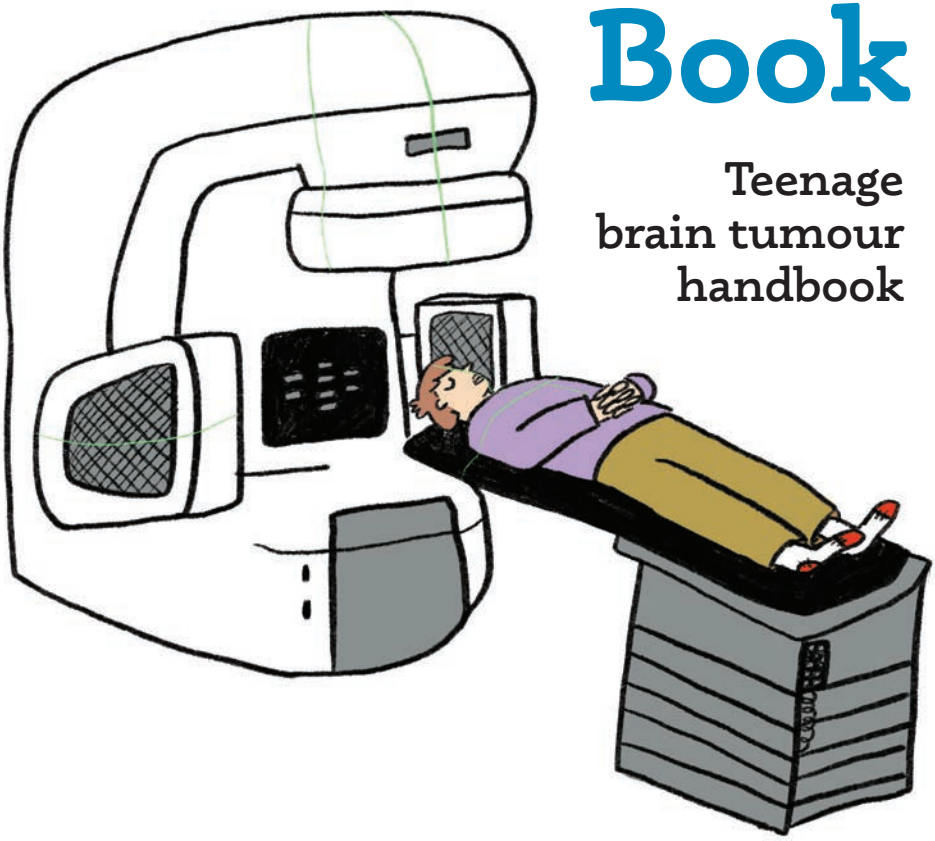
brainstrust
the brain cancer people

Radiotherapy Book

Teenage brain tumour handbook



Contents

If you are reading this, then your clinical team may be talking with you about radiotherapy as a treatment for you. This booklet should help you understand the range of radiotherapy treatments that are currently available and why one might be more appropriate for you over another.

We know how confusing it can be. Give *brainstrust* a call if you want to talk it through: **01983 292 405**. Or drop us an email at **hello@brainstrust.org.uk**.

Living with a brain tumour is complex. This is never more so than when you are a teenager or young adult who has been diagnosed with a brain tumour. This is a time when not only do you have the challenge of a brain tumour diagnosis, but you are also at a life stage when there is so much change and vulnerability.

In the 15 to 21 age group, your coping skills are emerging, and your challenges may involve education, finishing education or training, pursuing a career or vocation, expanding and reorienting your social networks, experiencing serious relationships for the first time and exploring intimacy and sexuality. So it is not surprising that this is potentially also a time for susceptibility to mental disorders.

When you are a young adult (22 to 29 years old), the challenges you face tend to take on a financial character – being independent, housing, first meaningful employment, identifying significant partners, building a home around them. Your needs with respect to your development, significant others, sexuality, career and early parenting demands will be vastly different.

And just as living with a brain tumour is complex, so is treating a brain tumour. Today, clinicians know much more about which cancers may respond to specific treatments, and which won't. And this includes radiotherapy (sometimes referred to as radiation therapy) treatments.

Treatments are personalised to match your needs. Some treatments will be inappropriate, so it is a question of finding which treatment is the best option for you. It is not that one treatment is better than another. It is a case of which is the most appropriate treatment for you.

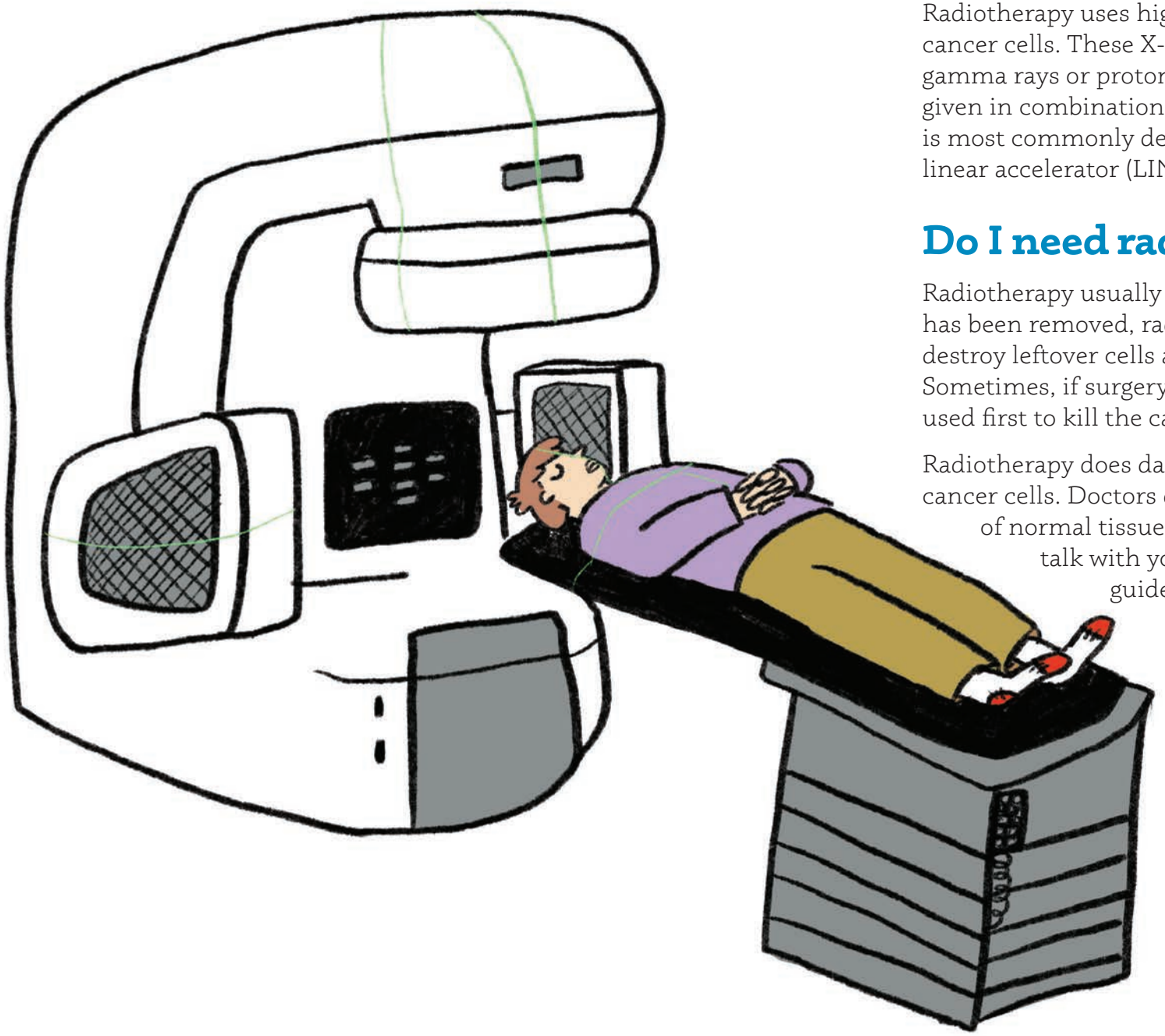
How a brain tumour is treated

The current options for treating a brain tumour include surgery, radiotherapy and chemotherapy, or sometimes what is called active surveillance (watch and wait). Many people have a combination of treatments, and the choice of treatment depends mainly on:

