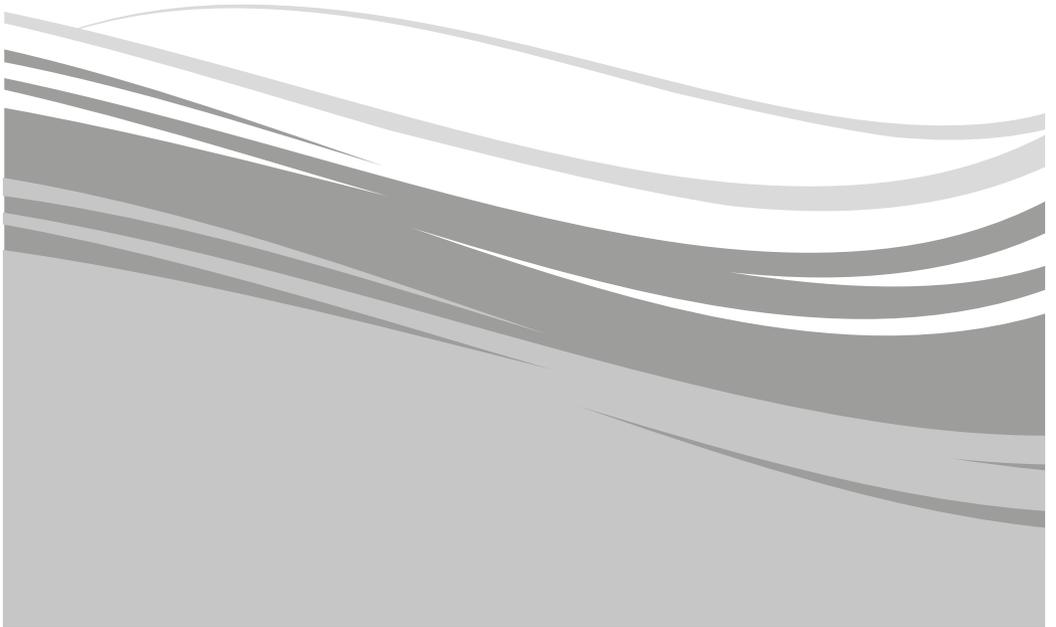


Radiotherapy for Children with Medulloblastoma



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Your child is due to have a course of radiotherapy as part of their treatment plan. This leaflet will explain:

- Preparation for radiotherapy.
- Planning and delivery of the treatment.
- Possible side effects that your child may experience and how best to cope with them.
- What happens when treatment finishes.

It is important to point out that the information in this leaflet is very general. 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 may be followed by extra treatments (boosts) to the area where the tumour was originally found.

Going through radiotherapy planning and treatment can be difficult for younger children. It is sometimes easier if your child is given a general anaesthetic to make them sleep during the treatment. Your child's doctor will discuss this in more detail with you.

Preparing for radiotherapy

Your child will need to lie very still for treatment. To make this easier a special plastic mould of their face and neck will be made. It is called a **BDS (beam directional shell)** and it is used to help keep their head and neck completely still during treatment. If your child is anaesthetised, they will still need to have the shell made.

This shell is made in the **mould room**.

Picture 1: Shell



The mould room staff will explain the procedure. They will ask your child to remove their clothing to the waist. If your child has a cotton vest top with thin straps they may prefer to wear this as they will be able to 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. It can affect the fitting of the shell.

This appointment will last about 50 minutes.

Planning the Treatment

The next appointment will be at the **CT simulator**. This is very similar to a CT scanner. The images from this scan are used to produce an individual treatment plan for your child.

Picture 2 and 3: CT Simulator



Your child will usually visit the CT simulator on the day that they have their shell made. They will wear their shell for the scan. This is also the position they will lie in for treatment.

As it is very important that your child is lying straight, the radiographers may have to go into the scan room to reposition them slightly. The time in the scan room is normally about 15 minutes.

When the scan is finished, the radiographers will need to put some permanent marks called tattoos on your child's skin. These marks are barely visible but will help the staff to position your child correctly each time they are treated. The radiographers will ask permission before doing this.

Contrast: We **may** give your child intravenous contrast (dye) immediately before the CT scan to improve the images 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.

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.

