

Total Skin Electron Therapy - TSET

Information for patients



Leeds Cancer
Centre

TSET stands for Total Skin Electron Therapy. Electron therapy is a type of radiation. It is also sometimes referred to as Total Skin Electron Beam Therapy (TSEBT). It has been used for many years in the treatment of skin lymphomas including mycosis fungoides.

This leaflet aims to help you and your family understand more about this treatment. It will be given to you in addition to the information you will receive from your Clinical Oncologist (who is a specialist doctor in cancer treatment). His/her team will be caring for you during your treatment. This team will include radiographers and clinical nurse specialists but may also include social workers, physiotherapists and occupational therapists.

This leaflet describes radiotherapy planning and treatment. It also explains the side-effects which you may experience during and after treatment. Each person's treatment will vary, so the information given is a general guide. The healthcare team looking after you will explain your treatment and the side-effects in detail. If you have any questions after reading this leaflet, please speak to the team looking after you or ring the numbers at the end of leaflet. Staff will make every effort to meet your individual needs or will direct you to the person who can help.

**All your radiotherapy planning and treatment will take place in the Radiotherapy Department on Level -2, Bexley Wing, Leeds Cancer Centre (LS9 7TF).
Radiotherapy Reception Desk tel: 0113 206 8940.**

Please do not bring any valuables into hospital with you as the Trust cannot accept liability for loss or theft.

What is radiotherapy?

Radiotherapy is the use of high energy X-rays and other types of radiation to treat cancer. The radiotherapy causes damage to cancer cells in the treated area. Although normal cells are also affected, they can repair themselves and are able to recover. When you are having your radiotherapy you do not feel anything and it does not make you radioactive. It is perfectly safe for you to be with other people, including children and anyone who may be pregnant, throughout your treatment. You may hear a buzzing noise when the machine is switched on. The radiation is delivered by a treatment machine called a 'linear accelerator', as shown here in the photograph.



You will see your radiographers at each treatment session, and they will be happy to answer any questions that you may have.

How often is it given?

The doctor will discuss how many treatments are appropriate for you. This can vary from person to person but is usually between 5 and 12 treatments. Treatment is given daily, usually Tuesday to Friday, however occasionally there may also be treatment on a Monday.

Your treatment will usually be given as an outpatient. Sometimes the doctor may decide to give you extra treatments to other small areas of your body. If this is required, it may be given before or after TSET treatment.

Visiting us before your treatment

If you would like to visit the radiotherapy department before starting treatment, please call **0113 206 7603**. This visit can be very useful as you can find out more information about radiotherapy.



'I was so pleased to see the machines before my treatment and the staff were so helpful and really put my mind at rest.'

Who will I meet?

Therapeutic radiographers

Radiotherapy is given by therapeutic radiographers of any gender who are highly trained in the accurate planning and delivery of radiotherapy treatment.

You will see your radiographers at each treatment session and they will be happy to answer any questions you may have.

Student radiographers

The radiotherapy department is a training centre for therapeutic radiographers. They are supervised at all times. If you do not wish students to be present, please speak to a member of staff. This will not affect your treatment or care.

Important advice before your treatment

Pregnancy

It is very important that patients of child bearing potential are **not** pregnant at the start of a course of radiotherapy and that they **do not become pregnant** during a course of radiotherapy because it can have an effect on the unborn child. Use an effective form of contraception, for example condoms, coil, depo injection or contraceptive pill.

For more information see the '**Contraception and pregnancy during cancer treatment**' leaflet. Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Planning your treatment

Your first appointment for radiotherapy will be a planning appointment. This will be used to gather all the information we need to accurately plan your treatment. We will contact you by phone, with an appointment for your radiotherapy planning session. Directions to the hospital and transport arrangements will be discussed with you at this point.

You may see your clinical oncologist (or a member of their team) at this appointment. This is an ideal opportunity for you to ask questions. If you have not previously consented to your treatment you will be asked to sign a consent form.

What to bring with you:

- a list of all questions you may have;
- an up-to-date list of all the medications you are taking (including inhalers, sprays, vitamins or herbal products);
- any medication that you may need during your visit;
- something to eat and drink and something to occupy yourself with, as this first visit can be quite lengthy (up to two hours).

