

External Beam Radiotherapy for Thyroid Cancer

Information for patients



Leeds Cancer
Centre

This leaflet aims to help you and your family understand more about your external beam 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 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 have any questions after reading this leaflet, please speak to the team looking after you or ring the numbers at the end of this 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.

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. 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 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 and anyone who may be pregnant throughout your radiotherapy.

You will have your radiotherapy on a treatment machine called a linear accelerator, as shown here in the photograph. You will see your radiographers at each treatment session, and they will be happy to answer any questions you may have.



How often is it given?

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.

You may need to be treated on a weekend during the day due to a bank holiday and we will let you know if this is the case. Your radiographer will be able to explain the details of your individual radiotherapy appointments. Your treatment will usually be given as an outpatient.

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.

Pregnancy

It is very important that patients who are of child bearing potential are not pregnant at the start of a course of radiotherapy and that they do not become pregnant during a course of 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. 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 where your radiotherapy mask will be made. Directions to the hospital and transport arrangements will be discussed with you at this point.

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).

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 can help you.



You can email them on leedsth-tr.RTpatientsupport@nhs.net or contact them on **0113 206 7616**.

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 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 scanner. 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 may include therapeutic radiographers, a mould room technician and a dosimetrist (the person who will produce the computer plan for your treatment).

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

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 (see picture).

These permanent 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.



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.

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.

Contrast side-effects

You may notice a warm feeling throughout your body and have a metallic taste in your mouth. You may also feel as if you have passed urine. This will pass very quickly. There is a slight risk of an allergic reaction to the injection, such as a skin rash, but very rarely may lead to other complications.

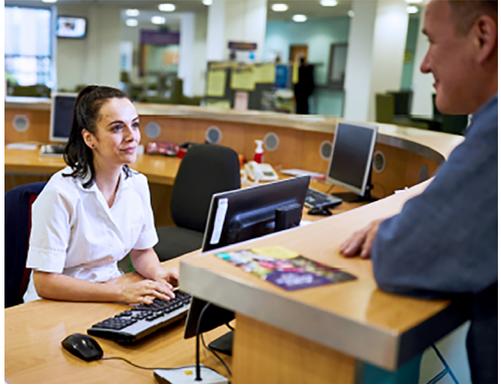
The staff in the radiotherapy department are highly trained to manage any complications and again the risk involved is very small.

You will be able to drive your car or go to work after your scan.

The radiographers will advise you about drinking plenty of fluid after your injection.

Having your treatment

When you arrive for your treatment you should go to the main reception at the entrance of the radiotherapy department. On the first occasion you will be given all your appointments and be 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 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.

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. 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.

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.



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.

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.

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. There is a restaurant and café available on Level 0.

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.

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 treatment, and long term effects occurring months or years later. Some side-effects are common, whilst others are rare. The area and amount of treatment given to you will affect which side-effects are most likely to happen to you. Your oncologist will discuss this with you. If you develop any radiotherapy side-effects you will be given advice and support by your healthcare team.

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 a 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 months 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

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. Sometimes later in treatment 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**.

Hair loss

Two weeks after the start of radiotherapy you may notice a small amount of hair loss on the back of your neck. It will slowly grow 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)

Nearly all patients having radiotherapy will feel tired. Be prepared to take things easy during treatment and allow for extra rests. Fatigue usually improves in the weeks to months after treatment.

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.

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.

When radiotherapy has finished

Your side-effects may get worse in the first few weeks after treatment and will then gradually settle. You should start getting back to normal about 4-6 weeks after treatment but it may take a little longer. Tiredness can last for several months and you may need to continue to rest more than usual. You may be asked to attend the hospital where you were first seen by your oncologist for follow-up checks at regular intervals.

Please discuss this with your doctor if you have any concerns.

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, and 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 who will be helping to run the trial.

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 treatment. If this is the case you may benefit from seeing the Macmillan radiographer or nurse specialist. Your oncologist, radiographer or nurse can refer you at any point before.

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.

The Sir Robert Ogden Macmillan Centre

The Centre offers a variety of free health and wellbeing and supportive therapies for patients, their family members and carers. These include Hypnotherapy, mindfulness coaching, acupuncture (for hot flushes) and pilates.