Picture 4: Linear accelerator / treatment position



Treatment time can vary, but as a guide it is usually between 4 and 6 weeks. The radiotherapy will be given in small daily doses, Monday to Friday but not at weekends.

The radiographers will position your child just as they did in the CT simulator. The lights in the room will dim for a few minutes while they do this. Your child can bring a small toy with them, or their favourite music or story can also be played during treatment.

Radiotherapy treatment does not hurt and your child should not feel any differently afterwards. The whole process will take approximately 30-60 minutes. When the machine is ready for use there is a warning alarm that sounds. The machine also makes a faint buzzing noise when it is switched on. If you have any questions about the treatment please speak to your 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 The Royal Hospital for Children (RHC). 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. 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 will take a bit longer than it would without an anaesthetic. Children who have had an anaesthetic will need to stay in the Beatson or go back to The Royal Hospital for Children for a few hours each day until they have recovered from the anaesthetic.

Side effects during radiotherapy

Below is a list of possible side effects that can occur. It 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). 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 styling products.

Skin care: Your child's scalp and the skin down their back may become red and itchy. It is important that you do not apply any creams or lotions 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. Any skin reaction 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. Your doctor may prescribe a liquid medicine to soothe the throat or in some cases, 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 usually starts to grow back about 3 months after all treatment has finished. Sometimes the hair does not grow back, especially over the lower part of the back of the head. Some children have thinness of the hair for a number of years; this can be more noticeable around the back of the head.

Tiredness or sleepiness: Your child may become tired and sleepy during their course of radiotherapy or after treatment is 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 The Royal Hospital for Children 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 side effects 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 effects.

Growth: Radiotherapy to the brain affects the gland that controls growth (pituitary gland). Therefore, 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 effect on 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 may develop another type of tumour in years to come. However, it is important to bear in mind that this is rare and radiotherapy is necessary to cure their current cancer.

If you have any questions or concerns, please speak to your child's doctor.

After radiotherapy 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 The Royal Hospital for Children by the oncology team.

Follow up

We will see your child regularly at The Royal Hospital for Children after all the treatment is finished.

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 The Royal Hospital for Children to minimise the number of times you need to come to hospital.

Some children may need to be seen at the neuro-ophthalmology (eye) clinic either at The Royal Hospital for Children 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

Tel: 0141 452 4629

Schiehallion Daycare (ward 2B, RHC) Tel: 0141 452 4475/6

Schiehallion Ward (ward 2A, RHC) Tel: 0141 452 4450

Paediatric Liaison Nurse Tel: 0141 301 7337 page 15185

CLIC/Sargent Social Work Team at RHC Tel: 0141 452 6395

Ward 3A RHC Tel: 0141 452 4500

Paediatric Radiographer: Email: jill.scott@ggc.scot.nhs.uk

Macmillan Clinical Nurse Specialist for Teenagers and Young Adults with Cancer Tel: 0141 301 7616

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. Please leave your name and telephone number and a radiographer will call you back as soon as possible.

Tel: 0141 301 7432

The Macmillan Information & Support Centre is on Level 1 at the main entrance of the Beatson. They offer emotional support, information and signposting to services within and near to the Beatson and in your own local area. Open Monday to Friday 8.15am to 4.15pm. **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: 0300 330 0803 or www.clicsargent.org.uk
- **Teenage Cancer Trust** has a unit within Ward B4 and B7 in the Beatson. There is a chill out zone located in B7.
Tel: 0141 301 7586 or 0141 301 7616
- **Children's Cancer and Leukaemia Group (CCLG)** can be contacted via www.cclg.org.uk
- **Macmillan Cancer Support** 0808 808 0000
www.macmillan.org.uk
Provide practical, medical, emotional and financial advice for those affected by cancer.
- **Maggie's Centre Gartnavel:** 0141 357 2269
- **Maggie's Centre, Monklands Hospital:** 01236 771199
- **Maggie's Forth Valley:** 01324 868069
Provide information and support offering a programme of courses to those affected by cancer. A Counselling service is also available.
- **Cancer Support Scotland – The Calman Centre, Gartnavel Complex.** Freephone 0800 652 4531.
Provides emotional and practical support on a one-to-one basis and through community based groups. Complementary therapies available.
www.cancersupportscotland.org
- **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
- **NHS 24 111**

