Radiotherapy to the Brain

Information for patients
This leaflet aims to help you and your family understand more about radiotherapy to the brain. This is in addition to the information you will receive from your clinical oncologist, a specialist doctor in cancer treatment.

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

This leaflet describes about you coming for your radiotherapy planning appointment and your 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.

Staff will make every effort to meet your individual needs or will direct you to the person who can help.

All your radiotherapy planning and treatment will take place in the Radiotherapy Department on Level -2, Bexley Wing, Leeds Cancer Centre (LS9 7TF).

Please do not bring any valuables into hospital with you as the Trust cannot accept liability for loss or theft.
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 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 is a local treatment. This means it only affects the part of the body that is treated. You do not feel anything and it 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 a brain tumour, or as an addition to surgery.

You will have your radiotherapy on a treatment machine called a Linear Accelerator as shown above.

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 (CT scanning area used in your planning appointment) and treatment areas.

“I was so pleased to see the machines before my treatment and the staff were so helpful and really put my mind at rest”
Therapeutic Radiographers
Radiotherapy is given by male and female therapeutic radiographers who are highly trained in the accurate planning and delivery of radiotherapy treatment. You will see your radiographers at each treatment session and they will be happy to answer any questions you may have.

Students
The radiotherapy department is a training centre for male and female 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 important that women **do not** become pregnant whilst having cancer treatment because the radiotherapy and chemotherapy can have an effect on the unborn child. It is suggested that you use a barrier form of contraception (for example condoms). For more information see the ‘Contraception and pregnancy during 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 in the Bexley Wing. You will see your clinical oncologist or a member of their 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);

• something to eat and drink and something to keep you occupied 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 will make a mask for your head (shown here in the picture). You will wear your mask for your planning scan and treatments.

For the mask you will be given an appointment to attend the 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 leaflet available - Having a radiotherapy mask made. If you would like a copy please ask your consultant or contact the radiotherapy information lounge on 0113 206 7603.
Planning CT Simulator

You will need to have a Planning 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 involves a separate appointment in the radiology department.

Your radiotherapy is individually planned by your oncologist and a specialist physics team using information from the CT and MRI scans, this can take up to a few weeks if it is a complex treatment. When you attend for your planning visit you will be given information on when the treatment is expected to start.

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. This feeling 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.

The scan will have no after effects, so you will be able to carry on your day as normal when it has been done. 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 on Level -2 of the Bexley Wing. 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.
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. You will also hear the radiographers giving each other instructions and information relating to your treatment. It is important to stay as still as possible and breathe normally.

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 an intercom system so the radiographers can talk to you.

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 anything.
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, also situated in the department, 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. Please look out for information screens, and signs displayed in waiting rooms.

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 number on your appointment letter 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, DVLA, Longview Road, Swansea. SA99 1TU. Tel: 0300 790 6806
Car parking

Car Parking in the multi storey is **FREE** for those attending radiotherapy planning and treatment appointments.

- 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.
- If you need assistance or are unable to leave your car please press the button on the barrier.

**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.

- 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.
Side-effects
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 can be divided into short term (acute) side-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. 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 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 has usually improved significantly by six months. Only rarely does it last longer than this.
There are some things you can do to help yourself:

- Gentle 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 the things you enjoy, and try to accept help with other tasks.
- Little and often is the rule of thumb.

There is a Macmillan information leaflet about fatigue available. 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

Before you go in for your treatment the radiographer will explain what will happen to your skin and how to look after it. They will also give you a leaflet to take home. The same will happen at the end of your treatment.
If you are concerned about your skin reaction please talk to your radiographers or contact the review clinic nursing staff in Princess Royal Suite. **Telephone: 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 headwear worn should not be too tight. There is a hair loss workshop and support available for anyone experiencing hair loss, for more information please contact the Sir Robert Ogden Macmillan Centre: **0113 206 6498.**

Macmillan Cancer Support has a booklet about coping with hair loss, which they will send to you free of charge if you phone Freeline: **0808 800 0000,** 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.

**Hearing**
If radiotherapy is delivered close to an ear, then it is sometimes possible for inflammation inside to temporarily cause some hearing loss on that side. This can sometimes last for a few weeks or months.

**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.

Patients who live many years after radiotherapy may experience some cognitive effects (e.g. memory disturbance). Usually these are subtle and do not interfere significantly with day-to-day life. Similarly, there is also a very slightly increased risk of developing other brain tumours in the future.

Great care is taken to ensure radiotherapy does not affect your vision. However some patients may be at a slightly higher risk of cataracts many years after treatment. There may also be situations where a tumour lies close to an ear where there will be a risk of hearing loss in the long-term.

Modern radiotherapy seeks to minimise these risks by limiting the doses delivered to normal brain tissue. However, these risks are always considered carefully by your doctor before offering radiotherapy. Your oncology team will discuss any predictable long term side effects with you.

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 treatment area. An information leaflet is available, please ask a member of staff.
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 usually 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.

Refreshments

There is a restaurant and coffee shop available on Level 0, which are open daily. They serve drinks, light snacks and hot meals. Vending machines are also available in the main radiotherapy waiting room and Level 0. There is also a shop on Level 0 with books, papers and snacks.
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 Sir Robert Ogden Macmillan Centre on the St James’s Hospital site.

Contact numbers for Leeds Cancer Support:
Information Lounge Level -2 Radiotherapy Department
Open from 8.30am - 6.00pm Tel: (0113) 206 7603

Information Centre Level 1
Open from 10am - 4pm. Tel: (0113) 206 8816

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

National Information Services
The Pituitary Foundation Tel: 0117 370 1320
Brain Tumour Research and Support Tel: 0113 340 0111
Macmillan Cancer Support
Freephone 0808 808 0000 8am to 8pm, 7 days a week.
There is a textphone service for deaf and hard of hearing people 18001 0808 808 0000.
Website: www.macmillan.org.uk