

Radiotherapy for children with brain tumours

When your child is diagnosed with a brain tumour, radiotherapy is one type of treatment that they may receive.

Radiotherapy uses controlled doses of invisible, high energy beams of charged particles. These are targeted at the tumour to destroy the tumour cells, whilst causing as little damage as possible to surrounding healthy cells.

Not all children will be able to have radiotherapy.

This fact sheet gives information on radiotherapy in children, the treatment procedure and some of its possible side-effects.

In this fact sheet:

- Will my child need radiotherapy?
- What happens when my child is given radiotherapy?
- What are the side-effects of radiotherapy?
- How can I prepare my child?
- Answers to other questions you may have about radiotherapy to the brain in children

Our series of animations includes one on radiotherapy in children. Watch/listen to them here:
thebraintumourcharity.org/jake

Will my child need radiotherapy?

Not all children diagnosed with a brain tumour will be given radiotherapy.

Your child will have a team of highly specialised health professionals looking after them, who will assess whether or not radiotherapy is the best course of action for your child.

They may decide to give radiotherapy:

- If they are not able to operate on your child's tumour
- After surgery to try and destroy any remaining tumour cells (and so lower the chances of the tumour returning in the future)

At all times the type and dose of radiation needed for treatment will be taken into account and the benefits of treatment will be weighed against any immediate or long-term risks. Radiotherapy is only offered if there are no other, equally successful treatments available to your child.

If your child's healthcare team decide to give your child radiotherapy, they will have based their decision on a number of factors including:

- Your child's age (radiotherapy is rarely given to under 3's)
- Location of their tumour within the brain
- Type and size of their tumour
- Whether the tumour is growing or causing symptoms.

Why might the surgeons not operate to remove my child's brain tumour?

- The tumour is in, or near, a sensitive area of the brain and the operation is likely to cause damage to this area

e.g. the brain stem (which controls breathing) or the optic nerve (responsible for sight)

In this case, they may use chemotherapy and/or radiotherapy instead.

- The tumour is low grade

(slow growing, unlikely to spread and causing relatively minor or controllable symptoms)

and the risk of a major operation to remove the tumour is more likely to cause harm to the brain than not doing anything.

This is called 'watch and wait'.

For more information, please see the *Watch and wait* web page and fact sheet.

Radiotherapy may also be given alongside chemotherapy for some tumour types.

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.

What happens when my child is given radiotherapy?

Before your child is given radiotherapy treatment, a lot of planning and preparation is needed. To make sure the treatment is as effective as possible whilst minimising the side-effects.

Before radiotherapy treatment

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.

First your child will have a 'radiotherapy planning scan' . This is usually a CT (Computerised Tomography) scan, but sometimes is an MRI (Magnetic Resonance Imaging) scan .

For more information, see the *Scans in children* webpage and fact sheet.

The scan creates a three-dimensional image of your child's tumour, showing its shape and location within the brain. Together, the image and measurements from the scan help your child's medical team make precise plans of where the radiotherapy needs to be targeted.

All efforts will be made to avoid areas of the brain where irradiation (giving radiotherapy) may lead to long-term problems.

These areas include the brain stem (responsible for functions such as breathing and heart rate); the optic nerve (which helps you see); the hormone producing area; and the cochlear in the ear (to reduce long-term hearing loss).

Sometimes it is impossible to avoid more critical areas of the brain without compromising treatment.

So depending on their tumour and its location, your child may need to be given radiotherapy which includes one or more of these areas.

As well as helping to plan the area to be targeted, the scan also helps a specialist, known as a medical physicist, to plan the doses of radiation and how the treatment should be 'staged'.

This means how many sessions of radiotherapy will be needed and how much radiation needs to be given at each treatment session. This is important as it makes sure the normal cells have time to recover before the next dose of radiation.

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 will have a treatment mask designed and made especially for them to wear each time they have treatment.

It is made specifically to fit your child's head and fixes to the treatment couch to hold their head in the same position and same place each time they have radiotherapy.

This makes sure that the radiation reaches the correct part of their brain each time and does not move from the planned area.

How the mask is made:

- Your child will be taken to the 'mould room' at the hospital.
- It will take about 15 minutes to make the mask, though you should allow more time for the whole process.
- Different hospitals use different materials to create the mask, commonly a thermoplastic mesh, or sometimes Perspex.

- The thermoplastic mesh is warmed in water to make it soft.
- The mesh is then smoothed on to your child's face, so that the final mask is an exact replica 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 will be made for the eyes, nose and mouth so your child is always able to breathe easily.

