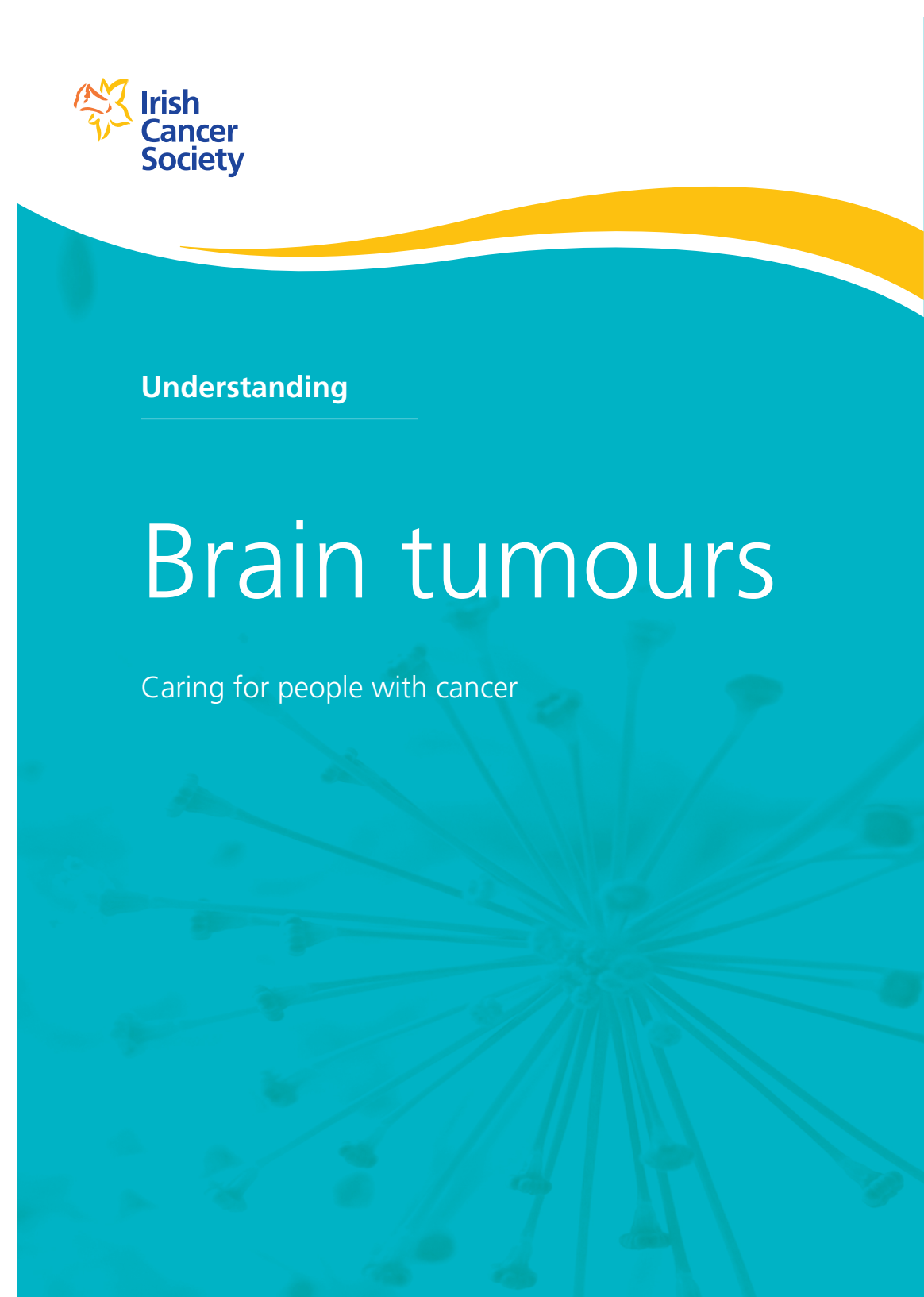


Understanding

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# Brain tumours

Caring for people with cancer



## Understanding

# Brain tumours

This booklet is about primary brain tumours – these are tumours that start in the brain. These are different to secondary brain tumours, which have spread to the brain from other parts of the body. It includes information on:

- Brain tumour treatments
- Side-effects and how to manage them
- Coping with the emotional side of your illness
- Financial and practical matters

## Useful numbers

Neurosurgeon (brain surgeon)

Neuro specialist nurse

Radiation oncologist

Radiation specialist nurse

Medical oncologist

Medical oncology specialist nurse

Neurologist

Epilepsy specialist nurse

Medical social worker

Family doctor (GP)

Emergency

Hospital records number (MRN)



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# Fast facts

## What kind of treatment will I have? Page 29

Surgery, radiotherapy and chemotherapy are the main treatments for brain tumours.

## Are there side-effects from treatment? Page 45

Any side-effects will depend on the type of brain tumour it is and the treatment you have. For example, radiotherapy side-effects include tiredness, headaches and hair loss.

You can read about the treatments to learn more about their side-effects and possible complications.

There are treatments to help with most side-effects so tell your doctor or nurse. Don't suffer in silence.

## Will I be OK? Page 26

What is likely to happen you (your prognosis) is hard to predict. The best thing to do is to ask your consultant about your own situation.

## Clinical trials Page 66

Clinical trials are research studies that try to find new or better ways of treating or diagnosing tumours or reducing side-effects. Ask your consultant if there are any trials suitable for you.

## We're here for you Page 106

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

### Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre
- Email us: [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

See page 106 for more about our services.



Support Line Freephone 1800 200 700

## Reading this booklet



This booklet is to help you throughout your treatment and afterwards. Keep it for reference. You may find different sections useful at different times in your illness.

If you need more information or don't understand something, ask your doctor or nurse.

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and your individual circumstances.



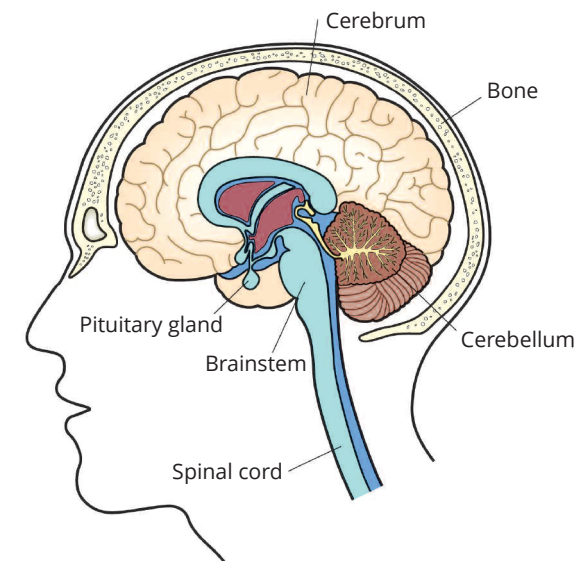
## About brain tumours

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## What is the brain?

The brain is a delicate structure made of countless nerve cells. It is the control centre of all the functions in the body. Different areas of the brain control different activities. The brain and the spinal cord make up the central nervous system (CNS). The 3 main parts of the brain are the:

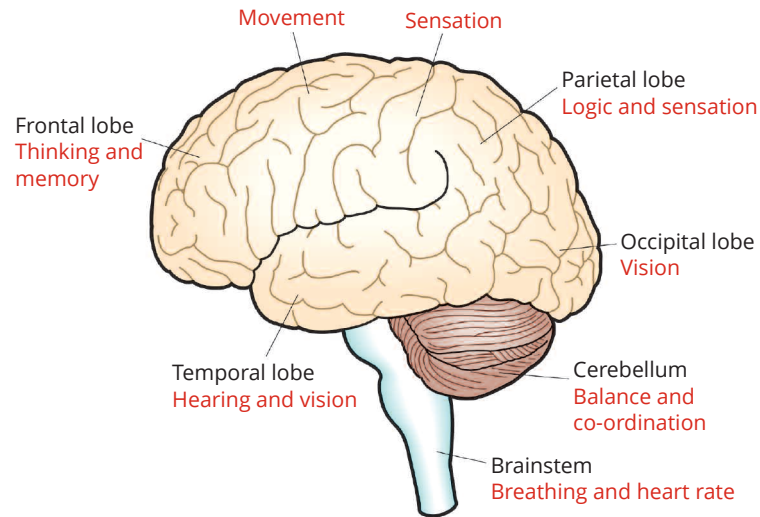
• **Cerebrum** • **Cerebellum** • **Brainstem**



The cerebrum is the largest area of the brain. The cerebrum controls thinking and memory. It receives messages from your senses to tell you what is going on and how to respond. The cerebrum is made up of 2 cerebral hemispheres. The right cerebral hemisphere controls the left side of the body and the left cerebral hemisphere controls the right side of the body.

