NHS
University Hospitals Birmingham
NHS Foundation Trust

Cranial Radiotherapy Information leaflet for parents and carers

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This booklet has been written to provide a guide to parents or carers of children who are receiving cranial radiotherapy. This booklet explains the side effects that may be experienced during and after treatment.

It attempts to cover any possible questions or concerns you may have. If you have further questions or would like clarification about anything you have read, please speak to a member of staff.

What is radiotherapy?

Radiotherapy is a highly accurate treatment using high energy X-rays, which destroys cancer cells in a specific area. It 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 leaflets.

External beam radiotherapy can be delivered in many different ways using high energy radiation beams. These can either be photons, electrons or protons. Photons and electrons are delivered from a machine called a linear accelerator whilst protons are delivered from a machine called a cyclotron.

Photon and electron radiotherapy treatment is available in many radiotherapy departments nationally. Proton beam therapy (PBT) is available in only a few radiotherapy departments in the United Kingdom. However, it is not appropriate to treat all kinds of cancers with proton beam therapy. If it is appropriate to treat your child with proton beam therapy then this will be discussed during the consultation with the radiotherapy team. Please be aware that if proton beam therapy is thought to be appropriate then this will require you to travel to another hospital for your child's treatment. More information about this will be given to you when you see the radiotherapy team.

Why does my child need to have radiotherapy?

Radiotherapy is usually given following surgery to destroy any remaining cancer cells. 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 and your consultant will discuss with you whether these are possible treatments for your child.

What are the benefits of radiotherapy?

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

When is radiotherapy given?

Radiotherapy is given every weekday, Monday to Friday, and may be for several weeks. The duration of treatment will be confirmed by your doctor.

Will my child be an inpatient for their radiotherapy?

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

Treatment is usually done as an outpatient so you'll come from home or if this is far away you may stay in accommodation locally which will be organised by the radiotherapy team. If your child is an inpatient and well enough for treatment then arrangements will be made for you to come over.

Radiotherapy waiting area

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.

The first visit to the Queen Elizabeth Hospital will be for radiotherapy planning. Your child will need a mask and cushion made and a CT scan prior to treatment. Your child may have had scans before, but this one will give the doctor the information they need to plan the radiotherapy treatment.

The mask is for two main reasons:

- To help keep your child still so that the radiotherapy treatment is as accurate as possible.
- So that we can put marks for alignment on the mask.

Your child will have a special cushion made for their head to rest on and then a mask will be made. Making the mask involves warming a sheet of plastic so that it softens and becomes flexible. The plastic is then gently draped over your child's head and moulded. The mask then needs to stay in position for about ten minutes whilst it hardens and sets. The plastic is warm and feels like having a warm flannel over the face. The mask needs to be a close fit, but has small holes in it so that your child can breathe easily.

Once the mask has been made a CT scan will be performed and your child will wear the mask during this procedure.

The radiographers will draw some marks on your child's mask to help with aligning your child into the position required for treatment.

We understand that lying and keeping still on a treatment bed is very difficult for most children – therefore every effort will be made to ensure that your child is as comfortable as possible in the position that is required for treatment.

If lying still is too difficult, especially if your child is very young, it may be suggested that they have a general anaesthetic each for treatment. This is done by a consultant paediatric anaesthetist from Birmingham Children's Hospital and is well tolerated by children.

Your child will need to be starved if they require a general anaesthetic for their appointments.

This procedure will be explained more fully to you by the radiotherapy doctor or paediatric radiographer.

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

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

CT scanner

What happens when my child comes for treatment?

The Therapeutic Radiographers, who are the specialists that deliver the radiotherapy treatment each day, will help your child lie in the same position as they were for their CT planning scan. This will include wearing the radiotherapy mask. You can be present in the room during this period.

Treatment may be given on a linear accelerator or a TomoTherapy machine, both are radiotherapy machines which deliver photon treatment.

There are lasers to help the radiographers align your child into the correct position. The radiographers then perform their checks of the treatment plan. Once the radiographers are happy that your child is in exactly the right position they will leave the room to switch on the machine. The radiographers will ask you to have a seat in the waiting area whilst your child receives treatment.

