

Radiotherapy to the brain (primary tumour)

Radiotherapy Department



Patient information leaflet

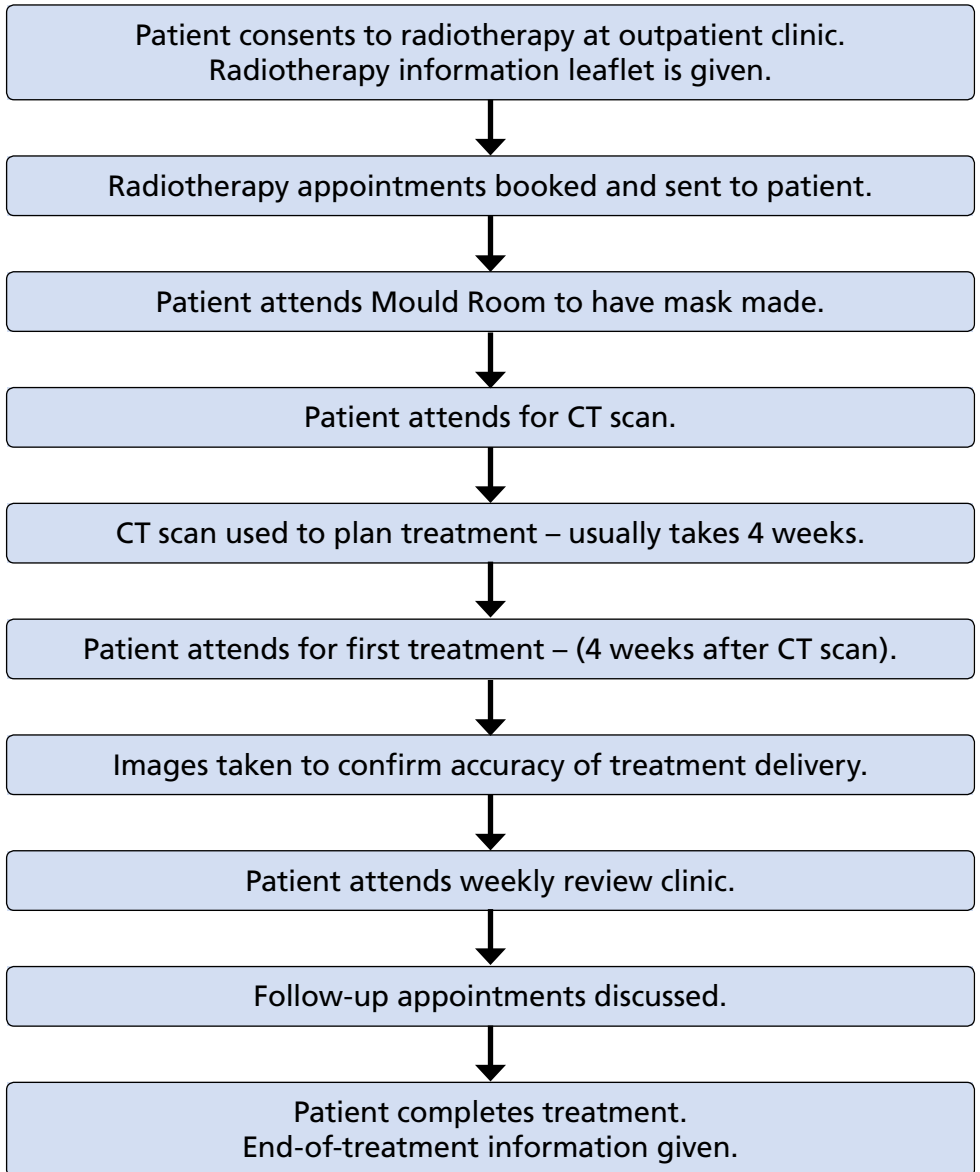
Contents

Introduction	4
Who is this leaflet for?	4
What is radiotherapy and how does it work?	5
What are the alternatives?	5
What happens before radiotherapy starts?	6
Mould Room	7
CT scanner	9
Why doesn't my treatment start straight away?	10
First day of treatment	10
The treatment	10
Chemotherapy and radiotherapy	11
What sort of side effects might I have, and for how long?	11
Short term risks	12
Long term risks	14
What happens when treatment ends?	16
Where can I get further support?	16
Useful telephone numbers	18
Additional information	19
Questions and Notes – for you to write down any comments or questions you may wish to ask when you visit the hospital.	21