Each cerebral hemisphere is divided into four areas, known as lobes: the frontal, parietal, temporal and occipital lobes. Each area of the brain controls different activities. This means that a tumour can affect different activities and give different symptoms depending on where it is found in the brain.





The **cerebellum** is the back part of the brain. It helps with balance and coordination.

The **brainstem** is located at the bottom of the brain and attaches the cerebrum to the spinal cord. It is here that our basic bodily functions are controlled, including breathing, heartbeat and blood pressure and reflexes.

The brain is wrapped in three thin membranes called meninges. A watery fluid called cerebrospinal fluid (CSF) fills the spaces between the meninges and cushions the brain. The brain is protected by the bones that form the skull.

### Types of brain cells

The brain is made up of two types of cell:

**Nerve cells (neurons):** Nerve cells form a network that carries messages back and forth between the brain and the rest of the body.

**Glial cells:** Glial cells surround the nerve cells and hold them in place. There are many different types of glial cells, including astrocytes, oligodendrocytes and ependymal cells.

## What is a brain tumour?

A brain tumour is a mass (lump) formed by an abnormal growth of cells in the brain.

Not all brain tumours are cancerous (malignant). Grades 1 and 2 are benign (not cancerous) – although they can come back and become malignant.

A brain tumour will cause symptoms either when it presses on the brain or if it grows into or invades the brain tissue. The symptoms will depend on which area of the brain is affected by the tumour, as different areas of the brain control different activities (see previous page).

If the tumour invades the brain tissue it is much more difficult to remove with surgery than a tumour that is causing pressure.

### What is a primary brain tumour?

Primary brain tumours develop either from cells inside the brain or from cells that make up the covering layers of the brain. Primary brain tumours usually do not spread to other parts of the body.

In general, tumours that arise from the covering layers of the brain cause pressure on brain tissue and tumours that develop from cells within the brain invade brain tissue.

In this booklet, when we talk about brain tumours we mean primary brain tumours.

## What is a secondary brain tumour?

Secondary brain tumours spread to the brain from cancer cells in other parts of the body such as breast cancer cells or lung cancer cells.

## How common are primary brain tumours?

In general, brain tumours are not common. About 500–550 people are diagnosed with primary brain tumours in Ireland each year.

### Children and brain tumours



Around 45 children are diagnosed with brain tumours each year in Ireland. While this booklet is about brain tumours in adults, we have information about brain tumours in children. For a copy of our booklet ***Helping Hand – A guide for parents of children with a brain tumour***, call our Support Line on 1800 200700, visit a Daffodil Centre or download it from our website [www.cancer.ie](http://www.cancer.ie)



Support Line Freephone 1800 200 700

## What causes brain tumours?

We don't know exactly what causes brain tumours, but there are things that can increase your risk of getting a brain tumour. If you want to know more about the risk factors for brain tumours, see our website [www.cancer.ie](http://www.cancer.ie), call our Support Line or visit a Daffodil Centre.

### Genetic conditions

There are certain rare genetic conditions that have been linked to an increased risk of brain tumours. These include neurofibromatosis type 1 and type 2, tuberous sclerosis, Li-Fraumeni syndrome, von Hippel-Lindau syndrome, Turcot syndrome and Gorlin syndrome.

If anyone in your family is worried about having a genetic risk linked to brain tumours, they should discuss it with their doctor.





## Grading brain tumours

Your brain tumour will be given a grade. Grading refers to how a sample of cells from your tumour looks under a microscope.

For tumours that arise within the brain, the grade is a number from 1 to 4. This number tells you how quickly the tumour might grow. A higher number means a faster-growing tumour. Sometimes a low-grade tumour can become a higher-grade tumour. How a tumour behaves will also depend on the type of tumour you have (see next page). It is common for higher-grade tumours to return some time after treatment. This is known as a recurrence.

- **Grade 1 tumours** are described as low-grade or benign. Usually they grow slowly and do not spread to other parts of the brain.
- **Grade 2 tumours** also grow relatively slowly (low grade) but in time they may spread to other parts of the brain or become malignant.
- **Grade 3 or 4 tumours** are described as high grade or malignant. They grow more quickly and are more likely to spread into normal brain tissue.

Tumours that arise from the covering layers of the brain are also graded. These tumours are normally graded from 1 to 3. Most of these tumours are grade 1 and they are usually cured by surgery.

Knowing the grade of the tumour helps your doctors to decide if you need more treatment and what the outlook (prognosis) is. Your doctor will explain the grade and type of your tumour to you and what this means for your treatment plan. See page 26 for more on asking about your prognosis.

## What are the types of brain tumour?

### Glioma

Most adult brain tumours start in the glial cells. Glial cells are glue-like cells that keep the brain together. These tumours are called gliomas and include:

### Astrocytoma

Astrocytoma is the most common type of glioma. These tumours develop from astrocytes. There are four grades of astrocytoma. The grade explains how abnormal the cells are and how likely it is that the cells will continue to grow and invade normal brain tissue. Astrocytoma can be slow growing (low grade) or fast growing (high grade).

### Types of astrocytoma

- **Grade 1 or pilocytic astrocytoma** is a slow-growing tumour that is most often benign and rarely spreads into nearby tissue. This is rare in adults. Depending on where it is found this unusual tumour may be cured completely by surgery alone.
- **Grade 2 or low-grade diffuse astrocytoma** is a slow-growing tumour that may spread into nearby tissue and can become a higher grade.
- **Grade 3 or anaplastic astrocytoma** is a malignant (cancerous) tumour that can quickly grow and spread to nearby tissues.
- **Grade 4 or glioblastoma multiforme (GBM)** is a very aggressive form of malignant astrocytoma. Grade 4 glioblastoma is the most common type of glioma in adults.

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### Oligodendroglioma

Oligodendrogliomas are tumours that develop from oligodendrocyte cells, and can be low grade or high grade.

### Mixed glioma

A mixed glioma is made of more than one type of cell. For example, gliosarcoma is a mixture of glioblastoma (GBM) and sarcoma.

### Ependymoma

Ependymomas are rare gliomas that starts in the ependymal cells lining the fluid-filled spaces in the brain (ventricles) and the spinal cord. They are usually slow growing. Sometimes ependymomas can spread to other parts of the central nervous system, through the cerebrospinal fluid (CSF) that circulates around the brain and spinal cord.



### Non-glial tumours

Non-glial tumours start in areas outside the brain tissue, for example in the nerves, the covering of the brain (the meninges) or the nearby glands, such as the pituitary or pineal gland. Types of non-glial tumours include:

#### Meningioma

Meningiomas are common type of primary brain tumour. These tumours begin in the meninges (the tissues covering the brain and spinal cord). Most meningioma tumours (about 75%) are grade 1 and the rest are grade 2 or 3. Grade 2 meningiomas are more likely to come back after surgery and may need further treatment. Grade 3 meningiomas are very rare.

A meningioma can cause serious symptoms if it grows and presses on the brain or spinal cord or grows into the brain tissue.

#### Primary central nervous system (CNS) lymphoma

A CNS lymphoma is a rare form of lymphoma (cancer that begins in the lymphatic system). A CNS lymphoma starts in the brain and can spread to the spinal fluid and eyes.

#### Pituitary gland tumours

Pituitary gland tumours start in the pituitary gland. This gland makes chemical messengers (hormones). Most pituitary gland tumours develop from the gland tissue and are called adenomas. Pituitary gland tumours are nearly always benign, so they grow slowly and tend not to spread. They can affect vision and hormone function.