- the type and grade of the brain tumour
- its location in the brain
- its size
- your age
- your general health
- potential side effects.

These are things you may want to ask the clinical team before you begin treatment:

- What are my treatment choices? Are there any choices available elsewhere that aren't available here?
- Which course of treatment do you recommend for me? Why? How does that treatment work?
- What are the expected benefits of each kind of treatment?
- What can I do to prepare for treatment?
- Do I need to stay in the hospital? If so, for how long?
- What are the possible side effects? How can side effects be managed?
- How will treatment affect my normal activities? Can I continue with my studies? Can I continue socialising?
- What is the chance that I will have to learn how to walk, speak, read or write again after treatment?
- Where can I go to get additional support throughout my treatment?
- Are there any clinical trials appropriate for me? If not, why not?
- I might decide to seek a second opinion. What questions would you ask?
- What help is available for a young person like myself?
- In your experience, how might my needs be different from an adult who is having the same treatment?



What is radiotherapy?

Radiotherapy uses high-energy X-ray beams to destroy cancer cells. These X-rays come in many forms: photons, gamma rays or proton beams. Radiotherapy may also be given in combination with chemotherapy. Radiotherapy is most commonly delivered through a machine called a linear accelerator (LINAC).

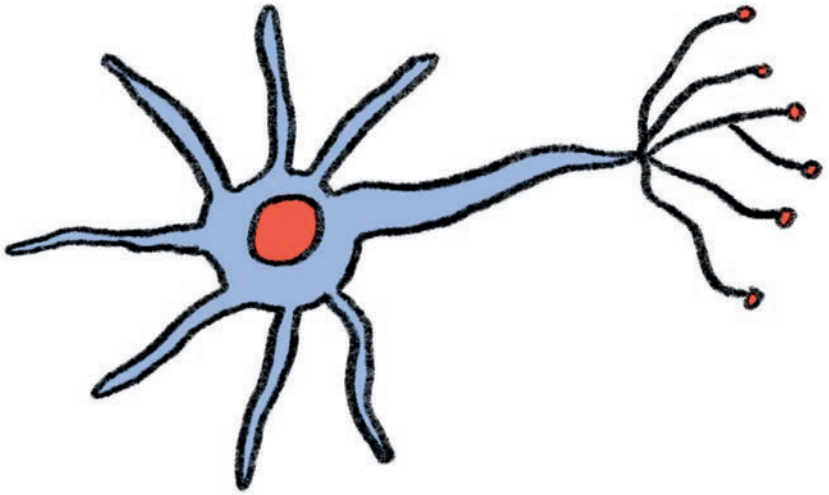
Do I need radiotherapy?

Radiotherapy usually follows surgery. Even if the tumour has been removed, radiotherapy may be recommended to destroy leftover cells and prevent a recurrence of growth. Sometimes, if surgery isn't possible, radiotherapy can be used first to kill the cancer cells.

Radiotherapy does damage some healthy cells around the cancer cells. Doctors do ensure that the least amount of normal tissue is damaged. If you have questions, talk with your doctors. Trust them and be guided by them.

How does radiotherapy work?

Radiotherapy treatments take advantage of the fact that healthy tissue repairs damage in about eight hours, so regular low to moderate doses of radiation can be delivered daily. Diseased tissue cannot repair like this, so eventually the tumour cells die, as they cannot reproduce effectively. The tumour then gets smaller. Treatment results, which are visible on follow-up scans, include shrinkage of the tumour or no further tumour growth. As cell destruction is a lengthy process, it can often take up to six months before the effect of treatment can be determined by doctors.

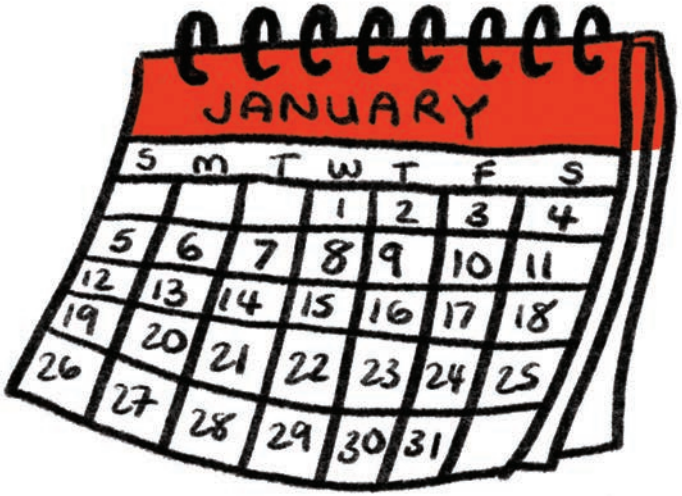


Fractionated radiotherapy

What is it?

Most people diagnosed with a brain tumour receive fractionated radiotherapy. The full dose of radiation is divided into a number of smaller doses, called fractions. This allows healthy cells to recover between treatments. It is also called external beam radiotherapy (EBRT). Fractionated external beam radiotherapy is the most common method of radiotherapy used for people with brain tumours.

Fractionated radiotherapy is often given over a period of about six weeks, and you will need to attend every day (except weekends).



Sometimes radiotherapy is given as a palliative, or supportive care, treatment. This is when radiotherapy is used to control the symptoms of your brain tumour, rather than treating the brain tumour.

For example, a shorter course of radiotherapy can shrink the tumour, which in turn will relieve symptoms of pressure, such as headaches, sickness and drowsiness. You still have radiotherapy to the brain as a course of daily treatment sessions, called fractions, but how long the course lasts will vary. It is likely to be one to two weeks of daily treatments, so a much shorter regimen.

It may be given in conjunction with palliative treatment or when active treatment is no longer appropriate. You will be living with a brain tumour, and may do so for a long time, but you may need supportive care that helps you lead the life you want. The focus here is on managing your symptoms so that you can lead a good quality of life.