Contact numbers for Leeds Cancer Support

Information Lounge Level -2 Radiotherapy Department

Open from 8.00am - 6.00pm **Tel: (0113) 206 7603**

Information Centre Level 1 Outpatients Department

Open from 9.00am - 4.00pm. **Tel: (0113) 206 8816**

Sir Robert Ogden Macmillan Centre

Open from 9.00am - 4.00pm. **Tel: (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.

Tel: (0113) 457 8364

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

Email: leeds@maggiescentres.org

Website: maggiescentres.org

National Support Organisations

Macmillan Cancer Support

Freephone **0808 808 0000**, 8am to 8pm seven days a week.

A textphone service for deaf and hard of hearing people is available on: **18001 0808 808 0000**

Website: www.macmillan.org.uk

Cancer Research UK

Website: www.cancerresearchuk.org

Live Through This

A cancer support and advocacy charity for the LGBTIQ+ community.

Email: contact@livethroughthis.co.uk

Website: <https://livethroughthis.co.uk>

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: 0739 956 4463

Website: 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: 0142 381 0093

Website: 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: 0189 251 6076

Email: info@amend.org.uk

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.

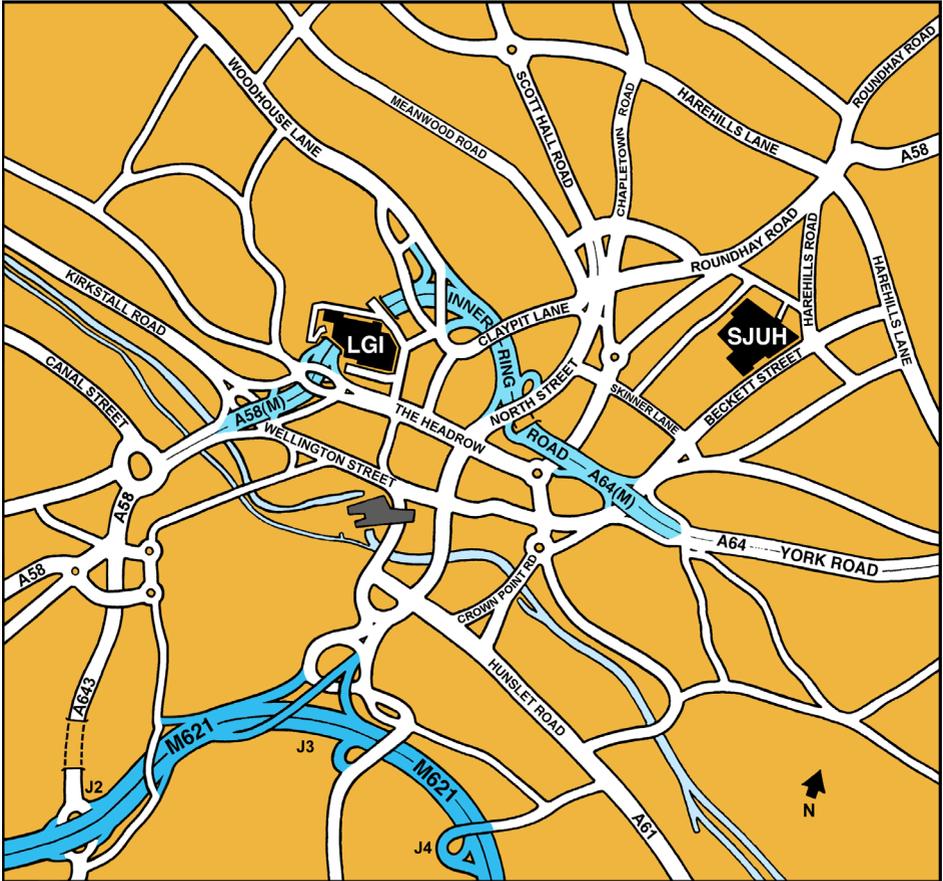
Hotel Bexley Wing

Patients having radiotherapy or chemotherapy sometimes use the hotel if they have a long way to travel. The hotel is located on the 8th floor of Bexley Wing and offers 19 twin rooms and 1 single room. All have en-suite, tea and coffee making facilities, a mini fridge, towels, hairdryer and digital television. There are two rooms with wheel chair access and a wet room. Patients are able to stay free of charge. There is a charge for relatives if they are staying in their own room.

