braintrust
the brain cancer people

my radiotherapy book

Information to help you understand the treatment

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Contents

Introduction

Having a brain tumour is complex. Treating a brain tumour is complex. Today, clinicians no longer treat just plain cancer; they use the knowledge of the biology of cancer to plan treatments more effectively, as they know so much more about it. They 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 each patient's needs. Technological developments mean that there are several options about which is the best radiotherapy treatment to be offered. Some treatments will be inappropriate, so it is a question of finding which treatment is the best option. It is not that one treatment is better than another but which is the most appropriate treatment for the patient.

This resource is to help you understand the range of radiotherapy treatments that are currently available, so that you understand what would be the appropriate and best treatment for the type of brain tumour you are living with, whether you are a caregiver or a patient. 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 hq@brainstrust.org.uk.

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, which means watching and checking at regular intervals. Many people have a combination of treatments, and the choice of treatment depends mainly on:

- the type and grade of brain tumour
- its location in the brain
- its size

- the age of the patient
- the patient's general health.

Cancer therapy often damages healthy cells and tissue, and therefore, side effects are common. Before treatment starts, ask your healthcare team, which will include your oncologist, clinical nurse specialist and radiographers, about possible side effects and how treatment may change your normal activities.

These are some questions you may want to ask before you begin treatment:

- What are my treatment choices? Are there any choices available elsewhere that aren't available here?
- Which 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?
- Will I need to stay in the hospital? If so, for how long?
- What are the risks and possible side effects of my treatment? How can side effects be managed?
- How will treatment affect my normal activities? What is the chance that I will have to learn how to walk, speak, read or write again after treatment?
- Would a research study (clinical trial) be appropriate for me? If it wouldn't, why not?
- I might decide to seek a second opinion. What questions would you ask?

There are two categories of brain tumours in cancer: primary (the cancer starts in the brain) and secondary (the cancer has spread from another part of the body). Primary tumours are usually treated with radiotherapy, whereas secondary tumours, which are usually smaller, deep-seated and in many cases multiple, are often better treated with radiosurgery.

Radiotherapy

What is it?

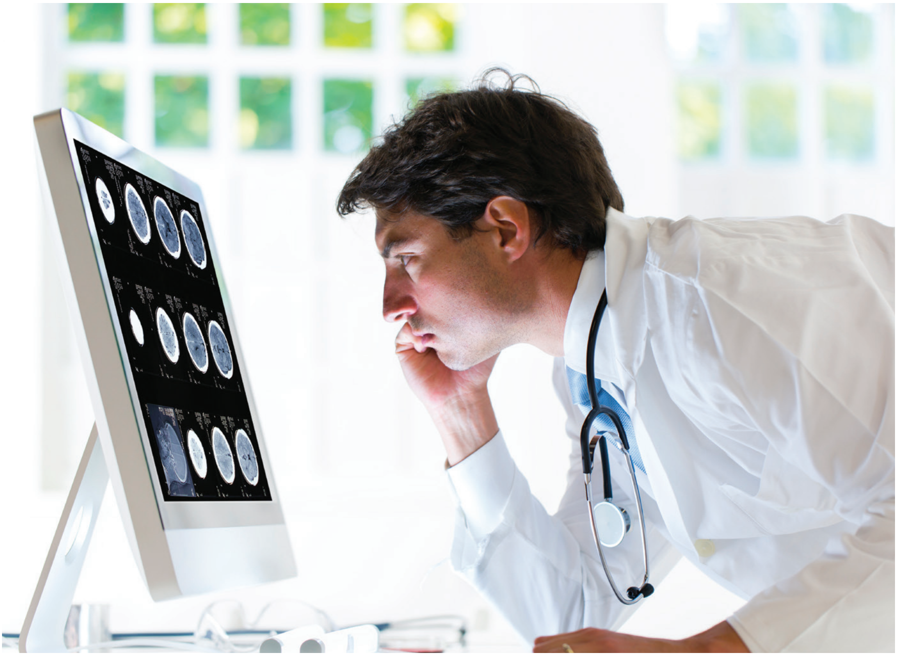
Radiotherapy destroys brain tumour cells with high-energy X-rays (photons), gamma rays or protons. It usually follows surgery. Radiation kills brain tumour cells that may remain in the area following surgery. Sometimes people who can't have surgery have radiotherapy instead. It may also be given in combination with chemotherapy. Overall, radiotherapy is required for 50% of **all** cancer patients. It is one of the most effective treatments for cancer.

Should I have radiotherapy?