To help children through the process of having their mask made and receiving radiotherapy treatment, a health play specialist may work with them.

The play 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 specialist 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 specialist 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.

To see a video of how a radiotherapy mask is made, see the Cancer Research UK video: bit.ly/radiotherapy-mask

Once the mask is made:

- Your child's radiographer (a specialist in giving radiotherapy) will 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, a small number of permanent pin-point tattoos will be used on their skin.

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 may meet.

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.

If this is the case, they will not be allowed to eat for a few hours prior to treatment. As a result, but only where possible, young children may be given an early morning appointment.

For children not having a general anaesthetic, a health play specialist will often work with them to make the process less daunting and help them lie still.

If your child is older and not having an anaesthetic, hospitals will often allow you to take a CD along, so your child can listen to their own choice of music or story while they are having radiotherapy.

During treatment:

- Your child will lie on the radiotherapy bed with the radiotherapy machine above them
- Medical staff will take some time positioning your child to ensure that the radiotherapy goes to the correct place
- During the positioning, the radiographer will place their mask over your child's head and attach it to the table to prevent your child from moving. This will stay on for the duration of the individual treatment (called a 'fraction')
- Before the radiotherapy machine is switched on, the medical staff and you (parents/carers) will leave the room.
- This is to prevent giving any radiation to people who do not need it
- The medical staff and you will be nearby though and easily able to hear and see your child should they need you.

The medical staff will also be able to speak to your child to prevent them from feeling lonely, and your child will be able to hear them and you, the whole time they are having radiotherapy.

- Once the treatment is finished, you and the medical staff will be able to go back into the room
- The medical staff will detach the mask from the radiotherapy table and remove it, so your child can sit up and get off the table
- Your child only needs to wear the mask during radiotherapy planning and treatment. They won't need to wear it at other times
- The medical staff will keep your child's mask until the next treatment session.

How long will treatment take?

Treatment times will vary, depending on your child's individual treatment plan.

However, each treatment session (fraction), when the radiotherapy is actually being given, generally lasts only a few minutes.

The individual treatment session as a whole, will take considerably longer, due to the medical staff spending some time positioning your child to make sure they are in the right place.

If your child is having radiotherapy to the brain and spine (known as craniospinal radiotherapy), it can take a bit longer.

An example of a typical radiotherapy plan is treatment once a day, Monday to Friday, with a break at the weekends.

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

Before the treatment begins, your child's medical team will be able to tell you how many sessions your child will need, how often and over what period. They will also be able to give you a guideline for how long each visit to the hospital should take.

After treatment

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

Once the whole course of treatment is complete, your child can take their treatment mask home, if they want to.

Some children like to use them to hang their earrings, headphones or hats on. They can be useful in helping siblings and friends to understand the treatment your child has undergone.

Following treatment, your child will have regular check-up appointments to monitor the effects of the radiotherapy on the tumour and any side-effects your child may get.

It is likely that they will experience some side-effects. Some of these will be temporary and gradually clear once the treatment has finished. Others may be long-term.

What are the typical immediate side-effects of radiotherapy?

Radiotherapy works because it has the greatest damaging effect on rapidly dividing cells, such as tumour cells. However, it can also affect any normal cells within the treatment area, particularly those which also divide rapidly.

Rapidly dividing cells include skin cells, cells lining the mouth and the digestive tract, and blood cells in the bone marrow. These areas therefore tend to have the most common side-effects.

Generally, the more immediate side-effects will gradually disappear within around 6-12 weeks after treatment finishes.

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.

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 '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

Unfortunately, your child will lose some hair during radiotherapy, and this can be quite distressing for your child, particularly for older children and teenagers, and also for you.

Knowing that there will be some hair loss means that you can plan ahead and prepare your child.

For tips and suggestions, see the section further on in this fact sheet - *How can I prepare my child for radiotherapy?*

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

Generally, hair will only be lost from the places where the radiotherapy beam enters and leaves their head.

If your child has whole brain radiotherapy, however, they are likely to have hair loss from their whole head.

Hair loss usually starts around 2 or 3 weeks after treatment starts.

Most hair will grow back in time, but it may not be as thick as it was before or it may have a different texture e.g. curly when it was straight before.

Sometimes hair loss can be permanent, depending on the dose of radiotherapy your child receives.

There are lots of places that sell hats, bandanas or wigs and hairpieces as practical suggestions for coping with hair loss. Some specialise in headwear for children.

See the *Where can I find a wig or headwear for my child?* section later in this fact sheet for details.