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 – Brain Tumours



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 the 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 will have side effects, it is felt that the advantages for you would outweigh the disadvantages.

At this stage your doctor 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 risks of receiving radiotherapy to your brain are outlined towards the end of this leaflet.

Who is this leaflet for?

This leaflet is specifically for patients having radiotherapy to the brain. See figure 1.

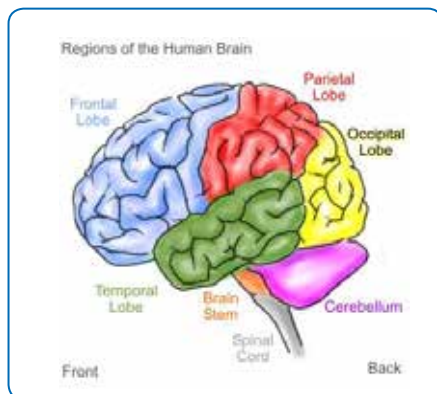


Figure 1

Please be aware that 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. You will have the opportunity to talk to a radiographer before the planning of your radiotherapy, and again before you start your first treatment. You may also ask to see your doctor or clinical nurse specialist if you wish.

What is radiotherapy and how does it work?

Radiotherapy is the use of high energy x-rays or electrons (ionising radiation) to treat tumours it is delivered from a machine called a linear accelerator or Linac for short. See photograph 1.

Most commonly 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 avoiding 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 quick and usually painless treatment.



Photograph 1

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 may request 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?

If you have had surgery to your brain, your clinical oncologist may request that you have a repeat MRI (Magnetic Resonance Imaging) scan prior to coming for your pre-treatment appointments. Having these extra images can help in the planning process of your radiotherapy.

Following your initial out-patient appointment with the doctor you will be sent a letter asking you to attend the radiotherapy department for a pre-treatment appointment. This appointment will be for the Mould Room and the Oncology C.T. 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 the procedure to you. However, if you feel you have questions that you would like to address to the doctor, a radiographer can organise a meeting 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:

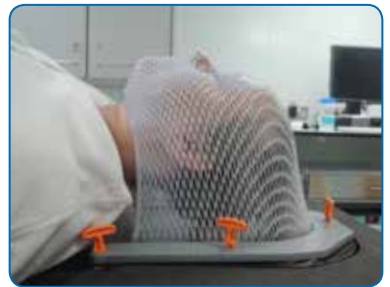
- **Confirmation of consent:** You will probably have already signed a consent form with your clinical oncologist. That consent will be re-confirmed with a radiographer prior to your first planning session to ensure that you still agree to proceed with the proposed treatment.
- **Pacemakers:** If you 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 contact 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 may be. 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 their pregnancy status before the first planning session starts. It is very important that you are not and do not become pregnant while undergoing 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.

The Mould Room

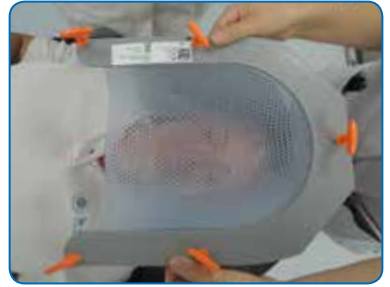
The brain area is very complicated and full of important structures, as well as being close to the lens of the eye. The aim of radiotherapy planning is to treat the tumour area while avoiding healthy structures as much as possible. It is therefore very important for you to be able to keep your head absolutely still during treatment.



