

Radiotherapy for children and young people

Information for parents, carers and young cancer patients

The purpose of this guide is to give information about radiotherapy for children and young people to help you understand more about this type of treatment.

This information should be used to support professional advice specific to your individual situation. If you have any questions it is important to speak to your medical team.

What is radiotherapy?

Radiotherapy is the treatment of cancer (and some other diseases) using high-energy radiation. This guide is about 'external beam radiotherapy', which includes using x-rays (photons) or protons. Radiotherapy beams can be directed very accurately to any area of your body, using highly sophisticated machines.

Radiotherapy is only given to children and young adults in specialist treatment centres, as not every hospital which gives radiotherapy to adults has the skilled staff needed for young people. It may be necessary to travel further away for radiotherapy treatment.

How does radiotherapy work?

The radiation leaves energy in the tissues as it passes through the body. As it does so, it injures or destroys cells in the area being treated.

Standard radiotherapy uses high-energy x-rays (called photons). The photons (x-rays) are aimed at the cancer in the body. They travel through normal cells to reach the cancer and pass through the body beyond the cancer cells.

Proton beam therapy uses small particles (called protons) instead of x-rays. The protons are made into a beam which is targeted at the cancer. The beam is set to stop when it reaches the cancer and release a large amount of energy.

Cancerous cells are more sensitive to radiation than normal cells within the same area. The DNA in the cancer cells is damaged, which means that they cannot grow and divide and so are destroyed. The normal cells are usually able to recover from the effects of the radiation and function properly.

Radiotherapy aims to deliver a highly-targeted dose of radiation to as many cancerous cells as possible, whilst causing as little harm as possible to nearby healthy cells. Radiotherapy treatment does not hurt.

Why have radiotherapy?

Radiotherapy is used as part of treatment to help destroy cancer cells within a targeted area of the body. It can be given as a treatment by itself, or it can be given before or after surgery. It may also be given with or after a course of chemotherapy. Sometimes it is necessary to treat the whole body with radiotherapy, for example, in preparation for a stem cell transplant.

Radiotherapy can be used to relieve symptoms such as pain or bleeding and improve quality of life when a cure is not possible. Your medical team will discuss this with you.

Are there any alternative treatments to radiotherapy?

Treatment for cancer often includes a combination of treatments such as surgery, chemotherapy and targeted therapies. Sometimes, other specialised types of radiotherapy such as brachytherapy and molecular radiotherapy are the best way of giving treatment. Your medical team will discuss an individual treatment plan with you.

How much radiotherapy is needed?

Treatment is different for everyone and will be planned individually. The radiotherapy doctor will decide the amount (dose) needed, over how many days.

How much radiotherapy is given depends on the type of cancer and where in the body it is, what other types of treatment are planned as well as general health. A course of radiotherapy may last a single treatment or could last for six weeks or more.

Each treatment is called a fraction. The treatment is given in separate daily fractions to reduce the damage to normal cells and hopefully cause fewer side effects.

Radiotherapy treatment is usually given once a day (and occasionally twice a day) from Monday to Friday. It is very important to follow the treatment plan and avoid any unnecessary interruptions. If there are any interruptions to treatment then these have to be compensated for, possibly with treatment at a weekend or by having an extra treatment on one day.

Who's who in radiotherapy care?

Your oncology or haematology consultant will continue to be involved with decisions about treatment and support care throughout the radiotherapy part of treatment. The multi-disciplinary team (MDT) who are already involved in your care, such as physiotherapists and occupational therapists, will continue to support with treatment related side-effects or any other issues that may arise. Radiotherapy care will be carried out by a team of specialists including some or all of the below:

Consultant clinical oncologists	Doctors specialising in radiotherapy. They are responsible for prescribing and supervising radiotherapy treatment. You will meet your clinical oncologist when you come for an appointment to find out about radiotherapy. They will go through your medical history before explaining about the different types of radiotherapy and what the treatment options are. Once treatment begins, they will see you regularly to discuss how it is going and answer any questions you may have.
Therapeutic radiographers	Trained in all aspects of radiotherapy and patient care. You will meet them when you come for the pre-treatment (also called radiotherapy planning) appointment and at every visit. They can provide support, advice and information. They also liaise with other healthcare professionals such as doctors, specialist nurses, play specialists, dieticians, physiotherapists and clinical psychologists.
Specialist paediatric radiographers/nurses	Many radiotherapy departments will have specialist paediatric radiographers or nurses who are skilled in treating children and young people and have access to a wide range of support.
Radiotherapy students or trainee assistant practitioners	Students or trainees work alongside the radiographers and are under supervision at all times.
Physicists, planning technicians or planning radiographers	Physicists or planning radiographers work with the clinical oncologist to draw up a personalised treatment plan.