Before you start treatment

If needed you may have an appointment to visit the Mould Room to make lead shielding to cover your finger and toe nails. This protects the nails from the radiotherapy. Sometimes we ask you to wear lead-lined swimming goggles during the treatment, and occasionally more shielding is used. These are quite heavy. If you need these you will try them on while you are in the Mould Room.

Your Test Spin

You will be asked to visit a treatment machine in the radiotherapy department for a Test Spin. This visit is to check you are able to cope with the treatment position (please see photo) you need to stand in. The turntable in the floor moves round very slowly but we need to make sure you are safe and comfortable.



We will ask you to stand on the treatment turntable and hold a handle which is suspended from the ceiling. You will hold a thin walking stick in the other hand to help you keep your balance. We then start the turntable while we are still with you and can stop this at any time if you ask. You will be asked to alternate (swap) your feet and hand positions on a daily basis once the treatment starts. We need to check that you are able to hold both arms up in the position shown.

Once we, including you, are all confident you will be able to manage the treatment, we will arrange for you to come back and start the treatment.

Having your treatment



When you arrive for your treatment you should go to the radiotherapy main reception desk at the entrance of the radiotherapy department. On the first occasion you will be given all your appointments and be escorted to the waiting area for your machine.

The radiographers will explain what will happen and answer any questions that you may have.

Treatment is given daily, usually Tuesday to Friday. It is likely the treatment time will be late afternoon. There may be occasions when you may have a longer stay in the department or be asked to attend at a different time, for example to see your oncologist.

You will be asked to remove all clothing and jewellery and change into paper pants and a paper gown. This is because anything that is between you and the treatment beam can reduce the dose that you receive, which will make the treatment less effective.

You will meet radiographers and physicists in the treatment room. They are all there to make sure that your treatment is delivered safely and accurately and that you remain comfortable throughout.

The radiographers will put on any shielding if required and help you into position. You will be asked to stay as still as possible during the treatment but you should breathe and swallow normally. A large see-through perspex screen will be placed in front of you, on which the physicist will place measuring devices. The turntable will start to move round while the radiographers are in the room and they will make sure you are okay before they leave the room.

As already mentioned before, when you are having your radiotherapy you do not feel anything and it does not make you radioactive. You may hear a buzzing noise when the machine is switched on.

Some patients notice a metallic smell. This smell is normal and is due to the ionisation of air particles by the radiation beam.

You will only be alone for about 10 minutes and the radiographers will always be watching you on a closed circuit TV (CCTV) monitor. The CCTV camera is not recording or saving any images. There is also an intercom system so that radiographers can talk to you. The staff can switch off the machine if needed and come to check you are okay if you shout out.

If you would like to listen to music during your treatment please let us know. As soon as the treatment is finished the radiographers will come back into the room and turn the turntable off. Once the treatment is completed you will be able to go home.

On some days the radiotherapy department may be busy and there may be a delay before your treatment. We will keep you informed of any delays, please see the delay signs in the waiting areas. It may be a good idea to bring something to eat and drink with you, including any supplement drinks you have been asked to have and any medication you may need. There is a restaurant and café available on Level 0.

It is very important that you do not miss treatment days as it may make your treatment less effective. If you feel you are unable to attend for any reason please telephone us so that we can discuss this with you. If you have any queries about your appointment times please discuss these with the radiotherapy co-ordinators on your treatment unit.

For appointment queries please telephone the radiotherapy reception desk 0113 206 8940 for further advice.

When will I see the consultant during my treatment?

The consultant/registrars (doctors) will see you once a week in Review Clinic. This gives you an opportunity to discuss how you are coping with the treatment. You will also see the Review Clinic nurses at least once a week to assess your skin.

You may be asked to have a full blood count (blood test) once a week before attending the review clinic appointment.

Side-effects

Side-effects can be divided into short term (acute) effects, that happen during or soon after treatment, and long term effects occurring months or years later. Some side-effects are common, whilst others are rare.

The area and amount of treatment given to you will affect which side-effects are most likely to happen to you. Your oncologist will discuss this with you. If you develop any radiotherapy side-effects you will be given advice and support by your healthcare team.

Skin reactions - How should I care for my skin during and after radiotherapy?

