



The Clatterbridge
Cancer Centre
NHS Foundation Trust

Information for parents and carers of children having radiotherapy

Radiotherapy



A guide for patients and carers

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This leaflet will provide you with information about what to expect when your child attends for radiotherapy treatment.

We understand that this can be a worrying time for you, your child and your family. You may feel overwhelmed by the amount of information that you have been given about your child's treatment. This booklet will help to explain this part of the treatment path.

Who has referred my child to The Clatterbridge Cancer Centre?

Your child's paediatric oncologist has requested your child be seen by a clinical oncologist at The Clatterbridge Cancer Centre (CCC), for consideration of radiotherapy treatment. The clinical oncologist will explain why they have recommended radiotherapy for them, and what to expect throughout treatment.

What is radiotherapy?

Radiotherapy treats cancer by using high-energy radiation (usually X-rays) to destroy cancer cells in a particular part of the body, while doing as little harm as possible to normal cells. Radiotherapy treatment is painless and takes a few minutes.

Your child will be receiving treatment as an outpatient.

Radiotherapy can be given to:

- Cure cancer (radical radiotherapy) - i.e. to take the cancer away permanently
- Control (slow down) the growth of cancer
- Relieve the symptoms of cancer (palliative radiotherapy)

Radiotherapy may be used on its own or in combination with surgery or chemotherapy. Your child's clinical oncologist will advise you on the best option for your child (having discussed and agreed this plan with the other members of your child's medical team).

How does radiotherapy work?

Radiotherapy affects all of the cells in the area being treated. It damages them and stops them growing and dividing. Normal cells usually have the ability to repair themselves from this damage, whilst abnormal (cancer) cells are destroyed. The aim of radiotherapy is to destroy as many abnormal cells as possible, whilst causing as little damage as possible to normal cells.



Who will we meet?

We will introduce you to the specific paediatric team members who will work closely with you and your family.

- **Consultant clinical oncologist**

A doctor who specialises in paediatric radiotherapy. This is the person who will discuss your child's intended radiotherapy treatment and its associated side effects. They have overall responsibility for the planning and care of your child at CCC and will also have a role in your child's long term follow-up and care

- **Paediatric specialist radiographer**

A radiographer who specialises in the care of children. They will liaise with staff across all sites to ensure that appointments and arrangements for radiotherapy run smoothly. If you have any questions about your child's treatment or appointment times, please contact the paediatric specialist radiographer, as they will be your key worker

- **Play Specialist**

Wherever possible, we will prepare your child for radiotherapy with the assistance of a play specialist at Alder Hey. The play specialist can attend treatment planning and may also attend on the first day of treatment with your child, if this is necessary

- **Mould room specialists**

Not every child will require this service. Those that do will meet radiographers and assistants who will work with you to design ways to help your child stay still during treatment, this will be take place at the planning appointment

- **Anaesthetic team**

Some children (especially those younger than 5 years old) find it very difficult to remain in the same position for radiotherapy treatment and so require an anaesthetic to help them to keep still. This team (led by a consultant anaesthetist along with specialist anaesthetic and recovery practitioners) will be responsible for putting your child to sleep before the treatment and waking them up after treatment. The team has lots of experience of working with us and our patients in the radiotherapy department and are trained in the care of children.

- **Therapy radiographers**

Therapy radiographers are the main people you will come into contact with in the radiotherapy department. They work closely with the clinical oncologist and the paediatric radiographer to help plan and deliver your child's treatment. Your child may see the same people every day, or they may meet a range of staff, depending on the time of their treatment and staff rotas in the department.

- **Teenage and Young Adult team**

The four-bedded Teenage and Young Adult unit (TYA) is located on Mersey ward and is a relaxed, professional and welcoming environment which was created with input from the Teenage Cancer Trust, young people and professionals.

The unit accommodates patients between the ages of 16 and 24 years as both inpatients and outpatients. It consists of four



individual side rooms and a social space which allows young people and their families to interact with each other.

Also based at Clatterbridge Cancer Centre - Wirral are the TYA Specialist psychosocial support team consisting of a lead nurse, clinical psychologist, youth support co-ordinator and social worker. The team will meet all young people within this age group referred to CCC.



