

Radiotherapy for Thyroid eye disease

Information for patients



Leeds Cancer
Centre

This leaflet aims to help you and your family understand more about your radiotherapy 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 radiotherapy.

Their team will be caring for you during your treatment. This team will include radiographers and nurses. The 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 the 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 Tel: 0113 206 8940.

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

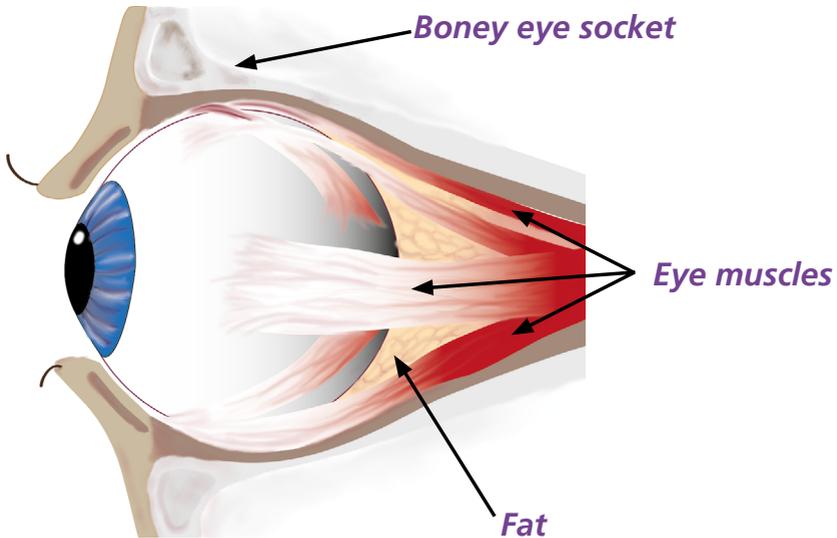
What is thyroid eye disease?

Thyroid eye disease is a benign condition (non-cancerous).

It can develop if you have an overactive thyroid. It can start before your thyroid becomes overactive or after treatment of your thyroid.

Thyroid eye disease is caused by swelling and inflammation of the fat and muscles behind your eye. In severe cases, the eye is pushed forward making it difficult for the eye to close properly and sometimes causing double vision.

In the very worst cases, your eyesight may be affected. This is caused by drying out of the front of the eye (cornea) or pressure on the optic nerve which carries messages from the eye to the brain.



The eye from the side showing the muscles and fatty tissue

What is radiotherapy?

Radiotherapy is the use of high energy X-rays and can be used to treat certain benign conditions such as thyroid eye disease. The radiotherapy dose to treat thyroid eye disease is much lower than the doses needed to treat cancer. You do not feel anything with radiotherapy 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 will have your radiotherapy on a treatment machine called a Linear Accelerator as shown here in photograph.

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



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 during your treatment please speak to a member of staff. This will not affect your treatment or care.

Others involved in your care

You may meet other staff whilst you are coming for radiotherapy. Everyone you meet will introduce themselves, tell you their job title and explain the role they have in your care.

Important advice before your treatment

Pregnancy

It is very important that patients of childbearing potential are not pregnant and that they **do not become pregnant** while having 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 (again, please note your condition is non-cancerous). Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Treating thyroid eye disease

Radiotherapy can reduce the cells which cause the inflammation and so reduce the swelling behind the eye. The time taken for you to notice an improvement from thyroid eye disease can vary. It may take up to a year for you to notice the full effect.

You will have ten radiotherapy treatments given over two weeks. Treatment is normally given daily, Monday to Friday, however your treatment may start on any day of the week. Whenever possible you will be treated at the time of day that suits you, but this cannot always be arranged or guaranteed. 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.

Radiotherapy for thyroid eye disease is more effective if you are a non-smoker. If you do smoke, your radiotherapy will work better if you stop smoking before your treatment starts.

Your oncologist may prescribe a course of steroids (oral prednisolone) just before you start your course of radiotherapy. Taking prednisolone may help make the radiotherapy more effective.

Please read the information leaflet enclosed with any medications, this will explain any side-effects you may experience when taking them. If you are at all concerned about any side-effects you are experiencing please talk to your pharmacist, nurse specialist or GP.

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.

Some tests and scans will be needed to help plan your treatment. We will explain which of these you will need when your appointment is made. 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 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 the first visit can be quite lengthy.

