

Radiotherapy information for patients with Lymphoma

(excluding skin, brain and head and neck lymphomas)

Radiotherapy Department



Patient information leaflet

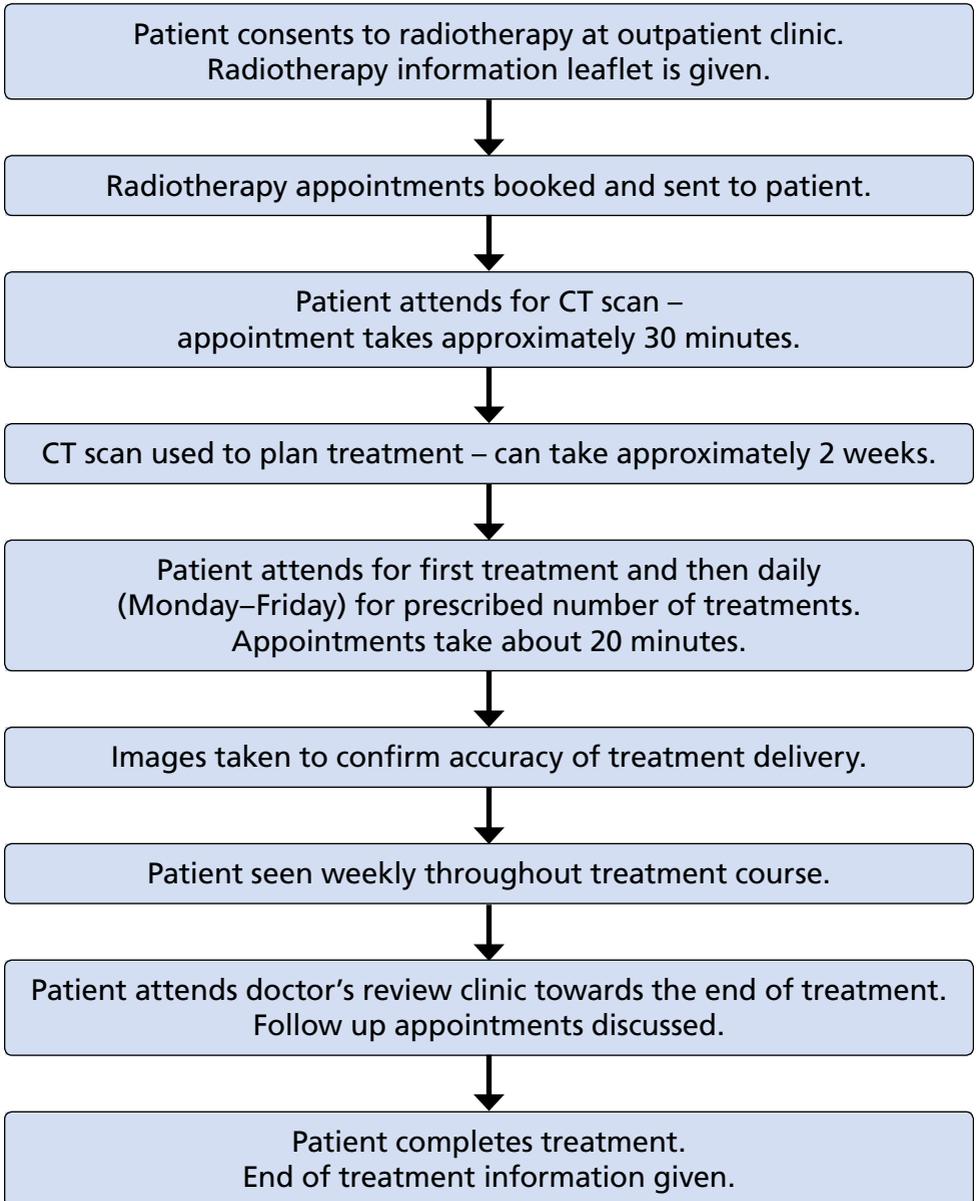
Contents

Introduction	4
Who is this leaflet for?	4
What is radiotherapy and how does it work?	5
What are the alternatives?	6
What happens before radiotherapy starts?	5
■ Oncology CT scan	
Why doesn't my treatment start straight away?	8
First day of treatment	8
Preparing for the treatment	8
The treatment	9
What sort of side effects might I have, and for how long?	9
■ Short term risks	
■ Long term risks	
What happens when treatment ends?	13
Where can I get further support?	14
Useful telephone numbers	16
Additional information	17
Questions and Notes – for you to write down any comments or questions you may wish to ask when you visit the hospital.	19

Please see the department's website for additional information. The site also provides information on recent patient surveys carried out in the department and any actions arising from the results.

www.royalsurrey.nhs.uk/st-lukes-centre

Patient Pathway – Lymphoma



St Luke's Cancer Centre

Please be aware that St Luke's Cancer Centre has two Radiotherapy Departments. One is located at the Royal Surrey County Hospital in Guildford and the other at East Surrey Hospital in Redhill. Please refer to your appointment letters for the location of all your appointments. All information contained in this leaflet is relevant to both sites.

