

# Treating Brain Tumours - A Quick Guide



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This is a brief summary of the information on 'Treating brain tumours' from CancerHelp UK. You will find more detailed information on the website.

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## Statistics and outlook for brain tumours

Outlook means your chances of getting better. Your doctor may call this your prognosis.

On CancerHelp UK, we have quite detailed information about the likely outcome of different types of brain tumours. The statistics are taken from a variety of sources, including the opinions and experience of the experts who check every section of

CancerHelp UK. They are intended as a general guide only and can't be used to predict your individual outcome.

## How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. The same type of cancer can grow at different rates in different people, for example. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

## Types of treatment for brain tumours

The most suitable treatment for a brain tumour depends on the type of tumour. It also depends on its position in the brain, its size and its grade. Your specialist will also consider your age and general health, and your own wishes about your treatment.

On CancerHelp UK, we have detailed information about treating each type of brain tumour.

## Surgery

Removing a growing brain tumour is important because as the tumour gets



bigger it increases the pressure inside the head. It is this increased pressure that causes some of the symptoms of brain tumours. The surgeon may be able to remove the whole tumour. Even if your surgeon doesn't think your brain tumour can be completely removed, they are still likely to want to take out as much as possible.

### **Radiotherapy**

Your specialist may suggest radiotherapy after surgery, or possibly as a treatment on its own. You may have radiotherapy just to the tumour, or you may have it to the whole brain or the brain and spine.

### **Chemotherapy**

Your specialist is most likely to recommend chemotherapy to help relieve symptoms in advanced brain tumours or tumours that have come back.

## **About brain tumour surgery**

You may have surgery to

- Diagnose the type of brain tumour you have
- Remove the whole tumour to try to cure it
- Remove as much of the tumour as possible to slow its growth, improve symptoms, and help other treatments work better
- Put in a tube to drain fluid away from the tumour
- Put in a small plastic capsule (an Omayo reservoir) under the scalp so that chemotherapy can be injected into it

If a tumour cannot be completely removed, it is often still advisable to have surgery. The surgeon will be able to remove some

of the tumour. This is called debulking. It is worth doing because removing some tissue will give a definite diagnosis. Removing some of the cancer may help to control symptoms and set back its growth. It also helps other treatments to work - the smaller the tumour, the easier it is for radiotherapy or chemotherapy drugs to reach the cancerous cells that are left.

On CancerHelp UK there is more information about the different types of brain surgery.

## **Having brain tumour surgery**

Before your surgery you will need to start taking drugs called steroids, and possibly drugs to stop fits.

### **Tests before your operation**

You may have various tests to check your general health. You may have an EEG. This painlessly records your brain waves using pads attached to your head. You may have an angiogram to show up the blood vessels in your brain so that the surgeon can avoid them.

You will also have tests called neuro observations. They include questions to see how alert you are, asking you to squeeze the nurse's hand or push your foot against it and shining a light into your eyes to check how your pupils react. This gives your doctors a baseline of what you are like before the operation, to see if you get better or worse later.

### **Shaving**

You may need to have some hair shaved before your operation. This is only done if absolutely necessary. But it can reduce the risk of wound infection.



### **Feeling frightened**

It is natural to feel frightened about having brain surgery. But it can help to talk to your doctor and nurses and ask as many questions as you need to.

### **After brain tumour surgery**

You will probably be in intensive care or a high dependency unit for at least one night after your operation. When you first come round, a nurse will make neurological observations and take your blood pressure every 15 minutes. You will have several different tubes in place. You will probably have a drip, a drain coming from your wound, a tube down your nose into your stomach to stop you being sick, and a tube (catheter) into your bladder.

### **Pain**

You may have a headache when you wake up. Your specialist may not want you to have strong painkillers because this could mask important symptoms. It is important to tell someone if your headache is getting worse. It could be a sign of swelling inside your skull, and you may need more steroids to control it. It is unusual to get a lot of pain after a brain operation.

### **The next few days**

It is important not to strain to do anything, as this could raise the pressure inside your head. You will be encouraged to move your arms and legs regularly. As soon as the surgeon says you can, your nurses will help you get up, starting gradually by sitting in a chair. You usually have a dressing on your wound for about 5 days.