Your skin may become very red and can become sore during and after your treatment. You will need to use moisturisers on your skin regularly during your treatment. If you do not have any moisturiser, the doctor will prescribe some for you. Please apply a thin layer of moisturiser to all your skin at least twice a day but it can be used more often if your skin feels dry or tight.

Avoid hair removal where possible, including shaving, waxing, cream and lasers unless advised otherwise by your consultant, nurse or radiographer.

If your skin breaks down (peels or weeps) the nursing staff in Review Clinic will assess you and provide dressings to the areas that need them. Please do not use any cream in areas where you have dressings.

If your skin starts to peel or weep then please ring:

The Princess Royal Suite (Review Clinic) Tel: 0113 206 7587

Hair loss

Many patients find that towards the end of radiotherapy and in the week afterwards their hair thins. This affects everyone differently. Usually your hair will grow back over the few months following radiotherapy. It's not always exactly the same as it was before though.

Ankle swelling

You may find that your ankles become slightly swollen during radiotherapy. This will settle down again after treatment but if you are worried about your ankle swelling, please discuss this with your consultant.

Tiredness (fatigue)

Nearly all patients having radiotherapy will feel tired. Be prepared to take things easy during treatment and allow for extra rests. There is a Macmillan information leaflet available and if you would like a copy, or support with your fatigue please ask a member of staff.

Fatigue usually improves in the weeks to months after treatment.

Things you can do to help include:

- Gentle exercise can help reduce the symptoms of fatigue.
- Having enough to drink can prevent tiredness from dehydration.
- Small meals or snacks eaten more often than three times a day may be easier to face.
- Try to get a good night's sleep where possible, a daytime nap may help.
- Try to 'pace' yourself, listen to what your body is telling you, rest if you need to.
- Pick out the things that you enjoy, and try to accept help with other tasks.
- Little and often is the rule of thumb.

When radiotherapy has finished

Your side-effects may get worse in the first few weeks after treatment and will then gradually settle. You should start getting back to normal after about 4-6 weeks but it may take a little longer. Tiredness can last for several months and you may need to continue to rest more than usual.

After your treatment follow-up checks will be carried out regularly by your consultant in Leeds and sometimes by the hospital team closer to your home.

Research at Leeds Cancer Centre

Leeds Cancer Centre is a major centre for cancer research. You may be asked if you would like to help with some of the clinical studies. You are under no obligation to take part in any trials, and your treatment will not be affected in any way if you do not wish to take part.

If you do take part in a clinical trial you may meet a research nurse or radiographer who will be helping to run the trial.

Further information and support

If you have any questions please ask your hospital team. We all have our own ways of coping with difficulties.

Some people have a close network of family and friends who provide emotional support. Others would rather seek help from people who are not involved with their illness.

The following are also available as sources of information and support that you may wish to use.

Clinical Nurse Specialists (CNS)

Your CNS is available to discuss any aspect of your treatment with you. You will be seen by a CNS before your treatment. This is to offer support and advice about the practicalities and effects of your treatment and answer any questions you may want to ask.

Your CNS will also assess and discuss any physical, psychological, social, occupational and spiritual needs that you may have.

Macmillan Specialist Radiographer and Macmillan Radiotherapy Nurse Specialist

Sometimes people need more help if they are feeling depressed, very anxious or are having problems with their Radiotherapy. If this is the case you may benefit from seeing the Macmillan radiographer or nurse specialist.

Your oncologist, radiographer or nurse can refer you at any point before or during your treatment.

Local Support Services

Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre

This centre offers a variety of free health & wellbeing and supportive therapies for patients, their family members and carers. These include hypnotherapy, mindfulness coaching, acupuncture (for hot flushes) and pilates.

Contact numbers for Leeds Cancer Support

Information Centre Level 1 Outpatients Department

Open from 9.00am - 4.00pm. Tel: **(0113) 206 8816**

Information Lounge Level -2 Radiotherapy Department

Open from 8.00am - 6.00pm Tel: **(0113) 206 7603**

Sir Robert Ogden Macmillan Centre

Open from 9.00am - 4.00pm. Tel: **(0113) 206 6498**

All the above services can be emailed on:

leedsth-tr.cancersupport@nhs.net

Maggie's Centre

If you or someone you love has cancer you may have lots of questions. Maggie's is a warm, welcoming place where you can meet people who are experiencing similar things to you.