Preparing young children for treatment

Hospital play specialists or specialist radiographers spend time with children to explain what is going to happen and prepare them for the treatment.

Young children may need to have a general anaesthetic so that they can keep completely still throughout the treatment. This will mean that they will not be able to eat or drink beforehand each day. They will usually have a morning appointment.

For children who stay awake during treatment there are various ways to help them feel reassured. Some hospitals have facilities to play music or audio stories, or for parents to read stories and talk over the communications system. The radiotherapy team will be able to help find what works for each child.



See our booklet and animation
'Will and Sophie have radiotherapy'
www.cclg.org.uk/publications

Giving consent

Before radiotherapy can begin, consent must be given. Parents or carers will need to give consent for children. In the UK, teenagers and young adults between 16-18 years or their parents can consent for treatment. Young adults over 18 years can consent themselves.

It is important to understand all the information about the radiotherapy treatment and have the opportunity to ask questions before a consent form is signed.

The form is a written record that you have agreed to the radiotherapy and give permission to carry on with planning and treatment.

Remember, radiotherapy treatment is an ongoing process so don't be afraid to ask questions at any time. There is no such thing as a silly question!

Pregnancy

It is important for patients not to become pregnant during radiotherapy treatment. If a person is sexually active, it is important to use contraception such as condoms, the pill or coil to avoid pregnancy. The radiotherapy team might ask some questions relating to this at the planning appointment and at the start of radiotherapy treatment. Please speak to a member of your team if you have any questions or need advice.

Planning appointment

Firstly, a visit to the radiotherapy planning team takes place. At this appointment, scans are taken to help plan the treatment.

Planning scans

These scans usually happen on a CT scanner, which uses x-rays to produce images. These images are then used alongside other scans previously done to plan the best position for the radiotherapy machine. Some types of radiotherapy will use MRI scans for planning.

For the radiographers to get the correct images, it is important to lie very still. The radiographers will explain what position is needed, depending on the area of the body to be treated. They may use cushions or specially shaped supports to help. Clothing over the area to be treated will need to be removed.

Masks and moulds

If radiotherapy is going to be given to the head, neck or a limb, then a special mask or mould may be needed. For other parts of the body, the radiographers may use foam blocks or special bags ('vac-bags') that are formed around the body and moulded to shape.

Masks and moulds are usually made from a material which is heated to make it very soft and then placed over the appropriate area of the body. This feels like a warm flannel and takes about 5-10 minutes to cool down and become hard again.

Some departments will use a plaster cast to take an impression of the relevant part of the body and then make a clear plastic mask or mould from that.

A vac-bag is a bag full of polystyrene balls (like a large bean bag) that is wrapped around the relevant part of the body and then the air is sucked out so that it moulds to the exact shape.

Masks, moulds or vac-bags help to keep the body in the correct position while the radiotherapy treatment takes place. They help to ensure that the same position is used every time.

Permanent skin marking

Once the radiographers are happy with positioning, they will draw some marks on the skin or mask and then stick some special markers over the top that will show up on the CT scan. During the scan, the couch will move in and out of the scanner for a few minutes. The scanner doesn't touch the body at all and cannot be felt although it will make noises as it is working.

After the scan, the radiographers will remove the special markers and, if the markers were on the skin, they will ask permission to make some permanent dots (like tiny tattoos) so that they don't wash off before or during your treatment.

The marks are important for the radiographers to make sure the scan position matches to the radiotherapy machine position each time treatment takes place.

Next steps

After the radiotherapy planning appointment, the treatment is carefully planned. Your clinical oncologist will work with the planning team to produce a personalised treatment plan. This may take several days or weeks depending on the complexity of the treatment and the area of the body that is being treated.

Once the treatment plan is ready, you may be asked to attend another appointment to ensure that everything fits as it should do before treatment starts. Before treatment starts, your radiographer will be able to give you a good idea of how long each treatment will take. They are usually quite short.

What can you do to help?

Before treatment starts it might be helpful to practice lying still at home for short periods.

Most radiotherapy departments have facilities for music or audio (using phones, iPods or MP3 players). To pass the time and provide some distraction while the treatment takes place, choose some music or audiobooks to listen to.

During treatment sessions, staff and family members can talk via the CCTV system to help reassure and encourage. Talk about what would be helpful in advance so that you can be prepared.

What happens on the day?

In the treatment room, the patient will need to lay on the treatment couch in the same position as set up in the planning appointment. The radiographers will check the position and help with any masks, moulds and vac-bags. The couch can also be moved to help make sure all marks made at the planning appointment match the treatment machine.