Your doctors will discuss with you treatment options and why radiotherapy has been suggested. Even if the tumour has been removed, radiotherapy can be recommended to keep unseen cells from growing. This should destroy leftover cells and prevent a recurrence of growth. There is a suggestion that, several years after radiotherapy treatment, another brain tumour could develop because of this treatment. There is also a risk that healthy cells may die in the brain. This is called radiation necrosis. This is rare. But you should take all factors into consideration. Again, talk with your doctors, trust them and be guided by them. Radiotherapy will not be recommended if you only have a few dividing cells in your cancer. The therapy would not be very successful.

How does radiotherapy work?

Radiotherapy treatments take advantage of the fact that healthy tissue repairs damage in about eight hours, so that 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. Because cell destruction is a lengthy process, it can often take up to six months before the effect of treatment can be determined by doctors.

Radiation is measured in units of gray (Gy) or centigray (cGy), which is one hundredth of a gray. Depending on the type of radiotherapy being given, a patient may be given just one dose of radiation or many doses over a period of weeks. This is called fractionated radiotherapy. The amount of overall dose and amount to be given each day will depend on the tumour type. The amount delivered to the brain is limited by how much radiation normal tissue can tolerate. From the experience of using radiotherapy, clinicians know how much radiation dose brain tissue can cope with.

Fractionated radiotherapy

What is it?

Most patients diagnosed with a glioma receive fractionated radiotherapy. Fractionated radiotherapy is a treatment in which 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. A large machine outside the body aims beams of radiation at the head. Because cancer cells may invade normal tissue around a tumour, the radiation may be aimed at the tumour and some surrounding brain tissue (called a margin), or at the whole brain. Some people will also need radiation aimed at the spinal cord. Fractionated radiotherapy is often given over a period of about six weeks, and you will need to attend every day (except weekends). See 'How is fractionated radiotherapy planned?' (page 9).

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 to treat the brain tumour. For example, a shorter course of radiotherapy (15 fractions) can shrink the tumour, which in turn will relieve symptoms of pressure, such as headache, 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 your brain tumour, and may do so for a long time, but you may need supportive care that helps you lead the life you want to lead. The focus here is on managing 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 when receiving palliative care.

Types of fractionated radiotherapy

In the late 1990s, conformal radiotherapy (CRT) was widely introduced. This provided an excellent way to shape the treatment to 'conform' to the shape of the target. In the last 10 years, developments include intensity-modulated radiotherapy (IMRT) and volumetric modulated arc therapy (VMAT). Both treatments destroy tumours by sending customised doses of radiation without exposing healthy tissue to radiation. While VMAT uses a machine that rotates continuously around you to send the beams, IMRT doesn't. IMRT takes longer to deliver than VMAT. These forms of radiotherapy are particularly useful for patients whose tumours have a more challenging shape or position.

Intensity-modulated radiotherapy (IMRT)

IMRT is a technique that allows better shaping of the radiotherapy dose to the shape of the tumour, and it is particularly useful if the shape of the tumour is complex, with concave parts. This allows the high dose to be moved away from normal tissue structures more effectively in complex tumours than is possible with conformal radiotherapy. As well as considerations of normal tissue, IMRT is useful for producing an even dose through the tumour or for producing a variation in dose where it is intended to give different dose levels to different parts of the tumour. IMRT is often faster to plan and deliver than conformal therapy.

IMRT is appropriate for both non-malignant and malignant tumours. The dose is varied to deliver higher, more effective doses to the tumour, which creates a 'hot spot' at the tumour site. It is like several torch beams being shone from different directions but at one spot. The light is most intense where the beams meet. But on its own, each beam is relatively weak and passes through normal tissue without much effect. It takes a bit longer to deliver because of the complexity, so about 15 to 45 minutes per treatment.

Volumetric modulated arc radiotherapy (VMAT) or RapidArc

VMAT is a type of IMRT. VMAT stands for volumetric modulated arc therapy and is also called RapidArc. VMAT is different from normal IMRT. The radiotherapy machine rotates around the patient during a treatment session. This is in an arc shape. The machine continuously reshapes and changes the intensity of the radiation beam as it moves around the body. Giving the radiotherapy in this way:

- makes it very accurate
- shortens the treatment time
- uses a lower overall dose of radiation.

The treatment usually takes about 10 minutes.

TomoTherapy

TomoTherapy is a type of IMRT. For this treatment, the patient lies on a radiotherapy couch, which moves through a doughnut-shaped machine. The radiation source in the machine rotates around the patient in a spiral pattern. It is also sometimes called helical TomoTherapy.

