Having total body irradiation (TBI)
Radiotherapy Department
Patient information series

University College Hospital

No 12
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We will try our best to meet your needs.
## Contents

- Introduction .......................................................... 5
- What is total body irradiation (TBI)? .................... 5
- What is radiotherapy? ............................................. 5
- Planning your TBI .................................................. 6
- Having radiotherapy .............................................. 6
- Side effects of TBI ................................................ 8
- Side effects after TBI ............................................... 11
- Late side effects of TBI ......................................... 11
- Support .................................................................. 12
- Useful contact numbers ....................................... 13
Introduction
This booklet has been written for patients who are having total body irradiation (TBI). You are having radiotherapy as part of your treatment regimen for a bone marrow transplantation (BMT). This booklet explains:

• What is TBI.

• What is radiotherapy.

• How your treatment is planned and delivered.

• The side effects you may experience during and after treatment, and how best to cope with them.

We understand that this is an anxious time for patients. You may feel that you have been given lots of information about what needs to be done in a short period of time. We hope this booklet answers some of your questions. If you still have any questions or concerns, please let your doctor, nurse or radiographer know. We are here for you.

What is total body irradiation (TBI)?
TBI is used as part of the regime for high dose treatment with bone marrow transplants (BMT) in patients with leukaemia, lymphomas, myelomas, some sarcomas and some rare blood disorders. The aim of the treatment is to destroy any malignant cells or abnormal cells, and to suppress your immune system. This will then allow new healthy bone marrow to grow.

What is radiotherapy?
Radiotherapy is the use of high energy X-rays and is entirely painless. It does not make you radioactive.
Planning your TBI

Normally a week before your TBI treatment you will need to visit the radiotherapy department for a TBI planning CT scan. This involves physicists and radiographers positioning you in the most comfortable but practical treatment position. The treatment position will involve you lying on your back with your arms either across the chest or resting on your lower abdomen. Support pads will be placed under your knees. The staff will take several measurements and then perform the CT scan.

No special preparation is required for the scan. Once the scan is complete the radiographers will mark two specific points on your pelvis. These are the co-ordinates for your treatment and ensure treatment accuracy on a daily basis. The points are permanent and are done by placing ink on your skin and then gently scratching the surface of the skin with a fine needle. The whole planning process takes about 30 minutes.

Whenever possible, and if you so wish, 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.

Having radiotherapy

TBI treatments occur twice a day. The first TBI treatment usually takes place first thing on a Monday morning (09:00), with the second treatment at least six hours later. You will have six or eight treatments over three or four days. It all depends on the type of bone marrow transplant you are going to have. The transplant team and doctors will inform you of this.

Your named nurse, or the ward, will have been given the times for you to attend for treatment. You will have been prescribed anti-sickness medication to take approximately 30 minutes before each treatment.
The radiotherapy treatment involves you lying on a special couch, in the same position as when you attended for the TBI measurements. There will be radiographers and physicists in the treatment room checking the measurements to ensure you are in the correct position. All that we ask is that you remain still and let the staff move you.

Once you are in the right position, bags of Vaseline® are placed over your feet, between your ankles and knees, and over your 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 (over your clothes) with tape, for each treatment. These small devices monitor the dose you receive throughout your treatment. After checking you are comfortable the staff will leave the treatment room.

Treatment is delivered to each side of your body. Once one side of your body has been treated, the radiographers and physicists will rotate the couch 180° and treat the other side. Treatment takes approximately 10 minutes from each side. You will not feel anything during treatment, the radiation will not hurt. You will only hear a buzzing noise when the machine switches on. The radiographers are watching you all the time on closed circuit television monitors, and members of your family can speak to you via an intercom system. If you are uncomfortable or feel distressed at any time, treatment can be interrupted and the radiographers will enter the room to resolve any problems.

A CD player is available in the treatment room. You are encouraged to bring your own CDs to play if you wish. You will be given a cotton top and trousers to change into for each treatment. You will have to remove any jewellery, watches, glasses and false teeth containing metal.

The entire treatment process will take about 45 minutes.
Side effects of TBI

There will be some side effects which will gradually appear during the course of your radiotherapy. These effects can vary from patient to patient. There are side effects that occur during treatment, some happen soon after treatment, and some can occur months or years after radiotherapy. Your consultant will have discussed these potential side effects with you as part of the consent process. The main side effects that occur during treatment are:

Skin changes

During radiotherapy there are usually no skin reactions. However, 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. Skin reactions after TBI are unusual. However, it is sensible to take special care of your skin during and for two to three weeks after treatment.

During 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 hand 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.

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 to dry shave the face and neck area using an electric shaver, taking care not to “drag” the skin. Do not use any aftershaves or creams.

Aqueous cream may be applied to your skin. This is a simple, unperfumed moisturising cream available over the counter from any
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 two and three times a day.

**Do not use any talcs, creams or lotions in the area being treated unless advised by a member of staff.**

**Hair loss**
Some patients will have already experienced total body hair loss due to chemotherapy. If you have a full head of hair prior to your TBI, you will experience total hair loss about the third week after your treatment. Your hair will begin to grow back within weeks to months after your radiotherapy treatment has finished, but the new growth might not be the same texture or colour as your original hair.

