



Information for parents and carers of children having cranio-spinal radiotherapy

What is radiotherapy?

Radiotherapy is a highly accurate treatment using high energy x-rays which destroys cancer cells in a specific area. Having radiotherapy is very similar to having an ordinary x-ray and does not hurt.

Normal cells within the treated area can also be affected resulting in some side effects. These will be discussed later in this information.

Why is radiotherapy given?

Radiotherapy is usually given after surgery to destroy any remaining cancer cells in the brain. As some cancer cells may have spread through the cerebro-spinal fluid (CSF) that circulates around the brain and spinal cord, radiotherapy is given to these areas too. Radiotherapy may also be given in combination with or after a course of chemotherapy.

Are there any alternative treatments to radiotherapy?

Cancer may also be treated with surgery and/or chemotherapy. Your consultant will discuss with you whether these are possible treatments for your child.

What are the benefits of radiotherapy?

The benefit of radiotherapy will be to improve or control the symptoms of your child's cancer. Your radiotherapy consultant will discuss this in more detail when you first see them.

When will radiotherapy begin?

When your child attends for their radiotherapy planning appointment, the radiographers will tell you exactly when treatment will start. Radiotherapy is given every day, Monday to Friday, and may be given for a number of weeks. The exact length of treatment will be confirmed by your doctor.

Will my child be an inpatient for their radiotherapy?

The radiotherapy treatment is given here at The Christie. Although this is an adult hospital it has the experience, staff and equipment to treat children with radiotherapy.

Most children come from home to have their daily treatment as an outpatient. If you live far away, you may stay in local accommodation or at the Royal Manchester Children's Hospital (RMCH)

and travel to The Christie. If your child is an inpatient at Royal Manchester Children's Hospital arrangements will be made for your child to come to The Christie for daily treatment.

What needs to happen before my child starts their treatment?

Once you have seen the radiotherapy doctor and they have explained the role of treatment, you will need to sign a consent form. Then there will be several preparation visits here to The Christie.

We understand that lying and keeping still on a treatment bed is very difficult for some children so every effort will be made to ensure that your child is as comfortable as possible in the position that is needed for treatment. If your child cannot lie still, the option of general anaesthesia will be discussed with you.

Your child will need to have a mask made for their treatment. Your child will wear the mask for each treatment.



Once the mask has been made, a planning CT scan will be performed (see picture below). Your child may have had lots of scans already, but this one will give the doctor the information they need to plan your child's radiotherapy treatment and are not intended to be diagnostic.



Your child will wear the mask and be in the same position as for the treatment. To enable the spinal treatment position to be reproduced every day, the radiographers will need to make tiny permanent marks called tattoos on your child's skin. These tattoos are the size of small freckles and will be used every day when the radiographers are getting your child into the correct position. They will also be an indicator in the future to show where the treatment has been delivered.

Your child may be required to undergo an MR scan, either here at The Christie or at RMCH. This is a special type of MR scan that enables the radiotherapy treatment to be planned accurately. You will be informed if this is required.

All of this information is then looked at alongside other scans that have been done previously and the doctor will decide which area needs to have radiotherapy treatment.

Each person's radiotherapy treatment is tailored to them individually and so the process of planning can take a couple of weeks.

What happens when my child comes for treatment?

The radiographers, who are the specialists who deliver the treatment every day, will help your child lie in the same position as for the scan. You can be present in the room during this period.

There are lasers to help the radiographers align your child into the correct position and a light that shines out of the machine to show the radiographers where the radiation will go.



The radiographers then move the machine around to check the treatment. Once they are happy that your child is in exactly the right position you and the radiographers will leave the room to switch on the machine.

The radiographers and you will watch your child from outside the room on TV screens. The machine will make a noise whilst it is working. When the machine switches off, the radiographers will go into the room and move the machine to the next position. The radiographers will tell your child each time they are leaving the room.

The treatment itself only takes a few minutes although getting your child into the right position may take longer. The first treatment visit will involve the radiographers checking all aspects of the treatment plan so additional time needs to be allowed for this visit.

Once treatment is finished for the day then you are all free to go home.

What does my child need to do?

The most important thing your child must do is to keep really still once they are lying on the treatment bed.

Secondly, they will need to be comfortable being in the room by themselves whilst the machine is switched on for treatment. You can talk to them or read them a story from the control room over the intercom system, or they can bring their own CD or DVD to listen to or watch in the treatment room.

What if my child cannot lie still?

Lying still can be difficult for some children, especially the younger ones, and it may be suggested that they have a general anaesthetic each day for their treatment. This is given by a specialist team from Royal Manchester Children's Hospital and is well tolerated by children.

When will my child be seen by the consultant?