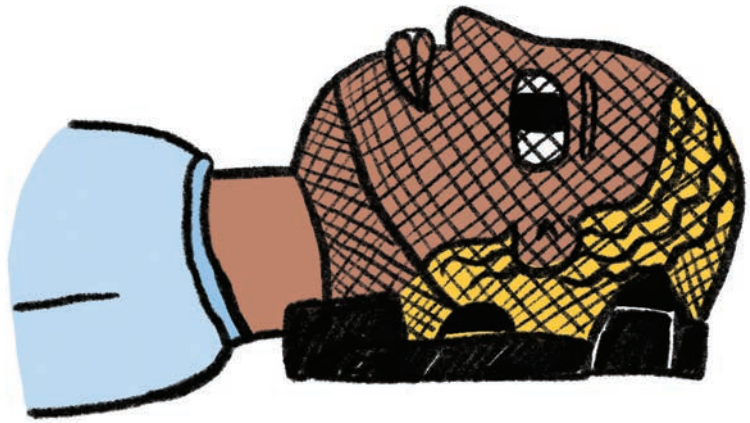
Remember – palliative care is not end-of-life care. These are two very different stages, and you can lead a good quality of life for a long time while receiving palliative care.

Planning session

Before your radiotherapy is delivered, your doctor will ask you to come in for a planning session. Because radiotherapy is so precise, you will need a radiotherapy mask made. A mask is essential to avoid any head movements during treatment.

Depending on the location of your tumour, the mask may be moulded around your neck and shoulders too.

The mask feels warm on the face when it is placed on you, and the technicians will mould the shape of the mask. Having the mask made takes around 30 minutes, and once the mould is made, the mask can be taken off and left to cool. Remember, you can breathe and relax into the bed.



If you suffer from claustrophobia, you should tell the technicians prior to the mask fitting so they can support you throughout.

Typically, on the same day the mask is made, you will have a CT scan too. This pre-treatment scan is done by therapy radiographers. A CT scan takes 3D images of everything inside your head, and this is the scan radiographers will use to match their image-guided radiotherapy (IGRT) treatment scans. During your scan appointment, therapy radiographers will also put some markers on your mask.

A CT scan is a doughnut-shaped machine and sounds a bit like a washing machine when on. The scan doesn't take too long. The bed will pass through the scanner a couple of times. Most scanners now have an intercom fitted, so you can ask the radiographers to speak to you.

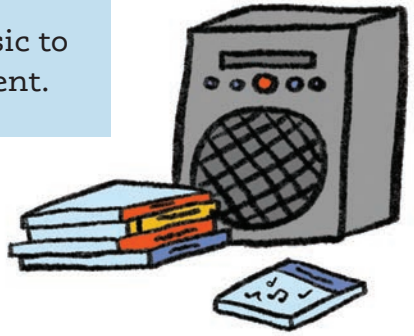
Once the CT scan is done, there is usually a two-week wait before you start your treatment. You will be given a letter with your first couple of appointments. If you have specific times in mind, mention it to the radiographers, and they will try their best to accommodate your request.

The radiotherapy room

If you would like to see the treatment machine before treatment starts, ask the therapy radiographers on your planning session to organise a visit. This is not always possible if the machines are super busy, but it is worth asking.

The LINAC is often at the end of a short maze or blocked off by a big electronic door. This is to make sure no radiation leaves the room.

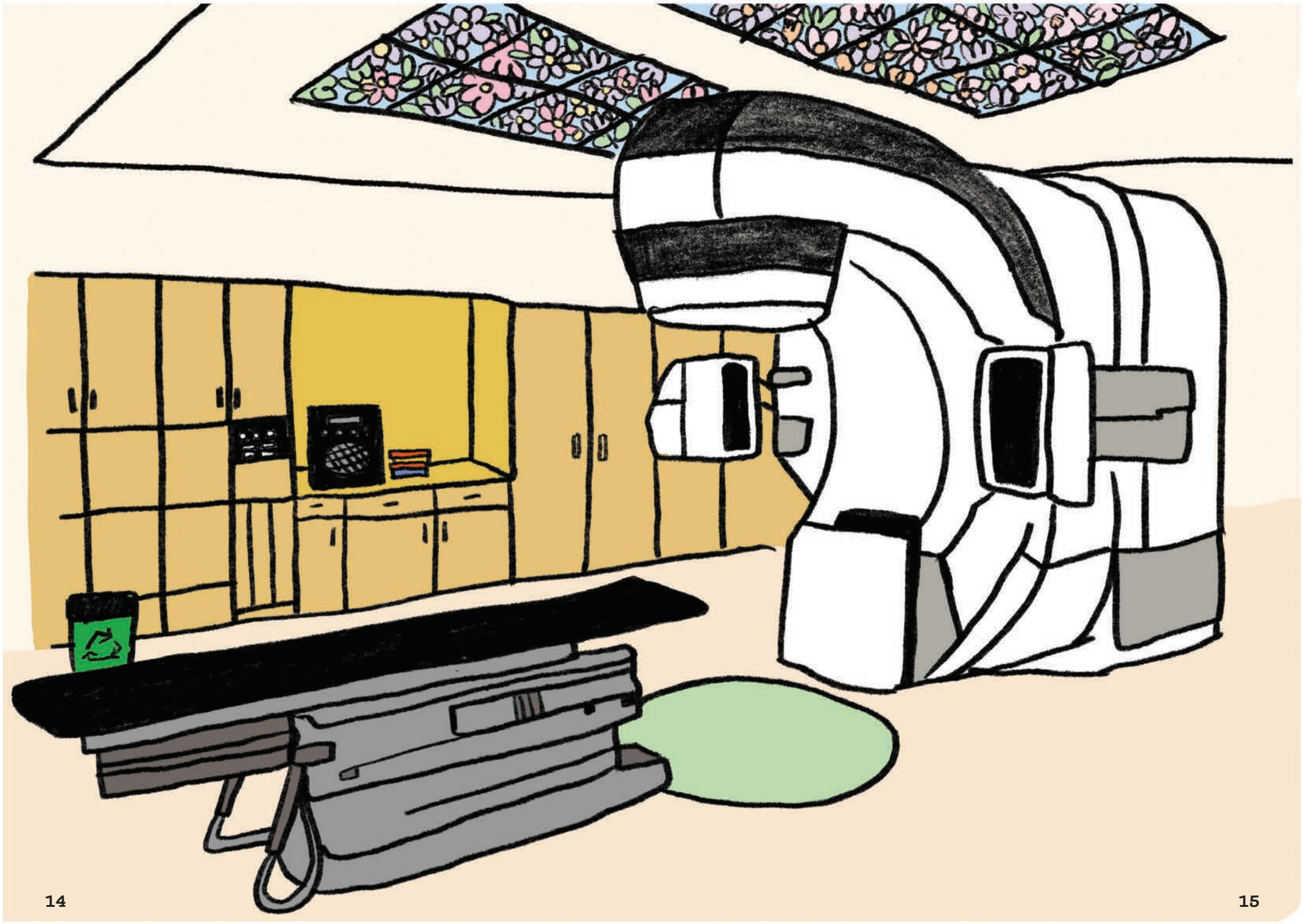
Top tip: Bring your favourite music to play while you have your treatment.



If you wish, you can take someone into the treatment room with you. They can stay with you while the therapy radiographers set up.

Once the set-up is complete, you will be left in the treatment room alone. There are many cameras in the treatment room that will be focused on you. For the treatment, the therapy radiographers will sit in the control room. The radiographers will keep an eye on you through the cameras in the room.

Most radiotherapy machines are also equipped with intercoms so that the radiographers can speak to you during treatment. The first couple of treatments may take longer, because the radiographers will take some X-ray images on the machine to confirm your position and to ensure the treatment is extremely accurate.