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.

Losing hair can be very distressing as it is a radical change in one’s body image. You may feel emotional about losing your hair and this is quite natural. Some people who lose their hair may require a wig. These are available on prescription (and free of charge for patients having radiotherapy and/or chemotherapy) through the NHS. Alternatively, you may wish to purchase your own through a large department store or your own hair stylist. If you wish to discuss wigs with the hair specialist, please ask to speak to the Macmillan information and support radiographer.
Alternatively, some people choose not to wear a wig, except on certain occasions. They may choose a fashionable and practical hat, turban, cap or scarf. If you are experiencing difficulties coming to terms with your hair loss and you feel the need to speak to someone, talk to your specialist nurse, the radiographers or radiotherapy nurses. They are here to help you, and can refer you to other health professionals for further advice and support.

**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 anti-sickness tablets to take half an hour prior to each treatment. 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 leaflets “Coping with nausea” or “Coping with constipation or diarrhoea”.

**Dry mouth**
This usually occurs two to three 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 one to two litres a day). This can include water, squash or hot drinks.

**Swelling and inflammation of the parotid (salivary) glands (parotitis)**
This affects a small proportion of patients and occurs within 24 hours of treatment. It can be controlled with mild painkillers, although the effects may last for only 24 to 72 hours.
Side effects after TBI

Somnolence syndrome
Is described as excessive sleep, drowsiness and lethargy. The majority of patients undergoing TBI will experience some degree of fatigue and drowsiness during their treatment. Set your own pace and allow yourself to get plenty of rest whenever the need arises. You are encouraged to lead as normal a life as possible.

There might be a particularly sleepy spell starting six to twelve 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 a normal reaction to the treatment but the long duration and sometimes the severity of the symptoms can cause anxiety. Please ask for the leaflet “Coping with fatigue and tiredness”.

Late side effects of TBI
Late side effects can occur months or years after radiotherapy has finished. These late effects are the hardest to predict and, unfortunately, when they do occur they are permanent. 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:

Cataracts
The development of mistiness of the lenses of the eye can occur because of unavoidable radiation to the eye. This usually develops three to four 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 be removed by a simple surgical procedure.

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 the doctors, BMT co-ordinators, or specialist nurses immediately.
Infertility
Most patients who undergo BMT will become infertile because of the doses of drugs and radiation given. Women may experience vaginal dryness or premature menopause. Men may suffer from a decreased sex drive. The BMT team and the radiotherapy doctors will discuss these issues with you.

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.

Support
This booklet deals with the physical aspects of your treatment, but your emotional well-being is just as important. Having treatment can be distressing for some patients. Within the radiotherapy department there will be access and support from the Macmillan information and support radiographer, the radiotherapy nurses and the treatment radiographers. However, if you require further medical or emotional support you can be referred to a variety of health professionals specialising in patients needs.

All the staff are here to make sure your treatment goes as smoothly as possible, and to support you through this difficult period. We will try to help you with any questions or problems you may have.
Useful contact numbers

Local

Macmillan Information and Support Radiographer
Mark Williams
Direct telephone: 020 3447 3711
Main switchboard: 0845 155 5000
    ext 73711
    bleep 1458
Alternative switchboard: 020 3456 7890
    ext 73711
    bleep 1458

Email: mark.williams@uclh.nhs.uk
**National**

**The Lymphoma Association**  
Freephone: 0808 808 5555  
Website: www.lymphoma.org.uk

**Leukaemia CARE Society**  
24 Hour Care Line: 0800 169 6680  
Email: enquiries@leukaemiacare.org.uk  
Website: www.leukaemiacare.org.uk

**Leukaemia Research Fund**  
Telephone: 020 7405 0101  
Website: www.lrf.org.uk

**African Caribbean Leukaemia Trust**  
Telephone: 020 8667 1122  
Fax: 020 8667 1626  
Website: www.aclt.org

**International Myeloma Foundation**  
Myeloma Infoline: 0800 980 3332  
Email: TheIMF@myeloma.org.uk  
Website: www.cancerhelp.org.uk

**Health Talk Online**  
Website: www.healthtalkonline.org

**Cancer Research UK**  
Website: www.cancerresearchuk.org

**Carers UK**  
Freephone: 0808 808 7777  
Wednesday to Thursday  
Email: adviceline@carersuk.org  
Website: www.carersuk.org
**Macmillan Cancer Support**
Cancer Line freephone: 0808 808 0000
Monday to Friday, 09:00 to 21:00
Textphone: 0808 808 0121
Monday to Friday, 09:00 to 18:00
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

**National Library for Health**
Covers all aspects of health, illness and treatments
Website: www.library.nhs.uk

**NHS Direct**
Telephone: 0845 4647
Available 24 hours
Website: www.nhsdirect.nhs.uk

**NHS 24**
Telephone: 08454 242424
Website: www.nhs24.com

**NHS Choices**
Website: www.nhs.uk

**Patient UK**
Comprehensive, free, up-to-date health information
Website: www.patient.co.uk