NHS
The Leeds Teaching Hospitals
NHS Trust

Radiotherapy for Sarcoma of the Limb

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 and the Leeds Soft Tissue Sarcoma Team.

Their team will be caring for you during your treatment. This team includes therapeutic radiographers and clinical nurse specialists but may also include physiotherapists 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 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 telephone: 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 to treat cancer. 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.

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.

It is perfectly safe for you to be around 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 above.

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 and ask questions.

Patient quote:

"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. They 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.

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 who could become pregnant, are not pregnant at the start of their radiotherapy course. Also, patients should not become pregnant during their radiotherapy treatment. This is because 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' (LN003721)** leaflet.

Please scan or click the QR code or visit:

https://www.leedsth.nhs.uk/patients/resources/contraception-and-pregnancy-during-cancer-treatment/

Please do not hesitate to ask your doctor or nurse if you have any questions or concerns about these issues.

Fertility preservation

Sometimes, 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:
https://carefertility.com/

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. Directions to the hospital and transport arrangements will be discussed with you at this point.

If you haven't signed a consent form yet, you may also need to see the consultant at this planning appointment. This is an ideal opportunity for you to ask questions.

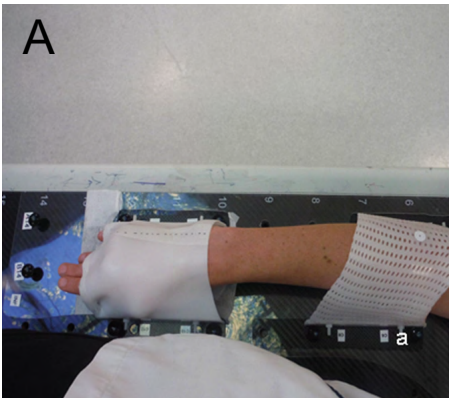
What to bring with you:

- 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. We also need 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.



At your planning appointment, the radiographers will explain to you which piece of equipment may be best for your position and comfort.

Your planning scan

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

In order to plan your treatment you will have a planning scan on a CT scanner, as shown in the photograph.

It allows the images to be sent to the radiotherapy computer planning system. There will be several members of staff present at your scan.

These will include radiographers, clinical assistants, possibly a mould room technician and a dosimetrist (the person who produces the treatment plan).

The position that you are asked to lie in is to ensure that we can accurately deliver your treatment. There are various pieces of equipment that we may use to help you achieve the best position. It is important that you are as comfortable as possible during the planning procedure. You will also need to be in this same position for treatment. If you have difficulties with your mobility or with lying flat, please discuss this with your doctor. You may be given advice to take painkillers before your scan or treatment.

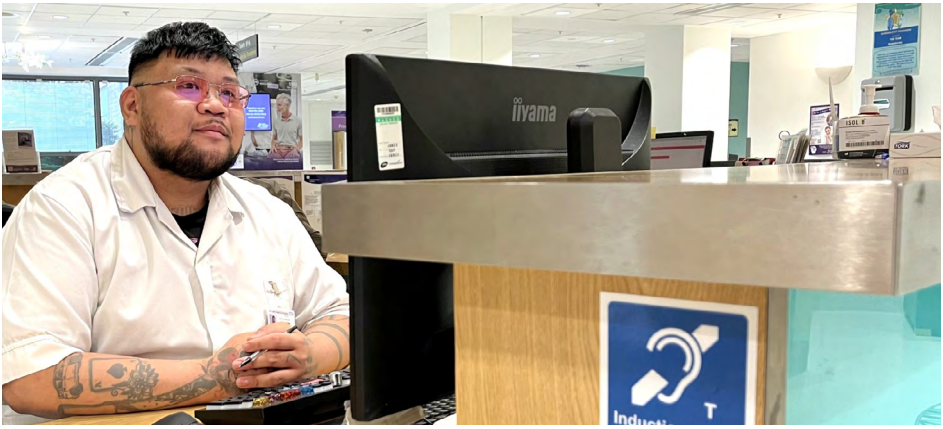
The radiographers will place some pen marks on your skin. At the end of the planning scan, the radiographers may ask to make permanent marks on your skin.

These are just one of many ways we can ensure that your position is the same every day. It also means that you can wash without the marks coming off.

Permanent mark next to 5 pence piece

Following the scan the radiographers will give you the time of your first appointment on the treatment machine. This 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. 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.

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 a list of all your appointments. You will then be escorted to the waiting area for your machine. The radiographers will explain what will happen and answer any questions that you may have.

A course of treatment may last between 2-6 weeks. Treatment is normally given daily, Monday to Friday however your treatment may start on any day of the week. 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.

You may need to undress and put on a gown; the radiographers discuss this with you when you first attend the department. The radiographers will position you, and adjust the treatment couch and machine to the correct positions.

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 minutes 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. 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.

For the first few treatments and also intermittently during treatment we will also take images to check the accuracy of the treatment. This will take a few more minutes.

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

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 over 30 minutes. Please see the delay boards in the waiting areas.

Your appointments for radiotherapy may not be at the same time each day and may need to change.

It is very important that you do not miss treatment days as it may affect the efficacy of your treatment.. 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 coordinators on your treatment unit.

