Patient Information Booklet

Radiotherapy for Children with Medulloblastoma

The Beatson West of Scotland Cancer Centre
1053 Great Western Road, G12 0YN
Radiotherapy for Children with Medulloblastoma

Your child is to have a course of radiotherapy treatment. This leaflet will explain how we plan and deliver the treatment. It will also tell you about possible side effects that your child may experience. It is important to point out that the information contained in this leaflet is very general and it does not mean that everything applies to your child or that your child will experience all of the side effects listed.

You will meet with a clinical oncologist (doctor who specialises in radiotherapy treatment) who will discuss the treatment with you and your child. Usually, for medulloblastoma we treat the whole head and spine. This is often followed by extra treatment (boost) to the area where the tumour was originally found.

Preparing for radiotherapy

Your child will need to lie on their front and stay very still for treatment. To make this easier a special head mask called a BDS (also called a shell or mask) will be made to help keep the head completely still for treatment. This involves a visit to the mould room where the mask will be made. Depending on the type of mask your child needs, one or two visits to the mould room will be needed. You will be told what your child needs and the procedure explained to you on the first visit. When you attend the mould room the staff will ask your child to remove their clothing to the waist, however if your daughter has a cotton vest top with thin straps she can keep this on. If your child has long hair and is planning on having this cut short for treatment, please do so before your first visit to the mould room as this can affect the fitting of the mask.

Going through radiotherapy planning and treatment can be difficult for younger children and sometimes it is easier if the child is asleep. If this is the case your child will have a general anaesthetic. Your child’s doctor will discuss this in more detail with you.
Planning the Treatment

The next step is planning your child’s treatment. Because each child is unique, they will have an individual treatment plan. There are 2 stages to planning the treatment.

- **CT Simulator:** Your child will usually visit the CT simulator on the day that they have their mask fitted. This is similar to a CT scanner and is specially designed for planning radiotherapy treatment. Your child will be lying face down wearing the mask that was made in the mould room. This is the position they will lie in for treatment. The time in the scan room will normally be about 15 minutes. We will use the scans to outline the exact area that will be treated. You will have to leave the room and watch through a window when the scan is actually taking place, this takes about 5 minutes.

- **Contrast:** We will give your child intravenous contrast immediately before the CT scan to improve the pictures we get. This is done using a hickman line (see later) if your child has one. If not we need to arrange for a small cannula (plastic needle) to be put into the back of their hand or arm before the scan. Anaesthetic (‘magic’) cream is used to numb the area. Your child will have already had this type of contrast for an earlier scan.

- **Simulator:** Approximately two weeks later your child will visit the simulator. This is a large x-ray machine that is similar to the treatment machines. At this visit the simulator radiographers will take some x-rays. You cannot be in the room when the x rays are being taken however you can watch through a window. We do not need to treat all of your child’s face and head so special alloy (a type of metal) blocks will be made to protect this area. These blocks do not touch your child. The radiographers and doctor check the x-rays to make sure the shielded area is correct.

It is usually necessary to put a tiny permanent mark on the skin of the lower back. This is only the size of a small freckle and involves a pin prick onto the skin. This is done at the end and is often called a tattoo.
Treatment

• Your child will have treatment on a **linear accelerator**, which is a special type of x-ray machine. The radiographers will explain everything to you and your child before treatment starts. They will check you know what to expect and how many treatments your child will have. This can vary but as a guide it is usually between 4 and 6 weeks. The radiotherapy will be given in small daily doses, lasting 5-10 minutes, Monday to Friday but not at weekends.

• The radiographers will position your child just as they did for simulation. The lights in the room will dim for a few minutes while they do this. You may accompany your child into the treatment room when the treatment positioning takes place. However you will need to leave the room with the radiographers while the machine is on. This is only for a few minutes and you can watch your child on the television screen from outside.

• Your child can bring a small toy with them, or their favourite music or story can also be played during treatment. Radiotherapy does not hurt and your child should not feel any differently afterwards. The whole process will take approximately 20 minutes. When the machine is ready for use there is a warning alarm that sounds which is normal. The machine also makes a faint buzzing noise when it is switched on. If you have any questions about the treatment please speak to the radiographers.
**General anaesthetic**
If your child is having a general anaesthetic, they will have a special plastic tube called a hickman line inserted under anaesthetic at Yorkhill. This allows the anaesthetists to put them to sleep without using needles. The line will stay in place until all the treatment has finished.