If your child is aged 16 to 24 years, we will refer you to the TYA team and supply you with an additional leaflet to go with this booklet.

What's involved?

Consent for treatment

Before starting radiotherapy, we will ask you to sign a consent form on behalf of your child which gives the staff permission to give your child treatment. The form will give you written details about the radiotherapy and any risks and side effects. Before you

sign the form, please feel free to ask questions or have any details repeated. We will give you a copy of the form for your reference. From the age of 16 years, your child can sign their own consent form, if appropriate.

Pre-treatment planning

Before radiotherapy treatment starts, your child will need to come to Clatterbridge Cancer Centre - Wirral for radiotherapy planning appointments. This is where we design the radiotherapy to suit the individual child and their tumour.

When you arrive at CCC, please report to the reception desk in the radiotherapy department. A radiographer will explain the treatment planning procedure to you. Please ask questions if there is anything you don't understand.

Radiotherapy planning normally consists of mask making, application of reference marks and a CT scan.

Pre-treatment - Mould Room

It is important to keep the parts of the body being treated as still as possible during treatment. If radiotherapy is required to the head and neck region (including the brain), a moulded cast support, called a mask, is made for your child to wear during planning and at each treatment session to keep the area still. This ensures the radiotherapy is given accurately to the correct area each day.

Any reference marks needed for treatment can be drawn on the mask, rather than on your child's skin. Sometimes, we may need



to keep other parts of the body still, depending on which area of the body your child is being treated. A moulded cast may be required to help.

Each cast is individually made to ensure it fits your child well and is comfortable. Staff will explain everything in detail when you attend.

Moulded head and neck mask

It is made from a special material called thermoplastic. This is a sheet of plastic net that when heated in warm water, becomes soft and stretchy. We place the plastic net on your child's face and neck, and as it cools it takes shape. This only takes a few minutes. Sometimes, we may use a thermoplastic cast to keep limbs in position. Your child will wear the same mask or cast for each radiotherapy treatment.



Vac Bag

The Vac Bag is used to make a 'pillow' to support the area of your child's body which is being treated. It is originally a large pillow shape, filled with small polystyrene balls. Once your child is in position, a vacuum pump is attached to the pillow and the air inside is sucked out. The vac bag then forms around the shape of your child and sets in that position. Your child will then have this same vac bag throughout treatment.

Planning CT scan

Treatment planning is done on a special x-ray machine called a CT scanner. Once in the scanner room, you may be asked to remove some of your child's clothing. We do all we can to respect the child's privacy and we



will cover them up as much as possible. The radiographers will ask your child to lie on the scanner bed. They will help them get into a comfortable position with their arms and legs supported. The position will be the same as the one they will lie in for their treatment.

The planning procedure can vary in the length of time but the planning radiographers will advise you on this. During the planning procedure, the radiographers will take x-rays and measurements to help create the treatment plan. The equipment will not touch your child or hurt them.

'Marks' may be drawn on your child's skin to help the radiographers position them accurately. This ensures that the treatment is given to the right place each time. These marks will be covered and **MUST** remain in place throughout your child's treatment.



Pregnancy and Radiotherapy - If your daughter is aged 12 years and above, we will ask them, before planning and the first treatment session, if they may be pregnant. This may seem insensitive, but by law radiographic staff must be sure patients are not pregnant before they use any radiation for diagnosis or treatment. We will ask them for their signature to show that we have discussed this question with them.

Appointments

Following the planning procedure, we will give you a list of treatment appointments. If your child is NOT having a general anaesthetic, we can be quite flexible with appointment times to allow your child to attend school, if they wish.

If your child is having an anaesthetic, you will need to be here for an appointment time of 08:15 am each day of their treatment.

General Anaesthesia

Radiotherapy is not painful, however it is important that your child is able to lie still and breathe normally, for approximately 15-20 minutes whilst the treatment is being delivered. Younger children who are unable to lie still for the treatment may be offered a general anaesthetic. Your child's clinical oncologist will inform you if your child needs to be anaesthetised. If anaesthesia is required, you will meet the anaesthetics team on your first visit and they will perform an assessment of your child's suitability for general anaesthetic. They will also give you important fasting guidelines for your child.

