

# Information for Patients Receiving Total Skin Electron Beam Therapy (TSEBT)



This leaflet is for patients receiving a course of electron beam therapy to their skin. It is intended to be a guide to highlight important details that you have discussed with your treatment team. If you have any questions or concerns, please ask us.

This leaflet describes:

- The electron beam therapy planning and treatment.
- The effects that you may experience during and after treatment.
- How best to cope with these effects.
- Who to contact if you have any questions or worries.

## **What is electron beam therapy?**

Electron beam therapy is a type of radiotherapy treatment. Radiotherapy uses radiation (high energy X-rays or similar rays) to kill cancer cells. Total Skin Electron Beam Therapy (TSEBT) is radiotherapy delivered to the entire skin surface. TSEBT is therefore used when cancer has affected many areas of your skin. The type of radiation used for your treatment is high energy electrons. The electron beam only treats your skin surface.

## **Who delivers my radiotherapy?**

Radiotherapy is given by therapeutic radiographers. We have both male and female staff members. They are highly trained in the accurate planning and delivery of radiotherapy. You will see them at each appointment and they will be happy to answer any questions you may have.

## **How is my treatment planned?**

Your doctor will explain the treatment to you and ask you to sign a consent form. This is to confirm that you understand the treatment and are happy to go ahead. If you have any

questions, please don't hesitate to ask. Your treatment will then be planned individually for you.

You will have 3 appointments in the radiotherapy department before your treatment starts.

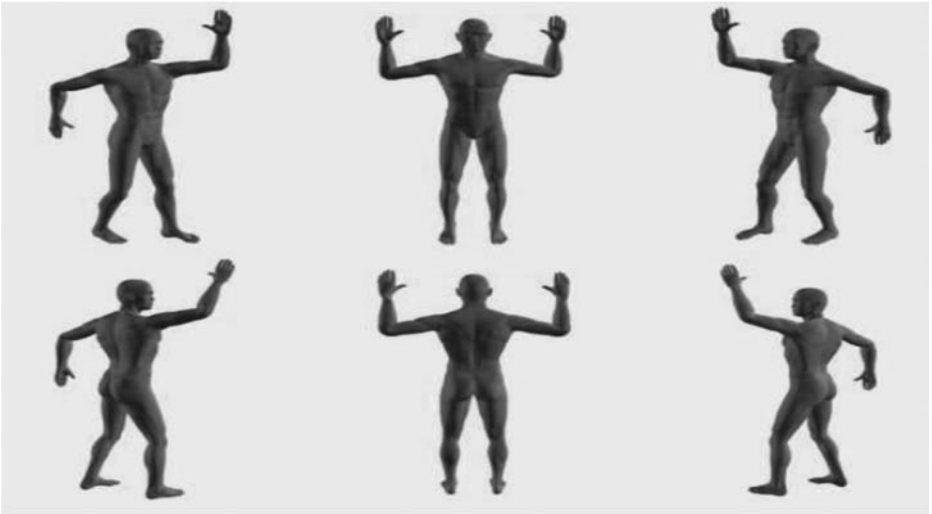
You will have 2 appointments for our Mould Room. During your first visit, the mould room technicians will make any customised shielding you may need for your treatment. The shielding helps to protect any unaffected areas of skin that do not require treatment. We may have to make small shields to protect your finger and toe nails. Before coming to your appointment, please ensure your nails are cut short. This appointment will take around 60 minutes.

Your second mould room appointment allows us to check the shielding that has been made for you. This appointment will take around 30 minutes.

A few days after this appointment, you will come for your planning appointment- this is sometimes called your 'mark-up' appointment. Your radiographers will explain everything to you. They will ask you to remove your clothes and put on special net underwear.

There is a specially designed frame which you will stand in for your treatment. This helps to ensure you are in the correct position and helps to support you. This allows us to deliver your treatment accurately.

Your radiographers and our physics planning team will ask you to stand in the frame and will take some measurements. They will ask you to stand in 6 different positions (as shown below). There are pieces of equipment to hold on to which will help you to maintain each position for the duration of treatment. Once all the measurements have been done, your radiographers may ask your permission to give you a small permanent tattoo on your tummy. This look like a small freckle and is used each day to help ensure your treatment is delivered correctly. This appointment will last 60 minutes.