For appointment queries please telephone the Radiotherapy Reception Desk on 0113 206 8940.
(Monday - Friday 08.00 - 18.00).

Side-effects

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)

Nearly all patients having radiotherapy will feel tired. Be prepared to take things easy during treatment and allow for extra rests. Try to continue with some of your normal routines and activities if possible.

Fatigue usually improves in the weeks to months after treatment.

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

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 may start to redden or darken around 10 days after starting your radiotherapy. It may become dry and itchy. For a very small number of patients, it may peel and become weepy. Avoid hair removal where possible, including shaving, waxing, cream and lasers unless advised otherwise by your consultant, nurse or radiographer.

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.

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**. (Monday - Friday 08.00 - 18.00).

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. They can refer you to other services if needed, for instance, benefits advice.

You should be given a 'key worker' as a contact for support through your treatment; this is usually your CNS.

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

Late side-effects

The risk of late side-effects will be discussed with you before you consent to treatment. It depends on the area that has been 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. 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. This can damage the lymph system, which results in a disruption of 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 cancer

When you have had radiotherapy there is a risk that cancer can develop in the treated area many years later. However, this risk is very small. It is far outweighed by the benefits of its ability to prevent the sarcoma from coming back in the future.

Weakness of the bones

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

Early arthritis

Radiation can affect tissues in the joints. If you have had radiotherapy to a limb, there is an increased risk of developing osteoarthritis and its symptoms.

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. In the second year it will be every four months. For the next five years it will be every six months, and then once a year up until ten 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. Please 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

Sarcoma Nurse Specialist

- Telephone: **0113 206 8902** (Monday - Friday 08.00 - 16.00).
  0113 206 8988 (Monday - Friday 08.00 - 16.00).
  0113 206 7646 (Monday - Friday 08.00 - 16.00).
  0113 206 8966 (Monday - Friday 08.00 - 16.00).

Sarcoma Physiotherapist

- Telephone: **0113 206 8117**
  (Monday, Wednesday and Friday 08.00 - 16.30).

Dr Sun and Dr Turner (Secretary)

- Telephone: **0113 206 7406** (Monday - Thursday 07.30 - 17.30).

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 (behind the Thackray Medical Museum).

The Sir Robert Ogden Macmillan Centre

The Centre is on the St James's Hospital site and offers a variety of support services including complementary and supportive therapies.

Contact numbers for Leeds Cancer Support

Information Lounge Level -2 Radiotherapy Department
Open from 8.00 am - 6.00 pm Telephone: **0113 206 7603**

Information Lounge Level 1 Outpatients Department
Open from 9.00 am - 4.00 pm Telephone: **0113 206 8816**

Sir Robert Ogden Macmillan Centre
Open from 9.00 am - 4.00 pm Telephone: **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 9.00 am - 5.00pm.
Telephone: **0113 457 8364**

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

Email: leeds@maggies.org
Website: www.maggies.org

National Support Organisations

Macmillan Cancer Support

Freephone: **0808 808 0000**, 8.00am to 8.00pm seven days a week.

A textphone service for deaf and hard of hearing people:
Textphone: **18001 0808 808 0000**.

Website: www.macmillan.org.uk

OUTpatients

A cancer support and advocacy charity for LGBTIQ+ community.

Email: contact@outpatients.org.uk
Website: https://outpatients.org.uk/

Stopping smoking

NHS Smokefree service helpline: **0300 123 1044.**
Monday - Friday 9.00 a.m. to 8.00 p.m., Saturday & Sunday 11.00 a.m. - 4.00 p.m.

Website: www.nhs.uk/better-health/quit-smoking/

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

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.

Hotel Bexley Wing

The hotel is located on the 8th floor of Bexley Wing and offers 19 twin rooms and one 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 no charge for a relative staying in the same room as the patient.

However, there is a charge for relatives if they need their own room. Availability for this cannot be guaranteed.

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 3.45pm until the next morning** in this facility.