Image-guided radiotherapy (IGRT)

Before the introduction of IMRT, radiation oncologists had to contend with variations in patient positioning and internal movement, such as breathing. Generally, breathing in patients having treatment to their brain is not an issue, as the patient wears a mask that keeps the head very stable. Radiation oncologists manage these variations by treating a wider margin of the tumour. So, for example, to treat a golf-ball-sized tumour, they would treat a tennis-ball-sized area. With IGRT they can treat a golf-ball-sized area. IGRT gives high-resolution, three-dimensional images to pinpoint the tumour site, adjusting the patient's position as necessary, and completes a treatment – all within the time slot.

This is usually done with X-rays or an X-ray-based CT scanner, and there are different types of IGRT in use. The use of this imaging allows for greater precision, and in turn this allows for a reduction in the safety margin that is required to ensure effective coverage of the target.

The best results from IMRT are produced when it is combined with image guidance, and most modern radiotherapy machines are fully equipped with both technologies, which can be used together.

Internal radiation therapy (implant radiation therapy or brachytherapy)

Internal radiation isn't commonly used for treating brain tumours and is under study. The radiation comes from radioactive material usually contained in very small implants, called seeds. The seeds are placed inside the brain and give off radiation for months. They don't need to be removed once the radiation is gone.

How is fractionated radiotherapy planned?

The fractions are given as a series of treatment sessions that make up a radiotherapy course. This means that the course of radiotherapy is usually given every weekday, so you will need to attend your radiotherapy centre every day. Treatment can start on any day. Most patients are not treated at weekends. However, some centres are now opening at weekends. The radiographers who plan your radiotherapy will arrange your appointment dates and times with you as soon as they can. Because radiotherapy is complex and your treatment is planned individually for you, you will need to attend the cancer centre for a planning appointment before you start treatment. There will be a time delay between attending your planning appointment(s) and your first treatment. This is so your personal treatment is calculated to ensure your tumour gets the correct dose, and the surrounding tissues that do not need treatment get as low a dose as possible. This can take up to four weeks. Ask your radiographers about your future treatment dates when you attend your planning appointment. If you have had surgery, a short period of time to recover before you start radiotherapy can be helpful.

You will need to go to a planning session so that all the measurements can be taken. These are called simulations, when the mapping is done on a CT scanner to work out how best to arrange the radiation beams and how best to protect the healthy tissue. If you are having radiotherapy, it is likely that you will need to wear a mask, made just for you, which is attached to the table to hold your head in place while you are receiving the treatment.

'To be honest, having the mask made was worse than the actual treatment for me. But it is only a moment. After this the whole thing was a breeze.'

Patient, Southampton

The mask will enable you to breathe and see normally, but it can feel claustrophobic. You will need to wear it for the whole appointment time. If you are having whole-brain radiotherapy (for secondary brain tumours), most centres will make a mask.

How is fractionated radiotherapy delivered?

You will be positioned carefully on a table, and the mask will be fitted. Powerful and precisely placed radiation beams are directed at the tumour using a sophisticated device called a medical linear accelerator (linac). This rotates around you, delivering beams from different angles. When these beams converge on your tumour, the effect allows the maximum dose to be delivered to the tumour site. It is not painful, but you will need to keep still. You may be able to talk to the radiographer, who will keep a close eye on you from the next room.

Side effects of fractionated radiotherapy

During your treatment, you should only use fragrance-free and mild soap. There should also be nothing on your hair, like gel or colouring. E45 Cream is an excellent moisturiser to use on your skin, which may react. Any moisturiser without perfume or sodium lauryl sulphate (SLS) can be used.

You will probably not feel any side effects for at least two weeks. Then, in week three, the following will start to happen:

Fatigue – It is important to stay active. Some people continue to work. However, you must rest when you need to.

‘People warned me that four to six weeks AFTER the treatment has finished, I would feel really tired. This lasted about a month; having a shower was a supreme effort, and I had to lie down afterwards. A course of radiotherapy is the equivalent to having another round of major surgery. Listen to your body.’

Patient, Leeds

Brain swelling – Sometimes, but not often, radiotherapy causes brain tissue to swell. You may get a headache or feel pressure. Your healthcare team will watch for signs of this problem. They can provide medicine to reduce the 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.

Hair loss – Not everyone will lose their hair. Permanence of hair loss depends on the dose delivered. If there is hair loss, it is gradual. It thins and then becomes patchy, usually where the beams leave your head. Apart from affecting appearance, hair loss makes you notice change in temperatures. Hair will often grow back; it might have a different texture, but you won't be bald forever.

Skin irritation – Your scalp may become red, dry and tender. Apply moisturiser at any time during your treatment. It is important that you don't use thick layers. Your healthcare team can suggest ways to relieve these problems.

Nausea – You may be sick or feel sick, particularly if the beams are catching your ear. Again, don't suffer in silence. Anti-sickness medication will bring relief.