The anaesthetic will be given in the treatment room or in another quiet place close to the treatment room, before your child is lifted into the treatment position. Once they have gone to sleep we will ask you to wait in the waiting area. Monitoring equipment used by the anaesthetist is placed inside and outside the treatment room so that we can closely observe your child during treatment. The treatment process will take a bit longer than without an anaesthetic. Children who have had an anaesthetic will need to stay in the Beatson or go back to Yorkhill for a few hours each day until they are sufficiently recovered.

**Side effects during radiotherapy**
During radiotherapy your child may have some of the following problems. This is a list of every side effect that can occur and does not mean that your child will experience them all. If you have any questions or need more information please ask.

- **Nausea and vomiting:** Some children feel sick and vomit, especially in the first few weeks of treatment. We usually give anti-sickness drugs that should be taken every day. These drugs can be changed if you think they are not working.

- **Bathing:** Your child may bath or shower during treatment but don’t have the water too hot (lukewarm). Do not add anything to bath water such as bubble bath and avoid shower gels. They may use **unperfumed soap** and pat their skin dry with a soft towel. When washing your child’s hair use baby shampoo and gently towel dry. Do not use a hairdryer or straighteners and avoid using hair gel or mousse.

- **Skin care:** Your child’s scalp and the skin along their back may become red and itchy. It is important that you **do not** apply any creams or lotion to this area unless we have given them to you. However soothing they may seem, they may interact with the
treatment and cause the skin to become worse. We can prescribe cream that will help and this will settle a few weeks after treatment has finished.

- **Sore throat:** Your child may develop a sore throat which can sometimes cause discomfort when eating or swallowing. This usually happens about 3 weeks after treatment has started. The doctor may prescribe a liquid medicine to soothe the throat or in some case pain killers. This completely recovers a week or two after treatment is finished.

- **Hair loss:** Your child will lose all of their hair. It starts to fall out about 2 weeks after treatment starts and is usually all gone by the end. It starts to grow back about 3 months after all treatment has finished. Some children have thinness of the hair for a number of years; this can be more noticeable around the back of the head. Sometimes the hair does not grow back, especially over the lower part of the back of the head.

- **Tiredness or sleepiness:** Your child may become tired and sleepy during radiotherapy or after treatment is finished. This could get worse again around 4 to 6 weeks after radiotherapy has finished. Some children might lose their appetite or show a lack of interest in games, TV or friends. It usually lasts a week or two and rarely requires treatment. However, if you are at all concerned about your child please contact Yorkhill and arrange to see your doctor there.

- **Bone marrow:** The bone marrow is the place where blood cells are made and it is temporarily affected by radiotherapy. This means that we need to do blood tests every week to monitor it. If your child’s blood count falls we may need to give your child something to boost it back up or in some cases, even stop the radiotherapy treatment for a few days.

- **Headaches:** A few children can get headaches or their original symptoms might return. Sometimes the after effects of the operation come back and may be worse than they were. If you or your child notice any of these problems let us know. They usually settle down but occasionally we may need to give your child steroids or arrange a scan to investigate the problem.
Long Term Side Effects of Radiotherapy

There are a number of problems that may develop after radiotherapy. These are hardest to predict and, to an extent, will depend on the age your child was when the radiotherapy was given. During follow up at the clinic we will be looking out for these problems.

- **Growth**: Radiotherapy to the brain affects the gland that controls growth (pituitary gland) which means that young children often need help to reach full adult height. We often need to give your child extra growth hormone to achieve this. We do not usually have to start until a year after treatment has finished. Younger children have more growing to do and so are more at risk from this. Also, radiation affects the bones of the spine (vertebrae) and they do not grow as they would have done. This means that as an adult your child will have a shorter back than they would have done. Even with growth hormone treatment, your child’s overall height will be slightly shorter than it would have been. Again this depends on the age at which your child was treated.

- **Pituitary gland**: This gland produces a number of other hormones which may be affected by the radiotherapy. Some children may start puberty earlier. Your child will need to have tests to monitor the levels of hormones and may need to take medicine to correct low levels.

- **Thyroid gland**: The thyroid gland is in the neck and will receive some of the radiation dose. This means that it can become under active in the future. This is easily corrected by a tablet called thyroxin, which will need to be taken every day.

- **Fertility**: Fertility may be affected by the radiotherapy. Some children may receive radiation to their ovaries or testes. This depends on the position of these organs at the time of treatment.

- **Education**: The combination of the tumour, surgery and radiotherapy can have an effect on your child’s learning ability. The damage to learning varies greatly from child to child but younger children tend to have more problems. The way children handle and process information after treatment may be different and it is important that they and their school understands this. Every child with a brain tumour gets an educational assessment after treatment.
by our clinical psychology team. They link very closely with local authority educational psychologists and schools. Most children who have had cranial irradiation will require extra and ongoing help with their learning.