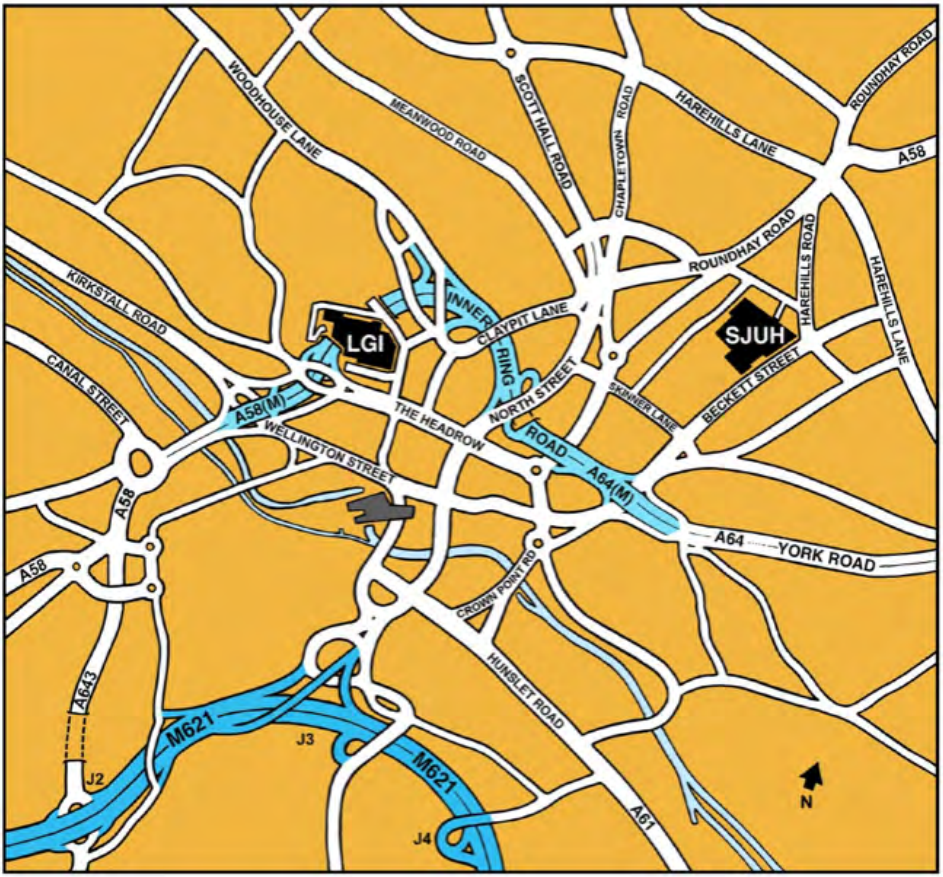
For further details please contact the Hotel Receptionist on 0113 206 7687, Monday to Friday 8.00 a.m. - 3.45 p.m.

Research at Leeds Cancer Centre

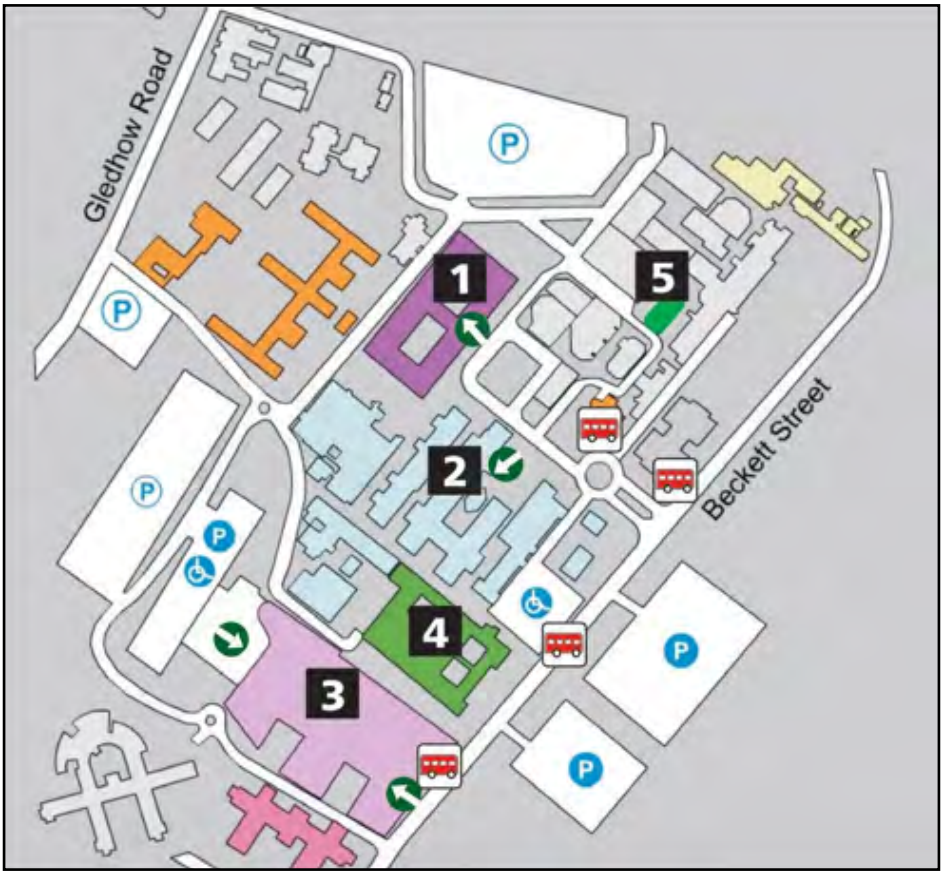
Leeds Cancer Centre is a major centre for cancer research. You may be asked if you would like to help with some of the clinical studies. You are under no obligation to take part in any trials. Your treatment will not be affected in any way if you do not wish to take part.

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

How to find us



St James's University Hospital - site plan



St James's University Hospital

1 Gledhow Wing	Entrances
2 Lincoln Wing	Visitor parking
3 Bexley Wing	Disabled parking
4 Chancellors Wing	Staff parking
5 Robert Ogden Centre	Bus stops

What did you think of your care?

Visit: www.leedsth.nhs.uk/patients/support/feedback-complaints/friends-family-test/

Scan or click the QR code - Your views matter

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