These instructions **MUST** be followed every time your child comes for radiotherapy **IF** your child requires general anaesthetic.

Fasting guidelines

- NO food / milk / juice after 02:00am
- Your child can continue to drink water until 06:00am
- Nothing by mouth after 06:00am

If these instructions are **NOT** followed, we will be unable to perform the general anaesthetic for safety reasons and your child will have their treatment cancelled that day.

The anaesthetist will anaesthetise your child in the treatment room. You will be able to stay with them until they are asleep. You will then return to the waiting room whilst we continue with your child's treatment. The anaesthetist will monitor your child throughout the treatment and when the treatment is finished your child will be transferred to a recovery room. Once your child has recovered, you are free to go home or back to your hospital.

If your child requires an anaesthetic and you are coming by your own transport, the child **MUST** come with two adults. One adult to drive and the other to look after the child whilst in the car. If you are coming by hospital transport, only one carer is required.

It is unlikely, but if you have any concerns about your child once you have returned home, please contact your referring hospital.



DO NOT return back to CCC as we do not have the specialised support your child may require. A list of local hospitals can be found at the back of this booklet

Frequently asked questions

Why is there a gap in between my child's planning appointment and the treatment?

Once the planning CT scan pictures have been obtained, your child's consultant, radiographers, physicists and technicians process the information gathered during planning to produce an individual treatment plan (a 3 dimensional computerised dose map) for your child. We need to check all the data carefully and discuss it with your child's consultant oncologist, before we transfer the plan to the radiographers on the treatment machine. This can take time, which is why your child will have a gap between their planning and first treatment date.

The treatment sessions

The radiotherapy is delivered using a large machine called a linear accelerator. Treatments are usually given from Monday to Friday with a rest at the weekends. The number of treatment visits will vary and this will be discussed with you by your consultant. The length of treatment time will be dependent on the treatment technique.



The radiographers will explain the process to you and your child. Our paediatric specialist radiographer will be present, so you can ask any questions at this point or raise any matters you need to discuss.

At the start of the treatment, the radiographers will position your child carefully on the bed and make sure they are comfortable. The radiographers will set-up the treatment machine, using your child's treatment plan. We usually dim the lights. Set-up may take a few minutes and the radiographers often need to talk to each other, rather than to you or the child. Your child can bring music or story CD's with them and the radiographers will put this on during the treatment.



When the radiographers have finished setting up, they need to leave the room to switch on the treatment machine. During the treatment, it is NOT possible for you (or the staff) to stay in the room with them. Some children like to make use of our giant loom band, they hold one end in the treatment room and their parents hold the other end outside of the treatment room. The radiographers watch your child through closed-circuit television.



When they are outside the room, the radiographers need to confirm the details of your child's treatment, so it is usual to have a short delay before they switch on the machine. Your child

may require some x-ray pictures at the start of treatment, as an additional check of their position. During the treatment, your child will hear a humming or buzzing noise coming from the treatment machine. Your child will NOT feel anything during treatment.

It is important to minimise any unscheduled gaps once the treatment has started, where possible. Treatment is usually daily, Monday to Friday. However, the first day of treatment does not necessarily have to be on a Monday.

Treatment side effects

Radiotherapy treatment is individualised, side effects may vary and depend upon a number of factors. These will be explained clearly during consent for your child's treatment. If you have any questions or concerns, you can contact the specialist paediatric radiographer at any point, who will be happy to discuss these with you.

What should I do if my child is unwell at home?

Please telephone ahead for advice and take your child straight to your referring children's hospital. Please ask one of the nurses at the referring hospital to contact the specialist paediatric radiographer, so that we can ensure the appropriate people are aware.

Skin care

Many children only have a mild skin reaction to their treatment area. The treatment radiographers will regularly assess the condition of your child's skin, provide advice and supply appropriate topical creams or dressings, if needed. Once your child has started their radiotherapy, only use those products on the skin in the treated area that we have provided.