Introduction

Your clinical oncologist has decided that a course of radiotherapy would be the most appropriate way of treating your cancer. When recommending radiotherapy, your doctor takes into account the risk of the cancer returning or growing if no radiotherapy is given. While the treatment has side effects, it is felt that the advantages for you would outweigh the disadvantages.

At this stage your clinical oncologist will probably have discussed with you the risks and benefits of undergoing a course of radiotherapy and you may have been presented with a consent form to sign agreeing to have the treatment.

The short and long term side effects of receiving radiotherapy are outlined towards the end of this leaflet.

Who is this leaflet for?

Lymphoma can occur in many parts of the body. Those with a brain, head & neck or skin lymphoma will be given a different leaflet to this one. This leaflet is specifically for patients having radiotherapy for a lymphoma to all other parts of the body. Your treatment will be tailor-made for your specific needs. It may differ slightly from what is described in this leaflet, and also from what another patient with a similar diagnosis may be having.

What is radiotherapy and how does it work?

Radiotherapy is the use of high energy x-rays or electrons (ionising radiation) to treat cancer. It is given by a machine called a linear accelerator (or Linac for short). See photograph 1. It is given externally with you lying on a treatment couch. Carefully calculated doses of this radiation are directed to a specific part of your body. Accurate planning of your radiotherapy means that the treatment is very localised and targeted in order to avoid as much healthy tissue as possible. However, some healthy tissue will be affected and this may cause side effects. Most side effects are temporary as healthy tissue is able to repair itself. External beam radiotherapy is a very quick and usually painless treatment.



What are the alternatives?

You may decide that you do not want to have radiotherapy; this is an option you can choose. Talk again with your doctor if you wish and let him/her know what you have decided.

You can ask for a second opinion on your diagnosis or treatment at any time during your consultation or treatment process. Please speak to your clinical oncologist or GP.

What happens before radiotherapy starts?

Following your initial outpatient appointment with the oncologist, you will be sent a letter asking you to come to the radiotherapy department for a pre-treatment appointment. This appointment will be for the Oncology CT Scanner.

Please check your appointment letter for the exact location of your appointment. It is helpful to bring your appointment letter and a dressing gown with you.

A member of the pre-treatment radiotherapy team will explain what is going to happen and give you a further opportunity to discuss your treatment and possible side effects before proceeding with the treatment preparation. However, if you feel you have questions that you would like to ask the doctor, a radiographer can organise an appointment for you.

During this discussion you will be asked to confirm your name, address and date of birth. You will be asked for this information before every procedure or treatment undertaken in the department. The following subjects will also be addressed:

- **Confirmation of consent:** you will probably have already signed a consent form with your clinical oncologist. That consent will be reconfirmed with a radiographer prior to your planning session to ensure that you still agree to proceed with the proposed treatment.
- **Pacemakers:** If you have a pacemaker and you did NOT discuss this with your clinical oncologist when you signed the radiotherapy consent form please phone the CT scanner to let them know. The number is at the end of this information leaflet. It is safe to give radiotherapy to patients who have a pacemaker but there are a few precautions we may need to take. The radiotherapy department will send you an information sheet entitled 'Pacemakers and Radiotherapy' for you to read and keep with your other patient information leaflets. This leaflet will explain why extra precautions may be needed and what those precautions are. It will also highlight any extra appointments you may need to attend the hospital for. Please bring your pacemaker ID card to your CT appointment.
- **Pregnancy:** All female patients under the age of 55 will be asked to confirm that they are not pregnant before the first planning session starts. It is very important that you are not and do not become pregnant while having radiotherapy planning and treatment. If you think you may be pregnant at any time during your course of treatment please tell your clinical oncologist or radiographer immediately. If necessary, please speak to your doctor about contraception methods suitable for use during radiotherapy.

Planning CT scan

A CT (computerised tomography) scanner is a special x-ray machine that produces a series of detailed pictures showing the organs in your body. The scan cannot be used for diagnostic purposes; it is purely for radiotherapy planning. The scans are sent to a computer and used to reconstruct a 3D image of your body. The radiotherapy team will then use this image to accurately target your radiotherapy.