Photograph 2

- To help to achieve this you will have a plastic mask made which you will wear during all your planning and treatment sessions. This will be fixed to the treatment couch to help you keep still. See photograph 2.
- The mask needs to fit as tightly as possible. Therefore, if you are likely to need a haircut please have it done before you come for your mould room appointment. If you have any queries about this please contact the mould room prior to your appointment. Telephone numbers are listed at the end of the leaflet.
- The mask making process is completely painless and is shown in the series of photographs below.

- The material used is a warm, soft plastic perforated with lots of holes. See photograph 3.



Photograph 3

- You will be able to breathe normally at all times.

- The mould room staff will mould the plastic to your face and head. See photograph 5.



Photograph 4

- As it dries, it cools down and holds its shape to form a mask. See photograph 6.

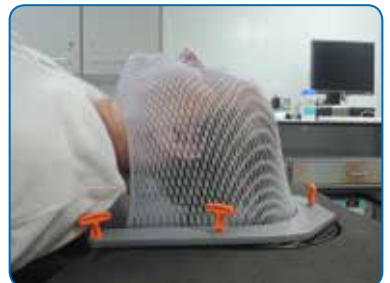
- When the mould is cool it will be removed.

- Your mould room appointment will take about 30 minutes.



Photograph 5

- Your next appointment will be with the CT scanner.



Photograph 6

Oncology CT scan

A CT (computerised tomography) scanner is a special x-ray machine that produces a series of detailed pictures showing the structures in your brain.

This scan will not be used for diagnostic purposes or for assessing whether the cancer has spread; it is only used for planning the radiotherapy so you will not be given any results from the scan. The scan is sent to a computer and used to reconstruct a 3-D image of your brain. The radiotherapy team will then use this image to accurately target your radiotherapy.

- Your oncologist may request that a contrast agent (a fluid that shows up on x-ray images) be used during your scan. This allows certain areas in your brain to show up more clearly on the images. This contrast agent is given through a needle in your arm. In a small number of people the contrast can occasionally cause side effects. A radiographer will give you a questionnaire to fill in, which will help highlight if you may be one of those people more prone to these 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.
- You will wear your mask during your CT scan.
- The couch will move slowly through the scanner. You won't feel anything and nothing will touch you. The scan should only take a few minutes.
- 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 raise your arm.
- The mask can be removed at any time should you feel anxious or uncomfortable.
- The scan is 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 define the exact area to be treated. The rest of the planning is carried out by physicists and planning radiographers. They will decide the best field arrangement and create shaped beams to focus the radiation on 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 up to four weeks.

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 treatment appointment times, the dates of your radiographer and doctor review clinics and any blood tests that you may need.

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 be 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 see you at all times so if you need to communicate with them raise your arm.

- The mask can be removed at any time should you feel anxious or uncomfortable.
- When you are positioned correctly the treatment couch will be quite high up (about 4.5 ft). Therefore it is very important you do not move or attempt to get off the couch. The radiographers will tell you when it is safe to sit up and get off the couch.
- The whole procedure will take approximately 15 minutes.

Chemotherapy and radiotherapy

In some circumstances your clinical oncologist may advise you to take a drug called temozolomide while you are having your radiotherapy. If this applies to you, your doctor will explain the medication to you and provide you with more detailed written information. The drug is taken every day during your course of radiotherapy, including weekends.

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

Although modern planning and treatment methods have helped us to reduce side effects, most people will experience some effects of 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 helpful. It is unusual to have to stop or postpone radiotherapy due to the severity of the side effects.

Radiotherapy side effects are closely related to the exact area of your body where you are treated. As you are to receive treatment to your brain, most side effects that you have will be limited to this area of your body.

Some side effects will depend on which part of your brain is being treated. You will be able to discuss this in more detail with your clinical oncologist.