Washing

You may wash the area being treated gently using lukewarm water and a mild un-perfumed soap, for example, baby soap. Use your hand to wash the area, rather than a flannel or sponge. Your child is likely to have pen marks on their skin, do not try to scrub these off. Dry the area gently by patting with a soft towel. If your child is having radiotherapy to their head, they can still wash their hair or scalp using baby shampoo. Avoid using a hair dryer or, if required, use the cool setting. Loose clothing around the treatment area is advisable and clothing which can easily be removed for treatment.

Medication

Please bring any medication with you that your child will need during the time period they are likely to be at CCC as it can be difficult for us to get medicine prescribed and dispensed at short notice.

Eating and drinking

Please encourage your child to eat and drink normally as it is an important part of coping and recovering from the radiotherapy. Try to encourage your child to drink water throughout the day, reducing their intake of an evening.

Sun awareness

During treatment:

Exposure to sunshine can increase the skin reaction. If you don't normally cover up your child's skin in the treated area, for example, face, neckline or arms, you may need to get them to wear different clothing such as a long-sleeved t-shirt or a hat. While outside, help protect your child's skin by keeping them in the shade, when you can. Avoid using sun cream whilst on treatment as this has ingredients which can cause a reaction with radiotherapy treatment. Your paediatric radiographer can advise you further.

After treatment:

In the longer term, the skin in the treated area will be more sensitive to the sun. You need to be more careful to protect your child's skin from excessive exposure to sunlight. Use a high-factor sun cream (SPF 30 and above). Your paediatric radiographer can advise you further.

Follow-up after radiotherapy has completed

Your child's follow-up will be at Alder Hey on completion of their radiotherapy treatment. The staff at Clatterbridge will liaise with Alder Hey to ensure appointments are in place.



Where are we?

By car

Clatterbridge Cancer Centre - Wirral is just off junction 4 of the M53. From junction 4, follow signs for Clatterbridge Hospital. Once you enter the grounds of the hospital, go straight ahead at the small roundabout. You will find Clatterbridge Cancer Centre - Wirral at the far end of the hospital site. At the front of the Centre's main entrance, we have a free car park for patients and visitors.

By ambulance

If you require hospital transport, please discuss this with the Paediatric Specialist Radiographer.



What facilities do we have?

Children's play area

Within the main radiotherapy department, we have a children's play area. Your child or siblings are welcome to use this area. There is a television, a variety of toys and books which are free to use. Your paediatric specialist will show you where it is. Children must be supervised by an adult at all times.

Refreshments

The RVS coffee shop (main entrance)

The coffee shop sells a selection of hot and cold food. Monday to Friday 8am - 5.30pm

RVS tea bar

The tea bar serves hot and cold drinks and snacks. Monday to Thursday 9am - 5.30pm, Friday 9am - 4pm



Useful address and contacts

The Clatterbridge Cancer Centre NHS Foundation Trust

Clatterbridge Road, Bebington, Wirral, CH63 4JY

www.clatterbridgecc.nhs.uk Tel: 0151 556 5000

Radiotherapy Contacts

Paediatric Specialist Radiographer - Tel: 0151 556 5701

Mobile: 07795 686127 or 07833 245558

Teenage and Young adult contacts

TYA Ward - Tel: 0151 556 5023

TYA Lead Nurse - Tel: 0151 556 5773

TYA MDT Co-ordinator - Tel: 0151 556 5122

Hospitals with A&E departments

Alder Hey Children's NHS Foundation Trust,

Eaton Road, West Derby, Liverpool, L12 2AP.

Tel: 0151 228 4811

Arrowe Park Hospital NHS Foundation Trust,

Arrowe Park Road, Wirral, Merseyside, CH49 5PE.

Tel: 0151 678 5111

Countess of Chester Hospital NHS Foundation Trust,

Countess of Chester Health Park, Liverpool Road Chester, CH2 1UL.

Tel: 01244 365000

How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

If you have a comment, concern, compliment or complaint, please call 0151 556 5203.

The Clatterbridge Cancer Centre NHS Foundation Trust
Clatterbridge Road, Bebington,
Wirral, CH63 4JY.

Tel: 0151 556 5000

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