



Radiotherapy to the skin: total skin electron beam therapy

A guide for patients and their carers



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Introduction

This booklet is to tell you about total skin electron beam therapy (TSEBT) which is radiotherapy delivered to the entire skin surface. The doctor, nurse or specialist radiographer will discuss your treatment with you and explain anything you do not understand.

Please share this booklet with your family and friends. They can have a role in helping you. It is important that they feel well-informed and understand what is happening. If you would like more detailed information about your own treatment, please ask the staff. There is also a film available to watch on The Christie website www.christie.nhs.uk

You may have heard about radiotherapy from people you know or from the patients at The Christie. Remember that their information may not apply to you.

When is radiotherapy offered and what are the benefits of this treatment?

Each patient has their treatment planned individually and your doctor at The Christie will discuss with you the type and length of treatment that is recommended for you. The doctor will use the following chart to discuss the reasons for treatment and the benefits of treatment you are being offered.

<p>When is total skin radiotherapy offered?</p>	<p>When you have cutaneous lymphoma involving different areas of the skin surface which will not be helped by skin – directed treatment such as PUVA or topical steroids.</p>
<p>What is the aim of treatment?</p>	<p>To treat as much of the skin surface as possible and heal the areas of lymphoma, and so alleviate symptoms.</p>
<p>Will I need chemotherapy?</p>	<p>Chemotherapy is not usually given with this.</p>
<p>What is the duration of the radiotherapy?</p>	<p>The treatment can vary between 5 and 8 daily treatments (not weekends) over 1 to 2 weeks. Alternative treatment schedules may be used in particular circumstances. The day of starting radiotherapy may not necessarily be a Monday.</p>
<p>Are there any alternative treatments?</p>	<p>We can deliver radiotherapy to individual areas of skin or offer treatment with a variety of different drugs. Ask your treating team and they will discuss this in detail.</p>
<p>What happens after radiotherapy?</p>	<p>You will be seen in clinic by your oncologist (specialist doctor) 4 to 6 weeks after completing treatment and regularly thereafter.</p>

What is radiotherapy?

Radiotherapy uses exact, carefully measured doses of radiation to treat diseases. It is often given in small doses over a specified period of days or weeks, but may be given in a single treatment. It is given by therapy radiographers who operate the machines which direct the radiation to the area needing treatment. The radiographers are specially trained professional men and women.

During your treatment you will be cared for by a team including consultants, registrars, radiographers and nurses. They will be able to answer any questions or concerns you may have.

What is total skin electron beam therapy?

Total skin electron beam therapy (TSEBT) is radiotherapy delivered to the entire skin surface. It is given by machines producing beams of electrons. An electron will only treat the skin surface and this limits the dose to underlying tissues and organs. The dose is selected for your particular type of lymphoma so you may find that you are having a different number of treatments from other people you meet at the hospital.

How does radiotherapy work?

Our bodies are made up of cells and all cells are able to divide. If radiation hits a cell that is dividing it will be damaged. Cancer cells suffer more damage from radiation than normal cells, so more of the cancer cells will be destroyed.

Consent to treatment

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written

description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you.

Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

Women of child-bearing age: Radiation can be harmful to the unborn child. It is important to let the radiographers know if you have missed a period, or suspect that you might be pregnant before you are exposed to any radiation.

Preparing for treatment

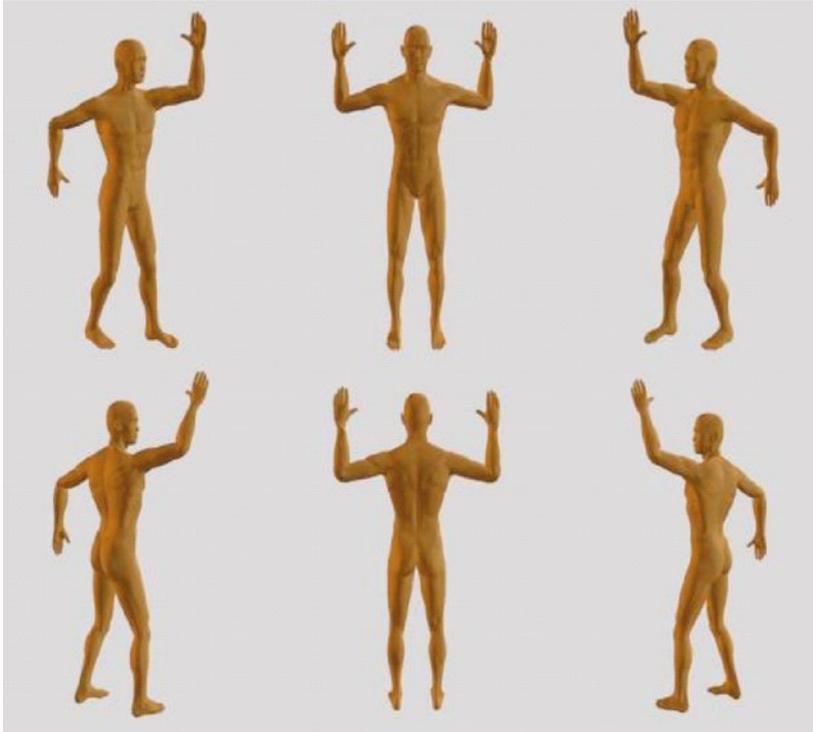
The doctor who is in charge of your treatment is a clinical oncologist. They will examine you and may arrange for tests such as X-rays, scans and blood tests. These are to check your general health, and to help decide on the details of your treatment.