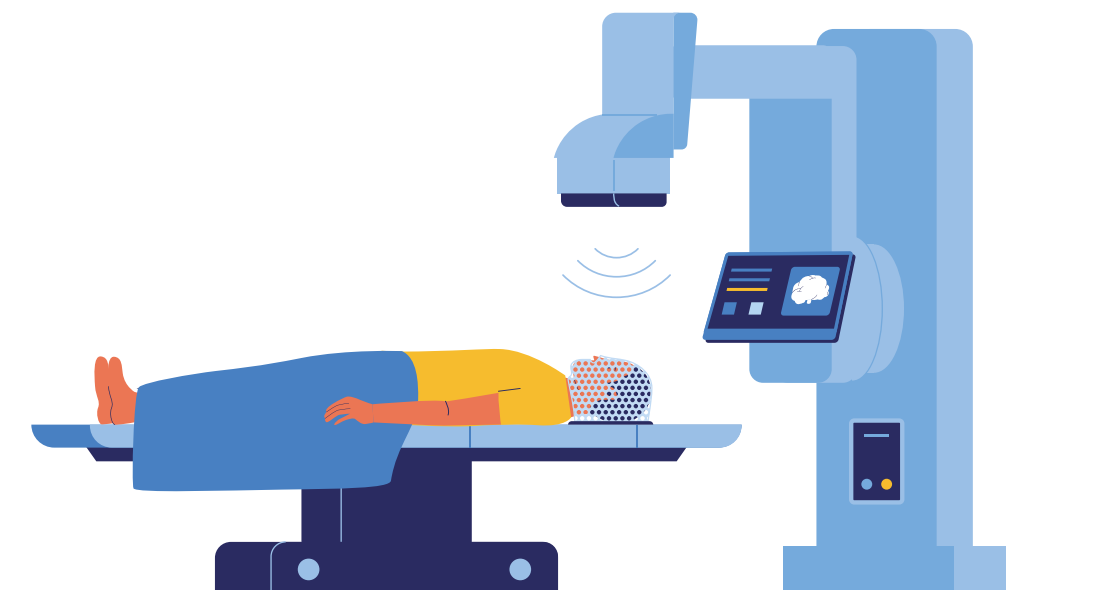
When the radiographers are happy that the position is correct, they will leave the treatment room while the treatment is being delivered. They will watch all the time on their monitors.

The machine comes close but does not touch the body and the treatment does not hurt.

There is nothing to see or feel when the machine is switched on, but there will be noises from the machine and a warning sound.

For at least the first few days, the radiographers will take some images of the treatment area during treatment. This is to ensure that exactly the same body position is used each day and that treatment goes in exactly the right place.

External beam radiotherapy treatment does not make you radioactive.



Are there any side effects of radiotherapy treatment?

Radiotherapy can cause some side effects. Not everybody will have the same side effects and some people will have more than others.

Side effects will depend on the area of the body being treated. There are general side effects of radiotherapy as well as side effects which may occur in the part of the body being treated. Your treatment team will provide more specific information and advice. The radiographers will monitor side effects every day.

Some side effects may not occur for a few weeks after starting radiotherapy treatment. Side effects may increase throughout treatment and may continue for a while after radiotherapy finishes.

Always tell your radiotherapy team about any side effects or if existing side effects get worse. They will be able to offer advice and medications to help prevent or reduce these.

General side effects may include:

- tiredness
- skin irritation
- increased sensitivity to the sun
- poor appetite
- nausea (feeling sick) and vomiting (being sick)
- headaches
- problems with balance and coordination

Tiredness

Tiredness is different for each person and does not happen straight away. After a couple of weeks of treatment, it is common to feel more tired than usual, especially if there is a lot of travelling needed each day. Tiredness may increase throughout treatment and continue for a while afterwards.

It is important to listen to body prompts and allow extra time to rest. This can be by going to bed earlier or having naps during the day. It can also help to do some gentle exercise, such as short walks, as this will help increase energy levels.

Tiredness can continue for a few weeks or months. If it does not get better, talk to your medical team.

Skin reactions

Some people develop a skin reaction during their treatment. This is dependent on the skin sensitivity, the area being treated, and the amount of treatment the skin receives. Some people don't experience any skin problems at all and others find that their skin is affected in a similar way to sunburn. Skin can become dry, sore and itchy. Depending on skin colour, it can become redder or darker.

Skin reactions don't generally happen straight away, but gradually build up over a period of time and can continue for a couple of weeks after the radiotherapy has finished. The radiographers will give you specific advice about how to care for skin while on treatment. It can help to:

- wear loose cotton clothing
- wash skin gently with mild soap and water, and pat dry
- use unperfumed moisturiser
- protect skin from strong sunlight during and after treatment — always use factor 50 sun cream and wear a hat

Eating difficulties

Radiotherapy may cause side effects that make eating difficult. Depending on what area of the body is being treated, it can become difficult or painful to swallow. It can cause nausea (feeling sick) or vomiting (being sick).