- Your oncologist may ask for a contrast agent (a fluid that shows up on x- ray images) to be used during your scan. This allows certain areas in the body to show up more clearly on the images. This contrast agent is given through a needle in your arm. A small number of people find that the contrast can cause side effects. You will be given a questionnaire to fill in which will help highlight if you may be one of the people more prone to side effects. The radiographer will then decide whether to go ahead with the contrast agent. If you do not have the contrast agent it does not mean that the planning of your treatment will be any less accurate.
- The radiographers will go in and out of the room several times during the procedure and you will hear them talking over you during the setting up process.
- They are able to hear and see you at all times so if you need to communicate with them call out or raise your arm.
- At the end of the scan the radiographers will, with your permission, place three or four permanent ink dots under the skin around the area being treated. These marks will not come off your skin but they do fade over time. The treatment radiographers will use these permanent marks to make sure that you are correctly positioned on the couch and to ensure an accurate treatment.
- Very occasionally, in order to show clearly how you are positioned on the couch, the radiographers may take a digital photograph of you. They will ask your permission for this beforehand and the image will only be accessible to the radiographers.
- The scan is a completely painless and the whole appointment takes about 40 minutes.

Why doesn't my treatment start straight away?

After your planning scan, the detailed images are sent to a specialised computer system. Your oncologist will then outline the exact area to be treated. The rest of the planning is carried out by planning radiographers and physicists. They will determine the best field arrangement and create shaped beams to direct the radiation onto the area to be treated while avoiding as much healthy tissue as possible.

The plan will then go through an extensive checking procedure which includes being checked and signed by your clinical oncologist. The planning process can take approximately two weeks.

The next step will be your treatment.

First day of treatment

Please check your appointment letter for the exact location of your appointment. It is helpful to bring your appointment letter and a dressing gown with you.

One of the treatment team will greet you and discuss your treatment with you. This discussion provides a good opportunity to ask questions that may have arisen since your last appointment. There is space at the end of this leaflet to write down anything you may want to ask.

You will be given a list of all your appointment times, including review clinics, blood tests and doctor's appointments.

Preparing for the treatment

Prior to your treatment, the radiographer will ask you to go into a changing room and remove your clothing and put on your gown. After your first visit you may get changed straight after booking in at reception.

The treatment

The radiographer will call you into the treatment room, introduce you to all the team members present and ask you to lie on the treatment couch. The radiographers will then begin to get you into the correct position.

- The radiographers will come in and out of the room several times during the treatment and you will hear them talking over you during the setting up process.
- They are able to hear and see you at all times so if you need to communicate with them call out or raise your arm.
- When you are positioned correctly the treatment couch will be quite high up (about 4.5 ft.). Therefore it is very important that you do not move or attempt to get off the couch. The radiographer will tell you when it is safe to sit up and get off the couch.
- The whole procedure will take approximately 20 minutes and is painless.
- All treatment rooms have a CD player so feel free to bring your own music along if you wish.

What sort of side effects might I have, and for how long?

Although modern planning and treatment methods have helped us to minimise the risk of side effects, most people still experience some effects from the radiotherapy. The severity of side effects varies from person to person.

You are most likely to be aware of side effects towards the end of your treatment course. Most of these are not severe and medication can often be of help. It is unusual to have to stop or postpone radiotherapy due to the severity of side effects.

Short and long term radiotherapy side effects are closely related to the exact area of your body where you are treated.

Lymphoma is very sensitive to radiation and this means that it does not require as high a dose in comparison to other cancers, resulting in fewer side effects.

Short term risks

These are side effects that may appear during radiotherapy or during the fortnight after it has finished. Listed below are possible side effects that may occur if you are to have radiotherapy to your chest, mediastinum, abdomen, or pelvis. Short term side effects may peak in the 2-3 weeks after completing treatment but should gradually start to improve after that.

Chest

- **Swallowing discomfort:** you may notice your throat gradually becomes uncomfortable and painful. You may feel as if you have heart burn or indigestion. The radiographers will be monitoring your reaction every day, so please keep them informed. You will be advised about any medication that may help.

Avoid eating or drinking anything that may irritate the throat like very hot or very cold drinks, alcohol, (particularly spirits), spicy food, rough foods such as crisps and citrus fruit juices.

- **Cough:** it is quite common to develop a cough while having treatment. It is usually a dry cough, which may be uncomfortable and tiring. It may be suggested that you try a simple cough linctus to help manage this.