You may also be able to find support groups specific to your needs and get advice and information from their professional staff. You don't need an appointment and all support is free.

Open Monday to Friday 9.00am - 5.00pm. Tel: **0113 457 8364**

Address: St James's Hospital (next to the multi-storey car park), Alma Street, Leeds LS9 7BE

Email: **leeds@maggiescentres.org**

Website: **www.maggiescentres.org**

National support organisations

Macmillan Cancer Support

Freephone: **0808 808 0000**, 8am to 8pm seven days a week.

A textphone service for deaf and hard of hearing people on **18001 0808 808 0000**

Website: www.macmillan.org.uk

Stopping smoking

NHS Free Smoking Helpline: 0300 123 1044 Monday to Friday 9am to 8pm, Saturday and Sunday 11am to 4pm.

Website: www.nhs.uk/smokefree

Live Through This

A cancer support and advocacy charity for the LGBTIQ+ community.

Email: contact@livethroughthis.co.uk

Website: <https://livethroughthis.co.uk>

Lymphoma Action

Lymphoma Action is the UK's only charity dedicated to lymphoma, providing in-depth, expert information for 35 years, helping thousands of people affected by lymphoma. Their mission is to make sure no one faces lymphoma alone. Get in touch Monday to Friday 10am-3pm by:

- Calling freephone **0808 808 5555** (press Option 1 for helpline)
- Using the Live Chat window in the bottom right of the screen via their website www.lymphoma-action.org.uk
- Emailing information@lymphoma-action.org.uk

Hotel Bexley Wing

The hotel is located on the 8th floor of Bexley Wing and offers 19 twin rooms and 1 single room. All have en-suite, tea and coffee making facilities, a mini-fridge, towels, hairdryer and digital television. There are two rooms with wheelchair access and a wet room.

Patients are able to stay free of charge. There is a charge for relatives if they are staying in their own room.

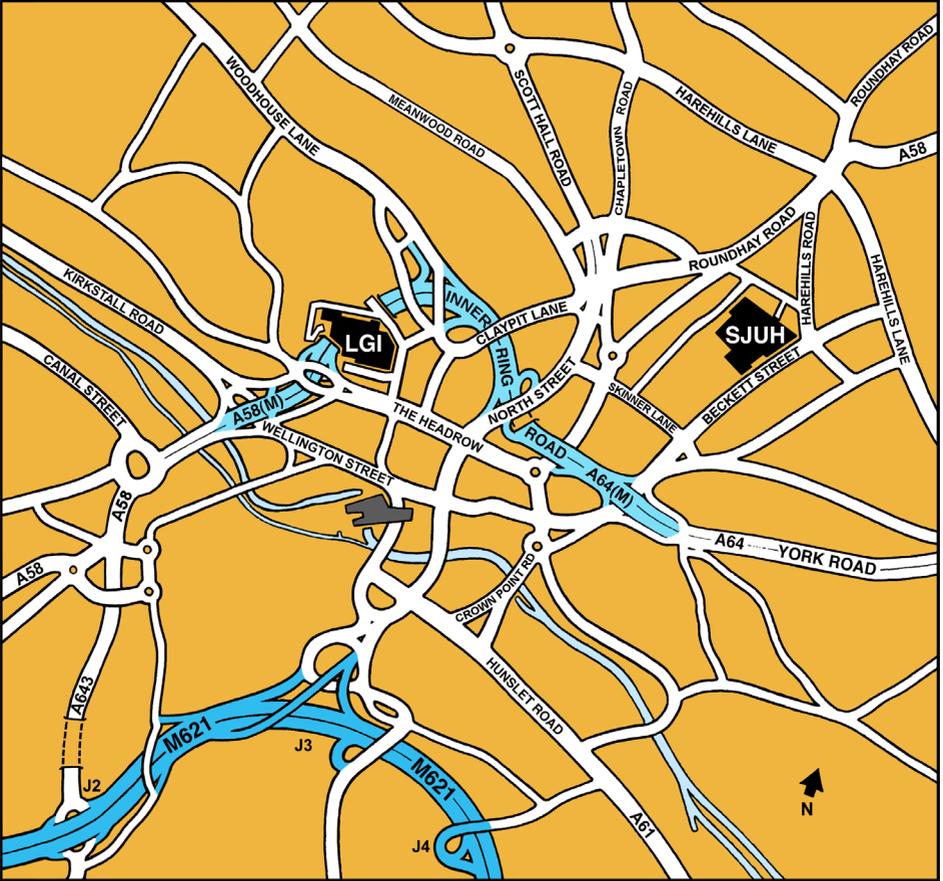
Meals can be purchased (at breakfast and lunch) if you are able to make your way to the restaurant in the Bexley atrium. At other times you will need to have something you have brought from home or purchased. There is a very small fridge for your personal use. **There are no staff after 4pm until the next morning** in this facility.

