

Patient Information for

Adults Receiving Total Body Irradiation



Patient information for adults receiving total body irradiation

This leaflet is for patients who are going to receive total body irradiation (TBI). This leaflet explains:

- What is radiotherapy?
- How your radiotherapy is planned and delivered.
- The side effects you may experience during and after treatment, and how best to cope with them.
- Who to contact if you have any questions or concerns.

What is radiotherapy?

Radiotherapy is the use of high energy X-rays to destroy cancer cells. TBI is a form of radiotherapy given as part of your treatment regimen prior to a bone marrow transplant (BMT). It aims to destroy any malignant or abnormal cells and suppress your immune system. This then allows new healthy bone marrow cells to grow.

The treatment is painless and each appointment lasts 20-30 minutes.

You will be admitted to the transplant ward at The Queen Elizabeth University Hospital while undergoing your radiotherapy.

Treatment planning

Before radiotherapy can begin, we need to plan your treatment carefully. We will produce an individual plan for you.

Your planning appointment will be in the 'mark-up room'. You will meet radiographers and two members of our physics team. They will ask you to remove any bulky clothing. This allows our physics staff to measure the thickness of various parts of your body. These measurements are used to calculate your individual treatment plan.

They will ask you to lie on a flat couch on your right side with your knees slightly bent up. You will place your left arm above your head with your hand resting on your head (see picture 1).

Your doctor will also meet with you at this appointment to discuss your treatment and the side effects you may experience.

When attending for your radiotherapy planning and treatment, please remove any jewellery, glasses, piercings or false teeth containing metal.

Treatment

Your radiographers will explain everything before treatment starts and check that you know what to expect. You will have 1-8 radiotherapy treatments. If you are having more than one treatment, you may be treated twice a day- usually about 9am and again about 4pm.

Each day you attend for treatment we will ask you to undress to your underwear only. If you normally wear a bra, you may prefer to wear a thin camisole top. Please do not wear an underwired bra.

You will lie in the same position as you did at your planning appointment. Your back and soles of your feet will rest on a Perspex screen. This will also provide support and help your radiographers to position you. A second Perspex screen is placed in front of you during treatment, but it will not touch you. Your treatment is delivered in two parts. The second Perspex screen is only in place for the first part of the treatment.

Picture 1: Treatment position 1



The lights in the room will dim for a few minutes while your radiographers ensure you are in the correct position for your treatment.

When your radiographers are happy, they will leave the room to start part one of your treatment. They monitor you on closed circuit TV. You will hear a buzzing sound while the machine is on. It is important that you stay as still as you can and breathe normally. The treatment is painless.

Your radiographers will then come back into the treatment room and turn the couch around. They will remove the second Perspex screen at this point. They will check your position again, and then leave the room to switch the machine on for the second part of your treatment.

Picture 2: Treatment position 2



If you are having more than one treatment, a member of the physics team will place small measuring devices on various parts of your body. They measure the amount of radiation received during your treatment. These measurements are done on your first day of treatment, and may also be repeated on your third treatment.

Picture 3: Measuring devices



During your treatment music can be played in the room. If you have a mobile phone or iPod with music on it, you can bring this with you and we may be able to play it for you. You will be in the treatment room for about 20 minutes but the machine is only on for approximately 10 minutes.

Early effects of radiotherapy

Each patient is an individual and the effects of treatment may vary from one person to another. Any side effects will develop gradually. You will have had chemotherapy as part of your treatment regimen, this may alter the side effects. The following is a general guide to some of the effects you may experience.

- **Tiredness:** You will begin to feel quite tired during treatment. Try to rest as much as possible.
- **Hair:** You may already have lost your hair due to your chemotherapy. However, radiotherapy will also result in the loss of all hair. This usually happens 2-3 weeks after treatment. It does **normally** grow back but there may be a

change in texture or colour. Occasionally the hair does not grow back. A wig can be arranged.

- **Nausea & vomiting:** Some patients may have experienced nausea and vomiting due to their chemotherapy treatment. Nausea from radiotherapy is generally milder. You will be given medication to help with this by the ward staff before you come for your treatment.
- **Diarrhoea:** This is a common side effect of the treatment. We can prescribe something to help with this. If you experience diarrhoea, it is important to drink plenty of fluids.
- **Sore mouth (mucositis):** The inside of your mouth, tongue and throat may become inflamed and sore. This can cause difficulty when eating and swallowing food and drink. If this is a problem, painkillers can be prescribed. You will be given advice on how to look after your mouth during treatment.
- **Inflammation of the parotid (salivary) glands:** There can be inflammation or swelling that looks a bit like mumps. This can cause some stiffness in your jaw. It usually settles quite quickly. Pain relief can be given if needed. The parotid glands may stop working for a period of days or weeks following treatment. This can result in a dry mouth and reduction in your sense of taste. This can make eating uncomfortable and difficult. You may find drinking more, especially whilst eating, is helpful.
- **Skin:** Your skin will be more sensitive and may become pink or red similar to sunburn. You may also experience an itching sensation. This can be treated with creams; however, while on treatment, it is very important that you use only those prescribed by your doctor here at the Beatson. Please tell us if you have any problems.

Skin care during treatment

- You may bath or shower, provided the water is not too hot (lukewarm). Pat your skin dry with a soft towel. You will find that you may be more comfortable if you wear loose fitting clothes, preferably with cotton next to your skin.

Late effects of radiotherapy

Many of the long term side effects are as a result of both your chemotherapy and radiotherapy. It is important to point out again that effects can vary from person to person. Your doctor will explain specific individual issues to you personally.