Short term risks

- **Worsening of brain tumour symptoms:** treatment may cause a temporary swelling of the brain which can lead to a worsening of your brain tumour symptoms but this does not mean your tumour is getting worse. Depending on the exact area of your brain that is being treated you may experience a return or an increase in the symptoms that were present at diagnosis such as headaches, struggling to find the right words (dysphasia), loss of balance, visual disturbances, numbness or weakness of limbs and seizures. Any of these can occur at any time during your course of treatment.

Before you start your treatment your clinical oncologist may prescribe you a course of steroids. They are not to treat the tumour itself, but to help reduce the swelling of your brain and thereby reduce the symptoms that you experience. The dose can be increased or decreased as necessary. It is very important that you carry on taking the steroids and don't allow your supply to run out as stopping your steroids abruptly can cause a worsening of any side effects that you may be experiencing. When the time comes for you to stop taking them you will be given instructions on how to taper the dose down gradually. If you are running low on tablets during your radiotherapy please let the radiographers know so that a repeat prescription can be organised for you.

If you experience headaches you can take painkillers to help.

If you have problems with seizures then your clinical oncologist will prescribe medication to help to manage them.

If you do notice changes in any of these symptoms please let the radiographers know as soon as possible. Symptoms may carry on for several weeks after the treatment has ended.

- **Nausea (feeling sick) and vomiting:** this is rare but can happen. There are a number of things that can be done to minimise these problems and medication, called anti-emetics, can be prescribed for you.

Any nausea and vomiting that you experience should begin to subside shortly after the treatment course has finished.

- **Tiredness:** as the treatment progresses you may feel yourself beginning to get more tired than usual. Have plenty of rest when you feel the need to and ask friends and family to help out when they can. You may find that drinking plenty of fluid helps. Tiredness can carry on for several weeks after your treatment has finished, but over time you should find your energy returning.
- **Hearing loss/changes:** if your eardrum is within the treatment area you may experience some temporary hearing loss or changes.
- **Hair loss:** hair loss as a result of radiotherapy tends to be patchy over the whole head. This will start to happen about halfway through your course of treatment. You will particularly notice hair coming out when you brush and wash your hair and you will also notice hair on your pillow in the morning. You may wish to have your hair cut shorter prior to your treatment starting although once your mask is made we would ask you to leave your hair as it is, otherwise the fit of the mask may change.

During your treatment we advise you to wash your hair using a mild or baby shampoo and lukewarm water. Do not use a hair dryer or rub your head too firmly with a towel. You should not have your hair coloured or permed during your course of treatment.

You may wish to cover your head with a soft hat or scarf. The Fountain Centre can help with methods and styles for tying head scarves. The radiographers can organise an appointment with the Fountain Centre if you wish or you can just drop in. Contact details are at the end of this leaflet.

Wigs: If you decide that you would like to have a wig this can be arranged for you through the Fountain Centre. If you are having treatment at East Surrey Hospital wigs can be organised through the chemotherapy suite – please ask one of the radiographers for details.

- **Skin reaction:** 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. Please do not use any other products in the treatment area without checking with your doctor or radiographer first as they could make any reaction worse.

Please also be aware that the treated area may be more sensitive to the sun. 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.

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 any issues that may be concerning you. You will also be seen regularly by your medical team

Delayed side effects

- **Somnolence (drowsiness):** can start any time from 3-4 weeks to approximately 3 months after your treatment has finished. You may notice that you have very little energy, are irritable, lethargic and find it hard to get motivated to do anything. This is known as somnolence. It has been likened to hitting a second wall of tiredness. It usually lasts for about two weeks and then begins to lessen.

Long term risks

Long term side effects can occur several months to years after the radiotherapy has finished. Once your radiotherapy has ended you will have regular follow-up appointments with your consultant and you will be carefully monitored for any signs of these long term effects. It may be useful to keep a note of your side effects during and after your radiotherapy so they can be more easily monitored.

- **Cognitive changes:** some patients may notice that they have changes in memory, concentration and thought processes. Please feel free to speak to your clinical oncologist about any concerns that you have.