#### Pineal tumours

The pineal gland is in the middle of the brain. It makes the hormone melatonin. Different types of tumour can grow in the pineal gland, including gliomas. Pineal gland tumours can be slow growing or fast growing. The most common are called germinomas (germ cell tumours).

## Medulloblastoma

Medulloblastomas begin most commonly in the cerebellum. It is one of the most common malignant (cancerous) brain tumours in children. It is not common in adults. Medulloblastomas can be fast growing and can spread to other parts of the brain and to the spinal cord through the cerebrospinal fluid (CSF).

## Craniopharyngioma

A craniopharyngioma is a rare benign tumour that begins near the pituitary gland located near the base of the brain.

Craniopharyngiomas are more common in children and young teenagers. However, they can occur later in life, usually among older adults.

These tumours do not usually spread, but they can cause problems as they grow. For example, changes in hormone levels and problems with eyesight.

## Vestibular schwannoma (VS)

Vestibular schwannomas (VS) are also called acoustic neuromas.

A VS is a rare tumour that begins in cells on the vestibular nerve.

This nerve helps to control hearing and balance. These tumours are usually described as benign, as they are nearly always slow growing and do not spread.

## Seizures



Seizures (fits) are a common symptom of some types of brain tumours. If you have seizure activity, anti-convulsant drugs may be prescribed to try to prevent the seizures. See page 70 for more about treating seizures.

# Diagnosis and tests

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## Being diagnosed with a brain tumour



Hearing that you have a brain tumour can be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next

However you feel, you are not alone.

If you need to talk to someone, or if you want support or advice:

- Ask to speak to the brain tumour liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a brain tumour diagnosis and really knows what you are going through. Our nurses can put you in touch with a volunteer.
- Talk to other people going through a similar illness. Join our online community at [www.cancer.ie/community](http://www.cancer.ie/community)
- Go to your local cancer support centre. For more information, see page 112.

‘However you feel,  
you are not alone.’



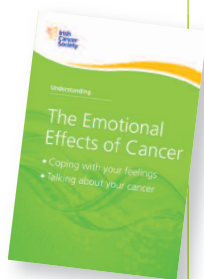
## Telling people about your diagnosis



It can be hard to tell other people the news that you have been diagnosed with a brain tumour.

You may want to talk about your diagnosis or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Understanding the Emotional Effects of Cancer*. This booklet can help you find ways to talk about your illness and to ask for the help and support you need.



## What tests will I have?



- After a diagnosis of brain tumour, you may have a neurological examination, brain MRI, CT scan and a biopsy.
- The tests will tell your medical team more about your tumour and help them to decide on the best treatment for you.
- You may or may not want to ask about your prognosis. This is information about what might happen with your tumour.

After being diagnosed with a brain tumour, you may have further tests to find out more about your tumour and your general health. You will have these tests at a specialist centre under the care of a brain specialist or neurologist.

The tests can give your doctor information about the tumour: how big it is, where it is and what type of tumour it is. This will help your doctors to decide on the best treatment for you. The tests may include:

### Neurological examination

Your doctor checks your vision, hearing, alertness, muscle strength, coordination and reflexes. Your doctor also examines your eyes to look for swelling caused by a tumour pressing on the nerve that connects the eye and the brain.

### Brain MRI scan

This scan uses magnetic energy to build up a picture of the tissues inside your brain. It does not hurt but can be noisy so you will be given earplugs to wear during the test. You might also have an injection beforehand to show up certain areas of your brain.



During the scan you cannot wear metal jewellery, hair clips or a prosthesis. If you have medical devices in your body, like a pacemaker or metal pin, you will not be suitable for the test. Your doctor will advise you about this. The test can be done as an outpatient, so you shouldn't need to stay in hospital overnight.

### CT scan

This is a type of X-ray that builds up a detailed picture of the tissues inside your head. You may be given an injection that helps to show up parts of your brain on the scan. Before you have the injection, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary between hospitals. Your doctor or nurse will tell you what to expect. The scan is not painful but you must lie as still as possible during it. Normally it takes between 10 and 30 minutes.



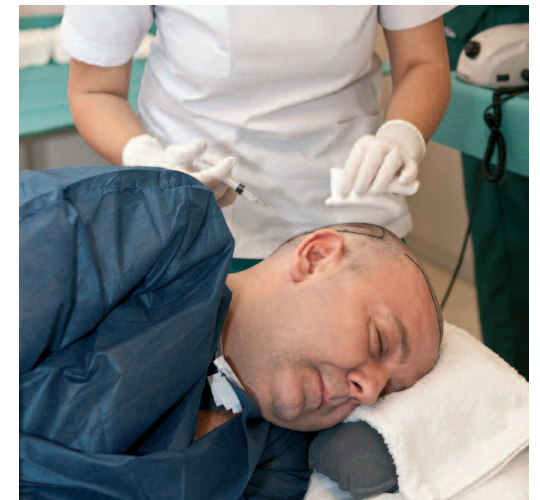
### Other tests

You may also have a chest X-ray, blood tests and any other tests that your doctor recommends.

### Biopsy

A biopsy means removing a small piece of the tumour so that it can be examined under a microscope. A biopsy is the only sure way to find out what type of brain tumour you have and how fast it is growing (the grade). For more about the types and grades of brain tumours see pages 14-18. The information from the biopsy can help your doctor to plan your treatment.

You may have a biopsy as part of an operation (surgery) to remove all or part of your tumour. You may have a biopsy and then go on to have other treatments such as radiotherapy and chemotherapy. Before the biopsy you will have an MRI or CT scan to show where the tumour is. The biopsy is done under general



anaesthetic. During the operation the surgeon uses a fine needle to remove a sample of the tumour through a hole drilled in your skull.

Using computers and scans to guide the biopsy is called a stereotactic biopsy. You may also have a head frame fitted to help the surgeon to pinpoint the right place. You usually need to stay in hospital for a few days when you have your biopsy.

After the operation, a special doctor called a pathologist examines the sample in the laboratory. The tests performed on the tumour in the laboratory may take 1-2 weeks to complete. If a sample of tumour is sent for genetic profiling (see page 54) it will take longer for your test results to come back.

**A biopsy is the only sure way to find out what type of brain tumour you have and how fast it is growing.**



## Waiting for test results



It usually takes 3-5 days for the first results to come back. However, it can take several weeks for more detailed genetic profiling (see page 54) to be done. This will not usually delay treatment.

Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a nurse.

## Asking about your prognosis



Your prognosis includes information about how your tumour is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

## Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on your prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular tumour type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie). Our nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

## Driving after diagnosis

If you drive and have been diagnosed with a brain tumour, you will most likely need to stop driving until well after your treatment has ended. Ask your doctor or specialist nurse about your situation. Contact the Road Safety Authority on 1890 40 60 40 for information on the Medical Fitness to Drive Guidelines.



## Treating brain tumours

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## How are brain tumours treated?



- The main treatments for brain tumours are surgery, radiotherapy and chemotherapy.
- A team of specialists will help you decide which treatment is best for you.
- You may be given other treatments to control your symptoms. For example, steroids.

The treatment you have will depend on:

- The type of brain tumour you have
- The size of the tumour
- The grade of the tumour
- Where the tumour is

Your doctor will also consider your general health and any symptoms you have when planning your treatment. They will explain to you if the treatment is expected to cure or control the tumour. They will also discuss if any symptoms caused by the tumour are likely to be improved by treatment. The main treatments used for brain tumours are:

### Surgery

Surgery aims to remove as much of the tumour as is safely possible. If the whole tumour cannot be removed, surgery can help to relieve symptoms. Surgery is not always possible, depending on where the tumour is in the brain and how big it is. See page 47 for more details on surgery.

Support Line Freephone 1800 200 700

## Radiotherapy

Radiotherapy uses high-energy X-rays to kill tumour cells. Radiotherapy may be given instead of surgery, if surgery is not possible. Or you may have radiotherapy after surgery to control the tumour. See page 56 for more about radiotherapy.

## Chemotherapy

Chemotherapy uses drugs to control the tumour. You may be treated with chemotherapy alone. Or you may have chemotherapy after surgery. Chemotherapy can also be given before, after or with radiotherapy treatment. See page 62 for more about chemotherapy.

