



**University Hospitals Birmingham**  
NHS Foundation Trust



# Total body irradiation

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This booklet has been written to provide a guide to patients and parents of children who are receiving Total Body Irradiation (TBI).

You or your child is having radiotherapy as part of a treatment regimen, for bone-marrow transplantation (BMT). This booklet explains the side effects that may be experienced during and after treatment.

It attempts to cover any possible questions or concerns you may have. If you have further questions or you would like clarification about anything you have read, please speak to a member of staff.

## What is radiotherapy?

Radiotherapy uses high energy X-rays to destroy cancer cells.

It can be targeted to specific areas of the body or it can be used in preparation for bone marrow transplantation when it is referred to as total body irradiation or TBI.

The treatment is like having a long X-ray, it is painless and, you will not see or feel anything. You do need to keep still for a few minutes.

Normal cells can also be affected by radiotherapy, resulting in some side effects but these cells are able to recover. These will be discussed later in this information.

The treatment will not make you radioactive so it is safe to be around children and others after your treatment.

Your radiotherapy will be delivered by radiographers, both male and female.

We are a teaching hospital and have student radiographers in the department each day who are supervised by trained staff at all times.

## Why does radiotherapy need to be given before bone marrow transplantation?

The rationale for using radiotherapy in preparing someone for a bone marrow transplant is threefold:

- Radiotherapy is good at getting rid of the existing bone marrow in order to make space for the transplanted marrow
- Radiotherapy is good at killing any malignant cells such as leukaemia or lymphoma that may be left behind following chemotherapy, in particular, sites that chemotherapy does not penetrate well, such as the brain and the testes in males
- It is good at suppressing the immune system so that the transplanted marrow is not rejected

## What are the benefits of radiotherapy?

Total body irradiation is an important part of the conditioning regime required prior to bone marrow transplant. Radiotherapy helps to make space for the transplanted marrow, kills any malignant cells that may be left after chemotherapy and suppresses the immune system to help prevent rejection of the transplant.

## Are there any alternative treatments to radiotherapy?

Chemotherapy and immunosuppressant drugs are also used as part of the conditioning regime prior to bone marrow transplant. Your consultant will discuss with you whether these drugs alone are a possibility for your conditioning regime.

## When is radiotherapy given?

Total body irradiation (TBI) is usually given in eight treatments over four days treating twice a day (some other conditions may have six treatments over three days such as multiple myeloma).

Treatment is given in the early morning and late afternoon each day to give a 6–8 hour gap between each treatment. The first day is usually a Tuesday.

Sometimes TBI is given as a single treatment. Your consultant will discuss with you if this is applicable to you and your treatment regime.

## Will radiotherapy treatment be as an inpatient?

The TBI treatment is given in the Radiotherapy Department at the Queen Elizabeth Hospital in Birmingham.

Adults will be inpatients for their TBI treatment.

Children will be inpatients at Birmingham Children's Hospital and transport will be arranged by the ward for appointments at the Queen Elizabeth. Although the Queen Elizabeth Hospital is an adult hospital it has the experience, staff and equipment to treat children with radiotherapy.

## What needs to happen before starting treatment?

Once you have seen the radiotherapy doctor and they have explained the role of treatment, you will need to sign a consent form.

You will then need to be seen by a radiographer at the Queen Elizabeth Hospital who will explain the TBI procedure and take some measurements of your body to help plan the treatment.

Sometimes it is necessary to have some areas 'boosted' with radiotherapy; areas such as the brain and/or the testes in young boys. Your doctor will explain to you if this additional treatment is required. If so, there will be some extra appointments at the radiotherapy department for some additional planning prior to treatment starting. The treatment for areas that require a 'boost' will be given on days preceding the TBI. The radiographers will

give you this additional information when you come for the measuring appointment.

If your donor is an unrelated donor then a boost to the pelvic area may be needed to ensure that the pelvis receives a sufficient dose of radiotherapy. This will also require an extra appointment for some additional planning. The additional treatment will be given the day before the TBI starts. Whether a pelvic boost is needed becomes apparent during the TBI calculations so it will not be apparent on the day you have measurements taken, but you will be contacted by phone to make arrangements if necessary.

## What happens for the treatment?

For the TBI treatment you will sit in a special chair with the radiotherapy machine to one side of you pointing the radiotherapy treatment towards you .

The machine does not come close to you or touch you. The treatment is given in two parts to either side of your body.

Please wear comfortable clothes with no metal zips or buttons. A pair of thin pyjamas, or track suit trousers and a long-sleeved T-shirt, would be suitable. You will need to remove anything from your person that contains metal e.g. jewellery or a watch.

The radiographers will make sure that you are in a comfortable position for treatment and may adjust your position as well as the position of the machine to ensure that the radiation beam will adequately cover the whole of your body.

