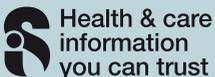




The Clatterbridge
Cancer Centre
NHS Foundation Trust

Total Skin Electron Beam Therapy (TSEBT)

Radiotherapy



The Information Standard

Certified
Member

A guide for patients and carers

Contents

| | |
|--|---|
| When is total body electron radiotherapy used? | 1 |
| Planning your treatment | 1 |
| Treatment | 1 |
| Radioactivity | 2 |
| How do I prepare for treatment? | 2 |
| What happens during the treatment? | 2 |
| Care during treatment | 4 |
| Possible side effects during treatment and in the first three months afterwards | 4 |
| Late effects (after three months) | 7 |
| What happens after the TSEBT? | 8 |
| Coping with treatment | 9 |

This booklet is a guide to your radiotherapy treatment. It is designed to be read once you and your doctor have decided that radiotherapy is the best treatment for you. If you are still unsure about radiotherapy or would like to discuss other options, please talk to your doctor.

You may find it helpful to read The Clatterbridge Cancer Centre patient information booklet called 'Radiotherapy' which explains how radiotherapy works.



When is total body electron radiotherapy used?

Radiotherapy is the use of 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. It is given by a radiotherapy treatment machine (linear accelerator) producing beams of high energy electrons. An electron beam will only treat the skin surface. TSEBT is used when the skin lymphoma has affected many areas of your skin. Normally patients have had creams (moisturiser and steroid cream), phototherapy (PUVA) and/or tablets to treat the skin condition in the past. TSEBT is very effective and controls skin lymphoma very well.

Planning your treatment

Your doctor will ask you to sign a consent form. This is to confirm that you agree to have radiotherapy treatment. If you have any questions, please do not hesitate to ask. Your treatment will then be planned according to your needs. You will be shown how to place yourself in the six treatment positions (see diagrams on page 3) and shown the equipment to be used for treatment.

Treatment

Treatment will start approximately 1-2 weeks after radiotherapy has been agreed. You will have either eight treatments (short course) over two weeks or 20 treatments (long course) over five weeks. The doctor will explain which schedule is appropriate for you. The treatment is given on four consecutive days, Tuesday to Friday. The duration of the treatment each day is 45 minutes.

Radioactivity

With TSEBT you will not be radioactive, so there is no need to avoid close contact with other people. You can be sexually active during your treatment with radiotherapy, unless your doctor tells you otherwise.

How do I prepare for treatment?

Once you enter the treatment room, the radiographer will ask you to undress in a changing area. You will be given special net underwear to wear for the treatment. If your nails are not affected, you will be given a special pair of gloves to protect your nails. These are quite heavy when you put them on.

What happens during the treatment?

You will need to stand for the treatment. The radiographers will position you for the treatment in the positions shown. You will need to hold each position for a few minutes then change to the next. The radiographer will give you instructions each time you need to move. We can interrupt the treatment after each position if you need a rest.

You may have to wear goggles over your eyes for treatment. The goggles shield your eyes from the radiotherapy. They are heavy and dark. This means that you will not be able to see anything while you are wearing them.

Special shielding may be used for your nails, hands, legs and feet, if these areas are not affected.



The six treatment positions



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

During treatment, you will be in the treatment room on your own, but the radiographers will be watching you via a monitor. When the machine is switched on, you will hear a buzzing sound, but you will not feel anything from the treatment. The treatment machine gets quite warm, so you may feel warmer in the later part of each session. If you have a particular lumpy area, we treat

these separately normally with 1-2 extra treatments before you start TSEBT. Your doctor will explain this to you, as every patient is different.

Care during treatment

You will have a weekly check-up with the radiotherapy doctor, who will monitor your treatment closely. The radiographer can advise you on skin care or any other problems that you may have.

Possible side effects during treatment and in the first three months afterwards

These side effects are usually less troublesome for patients receiving the eight treatments (short course) schedule.