## Treating symptoms

Surgery, radiotherapy and chemotherapy can all be given to help with some of the symptoms of a brain tumour. You may also be given other treatments to relieve symptoms. For example, steroids or anti-convulsants.

- **Steroids:** Steroids work by reducing inflammation and swelling. See page 69 for more details.
- **Anti-convulsants:** Seizures (fits) are a common symptom of some types of brain tumours. If you have seizure activity, anti-convulsant drugs may be prescribed to try to prevent the seizures from happening. See page 70 for more information.

You may be referred to palliative care for help in treating your symptoms. For more about palliative care, see page 85.

'Ask plenty of questions so you know how a treatment might affect you and possible side-effects.'

## Other treatments



New ways of treating brain tumours are being developed all the time. Your doctor will advise you about any other treatments that may help you. You may be offered a different treatment as part of a clinical trial. See page 66 for more about clinical trials.

## Specialist centres

Brain tumours are treated in specialist centres in Dublin and Cork. The staff at these centres have great expertise in managing patients with various types of brain tumours. As a result, you may be transferred to one of these hospitals from the one where you received your diagnosis.





## Deciding on treatment



### Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of tumour. For example, surgeon, medical oncologist, radiation oncologist, radiologist, pathologist, nurse specialist and other healthcare professionals. The team will meet to discuss your test results and your suggested treatment plan. You could use the fill-in page at the back of this booklet for your questions and answers. Remember to put your most important questions first.

### Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. If you do forget to ask a question or need more explanations, call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a nurse.

### Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

### Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or your GP will refer you to another specialist for a second opinion if you feel this would be helpful.

### Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.



## Who will be involved in my care?



Usually, a team of doctors and healthcare professionals will be involved in your treatment and care.

**Neurologist** A specialist in diagnosing, treating and managing disorders of the brain and nervous system. Neurologists do not perform surgery.

**Neurosurgeon** A doctor who specialises in operating on the brain and nervous system.

**Medical oncologist** A doctor who specialises in treating tumours using chemotherapy and other drugs.

**Radiation oncologist** A doctor who specialises in treating tumours using radiotherapy.

**Radiation therapist** A specialist who gives radiotherapy and advises cancer patients about their radiotherapy treatment.

**Neuropathologist** A specialist in diagnosing diseases of the brain and nervous system by examining tissue samples.

**Neuroradiologist** A specialist in diagnosing and treating disorders of the brain and nervous system using scans and X-rays.

**Oncology liaison nurse/clinical nurse specialist** A specially trained nurse who works in a cancer care unit. They can give you and your family information and reassurance throughout your treatment.

**Medical social worker** A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

**Epilepsy specialist nurse** A nurse who specialises in giving information and support about seizures and epilepsy.

**Physiotherapist** A therapist who treats injury or illness with exercises and other physical treatments.

**GP (family doctor)** You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or tell them if you are finding it hard to cope.

**Palliative care team** This team is trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. Most general hospitals have a specialist palliative care team.

**Dietitian** An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.

**Psycho-oncology team** A group of specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

**Psychologist** A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.



**Counsellor** A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

**Rehabilitation specialist** A person who specialises in helping people recover from physical and neurological (brain) conditions.

**Occupational therapist (OT)** A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities. They are mainly concerned with physical disability and cognitive function.

**Ophthalmologist** A doctor who specialises in the eye and visual system.

**Speech and language therapist** A specialist trained in the treatment, support and care of those who have difficulties with communication, or with eating, drinking or swallowing.

**Community health services** These include family doctors, public health nurses (who can visit you at home), community occupational therapists and physiotherapists, welfare officers and home help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

## Individual treatment



You may notice that other people with a brain tumour are not getting the same treatment as you. Their tumour may not be the same type or the same grade as yours. Everyone's treatment needs will be different. Do not be afraid to ask your doctor about your treatment.

## Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.



## Waiting for treatment to start



Planning treatment for your tumour takes time. Most people want to start treatment right away. You may worry that the tumour will grow during this time.

Treatment may start soon after diagnosis. However, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a nurse.

You might like to make some lifestyle changes while you're waiting for treatment. This can help you prepare for your treatment and feel more in control. See the next page for more about how you can prepare for treatment.

## How can I help myself?



It can be very difficult to cope with a brain tumour diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

### Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Recover more quickly

Ask to talk to the dietitian at the hospital for advice on the best diet for you.

You can also read our booklet ***Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website [www.cancer.ie](http://www.cancer.ie)

## Be active



Being active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you.

Be careful not to overdo it at the beginning – build up gradually.

Support Line Freephone 1800 200 700

## Quit smoking

If you are coping with a brain tumour diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Not smoking or drinking reduces the risk of other illnesses
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal more quickly after surgery

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have smoking cessation officers who can help and support you.



## Other ways to help yourself

### Get information about your tumour and treatment

Understanding your brain tumour and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

### Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

### Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.



### **Try relaxation and stress management techniques**

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

### **Accept change in your life**

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

### **Know that there will be ups and downs**

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

### **Try to cope day by day**

Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

## Types of treatment

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## Surgery



- Surgery aims to remove all or part of a tumour.
- Most people are ready to go home 1-5 days after surgery.
- Surgery can also be used to relieve symptoms.

Surgery is one of the main treatments for brain tumours. The aim of surgery is to remove as much of the tumour as is safely possible. Even if surgery cannot remove all of the tumour, it can still help to improve any symptoms you have. Removing some of the tumour is called a partial resection or debulking.

Your surgeon will also take a sample of your tumour (biopsy) during surgery. This will be tested by a doctor called a pathologist to give more information about your tumour. Knowing as much as possible about your tumour will help your medical team decide on the best possible treatment plan for you. See page 54 for more about pathology reports.

There are different types of surgery for brain tumours. The type of surgery you have will depend on the size of the tumour, where it is in the brain and your general health. Your surgeon will advise you on the best treatment for you.

Brain surgery is not a suitable treatment for everyone. If a surgeon is removing brain tissue there is a risk of causing damage to nearby parts of the brain. This can cause serious side-effects. Your surgeon may not recommend surgery or may not remove the whole tumour if they think it may damage other parts of your brain. If surgery is not an option for you, you may be treated with radiotherapy and/or chemotherapy.

## Worries and fears



Lots of people feel worried about having brain surgery. The idea of an operation inside your head can be scary and you may worry that something might go wrong. There are risks with any surgery, but remember that:

- Neurosurgeons are highly skilled
- Your medical team will only suggest brain surgery if they expect you to recover well from the surgery
- Brain surgery happens all the time and is safer and more successful than it has ever been

## Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery and what to expect. Discuss it fully with them so that you know exactly what is going to be removed and how it may affect you afterwards. If there is anything that you don't understand, ask again. Your doctor or nurse will be happy to answer your questions.

It is natural to feel very anxious about having surgery. Let your doctor or nurse know if you are feeling very anxious. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a nurse in confidence.

## Tests before surgery

You will need some extra tests to make sure you are strong enough for surgery. These tests are usually done a few days before your operation. Tests may include a chest X-ray, heart test (ECG), breathing/lung tests and some more blood tests.

## Steroids

You may be given a course of steroids before surgery, if you are not already taking them. They help to reduce any swelling in the brain caused by the tumour. Always take steroids exactly as your doctor has prescribed them. You will need to take them for a while after your operation. See page 69 for more about steroids.

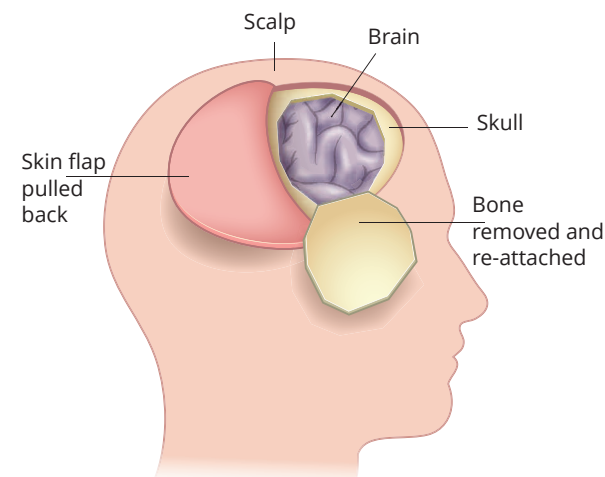
## Smoking

If you are a smoker, you will be advised to give up smoking before your operation. This will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 43 for advice.