Ear congestion – If the beams are passing through your ear, this will become dry and then irritated towards the end and beyond your treatment. You may find that your ear is 'leaking'. Again, see your doctor, who will provide eardrops.

Weight loss – You may lose weight. This is probably the only time when you will be told it is fine to eat foods that are high in fat. Eat little and often.

Late effects – There is increasing evidence that radiation can cause effects years after treatment, called late effects. These effects can include impairment in memory, concentration and higher mental functions. This is the reason why, wherever possible, focused treatment, particularly radiosurgery (see below), is increasingly used.

Stereotactic radiotherapy (SRT or FSRT)

What is it?

The term ‘stereotactic’ refers to accurate location in space. Stereotactic radiotherapy is a modern version of fractionated radiotherapy, delivered in a number of fractions. As the targeting is better than conventional radiotherapy (described in the previous section), it is usually delivered in a small number of sessions, spanning several days or even a few weeks. How many fractions or daily treatments will depend on the tumour type and fitness of the patient. It is important to know that not everyone is eligible for SRT, as it may not be the best treatment for every patient.

Stereotactic radiosurgery (SRS)

What is it?

This is another form of treatment with radiation, where the radiation dose is given in one single session, on one day. It is used for small tumours, usually smaller than 4 cm in diameter, that are well contained. It is not suitable for large, more diffuse tumours, which are better treated with one of the fractionated techniques (radiotherapy or SRT). However, it is suitable for many small tumours (e.g. brain metastases), all being treated usually in the same session. For this, the highest degree of precision is needed. Thus, usually a rigid frame is used to aid the targeting (see the next section, on Gamma Knife).

What are the differences between Gamma Knife and CyberKnife?

You may also hear radiosurgery being referred to as Gamma Knife (GK), which 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 (CK) 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 is not specific to brain tumours, whereas Gamma Knife specifically treats cancer and other diseases of the brain, head and neck. CyberKnife is a low-energy linear accelerator and does not require you to be placed in a frame fixed to the skull but a rigid mask, as in radiotherapy. Gamma Knife uses three-dimensional information from MRI and CT to provide treatment, and for the exquisite precision, a fixed frame is used. There is an overlap between their uses, as some doctors use CyberKnife for SRS, and Gamma Knife can also be used for SRT. But on the whole, with CyberKnife you are likely to be treated in several sessions, while with Gamma Knife it is likely to be a one-day treatment.

How is Gamma Knife delivered?

The Gamma Knife machine includes a metal helmet, shaped to hold the head still so that many beams of radiation can be directed to focus on a particular point (the 'target' or 'isocentre') in the head. The specific target in the head is imaged via an MRI scanner (and in the case of a vascular lesion, also an angiography machine) and then entered into a planning system. This provides the necessary coordinates so that the beams can all be focused on the right area. The treatment is then planned to deliver the effective dose of radiation to the target area, with minimal radiation to nearby areas. The beams coincide at the fixed focal point of the tumour or lesion. Each beam will contribute a small dose of radiation and have a minimum impact on the tissue on its way to the target. However, when all the beams meet at the target point, the resulting dose has the effect of destroying the tumour. The treatment-planning software can deal with irregularly shaped tumours. An average procedure takes from one to two hours. The treatment is done as an outpatient and is usually over in half a day.

Which patients can radiosurgery benefit?

Due to its power and accuracy, radiosurgery can give clinicians the ability to treat patients with cancers once considered untreatable and those for whom surgery is not an option, such as patients with tumours deep in the brain.

Of the 120+ types of brain tumours that people can contract, 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. However, radiosurgery is suitable to treat many small metastases, because even in the same session, several 'shots' can be delivered to treat each brain tumour throughout the brain. In this circumstance, traditional radiotherapy is only able to deliver a radiation dose across the whole brain, and this then becomes a one-off procedure that would not allow for further treatment of recurring tumours. On the other hand, radiosurgery is able to specifically target tumours in the brain, and due to its accuracy and low-dosage distribution, this treatment can be repeated if required. When a cancer patient has control of the underlying disease but is confronted with a small tumour in the brain, the ability to deal with the tumour efficiently and the knowledge that this can be repeated has significant implications for quality of life.

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, depending on the role of the affected nerves.

There are a number of benefits to 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.

Don't be misled by the words 'surgery' and 'knife'. There is no invasive surgery, so no knife.

Radiosurgery is also shown to be beneficial for the treatment of non-cancerous conditions. In addition, it tackles acoustic neuromas and other non-malignant tumours, and trigeminal neuralgia (a functional disorder).