The machine is controlled by therapy radiographers from the control room and will not touch you. Once the images and checks are done, the radiation treatment itself is usually very quick. When the radiation is on, you will not see or feel anything. You may hear a buzzing sound when the radiation is being delivered, and you may hear and see the machine move around to different positions.

Top tip: Use slow, relaxed breathing (breathe in for four seconds and out for four) to help you stay still, and know that the radiographers are always watching you, if you need help.

Side effects of fractionated radiotherapy

During your treatment, you should only use fragrance-free and mild soap. Aqueous cream or E45 is usually good to use for dry skin, which can be caused by the treatment. Wash your skin with warm water and gently pat skin dry with a soft towel.

Top tip: Ask your therapy radiographers or clinical nurse specialist about the best moisturisers to use.

You may not feel any side effect for the first week or so. As treatment progresses, the following may happen.

Hair loss – This is an important topic, so we'll spend some time on this.

Losing your hair can be scary, upsetting and traumatic if you are not prepared. We know that for some people, hair is an important part of their identity. We also know that it may not be until something happens to your hair that you think about the impact and sense of loss that this can bring. This can also come at a point when your self-confidence may be low and you are struggling with so many things. It's okay to tell people how you feel. It's okay to avoid mirrors. And it's okay to pick up the phone to us: **01983 292 405**.

Not everyone will lose their hair. If there is hair loss, it is gradual, and it may be a little or a lot. It thins and then becomes patchy, usually where the beam leaves your head. If you experience hair loss during treatment, this usually occurs towards the end of radiotherapy, as the effect builds up. Hair loss happens at different rates for all people. However, be prepared for it to suddenly thin and fall out.

Losing your hair may make you more sensitive to temperature change. If you are having chemotherapy too, this can also cause hair loss. Your hair will have staggered regrowth and may grow back feeling slightly different and patchy. Please speak to your specialist nurse if you are worried about hair loss; many hospitals also work with charities that donate wigs.

As your hair will be thinner than when your mask was originally fitted, your mask may have a looser fit. Radiographers will insert pads to fill the gap between your head and the mask to ensure it is securely in place.

Top tip: Take control! Cut your hair or shave it before treatment begins so that you get used to the feeling. Or, if this is a step too far, do it if you begin to lose your hair.

There are benefits to having a shaved head:

- You'll save time and money on cutting, dyeing, washing, drying and styling.
- You can be creative with scarves and hats.
- Earrings look better than ever.
- Wind and rain are no longer an issue.

And REMEMBER – hair grows back. In those low moments, think about the power and strength of your treatment. You are strong.

Thrush – You may notice that your mouth is sore, and this could be because the beam passes near it. Tell a nurse, who can provide medication to alleviate this.

Top tip: Hydration is key to recovery, so drink lots of fluids, whether it is water, squash or hot drinks.

Nausea – Sickness often comes in waves. You may experience it or not. Again, chemotherapy and other medication can also cause nausea. If you are experiencing this sensation, then please mention it to your nurse. They can prescribe you some anti-sickness medication.

Top tip: Eat little and often. And this is the one time when you can eat food that is high in fat. Cake for breakfast is okay.

Skin irritation – Radiotherapy can make your head red, dry and tender. You can apply moisturiser (such as E45 or aqueous cream) at any time. Just make sure you do not apply thick layers, especially before your treatment. The healthcare team can suggest ways to relieve these problems.

Some areas may get a bit more sensitive than others. For example, if the beam is passing by your ear, it can cause the skin behind the ear to feel moist and sensitive.

If you notice your skin is starting to break down, stop using the moisturiser around that area, and let a nurse know. They will have dressings and alternative ointments to use.

Radiotherapy makes the skin sensitive to the sun, and occasionally the sun does shine in the UK! For this reason, make sure your head is protected from the sun.

Pop a hat or cap on when you are outside. The treated area can remain sensitive for about a year after treatment, so it is important to keep your head protected. Once your skin has settled down, you can start introducing high-factor sun lotions (please consult your nurse before you start using these).

Ear congestion – If the beam is passing through your ear, it can become dry and irritated towards the end and beyond your treatment. You may notice the ear is 'leaking'. Again, see your doctor, who can provide eardrops.

Top tip: Use a soft pillow and cotton pillowcases.

Fatigue – Fatigue takes over the body in swarms. Some days will be better than others. Particularly following your treatment, make sure you rest and let your body recover. It may take months before you get back on your feet, but slowly increase your physical activity and keep hydrated.

Top tip: If you are struggling with fatigue, email **hello@brainstrust.org.uk**, and we can forward you our fatigue toolkit. More information about fatigue can be found here: **brainstrust.org.uk/fatigue**.

Brain swelling – Sometimes, but not often, radiotherapy causes brain tissue to swell. This can cause headaches or an additional pressure in your head. The healthcare team will watch for signs of swelling. They can provide medicine to reduce any discomfort. Radiation sometimes kills healthy brain tissue. Although rare, this side effect can cause headaches, nausea and seizures. Call your doctor immediately if you experience any symptoms that are new or different.

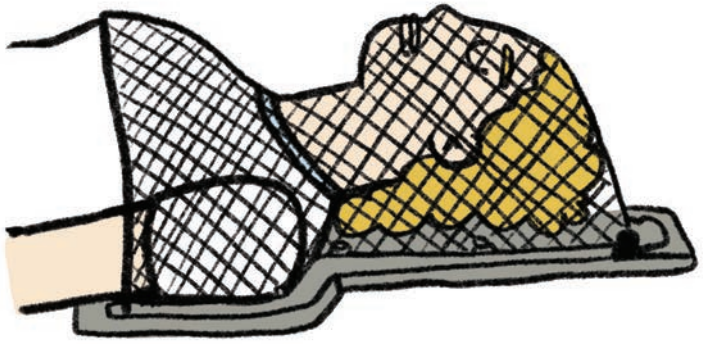
Weight loss – It is possible you may lose weight. This is probably the only time when it is okay to eat foods that are high in fat. A full meal may not appeal to you. Just make sure you eat little and often. Speak to a dietitian if you are concerned about your weight.

Late effects – There is increasing evidence that radiation to the brain causes effects years after treatment; these are referred to as late effects. Late effects are dependent on the location of your tumour. These effects can include impairment in growth, memory, vision, mobility, concentration and higher mental functions. Late effects will be discussed by your doctor, and support is available for their management. You may need to see an endocrinologist.

Radiotherapy for brain and spinal tumours

Brain tumours rarely spread to other parts of the body. However, they can spread within the brain and through the spinal cord tissue. You may often hear the brain and spinal cord referred to as the central nervous system (CNS). Some common CNS tumours are astrocytoma, ependymoma and medulloblastoma.

Radiotherapy to the CNS can be referred to as craniospinal irradiation. As the brain and spine need to be treated, it is important that your body is straight from your head down to your waist.



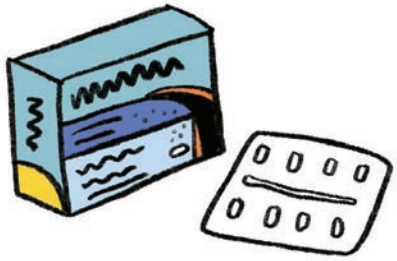
If you are expected to have CNS radiotherapy, your treatment mask will extend from the top of your head down to the middle of your chest. This is to keep your upper spine straight by preventing your shoulders, neck and head from moving. To prevent your lower spine from moving, you may need to have some small, permanent skin markers around your waist. These may also be referred to as tattoos. This involves a small drop of ink placed on your skin, and a small piercing of the skin's surface is done with a needle. You will feel a sharp scratch, and it is over super quick. If you have any questions about this process, please ask the therapy radiographers.

