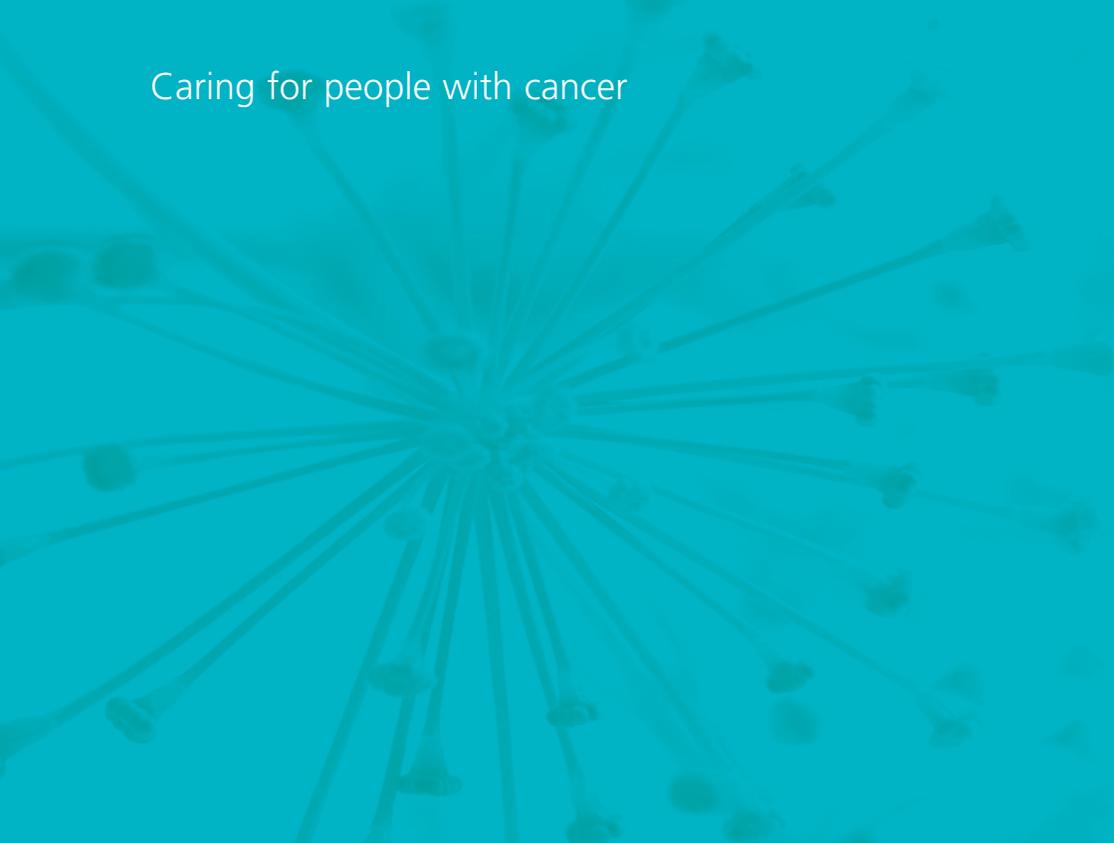


Understanding

Brain Tumours

Caring for people with cancer



Understanding

Brain Tumours

This booklet has been written to help you understand more about having a brain tumour. It has been prepared and checked by cancer doctors, nurses, radiation therapists and patients. The information is an agreed view on brain tumours, their treatment and how they may affect you.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also list below any contact names and information that you may need.



Neurosurgeon (brain surgeon)	Telephone
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Radiation centre	Telephone
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Medical oncologist	Telephone
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Neuro (brain) specialist nurse	Telephone
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Medical oncology specialist nurse	Telephone
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Radiation oncology specialist nurse	Telephone
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Epilepsy specialist nurse	Telephone
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Medical social worker	Telephone
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Emergency telephone number:	
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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.

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Introduction

This booklet has been written to help you learn more about brain tumours in adults.

This booklet is about **primary brain tumours** – these are tumours that start in the brain.

The booklet is divided into 4 parts:

- **About brain tumours** gives an introduction to brain tumours.
- **Treatment and side-effects** discusses the different treatments used for brain tumours and possible side-effects.
- **Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having a brain tumour.
- **Support resources** gives information on further sources of help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on the type of tumour you have and on your individual circumstances.



Reading this booklet

Remember you do not need to know everything about brain tumours straight away. Read a section about a particular item as it happens to you or if you are interested in it. Then when you want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700. It is open Monday to Thursday 9 am–6 pm and Friday 9 am–5 pm. You can also email the nurses at cancernurseline@irishcancer.ie or visit a Daffodil Centre. See page 59 for more about Daffodil Centres.