Mould room

Radiotherapy involves exact positioning of the radiation beam, so you will need to stay very still while you are having treatment. To help you stay still for your treatment we will make a mask for your head. You will wear your mask for your planning scan and treatments.

For the mask you will be given an appointment to attend the mould room where the masks are made.

If you have any concerns about the mask we have a support team available to help you. Please tell your clinical oncologist or clinical nurse specialist who will contact them.

Alternatively you can ring them on **0113 206 7616** or email: leedsth-tr.rtpatientsupport@nhs.net.

There is also a leaflet available, called '**Having a radiotherapy mask made**'.

If you would like a copy please ask your consultant or contact the radiotherapy information lounge on **0113 2067603**.

Your planning scan

In order to plan your treatment you will have a CT scan wearing your mask. This is done on a machine called a CT Scanner, shown here in the photograph. It allows the images from the scan to be sent to the radiotherapy computer planning system. There will be several members of staff present at your scan. These will include therapeutic radiographers, and possibly a mould room technician and a dosimetrist (the person who will produce the computer plan for your treatment).

The scan will be taken with you lying in the same position as for your treatment. The radiographers will draw some marks on the mask, to be used as a reference for your treatment.

You will then be scanned, which will only take a few minutes.

Planning scans are not diagnostic examinations and will not be reported on as such.

Following the scan the radiographers will give you the time of your first appointment on the treatment machine, which is most likely to be a couple of weeks after the planning visit. The radiographers will talk to you about any further appointments you have.



Having your treatment

When you arrive for your treatment you should go to the main radiotherapy reception desk at the entrance of the radiotherapy department. On the first occasion you will be given all your appointments and 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 usually given Monday to Friday however your treatment may start on any day of the week. Whenever possible you will be treated at a time of day that suits you, but this cannot always be arranged or guaranteed. 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 may need to partly undress, the radiographers discuss this with you when you first attend the department.

The radiographers will position you, adjust the treatment couch and machine to the correct positions. For the first few treatments we will also take images to check the accuracy of the treatment which will take a few more minutes.

These images do not monitor your condition but are purely for treatment accuracy.

You will be asked to stay as still as possible during the treatment but you should breathe and swallow normally. Once you are in the correct position the radiographers will leave the room to switch on the machine. You will only be alone for a few moments at a time. The radiographers will be watching you on a closed circuit TV (CCTV) monitor during treatment. The CCTV camera is not recording or saving any images. There is also an intercom system so the radiographers can talk to you. If you would like to listen to music during your treatment, please let us know.

The treatment only takes a few minutes but you will be in the treatment room for about 10-20 minutes. The machine stops automatically after your prescribed dose of treatment has been given. The radiographers can stop the machine at any time if needed. The treatment machine makes a buzzing sound when switched on. You do not feel anything. The radiographers may need to come in and out part way through each treatment. After the treatment is complete the radiographers will come back into the room and help you off the couch.



During the treatment course, please tell the radiographers how you are feeling. If you have any problems or questions, please let them know. The radiographers will monitor any side-effects you may be experiencing and offer advice in managing these. Your clinical oncologist, or a member of their team, will see you in the Princess Royal Suite towards the end of your treatment. You can expect to be in the department longer on this day.

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.

Your treatments will generally be on the same machine, although there may be days when this machine is being serviced and your treatment will be in a different room.

Your appointments for radiotherapy may not be at the same time each day and are subject to change. It is possible that during your course of radiotherapy you may miss a treatment due to unplanned machine maintenance or bank holidays. It is therefore important to speak to a health care professional before booking a holiday immediately following your radiotherapy.

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.

Side-effects

Side-effects can be divided into short term (acute) effects that happen during or soon after your treatment, and long term effects occurring months or years later. Some side-effects are common, whilst others are rare. In general radiotherapy only causes side-effects in the area being treated. Your doctor will discuss possible side-effects with you.

The side-effects listed here are a general guide, some may not apply to you. Please feel free to discuss this further with your doctor when you consent for the radiotherapy treatment.

Short term side-effects from radiotherapy

Most short term side-effects are temporary. Side-effects tend to build up from about the second week of treatment and will be at their worst at the end or just after the treatment course. They generally last a number of weeks or months after the treatment has finished.

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.

Skin reaction

The skin in the treated area starts to redden or darken about 10 days after the start of radiotherapy treatment. It may become dry and itchy.