During treatment your child will be reviewed by their consultant on a weekly basis, usually in the Monday or Friday clinics held on the Palatine Treatment Centre (PTC, department 30).

The radiotherapy review will involve checking for skin reactions and to assess for any complications related to the radiotherapy treatment.

You **must** also see the PTC day unit nurses on a **daily** basis, except when your child is reviewed by their consultant. A weekly blood test will be needed for the cranio-spinal treatment. This will be taken via the central line or through a cannula. The PTC day unit nurses are able to carry out central line flushes and blood tests during radiotherapy treatment.

What will happen at the end of treatment?

Your child will be reviewed by their consultant six weeks after radiotherapy treatment has finished. Your child will also be monitored by the doctors at the Royal Manchester Children's Hospital. A scan will be carried out a few months after treatment has finished when your child's body has time to recover from the radiotherapy.

Travelling and car parking

Please refer to our separate travelling and car parking leaflet, or visit our website for the latest information.

What short term side effects may occur during my child's treatment?

The short term side effects generally arise towards the middle of the course of radiotherapy, peak the week after the end of treatment then settle down within a couple of months.

- **Skin redness:** Radiotherapy can cause a very mild reddening of the skin, a little like sunburn. You can help take care of your child's skin by only using the creams and soaps advised by the radiographers and by keeping your child's skin in the treatment area covered on sunny days.
- **Headaches and nausea:** Radiotherapy can cause the brain to swell slightly causing some headaches and nausea. Medication can be prescribed to help if needed.
- **Hair loss:** There will be some hair loss in the area where your child is having radiotherapy. This will grow back in time but may appear slightly thinner.
- **Tiredness/lethargy:** As treatment continues your child may feel more tired. This is partly because of the travelling involved in coming to the hospital every day as well as the treatment. The tiredness may continue for a few weeks after your child has finished treatment and may peak again a few months after treatment is completed.

- **Sore throat:** Your child may develop a sore throat towards the end of treatment. Advice and medication can be given if necessary.
- **Vomiting:** This may occur if part of the radiotherapy treatment passes through a small part of the abdomen. This can be controlled with anti-sickness drugs.

What are the late or permanent reactions?

The late or permanent reactions are much harder to predict because each child is different. It is possible for some types of reaction to occur months or years after the treatment has finished although this is less common these days because of improvements in treatment.

Your doctor at The Christie will discuss any possible late effects with you. The following information is for guidance only and does not necessarily mean that all these side effects will happen to your child.

Hormone (endocrine) problems: There is a gland in the brain called the pituitary gland that controls many of the hormones within our bodies. The pituitary gland is sensitive to radiotherapy and if it is involved in the area of the brain that is treated, it can mean that there are problems with future growth and the timing of puberty.

The thyroid gland in the neck also produces a hormone to help with metabolism and if it receives radiation when the spine is being treated, normal production may be affected.

Your child will have long term follow-up with doctors that specialise in hormones (endocrinologists) and supplementary hormones can be given if necessary.

Bone development: Radiation affects growth of the bones of the spine (the vertebrae) which means that your child may not be as tall as expected when they are grown up.

The heart: The position of the heart means that when the spine is treated a part of it will receive a small dose of radiation which may lead to heart problems in the future. As a precaution your child will be monitored for many years at regular intervals.

Learning ability: The ability to retain new information and skills can be affected in children who have had radiotherapy to the brain. How much this will be affected does depend both on the age of the child when they have treatment and how much of the brain is treated.

Cataracts: These may occur due to the unavoidable exposure of radiation to the eyes. Fortunately, cataract surgery is very straightforward and successful.

Skin sensitivity: It is likely that your child's skin in the treatment area will be more sensitive. Good protection in the form of a hat and a total sun block should be used.

Radiation induced tumours: There is always the risk that being exposed to radiation may in the future cause a new tumour within the treatment area. Your doctor will discuss this with you.

Your child will be monitored for any of these long term side effects in a specialist clinic so that these can be managed in the best way.

Useful contact information

We hope that this leaflet will help you understand the treatment offered to your child. If you feel you need more information or have any questions or concerns, please speak to your consultant or a member of the paediatric team.

Paediatric radiographer:

0161 446 8395 / 0161 446 3000 bleep 12317

Play specialist and paediatric support co-ordinator:

0161 918 7034 / 0161 446 3000 - bleep 12304

Paediatric community liaison team leader:

0161 446 3955 / 07721 879437

PTC day unit: **0161 446 3858**

PTC outpatients: **0161 446 3593**

Ward 84 at the Royal Manchester Children's Hospital: **0161 701 7489** or **0161 701 7433**

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centre at Withington, Oldham or Salford.

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