Side effects of radiosurgery

The treatment day can be tiring, but the only side effects are 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, no patient usually 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 the three-, six- and twelve-month periods allow your consultant to see the effectiveness of the treatment.

'When having Gamma Knife treatment, the frame is held by screws. Once the frame was on, I did get the most excruciating pressure headache. However, I had a very switched-on nurse, who gave me IV paracetamol, and within 15 minutes the pain lifted. I felt great, hungry and ready to eat! I know everyone is different, but I suggest strike when the iron's hot and avoid any pain if possible. It's also a cliché, but to remain positive does make a difference. It's hard, but I came through a more resilient human being.'

Patient, London

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

This is now being delivered by The Christie, in Manchester, and University College London Hospitals. More detailed, comprehensive information can be found at brainstrust.org.uk/pbt.

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 conformal radiation therapy, there is exit radiation beyond the tumour, which is why you may lose some hair on the side where the beams leave your head, but proton beams slow down and stop within the target. Proton beam therapy is expensive. There are two proton beam therapy centres in the UK: one at The Christie, in Manchester, and one at University College London Hospitals. Patients now benefit from being treated in the UK.

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 where the cancer has developed near a place in the body where damage would cause serious complications, such as the optic nerve. These types of cancer make up a very small proportion of all cancer diagnoses. Even if there were unlimited access to proton beam therapy, its use would not be recommended in most cases.

Cancer Research UK estimates that only one in 100 people with cancer is suitable for proton beam therapy.

Is it effective?

It is important to know that proton beam treatment has never been compared with modern SRS or event SRT, so it may not be 'better' than the techniques detailed in the previous chapters. We cannot even say that proton beam therapy is 'better' overall than radiotherapy. 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 protects adjacent normal tissue.

As proton beam therapy is usually reserved for very rare types of cancer, it is hard to gather systematic evidence about its effectiveness when compared to radiotherapy.

People who 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.

Useful resources and links

Radiotherapy

brainstrust.org.uk/therapies.

www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/radiotherapy.

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

www.nhs.uk/conditions/radiotherapy.

www.macmillan.org.uk/information-and-support/treating/radiotherapy/radiotherapy-explained.

Advances in radiotherapy

www.bmj.com/content/345/bmj.e7765.long.

Proton beam therapy

brainstrust.org.uk/pbt. *Easy, downloadable guides that cover every aspect of proton beam therapy.*

Cancer Research UK: 'Proton beam therapy: where are we now?' news. https://news.cancerresearchuk.org/2015/07/16/proton-beam-therapy-where-are-we-now/ (accessed 18 February 2024). *This article provides an excellent overview of the current situation in the development of the national PBT programme.*

References about PBT

NHS commissioning specialised services: 'What is proton beam therapy?' https://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt/ (accessed 18 February 2024). *This article provides a good starting point describing what PBT is and how it works.*

NHS centres receiving PBT facilities

University College London Hospitals NHS Foundation Trust proton beam therapy webpage www.uclh.nhs.uk/our-services/find-service/cancer-services/proton-beam-therapy-pbt (accessed 18 February 2024).

The Christie NHS Foundation Trust proton beam therapy webpage www.christie.nhs.uk/patients-and-visitors/services/proton-beam-therapy (accessed 18 February 2024).

Together, UCLH and The Christie will see more children and teenagers with cancer than almost any other centre in the world, and more adults with brain cancers than any other centre in the UK.

Reviews on PBT

Crellin, A.M. and Burnet, N.G. (2014) ‘Proton Beam therapy: The context, future direction and challenges become clearer’, *Clinical Oncology*, 26(12), pp. 736–738. doi:10.1016/j.clon.2014.10.009. www.sciencedirect.com/science/article/pii/S0936655514003835. *This review highlights the challenges of developing a national PBT facility and strategies to help the UK to contribute to PBT research.*

Jones, B. and Burnet, N. (2005) ‘Radiotherapy for the future’, *BMJ*, 330(7498), pp. 979–980. doi:10.1136/bmj.330.7498.979. www.ncbi.nlm.nih.gov/pmc/articles/PMC557134/. *This editorial highlights the potential impact of a proton service to patients with hard-to-treat tumours.*

Radiotherapy research and clinical trials

www.nhs.uk/Conditions/Radiotherapy/Pages/clinical-trial.aspx.

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

De Ruysscher, D. et al. (2012) ‘Charged particles in radiotherapy: A 5-year update of a systematic review’, *Radiotherapy and Oncology*, 103(1), pp. 5–7. doi:10.1016/j.radonc.2012.01.003. 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.*

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 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	Not threatening to health, unlikely to recur and not progressive. 'Non-malignant' is the preferred term.
Biopsy	A medical test performed by a surgeon or an interventional radiologist who will take a sample of cells or tissues for examination.
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.
CSF (cerebrospinal fluid)	A watery fluid that flows in the ventricles within the brain and around the surface of the brain and spinal cord.
Chemotherapy	Drug therapy for cancer.
Clinical presentation	The picture of signs and symptoms, which leads to a diagnosis.