The CT scan process and treatment will be as stated above. The only difference is that these scans and treatments generally take longer, because there are more beams for craniospinal irradiation. Because there are more beams for these treatments, they may get split so that the whole treatment is not delivered on the same day. Talk to your clinician and therapy radiographers. They will explain the treatment plan and duration in more detail with you.

Side effects from craniospinal irradiation

All the side effects listed above still apply for craniospinal irradiation. You will notice your skin will be sensitive down your back. You may notice some redness on your chest and tummy. This is where the radiation beams exit.

Diarrhoea – The lower part of the spine (lumbar spine) is close to the bowel. Due to this, the radiation can cause loose bowel motions and irritation. Please mention this to your nurse, and they can provide some anti-diarrhoea medication.



Top tip: If you are suffering from diarrhoea, it is important to keep your fluids up, whether it is water, squash or hot drinks. Aim to drink one to two litres a day.

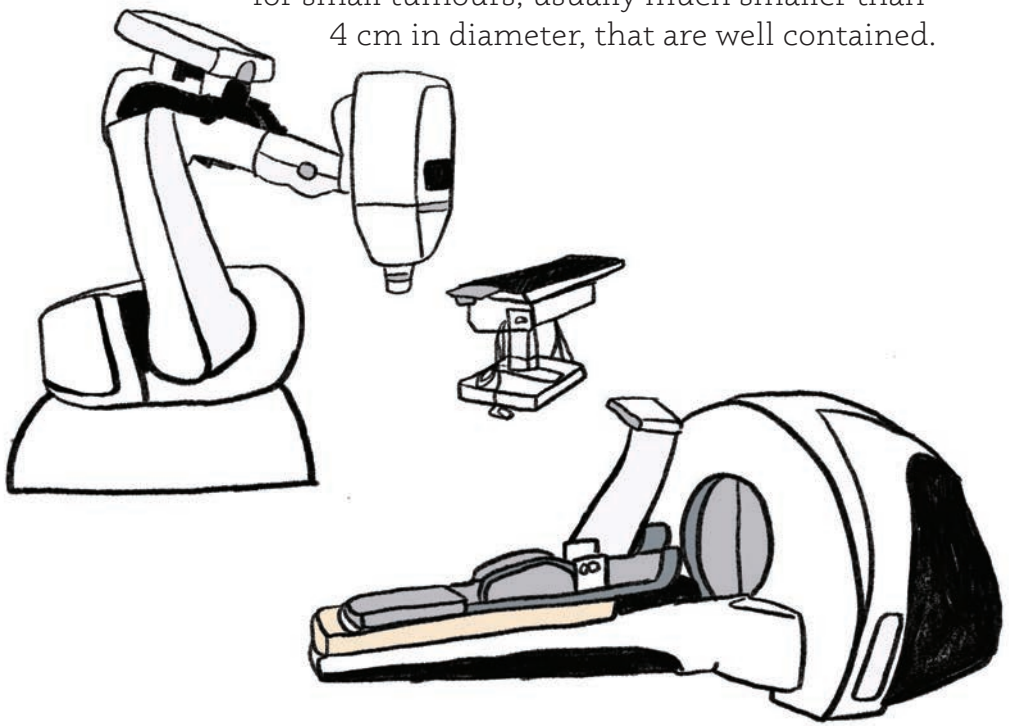
Sore throat – The upper part of the spine (thoracic spine) is close to the throat, which may become dry roughly two weeks into the treatment. You may find it difficult to eat or swallow, due to the dryness. If you are struggling with this, ask for a referral to a dietitian, who can help with the change of appetite and food texture.

Stereotactic radiotherapy (SRT) and stereotactic radiosurgery (SRS), what are they?

Stereotactic radiotherapy (SRT) is a type of radiotherapy treatment used to treat some brain tumours. SRT can be delivered by some specialised LINAC machines or by machines known as CyberKnife or Gamma Knife.

SRT is usually delivered in a small number of sessions, spanning several days or even a few weeks. How many fractions, or daily treatments, there are will depend on the tumour type and the fitness of the patient.

If SRT is delivered in one session on the same day, then it is known as stereotactic radiosurgery (SRS). This is used for small tumours, usually much smaller than 4 cm in diameter, that are well contained.



What are the differences between Gamma Knife and CyberKnife?

Gamma Knife delivers a focused dose to the tumour, and a limited dose of radiation outside the tumour area. There are other treatment machines that can offer the treatment, such as CyberKnife and LINAC-based X-Knife. These terms for treatment machines are the commercial names, like Hoover is for vacuum cleaners.

There are some differences between the two:

- CyberKnife can treat tumours anywhere in the body whereas Gamma Knife specifically treats cancer and other diseases of the brain, head and neck.
- CyberKnife is a low-energy linear accelerator with a robotic arm that moves around your head. You will need a rigid mask for your treatment, similar to the one used for radiotherapy. Gamma Knife requires a frame to be fixed to your skull at four points.
- Gamma Knife requires general anaesthesia for the procedure, while CyberKnife does not.
- You are likely to be treated in several sessions on CyberKnife, while Gamma Knife is likely to involve one high-dose treatment.

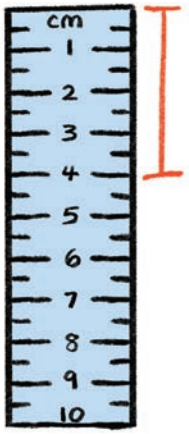
Which patients can radiosurgery benefit?

Of the 120+ different types of brain tumours that people can develop, you are most likely to have radiosurgery if you have an acoustic neuroma or a meningioma that is less than 4 cm in diameter. Radiosurgery can also be used for other brain tumours, including small secondary brain tumours, and for people who can't have brain surgery, due to other medical conditions.

Specialists don't recommend radiosurgery for larger brain tumours. It isn't possible to get the same dose of radiotherapy throughout the treatment area with a large brain tumour.

Radiosurgery may also not be suitable if there are certain nerves running through the treatment area. The nerves could be given too much radiation. This could cause problems such as hearing loss and facial paralysis, depending on the role of the affected nerves.

There are a number of benefits of this treatment. It involves minimal damage, so you can have it done as an outpatient, with the treatment usually lasting less than half a day. There should be limited side effects, as radiosurgery spares healthy tissue that surrounds the targeted area. This means that other healthy areas in the brain receive little radiation, so there are fewer complications and faster recovery times, compared to conventional surgery and radiotherapy. But remember, it can only be used to treat tumours that measure less than 4 cm in diameter and are well defined.



Side effects of radiosurgery

The treatment day can be tiring, but the only side effect is likely to be a heavy pressure headache once the frame has been removed, and possibly some minor bleeding from where the frame has been. Over the following weeks, some patients experience headaches, dizziness and nausea. However, usually no one experiences these for more than two to three weeks, and many patients experience no side effects at all. The SRS procedure means that follow-up and regular scans at three, six and twelve months allow your consultant to see the effectiveness of the treatment.

