

## Radiotherapy for children

*When your child is diagnosed with a brain tumour, one method that may be used to treat them is radiotherapy. The term radiotherapy comes from the words 'radio', meaning 'radiation' and 'therapy', meaning 'treatment'. It uses controlled doses of invisible, high energy beams of charged particles to destroy tumour cells, whilst causing as little damage as possible to surrounding cells. Not all children will be able to receive radiotherapy. This fact sheet gives information on radiotherapy in children and some of its possible side effects.*

### In this fact sheet:

- When will my child have radiotherapy?
- How is radiotherapy treatment planned?
- The treatment mask
- The treatment procedure
- After treatment
- Answers to some common questions you may have about radiotherapy to the brain

### When will my child have radiotherapy?

It is important to recognise that not all children will be given radiotherapy. The decision to give radiotherapy will be based on a number of factors including your child's age, the location of their tumour within their central nervous system (which consists of the brain and spinal cord) and the type and size of tumour. Other factors include whether the tumour is growing or causing symptoms. The levels of radiation needed for treatment will also be taken into account and the benefits will be weighed up against the immediate and long-term risks.

If your child is under three years old, it is unlikely that they will be given radiotherapy. This is because radiotherapy can be damaging to a very young child and can cause long-term impacts on cognitive (thinking) and intellectual development, as well as on physical development, such as spinal growth and hormone levels. However, some tumour types e.g. ependymoma, may be treated with radiotherapy in younger children if the tumour is in the posterior fossa (the back of the skull cavity).

Your child will have a team of highly specialised health professionals looking after them who will assess whether or not they think giving your child radiotherapy would be the best course of action and how the treatment should proceed. They may decide to give radiotherapy if they are not able to operate on your child's tumour or after surgery to rid any remaining tumour cells and hence lower the chances of the tumour returning in the future.

Radiotherapy may also be given alongside chemotherapy to increase the likelihood of giving the best possible outcome for your child. You should always understand why a particular course of treatment has been recommended for your child, including the decision not to give radiotherapy. If you have any questions or concerns, always discuss them with your child's healthcare team.

### Planning

Your child's radiotherapy treatment is very carefully planned by a team of medical specialists to ensure that it reaches as many tumour cells as possible, whilst avoiding as much healthy tissue

as possible. All efforts will be made to avoid areas of the brain where irradiation may lead to long-term problems. Areas that radiotherapists are keen to avoid include the brain stem (responsible for functions such as breathing and heart rate); the optic nerve (which takes visual information to the brain); the hormone producing area; and the cochlear in the ear (to reduce long-term hearing loss). Sometimes it is impossible to do this without compromising treatment, so these areas may have to be given radiotherapy.

Usually an additional CT (Computerised Tomography) scan and sometimes an MRI (Magnetic Resonance Imaging) scan is needed to plan the treatment (*See separate fact sheet on Scans in children for more information*). The scans create a three-dimensional image showing the shape and location of the tumour and allow for more precise planning.

Together, the image and measurements from the scan help your child's medical team plan their treatment. Often an additional imaging machine called a simulator is used either to plan simple treatments or to check the complex treatment planned from the CT scan.

### The treatment mask

It is important that your child lies very still during treatment so that the radiotherapy is directed to the correct part of the brain. To help them stay still, your child is likely to have a treatment mask designed and made especially for them to wear each time they have treatment. If your child is very young (around three to five years old) or they are extremely anxious, they may be given a general anaesthetic before they have their treatment. For children not having a general anaesthetic, a play therapist will often work with them to make the process less daunting and help them lie still. *There is more information later in this fact sheet about play therapy.*

Young children are often given an early morning appointment as they will not be allowed to eat for a few hours prior to treatment if they are having an anaesthetic.

### The purpose of the treatment mask:

- The treatment mask is specifically made to fit your child's face and head. It fixes to the treatment couch and helps to keep their head in the same position and same place each time they have radiotherapy. This ensures that the radiation reaches the correct part of their brain each time and does not move from the planned area.
- During the planning stage, your child's radiographer may make ink marks on the mask. These are used to help position your child more easily each time they have radiotherapy treatment and will make the process smoother.
- If your child is having craniospinal (whole brain and spine) radiotherapy, they may also have some very small markings put on their skin to line up the rest of their body. In some hospitals, these will be drawn on using permanent ink markers. Your hospital team will tell you how to take care of these. If they start to rub off, tell your radiographer - do NOT attempt to re-draw them yourself. In other hospitals, two or three permanent pin-point tattoos will be used on their skin.
- When your child is receiving radiotherapy, their treatment mask will be secured down to the table on which your child lies. The masks are secured down using a screw-like mechanism and will prevent your child from moving or speaking while the machine is working.
- After your child's treatment is finished they will usually be allowed to keep their mask. This may be useful in helping siblings and friends to understand the treatment your child has undergone.