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

Before you start your treatment, a radiographer will explain what could happen to your skin and how to look after it. They will also give you a leaflet to take home. If you are concerned about your skin reaction please talk to your radiographers or contact the review clinic nursing staff in the Princess Royal Suite, telephone: **0113 206 7587**.

Thyroid eye disease symptoms

These symptoms may get worse with radiotherapy but taking steroid tablets during your course of radiotherapy reduces this risk. Please read the information leaflet enclosed with any medications, this will explain any side-effects you may experience when taking them. If you are at all concerned about any side-effects you are experiencing please talk to your pharmacist, nurse specialist or GP.

Hair loss

You may lose patches of hair in areas receiving treatment, for example, the tip of the eyebrows or the edge of the scalp.

Hair loss is not common and usually grows back after the treatment finishes.

Late side-effects

Some side-effects do not show whilst you are having your radiotherapy but may develop months or even years later. These are not common.

Although we plan your treatment carefully to avoid treating the lenses of the eyes, there is a very small risk of cataracts developing in later years. These are easily treated.

There is a small risk of developing dry eyes in the long term.

There is an extremely small increased risk of cancer developing in the area treated. This is due to the radiation received by the normal tissues. This extremely small risk should be compared with the likely benefits of the treatment.

There is a very small risk of changes in the back of the eye (retina). This is more likely if you are diabetic or have high blood pressure.

What happens after my radiotherapy?

You will be seen about six to eight weeks after your treatment has finished by your oncologist. It may be possible to have this consultation over the telephone. After this appointment you will continue under the care of the ophthalmology team who will consider the need for any other treatments.

National organisations

British Thyroid Association

Website: www.british-thyroid-association.org

Thyroid Eye Disease Charitable Trust

National Help Line: 07469 921 782

Email: info@tedct.co.uk

Website: www.tedct.co.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

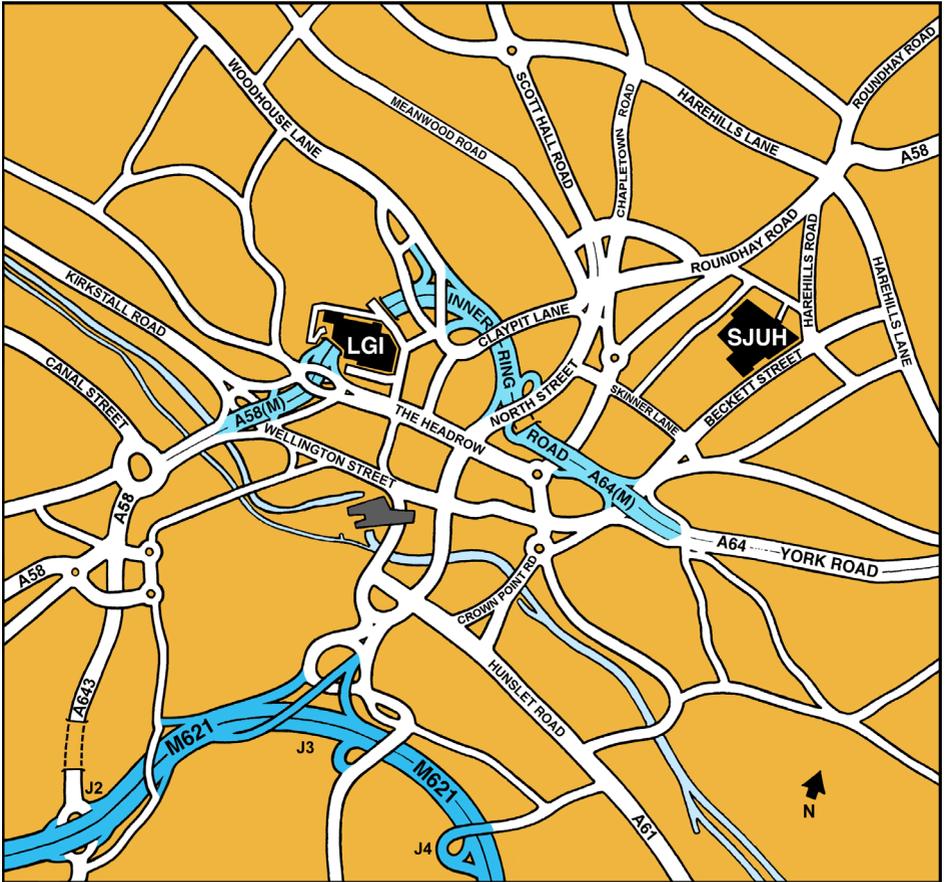
Car Parking

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.