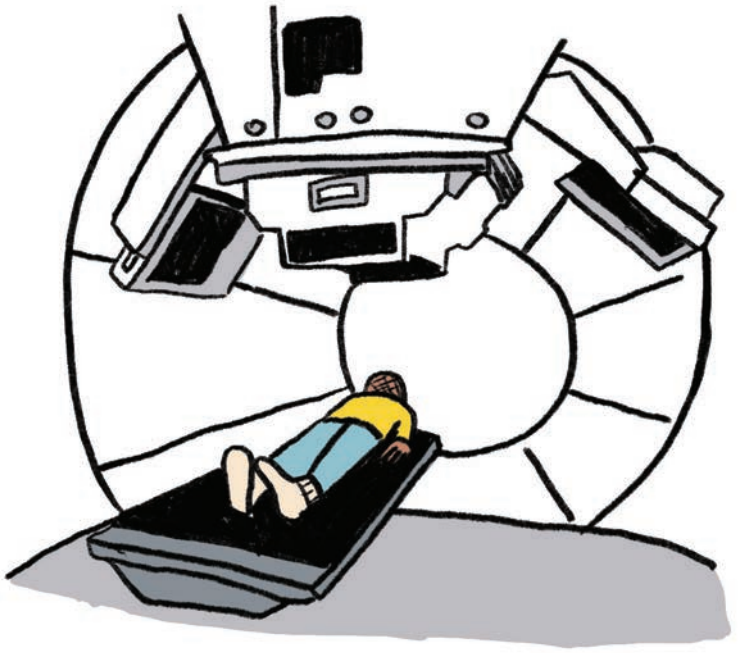
Accessing radiosurgery

Your consultant will discuss your treatment options with you. They will explain which type of treatment would be best for your condition. If it is thought that radiosurgery is the optimal treatment for you, then you will be referred to a centre where radiosurgery is carried out.

Proton beam therapy

What is it?

The source of radiation is protons rather than X-rays (photons). This is a type of particle therapy that uses a beam of protons to irradiate the tumour. The proton beam is aimed at the tumour. The dose of radiation to normal tissue from a proton beam is less than the dose from an X-ray beam. All protons of a given energy have a certain range; no proton penetrates beyond that distance, so this treatment is appropriate in cases where there is a need for the radiation dose to fall off to zero after it hits the target. In photon radiotherapy, there is exit radiation beyond the tumour, which is why you may lose some hair where the beam leaves your head, but proton beams slow down and stop within the target tissue.



Two NHS centres provide high-energy proton beam therapy in the UK.

The Christie, in Manchester, and the University College London Hospitals (UCLH), both of which have three treatment rooms. There are also private clinics that offer proton beam therapy.

Which patients can benefit from proton beam therapy?

Like SRT and SRS, this treatment is only appropriate for certain types of tumours and people. It is used most often to treat brain tumours in young children, whose brains are still developing. Proton beam therapy can also be used to treat adult cancers that have developed near a place in the body where damage would cause serious complications, such as the optic nerve. These types of cancers make up a very small proportion of all cancer diagnoses. Even if there was unlimited access to proton beam therapy, its use would not be recommended in most cases. Around 1,500 people will be treated in the UK once the proton beam therapy centres are fully operational.

Is it effective?

At the moment, there isn't the research evidence to say whether proton beam therapy is a more effective treatment than conventional radiotherapy. Proton beam therapy may cause less damage to healthy tissue, but it is still unclear whether it is as good at destroying cancerous tissue as conventional radiotherapy. At the same time, we have ample evidence that SRS and SRT protect adjacent normal tissue. As proton beam therapy is usually reserved for very rare types of cancers, it is hard to gather systematic evidence about its effectiveness when compared to radiotherapy.

People who travel abroad from the UK to receive proton beam therapy usually respond well. But these people have been specifically selected for treatment, as they were seen as 'optimal candidates' who would benefit the most. Whether this benefit would apply to more people with cancer is unclear.

We have patient guides about proton beam therapy available on our website, or email **hello@brainstrust.org.uk** to request them.

Useful resources and links

Radiotherapy

brainstrust.org.uk/therapies

www.cancerresearchuk.org/about-cancer/brain-tumours/treatment/radiotherapy

www.cancerresearchuk.org/about-cancer/brain-tumours/living-with/recovery-children

www.nhs.uk/conditions/radiotherapy/

www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/radiotherapy

Radiosurgery

www.cancerresearchuk.org/about-cancer/brain-tumours/treatment/radiotherapy/radiosurgery

Proton beam therapy

scienceblog.cancerresearchuk.org/2017/07/17/proton-beam-therapy-is-arriving-in-the-uk-what-does-that-mean-for-patients

www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt

NHS centres with proton beam therapy facilities

The Christie, in Manchester
www.christie.nhs.uk/patients-and-visitors/services/protons/proton-beam-therapy-at-the-christie

UCLH, in London
www.uclh.nhs.uk/our-services/find-service/cancer-services/proton-beam-therapy-pbt

Reviews of proton beam therapy

Crellin, A. and Burnet, N., 2014. Proton Beam Therapy: The Context, Future Direction and Challenges Become Clearer. *Clinical Oncology*, 26(12), pp.736–738.

Available at: www.sciencedirect.com/science/article/pii/S0936655514003835

This review highlights the challenges of developing a national proton beam therapy facility and strategies to help the UK to contribute to proton beam therapy research.

Radiotherapy research and clinical trials

www.nhs.uk/conditions/clinical-trials

www.ncri.org.uk/groups/radiotherapy-group

De Ruysscher, D., Mark Lodge, M., Jones, B., Brada, M., Munro, A., Jefferson, T. and Pijls-Johannesma, M., 2012. Charged particles in radiotherapy: A 5-year update of a systematic review. *Radiotherapy and Oncology*, 103(1), pp.5–7.

Available at: www.sciencedirect.com/science/article/pii/S0167814012000060

This review highlights the importance of a coordinated research effort through clinical trials to investigate the role of protons and to provide robust clinical data.

Teenager and young adult specific cancer charities

Teenage Cancer Trust
www.teenagecancertrust.org

Teens Unite
www.teensunite.org

Glossary

Here are some definitions of words that you may come across during your treatment. You won't hear all of them; many will not be relevant to you. For a more comprehensive glossary, visit: **www.brainstrust.org.uk/glossary**.

General words

Word	Definition
Adjuvant	Usually used as 'adjuvant therapies'. These are treatments that are added to increase effect, e.g. radiotherapy, chemotherapy.
Asymptomatic	If you are asymptomatic, it means you don't have any symptoms.
Benign	Unlikely to recur and not progressive.
Biopsy	A medical procedure performed by a surgeon or an interventional radiologist to take a sample of cells or tissues for examination.

Word	Definition
Blood brain barrier (BBB)	A barrier between brain tissue and circulating blood. It is there to protect the brain and prevents substances from leaving the blood and crossing into the brain tissues.
Cerebrospinal fluid (CSF)	A watery fluid that is continuously produced and absorbed within the brain and flows in the ventricles and around the surface of the brain and spinal cord.
Chemotherapy	Drug therapy for cancer.
Clinical presentation	A picture of signs and symptoms, which leads to a diagnosis.
Concomitant	Naturally accompanying or following something.
Concurrent	Happening at the same time. Radiotherapy and chemotherapy are often referred to as concurrent when they are given at the same time.