## What are the types of brain surgery?

### Craniotomy

A craniotomy is an operation where a piece of the skull is removed so that your surgeon can operate on your brain. The surgeon removes as much of the tumour as possible and replaces the piece of skull that was removed. The piece of skull (called a flap) is held in place with tiny metal brackets and your scalp is stitched in place over the top.



A craniotomy is usually done under general anaesthetic. The surgeon may shave off an area of your hair before starting the operation, but this is not usually done. The aim of the surgery is to remove the tumour without damaging healthy tissue.



- **Having a craniotomy when you're awake**

Some people have a craniotomy while they are awake. If you are awake, the surgeon can talk to you and do checks during the surgery to make sure the surgery isn't affecting your brain functions, like speech or movement. They can stop operating if they need to. A neurophysiologist or a speech and language therapist may be in the operating theatre to monitor you during the operation. Although you will be awake you will not feel any pain. You will have a local anaesthetic in the area where they make the incision (cut) to make it numb. You will also be given a sedative to help you relax.

- **Fluorescence guided surgery (5-ALA)**

A treatment called 5-ALA (Gliolan®) can be used in adults who are having surgery for high-grade glioma. Taking 5-ALA makes the brain tumour glow pink under a special light. This glowing is called fluorescence. Normal brain tissue appears blue. The pink fluorescence helps the surgeon to see where the tumour is and remove it more accurately. 5-ALA is given as a drink 3-4 hours before surgery. It is absorbed by the rapidly dividing malignant cells. Very rarely 5-ALA can cause side-effects such as making you temporarily more sensitive to light (photosensitivity), lowering your blood pressure and affecting your liver function.

- **Stereotactic surgery**

Stereotactic surgery uses scans and computer technology to give a 3D image of the brain. This helps the surgeon to target very accurately the area that needs to be operated upon and decide on the best way to do the surgery. This means your surgeon can safely remove as much abnormal tissue as possible, while doing the least damage to normal brain tissue, even if the tumour is very small or is deep within the brain.

## Transsphenoidal surgery

This is a type of brain tumour surgery done through the nose instead of opening up the skull. It is done for tumours that can be reached through the nose. For example, pituitary gland tumours. The surgeon may use an endoscope for this operation. An endoscope is a long, thin tube with a light and a camera on the end that guide the surgeon as they remove the tumour with small surgical instruments.

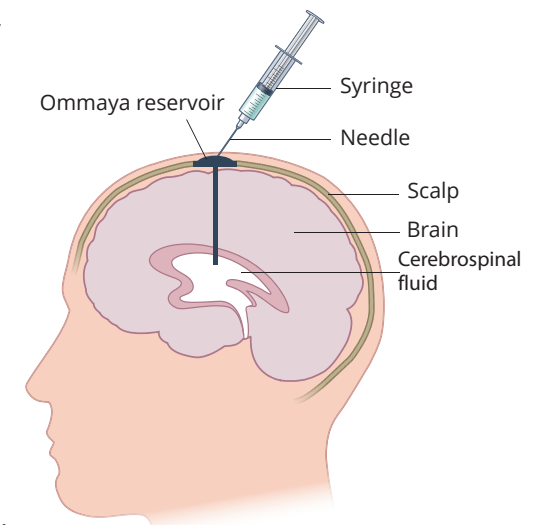
## Shunting

Shunting is a type of surgery to remove fluid from the brain. Some tumours can cause a blockage that causes the cerebrospinal fluid (CSF) in the brain to build up. This collection of fluid can be called hydrocephalus.

The fluid build-up can cause pressure inside the brain. A special tube called a shunt can be put in to drain away the fluid and relieve the pressure. The fluid is normally drained from the brain into the tummy (abdomen), where it is absorbed into your body.

Shunts can be temporary or permanent. Some patients have an Ommaya reservoir inserted. An Ommaya reservoir is a small soft, plastic, dome-shaped device that is placed under the scalp. The extra fluid collects in the reservoir and can be easily and safely drained.

In some cases, chemotherapy drugs may be delivered to the brain through the Ommaya reservoir.



### Endoscopic third ventriculostomy (ETV)

Endoscopic third ventriculostomy (ETV) is another way to remove a build-up of fluid from the brain. With ETV, a tiny hole is made in the membrane lining the space where the fluid has built up. The fluid can drain through this hole into another part of the brain, where it can be absorbed back into the body.

### After surgery

After surgery you will be transferred to the recovery area for about an hour. Then you will go to the neurosurgery ward, where observations will be performed regularly.

You will have neurological tests like reflex checks and answering questions to check how your brain is working.



You will have a bandage or dressing on your head. It is normal for your head to be sore, swollen or bruised after surgery. You will be prescribed painkillers for this and steroids to help decrease the swelling. You can eat, drink and start moving around as soon as you feel able. Often people can get out of bed and move around the first day after their surgery.

### Tubes

When you wake up, you will have some tubes attached to your body. Don't be alarmed as they are normal after an operation like this.

**Drip:** A drip will be put into a vein in your arm or neck. This will give you fluids until you can drink again.

**Catheter:** A small thin tube called a catheter may be put into your bladder. This helps to drain your urine into a bag.

**Drains:** Small tubes will drain any extra fluid from your surgery site and so help it to heal.

### Pain and sickness

You are likely to have some pain for the first few days, although it is often not as painful as you might expect after such a big operation. You may also feel or get sick. Your nurses can give you painkillers and medication to stop you feeling sick if needed. Always ask for help before the pain or sickness get too bad. If the medication isn't controlling your pain, let your nurse know, as it can be changed.

### Eating and drinking

Your doctor will tell you when you can start to eat small amounts of solid food again.

### Exercising

You will be asked to move your legs in bed and do deep breathing exercises at least once an hour to prevent clots. On the day after surgery, your nurses will help you out of bed and take you for a short walk. As you get better, you can go for longer walks on your own.

### Clips/sutures

Your surgical wound will be closed using clips or sutures. Usually these are removed 5 to 7 days after your surgery. Some surgeons use stitches that slowly dissolve by themselves and do not have to be removed or paper stitches that can be washed off.

## Pathology report



After brain surgery, a sample of the tumour (biopsy) will be looked at under a microscope by a doctor called a pathologist. The pathologist will write a report on the biopsy sample. This report will give your doctors more information about your tumour and its grade and help them to decide if you need further treatment.

### Genetic profiling

Samples of your tumour may be sent to a special laboratory to get information on your DNA. This is called genetic or DNA profiling. It can give your doctor more detailed information about your tumour to help plan the best course of treatment for you.

Tests performed on the tumour in the laboratory may take 1-2 weeks to complete. If you have genetic profiling the tumour sample may be sent abroad for testing, so it may take longer for these results to come back. An appointment will be made for you as soon as the results are available so that your doctor can discuss the results with you.

## Going home

Often people go home 1-5 days after surgery, but it varies from person to person. Your recovery time after brain surgery will depend on:

- The type of operation you had
- Where the tumour was in your brain
- Any areas of the brain affected by the surgery
- Your age and overall health
- If you had any complications or need further treatment

Before you go home, you will be given a date to come back for a check-up and to discuss pathology results. You may also have to visit the hospital or your GP so that your wound can be checked and sutures/clips removed if required.

## Help at home

If you live alone or have problems getting around the house, talk to your nurse or medical social worker. He or she can help to organise any community services you may need. For example, organising a public health nurse to visit you and give you support at home. The medical social worker can also advise you about social welfare benefits or entitlements you can apply for.