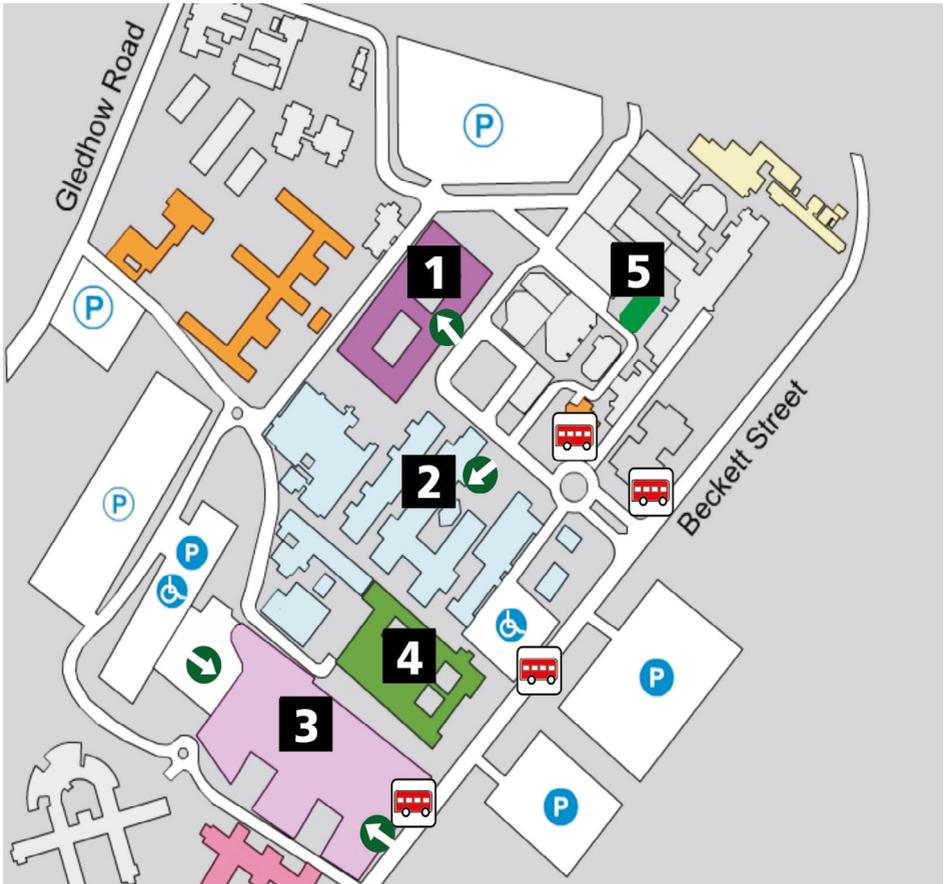
Meals can be purchased (at breakfast and lunch) if you are able to make your way to the restaurant in the Bexley atrium. At other times you will need to have something you have brought from home or purchased. There is a very small fridge for your personal use. **There are no staff after 4pm until the next morning** in this facility.

For further details please contact the Hotel Co-ordinator on **0113 206 7687**. Out of hours please contact the Non-Surgical Oncology Nurse Practitioner through main switch board on **0113 243 3144**.

How to find us

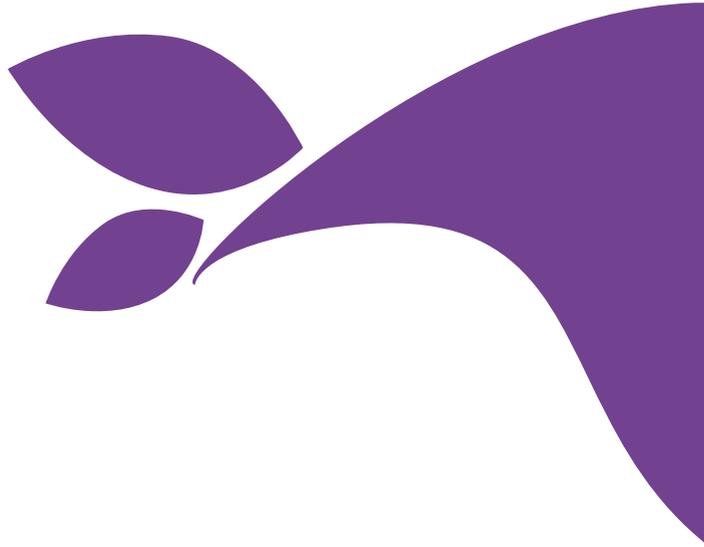


St James's University Hospital - site plan



- 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



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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