### How the mask is made:

- Your child will be taken to the 'mould room' at the hospital.
- It will take around 30 minutes to make the mask. However, it may take longer if your child is upset or nervous.
- Different hospitals use different materials to create the mask, including thermoplastic, Plaster of Paris and Perspex.
- The material is smoothed on to your child's face so that the final mask is an exact replication of the size and shape of their head. It will feel warm as it sets and has sometimes been described as a bit like having a warm flannel pressed onto the face. Gaps are left for the eyes, nose and mouth so your child is always able to breathe easily.

- Your child only needs to wear the mask during radiotherapy planning and treatment. They won't need to wear it at other times, but are usually allowed to take it home with them after their treatment has been fully completed. Some children like to use them to hang their earrings, headphones or hats on.
- To help children through the process of having their mask made and receiving radiotherapy treatment, a play therapist may work with them. This specialist will help your child understand what is happening and reduce any fears or anxiety they may have. They can let your child play with a small sample of the material used to make the mask before the mask is made and your child may be able to help make a mask for their favourite toy, which they can then take into the treatment room.

The play therapist can also arrange for your child to look at a radiotherapy machine before their treatment, so that they are mentally prepared when they see it for the first time. For younger children, the play therapist may make the radiotherapy sessions feel like an adventure and use stories, such as trips to space, to make the futuristic looking equipment seem less daunting.

### Radiotherapy mask being made



*Images reproduced with the kind permission of Cambridge University Hospitals NHS Foundation Trust.*

To see a video of how a radiotherapy mask is made, see the Cancer Research UK website:

[www.cancerresearchuk.org/cancer-help/type/brain-tumour/treatment/radiotherapy/about-brain-tumour-radiotherapy](http://www.cancerresearchuk.org/cancer-help/type/brain-tumour/treatment/radiotherapy/about-brain-tumour-radiotherapy)

## Treatment

Your child's treatment is planned to suit their individual needs and may therefore be very different to the treatment of other children you meet. An example of a typical plan is once daily treatments Monday to Friday with a break at the weekends. Each treatment is called a 'fraction'.

During treatment your child will lie on a table or bench with the radiotherapy machine above them. Staff will take some time positioning them to ensure that the radiotherapy goes to the correct place. During the positioning, your child's radiographer will attach their mask to the table to prevent your child from moving. This will stay on for the duration of the individual treatment (fraction).

Before the radiotherapy machine is switched on, staff will leave the room. This is to prevent over-exposure to radiation as they give a number of treatments each day. They will be nearby though and easily able to hear and see your child should they need them. They will also be able to speak to your child to help calm them if they are anxious. You will also need to leave the room while treatment takes place but you will be able to see and hear your child and they will be able to hear you the whole time they are having radiotherapy.

If your child is very anxious then the doctors may give them a general anaesthetic for the procedure.

## How long will treatment take?

Treatment times vary depending on your child's individual treatment plan, but each treatment (referred to as a 'fraction') can take anywhere from a few seconds to a few minutes. Craniospinal radiotherapy can take a bit longer.

For any radiotherapy, it is very important for the radiotherapy to go to precisely to the right place, so staff will spend some time positioning your child beforehand. This will make each individual treatment session considerably longer. Before the treatment begins your child's medical team will be able to give you a guideline for how long each visit to the hospital should take.

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The period of time over which your child's radiotherapy is spread will depend on their treatment plan, but it is common for it to last for around 4 to 6 weeks.

## Why is the treatment given in several small doses rather than one dose?

The full dose of radiation that needs to be given to your child will be carefully calculated, depending partly on the size, type and location of the tumour. The dosage is then usually divided into a number of smaller doses called fractions. There are two main reasons for this.

The first of these is that the sensitivity of a cell to radiation depends on where it is in its growth cycle. By giving radiotherapy in several doses it ensures that the tumour cells will receive radiation whenever they are in their most sensitive stage.

The second reason is to allow healthy cells to recover between treatments. Cells that grow and divide quickly (tumour cells) are much more sensitive to radiation than non-dividing, resting (normal) cells. Having a gap between doses gives the normal cells time to recover whilst still causing damage to the tumour cells.