Abdomen

- **Nausea (feeling sick) or vomiting:** You may find that the treatment makes you feel nauseous. This can happen quite early on in the treatment. Try some of these suggestions:
 - If possible, avoid preparing food yourself.
 - Avoid fatty, fried, and strong smelling food.
 - Eat several small meals a day, rather than one or two bigger meals.
 - Drink plenty of fluid with meals.

- Medication called anti-emetics can be prescribed by your doctor to help with nausea or vomiting. You may have been given a prescription for anti-emetics before your treatment starts. If the tablets you are given do not seem to be working tell the radiographers. There are lots of different anti-emetics and it sometimes takes a few tries to find the one that suits you. Support therapies such as acupuncture can also help. The radiographers can put you in contact with the Fountain Centre if this is something you would like to try.

Pelvis

- **Changes in bowel habits:** some patients experience the need to have bowel movements more frequently and with a greater urgency than usual. You may find that you have some diarrhoea, stomach cramps and wind. If necessary you will be offered medication that can help with both the diarrhoea and the discomfort. It is also very important to drink plenty in order to replace the fluids you have lost. You can continue to eat normally. Your bowel habit should begin to return to normal a few weeks after treatment is completed.
- **Skin soreness:** the skin in the area being treated may gradually become red, dry and itchy. Using a moisturiser can help to soothe the skin and a suitable cream will be recommended to you by the radiographers on your first day. In the majority of cases the skin reaction is usually mild to moderate. Please do not use any other products in the treatment area without checking with your doctor or radiographer first as they may make any reaction worse. Please do not soak in a hot bath. We advise that you do not use a razor or hair removal creams or waxes in the area you are having treated as this can add to skin soreness. Wearing loose clothing allows the air to circulate around the sore areas which can help to minimise the skin reaction. The radiographers treating you will give you additional skin care advice or medication if it becomes necessary.
- **Sun exposure:** the area being treated will be more sensitive to the sun both during treatment and for some time afterwards. While you are still on treatment and while any skin reaction is present it is advisable to keep the area covered up. After this time you can use a maximum factor sun cream.

- **Tiredness:** it is quite common to feel more tired than usual while having radiotherapy. We advise that you try to drink more fluid than normal during your treatment. A guide is about 2.5 litres of fluid each day. Rest if you need to, but if you feel well carry on with all your normal daily activities.

As your treatment progresses the radiographers will be talking to you each day to find out how you are feeling. This is so they may offer help and support if the treatment gives you any problems. Please feel free to discuss all issues that may be concerning you. You will also be seen regularly by the review radiographers and your medical team.

Long term risks

Lymphomas are treated with relatively low doses of radiation therefore long term side effects are not generally expected. However, there are some things that it is important you know about.

- **Risk of a second cancer:** Patients who survive and are cured of lymphoma are at an increased risk of developing a second cancer but it is important to remember that this only occurs in a small number of patients. There are also many other factors that may contribute to the development of a cancer, such as genetic make-up and environmental agents.

Women who receive radiotherapy to the chest area before they are 35 years of age are at an increased risk of developing breast cancer in later life. Treatment to this area also carries an increased risk of developing lung cancer, especially in men and women who smoke.

You will be able to discuss this matter with your clinical oncologist. They will balance your need for radiotherapy to either cure or control your lymphoma against the risks highlighted above. It will be many years before any second cancer would arise. You may be able to consider additional screening to detect any cancer early if the risk is deemed significant.

- **Infertility:** infertility will only be caused if the ovaries or testes are in the area to be treated. Your clinical oncologist will discuss this with you if it is seen as a possibility. There are some support group telephone numbers at the end of this leaflet for anyone affected by this issue.

- **Heart problems:** if the heart is included in the treatment area, you may be more likely to have heart problems in the future. This is especially true if you have also had chemotherapy. Try to avoid other heart risk factors such as smoking. There is a stop smoking help line number at the end of this leaflet. Exercising regularly and having a balanced diet can help reduce the risk. You will be able to discuss this issue with your clinical oncologist.

What happens when treatment ends?

- On the last day of your treatment a radiographer will explain that the treatment will carry on working for another 2-3 weeks. Any short term side effects may get somewhat more marked during this time but after that they should gradually improve..
- The radiographer will make sure you have a follow-up appointment with your clinical oncologist. This may be at a hospital nearer to your home.
- You will be given a leaflet and two copies of your discharge summary. One copy is for your records and the other for you to give to your GP. A letter summarising your treatment in more detail will be sent through the post to your GP.
- Please remember you can contact the radiographers at any time after your treatment has finished if you have any concerns or questions. Contact telephone numbers are at the end of this leaflet.
- Please do not book a holiday too close to the end of your treatment in case the treatment does not finish on the date originally planned. This also allows you time to recover from any side effects experienced.

