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Total Body Irradiation (TBI)

Radiotherapy

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This information is for patients who are going to receive Total Body Irradiation (TBI).

This leaflet will explain:

- What is Total Body Irradiation (TBI)
- Planning your TBI
- TBI treatment
- General information about side effects of TBI treatment
- Who to contact when you need advice

You may find it helpful to read our patient information booklet called 'Radiotherapy', which explains how radiotherapy works.

What is Total Body Irradiation (TBI)?

TBI is when your whole body is treated with radiotherapy as part of your treatment regimen, for an autologous, allogeneic or reduced intensity conditioning bone marrow transplant (BMT). Radiotherapy is a treatment with high energy x-rays and is entirely painless. It does not make you radioactive.

We use TBI in patients with leukaemia, lymphoma, myeloma and some rare blood disorders. The aim of the treatment is to destroy any malignant cells and your immune system. This will then allow the new healthy bone marrow cells to grow.

Prior to having your TBI treatment, you will have a period of between 2 and 5 days of chemotherapy conditioning regimen at the Royal Liverpool Hospital.

Planning your TBI

Two - four weeks before your TBI treatment, you will need to visit the Radiotherapy Planning Department at Clatterbridge Cancer Centre - Wirral. You will see the doctor who will discuss with you the proposed treatment plan. The doctor and the radiographer will explain the radiotherapy planning and treatment in more detail. Occasionally, the transplant team and radiotherapist may decide to use some additional boost radiotherapy treatments before the transplant. The doctor will explain to you the reasons for any additional boost treatments and appointments are arranged accordingly. During the appointment with the doctor, we will explain the potential side effects of TBI. If you have any questions, please write them down and bring them with you, so you don't forget them, and you can discuss this during your appointment. You will also be asked to sign a consent form.

Afterwards, you will be directed to the planning department where you will have a planning CT scan. You will be required to wear just your underwear (briefs and non-wired string bikinis only) for this scan. You will be asked to lie on your back with your arms across your chest hugging a support pillow. The radiographers will position you in a comfortable, but practical, treatment position. The radiographers and physicists will take several measurements and then perform the CT scan. With your permission, two permanent tattoo dots are placed on each side of your hips. We use them to position you for each treatment. No other special preparation is required and you don't need any contrast injection. The whole planning process takes about 20 minutes.



From the scan and measurements, the physicists and doctor will calculate the correct shielding to give you the same dose of radiotherapy to your entire body. Afterwards, you will be shown the treatment room and meet the treatment radiographers. This will give you a better understanding of what to expect through your treatment. If you are worried at all, or have any further questions, please do not hesitate to ask a member of staff.

A couple of days after your planning scan, you will be asked to attend another appointment at the Radiotherapy Department for a 'Test Dose'. This is like a practice run through of the actual treatment. Only a very small amount of radiotherapy is delivered, so there are no side effects from this session. You will be positioned on the couch in the same position as you were for the scan. The radiographers will gently move you into the correct position lining up the tattoos on your hips with the in-room lasers.

Once you are in the right position, bags of Vaseline called bolus are placed between your legs and over your knees, chest and neck. These bags are to ensure the radiation treatment is evenly distributed throughout your body. Special measuring devices will be attached to various parts of your body with tape to monitor the dose you receive throughout your treatment. After checking you are comfortable, the staff will leave the treatment room and deliver a small amount of radiation to these measuring devices and also to a film cassette to provide us with an image of the shielding position relative to your lungs. The radiographers will be watching you all the time on closed circuit television monitors. The radiographers then come back into the room and reposition the couch and take another film. The Test Dose takes about an hour. There are TV monitors in the room, so feel free to bring a DVD to watch or music to listen to.

TBI treatment

The transplant team and the doctors at the Royal Liverpool Hospital and your oncologist at The Clatterbridge Cancer Centre will discuss the number of treatments (fractions) you need with you. More recently, most treatments are in one fraction although they can be done in eight treatments. If it is more than one treatment, then the treatments will be twice a day with a minimum of six hours between each treatment.

Most chemotherapy conditioning regimes are given over a period of between 2 and 5 days before the TBI at the Royal Liverpool Hospital, however some regimes may involve post TBI chemotherapy. Adult patients who have eight treatments are admitted on a Sunday to Sulby Ward at Clatterbridge Cancer Centre - Wirral and remain an inpatient until they return to the Royal Liverpool Hospital, however some regimes may involve post TBI chemotherapy. The treatment is exactly the same as the Test Dose and the same duration except more radiation is delivered; hence you will be on your own in the room for longer. Treatment is delivered to each side of your body (right and left). You will not feel anything during treatment. The radiation will not hurt but you may hear a buzzing noise when the machine switches on. The radiographers are watching you all the time on closed circuit television monitors.

Side effects of TBI

Single fraction TBI has very limited side effect and you may only experience nausea vomiting and diarrhoea for the first 24 hours;



all other side effects are very rare. For the 8 fraction TBI, the side effects will gradually appear during the course of your TBI treatment. These effects can vary from patient to patient and your consultant will have discussed your potential risks with you during the consent process. Some side effects happen soon after treatment, and some can occur months or years later. Side effects for one treatment are normally much less noticeable and late effects are very rare. **The main side effects that occur during treatment are:**

Skin changes

Towards the end of treatment, you may notice that your skin reddens and feels warm to the touch. Your skin may also become dry. These are normal reactions to the treatment. However, it is sensible to take special care of your skin during, and for 2-3 weeks after, treatment. You may wash, bathe or shower normally. We advise that you wash your skin gently using warm water and a non-perfumed soap. Do not use perfumed bath creams or shower gels and do not soak in a hot bath. Gently wash your skin using your hands rather than a sponge or flannel. Pat your skin dry using a soft towel, paying particular attention to the armpits, between the legs and any other skin folds.

