External Beam Radiotherapy for Thyroid Cancer

Information for patients
This leaflet aims to help you and your family understand more about your external beam radiotherapy.

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). Their team will be caring for you during your treatment. This team may include radiographers, nurses, social workers, physiotherapists, occupational therapists, dietitians, and speech and language therapists.

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.
External Beam Radiotherapy (EBR)

This type of radiotherapy is used less often than radioiodine (internal radiotherapy) for treating thyroid cancer. It is more commonly used for medullary or anaplastic thyroid cancer. It can be used to destroy any cancer cells that do not take up and respond to radioiodine. If you want information about radioiodine please ask for a leaflet.

EBR (commonly called radiotherapy) is the use of high energy X-rays to treat cancer. The organs and tissues of the body are made up of tiny building blocks called cells. Radiotherapy causes physical and chemical damage to the cancer cells in the treated area. Although normal cells are also affected, they can repair themselves and are able to recover. Radiotherapy is carefully controlled high energy X-rays targeted at the neck and delivered by a radiotherapy machine shown here in the picture. This type of radiotherapy is a local treatment. This means it only affects the part of the body that is treated.

When you have radiotherapy you do not feel anything and it will not make you radioactive unlike radioiodine. It is perfectly safe for you to be with other people, including children, throughout your radiotherapy.
Therapy Radiographers

Radiotherapy is given by male and female therapeutic radiographers 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.

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.

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

Students

The radiotherapy department is a training centre for male and female radiographers. Students may be present on the treatment units, and 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 cancer treatment because the radiotherapy and chemotherapy can have an effect on the unborn child. It is suggested that you use a barrier form of contraception (e.g. condoms). 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. You will be contacted by phone, with an appointment for your radiotherapy planning session. This will include an appointment for the mould room.

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 wish to go ahead with the treatment and you have not consented for your radiotherapy treatment in another hospital, this will be completed at this visit. You will be asked to sign a form giving your consent to treatment.

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).
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 we make a mask for your head and shoulders. You will wear your mask for your planning scan and treatments. Radiotherapy positioning marks are drawn on the mask instead of your skin.

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. You can email them on leedsth-tr.RTpatientsupport@nhs.net

There is a leaflet available. If you would like a copy please ask your consultant or contact the Radiotherapy Information Lounge on: 0113 206 7603.

Your planning scan
In order to plan your treatment you will have a CT scan. This is done on a machine called a CT Simulator, shown in the photograph on the next page. 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).
Contrast (dye)

A special contrast agent, often called a dye, may be used for your scan to make specific organs, blood vessels and/or tissue types ‘stand out’. This can make it easier for the doctor to plan your treatment.

The dye is given through a small needle into a vein in your arm. You should tell the radiographer if you have any allergies, but they will go over this before they use any dye.

The most common side-effects of the dye are:

- warm or hot “flushed” sensation during the injection;
- a “metallic” taste in the mouth, which usually lasts less than a minute or so;
- You may also feel as if you have passed urine. This will pass very quickly and it should cause no ill effects.
There is a slight risk of an allergic reaction to the injection, such as a skin rash, but it may lead to other significant complications. The doctors in the radiotherapy department are trained to deal with any complications and again the risk involved is very small. You will be able to drive your car or go to work after your scan. The radiographers will advise you about drinking plenty of fluids after your injection.

The scan will be taken with you lying in the same position as for your treatment. The radiographers will draw some marks onto your mask and skin, to be used as a reference for your treatment. You will then be scanned, which will only take a few minutes and at the end of the scan the skin mark will be replaced by a small tattoo, (shown here in the picture).

These marks help us to reproduce your treatment with accuracy each day. It also means that you can wash without worrying about your marks coming off.

Following the scan you will receive the times of your first appointments on the treatment machine; this may be in a few days or weeks’ time. The radiographers will talk to you about any further appointments you have.
Coming for treatment

When you arrive for your treatment you should go to the reception at the entrance of the radiotherapy department.

You will be given directions to your treatment machine. The radiographers will explain what will happen and answer any questions that you may have. The number of treatments you will be having will be confirmed and you will be given a list with all the appointments you need.

Treatment is normally given daily, Monday to Friday over 2-7 weeks. 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.
Your radiotherapy treatment

The radiographers will take images to check your treatment position before giving you your first radiotherapy treatment. You may need more routine images taking during the course of your radiotherapy. Treatment times vary from 10-15 minutes each day depending on the type of treatment you are having. The treatment machine is only switched on for a fraction of this time. For most of the time the radiographers are carefully placing you and the machine in the correct position for your treatment.

The machine will move around you but does not touch you. 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. The radiographers will be watching you on a closed circuit TV monitor (CCTV) 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. Please let the radiographers know if you would like to use the intercom system.

We also have a patient buzzer available which you can hold in your hand, if you press this the radiographers will know to come back in the room to see if you are ok.

Although you have to lie still, you can breathe and swallow normally during your treatment. The machine stops automatically after your prescribed dose of treatment has been given. The machine can also be stopped at any time if needed. The treatment machines make a buzzing sound when they are switched on, you do 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.

Your clinical oncologist, or a member of the radiotherapy team will see you once a week in the radiotherapy review clinic to see how you are getting on. They will also monitor any side-effects you may be experiencing. You can expect to be in the department longer than usual 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 information screens or notices in the waiting areas.

We have a patient bleep that you can take if there is a wait so you can go for a drink or walk around the radiotherapy gardens and we can bleep you when it’s coming up to your turn.
Your appointments for radiotherapy may not be all at the same time each day and are subject to change. It is also possible that during your course of treatment you may miss a day's treatment due to machine maintenance or bank holidays. It is therefore important to speak to a health care professional before booking a holiday immediately following your radiotherapy.