Word	Definition
Concurrent	Happening at the same time. Radiotherapy and chemotherapy are often referred to as concurrent when they are given at the same time.
Concomitant	Naturally accompanying or following something.
End of life	A phrase used to describe a phase of an illness that 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. So 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.
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.

Word	Definition
Immunohistochemistry (IHC)	The process of detecting antigens or biological markers within tumours or brain tissue using antibodies. Immunohistochemistry provides insight about the classification of tumours by identifying cellular markers of phenotype, and about the tumour's potential to grow.
Intracranial	Inside the cranium (skull).
Intracranial pressure (ICP)	Pressure inside the cranium, caused by pressure of the subarachnoidal fluid.
Laterality	The localisation of symptoms in one side of the body.
Localised	Confined or restricted to an area.
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 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.
Metastatic tumour	A secondary tumour formed of cancer cells that began elsewhere in the body.
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.

Word	Definition
Microvascular proliferation	Abnormally thickened blood vessels, which tend to be seen in higher-grade gliomas. They tend to be leaky and cause contrast enhancement on imaging.
Modality	A method of treatment.
Morphology	The form and structure, e.g. of a tumour.
Neuro-oncology	The branch of medical science dealing with tumours of the nervous system.
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	Having 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 that a patient lives with the disease but it does not get worse.
Proliferation	An increase in the number of cells as a result of cell growth and division.
Prophylaxis	Preventive treatment or action.

Word	Definition
Radiotherapy	A treatment in which high-energy radiation is used to damage cancer cells and stop them from growing and dividing.
Regime	A regulated system of treatment.
Systemic	Affecting or circulating throughout the body.
WHO classification	The World Health Organisation (WHO) classification for the grading of brain tumours.

Anatomy

For more information on brain anatomy, visit brainstrust.org.uk/anatomy-tumour-types.

Word	Definition
Axial (intra and extra)	Axial describes the position of the tumour as it relates to the brain. Intra-axial describes a tumour within the brain. Extra-axial describes a tumour outside the brain.
Anterior	Placed before or it front.
Brain stem	The bottom portion of the brain, which connects the cerebrum to the spinal cord.
Cerebellum	The second-largest structure of the brain, the cerebellum is located just above the neck, in the back of the head.
Cerebrum	The largest area of the brain, which occupies the uppermost part of the skull. It consists of two halves (hemispheres).
Corpus callosum	Nerve fibres that pass through and connect the two cerebral hemispheres.

Word	Definition
Cranium	The skull, particular the part that encloses the brain.
Dura	The outermost of the three meninges.
Endocrine system	The tissues or glands in the body that secrete hormones.
Frontal lobe	The lobe at the front of the brain.
Hypothalamus	A region of the brain that controls multiple functions within the body, including the automatic nervous system, the endocrine system and homeostatic systems.
Infratentorial	Situated below the tentorium.
Lobe	One of four sections of the cerebrum.
Meninges	The three membranes that envelop 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 at the back of the head, just above the neck.
Parietal lobe	The lobe at the top of the head.
Posterior	Placed behind or to the rear.
Sagittal	Relating to the plane that divides the body into left and right halves.
Subcortical	Situated below the cortex.
Supratentorial	Situated above the tentorium.
Temporal lobe	The lobe at the base of the brain.

Word	Definition
Tentorium	A flap of the meninges separating the cerebral hemispheres from the brain structures.
Thalamus	The area of the brain that relays sensory information and perceives pain.
Ventricles	Four connected cavities in the brain through which cerebrospinal fluid flows.

Imaging

The use of technology to create a picture of the brain, e.g. an MRI scan.

Word	Definition
Anterior	Placed before or in front.
Artefact	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 tissue.
CT (computerised tomography)	A type of imaging whereby 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.
Contrast	A substance given to patients to increase the contrast in the scan and make it easier to see certain features.
Coronal	Relating to the plane created by an imaginary line that divides the body at any level into anterior and posterior portions. Also called the 'frontal plane'.
Cortex	The outer layer of the brain.

Word	Definition
Cortical mapping	Cortical maps identify the language, motor and sensory areas of the cortex and are often used during brain surgery.
Craniocaudal	Relating to the direction of entry of the X-ray beam. The beam enters at the cranial end of the part being examined and exits at the caudal end.
Cyst	Brain cysts are called neoplasms and are made up from natural brain matter, or they may represent more serious problems in the brain that need the attention of a neurologist.
Delineation	The outline of the tumour. Also used to delineate the target volume of a 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	Relating to an area of the brain that, if damaged or removed, will result in loss of sensory processing or linguistic ability.
Enhancement	A process whereby 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.

