Total Body Irradiation - Information for young people and families

Introduction
This factsheet is written to provide a guide to young people (and families) who are receiving Total Body Irradiation (TBI), as part of their conditioning therapy for a stem cell transplant (SCT). It explains TBI, including where you will have your radiotherapy, how the radiotherapy will be given and the side effects that may happen. Your SCT team will be able to discuss any of your questions with you.

Planning your Total Body Irradiation
Your SCT Consultant and team will discuss TBI and when your treatment will start. Usually about 3 - 4 weeks before you are admitted for your SCT, you will be invited to attend a planning appointment with your local Radiotherapy Department. You will meet the radiotherapy team who will care for you during this episode of treatment. Some patients will have to attend a different hospital to where they will have their SCT. Your individual team will explain how their centre works and arrange your care.

You will be introduced to your Radiotherapy Consultant who will discuss TBI, answer any questions that you may have and take consent for this treatment. The planning of your TBI may include a CT scan (Computerised Tomography: high resolution scan) or X-ray and a test dose in the radiotherapy room.

Following the CT scan a small permanent ink mark may be made on your chest which is very small and will look like a freckle. This mark is used by the radiographers during your treatment.

The radiotherapy test dose is a practice run (simulation) of the TBI treatment, where a small dose of radiation is received. The test dose can take up to an hour to complete and it involves making sure that you are in the correct position, then a short dose of radiation may be given. This ensures that the correct dose for the TBI treatment is planned.

The treatment position may involve you lying on your back or sitting in a chair with your arms across your chest, or occasionally young children may require sedation or a general anaesthetic for planning and TBI. Each unit has a Hospital Play Specialist who will prepare and support younger children throughout the whole process.

Having Total Body Irradiation
The number of treatment sessions that you will need will be discussed with you. It can be between one and eight treatments. If it is more than one, then you may have two treatments per day with at least six hours in between.

The TBI involves you lying or sitting very still. The radiographers will put you in the correct position and check that you are comfortable. Treatment is delivered to each side of your body (right and left). You will be lined up with the machine and once everything is in the correct position and you are ok, the staff will leave the room. The treatment takes about ten minutes each side.

You will not feel anything during the treatment but may hear a buzzing noise when the machine switches on. The radiographers are watching you all the time on a TV monitor outside the treatment room and they or your family can speak to you via an intercom. If you are uncomfortable or upset at any time, the treatment can be interrupted and the radiographers will enter the room to help you. You can also take in your own music to listen to which may help you to relax.

Once you have completed your TBI, you will return to your SCT room/hospital and continue your care.

What is radiotherapy?
Radiotherapy is the use of radiation to treat diseases. It is usually given via a high energy beam of X-rays that are delivered to a precise area of the body.

What is Total Body Irradiation (TBI)?
TBI is used as part of the conditioning therapy for some patients who need SCT. It is the exposure of the whole body to radiation. The aim of the radiotherapy is to remove your immune system and destroy any remaining cancer cells that may be in a part of your body.
You will be given advice on looking after your skin from your SCT team.

**Hair loss**
You may have already lost your hair due to previous chemotherapy. If you have not lost your hair, the TBI and your chemotherapy will cause hair loss. This happens about 2-3 weeks after your first treatment. It will not hurt when your hair falls out, but it can be very distressing and emotional. Staff caring for you will discuss a wig if you would like one.

**Nausea and vomiting (Feeling sick and sickness)**
Nausea and vomiting can happen during your radiotherapy and you will be given anti-sickness drugs (anti-emetics) to help you with this.

**Diarrhoea, wind (flatulence) and tummy (abdominal) pain**
These can occur a few days after the start of treatment. Painkillers will usually be needed.

**Sore, dry mouth**
Your mouth may become sore and your lips can become dry. Dryness can last up to three months. You can help to relieve this by regularly drinking and performing mouth care. Painkillers can be given if your mouth is sore and if your mouth is dry you can have artificial saliva.

**Loss of appetite**
This may be due to feeling sick and having pain in your tummy (abdomen). You will be seen regularly by a dietician who can advise on food and supplements.

**Low white cells, platelets and red blood cells (bone marrow suppression)**
Your original bone marrow cells will be destroyed and this will result in bone marrow suppression (low platelets, low white cells and low red blood cells). You will receive blood and platelet transfusions and protective antibiotics.

**Swelling and inflammation of the salivary glands (parotitis)**
This affects a small number of patients, it is controlled with painkillers and usually only lasts for 1-3 days.

**Possible side effects after treatment with TBI:**

**Radiotherapy sleepiness (somnolence syndrome)**
This is described as excessive sleeping, drowsiness and lethargy, and most people experience it. It is important to let yourself rest when you feel you need to.

Radiotherapy sleepiness usually starts 4-6 weeks after your TBI, and can last up to 2 weeks. You may notice that you have no energy. Some children and young people may sleep so much that they need to be woken up to drink and eat. It is very important at this time to make sure that you are drinking enough. If you have any concerns please discuss these with your SCT team and the dietician.

**Fertility**
The likelihood of infertility is very high following TBI. However you should be able to have normal sexual relationships with a partner. Your SCT team will discuss this with you.

**Altered hormone levels and thyroid function**
Radiation may affect the function of some of your glands that produce hormones. Your SCT Consultant may refer you to a hormone specialist (Endocrinologist). This will most likely happen in a long-term follow-up clinic.

**Growth and development**
The pituitary gland (in the brain) may be affected by the radiation so that it is unable to produce enough growth hormone.

When young children are treated with radiotherapy it may affect their future learning ability, and they may find it difficult to learn new information and skills. The Clinical Psychologist within the SCT unit will be able to do assessments pre-and post-TBI to help detect any problems so that appropriate support can be planned.

**Cataracts**
Cataracts occur in the lenses of your eyes and can cause your vision to be blurred. They can occur from around three years after TBI treatment. Your eyesight should be tested yearly by an optician. If you have any problems you will be referred to an ophthalmologist (Eye Specialist).
Lungs
Radiotherapy may affect your lungs. If you are having any problems then your SCT team may want to send you for lung tests. It is important to reduce your risk of having problems by not smoking.

Skin
Your skin may be dry for some time. Your SCT team will advise you on moisturising (emollient) creams to help with this. It is important to keep your skin well moisturised if it is dry.

To prevent further skin damage it is important that you take care of your skin in the sun and use a high factor sun cream and avoid sunburn.

Second malignancy (cancer)
TBI can increase your risk of having a malignancy later in life. To reduce this risk it is important to have a healthy life style.

Some of the things that you can do to have a healthy life style are to avoid getting sunburnt, maintain a healthy weight and exercise regularly, also to not smoke. Early detection of any possible problems is important. In the future if you are concerned about any possible later malignancies you should discuss these at your long-term follow-up clinic or visit your GP.

Psychological effects
Having a SCT and TBI can be a very emotional and stressful time for you and all your family and friends. You and your family may have fears and concerns related to changes in your body, uncertainty about the future, separation from your family and friends. Please speak to your SCT team if you are worried about anything.

TBI is a critical part of treatment and your SCT team believe it offers the best chance of curing the disease.

However, it is difficult to predict how each person is affected by TBI. It is important that you understand the potential effects before you start your treatment. You may feel worried, but please remember that you can discuss your fears and concerns with your SCT Team.