapy takes time to work and so it is at this appointment your doctor will assess you and discuss your progress and any continuing side effects with you and plan further appointments and further treatment if needed in the future.

Driving

All drivers who have a brain tumour must contact the DVLA and inform them of their diagnosis. Patients are not permitted to drive a car for a minimum of two years (high grade primary and secondary brain tumours) from the time of their treatment. In addition, patients with epilepsy must not drive for a minimum of 12 months from their last seizure. Failure to comply with these regulations is illegal and potentially dangerous, insurance is invalid and can incur a fine of up to £1000.

The DVLA can be contacted at: DVLA, Swansea SA6 7JL. You can also notify the DVLA of your medical condition by phone: 0870 600 0301. Full details and advice are also available on the website at: www.dvla.gov.uk
How to contact us

If you have any queries during your radiotherapy please do not hesitate to ask a member of staff treating you during normal working hours or when you come for treatment or contact the Oxford triage assessment team on 01865 572192 out of hours.

You can also contact the
The neuro nurse practitioner team – 01865 234372
(working hours Monday to Friday 09:00 - 17:00 – answer machine outside of working hours).

Or the specialist nurses at your local DGH, where you are treated.

Helpful Websites

Support network

www.braintumouruk.org.uk
Helpline: 0845 4500 386. Open 9-5, Mon-Fri
Txt Hedz: 07537410025

support@braintumouruk.org.uk

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call 01865 221473 or email PALSJR@ouh.nhs.uk