Word	Definition
End of life	A phrase used to describe a phase of illness in which the disease has become advanced, progressive and incurable.
First-line management	Initial treatment of an illness.
Grade	A brain tumour will be given a grade that refers to the way the cells of the tumour look under a microscope. Grade I (low grade) refers to tumours that appear less likely to spread, and grade IV (high grade) refers to tumours that appear to grow more quickly, or are most malignant. The brain tumour will be graded according to the highest grade of cell that the pathologist sees in the biopsy specimen. If the tumour has a high percentage of grade II cells and a small percentage of grade III cells, the tumour will be graded as a grade III.
Histology	The study of tumour cells under a microscope.

Word	Definition
Histopathology	The study of diseased tissues at a minute (microscopic) level.
Imaging	The use of technology to create a picture of the brain, e.g. an MRI scan.
Immunohistochemistry (IHC)	The process of detecting antigens or biological markers within tumours or brain tissue using antibodies. Immunohistochemistry provides insight about the classification of brain tumours by identifying cellular markers of phenotype and about the tumour's potential to grow.
Intracranial	Inside the cranium.
Intracranial pressure (ICP)	Pressure inside the cranium, caused by pressure of the cerebrospinal fluid.
Laterality	The side of the body in which symptoms are showing.
Localised	Confined or restricted to an area.

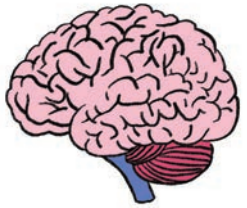
Word	Definition
Malignant	Cancerous, tending to invade normal tissue or to recur after removal.
Markers	Pathologists can test for markers in the tumour tissue. Markers can be genetic, molecular or immunohistochemical. These tests can: – aid the diagnosis of brain tumours that are sometimes hard to diagnose – allow clinicians to work out a prognosis – indicate whether a tumour will respond to a specific type of treatment.
MDT (multidisciplinary team)	A multidisciplinary team is a group of healthcare professionals specialising in a specific cancer type. They meet to discuss each patient's diagnosis and treatment at an MDT meeting.

Word	Definition
Metastatic brain tumour	A secondary brain tumour formed of cancer cells that initially developed elsewhere in the body, e.g. lung, breast, colon, kidney, skin.
Microvascular proliferation	Abnormally thickened blood vessels that tend to be seen in higher-grade gliomas. They tend to be leaky and cause contrast enhancement when imaged.
Modality	A method of treatment.
Morphology	The form and structure of a tumour.
MRI (magnetic resonance imaging)	A special radiology technique that takes pictures of internal structures of the body using magnetism, radio waves and a computer to produce the images of body structures.
Neuro-oncology	The branch of medical science dealing with tumours of the nervous system.

Word	Definition
Neuropathology	The study of diseases of the nervous system, which includes the brain.
Optimal	Most desirable or satisfactory.
Overall survival (OS)	The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease.
Palliative	Therapy with the goal of relieving symptoms and improving quality of life.
Pathology	The branch of medicine that looks at abnormal changes in cells and tissues that signal disease.
Prognosis	A forecast as to likely outcome, the chance of recovery.
Progression-free survival (PFS)	The length of time during and after the treatment of a disease in which a patient lives with the disease but it does not get worse.

Word	Definition
Proliferation	An increase in the number of cells as a result of cell growth and division.
Prophylaxis	Preventive treatment.
Radiotherapy	A treatment in which high-energy rays are used to damage cancer cells and stop them from growing and dividing.
Regimen	A regulated system of treatment.
Systemic	Affecting or circulating throughout the body.
WHO classification	The World Health Organization (WHO) classification for the grading of brain tumours.

Anatomy



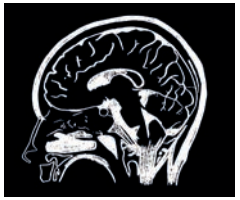
For more information on brain anatomy, look here: **brainstrust.org.uk/anatomy-tumour-types**.

Word	Definition
Anterior	The front of a structure, or a structure found toward the front of the body.
Axial (intra and extra)	The position of something as it relates to the central nervous system (CNS). Intra-axial is within the CNS; extra-axial is outside the CNS.
Brain stem	The bottom area of the brain that connects the cerebrum to the spinal cord.
Cerebellum	The second-largest structure of the brain, located just above the neck in the back of the head.
Cerebrum	The largest area of the brain, occupying the uppermost part of the skull, consisting of two halves (hemispheres).
Corpus callosum	Nerve fibres that pass through and connect the two cerebral hemispheres.

Word	Definition
Cranium	The top area of the skull.
Dura	The outermost of the three meninges.
Endocrine system	The tissues or glands in the body that secrete hormones.
Hypothalamus	The region of the brain that forms part of the wall of the third ventricle. It is part of the endocrine system.
Infratentorial	Below the tentorium.
Lobe	One of four sections of each cerebral hemisphere.
Meninges	The three membranes that envelops the brain and spinal cord.
Midline	An imaginary line running along the surface of the brain (front to back), which separates the right and left hemispheres.
Occipital lobe	The lobe of the cerebral hemispheres at the back of the head, just above the neck.

Word	Definition
Parietal lobe	The lobe of the cerebral hemispheres at the upper back area of the head.
Posterior	The back of a structure, or a structure found toward the back of the body.
Sagittal plane	The plane of the body that divides right from left.
Subcortical	The region of the brain below the cortex.
Supratentorial	Above the tentorium.
Temporal lobe	The lobe of the cerebral hemispheres that sits behind the ears.
Tentorium	A flap of the meninges separating the cerebral hemispheres from the brain structures.
Thalamus	The area surrounding the third ventricle. Its primary function is to relay sensory information.
Ventricles	Four connected cavities in the brain through which cerebrospinal fluid flows.

Imaging and technology used to capture pictures of the brain



Word	Definition
Anterior	The front of a structure, or a structure found toward the front of the body.
Artifact	Fuzziness or distortion in an image caused by manipulation, such as file compression.
Axial	Perpendicular to the long axis of the body.
Calcification	Calcium deposits in soft brain tissue.
Contrast	A dye that can be injected during an MRI scan. The dye helps the radiologist see certain areas more clearly. It helps show what is normal tissue and what could be a lesion.
Coronal plane	The plane of the body that divides front from back.
Cortex	The outer layer of the brain.

Word	Definition
Cortical mapping	The process of identifying the language, motor and sensory areas of the cortex. Cortical maps are often used during brain surgery.
Craniocaudal	Relating to the direction of the X-ray beam. The beam enters at the cranial end of the part being examined and exits at the caudal end.
CT (computerised tomography)	A type of scan in which X-rays are aimed at slices of the body (by rotating equipment) and the results are assembled with a computer to give a three-dimensional picture of a structure.
Cyst	Brain cysts are called neoplasms and are made up of natural brain matter, or they may represent more serious problems in the brain that need the attention of a neurologist.

Word	Definition
Delineation	The outline of the tumour. Also used to delineate the target volume of tumour for surgery and radiotherapy.
DTI (diffusion tensor imaging)	A refinement of magnetic resonance imaging (MRI) that allows the doctor to measure the flow of water and track the pathways of white matter in the brain. DTI is able to detect abnormalities in the brain that do not show up on standard MRI scans.
EEG (electroencephalogram)	A record of the tiny electrical impulses produced by the brain's activity. By measuring characteristic wave patterns, the EEG can help diagnose certain conditions of the brain.
Eloquent	Used to describe an area of the brain that is essential for basic neurological functions. Damage to these areas may result in the loss of sensory processing or linguistic ability.