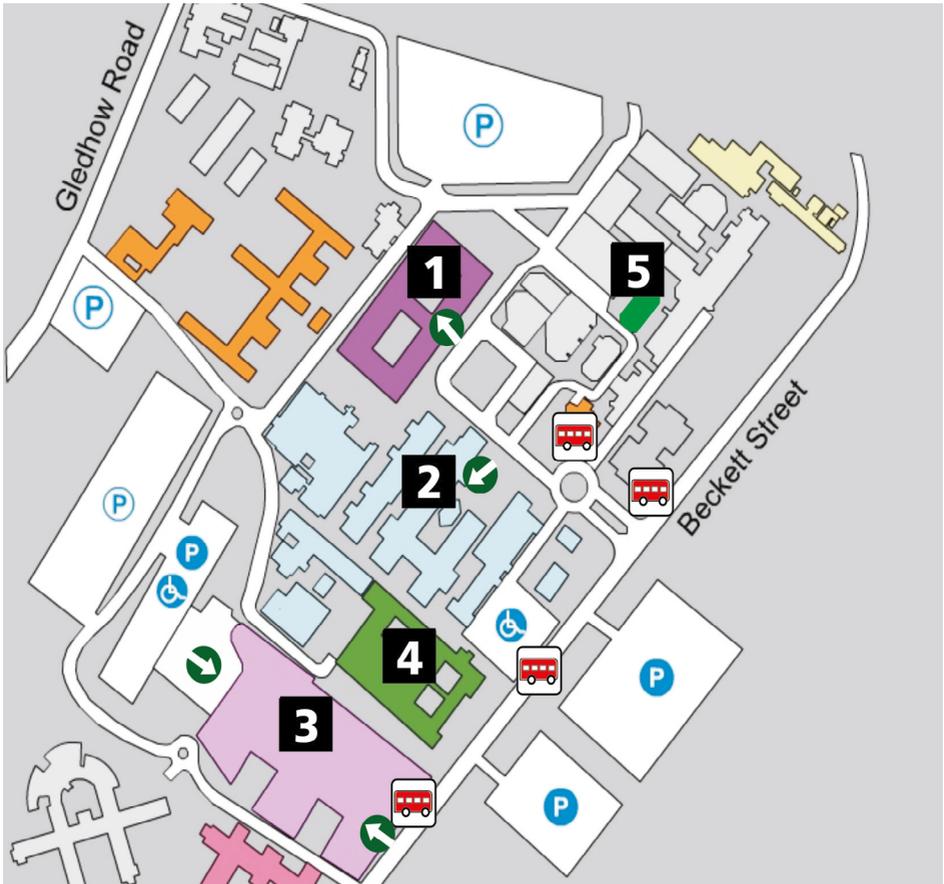
Refreshments

A restaurant is available serving drinks, light snacks and hot meals. There is also a Café for hot drinks and light snacks; both these are on Level 0. Vending machines are also available on Level -2, Level 0 and Level 1. There is also a shop on Level 0 with books, papers and snacks.

How to find us

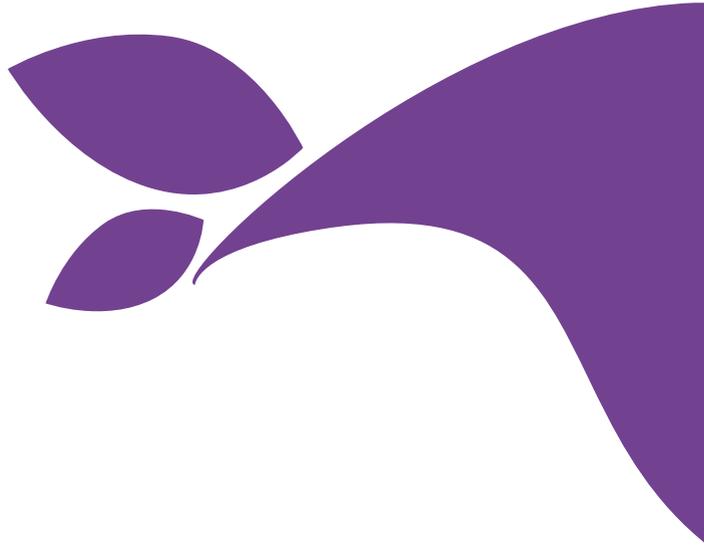


St James's University Hospital - site plan



- 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



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