In choosing your treatment, your clinical oncologist at The Christie has carefully considered the nature of your illness, and your particular needs with regard to your treatment plan.

You will be given treatment in 6 different positions (see diagram). Treatment can take approximately one hour to give so it may be beneficial to practise these positions before you start your treatment.

We will give you special net underwear to wear for the treatment. We may give you special gloves with lead in the fingertips to protect your finger nails and special goggles with lead across the eyes to protect them. The radiographers will carefully guide you into each treatment position.

The six treatment positions



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

What happens during treatment?

On the day of your first treatment, you will come to the radiotherapy department as an outpatient. If you are an inpatient a radiotherapy care assistant may collect you from your ward and escort you to the department.

Your treatment is given in the morning at approximately 8:30am because of the specific requirements of the treatment. The radiographers will explain the details of your treatment as well as the expected side effects and how to manage them.

They will also check whether you are still happy to go ahead with your treatment. This is the ideal opportunity to ask any questions you may have.

The Christie is a training centre, so you may meet male and female students in the radiotherapy department who may be involved in the delivery of your treatment. If you have any objections please let the radiographers know.

The radiographers will take you into the treatment room and ask you to remove your clothing and wear the special net underwear, gloves and goggles (if appropriate). They will take a measurement with a tape measure and put some pen marks on your skin to help position you correctly. They will help you into the different positions which you will need to hold for a few minutes. For the first 2 treatments, measurements of the dose will be taken involving about 10 small measuring devices being placed on the skin.

Each session may take about one hour but the actual treatment is painless and only lasts a few minutes for each position. The radiographers operate the machines from outside the room. Once the radiographers have positioned you in the first position and completed all of the checks, they will leave the room to switch the machine on.

There is nothing to feel and nothing to see. The machines make a buzzing noise when giving treatment. Occasionally there is a slight smell caused by the treatment machine. The radiographers will then return and help you into the next position, until treatment has been given in all 6 positions.

A closed circuit television on the control desk gives the radiographers a clear view of you and the radiographers will be watching you all the time. Please do not feel abandoned. If you feel you need to cough or sneeze the radiographers will tell you beforehand how to let them know this. They will switch the machine off and come in immediately.

Once your treatment has finished the staff will arrange your next visit. You are then able to return home or to your ward.

It is very important that you do not miss treatment days as this may make your treatment less effective. If you feel you are unable to attend for any reason please telephone the staff on your treatment machine and discuss the problem with a radiographer.

Some questions about radiotherapy

Is radiotherapy safe?

Radiation used in medical treatment is given in controlled, carefully measured doses. The aim is to include all tissues that could possibly contain cancer cells whilst minimising the dose to the normal tissue.

Will I be radioactive?

No. Patients treated by X-rays do not become radioactive. The radiation does not stay in your body after treatment, so you cannot do anyone else any harm. It is safe for you to mix with other people including children and pregnant women.

I already have problems with my health. Will radiotherapy treatment make them worse?

Not usually. The treatment may make you feel more tired than normal. Please tell your treatment team about any existing medical conditions and also continue with any medication that you may be taking unless your doctor or nurse tells you otherwise. Ask your Christie doctor if you are worried about any other health problems.

Can I come for treatment at any time of the day?

As this is a special technique, you will only be able to have treatment in the morning, usually starting at 8:30am.

You will meet your consultant or one of their team at least once a week during treatment. You do not need an appointment for this. We will take you to the clinic before or after your radiotherapy.

Will I be treated as an outpatient or an inpatient?