It may help to eat small snacks regularly throughout the day rather than large meals. Your medical team can give advice about nutrition, and provide anti-sickness medicines to help with feeling and being sick.

Long-term effects of radiotherapy

Some side effects from radiotherapy can be long-term or may happen many years after treatment has finished. This is called late effects of radiotherapy. These side effects will depend on the area of the body being treated, the dose of radiation given, and the age when it was given. Your clinical oncologist will discuss these late effects with you, and provide detailed information at the first introductory appointment, before consent for the treatment is given. Monitoring for late effects continues after treatment.

Are there any tests needed while on treatment?

Normally blood tests will be done before radiotherapy starts and possibly once or twice a week during treatment.

The number of blood tests will depend on the area of the body being treated. The tests will include a full blood count to monitor haemoglobin, neutrophil and platelet counts, to ensure that the radiotherapy treatment is as effective as possible.

Are there any other appointments during radiotherapy treatment?

Your clinical oncologist will want to have a catch up during treatment. This will help them monitor how treatment is going and discuss any questions or problems you may have.

What will happen after radiotherapy treatment finishes?

Depending on your individual plan, after radiotherapy finishes there may be other treatment planned or follow-up assessments to find out how well the treatment has worked. Your doctor will want to see you regularly and will discuss the plan in detail with you.

When all treatment has finished, your doctors will decide how frequently follow-up appointments should be and who will oversee follow-up. This will depend on several things, including diagnosis and what other treatments have been given.

To start with, follow-up appointments will be fairly regular but after a while clinic appointments will become further apart. If you have any queries or concerns about the radiotherapy follow-up, please talk to your radiotherapy team.

Useful information

CCLG: The Children & Young People's Cancer Association

www.cclg.org.uk

Information on childhood cancer, funding of research, and a full range of award-winning patient information resources, including Contact magazine for families of children with cancer

Scan to order or download this booklet or any other CCLG publications FREE of charge:
www.cclg.org.uk/publications



Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and their families.

www.younglivesvscancer.org.uk

Teenage Cancer Trust offers support to teenagers and young adults with cancer

www.teenagecancertrust.org.uk

Macmillan Cancer Support

Offers support and advice to those affected by cancer.
www.macmillan.org.uk

Cancer Research UK

Information and statistics on all cancer types, and a funder of research into cancer
www.cancerresearchuk.org

If proton beam therapy (PBT) is recommended, it will take place at one of two UK hospitals. For further information, please visit:



UCLH, London
www.uclh.nhs.uk/our-services/find-service/cancer-services/proton-beam-therapy-pbt



The Christie, Manchester
www.christie.nhs.uk/your-treatment-and-care/services/proton-beam-therapy

Medical terms explained

Brachytherapy

A type of internal radiotherapy that uses radioactive sources placed into, or as close as possible to, a tumour

Cancer

A large group of diseases, where abnormal cells divide without control and are able to invade other areas

Chemotherapy

Drug treatment that kills cancer cells

Clinical oncologist

Doctor who specialises in the treatment of cancer and is responsible for prescribing and supervising radiotherapy

CT scan

A series of x-rays, which build up a three-dimensional picture of the inside of the body

Diagnosis

The type of cancer you have

Electrons

A type of radiotherapy that is used to treat tumours on or near the skin's surface

Fractionation

The number of treatments the radiotherapy is split into

Gray

The measurement of the dose of radiotherapy

Impression

Mould taken of part of the body

Molecular radiotherapy

Use of radioactive drugs to treat cancer

Physicists

Specialists who work with the clinical oncologist to plan radiotherapy treatment; they also advise on issues that may affect radiotherapy treatment and are responsible for calibrating the treatment machines

Proton beam therapy (PBT)

Specialised type of radiotherapy that uses protons instead of x-rays to destroy cancer cells

Radiotherapy

The treatment of cancer (and some other diseases) with high-energy radiation

Side effects

Reactions caused by radiotherapy treatment

Surgery

Removal of a tumour during an operation

Therapeutic radiographer

A health care professional who specialises in radiotherapy and patient care during treatment

Thermoplastic

A material that becomes soft and mouldable when warmed

Tumour

An abnormal growth of cells



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This edition was reviewed by Dr Claire Esler (Consultant Clinical Oncologist, Nottingham City Hospital), Dr Jenny Gains (Consultant Clinical Oncologist, UCLH, London), Professor Ed Smith, (Consultant Clinical Oncologist, The Christie, Manchester) and Liam Herbert (Therapeutic Radiographer, The Midlands Paediatric Radiotherapy Service, Queen Elizabeth Hospital Birmingham) in conjunction with the CCLG Information Advisory Group, comprising parents, survivors and multiprofessional experts in the field of children and young people's cancer.

We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care, and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

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