Radiotherapy for Thyroid eye disease

Information for patients
This leaflet aims to help you and your family understand more about your 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 may 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 hear any words or phrases that you do not understand, please ask your doctor or a member of your healthcare team what it means. It does not matter how many times you ask.

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).

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, throughout your treatment course.

If you would like to visit the radiotherapy department before your treatment starts please call 0113 206 7603 to arrange a time. This visit can be very useful as you can find out more information about radiotherapy. It is a good opportunity to visit the hospital and tour the simulators and treatment areas. You will also have the opportunity to ask questions.

Radiotherapy is given by male and female therapeutic radiographers. You will see your radiographers at each treatment session and they will be happy to answer any questions you may have.

Students

Leeds Cancer Centre radiotherapy department is a training centre for male and female 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.

Pregnancy

It is important that women do not become pregnant while having radiotherapy because it can have an effect on the unborn child. It is suggested that you use a barrier form of contraception (e.g. condoms).
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, e.g. 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

Planning clinic and consent
Your first appointment will be with the doctor in clinic. You will see your clinical oncologist or a member of their team who will discuss your treatment with you. They will explain all about your treatment and its side-effects. If you wish to go ahead with the treatment, you will be asked to sign a form giving your consent to treatment. It is a good idea to bring a list of any questions you may have and an up-to-date list of all your medication with you to this appointment.

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 be given an appointment to attend Mould Room where the masks are made.

What is a mask?
The mask is made of thermoplastic material, shown here in the picture.

When heated in warm water (bath temperature) the thermoplastic sheet softens.

You will be asked to lie in the position that you will be in for your treatment. The warm thermoplastic sheet is then placed over your head and gently moulded to your shape. It gradually hardens in a few minutes and is then lifted off your face.
There are holes for your mouth and nose, so you will be able to breathe normally. If you have any concerns about the mask, please let your clinical oncologist or a member of their team know. We have a support team who will help you.

**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 Simulator, shown here in the photograph. This is a CT scanner that allows the images to be sent to the radiotherapy computer planning system. There will be several members of staff present at your scan. These may include therapy radiographers, a mould room technician and a dosimetrist (the person who will produce the computer plan for your treatment).
Having your treatment

You will have your radiotherapy on a machine called a Linear Accelerator, shown here in the picture.

When you arrive for your first appointment, a radiographer will explain all that will happen during your course of treatment and about any side-effects you may experience and how to manage these. You will be given a full list of all your appointments. It may be a good idea to bring a list of any questions you have for the radiographer to answer.

You can expect to spend about 10-20 minutes each day in the treatment room. The treatment machine is only switched on for a fraction of this time. For most of the time the radiographers are carefully positioning you and the machine.

The radiographers will help you onto the treatment couch and place your mask in position. They move the couch and the machine to accurately direct the treatment. The machine does not touch you. It is important for you to stay as still as possible but to breathe 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 minutes at a time. The radiographers will 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 the radiographers can talk to you.

An image will be taken to compare with the planning scan to make sure that the treatment will be delivered exactly as we have planned.

A team of radiographers work together in the treatment room. You will hear them giving each other instructions and information relating to your treatment.

Treatment only takes a few minutes. The treatment machine makes a low buzzing noise when switched on. This is the only way that you know that the machine is on. You will not feel anything.
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.

Some days the radiotherapy department may be very busy and your appointment time may be delayed. We will keep you informed of any delays, please see the signs in the waiting rooms.

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.

Please telephone the radiotherapy reception desk on 0113 206 8940 for further advice.
Side-effects

Side-effects can be divided into short term effects that happen during or soon after your treatment, and long term side-effects occurring months or years later. Some side-effects are common, whilst others are rare. The part of your body being treated and the dose of radiotherapy given will affect which side-effects may happen to you. 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.

Short term side-effects from radiotherapy

Most short term side-effects are temporary. These side-effects tend to build up from the second week of treatment, and may worsen for a short time after the treatment has finished. They usually settle down within four to six weeks of the treatment finishing. Please tell us how you are feeling, particularly if you have symptoms or concerns, so that we can advise and treat you.

Tiredness/fatigue

Radiotherapy can make you feel more tired than usual, especially if you have to travel a long way for treatment each day. You should try to ‘pace’ yourself, listen to what your body is telling you and rest if you need to. Keeping active has been shown to minimise the effects of fatigue. There is a Macmillan information leaflet available called ‘Coping with fatigue’, please ask a member of staff if you would like a copy.
Skin reaction
Around the second week after you start treatment you may notice changes to the skin in the area being treated. Before you go in for your treatment the radiographer will explain what will happen to your skin and how to look after it. They will also give you a leaflet to take home. The same will happen at the end of your treatment.

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.
Research at Leeds Cancer Centre

Leeds Cancer Centre is a major centre for cancer research. You may be asked if you would like to take part in clinical studies or trials linked to your condition. You do not have to take part in any trials, unless you wish to do so. If you do not wish to take part in a trial your treatment will not be affected in any way. If you do take part in a clinical trial you may meet a research nurse or radiographer, helping to run the trial.

National organisations

British Thyroid Association

Web: www.british-thyroid-association.org

Thyroid Eye Disease Charitable Trust

National Help Line: 07469 921 782
Email: info@tedct.co.uk
Web: www.tedct.co.uk
Stopping smoking

One You Leeds
Tel: 0800 169 4219
Web: www.oneyouleeds.org.uk

NHS Smokefree
Tel: 0300 123 1044
Web: www.smokefree.nhs.uk

Car Parking

*Parking for radiotherapy planning and treatment is free.*

- On entering the car park take a ticket and park as usual (disabled parking spaces are on Level 0).
- When exiting use the left hand lane next to the ticket office. Take your parking ticket and appointment letter to the attendant.
- They will process your ticket so that when you insert it at the barrier no charge will be made.
- If you need assistance or are unable to leave your car please press the button on the barrier.