Itchy skin

To help reduce any discomfort:

- Most patients have very itchy and irritated skin before they start radiotherapy, because of the lymphoma. This normally improves in the first week of treatment and tends to get worse during weeks 3-5. It should improve and disappear a few weeks after you finish TSEBT
- Keep your skin moisturised with an unperfumed moisturiser that suits your skin and use it at least twice a day all over your body. Please ask somebody to help you to cream your back and other areas which you are unable to reach. If you come as an outpatient, please ask a friend or relative to help. If there is nobody who can help you, we will get the district nurses to look after your skin



- Do not use moisturisers that are perfumed or contain metal agents, as they may increase any skin reaction you have. If you have questions about whether a moisturiser is appropriate, please ask the radiographers or your oncology doctor
- Please avoid excessive washing, as this will dry out the skin further. Use wash lotions for dry skin, rather than real soap. Use baby shampoo or a product designed for dry and scaly scalp
- Wear cotton clothes, avoid wool and synthetic fabrics
- Your oncology doctor will give you a steroid cream if the skin becomes itchy. If you develop a break in the skin, we will give you dry dressings
- Your doctor may prescribe anti-histamine medication to relieve the itching, this may make you drowsy

Fissures (cracks in your skin)

- Apply prescribed medication or dressings

Skin care

- You may bathe or shower daily in warm water with an emollient shower gel or bath additive. Use wash lotions for dry skin, rather than real soap as these dry your skin out too much
- Apply an unperfumed moisturiser after your bath, while your skin is still moist
- Reapply moisturiser regularly during the day

Skin infections

There is an increased risk of you getting skin infections during or after radiotherapy. If this happens, you may need a course of antibiotics.

- If you are worried about any areas of your skin, please tell the staff caring for you as soon as possible
- Do not wet shave or use hair removal creams or wax

Fatigue

You may feel very tired towards the end of your treatment. There are a number of reasons why patients develop tiredness during treatment with radiation therapy:

- The biological effect of radiation
- Travelling for treatment each day
- Lack of sleep
- Itchy skin or other symptoms
- Feeling anxious or depressed

The tiredness will gradually resolve, but it may last for several months.

Swelling

- Your ankles and feet may swell with water retention. This improves once the treatment is completed
- You may get blisters on your feet. Wearing soft shoes and slippers may help to prevent them



Hair loss (Alopecia)

- The hair on your head and body will fall out when you have TSEBT, but will normally grow back three to six months after treatment has finished. This can be difficult to come to terms with. If you would like more information or support, please talk to one of the radiographers/nurses caring for you, they will be able to give you information about how to get NHS assisted wig service and In-house Headstrong service

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

Late effects (after three months)

Dry skin

You need to continue to use moisturisers regularly.

Sun sensitivity

You will be permanently more sensitive to sunlight and will need to take precautions, for example:

- Wear a hat and long sleeves when you go out into sunshine
- Wear a sunscreen lotion that screens for UVA and UVB
- Wear sunglasses that screen for UVA and UVB

Temperature regulation

Sweating is your body's natural way of controlling its temperature. After TSEBT, your sweat glands may not work properly for a few months and you may sweat less than before. Avoid strenuous exercise in hot humid weather and drink plenty of fluids. In cooler weather, wear layers of clothes to keep you warm if you feel chilly.

Brittle nails

- If your nails are shielded during treatment, they should not change after completion of radiotherapy
- If you require treatment of the nails, they may become brittle and split. Keep nails trimmed
- Nails may fall out, but if they do they will re-grow a few months after treatment has finished
- Wear thin cotton gloves to protect your nails and to prevent scratching your skin or snagging your clothes

What happens after the TSEBT?

Your doctor will give you information about your care after you have finished your course of TSEBT. You may need additional treatments to certain areas of your body. If this is the case, your doctor will discuss these with you further. The doctor will see you in the follow-up clinic regularly and check on your condition.



Coping with treatment

Some people feel unable to cope with what is happening to them and feel anxious or depressed. It can be helpful to know that most people find these feelings ease with time.

Discuss your concerns with any of the staff that are involved in your treatment, as well as your family and friends. You may find that you are asking yourself lots of questions. Talking to other people can help you find the answers. We can refer you to the Psychologist for assessment, if you feel this would be useful. Sometimes medications are also helpful.

Contact details

The Clatterbridge Cancer Centre NHS Foundation Trust

0151 556 5000 or www.clatterbridgecc.nhs.uk

Macmillan Cancer Support

0808 808 0000 or www.macmillan.org.uk

Macmillan Cancer Information and Support at:

Clatterbridge Cancer Centre - Wirral 0151 556 5570

Clatterbridge Cancer Centre - Aintree 0151 556 5959

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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.

The Clatterbridge Cancer Centre NHS Foundation Trust
Clatterbridge Road, Bebington,
Wirral, CH63 4JY.

Tel: 0151 556 5000

Web: www.clatterbridgecc.nhs.uk

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