You may have difficulty swallowing. At first, your nurse will give you sips of water, then gradually, starting with clear soup, you can build up to having normal meals again.

### **Being unconscious**

Most people come round fairly quickly after brain surgery. But you may be unconscious for longer. You and your relatives may have been warned beforehand to expect this. But some people are unconscious for longer than expected. This doesn't necessarily mean they won't make a full recovery.

While you are unconscious you may be on a ventilator. This is a machine that breathes for you. The ventilator connects to a tube that goes down your throat and in to the main airway at the top of your lungs. Often the tube goes in through your mouth. Sometimes it goes straight into the airway through a small hole in your neck. This is called a tracheotomy.

### **Keeping you comfortable**

While you are unconscious the nurses will turn you from side to side regularly to stop you getting pressure sores. If you are unconscious for more than 3 or 4 days you will have liquid feeds through a tube that goes through your nose into your stomach.

Your nurses will clean your eyes and mouth regularly and give you a full wash every day. This is important for keeping your skin healthy.

It is very common for people to be able to hear, even though they do not appear to be awake. Your relatives can talk to you and bring you music to listen to.

### **Recovering from brain surgery**

After any surgery, it is not unusual at first to feel worse than you did before the operation. After brain surgery, it is not uncommon to have dizzy spells or to get confused from time to time. These



episodes can come and go. These effects will usually lessen and disappear as you recover. This may take only days. But it can take weeks or even months.

For some people, recovery will be complete. You may be able to get back to the same fitness level you had before, and return to all your usual activities and your job.

Because of the position of their tumour, some people have long term problems with speech or with weakness in an arm or leg. This can take a long time to recover from and you may never quite recover to the same level of fitness as before your treatment. But with effort and with help from speech therapists, physiotherapists and other rehabilitation specialists, you will get a lot better.

There is more information about recovering from a brain tumour in the living with a brain tumour section of CancerHelp UK.

### What to ask your doctor about brain tumour surgery

- What type of operation do I need?
- What do you expect the surgery to achieve?
- Will the operation cure my brain tumour?
- Will I need any other treatment after surgery?
- Is it possible to completely remove my tumour?
- How much of the tumour can be removed?
- How likely is it that the tumour will come back at some time in the future?
- What are the risks and benefits of this operation?

- What are the likely long-term effects of this operation?
- How can I best prepare myself for this operation?
- When I wake up will I be in intensive care?
- How long do you expect me to be unconscious after surgery?
- What are the possible complications of this type of operation?
- What will happen if I don't have surgery?
- Is there any other type of treatment I could have?
- How long will it take me to get over this operation?
- How can I help myself recover?

### About radiotherapy for brain tumours

Radiotherapy uses high energy waves (X-rays) to treat cancer. Doctors quite often use radiotherapy to treat brain tumours. It may be your main treatment if you have a brain tumour the surgeon cannot remove. Or you may have it after surgery to try and stop the tumour coming back, or to treat any tumour that could not be removed.

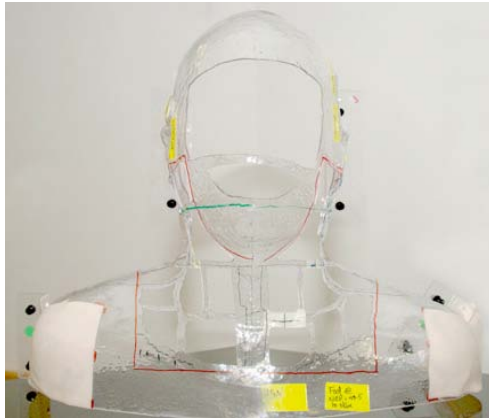
You have radiotherapy in the hospital radiotherapy department, usually as an out patient. You usually have one treatment a day, from Monday to Friday, for as many as 6 to 7 weeks. Each treatment only takes minutes. Having radiotherapy does not make you radioactive.