- **Cataract formation:** the lens of the eye is extremely sensitive to radiotherapy and even a very low dose can cause cataracts. Sometimes, in order to treat your tumour adequately it may be unavoidable that one of your eyes receives some radiation. If this situation arises, your doctor will discuss it with you carefully before you start radiotherapy. It takes about two years for a cataract to form but it can be removed in the same way that any patient with a cataract is treated.
- **Damage to optic nerve:** In many cases the optic nerves will receive a dose of radiation. Your doctor will be very careful to keep this to a minimum and effects on your sight are extremely rare. If, however, the dose to the optic nerve is considered to be higher than normal then your doctor will specifically discuss this with you before you start treatment.
- **Damage to brain tissue (brain necrosis):** This is a very rare side effect but can cause a number of symptoms depending on the exact area of brain damaged. Your clinical oncologist will be able to discuss this with you in more detail.
- **Hearing loss/changes:** if your eardrum was within the treatment area you may experience hearing loss some years after your treatment has finished. If you have problems with your hearing then you should see your GP so that they can check that there is not a problem that can be easily resolved. If this is not the case then your doctor will be able to discuss management of hearing loss if it becomes a problem.
- **Hormonal changes:** some parts of the brain help to produce and manage hormones in the rest of the body. If these structures have received treatment they may, over time, produce less hormones than you need. Problems that you may experience will vary depending on which hormones are affected. Your doctor will explain this to you and medication can usually be given if problems arise.
- **Second malignancy:** treatment with radiotherapy can give rise to a second primary cancer. This would normally occur in the area of the body that had received the radiation. This is a very rare late effect.
- **Driving:** All drivers who have a brain tumour are unable to drive and must contact the DVLA to inform them of their diagnosis. The contact details for the DVLA can be found towards the end of this leaflet.

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 even get slightly more noticeable during this time but after that they should slowly improve.
- The radiographer will make sure you have a follow-up appointment with your clinical oncologist.
- You will be given a leaflet and two copies of a discharge summary. One copy is for your records and the other for you to give to your GP. In due course a letter summarising your treatment in more detail will be sent through the post to your GP.
- Please remember you are welcome to contact the department at any time after your treatment has finished should you have any concerns or questions. Contact 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 listed on your appointment schedule. This also allows you time to recover from any side effects experienced.

Where can I get further support?

Further support can be given by various support centres at locations in Guildford, 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 East Surrey Macmillan Cancer Support Centre is located at East Surrey Hospital.

- Telephone: 01737 304176
- Email: informationcentre.sash@nhs.net

The Olive Tree is located in Crawley Hospital, Crawley.

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

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

The Pituitary Foundation

- Website: www.pituitary.org.uk
- Telephone: 0117 370 1320

Cancer Research UK

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

Macmillan Cancer Support

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

DVLA

- Website: www.dvla.gov.uk
- Telephone: 0300 790 6806

The Brain Tumour Charity

- Website: www.thebraintumourcharity.org
- Telephone: 0808 800 0004

Brains Trust

- Website: www.brainstrust.org.uk
- Telephone: 01983 292 405

Surrey Primary Care Trust

Stop Smoking Service

- 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
- Oncology CT Scanner 01483 406630
- Patient Support Office 01483 571122 ext 2066
- Mould Room 01483 406640
- Clinical Nurse Specialist 01483 571122 ext 2087

Redhill numbers

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

Additional information

- In order to 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 – Cranial Ependymoma – Royal Surrey County Hospital NHS Foundation Trust 2017
- Radiotherapy Clinical Protocol – Intracerebral Glioma and Ependymoma – Royal Surrey County Hospital NHS Foundation Trust 2017
- Radiotherapy Clinical Protocol – Meningioma – Royal Surrey County Hospital NHS Foundation Trust 2016
- Gliomas in Adults – Cancer Research UK 2015

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

Notes

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: May 2018

Future review date: May 2021

Author: Elizabeth West

PINPIN180521–1537a