## After treatment

If your child is having radiotherapy as an outpatient, they will be able to go home after each session. If they need to remain in hospital for another treatment, a nurse will take them back to their ward after radiotherapy treatment.

Once the whole course of treatment is complete, your child will have regular check-up appointments to monitor its effects. It is likely that they will experience some side-effects. Some of these will be temporary and gradually clear once the treatment has finished. Hair loss, unfortunately, can be a permanent effect, depending on the dose of radiotherapy your child receives, but most hair will grow back in time.

*(Please see sections further on in this fact sheet for side effects).*

## Who will make up my child's medical team?

Your child's treatment is planned very carefully to ensure that it is as effective as possible. The team will consist of a variety of specialists, including:

- Clinical Oncologist (specialising in radiotherapy and chemotherapy)
- Radiographer (trained in using X-ray equipment)
- Physicist (who you would not usually meet, but who specialises in, and is responsible for, the calculations used to create the precise and accurate individual treatment plan for your child)
- Play therapist (to help prepare your child for the treatment and to lie still)
- Anaesthetist (if your child needs to have a general anaesthetic for the procedure).

## Will treatment be painful?

No, your child won't be able to see or feel the radiotherapy beams and they won't feel any heat from it either. They will hear the machine though. This can be quite noisy, which some children find frightening. Some people describe the sounds as loud 'clicking' and 'whirring'. It may be helpful to talk about this with your child before they have treatment so that they know to expect it and are not afraid.

There have been some cases where children have said they have been aware of a strange smell during radiotherapy.

## Will my child be radioactive after treatment?

No. The radiation comes from the machine and will not stay inside your child's body. Once they leave the hospital it is safe for them to be around other people, including their siblings and other children.

## Will my child need to stay off school during treatment?

It is highly likely that your child will need to take some time out of school during the course of their radiotherapy treatment. This may be due to tiredness or due to daily trips to the hospital. You can help them keep up with school work by keeping in touch with their teacher to find out what their peers are currently learning and asking them to send any materials home (for example, work sheets). Alternatively your child's school may be able to organise formal home education or there may be a hospital school which they could attend while they are having radiotherapy.

Your child could qualify for additional support if they receive a special education needs (SEN) statement. To find out more about SEN statements, visit the UK Government's website page: [gov.uk/children-with-special-educational-needs/statements](https://www.gov.uk/children-with-special-educational-needs/statements)

It may also help your child if you encourage them to keep up friendships during treatment to prevent them from becoming isolated from their social circles. It could help to have a chat to the parents of your child's friends to gain their support and help with this and so that they are able to explain to their children what is happening. You could also arrange for friends to come to your house at times when your child is rested and able to engage.

If your child is older, social media sites and discussion forums can help them meet other children who have been through similar situations and stay in touch with what is happening with their group of friends. The Brain Tumour Charity has discussion forums here: [thebraintumourcharity.org/forums](https://thebraintumourcharity.org/forums)

## How can I help my child prepare for radiotherapy?

Many hospitals will ask you to take your child in to the hospital for a 'practice' session before they have treatment. During this session they go through the procedure without actually having

radiotherapy. This, as well as talking through the procedure with your child, can be helpful in reducing anxiety.

The Royal Marsden website has an animation video clip that shows radiotherapy from a child's perspective. You could show it to your child before they have treatment:

[royalmarsden.nhs.uk/cancer-information/treatment/radiotherapy/pages/children.aspx](http://royalmarsden.nhs.uk/cancer-information/treatment/radiotherapy/pages/children.aspx)

The Macmillan Cancer Support website also has an animation that may help you to explain cancer, including radiotherapy here: [macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Talkingtochildren/Talkingtochildren.aspx](http://macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Relationshipscommunication/Talkingtochildren/Talkingtochildren.aspx)

In addition to this, your child may be given access to a play therapist, who can help them to prepare for the radiotherapy procedure and deal with feelings of anxiety. A play therapist is a qualified member of staff.

## My child won't keep still during treatment

As mentioned, if your child is very young or extremely anxious, they will be given a short general anaesthetic to ensure that they remain still during treatment so that the radiotherapy beams go to the correct place. If your child is older and is not having an anaesthetic, they could get bored during treatment. Often, hospitals will allow you to take a CD along, so your child will be able to listen to their own choice of music or story while they are having radiotherapy.