Word	Definition
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 something about the biochemistry of brain tumour tissue in a specified location in the brain.
Focal	Limited to a specific area.
Foci	'Foci' is the plural of 'focus'. These are cells that can only be seen under a microscope.
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	The use of magnetic resonance imaging (MRI) to see tumours clearly while performing surgery.
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, which appear whiter on the scans.

Word	Definition
Inflammation	Swollen tissue.
Intrinsic	Originating from, or situated within, an organ or tissue.
Isotope	A form of a chemical element that has a different-from-normal 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 lesion describes damage or destruction to any part of an organ. It may be due to trauma or any disease that can cause inflammation, malfunction or destruction of a cell or tissue.
Margin	1. A border or edge of the tumour. 2. In surgery, 'margin' refers to an amount that is allowed but is beyond what is needed. So the margin taken around the tumour.
Metabolism	The chemical and physical processes that maintain the body and produce energy.
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 or the control of muscles.
Metastasis (plural – metastases)	The development of a secondary tumour in another part of the body. The tumour cells usually travel through blood vessels, lymph channels or spinal fluid.
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.

Word	Definition
Multifocal	Having many focal points, when damage caused by the disease occurs at multiple sites.
Neoplasm	A tumour, either non-malignant 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 (positron emission tomography)	A scanning device that uses low-dose radioactive sugar to measure brain activity.
Posterior	Situated behind or to the rear.
Pseudoprogression	Swelling or contrast enhancement on a scan that suggests tumour progression or recurrence related to treatment. Pseudoprogression can stabilise without additional treatments and often remains clinically asymptomatic.
Sagittal	Relating to the plane that divides the body into left and right halves.
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 weighting	An MRI image showing structures; cerebrospinal fluid appears black on the image.
T2 weighting	An MRI image showing water; oedema and cerebrospinal fluid appear white on the image.
Vascularity	The blood supply of a tumour.

Radiotherapy

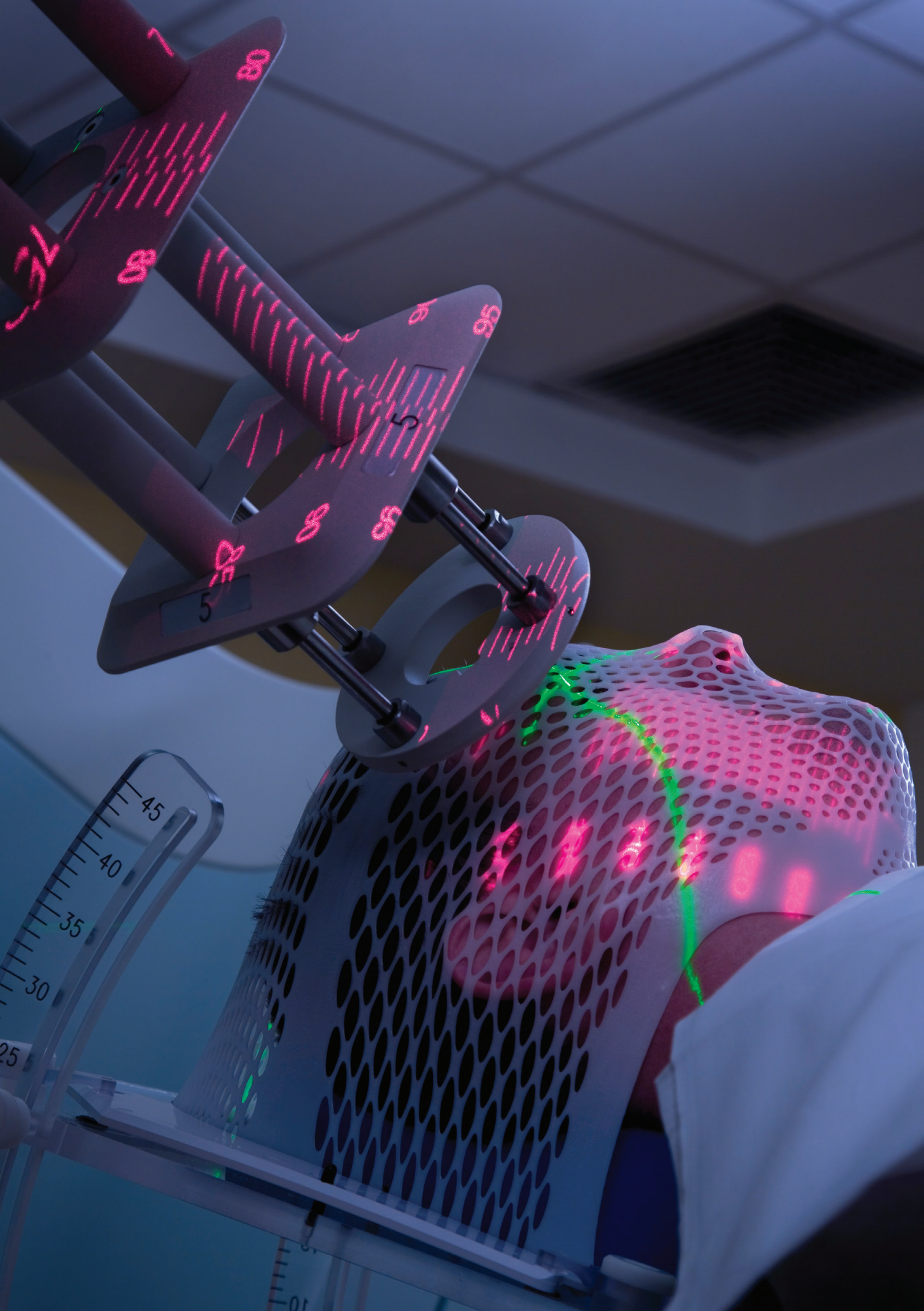
Word	Definition
cGy (centigray)	A unit of absorbed radiation dose equal to one hundredth of a gray.
Conformal	Relating to the shaping of radiotherapy beams in three dimensions to match the shape of the tumour.
CyberKnife®	Brand name of a machine used to deliver linear accelerator stereotactic radiosurgery.
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.
External beam radiotherapy	Radiation therapy that uses a machine to aim high-energy rays at a brain tumour.
Fractionated	Divided into parts. This relates to the dividing of the total dose of radiation to be given 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)	A form of radiation therapy that uses specialised equipment to shape radiation beams to the size and shape of the tumour.
Late effects	Health problems that occur months or years after a disease is diagnosed or after treatment has ended.