Where can I get further support?

Further support can be given by the various Support Centres at locations in Guildford, Redhill, Crawley and Purley. These centres provide information, complementary therapies, support groups and one to one support.

To find out more contact the individual centres or ask radiotherapy department staff for a leaflet.

The Fountain Centre is located in St Luke's Cancer Centre at Guildford.

- Telephone: 01483 406618
- Website: www.fountaincancersupport.com

The Olive Tree is located in Crawley Hospital, Crawley.

- Telephone: 01293 534466
- Website: www.olivetreecancersupport.org.uk

Macmillan Cancer Support is located at East Surrey Hospital.

- Telephone: 01737 768 511 ext 2078

South East Cancer Help Centre is located in Purley, Surrey.

- Telephone: 020 86680974.
- Website: www.sechc.org.uk

Please also see the department's website for additional information at

- www.royalsurrey.nhs.uk/st-lukes-centre

Other support websites and groups

Cancer Research UK

- Website: www.cancerresearchuk.org
- Telephone: 0808 800 4040

Macmillan Cancer Support

- Website: www.macmillan.org.uk
- Telephone: 0808 808 0000

Lymphoma Association

- Website: www.lymphomas.org.uk
- Telephone: 0808 808 555

Human Fertilisation and Embryology Authority

- Website: www.hfea.gov.uk
- Telephone: 0207 291 8200

Quit51

- Website: www.quit51.co.uk
- Telephone: 0800 622 6968

Useful telephone numbers

Telephone numbers across both sites (Guildford/Redhill)

- Treatment Appointments 01483 571122 ext 6632
- Onslow Ward (out-of-hours) 01483 571122 ext 6858
- For urgent enquiries (out-of-hours) call hospital switchboard on **01483 571122** and ask operator to bleep on-call oncology SHO.

Guildford numbers

- Radiotherapy Reception 01483 406600
- Patient Support Office 01483 571122 ext 2066
- Clinical Nurse Specialist 01483 571122 ext 2143
- Mould Room 01483 406640
- Oncology CT Scanner 01483 406630

Redhill numbers

- Radiotherapy Reception 01737 277311
- Oncology CT Scanner 01737 768511 ext 1202
- Patient Support Office 01737 277315

Additional information

- In order to continually improve treatments and services, audits are regularly carried out in the department. This can involve using patient notes. The notes will have all identifiable details removed to ensure patient confidentiality. However, if this is unacceptable to you please let your consultant know so your wishes can be respected.
- Clinical trials are undertaken within the department. If appropriate your doctor will discuss this with you.
- If you require this information in a different format or language please let a member of staff know as soon as possible.
- Staff at St Luke's Cancer Centre cannot take responsibility for patient belongings brought into the hospital. Please keep all your personal belongings with you at all times and leave valuables at home.

Reference sources

- Radiotherapy Clinical Protocol – Hodgkin's Lymphoma Royal Surrey County Hospital NHS Foundation Trust 2014
- Radiotherapy Clinical Protocol – Non Hodgkin's Lymphoma Royal Surrey County Hospital NHS Foundation Trust 2012
- Treating Lymphoma – Cancer Research UK – 2018

If you wish to make a comment or complaint about any aspect of the treatment or services provided by St. Luke's Cancer Centre and its staff please speak to a member of St. Luke's. Alternatively you can visit, email, phone or write to the **Patient Advice and Liaison Service (PALS)**. Their contact details are:

PALS office in the main hospital reception area, telephone **01483 402757** or write to:

PALS Manager
Royal Surrey County Hospital NHS Trust
Egerton Road
Guildford
GU2 7XX

- Email: rsc-tr.pals@nhs.uk
- www.royalsurrey.nhs.uk

You may also write to the Chief Executive of the Trust at:

Royal Surrey County Hospital NHS Trust
Egerton Road
Guildford
GU2 7XX

Radiotherapy contact details

Radiotherapy reception

Telephone: 01483 406 600

PALS and Advocacy contact details

Contact details of independent advocacy services can be provided by our Patient Advice and Liaison Service (PALS) who are located on the right hand side as you enter the main reception area. PALS are also your first point of contact for health related issues, questions or concerns surrounding RSCH patient services.

Telephone: 01483 402757

Email: rsc-tr.pals@nhs.net

Opening hours: 9.00am–3.00pm, Monday to Friday

If you would like information documents in large print, on tape or in another language or form please contact PALS.

Past review date: November 2018

Future review date: November 2021

Author: Priscilla Mahendran

PIN181127–1593