## What are the typical immediate side effects of radiotherapy?

Your child's health team should discuss side-effects with you before your child has treatment and you will be asked to sign a consent form indicating that you have understood and agreed to what they have explained. Generally, the more immediate side effects gradually disappear within around 6-12 weeks after treatment finishes, however some side effects will be permanent and others may not show until your child has begun to develop further. If you are concerned about any side effects your child is experiencing, please talk to their doctor.

Some of the common side-effects of radiotherapy include:

### Tiredness

It is very likely that your child will feel tired during their treatment and, as the weeks of radiotherapy go on, this tiredness could increase. This may be because their body is using its resources to repair any damage to healthy cells caused by the radiotherapy or because of all the journeys to and from the hospital. Unfortunately, the feeling of tiredness does not stop immediately once the treatment stops and could continue for a number of weeks afterwards.

Encourage your child to rest or nap when they need to and try to plan rest breaks into their days even if they are not feeling tired. A gentle walk from time to time can also be helpful.

Children who have received radiotherapy targeted at a large area of their brain can get something called post-radiotherapy somnolence syndrome. This is a form of extreme tiredness and can occur several weeks after finishing radiotherapy, just as you think your child is getting over the treatment. Your child may sleep a lot for 1-2 weeks, but they will recover.

### Hair loss

Your child will lose some hair during radiotherapy, but this will only be from the places where the radiotherapy beam enters and leaves their head. If, however, your child has whole brain radiotherapy, they are likely to experience hair loss from their whole head. Hair loss usually starts around 2 or 3 weeks after treatment.

Although re-growth is possible, the loss can be permanent or their hair can grow back thinner or patchy. If your child's hair does re-grow, it will not normally be as thick as it was before treatment. Hats and bandanas or wigs and hairpieces are some practical suggestions for coping with hair loss.

It may be possible for your child to have a hair graft/transplant. However, this is a specialised treatment that isn't available on the NHS. It can be expensive and treatment can take a long time. Your GP can refer you to a dermatologist (a specialist in skin conditions) or a plastic surgeon with expertise in this area. You can also contact a trichologist (a hair health specialist). The Institute of Trichologists can give you more information.

You can talk to your child's radiographer about where your child is most likely to lose hair to help them prepare for this.

### Skin sensitivity

During or a few weeks after radiotherapy, some children develop changes to their skin in the area being treated. These can be a bit like sun burn (redness, blotchy and itching) in children with pale skin, and darkening of the skin in those who have darker skin. As your child's skin will be more sensitive after radiotherapy, you should take care to protect them from strong winds and the sun and always ensure they wear a sunhat with neck protection when they are outside.

Usually, the sensitivity will fade in the month or so following treatment, but your child should continue to use high factor sunscreen long-term on the areas of the skin that have received radiotherapy. This is because radiotherapy increases the risk of developing skin cancer. Your child's health team will be able to give you further guidance if your child develops skin sensitivity.

### Feeling nauseous

If your child has radiotherapy to the lower part of their brain, they may feel nauseous or actually be sick following treatment. This can start from around an hour after treatment and last some weeks. Your child's radiotherapist can give them anti-sickness tablets to help manage this.

### Reduced appetite

Your child may temporarily lose their appetite after radiotherapy. You may find that they prefer to eat several smaller snacks throughout the day, rather than three 'regular' meals, so it can help to let them eat as and when they want to. *(For further information see the Helping your child eat fact sheet).*

## Will there be any long-term side effects of radiotherapy?

Unfortunately, because a child's central nervous system is still developing, radiotherapy treatment can cause some long-term effects (known as 'late effects'). The nature of these depends on various factors, including where in the brain your child has received radiotherapy and which other parts of the brain are included in the radiotherapy field.

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Your child's health team will talk through any side effects with you before any treatment is given.

Long-term effects could include impacts on:

#### **Growth and development**

- If radiotherapy has been directed at the pituitary gland, which controls hormones that are linked to growth and development, this can mean that not enough of the growth hormone is made. As a result, growth is slowed or delayed. An artificial version of the growth hormone can be given to address this as your child gets older.
- Puberty may also be affected and could start earlier or later than usual. In particular, girls who have had radiotherapy to the head are more likely to begin puberty earlier. However, medicines can be given to halt puberty if your child starts earlier than usual, or bring on puberty if it has been delayed.
- Growth can also be affected if radiotherapy is given to the spine. This is because radiotherapy can affect growing bones, such as the vertebrae in the spine. To prevent curvature of the spine such as a hunch or stoop, any vertebra needing radiotherapy will receive radiation to the whole vertebra to prevent it growing unevenly.