During the first treatment the radiographers will attach tape with special crystals in them to parts of your body. These are called dose meters and are used to check that the dose expected from planning your treatment is actually what is being received. Occasionally the radiographers are asked by the physicists to repeat some of the dose meters. Please do not worry if they are repeated.

Once you are in the correct position for treatment the radiographers will inform you when they are about to leave the

room . You are alone in the room during treatment but will not see or feel anything whilst the treatment is being given.

You will hear an alarm sound as the radiographers leave the room which is part of the safety procedure.

The radiographers will operate the machine from the control area and they can hear and see you at all times. If you need assistance, just call out or raise your hand.

For your own safety, please do not try to get off the chair as it is raised up off the floor.

The machine makes a noise whilst it is working and may switch on and off a few times to deliver your treatment. The treatment will take around 10–15 minutes. When the radiographers come back into the room please remain still. Half way through treatment the chair will be turned around so that the other side of the body can be treated . The radiographers will then leave the room again and treatment will take a further 10–15 minutes. The radiographers will watch you, or your child, from outside in the control area on TV cameras.

Family members will be asked to wait in the waiting room for the duration of treatment.

Young children may find it difficult to keep still or be in the treatment room by themselves so it may be suggested that they have their treatments under a general anaesthetic. This is done by a consultant paediatric anaesthetist from Birmingham Children's Hospital and is well tolerated by children. If an anaesthetic is required, rather than sitting in the chair your child will be lying on a treatment couch. This procedure will be explained more fully to you by the radiotherapy doctor or paediatric radiographer.

## CCTV monitors

The treatment rooms are monitored during your preparation for treatment, positioning and treatment delivery by television cameras. This is part of ensuring the accuracy of your treatment and your safety and wellbeing in the rooms at all times.

We assure you that the camera image feed is live and it is not possible to make a recording.

The images are viewable on screens situated in the machine control areas. The control areas are only accessible by authorised radiotherapy staff, some who may not be directly involved with your care at that time.

If you have any concerns about your privacy or dignity that you have not already discussed then please do not hesitate to highlight your concerns during the information discussion with the radiographers at your first treatment appointment.

## What happens at the end of treatment?

Once your course of treatment finishes you will be ready for your bone marrow transplant and the haematology team of professionals will take over your care and long term follow up.

## Are there side effects of treatment?

Radiotherapy affects the cancer cells and also the surrounding normal tissue which can lead to some side effects developing. It is difficult to predict which side effects will occur as everybody is different. The drugs involved in your conditioning regime may also produce similar side effects.

Side effects can be divided into early or acute side effects, which can start within a few hours of treatment and last several weeks or late/long-term side effects, which tend to develop several years after treatment. They do not affect everybody, usually only a small percentage of patients.

This information has been written as a guideline and your doctor will have discussed this in more detail with you. If you are worried about anything please speak to a member of staff.

## What are the early side effects?

**Nausea and vomiting** – most patients have experienced these symptoms as a result of their intensive chemotherapy. Nausea from radiotherapy is generally milder and can be prevented by anti-sickness medication. Please speak to the nursing team looking after you if you require some medication.

**Inflammation of the salivary (parotid) glands (parotitis)** – the inflammation may cause some stiffness of the jaw but this usually settles down after a few hours. The parotid glands produce most of your saliva and may stop functioning for a period of days or weeks following the treatment. This can make eating uncomfortable. You may find that drinking more, especially with meals is helpful. Your doctor can prescribe artificial saliva which may also help. Pain relief can also be used to ease any discomfort.

**Hair loss (alopecia)** – some patients will already have total body hair loss due to their chemotherapy. If you have a full head of hair prior to treatment you will experience hair loss about 2–3 weeks after your radiotherapy is finished. Your hair should start to grow back after a few months but may be a different texture or colour. A wig can be supplied from the hospital; please ask if you would like more information about this. The radiographers will talk to you about washing your hair during treatment when you come for your measuring appointment.

**Sore mouth (mucositis)** – TBI can cause inflammation of the lining of the mouth, tongue and throat. This usually develops 7–10 days after starting TBI. Good mouth care is important if this occurs. Once treatment begins you should use a soft toothbrush and use a prescribed mouthwash to help to reduce the risk of infections. Your doctor can also prescribe medication which may ease the symptoms.

**Diarrhoea** – usually occurs 10–14 days after starting TBI. If your symptoms persist please let the nursing/medical staff know, as medication can be prescribed. We encourage you to drink plenty of fluids to help prevent dehydration.

**Skin redness (erythema)** – may occur with some people, especially those with fair skin. To help reduce this, wash your skin gently with a mild unperfumed soap and use a mild shampoo for washing hair whilst attending for radiotherapy. Avoid any other products whilst receiving radiotherapy.

