

Craniospinal radiotherapy

You will shortly be starting radiotherapy. This factsheet provides information about the preparation and what to expect during treatment. It also includes other things that you need to be aware of, although it is not intended to be comprehensive. Some of the terminology used may be unfamiliar or you may have further questions after you have read this. If there is anything you do not understand, please ask your doctor, nurse or radiographer.

What is craniospinal radiotherapy?

Craniospinal radiotherapy refers to radiotherapy treatment of the entire brain and spinal cord (the central nervous system). This particular type of radiotherapy is necessary for brain tumours such as medulloblastoma, primitive neuroectodermal tumours (PNETs), some ependymomas, germ cell tumours and lymphoma. The aim of the treatment is to minimise the risk of seeds of the tumour settling elsewhere in the brain or spine. Following craniospinal radiotherapy, further radiotherapy is given to the site where the tumour was originally. This is usually described as 'local radiotherapy boost'. The aim of this treatment, in most cases, is to cure you of your cancer.

What happens to me before radiotherapy?

The preparation for craniospinal radiotherapy may take up to four weeks. We know that this delay before the start of treatment can cause anxiety to both you and your family. However, the preparation process is important to give the treatment accurately on each occasion. On your first visit to see the doctor in the outpatient department, we will give you a start date for your radiotherapy treatment and appointments for the preparation of the treatment. These will include visits to the mould room and CT scanner. We will also provide a list of contact numbers, should you have any queries, as well as additional booklets on radiotherapy and hair care.

Treatment preparation

Mould room

The first appointment will be in the mould room. An impression of your face is taken here, in order to make a plastic support for the face, head and shoulders. This is in the form of a plastic mask or a shell. This preparation is necessary to make sure that you are in the same position each time you come for planning and treatment, so we can give the treatment as precisely as possible. Each visit may last up to an hour.

Computerised Tomography (CT) scan

The next visit will be to the CT scanner where you will be asked to lie down in the treatment position, with the shell around the head and shoulders. You will also receive an injection of dye (contrast), which helps to define the area that will require the local boost. This procedure is similar to the scan you had before. The CT images of the brain and spine will be used to work out where the radiation should be directed. Each visit may last up to an hour. During the session on the CT

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scanner, a radiographer will make marks on the plastic shell and will ask your permission to make four small permanent tattoos on your stomach (about the size of a pencil head). These are not usually painful (no more so than having blood taken) and they are barely visible. The marks on the shell and your stomach are to make sure that you are in exactly the same position each time you receive radiotherapy. You may require a blood test in preparation for this scan.

What happens during radiotherapy?

The course of radiotherapy treatment will last between five and seven weeks. Treatment will usually be given once a day every working day (excluding weekends). We will try to keep any interruptions to the treatment to a minimum. If your treatment falls within holiday periods such as Easter or Christmas/New Year, and your condition requires it, we will try to offer you extra treatment days during a weekend or on one of the bank holidays.

Each visit to the hospital will take approximately one hour, of which about 20 to 30 minutes will be in the treatment room. The majority of the time in the treatment room is spent making sure you are in the right position, lying down with the plastic shell around the head and shoulders. When you are in the right position, the radiotherapy machine (linear accelerator or LINAC) is directed to give the treatment. For the daily treatment, the machine will be switched on and off several times and moved to different positions for each treatment field. The radiotherapy treatment itself only takes a few minutes. While you are receiving radiotherapy, you should not feel anything. It is a painless procedure rather like having an x-ray taken. The treatment machine may make some noises during treatment; this is normal and is nothing to worry about. Although you will be alone during the actual treatment, the radiographers can see, hear and talk to you by means of a TV monitor and intercom.

Throughout the course of radiotherapy to the brain and spine (during the first three to four and a half weeks), you will be asked to have weekly blood tests. This is because radiotherapy can interfere with the production of blood cells in the spine (vertebral column). After finishing the treatment to the brain and spine, you will continue with radiotherapy to part of the brain and/or spine which will last for another two to three weeks. Blood tests are not usually necessary during this time.

What should I expect during and after radiotherapy?

Most people remain well during treatment. However you may notice some side effects, which are usually mild and only rarely need treatment. These are listed below. Please discuss any problems with the radiographer, clinical nurse specialist or doctor either while attending the hospital for treatment or in the weekly on-treatment clinic.

Side effects during and shortly after treatment

Skin changes to the scalp

Your scalp may become red, as though you have been sitting out in the sun and this may start two to four weeks after the completion of treatment. It may feel hot and itchy. This is usually followed by dry and flaky skin - this is part of normal skin healing. During this stage it is best to apply an unperfumed moisturising cream such as aqueous cream or E45. For a limited period, the skin on your head will be more sensitive to the sun after radiotherapy. You should protect your head from



direct sunlight with a scarf or a hat. Sun cream containing sun protection factor (SPF) should be used indefinitely after radiotherapy.

Hair loss

It is usual to lose hair from the area being treated during radiotherapy. Hair loss may be permanent following the six week course of radiotherapy but this depends on the exact position of the tumour. We will discuss this with you in more detail during your first visit.

During radiotherapy, you can continue to wash your hair as frequently as you normally do. There are only minor precautions you should take. You should not use hair dye or perm your hair. We suggest that you use tepid water and a mild shampoo and not rub but pat your hair and scalp dry with a soft towel. You should not use a hair dryer as even on a low setting it can irritate the scalp. If you are used to having a facial wet shave, you may continue to do so. If you would like a wig, please ask about this when you are seen in clinic. For more information, please ask a team member to be put in touch with a hair loss advisor. The PALS help centre also has a range of leaflets available.