### Masks and head frames

There are two main ways to have radiotherapy to the brain. You will either have a mask made or a headframe fitted. The purpose of both is to keep your head completely still while you are being treated. The mask is made of clear plastic, with eye,



nose and mouth holes. You only wear it while you are being treated. When you are lying down, the mask will be put over your head and fixed to the treatment table. Below is a picture of a mask.



There is more information about how radiotherapy is planned and possible side effects in the radiotherapy section of CancerHelp UK.

### **Stereotactic radiotherapy for brain tumours**

Stereotactic radiotherapy is a way of targeting radiotherapy very accurately. You have the treatment aimed at your tumour from many different points around your head. This way of giving radiotherapy means that less of your healthy brain tissue is exposed to radiation. So there can be fewer side effects than with the usual type of radiotherapy.

#### **What this treatment is used for**

Stereotactic radiotherapy can be used for secondary brain tumours, and gliomas that have come back since they were first treated. It can also be used for a number of benign brain tumours. It is not suitable as the main treatment for high grade tumours.

### **Planning your treatment**

You will need to have a head frame or mask made to keep your head still during treatment. Then the specialist uses a CT or MRI scanner to work out how to shape the radiotherapy beam so that it exactly fits your tumour.

### **Having your treatment**

You will go to the hospital a number of times to have treatment. The treatment itself does not take very long. But it takes a little while to fit the mask and head frame and position you on the table. As soon as the treatment is over you can go home.

### **Radiosurgery for brain tumours**

Radiosurgery is a type of stereotactic radiotherapy, which aims radiotherapy beams very precisely at the tumour. Stereotactic radiotherapy is usually broken up into between 6 and 25 treatments. Radiosurgery is usually a single dose of treatment. It is sometimes called gamma knife treatment after one of the machines used to give it. This treatment gives a very high dose of radiotherapy to a small area of the brain. It can work very well for some types of brain tumour. It is usually used for small tumours.

### **Having your treatment**

To have radiosurgery you have a head frame fitted. This is fixed to your head under local anaesthetic and removed when the treatment is over. The treatment takes the best part of a day. You will be awake the whole time. Once the frame is in place you have a CT scan or MRI scan. There will then be a wait while your treatment is planned. The treatment itself takes an hour or two. You go back to the ward afterwards, and usually stay in hospital overnight.



### Side effects

You may have a dose of steroids after the treatment to help prevent swelling of the brain. You may feel a bit sick, faint or dizzy after the treatment, or have a headache. It is usual to feel very tired for some days after the treatment.

Over time, a few people develop some dead cells in the treated area. This is called radiation necrosis. For most people it causes no symptoms. A few people need to take steroids to treat the swelling it can cause, and a small number will need surgery to remove the dead cells.

### Side effects of brain tumour radiotherapy

You may have hair loss in the area of the head being treated. You do not lose all your hair as you do with chemotherapy. You may feel sick when having radiotherapy to the brain. This does not happen to everyone. Your doctor can give you anti sickness tablets.

### Tiredness

You are likely to feel more and more tired as your course of radiotherapy goes on. The tiredness usually goes on for a few weeks after the treatment has finished. It will gradually improve. A rarer complication is somnolence syndrome. This is extreme tiredness, where you sleep nearly all the time. It can begin a few weeks after treatment has finished. Somnolence syndrome will go away in time.

### Worsening of your brain tumour symptoms

With radiotherapy, symptoms can sometimes get worse before they get better. This is because it can cause swelling in the treated area. You will be given

steroids to try and prevent this. The symptoms will get better with time.

### Stereotactic radiotherapy

Stereotactic radiotherapy targets the tumour more precisely. So it tends to have fewer or milder side effects than conventional radiotherapy to the brain.

### Long term side effects of brain tumour radiotherapy

Treatment for a brain tumour can have long term effects. These will not happen to everyone. For most people, the benefits of radiotherapy far outweigh the risks. But some people have side effects that start months or years after radiotherapy.

### Early delayed side effects

Some delayed effects start from a few weeks to a few months after treatment finishes. You may have poor appetite, sleepiness, lack of energy, or worsening of your old symptoms. This early delayed syndrome usually clears up in about 6 weeks.