You will usually have your treatment as an outpatient. Some people continue to work during part of their treatment. However, after daily travel and treatment, you may feel tired and need to rest. Your treating team will have discussed with you about travelling daily for your treatment as an outpatient. However, if you do become unwell during your treatment you may be admitted as an inpatient to support you through your radiotherapy. You will not have to stay in bed, so bring suitable day wear, so that you can get dressed if you feel well enough.

What happens if I need ambulance transport to and from the hospital?

Many patients are able to bring themselves or can ask a friend or relative to help them out. If you think you may need ambulance transport, please discuss this with a radiotherapy support worker or radiographer on your first visit to the radiotherapy department.

Ambulance transport can be arranged subject to eligibility criteria based on medical need. There also needs to be a medical need for you to bring an escort on hospital transport.

There can be delays for some time either side of your appointment because of the high demand for transport. Please take this into account when you are deciding whether to use ambulance transport or not.

Hospital transport is provided by several different ambulance services. Contact the transport liaison office at The Christie directly on **0161 446 8114** or **8143** for advice and bookings (Monday – Friday, 8:00am – 6:00pm).

Patients attending The Christie at Salford can contact **0161 918 7800** and patients attending The Christie at Oldham can contact **0161 918 7700** for advice about transport.

Questions you may want to ask your doctor

- What type and extent (stage) of disease do I have?
- Why are you recommending radiotherapy for me?
- What might be the benefits and side effects?
- Is there any alternative treatment, and, if not, why is this?
- What will the radiotherapy involve and how many times will I have to visit the hospital?
- Will there be any lasting effects from treatment?

If you need any help or advice please contact Jane Gibson, lymphoma nurse clinician, on **0161 446 8573**.

If necessary, arrangements can be made for you a district nurse to visit you at home.

Side effects

There are short term (acute) and long term (late) side effects associated with this treatment. These are discussed below. It is common to experience most of the side effects to some extent.

Below is a table of acute common side effects experienced and what you can do to help.

Acute side effects

(See below for further information)

Reddening of the skin	<p>It is common for your skin to become dry, red, itchy and may breakdown in certain areas.</p> <p>You can use aqueous cream or E45 cream to help keep the skin moisturised. Do not use moisturisers that are perfumed or contain metal agents.</p> <p>It is best to try to wear loose, cotton clothes and avoid wool and synthetic fabrics.</p>
Cracked and broken skin	<p>If your skin does crack and break down you may be given other creams and dressings to use. The skin may become sore and painful and you may need painkillers. You can discuss this with your treating team.</p>
Tiredness	<p>This varies greatly from person to person. Gentle exercise and rest when you are feeling tired may be beneficial.</p>
Alopecia (loss of hair)	<p>You may notice that your hair begins to thin and you may lose all hair all over the body during treatment.</p>

The side effects happen because, as well as destroying cancer cells, radiotherapy can also damage healthy cells nearby. When planning treatment, the doctors choose the dose that will give the best chance of destroying the cancer cells with the smallest possible effect on healthy tissue. It seems that some patients are more sensitive to radiation than others, and are more likely to experience side effects. At present, it is not possible to identify these patients before treatment starts.

Acute side effects

Acute side effects will generally develop during the second half of the course of treatment usually after 3 to 7 days, and last up to 6 to 8 weeks after the treatment ends. They are usually temporary and may vary in severity from person to person. Some patients may develop minimal side effects and others may have more. If you have any questions about side effects, please ask any member of the team treating you.

Reddening of the skin

Your skin may become dry, red, itchy and may break down in certain areas. You can continue to use your normal daily moisturiser to help with this. You do not need to change from this unless you find that it starts to irritate your skin during your treatment. We do not recommend that you use any moisturisers that are perfumed or contain metal agents as they may increase any skin reaction you have. Your dermatologist may give you creams to use during your treatment, please discuss this with your treating team. It is best to try to wear loose, cotton clothes and avoid wool and synthetic fabric.

Ask the nursing or radiotherapy staff for a copy of 'Skin care during and after your radiotherapy treatment' which has information about coping with problems such as skin changes.

Cracked and broken skin

In a small number of cases, radiotherapy can cause the skin to crack and breakdown. If this happens we may advise you to use a different cream on your skin. It may be beneficial to use dressings in these areas. It is important that the area is kept as clean as possible to reduce the chance of an infection occurring.

Sometimes when the skin breaks down it can be uncomfortable and painful. If this happens, we may give you some painkillers to help with this. If you are worried about any areas of your skin, please tell the staff caring for you.

Fatigue

You may feel tired during treatment so rest is important, although a small amount of exercise each day has been found to be beneficial in reducing fatigue. This is explained further in The Christie booklet 'Be Active, Stay Active: a guide to exercising during and after cancer treatment'. Ask staff for a copy. This is also available to watch as a short film on The Christie website.