Smith BD, Wilson LD: Management of Mycosis fungoides. Part 2. Treatment. Oncology 17: 1419-1428

## **How long after my planning appointment will my treatment start?**

Your treatment will start 1-2 weeks after your planning appointment.

## **How many treatments will I have?**

Your doctor will explain how many treatments you will have. This will either be 8 treatments over 2 weeks (short course) or 20 treatments over 5 weeks (long course). Treatment is given on four consecutive days: Monday to Thursday or Tuesday to Friday.

If you have particularly lumpy areas on your skin, we treat these separately before you start TSEBT. This is usually done in 1-2 treatments. Your doctor will discuss this with you.

# What happens when I come for my treatment?

When you arrive for treatment, your radiographers will check some details with you and then show you into the treatment room. They will ask you to undress and put on the special net underwear. There is a changing room inside the treatment room.

You will stand in the frame and your radiographers will position you in the same 6 positions that you were in during your planning appointment. You will have to hold each position for a few minutes before being asked to move to the next position.

You will have to wear special goggles over your eyes for every treatment. The goggles protect your eyes from the radiation. They are heavy and dark. You won't be able to see through them.

If you had customised shielding made in the mould room, this will be used for each treatment. The shielding can feel a little bit heavy.

Once you are in the correct position for the first part of your treatment, your radiographers will leave the room. They are controlling the machine from outside but are watching you at all times on CCTV. When the machine is switched on, you will hear a buzzing noise. Your radiographers can talk to you or play music during your treatment. You won't feel anything. The machine is only on for about a minute. Your radiographers will then come back into the room and ask you to move into the next position. This process will be repeated until all 6 positions have been treated.

The whole treatment process takes around 45 minutes, but most of this time is getting you into the correct position. Once the treatment is finished, you are free to go home. You are not radioactive and are safe to be around other people, including pregnant people and children.

On your first day of treatment, a member of our physics team will place small measuring devices on various parts of your

body. They are just like small plastic stickers. They measure the amount of radiation received during your treatment. Although usually only done on your first treatment, they can be repeated if necessary.

You will have a blood test at the start of your treatment. This will also be repeated in week three and week five (if you are having five weeks of treatment). We will arrange this for you.

## **How should I look after my skin during my treatment?**

Following the advice below can help to reduce any discomfort you may experience:

- You may bath or shower daily in warm water with a soap substitute (emollient shower gel or bath additive). Do not use soap.
- Apply moisturiser after washing, while your skin is still moist.
- Re-apply moisturiser regularly throughout the day.
- Do not wet shave, use hair removal creams or wax. You can use an electric razor if you wish. Remember, your hair will fall out with the treatment.
- Do not go swimming as the chlorine can dry your skin.
- Do not use a sauna, jacuzzi and avoid sun exposure and direct sunlight.

## **Will I see a doctor during my treatment?**

Your radiotherapy doctor will see you once a week during your treatment. They will ask how you are managing and look at your skin. Your radiographers will see you each day you come for treatment so if you have any questions or worries, please speak with them.

# What are the possible side effects of treatment?

You may not experience all of the side effects listed below. This is a general guide. The staff are here to help so if you notice any of the side effects or need advice, please ask.

- **Itchy/irritated skin-** you may already have itchy or irritated skin due to your disease. This usually improves in the first week of treatment, but tends to then get worse during week 3-5. It should improve and disappear a few weeks after you finish your treatment. To help reduce any discomfort:
  - » Keep your skin moisturised- if possible, ask someone to help with areas you can't reach.
  - » Wear cotton clothes; avoid wool and synthetic materials.
  - » Your doctor may prescribe anti-histamine medicine or a steroid cream to relieve the itching.
- **Fissures (cracks in your skin)** - your skin may break and become weepy. We will give you advice about this and supply appropriate creams and dressings.
- **Skin infections** - You may be at risk of skin infections.
  - » Keep skin clean and well moisturised.
  - » You may be prescribed an antibiotic ointment to apply to any lesions.
  - » If you are worried about any areas of your skin, please let your radiographers or doctor know.
- **Sun sensitivity** - Your skin will be more sensitive to sunlight and you will need to take precautions to protect it:
  - » Wear a hat, long sleeves and trousers when you go out in the sunshine.
  - » After treatment, wear SPF50 sunscreen with both UVA and UVB protection.
  - » Wear sunglasses with both UVA and UVB protection.