### Late side effects

Late side effects only affect a small number of adults. Unfortunately they are more common in children. Because a child's nervous system is still developing, it is more likely to be damaged by radiation. Unfortunately, late side effects are usually permanent. The effects may also slowly get worse over a long period of time. They can start from a few months to several years after treatment.

Symptoms can be mild, moderate or severe. You may have problems thinking clearly or managing tasks that you previously found easy. You may have poor memory, confusion or personality changes.



Or you may have symptoms you had from your original tumour. If you have mild late effects you are likely to have treatment with steroids. A very small number of people need surgery to remove dead cells from the radiotherapy area. This is most likely after radiosurgery treatment.

### What to ask your doctor about brain tumour radiotherapy

- Why do I need radiotherapy?
- Is there any other type of treatment I could have instead?
- Is there any other treatment I should have as well as radiotherapy?
- What do you expect the treatment to achieve?
- What are the side effects of this treatment?
- How long will it take me to get over the treatment?
- Are there any long term effects?
- Is there anything I can do to help myself recover more quickly?
- What are stereotactic radiotherapy and the gamma knife?
- Are targeted radiotherapy treatments suitable for my type of brain tumour?
- How often will I have to come to the hospital to have treatment?
- Will I have to stay in hospital, or can I have the treatment as an out patient?
- Can I get help with fares to and from the hospital?
- When will I be able to get back to normal?
- Will I be able to go back to work and when?
- Will I need any more treatment in the future?
- What happens if my brain tumour comes back after the radiotherapy?

### About brain tumour chemotherapy

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. You may have chemotherapy after surgery, to try to prevent a brain tumour coming back. You may have it to treat a tumour that has come back. Or you may have chemotherapy to shrink a tumour that cannot be operated on, or to make an operation easier to do. Not all brain tumours respond to chemotherapy. So specialists don't suggest it for every type.

#### Chemotherapy in children with brain tumours

Children less than 3 years old may have chemotherapy instead of radiotherapy. Your child will have chemotherapy for up to 2 years. Once the child is over 3, they can have radiotherapy.

#### How you have chemotherapy

You have most chemotherapy drugs directly into your bloodstream, either as an injection or through a drip (IV). You can take some drugs as tablets or capsules. Methotrexate is a chemotherapy drug that is injected into the spine. This is known as intrathecal treatment (IT treatment). You may have a combination of drugs. You usually have chemotherapy for a few days every few weeks.

#### Implantable wafers

Wafers or implants are a different way of giving chemotherapy for brain tumours. The drug is fixed inside a gel wafer. At the end of your brain tumour operation, the surgeon puts the wafers inside the brain tissue. Over 2 or 3 weeks the gel dissolves, slowly releasing the chemotherapy drug directly into the brain.



## Chemotherapy drugs for brain tumours

To treat a brain tumour with chemotherapy your specialist will use drugs that can get from the blood into the brain through the natural protection filter around the brain (the blood-brain barrier). You may have a combination of several different drugs. Your specialist will decide on the treatment that is right for you. They will take into account the type of tumour you have, and also your age and general health.

You can find more information about having chemotherapy in the chemotherapy section of CancerHelp UK.

## What to ask your doctor about brain tumour chemotherapy

- Why do I need chemotherapy?
- What do you hope the treatment will do for me?
- Is there any other choice of treatment?
- How often will I have chemotherapy?
- Can I take chemotherapy tablets at home?
- What are the likely side effects?
- How can you help me to cope with the side effects?
- What should I do if I am worried about side effects?
- What should I do if I am sick after taking my tablets?
- How should I store the tablets at home?
- How will you know if the treatment is working?
- What will happen if the brain tumour comes back after this treatment?
- What are chemotherapy wafers?

## Steroid treatment for brain tumours

Steroids occur naturally in the body. They are very powerful anti inflammatories. An anti inflammatory is a drug that helps to stop swelling.

When you are first diagnosed, you are most likely to have steroids to reduce swelling. After successful treatment for the brain tumour, your specialist will slowly reduce your steroid dose. With advanced brain tumours or tumours that have come back, steroids can help to keep symptoms under control for as long as possible.

Remember that it is extremely important to take your steroids exactly as your doctor has told you. It can be extremely dangerous to stop taking your tablets suddenly.

