Radiotherapy to the Brain - Radical Course

Information for patients
This leaflet aims to help you and your family understand more about radiotherapy to the brain. It will be given to you in addition to the information you will receive from your Clinical Oncologist (who is a specialist doctor in cancer treatment).

Their team will be caring for you during your treatment. This team may include radiographers, nurses, social workers, physiotherapists, occupational therapists and dietitians.

The leaflet describes radiotherapy planning and treatment. It also explains the side-effects which you may experience during and after treatment.

Each person’s treatment will vary, so the information given is a general guide. The healthcare team looking after you will explain your treatment and the side-effects in detail. If you hear any words or phrases that you do not understand, please ask your doctor or a member of your healthcare team what it means. It does not matter how many times you ask.

If you have any special needs (physical, religious, cultural, emotional or medical), please inform a member of staff so every effort can be made to meet your individual needs.
What is radiotherapy?

Radiotherapy is the use of high energy X-rays and other types of radiation, to treat cancer. The organs and tissues of the body are made up of tiny building blocks called cells. Radiotherapy causes physical and chemical damage to the cancer cells in the treated area.

Although normal cells are also affected, they can repair themselves and are able to recover.

Radiotherapy itself is painless and does not make you radioactive. It is perfectly safe for you to be with other people, including children, throughout your treatment. Radiotherapy may be used as the main treatment for brain tumours, or as an addition to surgery.

If you would like to visit the radiotherapy department before your treatment starts please call 0113 206 7603 to arrange a time. This visit can be very useful as you can find out more information about radiotherapy. It is a good opportunity to visit the hospital and tour the simulators and treatment areas. You will also have the opportunity to ask questions.

Radiotherapy is given by therapy radiographers. You will see your radiographers at each treatment session and they will be happy to answer any questions you may have.
Students
Please be aware that the radiotherapy department is a training centre for radiographers. Students may be present on the treatment units. However, they are supervised at all times. If you do not wish students to be present during your treatment please speak to a member of staff. This will not affect your treatment or care.

Pregnancy
It is advisable that women avoid becoming pregnant while having cancer treatment because the radiotherapy can have an effect on the unborn child. It is suggested that you use a barrier form of contraception (e.g. condoms). For more information see the ‘Pregnancy and your cancer treatment’ leaflet. Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Planning your treatment
Your first appointment may be in the Planning Clinic or Level 1 Outpatients. You will see your Clinical Oncologist or a member of his/her team where they will discuss your treatment with you. You will be asked to sign a form giving your consent to treatment.

What to bring with you
• a list of all questions you may have;
• an up-to-date list of all the medications you are taking (including inhalers, sprays, vitamins or herbal products);
• any medication that you may need during your visit;
• if you have a stoma, please bring a spare bag and your changing equipment with you;
• something to eat or drink or something to read as this first visit can be quite lengthy (up to two hours).

**Mould Room**
Radiotherapy involves exact positioning of the radiation beam, so you will need to stay very still while you are having treatment. To help you stay still when treating the head, we may make a mask for your head and shoulders (shown here in the picture). You will wear your mask for your planning scan and treatments.

You will be given an appointment to attend Mould Room where the masks are made. If you have any concerns about the mask, please let your clinical oncologist or a member of their team know. We have a support team who will help you. There is a DVD and leaflet available. If you would like a copy please ask your consultant or contact the radiotherapy information lounge on **0113 206 7603**.

**CT Simulator**
You will need to have a CT scan as part of the planning process. This scan is taken on a machine called a CT Simulator, shown here in the photograph. You will need to wear your mask for this scan.
You may also need an MRI scan, this is done in the radiology department on Level 0.

The planning process is very important, when your plan is ready you will be given an appointment to start treatment. Your doctor will decide on the length of your course of treatment which may last from 4-6 weeks. Treatment usually starts 2-3 weeks after planning.

**Contrast (dye)**

A special contrast agent, often called a dye, may be used for your scan to make specific organs, blood vessels and/or tissue types ‘stand out’. This can make it easier for the doctor to plan your treatment.

The dye is given through a small needle into a vein in your arm. You should tell the radiographer if you have any allergies, but they will go over this before they use any dye.

**The most common side-effects of the dye are:**

- warm or hot “flushed” sensation during the injection
- a “metallic” taste in the mouth, which usually lasts less than a minute or so.
- You may also feel as if you have passed urine however to date no-one has! This will pass very quickly and it should cause no ill effects.

There is a slight risk of an allergic reaction to the injection, such as a skin rash, but it may rarely lead to other significant complications. The doctors in the radiotherapy department are trained to deal with any complications and again the risk involved is very small. You will be able to drive your car or go to work after your scan. The radiographers will advise you about drinking plenty of fluid after your injection.
Having your treatment

Treatment is given on a machine called a Linear Accelerator, shown here in the picture.

Treatment is normally given daily, Monday to Friday, however your treatment may **not** start on a Monday. Whenever possible you will be treated at the time of day that suits you, but this cannot always be arranged or guaranteed. There may be occasions when you may have a longer stay in the department or be asked to attend at a different time, e.g. to see your oncologist or nurse specialist.

When you arrive for your treatment you should go to the reception at the entrance of the radiotherapy department. You will be given directions to your treatment machine. The number of treatments you will be having will be confirmed by staff. You will be given a list with all the appointments you need.

Your first appointment on the Linear Accelerator is not for treatment (sometimes called ‘day zero’). On this day the radiographers will take a set of measurements and one or two x-ray pictures to compare with your planning scan. This comparison will be done after you have gone home. A team of radiographers work together in the treatment room; you will hear them giving each other instructions and information relating to your treatment. You may not notice much difference between the Day Zero and your usual treatment days. It may just be a little longer.
You can expect to spend 10-15 minutes each day in the treatment room. The treatment machine is only switched on for a fraction of this time. For most of the time the radiographers are carefully placing you and the machine in the correct position for your treatment. The machine does not actually touch you.

Once you are in the correct position the radiographers will leave the room to switch on the machine. You will only be alone for a few moments at a time. The radiographers will be watching you on a closed circuit TV monitor as shown here in the picture. The CCTV camera is not recording or saving any images. There is also a two-way intercom system so the radiographers can talk to you and you can talk to them if needed.

Although you have to lie still, you can breathe normally during your treatment. The machine stops automatically after your prescribed dose of treatment has been given. The machine can also be stopped at any time if required. The treatment machines make a buzzing sound when they are switched on. You do not feel pain, heat or any other sensation.

During the treatment course, please tell the radiographers how you are feeling. If you have any problems or questions, please let them know. Your Clinical Nurse Specialist (CNS) will see you once a week in the Princess Royal Suite to see how you are getting on. They work in close contact with your consultant and will monitor any side-effects you may be experiencing. You can expect to be in the department longer than usual on this day.
Some days the Radiotherapy Department may be very busy and your appointment time may be delayed. We will keep you informed of any delays.

Your appointments for Radiotherapy may not all be at the same time each day and may need to change. It is also possible that during your course of treatment you may miss a day’s treatment due to machine maintenance or bank holidays. It is therefore important to speak to a health care professional before booking a holiday immediately following your radiotherapy.

For appointment queries please telephone the Radiotherapy Reception Desk on 0113 206 8940 or 0113 206 8956 for further advice.

Driving
Because your brain may be affected by either your disease or your treatment you MUST NOT DRIVE. Your doctor will be able to provide further information about this restriction if this applies to you. Information can also be obtained by contacting the Medical Adviser, Drivers Medical Unit, DVLC, Longview Road, Swansea. SA99 1TU. Tel: 01792 783686.

Car parking
When you are coming for radiotherapy planning and treatment your car parking is free. On entering the car park take a ticket and park as usual (disabled parking spaces are on Level 0). When exiting use the left hand lane next to the ticket office. Take your parking ticket and appointment letter to the attendant. They will process your ticket so that when you insert it at the barrier no charge will be made.
Important

If you experience any of the following problems before starting, during or after your course of radiotherapy, please report them immediately to a radiographer, nurse or doctor. These symptoms may require changes in your medication or treatment schedule.

- Sensory / neurological changes
- A change in vision, hearing or speech.
- A change in sensation of the face, body, arms, legs.
- An abrupt change of bowel or bladder habit.
- Weakness.
- Unsteadiness.
- Dizziness.
- Seizures - ‘fits’ or ‘blackouts’.
- Severe headaches and vomiting.

The type and extent to which you may experience these side-effects is individual, and depends upon many factors such as the position and dose of your treatment. It is important to remember that not everyone experiences these side-effects.

Side-effects

Side-effects can be divided into short term (acute) effects that happen during or soon after your treatment, and long term side-effects occurring months or years later. Some side-effects are common, whilst others are rare. As your treatment progresses you may experience some side-effects. Not everyone will experience all of these reactions. If you do experience any of the following side-effects, do not worry, they are
normal reactions to treatment and are temporary. They usually begin about half way through the course of treatment, may last for several weeks after it has finished and then slowly settle down. Please tell us how you are feeling, particularly if your symptoms worsen, so that we can advise and treat you.

**Headache**
If you develop frequent headaches, that are not relieved by pain killers, during your treatment it is important that you are given the correct medical advice and medication. Please inform your nurse, radiographer or doctor immediately.

**Tiredness (fatigue)**
Radiotherapy can make you feel more tired than usual, especially if you have to travel a long way for treatment each day. Fatigue is most common in the first few months after treatment, but usually improves significantly between six months to a year after treatment. Very occasionally some people find that fatigue can last longer, up to two years or more.

**There are things you can do to help yourself:**
- Exercise can help reduce the symptoms of fatigue.
- Having enough to drink can prevent tiredness from dehydration.
- Small meals or snacks eaten more often than three times a day may be easier to face.
- Try to get a good night’s sleep where possible, a daytime nap may help.
- Try to ‘pace’ yourself, listen to what your body is telling you, rest if you need to.
- Pick out things you enjoy, and try to delegate other tasks.
- Little and often is the rule of thumb.
There is a Macmillan information leaflet available ‘Coping with fatigue’. If you would like a copy, or support with your fatigue please ask a member of staff.

**Somnolence Syndrome** is a delayed side effect of radiotherapy which occurs several weeks after treatment has finished. This is severe fatigue and exhaustion as described above. Please be aware that this can last for several weeks. This is a normal and expected reaction to radiotherapy.

Please contact your Clinical Nurse Team if you have any questions or concerns.

**Skin reaction**

10 to 12 days after starting your treatment, the skin where you are having your treatment may change especially around your ears. Your ears may feel temporarily blocked. You will be given a leaflet ‘Skin care during radiotherapy Skin 1’ which will give you more information about this. Another leaflet ‘Skin care after radiotherapy Skin 2’ will give you information on how to care for your skin after your radiotherapy. The radiographers will give you this leaflet when you have finished your course of treatment.

If you are concerned about your skin reaction please talk to your radiographers or contact the nursing staff in Princess Royal Suite on 0113 206 7587

**Hair Loss**

The hair follicles (roots) are very sensitive to radiation. Any hair directly in the treatment field, will gradually fall out during the course of treatment or shortly afterwards. You may start to notice your hair thinning 2-3 weeks after starting your radiotherapy. This hair loss is usually temporary.
When the course is finished your hair will slowly start to grow back but, in places, it may not be as thick as before. The texture and colour of the new hair may have changed. It can take up to six months before your hair re-grows. Sometimes there are areas of the scalp where the hair may not grow back at all.

A wig can be provided for you if you would like one. Please ask your nurse, radiographer or doctor. Turbans, scarves or hats are attractive alternatives to a wig. You may find wearing a hair piece, cap or hat more comfortable. Any head wear worn should not be too tight. Head Art Therapy is available to anyone experiencing hair loss, for more information please contact the Robert Ogden Macmillan Centre: 0113 206 6498.

Macmillan Cancer Support has a booklet on ‘Coping with Hair Loss’ which they will send to you free of charge if you phone Freeline: 0808 800 1234 or you can collect a copy from one of the information lounges.

Nausea and Vomiting
It is rare to experience either of these side effects while you are having treatment - but if you do have any problems please inform your nurse, radiographer or doctor. Anti-sickness medication can be prescribed if necessary.

Taste Changes
Occasionally, people may notice that their sense of taste alters during their radiotherapy and illness. Usually this is temporary, and it will gradually return to normal after the radiotherapy is finished.

Some people experience a sore mouth or throat depending on the area being treated. If you have any problems please speak to your radiographer or the nurses in Princess Royal Suite.
Anxiety and emotional stress
During treatment many people feel stressed, anxious, depressed or at times unable to cope. If you or your family feel that they need someone to talk to we are able to offer appropriate help and advice. Please discuss any problems with your nurse, radiographer or doctor.

Late side-effects
There are some side-effects that can develop many months or years after the radiotherapy. They depend on which part of the brain has been treated and the dose given. If for instance the pituitary gland (a part of the brain that produces hormones) receives a certain dose, regulation of some of the hormones can be upset. This can be treated by hormone replacements. Your doctor will tell you if you are at risk of pituitary underactivity or other problems.

Steroid treatments
When giving radiotherapy to the brain it is often necessary to use a steroid drug (such as dexamethasone). The purpose of the steroid is to reduce the amount of swelling (oedema) around the tumour. Please see the ‘Understanding steroids’ leaflet.

After treatment has finished
Some people find their symptoms temporarily get worse after radiotherapy has finished. This may make you think that your tumour is growing back. However it may simply be a reaction to the radiotherapy. If you find your symptoms get worse please discuss it with your nurse or doctor. You may need to increase or re-start your steroid treatment.
Your doctor will see you in the outpatient clinic approximately 4-6 weeks following your treatment. Then your doctor will arrange to see you as necessary. Please discuss any problems and worries you may have with them at these appointments.

If you are worried about anything to do with this illness or treatment between your appointment visits, please contact your Key Worker or GP.

There is also a support group called Andrea’s Gift which runs weekly in Leeds. Please see the leaflet in your pack for more information.

Useful organisations and contact numbers

Leeds Cancer Support
Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Robert Ogden Macmillan Centre.

The Robert Ogden Macmillan Centre
The Centre is on the St James’s Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime. Open from 10am - 4pm Monday to Friday.
Contact numbers for Leeds Cancer Support

**Information Lounge Level 1 Outpatients Department**
Open from 10am - 4pm. Tel: (0113) 206 8816

**Information Lounge Level -2 Radiotherapy Department**
Open from 8.30am - 4.30pm Tel: (0113) 206 7603

**Robert Ogden Macmillan Centre**
Open from 10am - 4pm. Tel: (0113 206 6498)

All the Leeds Cancer Support services can be emailed on: leedsth-tr.Cancersupport@nhs.net

**National Information Services**

**The Pituitary Foundation**  
Tel: 0117 927 3355.

**Brain Tumour Foundation**  
Tel: 0181 336 2020.

**Brain Tumour Action**  
Tel: 0131 4660236

**Macmillan Cancer Support**  
Free phone 0808 808 0000

Monday to Friday 9am - 6pm. A textphone service for deaf and hard of hearing people 0808 808 0121.

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)