We believe that the benefit of your radiotherapy treatment outweighs any longer term risks involved. However, you should be aware of these **potential** long-term effects. In general, these late effects depend to a certain extent on your age at the time of treatment.

- **Fertility:** The testes and ovaries are sensitive to radiotherapy and chemotherapy. TBI will cause infertility. Fertility preservation/sperm storage may be possible prior to any treatment. Your doctor will discuss this with you.
- **Menopause:** Treatment is likely to cause early menopause if you are currently having periods. Hormone therapy may be advised.
- **Cataracts:** These may develop following TBI. If they do develop, a relatively minor operation can be done to improve vision.
- **Hormone (endocrine) problems:** The thyroid gland (in your neck) produces hormones to help with metabolism. TBI can affect the production of these hormones. Tests will be required to check your thyroid gland has not been affected. If there are signs it is not working properly, you may require Thyroxine tablets to replace the normal hormone produced by the thyroid gland.

- **Radiation induced tumours:** Very rarely, patients who have been successfully treated may develop a secondary tumour some years later. Your doctor will discuss this with you.
- **Memory:** 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 number of patients this can occur 6 weeks to 6 months after TBI. You may experience shortness of breath and a cough. If this occurs, please mention this to your doctor as soon as possible.
- **Heart:** Your heart will receive a dose of radiation which may lead to heart problems in the future. Some of the drugs used for treatment and conditioning can also cause heart problems. You will be monitored to check your heart at regular intervals.

If you have any questions after reading this leaflet please discuss them with the doctor, nursing or radiotherapy staff responsible for your care.

After treatment ends

Once you have completed your course of radiotherapy and had your transplant you will be closely followed up at the transplant unit.

Where can I get help?

Information and support

All our staff are here to make sure your treatment goes as smoothly as possible and will try to help with any questions or problems you may have. Further specialist help is available from:

Information and Support Radiographer ☎ 0141 301 7427

The Macmillan Information & Support Centre is on Level 1 at the main entrance of the Beatson. They offer emotional support, information and signposting to services within and near to the Beatson and in your own local area. Open Monday to Friday 8:15am to 4:15pm. ☎ 0141 301 7390

The Beatson Cancer Centre has a **Radiotherapy Advice Line** available for patients who have completed treatment. This is an answer phone service and covered Monday to Friday. Please leave your name and telephone number and we will call you back as soon as possible. ☎ 0141 301 7432

The Cancer Centre also has a **Cancer Treatment Helpline** for urgent calls. This is for patients on or within 6 weeks of treatment who have urgent or severe symptoms such as:

- Shivering or flu-like symptoms.
- Temperature greater than 37.5°C.
- Gum/nose bleeds or unusual bruising.
- Worsening or sudden breathlessness.
- Leg weakness/difficulty walking.
- Severe nausea/vomiting/diarrhoea/constipation.
- Sudden increased or uncontrolled pain.
- Other concerning symptoms associated with your cancer treatment.

The line is available 24 hours for emergencies, although it would be helpful if you called early in the day if this is at all possible.

For Urgent Calls:

Beatson 8am-8pm ☎ 0141 301 7990

National 8pm-8am ☎ 0800 917 7711

Counselling and Clinical Psychology

This leaflet deals with the physical aspects of your treatment, but your emotional well-being is just as important to us. Being diagnosed with cancer can be a distressing time for you and those closest to you. At times it can also be difficult coping with treatment but you do not have to cope on your own. Within the department we have a counselling and clinical psychology service that may be able to help with worries and difficulties you might be having before, during or after treatment. If you think this may be helpful to you, please ask staff to put you in touch.

There are also voluntary organisations providing information and support. These include:

Leukaemia Care	☎ 08088 010 444 (24 hrs)
Aims to promote the welfare of those suffering from leukaemia and allied blood disorders.	
🌐 www.leukaemiacare.org.uk	
Myeloma UK	☎ 0800 980 3332
Provides information and support to all those affected by myeloma.	
🌐 www.myeloma.org.uk	
Lymphoma Action	☎ 0808 808 5555
Provides emotional support and information to anyone with lymphatic cancer and to families, carers and friends.	
🌐 www.lymphoma-action.org.uk	

Macmillan Cancer Support:	☎ 0808 808 0000 🌐 www.macmillan.org.uk
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Providing practical, medical, emotional and financial advice for those affected by cancer.

Maggie's Gartnavel	☎ 0141 357 2269
Maggie's Lanarkshire, Monklands Hospital	☎ 01236 771 199
Maggie's Forth Valley	☎ 01324 868 069
	🌐 www.maggies.org

Provides information and support with a regular programme of courses. Counselling service available.

Cancer Support Scotland – The Calman Centre, Gartnavel Complex.	Freephone ☎ 0800 652 4531 🌐 www.cancersupportscotland.org
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Provides emotional and practical support on a one-to-one basis and through community based groups. Complementary therapies available.

Macmillan Benefits Team (within the Beatson)	☎ 0141 301 7374
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Provides free and confidential advice for people affected by cancer and their carers.

Beatson Cancer Centre	
If you would like to know more about our Centre please visit:	
🌐 www.beatson.scot.nhs.uk	

NHS 24	🌐 111
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You may find some useful information on the websites listed above. However, it is important to note that The Beatson West of Scotland Cancer Centre cannot accept responsibility for the quality and content of any information provided by other organisations.

Care Opinion

We welcome your comments and feedback about our service. If you would like to give us feedback please go to:

 www.careopinion.org.uk or telephone:

 0900 122 3135 or scan the QR code:

