

# A patient's guide to radiotherapy

Information for patients



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## Introduction

Welcome to the radiotherapy department. This booklet gives you:

- an introduction to the department – who you will meet and how we work
- an explanation about external beam radiotherapy
- a description of the support services we offer.

You will also receive a leaflet describing radiotherapy for your particular type of cancer.

Please ask for any further information you require about your illness, treatment and its effects. We have many other leaflets and publications.

We encourage you to ask as many questions as you wish to any member of staff. We are happy to help and our aim is to keep you fully informed at all times.

Please keep your personal belongings with you at all times and don't bring expensive items or large amounts of money with you when coming to the hospital.

We cannot accept responsibility for loss or damage to personal property of any kind, including money and laptop computers, regardless of how the loss or damage may occur.

## Our multidisciplinary team

You will meet many different people in our department. The team consists of:

- **consultants** called clinical oncologists. They are the doctors in charge of your care.

- **specialist registrars** are specialist doctors who work with your consultant to provide your medical care.
- a **senior house officer (FY2)** who is also part of the medical team. You mainly meet them on the ward.
- the **radiotherapy review specialists** who are nurses/radiographers. They will meet you when you are first told you are going to have radiotherapy and they will see you regularly throughout your treatment. They are here to support and advise you during your treatment.
- a team of **radiographers** who organise the planning and delivery of your radiotherapy treatment. They have specialist training in all aspects of radiotherapy treatment.

If you would prefer to be treated by a female or male radiographer please discuss this with the radiographer at your planning appointment. We will try not to let this delay you, but you may have to wait until the appropriate members of staff are available. We aim to be sensitive to your needs so please do not hesitate to discuss any concerns with the team caring for you.

- you may also meet a **research radiographer** if your doctor feels you could benefit from participating in a clinical trial. This is a radiotherapy radiographer who specialises in co-ordinating trials and works closely with your team to provide information and support. Our department is actively involved in clinical research with an aim to provide best possible care for patients and improve treatments and outcomes. If you would like more information, please contact our dedicated **research radiographer**.

- as part of their training **student radiographers** work under supervision. We ask for your co-operation in allowing our students to work alongside us, but please tell us if you do not wish them to be present. This will not affect your care in any way.
- a team of **dosimetrists and physicists** who are specialist scientists who plan and calculate your treatment. Along with an **engineer**, they also check the machines to monitor their performance. You may not meet these people directly, but may see them in the department.
- you may also meet a **clinical nurse specialist** for your particular type of cancer, who works closely with the team providing radiotherapy and care.
- **counsellors** who offer time and space to discuss any emotional or psychological issues you wish to explore.
- the **dietitian** who provides support, care and dietary advice. The radiotherapy review specialists or your doctor will contact them as necessary.
- **complementary therapists** who offer a free 15 minute massage once a week throughout your treatment.
- **other students.** As we are a teaching hospital, from time to time we ask for your co-operation in allowing students to gain knowledge of your condition and needs. We value this, but respect that you may prefer not to have them present. Please tell us if this is the case. This will not affect your care in any way.

## Confidentiality

All of our team of professionals respect your dignity and privacy. All information is kept confidential. Your case notes will only be shared among those who need to see them to provide your care. Please discuss any concerns about this with us.

## How to find us

The radiotherapy department is located on the ground floor of the Royal Free Hospital. It can be accessed via a separate entrance to the side of the main hospital entrance. You can also follow signs to the heart attack centre.

The out-patients clinic is situated in a corridor immediately behind the main hospital lifts on the ground floor. It is signposted 'oncology out-patients'.

The Macmillan cancer information and support centre is also located in the oncology out-patients area.

## Transport

Hospital transport is provided for those in medical need. You will be assessed to determine your need for this, and if suitable, you will then need to book your transport by contacting the transport office directly. You cannot normally bring an escort with you.

The hospital is well served by public transport. The 24, 46, 168, 268 and C11 buses stop near the hospital. London Overground trains stop nearby at Hampstead Heath station and the nearest tube station is Belsize Park on the Northern line.

Car parking is extremely limited. We have a few allocated parking slots for radiotherapy patients. These allocated parking spaces are only for patients while on radiotherapy treatment and **cannot be used for follow up appointments or chemotherapy appointments.**

To use these, you must have a parking permit which can be issued during your first planning appointment. The radiotherapy receptionist will explain to you where the allocated parking spaces are located. You must display your permit in your car otherwise you will receive a parking fine.

Please note that if there are no allocated spaces available to park in then you will have to find alternative parking and pay.

## **Travel expenses**

Patients coming for NHS treatment may be able to claim a refund of reasonable travel expenses under the Healthcare Travel Costs Scheme (HTCS). Further details and forms needed are available on the NHS Choices website:

[www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx](http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx)

You will need to bring proof of your benefit, travel receipts and ask for proof of attendance from the radiotherapy receptionist. You then need to take these to the hospital cashier on the lower ground floor of the main hospital.

There is a Macmillan/CAB advice service for cancer patients next to the Macmillan information and support centre in the Royal Free Hospital. Please ask a health professional to refer you.



## **What is radiotherapy?**

Radiotherapy uses precise, carefully measured doses of high energy x-rays to treat cancer. Cancer cells are more sensitive to radiation than normal cells. The x-rays either destroy the cancer cells or stop them from growing.

Radiation also damages normal cells in or around the area being treated causing side effects, but these will usually recover and heal after treatment. The aim of treatment is to destroy the cancer cells while avoiding and protecting the healthy cells as much as possible.

The specialist team looking after you will help you understand the treatment and answer any questions you may have. If you have any doubts or concerns, please do not hesitate to speak to a member of your healthcare team, however insignificant it may seem.

## **How often is it given?**

Radiotherapy is given over a period of days or weeks. It is generally given from Monday to Friday. The number of treatments is decided on a case by case basis, and your doctor will discuss your treatment schedule with you.

## **How long will it take?**

Before treatment begins you will need to be seen by the clinical oncologist or registrar (your initial consultation) and you may also see the radiotherapy review specialist. Occasionally, you may have more than one visit for planning, spaced over a few days.

Treatment is usually daily on weekdays for the number of treatments your doctor has prescribed – we do not normally give treatments on the weekend. You may be seen for follow-up appointments.

Please note when arranging holidays, that the planning and treatment process will take time. We do not advise breaks in treatment and after treatment is complete it takes a few weeks to recuperate.

## **Agreeing to treatment**

Your doctor (clinical oncologist) will discuss the treatment options with you and give you a clear explanation of your treatment. Together you will consider the risks and benefits of the different treatment options and decide which are best for you.

A family member or carer is welcome to attend this appointment with you.

You will be asked for your consent to begin treatment. This consent is based on information being given to you about your treatment including the risks and benefits. The decision to have treatment is yours and should be made once you feel you have had sufficient time to consider all the options in consultation with the team.

Please contact the relevant team member (useful numbers are listed at the end of this booklet), if at any stage you wish to discuss your treatment and care. We want you to be an equal partner in your care, and will respect any decisions you make.

Once you have taken the decision to have treatment, we will give you an appointment for planning or we will contact you. Sometimes more than one planning appointment is needed before beginning treatment.

## Planning

Before starting your treatment, we need to tailor it to your specific needs. This is where the doctor, with the help of the radiographers, decides on the exact area to be treated. You will need to attend the radiotherapy department for a planning scan. This is done using a CT scanner, which takes x-rays of the area to be treated.

Those having their head and/or neck area treated will need a special mask to keep them still during their treatment.

Those having radiotherapy to their skin do not need to attend for CT scanning and will have their treatment planned on the treatment machine.

We will ask you to lie down on the couch of the machine. We will position you in the best way possible that will maximise the benefits of treatment, where you will be supported by a special piece of equipment designed specifically for this purpose.

Treatment planning is a very important part of radiotherapy. Marks will be drawn on your skin by the radiographer. They will also stick markers on your skin that are visible on the CT scan to help the doctor when planning your treatment. At the end of the CT scan, one to three tiny permanent markings will be made on your skin using a pinprick of ink. These are used to make sure that you are accurately positioned for your treatment each day.

If you would prefer not to have these marks then please discuss this with the radiographers.

This appointment takes approximately one hour. The information gathered at your planning appointment is carefully considered to produce an individual treatment plan for you. This may take a few weeks and you may need to come in for a further appointment to

check aspects of this plan shortly before your treatment begins. We will inform you if this is necessary.

**Please let us know if you have a pacemaker.**



## **Treatment**

Radiotherapy is given on treatment machines called linear accelerators. You will be asked to lie in the same position as during your CT planning appointment.

Radiotherapy treatment is painless – you cannot see or feel the x-ray. This type of radiotherapy does not make you radioactive.

The radiographers will align your permanent marks with the machine. The treatment machine will not usually touch you. If you are receiving radiotherapy to your skin you will be treated on a different machine which does gently touch you. We need you to remain still and not move throughout your treatment, so we will not make conversation with you once you are in the correct position.

You will hear a beeping noise, which shows the machine is on. Treatment normally takes about 15 minutes, but it may take longer on your first few treatments while the set-up is checked and further x-rays/images are taken.

You may be treated from several different angles, each position taking a few minutes. During this time you will be left alone in the room, although you can be seen and heard via CCTV and intercom by the radiographers at all times. Please try to remain still until we tell you that treatment is complete.

We try not to keep you waiting but suggest you allow one hour for each treatment visit. You can discuss suitable appointment times with the radiographers who will do their best to accommodate your needs.



## **Are there any side effects?**

You will be seen regularly by the radiotherapy review specialist, who will be there to manage any side-effects you may be experiencing. These vary depending on the part of the body you are having treated.

Your doctor and the radiotherapy review specialist will explain these to you and will give you a leaflet explaining radiotherapy for your type of cancer. Please ask if you are uncertain about anything.

The following information describes some of the general side-effects you may experience, as well as other things you may be concerned about.

### **Effects on the skin**

Your skin in the treated area may become pink and occasionally feel sore depending on your type of treatment. We will tell you if this is likely to happen to you. Following the instructions given to you by the radiotherapy review specialists will help.

You can continue to wash your skin and have a bath or shower, but we advise you not to soak too long or have the water very hot. Use mild non-perfumed soap and pat the area dry rather than rubbing it.

If your skin becomes sore, the radiotherapy review specialists will provide advice and will intervene as necessary.

On rare occasions your skin may become discoloured. This is mainly if the skin itself is being treated and will fade over time. We will discuss this with you if there is a possibility of this occurring.

## **Will my hair fall out?**

This will only happen if you have treatment to a hair bearing area. We will warn you if this might occur and advise you how to care for your hair. We can arrange for a wig to be provided to you if you lose the hair on your head. Please discuss this with the radiotherapy review specialists.

## **Eating and drinking**

Most patients can eat and drink normally during treatment. If you are losing weight please inform us. If you are concerned about what to eat and drink please discuss this with us.

You can normally drink alcohol, but we suggest beer or wine rather than spirits. Please check with your doctor in case the medication you are on makes this inadvisable.

For some patients you will be given advice if you need to follow a modified diet of food and drink during your radiotherapy treatment. This will be discussed with you before your planning scan.

## **Sickness and diarrhoea**

Some patients may feel sick depending on the area being treated. Please tell us immediately so that we can get medication prescribed for you.

## **Tiredness/fatigue**

This is a common side-effect of treatment, and tiredness normally increases as treatment progresses. Once your course of radiotherapy is completed, your energy levels may take several weeks to improve. You can help to manage fatigue by doing gentle exercise, and planning your day so that you have rest periods. It may also help to save your energy for doing things you enjoy.

If you would like further information about fatigue please ask.

## **Fertility and reproduction**

If your pelvis is being treated, radiotherapy will affect your fertility.

Please note we advise all patients to avoid conceiving children during radiotherapy. Please discuss this with your doctor.

## **Pregnancy**

Please inform us at any time during the planning or treatment if you think that you may be pregnant.