Sore throat or dry cough

Radiotherapy aimed at the spine reaches the windpipe (trachea) and the gullet (oesophagus). It may cause mild inflammation of the fine membrane lining. As a result, you may experience a dry cough or slight discomfort on swallowing, resembling a sore throat. This is temporary and completely resolves shortly after finishing treatment. If you have a cough or sore throat, we can prescribe a syrup to ease this.

Appetite and nausea

Some patients may experience a loss of appetite and should seek advice for this. Nausea (feeling sick) is not usually a problem but if this should happen, please tell your radiographer, clinical nurse specialist or doctor. They will be able to give you some anti-sickness medication.

Tiredness

Radiotherapy may make you feel exhausted and you may find that your energy levels are lower than before. Tiredness can last for six to eight weeks after finishing radiotherapy. This is also called 'somnolence'. Take frequent rest, drink plenty of fluids and try not to overexert yourself.

Long term side effects after craniospinal radiotherapy

The reason for giving craniospinal radiotherapy is to clear tumour cells from the central nervous system (which is made up of the brain and spinal cord) and to reduce the likelihood of the tumour regrowing. This form of treatment is very successful, but any form of intensive radiotherapy can contribute to changes of the normal brain and there is concern that radiation may cause some damage in the future.

Brain

The chances of radiotherapy damaging the brain are small. Treating the brain may have an effect similar to speeding-up the ageing process. This may result in reduced short-term memory and concentration which may become noticeable many years after treatment.



Eyes

The lenses of the eyes may be at risk of developing cataracts, a condition that is easily treatable. If you are at risk of this your team will inform you.

Hormones

Radiotherapy may affect the hormone producing mechanism of the brain (hypothalamus) and the pituitary gland. This will be monitored with blood tests during follow up. Hormone deficiencies are easily treated with medication that is taken by mouth or as an injection. Should this be required, hormone replacement will usually have to continue indefinitely and you will be referred to an endocrinologist who will manage this for you.

Fertility

Craniospinal radiotherapy may carry a small risk of infertility, more so for women than for men. Your team will discuss this with you. As a precautionary measure, women can have a minor operation to move the ovaries out of the treatment field (oophoropexy) and men can store some sperm before starting radiotherapy.

Contraception

Men and women of childbearing age should use appropriate contraception during the treatment and for several months after completion of radiotherapy.

Other tumours

The aim of radiotherapy is to prevent the tumour from coming back. However, the use of radiation for treatment carries a small risk of developing another tumour many years after treatment. The risk is about five in 100 people within 20 years after treatment. Some of those tumours are easily treatable with surgery.

Other side effects

Effects of radiation on the brain

Radiotherapy is given to the tumour and a margin around the tumour over a period of six weeks. This minimises any damaging effect of radiation. However, high dose irradiation carries a small possibility of damage to the area being treated. This happens in up to five in 100 people (5%). This type of damage from radiation is called 'radiation necrosis'. Irradiating part of the brain which is not directly affected by the tumour can cause some damage to the blood vessels, which results in an effect similar to speeding up the ageing process. In very rare cases, the treatment can affect the eyesight causing varying degrees of visual loss and hearing may also become impaired.

The reason for giving radiation is to reduce the risk of damage to the brain from the tumour. While you may be concerned about the potential damage from radiation, though small, the risk of damage from an untreated tumour is far greater than the risk of damage caused by treatment. We will discuss the risks and benefits of radiotherapy with you before you give consent to treatment. If you are unsure or do not understand what is being said, please tell the doctor or the nurse specialist working with your consultant.

What arrangements are made after I have completed my radiotherapy?



Approximately six weeks after you have finished treatment, we will ask you to come back to clinic for a first assessment and review. We will arrange an MRI scan of your brain and spine (three months after the end of radiotherapy treatment) to document the effects of the treatment. You will need to attend the follow up clinic on a regular basis. This will be four times a year during the first two years. After this, the time intervals will gradually increase until it becomes suitable for you to attend the long-term follow up clinic once a year. This is because some side effects may take many years to develop and we need not only to check if your tumour is well controlled, but also to identify potential problems. We can then offer appropriate treatment and support as needed.

Additional information

Steroids

Dexamethasone tablets (commonly known as steroids) may occasionally be prescribed at some time during your treatment should you suffer with persistent headaches or nausea. They should be taken with food or a milky drink, and before 3pm (as they may keep you awake at night). **Do not** stop taking the steroids without medical advice. Please inform us if you have a past medical history of ulcers or indigestion. (Please see The Royal Marsden leaflet on steroid medication).

Driving

If you have had a brain operation, a brain tumour and/or epilepsy (also known as fits or seizures) you must not drive until the DVLA allows you to. Please write to the DVLA and let them know about your condition and ask the clinic staff to discuss this with you in more detail if needed.

Finance

If you take anti-epileptic medication (anticonvulsants), have cancer or have a continuing physical disability which means that you cannot go out without the help of another person, you are entitled to free NHS prescriptions. Ask at the chemist or pharmacy for an exemption certificate form FP92 and get your doctor to sign this. You may be entitled to other benefits. Please discuss this with the clinical nurse specialist or the clinic nurse who can refer you to the welfare benefits officer.

Support

At times, it may be necessary to involve other members of the hospital or community such as dietitians, district nurses, occupational therapists or physiotherapists in your care. This is to ensure that all available support is there for you during and after radiotherapy. We will always discuss changes in your care with you and any change to the services provided will not be introduced unless you agree. During your treatment, either the neuro-oncology clinical nurse specialist or the doctor, will see you weekly in the on-treatment clinic. They will address any problems and answer any questions that you may have.

Questions

If you have any questions remaining following your consultation or at any other time, please ask a member of our staff or give us a call. You may find it helpful to write your questions down before any further consultation to ensure that we answer all your questions to the best of our abilities and respond to any concern you may have.

Please see separate information sheet for contact details.