- **Hair loss (alopecia)** - You may lose the hair on your head and body. It will normally grow back three to six months after your treatment finishes. We can provide you with a voucher for a wig. Please speak to your radiographers and they can arrange this.
- **Temperature regulation changes** - Sweating is your body's natural way of controlling your temperature. After this treatment, your sweat glands may not work properly for a few months. You may sweat less. It may help to:
  - » Avoid strenuous activity in hot humid weather and drink plenty of water.
  - » Wear layers of clothes to keep you warm if you feel cold.
- **Swelling** - You may notice your ankles and feet swell during the treatment. You may get blisters on your feet. This will improve when treatment finishes. To help with this:
  - » Wear soft shoes and slippers.
- **Brittle nails** - If your nails are shielded during treatment, you shouldn't notice any changes to them. If they are not shielded, they may become brittle and break. They may fall off but will regrow a few months after treatment has finished. It may help to:
  - » Keep your nails cut short.
  - » Wear thin gloves to protect your nails and to prevent scratching your skin or snagging your clothes.
- **Fatigue** - You may feel very tired towards the end of your treatment. The tiredness will gradually improve, but it may last for several months. Below are some suggestions to help manage tiredness:
  - » Plan rest periods into your daily routine.
  - » Do some gentle exercise.
  - » If you are working, you may wish to work reduced hours.



- » Drink 1.5-2 litres of water a day.
- » Eat a normal healthy diet.

### **Other side effects can include:**

- Changes to your taste.
- A dry mouth/eyes.
- Nose bleeds.
- Stiffness in your hands and feet.

If you experience any of these side effects, please let your radiographer or doctor know.

## **What happens after my treatment?**

Your doctor will give you information about your care when you finish your treatment. They will see you regularly in the follow-up clinic and they will monitor your condition.

Sometimes people need additional treatments to certain areas of their body. Your doctor will discuss this with you if necessary.

## **Where can I get help?**

All the 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 help, support and information is available from:-

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. It is an answer phone service. Please leave your name and telephone number with a short message 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**

**Beatson Cancer Centre** – if you want to find out more about our Centre please visit  [www.beatson.scot.nhs.uk](http://www.beatson.scot.nhs.uk)

**NHS 24**  **111**




**Macmillan Cancer Support**  **0808 808 0000**


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

## **Maggie's**

Maggie's Centre provides a comprehensive cancer support programme for people and their families affected by cancer.


 [www.maggies.org](http://www.maggies.org)

- **Maggie's Glasgow** situated in the same grounds as the Beatson Glasgow radiotherapy site:  **0141 357 2269**
- **Maggie's Lanarkshire** situated in the same grounds at the Beatson Monklands radiotherapy site:  **01236 771 199**
- **Maggie's Forth Valley** Situated next to Forth Valley Hospital:  **01324 868 069**

**Cancer Support Scotland**, The Calman Centre, Gartnavel Complex:  **0800 652 4531**.

 [www.cancersupportscotland.org](http://www.cancersupportscotland.org)

Provides emotional and practical support on a one-to-one basis and through community based groups. Complementary therapies available.

**Macmillan Benefits Team** (located within the Beatson Glasgow):  **0141 301 7374**

Provides free and confidential advice for people affected by cancer and their carers.

**Lymphoma Action:**  **0808 808 5555**

 [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)

Provides information and support to people affected by lymphoma.

# Counselling and Psychology Service

This leaflet deals with the physical aspects of your treatment, but your emotional wellbeing 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. 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.

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](http://www.careopinion.org.uk) or telephone:

 0900 122 3135 or scan the QR code:

