Brain tumour



The **Brain & Spine Foundation** provides support and information on all aspects of neurological conditions. Our publications are designed as guides for people affected by brain and spine conditions – patients, their families and carers. We aim to reduce uncertainty and anxiety by providing clear, concise, accurate and helpful information and by answering commonly asked questions. Any medical information is evidence-based and accounts for current best practice guidelines and standards of care.

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Introduction

This booklet provides information on brain tumours. The information is on brain tumours in adults and focuses on primary brain tumours. The booklet describes brain tumours and provides information on common symptoms, tests and investigations and possible treatments. It also provides information on rehabilitation and returning to everyday activities. Sources of further support and information are listed in the Useful contacts section. References are available on request.

Common questions

What is a tumour?

Our bodies are made from building blocks called cells, each with its own structure and function. Cells grow and multiply naturally and normally as we grow up through childhood into adulthood and as our bodies repair tissue and damage (for example, when our skin heals after a cut or graze).

A tumour is a swelling or lump formed when certain cells grow and multiply abnormally.

What is a brain tumour?

A brain tumour is an abnormal growth of cells in the brain.

If any brain cells grow and multiply abnormally to cause a brain tumour, this is called a **primary tumour**.

If abnormal cells have spread to the brain from a cancerous tumour in another part of the body, this is called a **secondary tumour** or a **metastasis** ('secondaries' or 'metastases' if talking about more than one).

What are the different types of brain tumour?

Brain tumours are graded by doctors according to the speed at which they are growing. Slower-growing tumours are given lower grades (grades I and 2) and faster-growing tumours are given higher grades (grades 3 and 4). The grading system was devised by the World Health Organisation.

Low grade brain tumours are always primary tumours (that is, they start in the brain). They do not spread into and invade the brain tissue surrounding them in the same way as malignant tumours (see below), and

they do not send secondary tumours to other parts of the body. However, these tumours can grow to a considerable size, creating pressure on the surrounding brain tissue and damaging it.

Historically, the term 'benign' has been used to refer to grade I and grade 2 brain tumours. However, increasingly this term is not being used to describe brain tumours. This is because, by definition, a 'benign condition' is one that doesn't cause harm whereas, in fact, all brain tumours have the potential to cause significant harm, even if they are slow growing and less aggressive when they are discovered.

In this publication, we will use the term 'non-malignant' to describe low grade brain tumours.

High grade brain tumours are referred to as malignant brain tumours. These tumours are cancerous. They spread into and invade the brain tissue surrounding them. The rate at which they invade the surrounding tissue depends on how malignant they are.

Primary malignant brain tumours very rarely spread from the brain to other parts of the body but they can cause problems by invading the cerebrospinal fluid (CSF) which surrounds the brain and spine. CSF flows between four chambers in the brain (two lateral ventricles (cavities), the third ventricle and the fourth ventricle). Brain tumours can block the flow of CSF between these chambers and cause physical symptoms and problems such as headaches.

Metastases or secondary brain tumours that have spread to the brain from malignant primary tumours in other parts of the body are the most common type of brain tumour. Metastases are always malignant. Malignant primary tumours in the lungs, breasts, skin (malignant melanomas) and bowel are the most common sources of metastases in the brain.

What causes brain tumours?

We do not yet know with any certainty what causes primary brain tumours, and we do not know why some are non-malignant and some are malignant.

Radiotherapy for childhood cancers and leukaemia has been identified as a risk factor, and people who have undergone this treatment as children are at an increased risk of developing brain tumours as adults. However, the risk is low.

It used to be thought that some types of brain tumour occurred after head injuries but we now know that this is not the case except for a very small link between head injuries and some meningiomas (tumours that grow on the layers of membrane that surround the brain).

Secondary brain tumours are always caused by a malignant tumour in another part of the body.

There have been concerns that the use of mobile phones is a risk factor for developing brain tumours. Currently, the scientific evidence that we have available suggests that this is not the case. However, because the widespread use of mobile phones is still relatively recent, there has not been extensive research into any possible health risks. Studies into the use of mobile phones have begun but it might be many years before any possible links to brain tumours are established.

Could I have prevented it?

No. We have not established clear risk factors for the majority of brain tumours in the way that, for instance, smoking has been established as a clear risk factor for lung cancer.

Are there warning signs?

No, there are no warning signs before the onset of symptoms. Some non-malignant tumours grow very slowly over several years and can reach a large size before they are detected. Malignant tumours tend to grow more quickly and will usually have been present for a shorter time when they are discovered.

The onset of symptoms does not tell us how long the tumour has been there, nor whether it is malignant or not.

Why me?

We do not know why the majority of brain tumours happen and, in most cases, there is no way of identifying the people who are at risk. There is a slight hereditary factor. A very small number of people can inherit from their family a greater risk of having a brain tumour.

Are my family at risk?

The hereditary risk of brain tumours is very low. It is extremely rare for a brain tumour to be traced to a genetic factor passed on within a family. If one of your relatives has also had a brain tumour it can almost certainly be put down to coincidence.

There are some very rare family cancer syndromes that affect the genes that control the multiplication of cells and can increase the risk of brain tumours. For example, neurofibromatosis or Li-Fraumeni syndrome.

How common are brain tumours?

Brain tumour statistics can be confusing and often only take into account primary malignant tumours. The charity Brain Tumour Research estimates that, in total, I 6,000 people are diagnosed with some type of brain tumour each year in the UK, although it may be more than this. It is also estimated that there are over 60,000 people living with a brain tumour in England (estimated by brainstrust and National Cancer Registration Service).

Primary brain tumours can affect people of any age. They are more common in people aged between 50 and 70 years but are also the most common cancer (after leukaemia) to affect children.

In addition, the number of people being diagnosed with secondary tumours (metastases) is increasing. This is because improved screening and treatments mean that more people are now surviving other types of cancer, such as breast cancer, and so there is more chance for secondary tumours to develop.

Please note that, currently, the number of people diagnosed with brain tumours in the UK is not systematically recorded for all types of tumour. The above numbers are approximate and they are conservative estimations.

What other terms are used to describe brain tumours?

Lots of different terms are used to describe brain tumours. They include: 'swelling' (the word tumour literally means 'a swelling'), 'growth' (because tumours form when cells grow abnormally) and 'lesion' or 'space-occupying lesion' (SOL). Space-occupying lesion is a term used when the medical team are not yet sure whether the abnormal area seen on a brain scan is a tumour or another problem such as an abscess, inflammation or bleeding (haemorrhage) in the brain.