## Healthcare team

You will be given contact numbers so that you can reach your doctor, nurse or hospital at any time. Contact a member of the team as soon as possible if you:

- Feel drowsy
- Have weakness in your limbs, problems with speech or vision, or if you have a seizure
- Have a temperature of 38°C (100.4°F) or higher
- Have diarrhoea for more than 24 hours
- Feel unwell or vomit
- Have problems with your wound such as redness, swelling or a discharge
- Have symptoms again that you had before your treatment
- Have an increase in pain that is not relieved by taking regular pain medication
- Develop excessive thirst or pass urine more regularly
- Become confused

If you have any other worry or symptom that is causing you concern before your check-up date, contact your nurse specialist or hospital ward for advice.

## Radiotherapy

- Radiotherapy uses high-energy rays to treat tumour cells.
- Radiotherapy can be used alone or with other treatments like surgery or chemotherapy.
- External beam radiotherapy is the type of radiotherapy used for brain tumours.

Radiotherapy uses high-energy X-rays to kill tumour cells. The doctor who specialises in radiotherapy is called a radiation oncologist. The aim of radiotherapy is to destroy the tumour cells with as little damage as possible to normal cells.

Radiotherapy can be used alone or with other treatments like surgery or chemotherapy. If given after surgery, it can destroy any tumour cells left behind. Radiotherapy can also be used to control and relieve symptoms. This is called palliative radiotherapy.



## External beam radiotherapy

External beam radiotherapy is the type of radiotherapy used for brain tumours. The radiation comes from machines which aim rays directly at your tumour or the tumour site. The radiation is also aimed at a small area of normal tissue around the tumour just in case the tumour cells have spread. This is called a margin. The machines are called linear accelerators.



## Planning your external radiotherapy treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

You will have a CT scan to pinpoint the area to be treated. The dose of radiation will be decided and tightly controlled for your treatment. You will need to wear a mask during your treatment to make sure your head stays still. The mask is moulded from plastic to the shape of your face.

## Making your mask



You will need a plastic mould or mask fitted before treatment is given. Marks are put on the mask to show where treatment will be given. The mask keeps your head still. It can be made from clear plastic (Perspex) or thermoplastic.



## Getting your treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

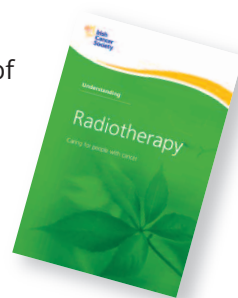
## How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (6 to 8 weeks) or between 1 and 10 doses for treatment to relieve your symptoms.

External radiotherapy does not make you radioactive. It's completely safe for you to mix with family and friends, including pregnant women and children.

Radiotherapy is normally given in special treatment centres, so you may have to attend a different department or hospital from where you had surgery or chemotherapy.

For more information on radiotherapy or a copy of our booklet ***Understanding Radiotherapy***, call the Support Line on 1800 200 700 or visit a Daffodil Centre.



External radiotherapy does not make you radioactive. It is safe for you to mix with family and friends. Pregnant women or children are not at risk from you.

## Other ways of giving radiotherapy

### Stereotactic radiotherapy

Stereotactic radiotherapy is a very precise type of radiotherapy. With stereotactic radiotherapy, the radiotherapy beams are aimed at the tumour from many different directions around your head. Only a very small area is targeted with a high dose of radiotherapy.

Because it is very precise, this treatment is less likely to affect healthy brain tissue near the tumour. The planning process and the machine used for stereotactic radiotherapy and standard radiotherapy are very similar.

Because the area to be treated is smaller than with standard radiotherapy, it is very important that your head is still and in the same place for each treatment session. So you will need to wear a head frame or mask during your treatment. See page 57 for more on making radiotherapy masks. If you have a head frame it will be made to fit your head exactly, using information from scans. The head frame is attached to your skull using pins.

Stereotactic radiotherapy treatment is usually divided into between 3 and 30 daily doses called fractions. If you only have 1 to 5 fractions of very high-dose stereotactic radiotherapy, this is called stereotactic radiosurgery (see page 60).

Stereotactic radiotherapy is not available at all hospitals. Not all types of brain tumours are suitable for this treatment.

### Side-effects

Stereotactic radiotherapy treatment has fewer side-effects than the usual type of radiotherapy, mainly because the area being treated is smaller. But you may feel tired for a while afterwards.



Your radiotherapy consultant will advise you on which type of treatment is best for you, depending on the type, size, location and grade of your tumour.

### Stereotactic radiosurgery

Radiosurgery is not actually surgery. It is a type of stereotactic radiotherapy that uses more radiation beams and gives a higher dose. Usually 1-5 sessions of stereotactic radiosurgery are required. Stereotactic radiosurgery treatment can take from 30 minutes up to a few hours. As with other types of radiotherapy, you will be required to wear a special frame or mask to keep your head still. This helps to make sure that the treatment is directed at the right area.

There are different treatment machines that can deliver stereotactic radiosurgery. Linear accelerator, gamma-knife and cyberknife machines can all deliver this type of radiotherapy.

### Side-effects of radiotherapy to the head

Radiotherapy is given directly to the site of the tumour. Therefore, most of the side-effects are related to the part of your body being treated. When the brain is being treated, the most common side-effects are:

- Tiredness (fatigue)
- Headaches
- Hair loss in the treated area
- Skin changes in the treatment area
- Drowsiness
- Nausea or feeling sick

How severe these side-effects are will vary from person to person, depending on the amount of treatment received. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent.

If you feel unwell or have any other side-effects or symptom – during or at any time after treatment – tell your doctor, nurse or radiation therapist.

For more information on the side-effects of radiotherapy or for a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.





## Chemotherapy



- Chemotherapy uses drugs to kill tumour cells.
- With brain tumours, chemotherapy can be given after surgery or before, with or after radiotherapy.
- The drugs can be given on their own or as part of a combination of drugs. They are given in tablet form or injected into your bloodstream.

Chemotherapy drugs can be given on their own or as part of a combination of drugs. They are either given in tablet form or injected into your bloodstream.

Your medical oncologist (doctor who specialises in using drugs to treat tumours) will decide the type, schedule and dose of your chemotherapy. When and how much chemotherapy you have will be based on the grade, size and location of the tumour and your general health.

### Understanding your drug treatment



It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

## Where will I have my treatment?

Where you go for chemotherapy can vary. It can be given as a day patient or sometimes as an inpatient, depending on the drugs being used. Often with a brain tumour you will be given tablets to take at home. Your nurse will give you more information about your treatment. This includes where and how often you will receive it and any possible side-effects. Ask as many questions as you like so that you know what to expect.

## What are the side-effects of chemotherapy?

The side-effects of chemotherapy depend on the individual drug and vary from person to person. Side-effects happen because the drugs work not only on tumour cells but on normal cells too. In most cases, the side-effects go away once the treatment ends or soon after. Some people who have chemotherapy have few or no side-effects.

Before you start your chemotherapy, ask your doctor about any possible side-effects that you may have. Tell them how you are feeling during your chemotherapy, as there are treatments to ease most side-effects.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

### Infection

Chemotherapy drugs can make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, or pain passing urine.

### Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help your blood to clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

### Anaemia

Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.



### Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 73.

### Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemo.

### Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). Always take any anti-sickness medication you are given, even if you don't feel sick, as it can stop the sickness from happening in the first place.

### Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help with these side-effects, if necessary.

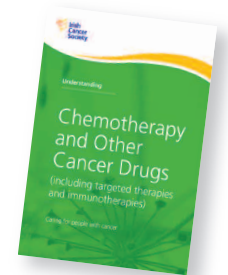
### Mouth and throat problems

Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

### Other side-effects

Other side-effects include headaches, a loss of appetite and an itchy rash or dry skin. For the effects of chemotherapy on fertility see page 77. If you have any other side-effect or symptom that concerns you tell your doctor or nurse straight away. They will give you advice.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website [www.cancer.ie](http://www.cancer.ie) for tips on coping with different side-effects.



## Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing tumours or reducing side-effects. They can also help improve a person's quality of life, when living with a diagnosis.

Patients with tumours are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular type of tumour or treatment, so you may not be suitable for a trial. Your doctor can advise you about this.

### More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet ***Cancer and Clinical Trials***. It's available to read or download on our website, [www.cancer.ie](http://www.cancer.ie).