Skin sensitivity

During, or a few weeks after, radiotherapy, some children develop changes to their skin in the area being treated i.e. on their scalp.

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 after treatment.

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.

Your child should continue to use a high factor sunscreen for the long-term on areas of the skin that have received radiotherapy.

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 doctor 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.

Meal supplement drinks can be a good alternative, but always ask your child's health team first, as some drinks could affect their treatment.

For further tips, see the *Helping your child to eat* webpage and fact sheet.

Myelosuppression (slowing of the production of blood cells by the bone marrow)

Radiotherapy can temporarily slow the production of the various types of blood cells by the bone marrow.

This can lead to anaemia, increased risk of infection and/or bleeding, such as bruising or nosebleeds.

If your child has had radiotherapy to the brain and spine, or if they are also having chemotherapy, they are more at risk of these effects. Some children may need a blood transfusion to correct these effects.

Your child's health team will discuss possible side-effects with you before your child has treatment. Feel free to ask them any questions to make sure you understand.

You will be asked to sign a consent form indicating that you have understood and agreed to what they have explained.

You can speak to your child's health team at any time about any concerns you have or side-effects your child may be experiencing.

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. These can be initial side-effects that remain permanently e.g. hair loss; or they can appear, or become more pronounced, in later years. These are known as 'late effects'.

The nature of these late effects depends on various factors. These include where in the brain your child has received radiotherapy and which other parts of the brain are included in the radiotherapy treatment area.

Your child's health team will talk through any side-effects with you and, if appropriate, your child before any treatment is given.

Long-term effects of radiotherapy could include impacts on:

Brain development, cognitive skills and emotions

- 'Cognitive skills' include thinking, memory, learning, concentration, decision-making and planning. They also include 'processing skills' - recognising and making sense of information from your senses, particularly sight and hearing.
- 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.
- Cognitive difficulties are often 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.

- Emotional difficulties can arise from anxiety (For example, that the tumour will return. Or, for older children, they may worry about whether they may have difficulty in developing relationships).

If you are worried that your child is showing concerning behaviour, you may wish to find psychological support.

You could do this as a preventative measure and involve all family members - to help your family cope with such emotions, if and when they arise.

Or emotional difficulties can arise from 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. Your child may:

- Show heightened emotions
- Have difficulty controlling anger
- Be impulsive
- Take excessive risks without fully understanding the danger.

Growth and development

- If your child has radiotherapy directed at the pituitary gland at the base of the brain, it is possible that they may grow more slowly or start growing later than their friends.
- This is because the pituitary gland controls the hormones that are linked to growth and development, and radiotherapy to the gland can mean that not enough of the growth hormone is made.
- However, an artificial version of the growth hormone can be given to your child to counteract this effect as your child gets older.
- Puberty may also be disrupted by the effect of radiotherapy on the pituitary gland and the hormones it controls.
- As a result, your child may start puberty earlier or later than usual. Girls, in particular, who have had radiotherapy to the head, are more likely to begin puberty earlier.
- Medicines can be given to halt puberty if your child starts earlier than usual, or to 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 stop it growing unevenly.

Other possible long-term effects

Cataracts 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.

Heart conditions If radiotherapy is given to the spine as well as the brain (craniospinal radiotherapy), there is a slightly increased risk of developing heart conditions later in life, as some radiation will enter the chest area.

Second tumour There is a slightly increased risk of later developing a second (different) tumour in the area of the brain where the radiotherapy was delivered.

Proton Beam Therapy (PBT)

Proton Beam Therapy is a specialised type of radiotherapy that uses different particles (protons instead of photons). Depending on the area treated, PBT is thought to cause fewer long-term side-effects.

However, it is only suitable for certain tumour types and there are currently no facilities within the UK to provide PBT to children with brain tumours.

It is hoped there will be suitable facilities in the UK from 2018 onwards. In the meantime, if PBT is felt to be beneficial for your child, there is a formal referral process to support such treatment overseas, usually in the USA.

Your child's health team can discuss this further with you.

For more information, see the *Proton Beam Therapy* webpage and fact sheet.

Other frequently asked questions

How can I help my child prepare for radiotherapy?

To help prepare your child for radiotherapy and to explain about what happens and what to expect, The Brain Tumour Charity has produced an animation about an eight-year old boy, Jake, who has radiotherapy to treat his brain tumour.

It includes an example of the noise a radiotherapy machine makes.

You could show it to your child before they have treatment.

thebraintumourcharity.org/jake

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

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

How can I help my child prepare for hair loss?