The radiographers watch your child from outside the room on CCTV screens. The machine will make a buzzing noise whilst it is working and the radiographers might need to go into the room to make adjustments before they start treatment. The radiographers will tell your child each time they are leaving the room.

The treatment can take several minutes. However, getting your child into the right position and performing all the necessary positional and safety checks can take considerably longer.

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

The doctor will normally review your child once a week at the Queen Elizabeth Hospital whilst they are having treatment.

TomoTherapy treatment room

Linear Accelerator treatment room

What does my child need to do?

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

Secondly they will need to be comfortable being in the room by themselves when the machine is switched on for treatment.

We work closely with the play specialist team to ensure your child is prepared for their radiotherapy treatment.

You are more than welcome to bring music for your child to listen to whilst having treatment.

Please ensure your child is wearing comfortable clothes when they come for their appointment. Please be aware that some of your child's clothing may need to be removed during the planning and treatment appointments but we will endeavour to keep them warm and maintain their dignity.

If your child requires a general anaesthetic to keep still for their treatment then you will be able to be with your child whilst they are anaesthetised in the treatment room. You will then be asked

to have a seat in the waiting area whilst your child is having the treatment. After the procedure is complete your child will be taken into the recovery room. The anaesthetics team will come and get you when it is appropriate for you to be with your child.

What will happen at the end of treatment?

Your child will be monitored by the doctors at Birmingham Children's Hospital and have a scan a few months after treatment has finished.

CCTV monitors

The treatment rooms are monitored during your child's preparation for treatment, positioning and treatment delivery by television cameras. This is part of ensuring the accuracy of treatment, safety and wellbeing in the rooms at all times. The camera image feed is live and it is not possible to make a recording. The images are viewable on screens situated in the machine control areas. The control areas are only accessible by authorised radiotherapy staff, some who may not be directly involved with your child's care at that time. If you have any concerns about your child's privacy or dignity that you have not already discussed then please do not hesitate to highlight your concerns to the radiographers.

Radiotherapy and Pregnancy

As we will be using radiation at the CT scan appointment and for treatment we have a legal duty to ensure that any patient with the ability to bear a child, aged 12 years or over is not pregnant. We will need to check at the CT scan and on the first day of treatmetn that your child is not pregnant. We understand that the nature of this conversation is very sensitive and our staff will try to minimise any distress this may cause to you or your family and it will be carried out in confidential manner and environment.

Please remember that even a small amount of radiation may harm an unborn foetus (baby) so it is very important to let the radiographers know immediately if there is even a small possibility that your child may be pregnant, before being exposed to any radiation on the CT scanner or during treatment.

Are there any side effects of treatment?

Radiotherapy affects the cancer cells and also the surrounding normal tissue, which can lead to some side effects developing. It is difficult to predict which side effects will occur as everybody is an individual.

Side effects can be divided into early or acute side effects which can start within a few hours of treatment and last several weeks or late or long-term side effects which tend to develop several months to years after treatment and do not affect everybody, usually only a small percentage of patients.

This information has been written as a guideline and your doctor will have discussed this in more detail with you. If you are worried about anything please speak to a member of staff.

Remember radiotherapy is given to a certain site therefore the side effects that may occur will only be in this area.

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 (Erythema) – may occur following treatment, especially those with fair skin. Please use gentle unperfumed soaps that you have used previously with your child and have not caused any skin reactions.

Please only use moisturising products on your child's skin that you have discussed with the nurses or radiographers.

Please keep your child's skin in the treatment area covered on sunny days.

Please do not use sun protection or after sun on your child's skin whilst they receive treatment.

If your child develops a skin reaction the nurses, doctors or radiographers can offer you further advice.

Headaches – some children receiving radiotherapy to the brain may experience headaches. Medication can be prescribed to help with this, including steroids, if required.

Vomiting – nausea and vomiting may occur during treatment. Medication will be prescribed for your child to take on a daily basis prior to radiotherapy

Hair loss – there will be some hair loss in the area that 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.

Return of symptoms – any symptoms that your child had before the radiotherapy may come back or increase whilst on treatment due to the swelling the radiotherapy can cause. This can include hearing problems, visual disturbances and weakness.