### Side effects of steroids

When you take steroid tablets, there are a lot of possible side effects. These include

- Increased appetite, weight gain and water retention
- Sugar in your urine (diabetes), causing thirst and passing a lot of urine
- Difficulty sleeping
- Mood changes
- Increased risk of infection or hiding the symptoms of infection
- Stomach irritation, which can lead to an ulcer (always take tablets with food)
- An acne type rash, or skin thinning causing stretch marks
- Flushing and night sweats
- Muscle wasting and bone thinning (with long term use)



## If your brain tumour comes back

Some brain tumours will be completely cured with the first round of treatment. Others will come back at some time. It may be possible to have further treatment to try to control the tumour once again. Even if the tumour cannot be cured, further treatment may keep it under control for longer and reduce the symptoms.

It may be possible for you to have more surgery. But this is a decision that has to be made individually. It may not be possible to have more radiotherapy. This is because further radiotherapy to the same area is likely to cause too much damage to your healthy brain tissue. But if the tumour grows back in a different place, more radiotherapy may be an option. If it grows back in the same area of the brain, targeted radiotherapy may be used for some types of tumour.

Chemotherapy is often kept in reserve in case a brain tumour comes back (recurs). So it is often possible to have it for a recurrence. Even if you have had chemotherapy before, there may be another drug you can try.

### Controlling symptoms

The first way to control your symptoms will be with treatment. If you have had all the treatment you can have, it will still be possible to help relieve your symptoms to some extent. Steroids will bring down the swelling inside the head. This will help ease headaches, sickness and drowsiness. You can also take painkillers, including morphine, to help with headaches.

You will probably also have medicine to help control fits. Fits are quite common with advanced brain tumours. It is better to

prevent them from happening as they can be scary for you and for anyone who is with you.

## Follow up for brain tumours

After your treatment has finished, your doctor will want you to have regular check ups. At the check ups your doctor will examine you and ask about any symptoms you are having. You may also have CT or MRI scans from time to time. You won't have a scan at every visit. A growing brain tumour is likely to produce new symptoms. If you don't have any, it's unlikely that a scan would find a change in your condition.

### Worrying symptoms

It is normal to worry about your health when your treatment is over. If you are worried between appointments, get in touch with your doctor or specialist nurse.

If your brain tumour does come back, you are likely to have symptoms similar to the ones you had before. But having symptoms does not necessarily mean the tumour is back or is growing. Other possible causes include delayed or long term side effects of radiotherapy, or temporary swelling after chemotherapy. Fluid imbalance, high blood pressure or infection can also cause neurological symptoms such as headache.

Depression is very common in people who have had a brain tumour. There are things that can help with depression. If you (or your family) think you are depressed, see your doctor or specialist nurse. It is quite common now for people to have counselling after cancer treatment. To find out more about counselling, look in the coping with cancer section of CancerHelp UK.



## Brain cancer research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to test are they tested in people, in clinical trials.

There is research into the causes and diagnosis of brain tumours. There is a lot of research into treatment for brain tumours, including into treating children.

## What to ask your doctor about brain tumour treatment

- What can you tell me about the type of brain tumour I have?
- What is the likely outcome for this type of brain tumour?
- What type of treatment do I need?
- What written information can you give me about these treatments?
- Is there any choice of treatments?
- Should I have any treatment before surgery?
- Should I have any other treatment after surgery?
- What about radiotherapy or chemotherapy?
- Would stereotactic radiotherapy or radiosurgery be an option for me?
- What are the risks and benefits of these treatments?
- What are the side effects?
- How can I help to reduce the side effects?
- How often will I have to come to the hospital for treatment?

- Is there any transport available?
- Is it possible to have any help with the cost of fares to the hospital?
- How long will the treatment last?
- Can I have a second opinion?
- Are there any experimental treatments or trials that might help me?
- Is there a counsellor here I could talk things through with?
- How often will you see me when my treatment is finished?
- What will happen at my follow up appointments?
- How often will I have a brain scan?
- What should I do if I am worried between appointments?



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## Notes

### More information

For more information about brain tumours, visit our website  
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

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