This is often the situation after a scan has been done but before the results of a biopsy are known.

Doctors might use swelling, growth or space-occupying lesion when they do not yet know what type of tumour is involved.

The term cancer is sometimes used to describe malignant brain tumours but this term is usually reserved for describing malignant tumours elsewhere in the body.

If you are confused by any of the terms used by your doctors, you should ask them to explain. They are not deliberately trying to baffle you. Sometimes doctors forget how confusing these different terms can be.

Names of brain tumours

There are many different types of brain tumour, some of which have long and complicated medical names.

The names of specific brain tumours tend to be based on the type of cell that is growing abnormally, or their particular location in the brain. For example, gliomas grow from glial cells and, more specifically, astrocytic gliomas grow from particular types of glial cells called astrocytes ('star-shaped' cells). Pituitary tumours, such as pituitary adenomas, are named after their location in the pituitary gland in the brain.

Meningiomas are intracranial tumours (tumours within the skull) found *on* the brain rather than *in* the brain. They originate from the meninges (the layers of membrane that surround the brain). They are usually non-malignant and can be managed effectively with surgery and sometimes radiotherapy.

What are the symptoms?

The main symptoms of a brain tumour are drowsiness, memory problems, visual problems, speech problems, numbness or weakness in one side of the body, seizures (epileptic fits), headaches, nausea (feeling sick) and vomiting (being sick). Some people can also experience hormonal changes and personality changes. The symptoms that you experience depend largely on where the tumour is situated in your brain and which parts of the brain it is affecting. Some symptoms are caused by the tumour creating increased pressure on the brain within the skull. Symptoms might

Main symptoms

- Drowsiness
- Memory problems
- Visual problems
- Speech problems
- Physical problems on one side of the body
- Hormonal changes
- Seizures (epileptic fits)
- Personality changes
- Headache
- Nausea (feeling sick) and vomiting (being sick)

appear gradually over time rather than all at once.

It is important to note that experiencing one or more of these main symptoms does not necessarily mean that you have a brain tumour. If you have been experiencing any of these symptoms you should see your GP or specialist. Family and friends are often the first people to notice the symptoms or any changes in individuals.

Drowsiness

If a brain tumour is causing increased pressure on the brain it can cause drowsiness and sleepiness. You might feel drowsy during the day and sleep more than usual at night. You might feel that you do not have a clear head and that you are unable to concentrate.

Memory problems

Memory problems caused by a brain tumour might include general forgetfulness, short-term memory problems and problems with longer-term memory.

You might find that you are able to remember things that happened to you a few years ago but find it difficult to remember new information, like the name of the person you just met or a new telephone number.

Visual problems

You might experience difficulty focusing, blurred vision, double vision or problems with one side of your vision (you might knock into things to your left or right because you don't see them on that side).



Speech problems

If you experience problems with your speech as a symptom of a brain tumour you might slur your words or, more commonly, mix up and jumble your words. The term for this mixing up and jumbling of words is 'dysphasia'.

Often, if you have dysphasia, you are able to understand what is being said to you and know what you want to say but, when you attempt to speak, the wrong words come out. You know that the words are wrong and might become frustrated and upset. Dysphasia usually begins with having difficulty finding the right word or tripping up over simple sentences.

We all do this from time to time but, for people with brain tumours, speech problems can gradually become worse until a person's speech is incomprehensible and they are no longer able to communicate. These people might also develop problems with understanding speech.

Physical problems on one side of the body

A brain tumour might cause physical problems such as numbness, tingling, weakness or lack of co-ordination and balance affecting one side of the body, particularly in the arms or legs.

The symptoms might come and go but often people find that their physical problems become worse over the days and weeks immediately following their first appearance.

Hormonal changes

Tumours might affect the production of hormones in the brain. This can result in hormonal changes. You might experience a reduction in your sex drive or a loss of interest in sex. Men might experience impotence and women might find that their periods stop.

Seizures (epileptic fits)

A brain tumour might cause abnormal electrical activity in the brain which can cause seizures (fits). Epilepsy is diagnosed when someone has more than one seizure.

There are many different types of seizure and each person's experience will differ. Seizures range from momentary absences to longer seizures during which people experience convulsions and lose consciousness. The type, length and severity of the seizure will depend on the extent of the abnormal electrical activity and the particular part of the brain affected.

(You might be interested in reading our fact sheet, *Epilepsy*, for further information.)

Personality changes

A brain tumour might cause changes to an individual's personality and behaviour. These changes can be very upsetting for the individual and for their family and friends. Existing personality traits or characteristics might be exaggerated, or new ones might develop.

Previously quiet and mild-tempered people might become angry, aggressive and quick to lose their temper. They might shout and swear. They might experience a loss of inhibitions and behave in ways that they wouldn't usually.

Changes in personality and behaviour can be difficult to deal with, especially as the person experiencing them might not be aware of the changes and how they are affecting their family and friends.

Headache

People with brain tumours tend to experience regular and increasingly severe headaches. If you have not previously experienced headaches and begin to experience repeated and worsening headaches you should seek medical advice.

Headaches on their own are very rarely due to a tumour. They are much more likely to be related to tension, dehydration, a cold, the flu or migraine.

You might experience **nausea** (feeling sick) and **vomiting** (being sick) with the headache but these are also possible symptoms of migraine.

If you experience headaches alongside any of the other main symptoms of brain tumour they should be taken more seriously and you should seek medical advice.

Does earlier diagnosis make a difference?

Modern scanning equipment is accurate enough, in some cases, to identify abnormalities or changes caused by a tumour before people would usually begin to experience any symptoms, or before they are detectable in an examination by a doctor. However, in practice, people are unlikely to see a doctor in these early stages.

Delays in diagnosis can be harmful. For example, parts of the brain surrounding the tumour might be compressed and permanently damaged. Therefore, if a brain tumour is suspected, it is best to start the process of tests, investigations and treatment as soon as possible. However, while this means not waiting for months, it does not mean that everything needs to be done on the same day. Unfortunately, some people do experience delays in starting their treatment.

Brain tumours are often diagnosed late because the first symptoms people experience are vague and do not necessarily indicate a serious problem.

Tests and investigations

After the onset of symptoms, most people would usually see their GP, who then refers them to a local hospital, or directly to a neuroscience centre, for tests and investigations.

Doctors will ask you questions to help them form a detailed medical history and you will have a physical examination as part of the assessment of your symptoms. You will have an initial brain scan (either a **CT scan** or an **MRI scan**).

CT scan

A CT (computerised tomography) scan is a special type of X-ray which takes pictures of the brain from different angles.

During the scan you will be asked to lie on a scanner table while the scanner rotates around your head. It is a guick and painless examination.



Sometimes a dye (CT contrast agent) is injected into a vein in your arm to help show the tumour more clearly in the pictures.

MRI scan

An MRI (magnetic resonance imaging) scan produces pictures of the head and brain using strong magnetic fields and radio waves. It differs from a standard X-ray as it produces very detailed pictures.

During the scan, you will lie in a long tube. The scan is painless but the scanner is very noisy. Earplugs or headphones (often both) are provided. The headphones allow the hospital staff to talk to you while you are in the scanner.

If you think you will feel anxious or uncomfortable in the confined space of the scanner tunnel you should tell the staff before the scan. You should also tell them if you unexpectedly feel anxious just before you are due to enter the scanner tunnel.

Sometimes a dye (MRI contrast agent) is injected into a vein in your arm to help show the tumour more clearly in the pictures.

It is not unusual to have an MRI scan after an initial CT scan.

(You might be interested in reading our fact sheet, *Brain and spine scans*, for further information.)

Other scans

PET scan

A small number of people might also have a different type of scan called a PET scan following their CT or MRI scans. PET (positron emission tomography) scans produce detailed three-dimensional colour images of the brain. However, these scans are only available in a small number of hospitals so they might not be available in your area. You will only have this type of scan if your consultant requests one for you.

EEG

Occasionally, if your first symptom was a seizure, you may have an EEG (electroencephalogram). An EEG involves having wires attached to your head for 20 to 30 minutes, during which time a recording of the electrical activity in your brain is made. The wires are connected to small pads that are gently attached to your scalp. A skin-friendly glue might be used.

Results of the tests and investigations

The results of these tests will confirm whether your symptoms are caused by a physical problem in your head and will give your medical team some idea whether that problem is a tumour.

If your medical team are able to identify the problem as being a tumour, they might also have some idea whether it is non-malignant or malignant. However, these initial test results alone are unlikely to reveal any definite information about the type of tumour you might have.

Further tests and investigations

Once your doctors have established from your scan or scans that you have a tumour, they might need to obtain a sample of it to be examined by a pathologist (a doctor who specialises in the causes, effects and behaviour of diseases). This procedure is called a **biopsy**. The pathologist will identify what type of tumour it is and whether it is non-malignant or malignant.

You might also have further brain scans, such as those already explained or an angiogram, to help the surgeon plan any surgery.

Biopsy

A biopsy is an operation to remove a small sample of a tumour for examination by a pathologist (a doctor who specialises in the causes, effects and behaviour of diseases). A preliminary diagnosis is often made during the surgery but it might not be confirmed for several days.

Usually the procedure is carried out through a burr hole (a small opening the surgeon makes in the skull). A needle is passed through the burr hole and into the tumour. A sample of the tumour is taken via the needle.

Often the needle is guided to the tumour with the use of scanning equipment and a special frame that is attached to the head. This is called a stereotactic biopsy. You will be fitted for the frame before the biopsy. Recent advances now allow the procedure to be done without the frame in some cases. This is known as 'frameless stereotaxis' or 'image-guided surgery'.

Biopsies are usually carried out under a general anaesthetic but are sometimes done under a local anaesthetic.

The aim of a biopsy is to help with diagnosis rather than provide treatment. However, in some cases, a larger piece of the tumour can be removed and in this case the biopsy can form part of someone's treatment.

As with any form of surgery, there are risks associated with biopsies. There is a risk that your symptoms might worsen after the biopsy or that it might cause seizures. Your neurosurgeon will discuss the risks with you before the operation. The risks associated with biopsies are generally small.

Angiogram

An angiogram is an X-ray test used to produce pictures of blood vessels. Occasionally, people will have an angiogram to show the blood supplies of a suspected brain tumour. The test results can sometimes help to show doctors whether or not the tumour has spread and can help them to decide on the best treatment options for you.

After you have had a local anaesthetic, a very small, flexible tube (catheter) is inserted into the blood vessel in your groin (the femoral artery). This is passed through other blood vessels in your body until it reaches the arteries in your neck. While this happens, you will receive injections of a special dye (called contrast agent) to produce more detailed pictures.

You have to be admitted to hospital to have an angiogram and you may need to stay overnight.

(You might be interested in reading our fact sheet, *Angiogram of the brain*, for further information.)

Watch and wait

In some cases, your doctors might advise a 'watch and wait' policy at this stage. The watch and wait approach is most commonly used for non-malignant tumours. It is used in circumstances where other possible treatments risk causing more harm than doing nothing.

As the name suggests, the approach involves carefully monitoring the tumour without actively trying to treat it. You will have regular scans and check-ups with your specialist to keep a close eye on your condition. However, no treatment will be started unless your tumour grows, becomes more aggressive (starts to grow faster) or your symptoms get worse.

Living with a brain tumour without receiving any targeted treatment for it can be a very frightening prospect. It might help to use this time to learn more about the treatment options that may become available to you further down the line, before you have to make any decisions. You might also like to spend some time talking with your friends and family about these options. Being better informed and prepared may help you to feel more in control.

Possible treatments

There are different treatment options for brain tumours, and specific treatment pathways will differ for each individual.

National recommendations set out by NICE (National Institute for Health and Care Excellence) say that every brain tumour patient should be looked after by a team of specialists working together. These people are known as your multidisciplinary team (MDT) (see Health professionals section). Your MDT will meet to discuss your case and will create a personal treatment plan that is tailored for you.

Following their meeting, one of the specialists from your MDT will discuss your treatment options with you. If you have been introduced to a clinical nurse specialist (CNS) they will be able to answer any questions that you have about your diagnosis or your treatment. Your CNS is there to provide you and your family with information and support.

It is important to be aware that, regardless of the options offered to you by your consultant, you have the right to a second opinion. You can speak to your consultant about getting another opinion or, if you are not comfortable doing this, you can talk to your GP who will be able to refer you. However, you should also bear in mind that seeking a second opinion is likely to delay the start of your treatment. If you are considering seeking a second opinion, you should discuss with your GP or specialist whether this delay could be harmful.

Brain tumours can be serious and life-threatening. Even with the best available treatments and the expert knowledge of the specialists involved in your care, it is not always possible to cure them. In this case, your treatment and care will be focused on managing the symptoms that your tumour is causing.

Steroids

Steroids are used to reduce the swelling around the tumour. This helps to relieve headaches and reduce the levels of physical disability the tumour might cause (for example, weakness or numbness). It also makes surgery much safer and easier. Dexamethasone is the name of the steroid most commonly used to treat brain tumours.

Possible side effects of steroids

Side effects of steroids might occur after several weeks of treatment and can include increased appetite and weight gain, acne, muscle weakness, diabetes, sleep disturbance and feelings of restlessness and agitation. For most people, these side effects go away when the steroids are stopped. If you have been on steroids for more than a week you will need to gradually reduce the dose before stopping. Do not stop taking any medication without speaking to your doctor first. Steroid tablets can irritate the lining of the stomach and increase the likelihood of getting stomach ulcers. You might be given anti-ulcer drugs to reduce the risk. You might also be given an antacid drug in either liquid or tablet form.

Craniotomy (surgery)

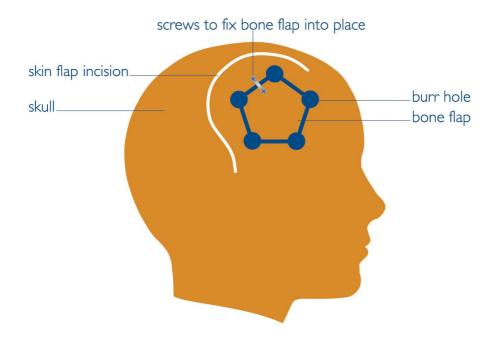
A craniotomy is an operation to open the head in order to expose the brain. The word craniotomy means making a hole (-tomy) in the skull (cranium). The operation is carried out by a neurosurgeon who specialises in surgery of the brain and spine.

The aim of a craniotomy is to remove the tumour entirely without damaging the surrounding brain tissue. While this can be possible for some non-malignant tumours, it is rarely possible for malignant tumours as they invade the surrounding brain tissue, which must be left behind to avoid causing serious disability. In most cases of malignant tumours, the neurosurgeon removes as much of the tumour as they judge to be safe.

The operation is usually carried out under a general anaesthetic, which means you will be asleep throughout and will not feel anything. However, an 'awake craniotomy' might be carried out if the tumour is near to areas of the brain responsible for important functions. This procedure allows the surgeon to test your functions throughout the operation (for example, by asking you to read aloud) to make sure that these important regions of the brain aren't damaged during the surgery.

A small horseshoe-shaped area of your hair is shaved over the point at which the tumour can be reached. An incision (cut) is made in the scalp, a skin flap is peeled back, burr holes are drilled in the skull, and then a piece of bone ("bone flap") is cut out to reveal the brain and tumour underneath.

Craniotomy incision and replacement of the bone flap



The surgeon then removes as much of the tumour as possible. This is known as 'debulking'. A pathologist will then look at some of the tumour cells that have been removed to establish what sort of tumour it is. The operation serves two functions: first, to obtain some of the tumour to be examined by a pathologist (like a biopsy), and second, as a treatment for the tumour by removing as much of it from the brain as can be done safely.

The bone flap is replaced and the scalp is stitched together. The bone flap is usually fixed into place with small metal screws to prevent movement and encourage better healing.

Possible problems after a craniotomy

People can experience various problems after a craniotomy. These potential problems depend to an extent on which area of the head was operated on.

You might have a stiff jaw and difficulty opening your mouth, swelling and bruising to your face, pain and discomfort as the wound on your head heals and headaches after your operation. It might also feel like the bone flap is moving or clicking. Although this feels strange, it is not dangerous. The bone flap is not loose. It is secured when it is replaced and will heal back into place.

(You might be interested in reading our fact sheet, *Craniotomy*, for further information.)

Other surgery

Sometimes, certain types of brain tumour are located in a position that makes them easier to reach and remove with surgery through the nose rather than with a craniotomy. Pituitary tumours and adenomas are sometimes approached with surgery through the nose.

Some people might require other surgical procedures. These might include the insertion of a device called a shunt to drain any fluid from the brain or to remove fluid from within a tumour cyst.

(You might be interested in reading our fact sheet, *Hydrocephalus and shunts*, for further information.)

Radiotherapy

Radiotherapy is often used after surgery, most commonly for the treatment of malignant tumours. Occasionally, radiotherapy will also be used to treat non-malignant tumours. If you have had surgery, you will be given time to recover before starting your radiotherapy treatment.

Radiotherapy uses X-rays and gamma rays to damage or destroy the tumour. The effect on the tumour is to slow its growth and lengthen the time before it regrows. In some circumstances, radiotherapy can completely cure the tumour.

The treatment is painless and involves lying on a specially designed table for a few minutes. You will be fitted for a special mask that you will wear over your face during the treatment. Some people find the mask uncomfortable. If you do you should tell staff so that they can try to adjust it.

A typical pattern is to receive six weeks of daily radiotherapy (Monday to Friday), usually as an outpatient. Some people might receive a shorter course of the treatment.

Radiotherapy treatment is given by a radiotherapist who will work with an oncologist (a doctor who specialises in cancer). It is likely that your oncologist will work closely with the neurosurgeon who performed the surgery as part of your treatment. They will explain the radiotherapy treatment to you and

talk through any worries or concerns you might have.

Radiotherapy will not always be available at the hospital where you have your surgery but there is always a close link between the hospitals providing your treatment.

Occasionally, radiotherapy might be administered by inserting implants into the tumour (brachytherapy). This form of the treatment is uncommon and only appropriate for a small number of people. Your doctors will discuss this treatment with you if they think it could be useful in your case.

Possible side effects of radiotherapy

Common side effects of radiotherapy are a temporary worsening of symptoms, tiredness, short-term memory loss, and inflammation of the skin which might lead to temporary hair loss. For most people, their hair grows back in the first few months following the treatment. The hair might not be as strong as it was before and it might be patchy or thin. Until an adequate covering of hair has grown back you should avoid strong sunlight or wear a hat. Occasionally, hair loss is permanent.

Most people feel tired towards the end of their course of radiotherapy. The level of tiredness varies for individuals and can depend on the particular area of the brain being treated. Some people might be able to manage their usual everyday activities and only experience mild tiredness. Others might experience severe problems with tiredness. It is important that you do not expect too much of yourself during this time and try not to become too frustrated by your tiredness. (For more information on radiotherapy please see the Further reading section.)

Radiosurgery

The two main methods of carrying out radiosurgery are by **gamma knife** and by **modified linear accelerator** (**LINAC**). Both methods use a high-energy dose of radiation that can be focused on a very precise point within the brain.

The LINAC uses only one beam of high-energy radiation which arcs around a single point, treating that specific area but not affecting the surrounding tissue. The gamma knife uses hundreds of energy beams which combine to form a high-energy point at their focus, each individual beam being too weak on its own to damage any healthy brain tissue in its path.

Unlike radiotherapy, which might require several sessions over weeks and months, radiosurgery is completed in one session and does not usually require an overnight stay. You will be able to return to your normal routine immediately after the treatment without experiencing any of the side effects of craniotomy or radiotherapy.

Radiosurgery is thought to be suited to deep-rooted tumours within the brain which might be difficult to reach without damaging the surrounding healthy brain tissue using other methods of treatment. It is not commonly used to treat gliomas.

Radiosurgery is not appropriate for everyone and your doctor will discuss your best treatment options with you. (For more information on radiosurgery please see the Further reading section.)

Chemotherapy

Chemotherapy is the use of drugs to destroy tumour cells in a way that is similar to the use of antibiotics to kill bacteria. The drugs work by damaging the cancer cells so that they cannot multiply and spread. Chemotherapy is usually recommended if a cancer has spread or if there is a chance that it will.

There are different types of chemotherapy. Some are taken by mouth and others are given via a drip into a vein. Chemotherapy is usually prescribed by an oncologist who has expertise in both radiation and chemotherapy. The consultant in charge of giving chemotherapy will be happy to discuss it with you if you are referred to them for treatment by your neurosurgeon.

Possible side effects of chemotherapy

The possible side effects of chemotherapy vary considerably depending on the particular drug used. Possible side effects include nausea, vomiting, tiredness, hair loss and a reduced resistance to infection. You should discuss these possible side effects with the specialist providing your treatment.

Some of the newer chemotherapy drugs, such as temozolomide, produce lower levels of side effects and are often very well tolerated. They are available as pills so you can take them at home and do not need to be in hospital.

Proton beam therapy

Proton beam therapy uses beams of protons (charged particles) to damage and destroy tumour cells. Unlike the X-rays used in conventional radiotherapy, proton beams stop when they hit the tumour. This means that less of the healthy tissue surrounding the tumour is damaged. This is particularly useful if a tumour has developed in a place where damage to surrounding tissue could cause serious side effects.

Currently, patients with certain types of tumour can be referred abroad to receive proton beam therapy. Eligible patients are referred to one of three centres in Switzerland and the USA (Florida and Oklahoma). New NHS proton beam therapy centres are being built to allow more patients who could benefit from the treatment to receive it in the UK.

Other treatments

Anti-epilepsy drugs

Anti-epilepsy drugs (AEDs) are used to control seizures (epileptic fits).

There are many different types of AEDs. The AED you are prescribed will depend on your individual situation. If you have epilepsy (or are being treated for cancer) you are entitled to free prescriptions.

Pain-relief drugs

For people with brain tumours, pain-relief drugs are used mainly to control headaches. They might be combined with other drugs to control nausea and vomiting. There are many different types of pain-relief drugs and your doctors will try to use the most effective one for your individual situation. If a drug that you have been prescribed is not working well for you, you should speak to your CNS or consultant.

Complementary treatments

There is still a great deal we do not know about brain tumours and you might find that complementary treatments such as aromatherapy or reflexology are helpful for you. Various dietary and vitamin supplements are also available. Most doctors would only recommend using these alongside established treatments rather than as a substitute for them. You should check with your doctor or pharmacist that it is safe for you to start taking dietary and vitamin supplements, especially if you are taking any medication.



Complementary treatments and therapies are unlikely to provide specific treatment for your tumour but they might help to improve your general well-being.

New treatments

Several treatments for different types of brain tumour have a limited success rate and there is a continuous search for new treatments.

It is very common to be concerned about the outcome of your treatment. Your medical team will always be ready to discuss your concerns with you, tell you about some of the newer, more experimental treatments, and say whether they might be worth considering in your case.

Some of the new treatments currently being developed include **photodynamic** therapy, gene therapy, immunotherapy and anti-angiogenesis therapies.

Photodynamic therapy (PDT) is being developed as an additional treatment to surgery, and for the treatment of brain tumours that can't be operated on. The patient is given a drug, usually through intravenous injection although sometimes directly into the tumour, that makes the tissue sensitive to light. A laser light is then directed at the tumour. This activates the light-sensitive substance in the drug, which kills the tumour cells.

Gene therapy involves inserting genes (DNA) into the tumour, either to replace defective genes and regulate the growth of the tumour, or to add specific genes which can stop the tumour growing and might trigger the death of the tumour cells.

Immunotherapy drugs aim to increase the ability of the body's own immune system to target and kill tumour cells.

Anti-angiogenesis drugs reduce the formation of new blood vessels in and around the tumour, which prevents blood flow to the tumour increasing. This causes tumour cells to die and tumour growth to slow down.

Clinical trials

You might be asked if you would like to take part in a clinical trial as part of your treatment. Clinical trials involve testing new treatments on patients. Your medical team will discuss this with you and answer any questions you have about taking part in a clinical trial.

Cancer Research UK has a database of clinical trials that you can search on their website: www.cancerresearchuk.org/about-cancer/find-a-clinical-trial.

If there is a trial that you are interested in it is best to discuss it you with your doctor. They will be able to tell you whether or not the trial is suitable for you and will be able to refer you if it is.

(You might be interested in reading our fact sheet, *Clinical trials*, for more information.)

Feelings and worries

Many people find it difficult coming to terms with being diagnosed with a brain tumour. You might feel low, tearful, angry or anxious. These feelings can be physical (related to damage to your brain), emotional (a reaction to the seriousness of your situation),



or both. The first few weeks and months can be a particularly intense time. You might find that friends and family treat you differently, often because they are worried about upsetting you. (See the Information for family and friends section for more about how a brain tumour diagnosis can affect these people.) At first they might not know what to say or how they can help, but try not to shut them out: most people with brain tumours find the support of family and friends very important.

Being diagnosed with a brain tumour is very distressing and lots of things in your life may change as a result. It is natural to feel shocked about your situation and to feel uncertain about the future. Many people worry about dying. It is normal to worry about this but questions about dying are very difficult to answer. Brain tumours can make you very ill but they can often be controlled successfully for a period of time.

It can be hard to express and explain to others how you feel and the worries you have. This can lead to feelings of isolation. It often helps if you can talk to a friend or relative about how you are feeling rather than keeping your feelings bottled up inside.

If you find it difficult talking to your friends or family, you might find it easier to talk to an independent person such as a counsellor or someone on a helpline. You might like to talk to your clinical nurse specialist (CNS), if you have been introduced to one. As well as offering information and support to you and your family and answering your questions, he or she can also refer you to an appropriate psychological service, such as a counsellor.

You might also find it helpful to talk to other patients.

(You might like to contact one of the organisations in the Useful contacts section about any patient support groups that meet in your area.)

You can talk to one of our neuroscience nurses by calling the **Brain & Spine Helpline** on **0808 808 1000**.

Depression

If feelings of sadness and despair are persistent, to the point where they interfere with daily living, you may be depressed. Depression can make life feel purposeless and stops you from enjoying the things you normally would. Other common symptoms of depression include a loss of appetite and insomnia.

If you think that you might be depressed you should speak to your GP immediately. Depression is not something you have to live with. Your GP will be able to advise you on the best treatment or therapy.

What should I tell my children?

It is usually best to be as open and honest as possible with your children. Of course, this can be difficult, even if you have grown-up children. Young children might not fully understand what is going on but could be upset if you go into hospital without telling them. It might be helpful to talk to them, prepare them for your stay in hospital, and explain your treatment to them.



If you have been told by your medical team that it is very unlikely that you will survive your brain tumour, it is usually best to discuss this with your children, however difficult and painful it might be. There are no set rules for this situation and different families will find their own ways of coping. Discussing things with your children, and allowing them to talk about their thoughts and feelings with you and your family, might be a way of helping them to cope.

Going home

What follow-up tests and treatment will I need?

Follow-up tests and treatment will be different for each individual but might involve further consultation with your oncologist, radiologist, neurosurgeon or other specialist.

You might have further scans to monitor your situation and assist your continuing treatment. You can discuss any concerns you might have about your follow-up tests and treatment with your doctors or with your clinical nurse specialist, if you have one.

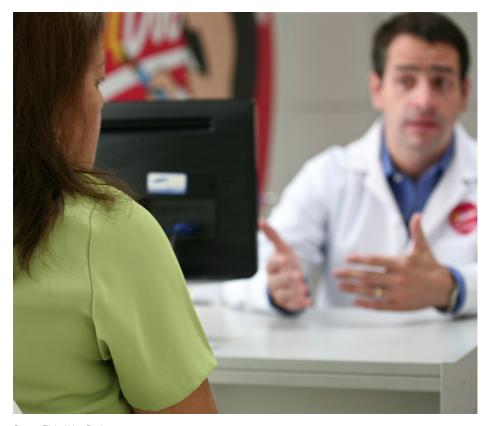


Photo: Flickr/Alex Proimos

What if the tumour comes back?

If the tumour comes back, your symptoms may be the same as before. The pattern is sometimes identical.

You will need another scan, which will show if the tumour has gone, stayed the same or grown. For some people, even if the tumour has grown, there might be a treatment to stop any further growth. With malignant tumours, even if there is no sign of growth or signs of the tumour returning, your doctors will interpret your scan results with great caution. It might be that the scans look favourable for a long time but that the tumour eventually returns. Obviously, this depends on the particular type of tumour you have, and you should discuss this with your doctors.

The treatment options for a recurring brain tumour are fundamentally the same as those for a first time tumour: craniotomy (surgery) and chemotherapy, though radiotherapy is not usually repeated. The best treatment for you will depend on the particular type of tumour you have and the nature of the recurrence.

A recurrence of any of your symptoms does not necessarily mean the tumour has come back. There might be other reasons for the symptoms.

Rehabilitation

Physiotherapy, speech and language therapy, occupational therapy

Your tumour might have left you with physical disabilities or other problems. The aim of physiotherapy, speech and language therapy and occupational therapy is to minimise the effects of the brain tumour and to maximise the speed and extent of your recovery. Although progress and recovery are not guaranteed, it is often possible to improve the quality of your life and gain relief from some of your symptoms.

Physiotherapy helps physical recovery and the recovery of movements (for example, walking).

Occupational therapy helps redevelop the skills you need to perform everyday activities (for example, washing, cooking and using equipment around the home).

Speech and language therapy helps with the recovery of communication skills and problems with swallowing.

Tiredness

Tiredness is very common after any serious illness, especially if you have had surgery or are undergoing a course of radiotherapy. Additionally, tumours in certain parts of the brain can cause tiredness as a specific symptom.

You might find that you become exhausted even after commonplace activities like getting washed and dressed, going to the shops, watching television or talking with friends. Taking regular breaks can help. Try to do this at least three times a day for around 20-30 minutes. Listening to your favourite music

can help, but try to avoid anything too stimulating like watching television or reading.

It can help to have a daily routine. Try to get up and go to bed at the same times each day. Plan some relaxation breaks during the day. If you have returned to work, you could talk to your employer about the possibility of being given time for some extra breaks during the working day.

Practical support

There are a number of organisations that help people affected by brain tumours and other forms of cancer (see Useful contacts). The most well known are the Macmillan Cancer Support teams and the hospice movement. These services are available throughout the country and you might have been introduced to them already. They deal mainly with people affected by malignant tumours. If you feel that you might need the type of support they are able to offer, you can discuss this with your GP or the specialist team looking after you.

If you feel depressed or worried while staying in hospital or attending an outpatient appointment, you should feel free to speak to the specialist cancer nurse attached to your medical team. The specialist nurse might be available to offer counselling, support and advice.

If you are having, or think you might have, financial problems because of the impact on your ability to work, you might be eligible for several different benefits. It is likely that a social worker is attached to the unit where you are receiving your treatment. Whatever your financial situation, it could be helpful to talk to them as soon as possible. It might also be helpful to talk to your local Citizens Advice Bureau for advice on what financial support is available to you.

Everyday activities

Can I drive?

Having a brain tumour is likely to affect your right to hold a driving licence. You are legally obliged to notify the Driver and Vehicle Licensing Agency (DVLA) of your condition and you must not drive until you have DVLA approval. Failure to notify the DVLA is a criminal offence. (See the Useful contacts section for the DVLA's contact details.)