Tiredness often affects people after treatment ends, so you may need help with housework and shopping. Please ask any member of the team treating you if you would like to see a social worker who can advise on help available. Radiotherapy treatment can be a demanding treatment. If you are feeling low or are not coping, let the nurses, doctors or radiographers treating you know so they can discuss with you what might help.

Hair loss

For most people receiving this treatment, the most distressing side effect is hair loss. Almost everyone receiving this type of treatment will develop loss of hair on their scalp,

and to a lesser extent, loss of other body hair. Most people will have good re-growth of hair following completion of treatment, however this may take several months. In some instances, when hair regrows it returns in a different colour or texture. Occasionally we shield the head and in such cases hair loss is less likely.

The cancer information centre offers a coping with hair loss service to all patients where support, information and advice will be given. Drop in, contact **0161 446 8100** or email **informationcentre@christie.nhs.uk**. Information about the wig service can also be found here and vouchers can also be obtained for eligible patients. The wig room provides a drop in service, please see The Christie leaflet 'The wig fitting service' for further information.

The Maggie's Centre runs a Talking Heads hair loss support workshop for anyone who is anticipating or experiencing hair loss (both men and women). These sessions cover the practicalities of hair loss as well as offering support with its emotional impact. Contact Maggie's on **0161 641 4848** or email **manchester@maggiescentres.org**

Brittle nails

Your nails may be shielded during treatment; however, they may become brittle and split and temporarily stop growing. It is important to keep your nails trimmed. Occasionally the nails may fall out. If this occurs, they normally re-grow a few months after treatment has finished, although some people do experience long-standing problems.

Sweating

Sweating is your body's natural way to control your temperature. After treatment, your sweat glands may not work properly for a few months and you may notice that you sweat less than before. It is important that you avoid

strenuous exercise in hot humid weather and drink plenty of fluids. In cooler weather it may be beneficial to wear layers of clothes to keep you warm if you feel chilly.

Other side effects

Some patients do find that they experience the following side effects:

- change in taste – if this occurs the advice in The Christie booklet 'Eating – help yourself' may be helpful
- a dry mouth – we advise that you try to drink 2 to 3 litres of fluids everyday during treatment, ideally water. Sipping cool water or a hard boiled sweet sometimes helps with a dry mouth
- dry eyes – you can buy Hypromellose eye drops from any pharmacy to help with this
- swelling of ankles and legs – gentle leg exercises may be beneficial to reduce the risk of this occurring. There is helpful advice in the booklet and film 'Be Active, Stay Active: a guide for exercising during and after treatment for cancer'
- stiffness in hands and feet

Late effects

There are some late side effects of radiotherapy that your doctor will discuss with you. These may occur months or years after your treatment and happen only in a very few cases. For anyone having radiotherapy there is a small risk of developing these long term effects.

Skin changes

Some people find that they have general changes in their skin colouring (pigmentation) and their skin is dry in

certain areas. This happens because less oil and sweat is being produced. If your skin becomes dry, you may find it beneficial to continue using aqueous cream or E45 cream on a regular basis.

Radiotherapy can cause scattered dilated blood vessels seen on the skin surface (known as telangectasia). These marks may fade slightly over time.

You will be seen on a regular basis by your treating team here at The Christie which includes a dermatologist. If these changes are a concern please discuss them with the team. There is a very small risk of developing other skin cancers many years after radiotherapy to the skin.

Research at The Christie

The Christie, along with the Manchester Cancer Research Centre, is a major centre for cancer research of all kinds. You may be asked if you are willing to help with some of the clinical trials and audits. You are under no obligation to take part in any of these. You will meet some of the research nurses who help to run the trials. They will also give you support and advice throughout your treatment, whether you are taking part in a trial or not.

Travel and holidays

The treatment works better if there are no breaks. It is preferred that you do not go on holiday during treatment.

Most people do not feel like travelling for the first few weeks after their treatment, however everyone is different. It may take 4 to 6 weeks before your side effects settle and it may be some time after this before you feel like going on holiday. Once you feel like going on holiday there should be no problem travelling within the UK.

However, if you are thinking about going abroad; you will need to ensure your skin has healed and ensure you keep yourself covered and out of the sun. It is important to have adequate health insurance which includes your cancer diagnosis.

This may mean that the cost of your insurance policy is higher than it has been previously. Some people have found it useful to get a quote for their insurance before booking a holiday, as this could affect your choice of destination. More information about this and other things to consider are in the booklets 'Getting Travel Insurance' and 'Travel and Cancer' Macmillan Cancer Support, available from www.macmillan.org.uk

Benefits and finance

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help.

Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16 or over and have not reached State Pension age. You can apply for DLA if you are under 16.

If you are State Pension age or older and need help with personal care or supervision, you could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs.

To find out more:

- To get a claim pack for Attendance Allowance, call **0800 731 0122** and for PIP call **0800 917 2222**.
- For Disability Living Allowance call **0800 121 4600**.
- Carer's Allowance: call **0345 608 4321**.
- For benefits advice, contact Maggie's centre on **0161 641 4848** or email manchester@maggiescentres.org
The Christie at Oldham has a benefits advice session on Thursday afternoons, call **0161 918 7745**.
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit www.gov.uk for further information.
- Macmillan Cancer Support can give advice on helping with the cost of cancer on **0808 808 00 00** or www.macmillan.org.uk

Prescriptions

NHS patients being treated for cancer are entitled to free prescriptions. You will need an exemption certificate. These are available from The Christie Pharmacy or from your GP.

Car parking

Please check the website (www.christie.nhs.uk) for the latest details, or ask at the information centre for a copy of the leaflet 'Travelling and car parking for patients and patient's visitors to The Christie'.

Further information

Lymphoma Action

Lymphoma Action is the UK's only charity dedicated to lymphoma. It provides information and support to people affected by lymphoma.

You can access information and support through:

- A freephone helpline **0808 808 5555** where specially trained staff offer a listening ear and the information you need about your lymphoma.
- Their website is **www.lymphoma-action.org.uk** where you can access information that is written and regularly updated by lymphoma specialists, including information about skin lymphoma. Information is also available about support groups and online forums.

Macmillan Cancer Support

This is a national charity which runs a cancer information service. The cancer support service freephone number is **0808 808 00 00**. (Monday to Friday, 9am to 8pm). If you are hard of hearing, use the textphone service on **0808 808 0121**. If you are a non-English speaker, interpreters are available. Calls are answered by specially trained cancer nurses who can give you information on all aspects of cancer and its treatment. Information and advice about finance and benefits are also available.

Macmillan Cancer Support publish booklets which are free to patients, their families and carers. You can get a copy by ringing the freephone number. The information is on their website: **www.macmillan.org.uk**

Information is available on cancer treatments – such as Understanding radiotherapy and Understanding chemotherapy. There are also booklets on living with cancer – some of these are listed below:

- Talking about your cancer
- Talking to children and teenagers when an adult has cancer
- What do I tell the children?
- Cancer and complementary therapies
- Travel and cancer

The cancer information centre at The Christie has a full range of booklets available free to patients and their relatives/carers, and staff who can offer information and support.

Cancer information in your language

If English is not your first language, you can speak to a nurse at Cancer Research UK through a qualified interpreter. The service is free and over 170 languages are available on **0808 800 4040** (Monday to Friday, 9am–5pm).

Christie information

The Christie produces a range of patient information booklets and films. Some of these are listed below.

Booklets are free to patients coming to The Christie and are available from the cancer information centre. If you are an inpatient and would like a copy, please ask the ward staff. If you are an outpatient please ask your nurse, doctor or radiographer.

■ **Radiotherapy: a guide**

Short films can be viewed on The Christie website at www.christie.nhs.uk under 'patient information'.

■ **Where to get help: services for people with cancer**

This provides sources of help when you have cancer, where to go for financial help, palliative care and cancer support groups.

■ **Eating – help yourself**

This gives advice on eating problems when you don't feel well and you are having treatment. Other booklets give helpful advice on diet: 'Advice about soft and liquidised foods', and 'Nutritional products'. Please ask a member of staff for a copy.

■ **Be Active, Stay Active: a guide for exercising during and after treatment for cancer**

A booklet and film with a simple exercise programme you can follow. There is also more information about coping with fatigue and the benefits of exercise. Available with sub-titles, and in Urdu and Chinese. This is also available to watch on The Christie website: www.christie.nhs.uk under 'patient information'.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

Student training

The Christie is a training hospital for postgraduate and undergraduate trainees so you may meet students

in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients.

Placements at The Christie are an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education.

Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this and your treatment will not be affected in any way.

We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

Useful contacts

- Treating team – **0161 446 3501**
- Benefits advice at Maggie's centre – **0161 641 4848**
- The Christie Hotline – **0161 446 3658**

Contacts via your consultant's secretary

Professor R Cowan – **0161 446 3332**

Christie website

For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centre at Withington, Oldham or Salford.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

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0161 446 3000

www.christie.nhs.uk



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