For appointment queries please telephone the Radiotherapy Reception Desk on 0113 206 8940 for further advice.

**Side-effects**

As your treatment progresses you may experience some side-effects. Not everyone will experience all of these reactions.

If you do experience any of the following side-effects, do not worry, they are normal reactions to treatment and are temporary. They usually begin about half way through the course of treatment, may last for several weeks after it has finished and then slowly settle down. Please tell us how you are feeling, particularly if your symptoms worsen, so that we can advise and treat you.

**Sore throat**

Radiotherapy tends to make the inside of your throat quite sore. You will notice this happening about 14 days from the beginning of treatment. Painkillers can be prescribed to help this. You are more likely to get throat infections (e.g. thrush). It is therefore very important to keep your mouth and throat clean. You will be given advice about this.

It is also very important to stop smoking if you are a smoker. Smoking makes the soreness in your throat much worse, as well as slowing down the healing process. Advice and help is available, please ask a member of your hospital team.
Taste changes
You may notice that your sense of taste alters during your treatment and gradually returns to normal over 6 to 12 months.

Eating problems
It may be difficult to swallow whilst your throat is sore. Recovery is better if you eat well during your treatment and if weight loss is kept to a minimum. The dietitian will advise you on how to cope with this. It is important you report any difficulties as soon as they occur. Occasionally patients can develop swallowing problems years after radiotherapy.

Dryness of the mouth and throat
Some of your salivary glands may be affected by the radiotherapy. Soon after the start of radiotherapy your saliva may become thick and sticky and your throat may feel dry.

Usually this gets better with time. Occasionally a dry mouth is permanent. You may find it helpful to carry a small bottle of water or chew sugar free gum. Artificial saliva spray or lozenges may help. If a dry mouth continues to be problem your doctor can prescribe a drug called Pilocarpine which stimulates saliva. If you have a dry mouth and have your own teeth, your teeth will need extra care to prevent decay. You should see a dentist before radiotherapy and six monthly after the radiotherapy.

Loss of voice
Your voice may become hoarse, due to inflammation around your vocal cords. Sometimes patients can develop hoarseness several weeks after finishing radiotherapy. It usually recovers two to three months after finishing radiotherapy.
Skin reaction
10 to 12 days after starting your treatment, the skin where you are having your treatment may change. The radiographers will discuss this with you when you start treatment and explain how to look after your skin. They will give you a leaflet to take home.

Another leaflet will give you information on how to care for your skin after your radiotherapy. The radiographers will talk to you at the end of your treatment about what happens next and will give you this leaflet when you have finished your course of treatment.

If you are concerned about your skin reaction please talk to your radiographers or contact the nursing staff in Princess Royal Suite on 0113 206 7587.

Hair loss
Two weeks after the start of radiotherapy you may notice a small amount of hair loss in the nape of your neck. It will slowly regrow back to normal after treatment.

Tingling sensations
This rarely happens after radiotherapy. Occasionally tingling sensations down your spine and arms can develop several weeks after radiotherapy and disappear spontaneously.
Tiredness (fatigue)
Radiotherapy can make you feel more tired than usual, especially if you have to travel a long way for treatment each day. Fatigue usually improves between six months to a year after treatment. Some people find that fatigue can last longer, up to two years or more. There are things you can do to help yourself:

- 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 ask for help with other tasks;
- Little and often is the rule of thumb.

There is a Macmillan information leaflet available. If you would like a copy, or support with your fatigue please ask a member of staff.

Refreshments
There is a restaurant and coffee shop available on Level 0, which are open daily. They serve drinks, light snacks and hot meals. Vending machines are also available in the main radiotherapy waiting room and Level 0. There is also a shop on Level 0 with books, papers and snacks.
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 the car park 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.

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. Your treatment will not be affected in any way if you do not wish to take part in a trial. 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.
Useful addresses for support and information

Leeds Cancer Support
Leeds Cancer Support is here to help you and your family. We aim to offer high quality information, advice and support, to patients, families and friends. The two information lounges both open Monday - Friday. They are situated on:

Level -2 Radiotherapy Department
Tel: 0113 206 7603  8am to 6pm.

Level 1 Oncology Outpatients Unit
Tel: 0113 206 8816  10am to 4pm.

The Sir Robert Ogden Macmillan Centre
The centre provides an environment where patients and their families can drop in for a drink, take some time out, or just chat. The centre also offers a variety of support services including counselling, support groups and complementary therapies.

The Sir Robert Ogden Macmillan Centre
St James’s University Hospital, Beckett Street, Leeds LS9 7TF
Tel: 0113 206 6499 between 10am-4pm Monday to Friday for information.

More details are also available from the information lounges. Leeds Cancer Support Services mentioned above can be contacted by email on: leedsth-tr.Cancersupport@nhs.net
Macmillan Cancer Support
Freephone 0808 808 0000, 9am to 6pm Monday to Friday. A textphone service for deaf and hard of hearing people is available on: 10800 0808 808 0000
www.macmillan.org.uk

Cancer Research UK
www.cancerresearchuk.org

Thyroid cancer groups

**Butterfly Thyroid Cancer Trust UK**
This is a voluntary support group for patients affected by thyroid cancer based in Newcastle. It is a patient-led group and they are happy to receive calls and emails from Leeds patients.

Tel: 01207 545469 www.butterfly.org.uk

**The British Thyroid Foundation**
This group deals mainly with patients that are hypo-thyroid and hyperthyroid. We advise asking to speak to the thyroid cancer expert for information and support.

Tel: 01423 810093 www.btf-thyroid.org

**AMEND (Association for Multiple Endocrine Neoplasia Disorders)**
Support group for patients with medullary thyroid cancer

31 Pennington Place, Southborough, Kent, TN4 0AQ
Tel 01892 516076 email: info@amend.org.uk