The DVLA's Drivers Medical Group imposes special driving regulations for people who have, or have had, a brain tumour. You are required by law to give up your licence and failure to do so will automatically invalidate your car insurance.

The DVLA, after liaising with your GP or specialist, will decide the period of time during which you will not be permitted to drive. This decision will depend on the type of tumour, the symptoms it might be causing (for example, visual problems), the treatment you have received, and whether you have experienced seizures (epileptic fits). People who have experienced seizures will not be permitted to drive until they have gone one year without having a seizure. If you have a malignant tumour you are unlikely to be permitted to drive for a longer period of time (two years), to be sure that the tumour remains inactive.

Regulations are stricter for HGV (heavy goods vehicle) and PSV (public service vehicle) licences. These licences are more likely to be permanently withdrawn.

If and when you do resume driving, it might be worth contacting several insurance companies to get competitive quotes for your car insurance. Some companies increase the cost of insurance for people who have experienced medical problems.

Can I fly?

Yes, you will usually be allowed to fly approximately three months after your treatment. You might experience headaches during take-off and landing due to pressure changes. You will probably find that it is more difficult and more expensive to get travel insurance.

Can I play sport?

Yes, you can resume most sports once you have recovered. You should avoid all contact sports like rugby, boxing or martial arts. You can discuss with your specialist any concerns you have about resuming sports.



Can I swim?

Yes, swimming is encouraged once any wounds have healed but you should not swim unaccompanied until the risk of having seizures has passed (after approximately one year). If you do have epilepsy you should swim with a companion and let the lifeguard know about your condition.

Can I have sex?

Yes, you can have sex as soon as you feel ready. Women are advised not to become pregnant for the first six months after their treatment. A brain tumour itself does not affect fertility but some forms of chemotherapy and radiotherapy can do, and you should ask your doctor about this if you have concerns. If you are planning to become pregnant you should discuss this with your medical team.

Can I wash or colour my hair?

Yes. You can use any hair products like shampoo, conditioner or hair dyes. You can also have treatments like perms. However you should avoid using hair dyes or having treatments during and immediately after radiotherapy as your scalp is likely to be sensitive. You might find that baby shampoos and soaps are milder and less likely to cause discomfort. After a craniotomy, you should wait until the wound on your head has healed.



Can I drink alcohol?

There is no reason to avoid drinking alcohol but you might find that it suits you to drink less because you feel the effects more than you used to. There is also

a risk of provoking a seizure if you drink too much. Some people find that they have more severe hangovers after a brain tumour.

If you are taking any medication, you should always check that it is safe to drink alcohol.

When can I go back to work?

Being diagnosed with a brain tumour does not mean you have to give up work, although you will need to take time off during your treatment and for recovery after surgery.

The timing of your return to work will depend on what sort of work you do. For example, you might need to wait for the renewal of your driving licence. If you experience seizures (epileptic fits) you should not work at heights or with dangerous machinery.

You will certainly need to have regained enough physical and mental energy during your rehabilitation before you return to work. Obviously, this will differ for each individual but the general advice is to use your common sense and only return to work when you feel able. You might find it helpful to discuss this with your doctors or nurses. Many people return to work on a part-time basis before returning to full-time work.

Most people find that returning to work is a positive part of their rehabilitation and a big step in getting back to their normal lives. If you have a particularly busy or stressful day at work, the worst that will happen is that you will become tired more easily. Over-stimulating the brain will not bring the tumour back.

Information for friends and family

If your partner, friend or family member has been diagnosed with a brain tumour it can be difficult to understand what is happening to them.

You may find it hard to know what to say to them, whether to ask if they are okay or to behave as if nothing has changed. People who have a brain tumour might find it difficult to talk about the problems or feelings they are experiencing and might feel isolated as a result. You could mention that you have read this booklet as a way to introduce talking about how the person is feeling. (You might also like to read the Feelings and worries section of this booklet.)

Irritability or angry outbursts from the person you care about can be very difficult to cope with. Try to keep calm and try not to take remarks personally. There are likely to be good days and bad days.



Your loved one may need a lot of practical care and support because of their illness. If you are a close friend or relative, you may find that you become the person's caregiver. Even though you will want to do all you can to help, these extra demands can be stressful, especially when these new pressures are in addition to other responsibilities such as work, finances and taking care of other family members. Remember, it is okay to ask for help and it is okay to need a break. Other family members and friends are likely to want to help wherever they can, so involve them when you need some support.

Being a carer can feel lonely at times but there is a lot of support out there. In the UK, there are over 6.5 million people caring for friends and family and there are numerous support groups that meet across the country. (You might like to contact one of the organisations listed in the Useful contacts section of this booklet to find out about groups in your area.)

Caring for someone with a brain tumour is also likely to have big financial implications but government benefits can sometimes offer a little relief.

Organisations like Carers UK can give advice on what benefits are available (see Useful contacts).

Brain tumours are not an easy subject to talk about. There is no strictly right or wrong way to deal with it. Whatever works best within your family or within your friendship group is likely to be your best approach.

Brain tumour professionals

The multidisciplinary team (MDT) overseeing your care and treatment will be made up of various health and care specialists. Some of the specialists who may be involved are listed below.

Clinical nurse specialist (CNS): a nurse who specialises in a particular condition, for example cancer, and often the main point of contact between a patient and the medical team treating them. They may be referred to as your key worker.

Counsellor: a person trained to give guidance on personal or psychological problems.

Neurologist: a doctor who specialises in the diagnosis and treatment of people with neurological conditions, for example epilepsy.

Neurophysiotherapist: a physiotherapist who specialises in treating people with neurological conditions. A neurophysiotherapist assesses symptoms, plans treatment and treats people with physical problems.

Neuropsychologist: a psychologist specialising in the functions of the brain, particularly memory, concentration and problem solving.

Neurosurgeon: a specialist doctor who performs brain and spine operations.

Occupational therapist: a specialist health professional who offers practical support and advice on everyday skills and activities like washing, cooking and using equipment at home.

Oncologist: a doctor who specialises in the diagnosis and treatment of cancer.

Pathologist: a doctor who specialises in the causes, effects and behaviour of diseases.

Radiologist: a specialist doctor who performs, reads and reports on scans such as angiograms, CT scans, MRI scans and X-rays.