Word	Definition
Enhancement	A process in which a substance is used to enhance the structures within the brain during a scan. This reduces the lowest grey values to black and increases the highest to white.
Fibrillary	Made up of minute fibres.
FLAIR (fluid-attenuated inversion recovery)	A pulse sequence used in scanning to null signal from fluids. For example, it can be used in brain imaging to suppress cerebrospinal fluid (CSF).
fMRI (functional MRI)	Functional MRI takes the map obtained with traditional MRI imaging and adds on additional dimensions, such as measuring regional blood flow over time or assessing the biochemistry of tissue of a brain tumour in a specified location in the brain.
Focal	Limited to a specific area.

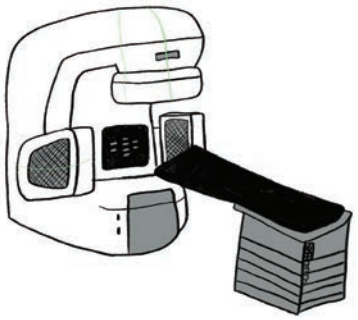
Word	Definition
Foci	Foci is the plural of *focus*. It suggests microscopic visualisation of the tumour cells. Under a microscope, therefore, you might see more than one indication of one or two microscopic foci of possible invasion.
Gadolinium	A substance that enhances tumour images using magnetic resonance imaging (MRI).
Heterogeneous	Having different characteristics and qualities.
Homogeneous	Of a uniform, consistent nature.
Hydrocephalus	An abnormal build-up of cerebrospinal fluid (CSF) in the ventricles of the brain.
Hyperostosis	An excessive growth of bone.
iMRI (intraoperative MRI)	A form of MRI called intraoperative magnetic resonance imaging. It is used to see brain tumours clearly while performing surgery.

Word	Definition
Increased (high) signal	Hyperintensity signals show up as increased brightness (white) on MRI, using different scanning techniques. The nature of brain scans causes tissues with more water to give off brighter signals that appear whiter on the scans.
Inflammation	Swollen brain tissue.
Intrinsic	Originating from, or situated within, an organ or tissue.
Isotope	A form of a chemical element that has a different atomic mass. Isotopes are used in a number of medical tests because they can produce images of tissues that can be used to detect diseases or conditions.
Lesion	A brain lesion describes damage or destruction to any part of the brain. It may be due to trauma or any other disease that can cause inflammation, malfunction or destruction of brain cells or brain tissue.

Word	Definition
Margin	1. The border or edge of the tumour. 2. In surgery, *margin* refers to an amount that is allowed but is beyond what is needed, e.g. the margin taken around the tumour.
Metabolism	The chemical and physical processes that happen to maintain the body and produce energy.
Metastasis/metastases	A cancer that has spread from another part of the body, usually through blood vessels, lymph channels or spinal fluid.
Midline	An imaginary line running along the surface of the brain (front to back), which separates the right and left hemispheres.
Motor	Relating to movement, control of muscles.

Word	Definition
MRI (magnetic resonance imaging)	A special radiology technique that takes pictures of internal structures of the body using magnetism, radio waves and a computer to produce the images of body structures.
Multifocal	Having many focal points. Occurring at multiple sites.
Neoplasm	A tumour, either benign or malignant.
Oedema	Swelling caused by fluid.
Perfusion MRI	A special type of MRI that uses an injected dye in order to see blood flow through tissues.
PET (position emission topography)	A scanning device that uses a low dose of radioactive sugar to measure brain activity.
Posterior	The back of a structure, or a structure found toward the back of the body.

Word	Definition
Pseudo-progression	Swelling or contrast enhancement on a scan that suggests tumour progression or recurrence when in fact it is treatment effect. Pseudo-progression can stabilise without additional treatments and often remains clinically asymptomatic.
Sagittal plane	The plane of the body that divides right from left.
Signal	Brightness of a tissue or structure on MRI.
SPECT (single-photon emission computed tomography)	A scanning technique that uses radioactive materials.
Subcortical	Situated below the cortex.
T1-weighted image	An MRI image showing structures; cerebrospinal fluid appears black on the image.
T2-weighted image	An MRI image showing water; oedema and cerebrospinal fluid appear white on the image.
Vascularity	The blood supply of a tumour.



Radiotherapy

Word	Definition
Centigray (cGy)	A unit of absorbed radiation dose equal to one hundredth of a gray.
Conformal	Relating to radiotherapy beams that are shaped in three dimensions to match the shape of the tumour.
CyberKnife®	Brand name of a machine used to deliver linear accelerator stereotactic radiosurgery.
Demyelination	Loss of the myelin sheath of a nerve.
Dose	The total amount of ionising radiation absorbed by material or tissues, expressed in centigrays .
Dose rate	The quantity of a treatment given over a period of time .

Word	Definition
External beam	Radiation therapy that uses a machine to aim high-energy rays at a brain tumour.
Fractionated	(Of radiation dose) divided into several smaller, equal portions delivered over a period of days.
Gamma Knife®	Brand name of a machine used to deliver stereotactic radiosurgery (SRS), a focal form of radiation therapy.
IMRT (intensity-modulated radiation therapy)	An advanced form of radiotherapy that uses specialised equipment that shapes radiation beams to the size and shape of the tumour.
Late effect	A health problem that occurs months or years after a disease is diagnosed or after treatment has ended.
LINAC (linear accelerator)	A treatment machine that creates ionising radiation in the form of X-rays (photons).

Word	Definition
Mask	A mould to keep your head from moving so that you are in the exact same position for each treatment.
Necrosis	The death of cells.
Palliative radiation	Radiation therapy with the goal of relieving symptoms and improving quality of life.
Proton beam therapy	A treatment that uses high-energy proton beams to treat tumours.
Radiation oncology	The use of radioactive substances and X-rays for the treatment of brain tumours.
Radiosurgery	A special form of radiation therapy that uses a large number of narrow, precisely aimed, high-dose beams of ionising radiation.

Word	Definition
Stereotactic radiosurgery (SRS)	A form of radiation therapy that focuses high-powered X-rays on a small area of the body, better targeting the abnormal area. It is a treatment, not a surgical procedure. Some types of stereotactic radiosurgeries require a specially fitted face mask or a frame attached to the scalp. Other names: Gamma Knife, CyberKnife, stereotactic radiotherapy, SRT, stereotactic body radiotherapy, SBRT, fractionated stereotactic radiotherapy.
Toxicity	State of being poisonous.
Tumour progression	When a tumour recurs, or begins to grow again. The second stage of tumour development.
WBRT (whole-brain radiotherapy)	A type of external beam radiotherapy that is given to the whole brain over a period of weeks.

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brainstrust.org.uk/glossary

Cancer Research UK (CRUK)

Clinical specialist radiographer

Consultant neuropathologist

Consultant neurosurgeon

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Patient/caregiver representative

Radiation oncologist – neuro-oncologist

Summary of data held in brain tumour registry (BTR) records with the National Cancer Registration and Analysis Service (NCRAS).

TYA patient

Illustrations by Alice Bowsher.

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