**Tiredness/lethargy** – you may feel a sense of fatigue or have less energy during and after your course of treatment. You can help yourself by taking time to rest and relax.

## What are the long-term side effects of treatment?

The long-term side effects are much harder to predict because each person is an individual. Unfortunately when these side effects do happen they are permanent. Your radiotherapy doctor will have explained the potential late effects of radiotherapy as part of the consent process. The following information is for guidance only and does not necessarily mean that all these side effects will happen.

**Sleepiness (somnolence)** – somnolence syndrome is described as excessive sleep, drowsiness and lethargy. You might have a particularly sleepy spell starting 6–12 weeks after treatment ends which may go on for a further 2–6 weeks or even longer. You may notice that you have a lack of energy and cannot be bothered to do anything. This is a normal reaction to the treatment but the long duration and sometimes the severity of the symptoms can cause anxiety.

**Cataracts** – the development of mistiness of the lenses of the eye can occur because of unavoidable radiation to the eye. This usually develops 3–4 years after TBI treatment. As treatment is now given over several days the formation of cataracts is less common. If, however, cataracts form they can usually be removed by a simple surgical procedure.

**Learning ability** – the ability to retain new information and skills can be affected in children who have had radiotherapy to

the brain. How much this will be affected does depend on the age of the child when they have treatment and also the dose of treatment they receive. Adults having TBI can occasionally have problems in the future with their short-term memory.

**Pneumonitis** – this is inflammation of the lung tissue. In a very small percentage of patients it can occur six weeks to months following TBI. You may experience shortness of breath and a cough. If this occurs please mention this to your doctor or your clinical nurse specialist as soon as possible.

**Hormone (endocrine) problems** – there is a gland within the brain called the pituitary gland that controls many of the hormones within our bodies. The pituitary gland is sensitive to radiotherapy and treatment to it at a young age, particularly in children, can mean that there are problems with future growth and the timing of puberty.

The thyroid gland in the neck also produces a hormone to help with metabolism and is sensitive to radiotherapy therefore normal production may be affected after TBI.

You will be followed up long-term by doctors that specialise in hormones (endocrinologists) and supplementary hormones can be given if necessary.

**Bone development** – radiation affects the growth of bones particularly in children, which means your child may not be as tall as expected when they reach adulthood.

**The heart** – the heart will receive a dose of radiation which may lead to heart problems in the future. Many of the drugs used for treatment and conditioning can also cause heart problems. As a precaution you will be monitored for many years at regular intervals.

**Fertility** – the testes and ovaries are very sensitive to radiotherapy. The combination of TBI and drugs used in preparation for BMT will usually cause permanent infertility. If this is an important issue for you please tell your doctor so they can provide you with further advice and support.

- **Females** are likely to experience premature menopause if they are currently having periods. If your daughter has not yet entered puberty, it is highly unlikely that this will start naturally. Normal female development and menstrual cycles will be achieved by hormone replacement therapy. Please speak to your consultant for further information about female fertility preservation.
- **Males** it is possible for men and young boys who have gone through puberty to undertake sperm preservation prior to treatment. However this must be done before any cytotoxic drugs or radiotherapy is given, your doctor will discuss this further with you if it is appropriate. The production of the hormone testosterone is not usually affected so normal male development and function continues.

**Radiation induced tumours** – There is always the risk that being exposed to radiation may cause a new tumour within the treatment area in the future. Your doctor will discuss this with you.

You will be monitored for any of these long term side effects in a specialist clinic so that they can be managed optimally.

## Data protection

We collect information which is relevant to patients and their diagnosis and treatment. We store it in written records and on computer. We may have to share some of this information with other people and organisations. If you have any questions and/or do not want us to share that information with others, please talk to the consultant looking after your child or contact the PALS (Patient Advice and Liaison Service) on telephone: **0121 333 8403/8505** at Birmingham Children's Hospital or **0121 371 3280** at Queen Elizabeth Hospital Birmingham.

## Further information

We hope that this leaflet will help you to understand the treatment offered to you or, your child.

Further information and support is available:

### **The Patrick Room**

The Cancer Centre, Heritage Building (Queen Elizabeth Hospital)  
Edgbaston, Birmingham, B15 2TH

Tel: **0121 371 3539**

### **Macmillan Cancer Support Anthony Nolan**

Tel: **0808 808 0000**

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

### **Anthony Nolan**

Tel: **0303 303 0303**

**[www.anthonynolan.org.uk](http://www.anthonynolan.org.uk)**

### **Macmillan Paediatric Liaison Radiographer**

Tel: **0121 371 3547**

### **Child and Family Information Centre**

Birmingham Children's Hospital NHS Foundation Trust  
Steelhouse Lane, Birmingham, B4 6NH

Tel: **0121 333 8505**

### **Children's Cancer and Leukaemia Group**

**[www.cclg.org.uk](http://www.cclg.org.uk)**

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