You are advised not to apply any cosmetics, perfumes or skin creams to your skin whilst on treatment.

Ladies are advised not to apply any cosmetics, perfumes or skin creams to your skin whilst on treatment. You should avoid shaving your armpits whilst on treatment, as these areas can be particularly sensitive during treatment.

Gentlemen are advised not to use a razor or to have a wet shave. Electric shavers may be used as infrequently as possible taking care not to “drag” the skin. Do not use any aftershave lotions, balms or other perfumed products.

Aqua Max may be applied to your skin. This is a simple, unperfumed moisturising cream available over the counter from a local pharmacy. This cream can be used from the start of treatment. It helps prevent your skin from becoming too dry. Smooth a little cream very gently onto your skin 2-3 times a day.

Hair loss

You may experience hair loss after your treatment and this can affect all areas of the body. Hair does usually grow back but may be different in texture.

You may wash your hair/scalp normally using warm water and a mild shampoo, such as a baby shampoo. Gently massage your scalp and dry with a soft towel, a hairdryer on a cool setting, or leave to dry naturally. Do not use any harsh hair treatments such as hot rollers, conditioners, perm solutions, hair sprays or hair colourings. Brush and comb your hair gently using a baby (or other soft) brush or a wide rounded toothed comb.

Nausea, vomiting and diarrhoea

Most patients have experienced these symptoms as a result of their intensive chemotherapy. Medication can control these symptoms but the radiotherapy may intensify these reactions. You will be prescribed routinely a continuous infusion of anti-sickness drugs (ondansetron and dexamethasone) on the ward. However,



if you are still experiencing symptoms, it is important to inform the radiographers and your medical support team as further medication can be prescribed. **Please ask for a copy of the Macmillan leaflets “Coping with nausea” or “Coping with constipation or diarrhoea”.**

Dry or sore mouth

This usually occurs 2-3 days into treatment and can last up to three months following treatment completion. You can alleviate this by regularly taking drinks and performing regular mouth care as instructed by the nurses. It is important that you try to drink plenty of fluids (between 1 to 2 litres a day). This can include water, squash or warm drinks.

Swelling and inflammation of the parotid (salivary) glands (Parotitis)

This affects a small proportion of patients and occurs within 24 hours of treatment. The effects may last for only 24-72 hours and can be controlled with mild painkillers.

Infections

You are at increased risk of developing infections until your new bone marrow engrafts and functions. Healthcare staff (including your transplant team at the Royal Liverpool Hospital) will keep you under very careful observation and treat any infections, should they occur.

Diarrhoea

Usually occurs 8-10 days after starting TBI. Please let the nursing staff know, as it is important to check for any infection and prescribe the appropriate medication.

Late side effects of TBI

Late side effects can occur months or years after radiotherapy has finished and are the hardest to predict. Your radiotherapy doctor will have explained the potential late side effects of radiotherapy to you as part of the consent process. The effects may include:

Common effects

Somnolence syndrome: The majority of patients undergoing TBI will experience some degree of fatigue and drowsiness during their treatment. There might be a particularly sleepy spell starting six to 12 weeks after treatment ends and going on for two to six weeks or even longer. You may notice that you have a lack of energy and cannot be bothered to do anything. This is quite rare, but resolves normally without specific treatment. **Please ask for the Macmillan leaflet “Coping with fatigue and tiredness”.**

Cataracts: Due to the unavoidable radiation to the eye, the development of mistiness of the lenses of the eye may occur. This usually develops three to four years after TBI treatment and affects about 30-40% of patients. If cataracts form, they can be removed by a simple surgical procedure.

Infertility: Most patients who undergo BMT will become infertile because of the doses of chemotherapy and radiation given. Women may experience vaginal dryness or premature menopause. Men may suffer from a decreased sex drive. The transplant team and the radiotherapy doctors will discuss these issues with you.

Hormone changes: Certain hormone producing tissues are sensitive to radiation; the normal production may be impaired



years after you had TBI. You will require regular blood tests for it and some patients need supplementary hormones.

Rare side effects

Pneumonitis: This is inflammation of the lung tissue. In a very small percentage of patients, it can occur six weeks to six months following TBI. You may experience shortness of breath and a cough. If this occurs, it must be reported to any of the doctors, at either hospital, BMT co-ordinators or specialist nurses immediately.

Second malignancy: Very rarely, patients who have been successfully treated may develop a secondary malignancy some years later. The radiotherapy doctors will discuss this with you.

Contact details

Macmillan booklets about coping and living with cancer and treatment side effects are available free of charge. These can be ordered by telephoning 0808 808 00 00 or by visiting a Macmillan Information Centre (sited in the main entrances of Clatterbridge Cancer Centres - Wirral and Clatterbridge Cancer Centre - Aintree).

Macmillan Cancer Support

www.macmillan.org.uk or tel 0808 808 0000

Macmillan Cancer Information and Support at:

Clatterbridge Cancer Centre - Wirral 0151 556 5570

Clatterbridge Cancer Centre - Aintree 0151 556 5959

Lead TBI radiographer based at Clatterbridge Cancer Centre - Wirral

0151 556 5268

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

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