You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at [www.cancertrials.ie](http://www.cancertrials.ie)



## Managing side-effects and symptoms

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## How can my symptoms be relieved?

Let your doctor know if you have side-effects or symptoms that are troubling you. There are treatments that can help. For example, medication for pain or drugs to stop you getting sick. Surgery, radiotherapy and chemotherapy can all be given to help with some of the symptoms caused by brain tumours. You may also be given steroids (see below) or anti-convulsants (see page 70).

## How is swelling treated?

### Steroids

Steroids are often given to help reduce the swelling around the tumour. This can help control headaches and any other symptoms caused by the swelling, such as nausea and seizures (fits).

It is important to always take the correct dose of steroids. Also, if you stop taking them suddenly it can make you ill, so always cut down gradually, following your doctor's advice.

**Side-effects:** Steroids can cause side-effects, such as indigestion, weight gain, increased appetite, difficulty sleeping, mood changes, irritability, a restless mind, skin thinning, stomach irritation, an increased risk of infection, taste changes or sugar in your urine. Long-term use can cause other side-effects such as diabetes, bone-thinning or muscle-wasting.



Your doctor will discuss possible side-effects with you. Most side-effects go away after you have finished your treatment. Tell your doctor if you have any side-effects that are troubling you.

## How are seizures treated?

It is quite common for someone with a brain tumour to have a seizure (fit). A seizure is caused by a burst of electrical activity in the brain. There are different types of seizures. Symptoms depend on the type of seizure and include:

- Shaking in one part of the body, such as a hand, or shaking of the whole body
- Feeling a bit strange, being unaware of what's going on around, staring blankly
- Noticing odd smells and sensations, a feeling of déjà vu
- Twitching muscles
- Getting confused
- Becoming unresponsive or unconscious

### Anti-convulsants

If your brain tumour causes you to have seizures, you may be given anti-convulsant drugs to try to stop this from happening.

**Side-effects:** Side-effects of anti-convulsants depend on the drug being used. They include difficulty concentrating, drowsiness, feeling sick, dry mouth, dizziness, mood changes, diarrhoea or constipation. Contact the hospital if you experience these or other side-effects. If you have a skin rash it may mean you are allergic to the drug. You should contact the hospital straight away if you have a rash while you are taking an anti-convulsant.

If you are having seizures, it is important to stop driving. See [www.rsa.ie](http://www.rsa.ie) for guidelines.

## Seizures: advice for carers

Although it can be upsetting to see your loved one having a seizure, seizures usually pass quite quickly. After a seizure, it may take a short while before the person feels back to normal again. It's important for them to rest until they have fully recovered.



Here are some things you can do to care for the person during and after a seizure.

### Convulsive seizures

This is where the person's body shakes rapidly and uncontrollably.

#### How to help

- Keep calm
- Stay with the person
- Move things like chairs and other objects away from them so they don't hurt themselves
- If you can, put something soft under their head
- Reassure the person throughout the seizure and when it is over



- Stay with the person until the seizure is over and try to place them in the recovery position
- If possible, contact a family member or friend

#### **Do not:**

- Try to physically stop the seizure or restrain the person
- Put anything in their mouth

#### **Partial seizures**

With partial seizures the person may stare blankly, chew, fumble, wander or become confused.

#### **How to help**

- Keep calm – speak quietly and reassure the person
- Protect them from hazards without restraining them
- Explain to others what is happening
- Do not leave the person alone until they are fully conscious and aware. Make sure they know the date, where they are and where they are going next

#### **When should I call an ambulance?**

- If the seizure lasts longer than is usual for the individual or for more than 5 minutes
- If the person has more than one seizure, one after the other
- If the person is injured
- If the person is unusually slow to recover, for example, if they do not regain full consciousness or remain confused
- If the person has had a seizure in the sea or swimming pool

## **How can I cope with fatigue?**

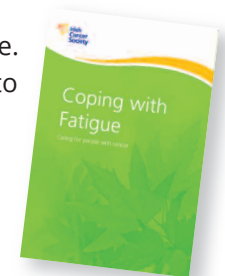
Fatigue means feeling extremely tired. Fatigue is a very common symptom. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Fatigue when you have a brain tumour can be caused by many things, including:

- The illness itself
- Tests and treatments
- Not eating well
- Low levels of red blood cells (due to the treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

Our booklet ***Coping with Fatigue*** has more advice. Call our Support Line on 1800 200 700 or call into a Daffodil Centre for a free copy. It's also on our website [www.cancer.ie](http://www.cancer.ie)



## Tips and Hints — fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants such as caffeine and alcohol before bedtime.
- Try complementary therapies if your doctor says they're safe for you. These might include meditation or massage.



## Will treatment affect my sex life?

Your illness can affect how you feel about sex and your relationships. Coming to terms with the fact that you have a brain tumour can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.



There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching, caressing and holding each other can help you to stay physically close.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

## Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment, even if your periods stop. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or to have more children. This gives your body a chance to recover from the effects of the tumour and its treatment.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

## Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a nurse in confidence. Or email the nurses at [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

## Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. Infertility is especially hard if you had plans to start a family, or to have more children. It can help to share your concerns with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

## Complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage and counselling.

Complementary therapies can't treat or cure brain tumours, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their illness and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your diagnosis.

## Integrative care



Integrative care means combining (integrating) your standard treatment with complementary therapies to try to feel as well as possible and to cope better with your illness.

### What's the difference between complementary and alternative therapies?

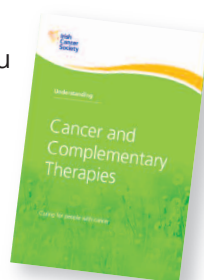
Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

### More information

To find out more about complementary therapies, you can talk to one of our cancer nurses — call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website [www.cancer.ie](http://www.cancer.ie)



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## What follow-up will I need?

After your treatment has ended you will still need regular check-up appointments. This is called follow-up. The follow-up may involve having a physical examination and blood tests, X-rays and scans. At first you will see your consultant every 3-6 months but these check-ups may become less frequent over time.



Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about:

- Any new symptoms, aches or pains you have
- If you're finding it hard to cope

Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget anything.

It's important to go to your follow-up appointments. They give your doctor the chance to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the tumour coming back (recurrence)



It is better to be aware of any changes as early as possible so that suitable treatment can be given.

If you're between check-ups and have a symptom or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary.

Go to your GP or the hospital emergency department if you become suddenly unwell and you can't contact the hospital team.

### Driving after brain tumour treatment



If you have been treated for a brain tumour, you will have to wait for some time before you are allowed to drive again. The amount of time depends on the treatment you have had, the type of brain tumour, and any symptoms you may be experiencing. Contact the Road Safety Authority on 1890 40 60 40 for information on the Medical Fitness to Drive Guidelines. You can also read and download the guidelines from the Road Safety Authority website at [www.rsa.ie](http://www.rsa.ie)



## Life after treatment

It can take some time to adjust to life after treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

### Feelings you may have include:

- Fear of tumour coming back and worrying about every small symptom
- Loneliness without the company and support of your medical team and fellow patients
- Stress at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- Isolation or guilt if your family and friends expect you to get back to normal before you are ready
- Anxiety and self-doubt about sexual and romantic relationships
- Anger at what has happened and the effect on you and your loved ones
- Depression or sadness

There is more about how to cope with these feelings and adjusting to life after treatment on our website [www.cancer.ie](http://www.cancer.ie)

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 92 for other ways to get emotional support.

'I am very happy and content ... even though I have to live with this.'

## Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Cope better with the side effects of treatment

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website [www.cancer.ie](http://www.cancer.ie) for tips and publications on healthy living.



## What if the brain tumour comes back?

Sometimes a tumour comes back after treatment. This is called recurrence. If this happens, your doctor will discuss your options with you and what the aim of the treatment will be. In some cases surgery may be possible. Radiotherapy may be given to the area if it has not already been used before. In other situations, chemotherapy may be given to try to control the tumour for as long as possible. Your doctor may also refer you to specialist palliative care doctors and nurses.

### Palliative care



Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced disease. You don't need medical insurance.

## Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead enables people to concentrate on their illness and its treatment knowing that their wishes and desires are clearly documented should a need arise.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Talking about what you want** to your family, friends, carers and healthcare providers.

### Who can help me plan?

*Think Ahead* is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at [www.hospicefoundation.ie](http://www.hospicefoundation.ie)



## Coping and emotions

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## How can I cope with my feelings?

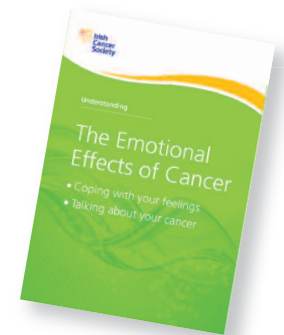
There are many different reactions to getting a diagnosis of a brain tumour. There is no right or wrong way to feel and there is no set time to have any particular emotion.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

Being diagnosed with a brain tumour can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions and get help if you need it.

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the Emotional Effects of Cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.



Support Line Freephone 1800 200 700

## Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help  
or to feel unable to cope on your own.



## Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie)

A list of counsellors funded by the Irish Cancer Society is available at [www.cancer.ie](http://www.cancer.ie)

'Counselling has helped  
me with every part of my life.  
I feel I have a future now.'

## Positive feelings

In time, some people say they can find positive things in their brain tumour experience. They say that their diagnosis brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.



## Ways to get emotional support

**Find out about support services in your area:** Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 112 for more about cancer support services.

**Join a support or educational group:** You might find it reassuring to talk to other people who are facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by a brain tumour. Or contact Brain Tumour Ireland, which has support groups located throughout Ireland (see [www.braintumourireland.com](http://www.braintumourireland.com)).

**Ask about psycho-oncology services at the hospital:** Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

**Get online support:** Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit [www.cancer.ie/community](http://www.cancer.ie/community) to join the Irish Cancer Society online community.

**Talk things through:** It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

**Seek spiritual support:** For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

## You and your family

Every family deals with illness in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Understanding the Emotional Effects of Cancer* can help to you find ways to talk about your illness and to ask for the help and support you need.

## Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel and find out how they feel. If you find it hard, ask another family member or friend to talk to them.

## Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.





## Supporting someone with a brain tumour

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## How you can help

Finding out someone you love has a brain tumour and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

### Learn about brain tumours

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Support Line for free copies of our information booklets.

### Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a nurse in confidence.



## Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

## Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated support centres. Talk to your GP or see page 91.

## Find out about support for carers

Find out about groups and organisations for carers. Many local cancer support centres have services for carers too.

## Talking to your loved one about their illness



When someone close to you has a brain tumour, it can be hard to know what to say. You may find it difficult to talk about their illness. Or you may be afraid of saying the wrong thing. Often what people want most is someone to listen to them.

If you want advice on how to support a friend or loved one with a brain tumour, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at [www.cancer.ie](http://www.cancer.ie)

## Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie) for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer*, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website [www.cancer.ie](http://www.cancer.ie)



'The emotional support I got made a huge difference to me.'





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## Money matters



- If you have a brain tumour you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of a brain tumour often means that you will have extra expenses, such as medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with your illness if you are worried about money.

### Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

**If you have a medical card**, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

**If you don't have a medical card** you will have to pay some of the cost of your care and medication.

**If you have health insurance** the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.

## Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.

## If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 109 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Support Line 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

## More information

Go to [www.cancer.ie/publications](http://www.cancer.ie/publications) and check out our booklet, *Managing the Financial Impact of Cancer*. This explains:

- **Medical costs and help available**
- **Benefits and allowances that you or your family may qualify for**
- **Travel services**
- **Ways to cope with the cost of cancer**

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.



## Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- **Support Line**
- **Daffodil Centres**
- **Survivor Support**
- **Support in your area**
- **Patient travel and financial support services**
- **Night nursing**
- **Publications and website information**

### Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our nurses for confidential advice, support and information. It's open Monday–Friday, 9am to 5pm.

You can also email us any time on [supportline@irishcancer.ie](mailto:supportline@irishcancer.ie) or visit our online community at [www.cancer.ie](http://www.cancer.ie)

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: [remote@slis.ie](mailto:remote@slis.ie)



'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

## Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.



### Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email [daffodilcentreinfo@irishcancer.ie](mailto:daffodilcentreinfo@irishcancer.ie) or visit [www.cancer.ie](http://www.cancer.ie) to find your local Daffodil Centre.

## Survivor Support



Speak to someone who has been through a diagnosis similar to yours. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

### Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to [www.cancer.ie](http://www.cancer.ie) and search 'Find Support'.

## Patient travel and financial support services



We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

To access either of these services please contact your hospital healthcare professional.



## Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

'Our night nurse was so caring and yet totally professional. We were so grateful to her for being there for Dad and us.'

## Publications and website information



We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



## Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses



- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at [www.cancer.ie/cancer-information-and-support/cancer-support/find-support](http://www.cancer.ie/cancer-information-and-support/cancer-support/find-support)

## What does that word mean?

<b>Anaemia</b>	A reduced number of red blood cells in your blood. It causes fatigue, weakness and shortness of breath.
<b>Anti-convulsant</b>	The name given to drugs that help to reduce or prevent seizure activity.
<b>Biopsy</b>	Removal of a piece of tissue for examination under a microscope and sometimes molecular testing.
<b>Benign</b>	Not cancer. A tumour that does not spread.
<b>CT/Cat scan</b>	(Computerised axial tomography) A computer aided X-ray that shows up tissue mass as well as bone.
<b>Cyst</b>	An abnormal sac or closed cavity that is filled with fluid or semisolid matter.
<b>Craniotomy</b>	The surgical opening of the skull in order to expose the brain underneath.
<b>Dysphasia</b>	A language disorder where words are jumbled when spoken or interpreted.
<b>EEG</b>	(Electroencephalogram) A recording of the electrical activity of the brain.
<b>Epilepsy</b>	Disorder of the brain function characterised by fits or seizures.
<b>High-grade tumour</b>	A tumour that grows quickly, normally over a few months.
<b>Low-grade tumour</b>	A tumour that develops slowly over a number of years.

<b>Malignant</b>	Cancer. A tumour that can spread.
<b>Meninges</b>	The covering of the brain and spinal cord of which there are three layers: Dura, arachnoid and pia matter.
<b>Metastasis</b>	The spread of cancer from one part of your body to other tissues and organs.
<b>Nausea</b>	Feeling sick or wanting to be sick.
<b>Oncology</b>	The study of cancer.
<b>Pathologist</b>	A doctor who specialises in the examination of tissues/cells in the laboratory to determine their exact nature.
<b>Pathology</b>	The study of tissues/cells to determine their exact nature.
<b>Primary</b>	The area in which the tumour first started.
<b>Prognosis</b>	The assessment of the future course and probable outcome of a patient's condition.
<b>Shunt</b>	A device/catheter that is inserted in order to remove excess fluid from the brain or the tumour.
<b>Tumour</b>	A mass formed by the overgrowth of abnormal cells.

## Questions to ask your doctor

Here is a list of questions that you might like to ask. There is also some space for you to write down your own questions if you wish. Never be shy about asking questions. It is always better to ask than to worry.

How long will it take to get the test results?

---

Where is the tumour?

---

What grade is the tumour?

---

What treatment will I need?

---

Will surgery remove the tumour?

---

Why is this treatment best for me?

---

Are there other treatment options?

---

Would I be suitable for a clinical trial?

---

How long will my treatment take?

---

Do I have to stay in hospital for my treatment?

---

What side-effects will I expect?

---

Is there anything I can do to help myself during treatment?

---

Will treatment affect my fertility?

---

How often will I need check-ups?

---

What if the tumour comes back?

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## Your own questions

## Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals – particularly from Beaumont Hospital, St Luke's Hospital and Cork University Hospital – who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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The following sources were used in the publication of this booklet:

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- *Cancer in Ireland 1994-2017 with estimates for 2017-2019: Annual report of the National Cancer Registry* (2019)
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- *The Chemotherapy Source Book*, M Perry. Lippincott Williams and Wilkins, 5th Ed (2012).

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## Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

### Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

### Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

### Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

### Did you like this booklet?

We would love to hear your comments or suggestions.

Please email [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)



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