- **Cataracts:** There is a chance that cataracts may develop in the future, normally after several years. If you are concerned about your child’s eye sight you should have it checked. If a cataract develops it can easily be corrected but this will require a small operation.

- **Teeth:** We try not to include the teeth in the treatment area, however part of the lower jaw may receive some radiation. This increases the chance of dental problems in the future. It is therefore very important to encourage your child to brush their teeth regularly and to visit the dentist.

- **Second Tumours:** There is a small chance a child who has had radiotherapy for one tumour may develop another type of tumour some years later. However, it is important to bear in mind that this is rare and radiotherapy is necessary to cure their current cancer. Feel free to discuss this with your doctor.

**After radiation treatment has finished**

**Chemotherapy:** Radiotherapy is only part of the overall treatment. Your child may need to have chemotherapy after the radiotherapy has finished. Your doctors will have discussed this with you at the initial consultation. The chemotherapy will be given at Yorkhill Hospital by the oncology team.

**Follow up**

We will see your child regularly at Yorkhill after all the treatment is finished.

You will also have appointments at the Institute for Neurosciences at the Southern General Hospital to see the neurosurgeon.

Your child will visit the endocrine (hormone) clinic about a year after all treatment has finished so that we can monitor growth, sexual development and other hormone issues. We do combined clinics with the endocrine team at Yorkhill to minimise the number of times
you need to come to hospital
Some children may need to be seen at the neuro-opthalmology (eye), clinic either at Yorkhill or at the Institute of Neurosciences.
Your child will have scans at regular intervals.
We will continue to see your child into adulthood.

Information and Support
All our staff are here to make sure your child’s treatment goes as smoothly as possible. If you have any questions or concerns about the treatment please speak to the doctor, radiographers or nurses who will try to help with any questions or problems you may have. Further specialist help is available from:
The Paediatric Oncology Outreach Nursing (POONs) Team at Yorkhill
Tel: 0141 201 9313
Schiehallion Daycare Tel: 0141 201 0301/2
Schiehallion Ward Tel: 0141 201 0317
Paediatric Liaison Nurse Tel: 0141 301 7598 page 3880
CLIC/Sargent Social Work Team at Yorkhill Tel: 0141 201 0057/8
Macmillan Information Radiographer Tel: 0141 301 7423
Information and Support Radiographer Tel: 0141 301 7427
The Beatson Cancer Centre has a Radiotherapy Advice Line available for patients who have completed treatment. This is an answer phone service which is checked periodically. Please leave your name, telephone number and brief description of your concern and a radiographer will call you back. It can help us if you leave your child’s hospital number or date of birth. Tel: 0141 301 7432
We also have an Information Centre on level 1 in the Beatson where you can find further information and signposting to other services. Tel: 0141 301 7390
There are also voluntary organisations providing information and support.
These include;

• **CLIC Sargent** provides a range of practical, emotional and financial support: Tel: **0800 197 0068** or [www.clicsargent.org.uk](http://www.clicsargent.org.uk)

• **Teenage Cancer Trust** has a unit within Ward B7 in the Beatson.  
  Tel: **0141 301 3708**

• **Children’s Cancer and Leukaemia Group (CCLG)** can be contacted via [www.cclg.org.uk](http://www.cclg.org.uk) or Tel: **0116 249 4460**

• **Macmillan Cancer Support.**  **0808 808 0000**  
  [www.macmillan.org.uk](http://www.macmillan.org.uk)  
  Provide practical, medical, emotional and financial advice for those affected by cancer.

• **Maggie’s Centre:** **0141 330 3311**

• **Maggie’s Gartnavel:** **0141 357 2269**

• **Maggie’s Centre**, Wishaw General Hospital: **01698 358392**  
  Maggie’s Centre provides a comprehensive cancer support programme for people and their families affected by cancer.

• **Cancer Support Scotland Tak Tent:** **0141 211 0122**  
  within The Calman Cancer Support Centre, Gartnavel Complex:  
  0800 652 4531 Provides emotional and practical support on a one-to-one basis and through community based groups.

• **Macmillan Benefits Team** (within the Beatson) **0141 301 7374**  
  Provide free and confidential advice for people affected by cancer and their carers.

• **Beatson Cancer Centre** – if you want to find out more about our Centre please visit [www.beatson.scot.nhs.uk](http://www.beatson.scot.nhs.uk)

• **NHS 24  08454 24 24 24**