Speech and language therapist: a specialist health professional who assesses symptoms, plans treatment and treats people with communication and swallowing problems.

Useful contacts

Brain tumour

Brain & Spine Foundation

Office LG01, Lincoln House

Kennington Park

1-3 Brixton Road

London

SW9 6DE

Helpline: 0808 808 1000

helpline@brainandspine.org.uk

www.brainandspine.org.uk

Run by neuroscience nurses, the Brain & Spine Helpline provides support and information on all aspects of neurological conditions for patients, their families and carers, and health professionals. Further information on a range of neurological problems is available online.

Astro Brain Tumour Fund

The Cart Lodges

I West Hall Farm Barns

Sedgeford

Norfolk

PE36 5NA

Tel: 01485 572767

www.astrofund.org.uk

Provides support and information for people affected by low grade brain tumours and raises funds for research.

BASIC (Brain and Spinal Injury Charity)

Brain and Spinal Injury Centre

554 Eccles New Road

Salford

M5 5AP

Helpline: 0870 750 0000

www.basiccharity.org.uk

Provides support and information on neurological conditions.

Brain Tumour Action

25 Ann Street

Edinburgh

EH4 IPL

Tel: 0131 466 3116

www.braintumouraction.org.uk

Provides support and information on brain tumours.

Brain Tumour Research

Suite 3, Shenley Pavilions

Chalkdell Drive

Shenley Wood

Milton Keynes

MK5 6LB

Tel: 01908 867200

info@braintumourresearch.org

www.braintumourresearch.org

Brain Tumour Research is funding long-term sustainable research into brain tumours at UK Centres of Excellence.

Brainstrust

4 Yvery Court

Castle Road

Cowes

Isle of Wight

PO31 7QG

Helpline: 01983 292 405 hello@brainstrust.org.uk

www.brainstrust.org.uk

Provides information and support for anyone affected by a brain tumour.

Cancer Research UK

Angel Building 407 St John Street London

ECIV 4AD

Helpline: 0808 800 4040 www.cancerresearchuk.org

Provides information on cancer and funds research.

Macmillan Cancer Support

89 Albert Embankment London

SEI 7UQ

Helpline: 0808 808 0000 www.macmillan.org.uk

Provides support and information on cancer and an online community for anyone affected by cancer that is free to join.

Maggie's Centres

Across the UK

Tel: 0300 123 1801

enquiries@maggiescentres.org

www.maggiescentres.org

Face-to-face support for anyone affected by cancer.

The Brain Tumour Charity

Hartshead House

61-65 Victoria Road

Farnborough

Hampshire

GU147PA

Helpline: 0808 800 0004

support@the brain tumour charity.org

www.thebraintumourcharity.org

Provides support and information on brain tumours.

Epilepsy

Epilepsy Action

New Anstey House

Gate Way Drive

Yeadon

Leeds

LS19 7XY

Helpline: 0808 800 5050

www.epilepsy.org.uk

Provides support and information on epilepsy.

Epilepsy Society

Chesham Lane

Chalfont St Peter

Buckinghamshire

SL9 ORJ

Helpline: 01494 601 400

helpline@epilepsy

www.epilepsysociety.org.uk

Provides support and information on epilepsy.

Communication problems

Speakability (part of the Stroke Association)

Stroke Information Service. Stroke Association

Life After Stroke Centre

Church Lane

Bromsgrove

Worcestershire

B61 8RA

Helpline: 0303 3033 100

www.stroke.org.uk/finding-support/what-aphasia

Speakability self-help groups, run by and for people with aphasia, meet across the country. Information on aphasia and communication is also available online.

General

NHS Choices

NHS non-emergency line: 111

www.nhs.uk

Medical advice and information on health services.

Carers UK

20 Great Dover Street

London

SEI 4LX

Helpline: 0808 808 7777

advice@carersuk.org

www.carersuk.org

Provides expert advice, information and support for carers and an online discussion forum for carers that is free to join.

Driving

Driver and Vehicle Licensing Agency (DVLA)

Drivers Medical Group

Longview Road

Swansea

SA99 ITU

Tel: 0300 790 6806

www.gov.uk/driving-medical-conditions

Information on medical rules for drivers.

Support groups

The Brain & Spine Foundation's online discussion forum offers the opportunity to post messages, exchange views, share experiences and ask questions.

www.brainandspine.org.uk/forum

Brain & Spine Helpline: 0808 808 1000

There are various types of patient support groups, many of which are organised on a local basis. You might like to contact one of the organisations listed in the Useful contacts section for information on any support groups that meet in your area.

Further reading

The Brain & Spine Foundation produces a number of fact sheets that give more information on topics mentioned in this booklet: *Brain and spine scans, Angiogram of the brain, Craniotomy, Epilepsy, Hydrocephalus and shunts* and *Clinical trials*: www.brainandspine.org.uk

My radiotherapy book, produced by the charity brainstrust, is a comprehensive guide for patients and carers on the different types of radiotherapy treatments that are available (including radiosurgery and proton beam therapy). The organisation produces a number of other useful resources that are free of charge to anyone affected by a brain tumour: www.brainstrust.org.uk/advice-resources.php

References

Details of medical references used for this booklet are available at www. brainandspine.org.uk/references or on request from the Brain & Spine Helpline: 0808 808 1000.

Thank you

We would like to thank everyone who contributed to this booklet, especially Fiona McKevitt (Consultant Neurologist), Geoff Pilkington (Professor of Cellular and Molecular Neuro-oncology), Orla McKee (Neuro-oncology Clinical Nurse Specialist), Dr Paul Mulholland (Consultant Medical Oncologist), Dr Nicholas Brown (Clinical Research Fellow in Medical Oncology), Sue Farrington Smith MBE (Brain Tumour Research) and Dr Helen Bulbeck (brainstrust).

Brain & Spine Foundation

Our mission is to improve the quality of life of people affected by neurological problems by providing expert information, support and education. We rely on donations to provide our services to anyone who needs us.

How to donate

- Online: www.brainandspine.org.uk/donate
- By phone: 020 7793 5900
- By post: send a cheque to the address below

Contact us

Brain & Spine Foundation LG01 Lincoln House, Kennington Park, 1-3 Brixton Road, London SW9 6DE

Telephone (switchboard): 020 7793 5900 info@brainandspine orguk

Helpline: 0808 808 1000 helpline@brainandspine.org.uk

Registered charity number: 1098528

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