## **Late side-effects**

Late side effects can occur months or years after your radiotherapy has finished. These late effects depend on the dose of radiotherapy and the area treated. They are described in the individual treatment guides. Your doctor will tell you about any potential late side-effects as part of the consent process.

## **Driving**

The Medical Advisory Branch of the Driving and Vehicle Licensing agency (DVLA) issue guidelines regarding health. These request that certain health conditions are brought to their notice. Information regarding this is available on the DVLA website: [www.gov.uk/health-conditions-and-driving](http://www.gov.uk/health-conditions-and-driving).

It is also important to be aware of the situation regarding motor insurance. The Automobile Association (AA) advise that insurance companies must be informed about any new diagnosis of drivers as soon as possible. This is termed 'a duty of disclosure'. This is recommended as failure to inform your insurer could lead to problems in the event of making a claim.



## **Working**

Whether you choose to work or not during your radiotherapy will depend on your individual circumstances. You can discuss this with your doctor or radiotherapy review specialist.

## **Care during treatment**

You will be seen regularly by the radiotherapy review specialists during your treatment.

We also have a team of staff who can support you during your treatment, including counsellors to help you discuss any issues that concern you.

If you have any concerns out of the hours – the radiotherapy department is open 9am-5pm only – please contact your GP or 11 East ward (the oncology ward).

If you are acutely unwell please call the emergency services or visit your nearest emergency department.

## **Arranging child care**

Please note that we cannot care for children during your planning appointment or treatment. If you do need to bring a child with you, please ensure you bring a responsible adult to care for them.

## **When treatment has finished**

The side-effects may continue and even become a little worse. They will then get better. Symptoms will vary in the way they lessen.

You may see a doctor six to eight weeks after you finish treatment, but if you have any concerns related to your radiotherapy please contact the radiotherapy review specialists.

We also have a leaflet entitled 'Completing your radiotherapy' available on the radiotherapy reception desk or you can ask for a copy if you do not receive one before you finish your radiotherapy.

Alternatively you can download the leaflet and others from our library, on our website at:

[www.royalfree.nhs.uk/cancer-services/leaflets](http://www.royalfree.nhs.uk/cancer-services/leaflets)

## **Additional information and support**

We appreciate that this may be a time when you need additional information about your illness, treatment, its side effects and other issues.

### **Macmillan cancer information and support centre**

There is a Macmillan cancer information and support centre at Barnet Hospital, Chase Farm Hospital and the Royal Free Hospital:

- main entrance, level 1, Barnet Hospital
- main entrance, ground floor, Chase Farm Hospital
- oncology out-patients, ground floor, Royal Free Hospital

Each has a large selection of information on all aspects of living with cancer including free internet access, various activities/events and information about massage therapy. Please see below for contact details and call for opening hours. As part of this service there is a Citizens Advice Welfare Benefits Service available through referral. Please ask your radiotherapy review specialist to refer you for an appointment for expert benefits advice.

### **Counselling service**

There is a counselling service available to discuss any emotional concerns you may have.

### **Complementary therapy service**

We have a team of complementary therapists available to provide massage. You can have a free 15 minute massage once a week during your treatment. Please ask the radiotherapy review specialist or radiographers to refer you.

### **Maggie's at the Cancerkin Centre**

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends. They provide a

number of activities including counselling and Reiki in group and one-one sessions.

They also hold ‘Look good, feel better’ makeover sessions for women having treatment. If you would like more information or to book, please ask the radiotherapy review specialists, radiographers or contact Maggie’s on 020 3981 4840.

## **Contact us**

- Radiotherapy review specialist: 020 7830 2919
- Radiotherapy and oncology counsellors: 020 7472 6739
- Radiotherapy department reception: 020 7830 2919
- Radiotherapy treatment planning: 020 7830 2919
- Out of hours advice – 11 East ward: 020 7830 2989

Please call your GP or the emergency services if you are acutely unwell during your radiotherapy (ie in the evenings and weekend).