Seizures - rarely radiotherapy to the brain can trigger a seizure.

What are the long-term side effects?

The long-term side effects are much harder to predict because each child is different e.g. age, size, skin tone, tumour type and treatment regime. Unfortunately when these side effects do happen they are permanent. 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 within the brain called the pituitary gland that controls many of the hormones within our bodies. The pituitary gland is sensitive to radiotherapy and if affected, it can mean that there are problems with future growth and the timing of puberty.

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

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 on the age of the child when they have treatment and how much brain is treated.

Tiredness/lethargy – even if your child has not had any tiredness during their radiotherapy, 4–6 weeks after treatment there may be a period of time when they feel particularly sleepy or that they do not have the energy to do anything. This can last for six weeks or longer. This duration of tiredness can cause people to worry as it does not seem to settle down but this is quite a normal reaction to the treatment. It will settle down.

Hearing – this can sometimes be affected due to the unavoidable exposure of the hearing apparatus to radiation.

Vision and cataracts – vision can sometimes be affected due to the unavoidable exposure of the visual apparatus to radiation. The lenses of the eyes are very sensitive to radiation and cataracts may occur due to unavoidable exposure during treatment. Fortunately, cataract surgery is very straightforward and successful.

Other disabilities – long-term damage to the brain from radiotherapy is rare. When it does occur it may simply become apparent as changes on brain scans, which are part of your routine monitoring, without any associated symptoms. However, occasionally the changes will be associated with disability. This is because a specific part of the brain sending signals to your body is not working effectively. The precise disability will depend

upon the location within the brain that has been affected. Severe problems are very rare and the risk has to be balanced against a growing tumour, which often causes such disability sooner.

Stroke – radiotherapy may cause long-term damage to blood vessels. Long-term follow-up studies have shown that patients receiving radiotherapy to the brain in the region of the major blood vessels are at an increased risk of stroke decades later. However, the precise relationship remains poorly understood as many of these patients had also undergone complex surgery.

Skin sensitivity – it is likely that your child's skin in the treatment area will always be more sensitive. Good protection with total sun block, (minimum of SPF 30), 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 they can be managed optimally.

Data protection

We collect information about your child and family relevant to their diagnosis and treatment. We store it in written records and on computer. We may have to share some of your information with other people and organisations. If you have any questions and/or do not want us to share that information with others, please talk to the consultant looking after your child or contact the PALS (Patient Advice and Liaison Service) on telephone: **0121 333 8403/8611** at Birmingham Children's Hospital or **0121 371 3280** at Queen Elizabeth Hospital Birmingham.

Further information

We hope that this leaflet will help you to 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 the specialist paediatric radiographer:

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Telephone number: .....

Further information and support is available at:

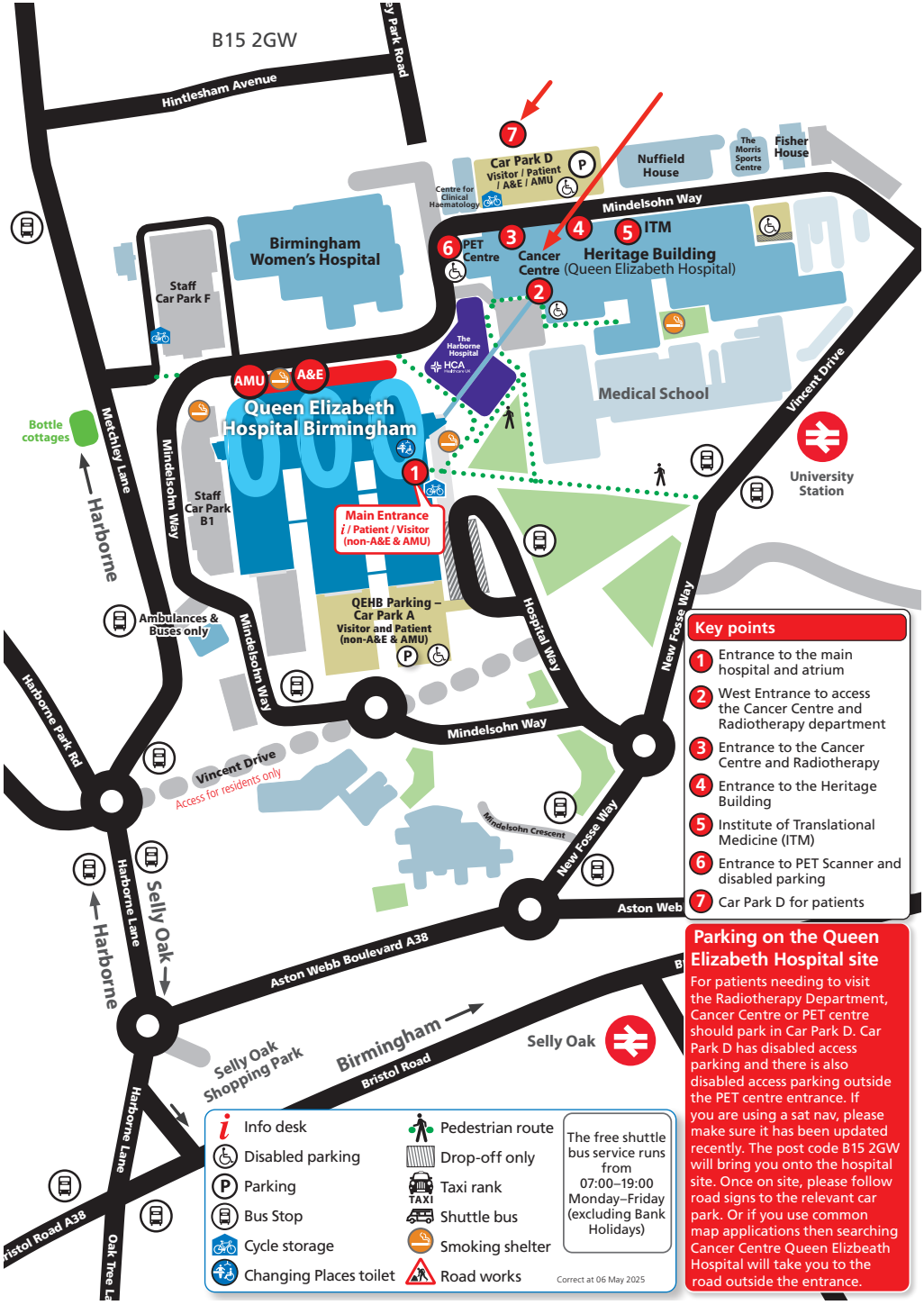
The Patrick Room
The Cancer Centre
Queen Elizabeth Hospital,
Edgbaston, Birmingham, B15 2TH
Telephone: **0121 371 3539**

Child and Family Information Centre
Birmingham Children's Hospital NHS Foundation Trust
Steelhouse Lane, Birmingham, B4 6NH

Telephone: **0121 333 8505**

Macmillan Cancer Support
www.macmillan.org.uk
Telephone: **0808 808 0000**

This leaflet has been produced by the Radiotherapy Department, Queen Elizabeth Hospital Birmingham.



Key points

1. Entrance to the main hospital and atrium
2. West Entrance to access the Cancer Centre and Radiotherapy department
3. Entrance to the Cancer Centre and Radiotherapy
4. Entrance to the Heritage Building
5. Institute of Translational Medicine (ITM)
6. Entrance to PET Scanner and disabled parking
7. Car Park D for patients

Parking on the Queen Elizabeth Hospital site

For patients needing to visit the Radiotherapy Department, Cancer Centre or PET centre should park in Car Park D. Car Park D has disabled access parking and there is also disabled access parking outside the PET centre entrance. If you are using a sat nav, please make sure it has been updated recently. The post code B15 2GW will bring you onto the hospital site. Once on site, please follow road signs to the relevant car park. Or if you use common map applications then searching Cancer Centre Queen Elizbeath Hospital will take you to the road outside the entrance.

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email **interpreting.service@uhb.nhs.uk**.

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PI24/0847/05 Author: Liam Herbert
Date: May 2025 Review date: May 2027