Word	Definition
Linac (linear accelerator)	An electrical device that creates ionising radiation in the form of X-rays (photons).
Mask	A mould to prevent the head from moving so that the patient is in the exact same position for each treatment.
Necrosis	Dead cells.
Palliative radiation	Radiation therapy with the goal of relieving symptoms and improving quality of life.
Proton beam therapy	A form of radiation therapy that uses high-energy protons to treat tumours.
Radiation oncology	The use of radioactive substances, X-rays or high-energy particles, such as electrons or protons, for the treatment of tumours.
Radiosurgery	A special form of radiation therapy that uses a large number of narrow, precisely aimed high-dose beams of ionising radiation.
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 radiosurgery require a specially fitted face mask or a frame attached to the patient's scalp. **Other names:** Gamma Knife, Cyberknife, stereotactic radiotherapy (SRT), stereotactic body radiotherapy (SBRT), fractionated stereotactic radiotherapy.
Toxicity	State of being poisonous.

Word	Definition
Tumour progression	When a tumour recurs or begins to grow again. The second stage of tumour development.
VMAT (volumetric modulated arc therapy)	VMAT delivers the radiation dose continuously as the treatment machine rotates. This accurately shapes the dose to the tumour while minimising the dose to organs around the tumour.
WBRT (whole-brain radiotherapy)	A type of external beam radiotherapy that is given to the whole brain over a period of weeks.

Resources used

- Patient and caregiver representatives.
- Clinical specialist radiographer.
- Radiation oncologist – neuro-oncology.
- Consultant neurosurgeon.
- Consultant neuropathologist.
- Cancer Research UK (CRUK).
- National Institute for Health and Care Excellence (2006) *Improving Outcomes for People with Brain and Other CNS Tumours*.
- Norden, A., Reardon, D. and Wen, P. (eds.) (2011) *Primary Central Nervous System Tumors: Pathogenesis and Therapy*. New York: Humana Press.
- NCRI Clinical and Translational Radiotherapy Research Working Group (CTRad).
- Summary of data held in brain tumour registry (BTR) records.
- Abrey, L.E. and Mason, W.P. (2011) *Brain Tumors (Fast Facts)*. Health Press Limited.
- Young, B. et al. (2011) *Wheater's Basic Pathology: A Text, Atlas and Review of Histopathology*. London: Churchill Livingstone.
- TheFreeDictionary's Medical Dictionary: medical-dictionary.thefreedictionary.com.
- brainstrust.org.uk/glossary.



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the brain cancer people

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