For further details please contact the Hotel Co-ordinator on **0113 206 7687**. Out of hours please contact the Non-Surgical Oncology Nurse Practitioner through main switch board on **0113 243 3144**.

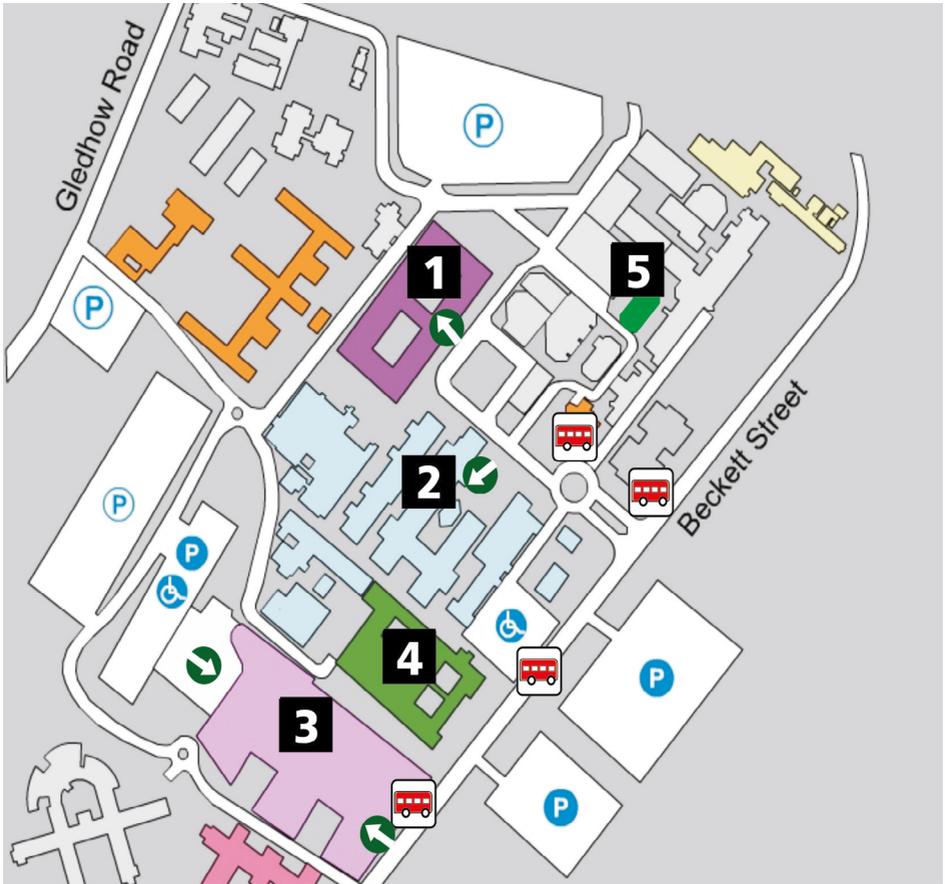
Car Parking

When you are coming for radiotherapy planning and treatment your parking is **free** in the on-site multi-storey car park. Please ask for more information at the radiotherapy main reception desk.

How to find us



St James's University Hospital - site plan



- 1** Gledhow Wing
- 2** Lincoln Wing
- 3** Bexley Wing
- 4** Chancellors Wing
- 5** Robert Ogden Centre

-  Entrances
-  Visitor parking
-  Disabled parking
-  Staff parking
-  Bus stops



What did you think of your care?

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Your views matter



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