Radiotherapy for Sarcoma of the Limb

Information for patients
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 the Leeds Soft Tissue Sarcoma Team.

During radiotherapy you will be supported by radiographers, radiotherapy specialist nurses, social workers, and occupational 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 sarcoma 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 a member of the 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).

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 organs and tissues of the body are made up of tiny building blocks called cells. Radiotherapy causes 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 a local treatment. This means it only affects the part of the body that is treated.

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.

You will have your radiotherapy on a treatment machine called a Linear Accelerator as shown above.

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.’
Therapeutic 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.

Students
The radiotherapy department is a training centre for male and female radiographers. Students may be present on the treatment units. However, 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 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 (for example 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.

Fertility preservation
Sometimes, for male patients, treatment may involve some unavoidable radiotherapy dose to the testicles. This may permanently affect sperm production and fertility (ability to father children). If there is a possibility this may happen, your clinical oncologist will discuss this with you.

Further information about sperm storage can be found at: http://www.leedsfertilityclinic.co.uk/
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. Some tests and scans may 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 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).

Radiotherapy involves the careful positioning of the radiation beam to ensure accurate treatment delivery. There are many different things we have to consider when deciding upon the best treatment position for you. We need to make sure other parts of your body are not in the way, also to ensure the treated area is kept very still and that you are as comfortable as possible.
Here are two examples of custom made equipment.
Photo (a) shows how we keep joints still during treatment, whereas photo (b) shows how we support the whole limb using a bean bag.

When you arrive for your planning appointment, the radiographers will explain to you which piece of equipment may be best for your position and comfort.
The radiographers will then draw some marks onto your 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 these marks will be replaced by permanent marks, with your permission.

These marks are no bigger than a freckle and will be used each day for your treatment.

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

When your planning is completed you will be able to start your treatment, this will, most likely, be in approximately two weeks’ time. The radiographers will talk to you about any further appointments you have.

Some sarcomas will be treated with chemotherapy given at the same time as radiotherapy. Your oncologist will inform you if this is the case and you will be given further information. The radiotherapy department and the chemotherapy day unit work together to arrange your appointments.
Having your treatment

A course of treatment may last 2-6 weeks. 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 however your treatment may start on any day of the week. Treatment times vary from 10-20 minutes each day depending on the type of treatment you are having. 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.

Although you have the small permanent marks on your skin, the radiographers may need to draw around them each time you come for treatment. This is part of the quality checking procedure for your treatment. If you have pen marks on your skin you may prefer to wear older clothing as the marks may discolour fabric. It is also generally advisable to wear loose clothing around the treated area.
Once you are in the correct position (the same as when you came for your ‘planning’) 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 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.

The radiographers will take images to check your treatment position before giving you your first radiotherapy treatment. You may need more routine images taken during the course of your radiotherapy. 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 in the correct position for your treatment. The machine will move around you but does not touch you.
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 regularly 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 these days.

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 in the waiting areas. There may be occasions when we are able to transfer you to another treatment machine to allow us to minimize your wait.

Your appointments for radiotherapy may not be at the same time each day and may need to change. Occasionally, you may miss a day’s treatment due to bank holidays or unavoidable machine maintenance. It is therefore important to speak to a health care professional before booking a holiday immediately following your radiotherapy.
Side-effects of treatment

Side-effects can be divided into short term (acute) 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. 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.
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:
• 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 others for help with other tasks.
• Little and often is the rule of thumb.

Try to continue with some of your normal routines and activities if possible. If you usually work you may find this can help maintain your mood but you may find it better to reduce your hours or take some time off.

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

The skin in the treated area starts to redden or darken from the second week of treatment. It may become dry and itchy. Sometimes later in treatment it may peel and become weepy. The skin reaction towards the end of treatment can look quite alarming. This is normal and will heal over a few weeks.

If you feel you must shave in the treatment area only use an electric razor with extreme care.

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.

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**.

**Anxiety and emotional support**

During treatment many people feel stressed, anxious, depressed and sometimes unable to cope. If you or your family feel that they need someone to talk to, we are able to offer help and advice. Please discuss any problems with your nurse, radiographer or doctor.
Late side-effects

The risk of late side-effects will be discussed with you before you consent to treatment, and are dependent upon the area treated. Please do not hesitate to ask any questions if you are worried about side-effects.

Stiffness of limbs and reduced mobility

The combination of surgery and radiotherapy may affect how the affected area can move. This may happen soon after, or develop over the months following treatment. It is important to continue to move the area as much as possible. You may need to see a physiotherapist to help with this. The treated area may not recover the full sensation and function that it had before. This will depend on the site and the operation you have had. This means that your problems will also vary and the physiotherapist will make an individual care plan for you.

Some of the common problems you may experience are:

- muscle weakness,
- muscle tightness,
- reduced joint movement and
- swelling.

Any combination of these may affect you in everyday activities. The aim of the physiotherapy is to restore your normal movement and activities as much as possible.
**Lymphoedema**

After surgery and radiotherapy for sarcoma of a limb you may develop lymphoedema. Lymphoedema is a swelling caused by a build-up of lymph fluid in the tissues. The lymphatic system is made up of lymphatic vessels that are rather like veins.

The lymph system drains the fluid away from the tissues and returns it back into the big blood vessels. Scarring of the tissues can develop because of treatment, and this can damage the lymph system which disrupts the movement of fluid out of the tissues.

If you notice any swelling around your treatment area, you need to tell your consultant, specialist nurse or physiotherapist. You will be referred to a team of nurses who will be able to help you to reduce and control the swelling.

**Secondary cancers**

As radiotherapy is an X-ray treatment, there is a very slight risk that it could cause a cancer to develop in the treatment area in the future. This risk is very small and is far outweighed by the benefits of its ability to prevent the sarcoma coming back in the future.

**Weakness of the bones**

There is a small risk of bones in the area being treated becoming weak and more likely to break. This can happen many years after treatment.
After treatment has finished

Your consultant or a member of their team will see you in the clinic of your local hospital or at Leeds Cancer Centre approximately six weeks after your treatment. You will then be seen every three months for the first year, four monthly for the second year, six monthly for the next five years then annually up until 10 years after treatment.

There is a risk that soft tissue sarcomas can spread to other parts of your body. The main area where this could occur is in your lungs, so part of your follow up includes regular chest X-rays.

The doctor will also examine the area that has been treated at each appointment. It is important that you tell your consultant or specialist nurse if you see or feel any changes in the treated area such as a swelling or lump. You can also contact them if you have any other concerns or worries in between appointments.

Useful contact numbers

Main office administration  0113 206 8966
Sarcoma Nurse Specialist  0113 206 8902
                          0113 206 8988
                          0113 206 7646
Sarcoma Physiotherapist  0113 206 7992
Macmillan Specialist Radiographer  0113 206 7616
Dr Turner (Secretary)  0113 206 7406
Dr Dickinson (Secretary)  0113 206 7406
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

The Centre is on the St James’s Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime. Open from 10am - 4pm Monday to Friday.

Contact numbers for Leeds Cancer Support

Information Centre Level 1 Outpatients Department
Open from 10am - 4pm. 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 10am - 4pm. Tel: (0113 )206 6498

All the above services can be emailed on:
leedsth-tr.cancersupport@nhs.net
Useful Organisations

Macmillan Cancer Support
Freephone **0808 808 0000**, 9am to 6pm Monday to Friday A textphone service is available for deaf and hard of hearing people on **108001 0808 808 0000**. Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

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

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.