Talk to your child and encourage them to express any worries they have about losing their hair.

It is important to remember that your child is not alone and there are things to help them cope.

Take a picture of your child with how their hair is usually worn, so that a hairdresser can shape a wig. Also keep a lock of their hair to match the colour and texture.

There are many styles of wig that your child can choose from, including synthetic (monofibre) and human hair wigs.

Some people have found (gradually) cutting their hair shorter, or even shaving it all off, before the start of treatment can help it feel less of a shock.

You can also buy colourful headscarves and other headwear. Children may like to wear a baseball cap or bandana if they have lost some of their hair. Practice with different styles.

Ask your health team/hospital social worker if there are other young people who have had hair loss that your child can talk to.

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

While we cannot recommend specific companies, but some organisations that provide or sell wigs and headwear include:

Little Princess Trust

This charity provides real-hair wigs free of charge to children and young adults (boys and girls) between the ages of 2 and 24, , who have lost their own hair through cancer treatment. (UK and Ireland)

littleprincesses.org.uk or call **01432 760060**

Hero by LPT

Part of the Little Princess Trust, this service was set up in response to some boys not being comfortable receiving a wig from a charity called Little Princess Trust. It provides free real hair wigs to boys and young men aged between 2 and 24, who have lost their hair through treatment for cancer.

herobylpt.org.uk or **01432 760060**

Cosifits-Headwear for those with hair loss

Cosifits supplies a range called 'Cosikids'. These are soft fleece hats for children (boys and girls) aged 4-12 years old.

chemoheadscarves.com or **01323 325098**

Bohemia Fashions headwear

Stocks a range of headwear (scarves, bandanas and turbans), including those designed for hair loss. Also has a youth/petite range.

bohemiaheadwear.co.uk or call **01582 750083**

NHS

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

Ask your child's health team for more information.

Other resources for help with other side-effects of radiotherapy, as described in this factsheet, are listed in our *Helping your child to eat* and *Chemotherapy for children* web pages and fact sheets .

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, other side-effects or for daily trips to the hospital.

The Brain Tumour Charity has produced some *Education resources* to help them get the support they need to minimise the impact on their school/college work and keep up their friendships during treatment.

View and download them at: thebraintumourcharity.org/education-resources

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. 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. The Brain Tumour Charity animation about radiotherapy for children includes a sample of the noise.

A health play specialist can also help your child become used to the sounds of the machine.

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 brothers and sisters and other children.

Why are children under three years old not usually given radiotherapy?

If your child is under 3 years old, it is unlikely that they will be given radiotherapy.

Radiotherapy affects some normal brain cells around and beyond the tumour. With adults many of these cells can recover, though they can still result in side-effects.

However, the brains of children are still developing and those under 3 years still have much developing to do. Radiotherapy can interfere with this development, causing serious long-term side-effects - for example on cognitive development (thinking) , physical development and/or hormone levels.

Despite this, 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).

If your child is under three and their health team recommend radiotherapy, make sure they talk through the reasons for this decision with you.

What if I have further questions or need other support?

You can contact our Information and Support Team in the following ways:

- Call 0808 800 0004 (free from landlines and most mobiles including 3, O2, EE, Virgin and Vodafone)
- Email: support@thebraintumourcharity.org
- Live Chat: Get in touch with us online via thebraintumourcharity.org/live-chat
- Join one or more of our closed Facebook groups: bit.ly/FBSupportGroups
- Website: thebraintumourcharity.org/getsupport

Disclaimer

This resource contains information and general advice. It should not be used as a substitute for personalised advice from a qualified specialist professional. We strive to make sure that the content is accurate and up-to-date, but information can change over time.

Patients must seek advice from their medical teams before beginning or refraining from taking any medication or treatment.

The Brain Tumour Charity does not accept any liability to any person arising from the use of this resource.

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard – an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology.

Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you have already been given. Please do continue to talk to your medical team if you are worried about any medical issues.

If you would like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on **0808 800 0004** or support@thebraintumourcharity.org

About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research worldwide, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We wouldn't be able to make the progress we have without the incredible input we receive from you, our community.

Whether it's reviewing our information resources, campaigning for change, reviewing research proposals or attending cheque presentations, everything you do helps to make the difference.

To find out more about the different ways you can get involved, please visit thebraintumourcharity.org/volunteering

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 leaving a gift in your will or fundraising through an event, please get in touch: Visit thebraintumourcharity.org/get-involved, call us on 01252 749043 or email fundraising@thebraintumourcharity.org

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