#### **Intellectual development and cognitive impairment**

- These difficulties vary greatly from child to child. They can depend to some extent on how old your child was when they were treated and the intensity of their treatment.
- These difficulties are often more subtle and can therefore take longer to diagnose and support. If your child has had radiotherapy to a large area of their brain, they should have a neurological assessment to identify specific learning or processing difficulties. (Processing difficulties are problems with recognising and interpreting information received by your senses, particularly vision and hearing).
- Emotional difficulties can arise from anxiety (for example that the tumour will return or, if your child is older, perhaps about having a relationship) or anger (at having had to go through treatment when other children they know have not). They can also arise due to physical changes to the area of the brain which controls emotions and inhibitions.

- Emotional difficulties can be wide ranging and could include your child displaying heightened emotions and having difficulty controlling anger to being impulsive or taking excessive risks without fully understanding the danger. If you are worried that your child is demonstrating behaviour that is concerning you may wish to seek psychological support for your child, their siblings and yourself as a preventative measure to help limit the impact of such emotions, if and when they arise.

#### **Other long-term effects**

If your child's radiotherapy is delivered near to their eyes, there is a chance that they could develop a cataract several months or even years later. Cataracts can cause impaired vision, for example, blurring or cloudiness. However, they can be easily treated with a simple operation.

## **Where can I find a wig or headwear for my child?**

There are many styles of wig for your child to choose from, including synthetic (monofibre) and human hair wigs. You can also buy headscarves and other headwear. Children may like to wear a baseball cap or bandana if they have lost some of their hair. While we cannot recommend specific companies, below are some organisations that provide or sell wigs and headwear, or give information about hair grafts:

#### **Little Princess Trust**

This charity provides real-hair wigs free of charge to boys and girls who have lost their own hair through cancer treatment.

[littleprincesses.org.uk](http://littleprincesses.org.uk) or call **0845 094 4509**

#### **cancerwigboutique.com**

An online boutique that lists numerous companies selling wigs and headwear. You can search specifically for children's items.

#### **Cosifits-Headwear for those with hair loss**

Cosifits supplies a range called 'Cosikids chemo hair loss headwear for children'. These are soft fleece hats for children aged 4-12 years old. [chemoheadscarves.com](http://chemoheadscarves.com)

#### **Bohemia Fashions headwear**

Stocks a range of headwear (including scarves, bandanas and turbans) and has a youth/petite range.

[info@bohemiaheadwear.co.uk](mailto:info@bohemiaheadwear.co.uk) or call **01582 750083**

If your child is under the age of 16 or under the age of 19 and in full-time education, they will be entitled to a free synthetic wig on the NHS.

#### **The Institute of Trichologists - [trichologists.org.uk](http://trichologists.org.uk)**

*You may also find resources listed on our [Helping your child to eat and Chemotherapy for children fact sheets](#) useful to help with other side effects of radiotherapy described previously in this factsheet.*

#### **Disclaimer:**

The Brain Tumour Charity provides the details of other organisations for information only. Inclusion in this fact sheet does not constitute a recommendation or endorsement.

## What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team, which includes a dedicated Children and Families Worker:

Call: 0808 800 0004

(free from landlines and most mobiles:  
3, O2, Orange, T-mobile, EE, Virgin and Vodafone)

Email: [support@thebraintumourcharity.org](mailto:support@thebraintumourcharity.org)

Join our online forums at:

[thebraintumourcharity.org/forums](http://thebraintumourcharity.org/forums)

## About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours. We hope that these will add to the medical advice you have already been given. Please do continue to talk to your doctor if you are worried about any medical issues.

We are the UK's leading brain tumour charity. We fund scientific and clinical research into brain tumours and offer support and information to those affected, whilst raising awareness and influencing policy.

We rely 100% on charitable donations to fund our vital work.

If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at [thebraintumourcharity.org](http://thebraintumourcharity.org), call us on **01252 749043** or email [fundraising@thebraintumourcharity.org](mailto:fundraising@thebraintumourcharity.org)

## About this fact sheet



This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team and is supported by the Children's Cancer and Leukaemia Group (CCLG).

The accuracy of medical information has been verified by leading neuro-oncologists. Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence. If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.



# Radiotherapy for children

Your notes

**Saving lives through research,  
information, awareness & policy**



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