## **Other useful contacts and websites**

### **Macmillan Cancer Support**

- Macmillan cancer information and support centre at the Royal Free Hospital: 020 7794 0500 ext 31337
- Macmillan cancer information and support centre at Barnet Hospital: 020 8216 4142 (10am-4pm)
- Macmillan cancer information and support centre at Chase Farm Hospital: 020 8375 2247
- Macmillan’s support line: 080 8808 0000
- Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

### **Maggie’s at the Cancerkin Centre**

- Phone: 020 3981 4840
- Website: [www.cancerkin.org.uk](http://www.cancerkin.org.uk)

## How to comment on our service

We welcome comments and suggestions about your care, both good and bad. Please contact the radiotherapy manager via reception.

We have comments slips in the waiting area – please help us improve our service with your feedback. We regularly display information in the waiting room about our responses to your comments and results of surveys that we ask you to complete. If you would like a personal reply please let us know.

Alternatively, you can leave us feedback via Twitter (@RoyalFreeNHS), Facebook or NHS Choices.

## How to raise a concern or make a complaint

If you are unhappy with any aspect of your care, please speak to those involved. If you remain unhappy please speak to the radiotherapy manager (contactable via reception).

We also have a PALS (patient advice and liaison service) team at the front of the hospital on the ground floor who are there to help you get the care you need. You can contact them by completing their online form at: [www.royalfree.nhs.uk/contact-us/patient-advice-and-liaison-service-pals/contact-pals-online-form/](http://www.royalfree.nhs.uk/contact-us/patient-advice-and-liaison-service-pals/contact-pals-online-form/).

Alternatively you can:

- Email: [rf.pals@nhs.net](mailto:rf.pals@nhs.net) for the Royal Free Hospital or [bcpals@nhs.net](mailto:bcpals@nhs.net) for Barnet or Chase Farm Hospitals
- Tel: 020 7472 6446/6447; (020 7472 6445 – 24 hour answer phone) for the Royal Free Hospital or 020 8216 4924 for Barnet or Chase Farm Hospitals
- Fax: 020 7472 6463
- SMS: 447860023323 (Deaf, hard of hearing and hearing impaired patients only)

## **Accessing your medical record**

If you wish to view your medical records there is information about how to do this on our website:

<https://www.royalfree.nhs.uk/patients-visitors/your-health-records/>.

## **How we use your information**

Patient information is only ever shared with external organisations in accordance with national laws and regulations, including the Data Protection Act. At the Royal Free London, like all other trusts, there is a member of staff known as the Caldicott Guardian who is responsible for ensuring patient data is shared appropriately.

The radiotherapy department holds information about you relevant to providing radiotherapy services. At your first visit we will ask you for your permission to use your information to improve our services by reviewing treatment care in clinical and quality audits and for training purposes. All staff members are contractually and ethically bound to keep information about you confidential.

You have the right to object to the use and disclosure to other agencies of confidential information that identifies you. This will not affect your care in anyway.

For more details about how we use patient information, please visit our website: [www.royalfree.nhs.uk/patients-visitors/how-we-use-patient-information](http://www.royalfree.nhs.uk/patients-visitors/how-we-use-patient-information).

## **Statement of purpose**

### **Our commitment to you**

We aim:

- to offer our patients world class care and expertise and to be positively welcoming, actively respectful, clearly communicating and visibly reassuring.
- to consolidate world class care delivery with a strong commitment to continual associated improvement in patient and staff satisfaction.

Our objective is to ensure:

- high quality prompt care and excellent treatment of patients, by providing a safe, comprehensive, effective service incorporating current best practice, to meet the individual needs of our patients and their relatives and carers.
- that our equipment, techniques and staff training are updated to be able to deliver cutting edge treatment.
- we provide facilities and services that respect the dignity and individual choices of our patients.

## **More information**

For more information about the cancer services at the Royal Free London, please visit our website at:

[www.royalfree.nhs.uk/services/services-a-z/cancer-services](http://www.royalfree.nhs.uk/services/services-a-z/cancer-services)

## **Your feedback**

If you have any feedback on this leaflet or for a list of references for it, please email: [rf.communications@nhs.net](mailto:rf.communications@nhs.net)

## **Alternative formats**

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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[www.royalfree.nhs.uk](http://www.royalfree.nhs.uk)