Cancer Nurseline Freephone 1800 200 700

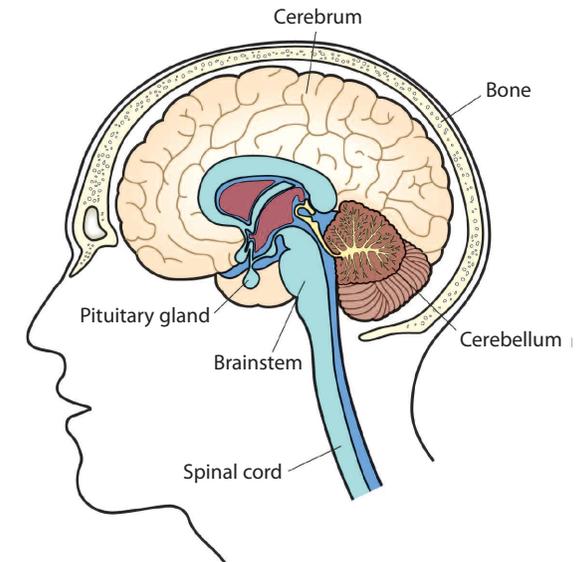
About brain tumours

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:

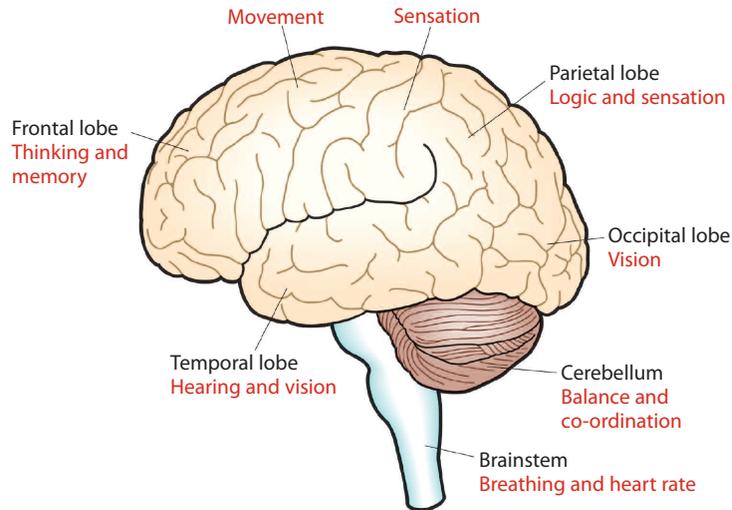
- The cerebrum
- The cerebellum
- The brainstem



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 hand 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:

Nerves 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).

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 newly 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. If you want information on brain tumours in children, please see our booklet: *Helping Hand – A guide for parents of children with a brain tumour.*



Grading of 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. The number tells 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 page 9). It is common for higher-grade tumours to return some time after treatment. This is known as a recurrence.

- **Grade 1 tumours** are usually called 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 called 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.

What are the different 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.

Oligodendroglioma

Oligodendroglioma are tumours that develop from oligodendrocyte cells. Oligodendroglioma 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

Ependymoma is a rare glioma that starts in the ependymal cells lining the fluid-filled spaces in the brain (ventricles) and the spinal cord.

Ependymoma is usually slow-growing. Sometimes ependymoma can spread to other parts of the central nervous system, through the fluid that circulates around the brain and spinal cord (cerebrospinal fluid (CSF)).

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

Meningioma is a common type of primary brain tumour. These tumours begin in the meninges (the tissues covering the brain and spinal cord). Around 2 in every 3 meningioma tumours are grade 1 and one in 3 is grade 2. Grade 2 meningioma is more likely to come back after surgery and may need further treatment. Grade 3 meningioma is very rare. 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

CNS lymphoma is a rare form of lymphoma (cancer that begins in the lymphatic system). 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

Medulloblastoma begins 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

Craniopharyngioma is a rare benign tumour that begins near the pituitary gland located near the base of the brain. Craniopharyngioma is more common in children, teenagers and young 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 schwannoma (VS) is also called acoustic neuroma. 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.

What are the risk factors for brain tumours?

The exact cause of brain tumours is unknown. But there are things called risk factors that can increase your chance of getting a tumour. These include:

Age: Primary brain tumours are more common in people between the ages of 50 and 70. Certain types of brain tumour are more common in young adults and children.

Gender: Men are more likely than women to develop most types of brain tumours.

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 you have these conditions it does not mean you will develop a brain tumour. But you have a slightly higher risk than someone without these conditions. Your doctor can discuss this with you in more detail.

Previous radiation: If your head has been exposed to radiation in the past, for example, radiotherapy, you may have a slightly higher risk of developing a brain tumour.

Research is ongoing into other possible causes of brain tumours. This includes viruses, power lines and mobile phones. At present, there is no scientific evidence to prove there is a link between these and brain tumours.



To sum up

- In general, brain tumours are not common.
- The exact cause of brain tumours is unknown. Your risk increases if you are older, male or have a genetic condition that increases your risk.

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
- **Scared** about the future

Everyone reacts differently to hearing that they have a brain tumour. However you feel, you are not alone. There are many people who can help and support you at this time.

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

- Ask to speak to the 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 cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.
- Email our cancer nurses at cancernurseline@irishcancer.ie

- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with a brain tumour. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website www.cancer.ie

Telling people about your diagnosis

It can be hard to tell other people the news that you have 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 Cancer Nurseline 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 *Who Can Ever Understand?*, which can help you to find ways to talk about your diagnosis and ask for the help and support you need.

What tests will I have?

After you have been diagnosed with a brain tumour, your doctor will want to do 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: MRI stands for magnetic resonance imaging. This scan uses magnetic energy to build up a picture of the tissues inside your brain. It does not hurt but can be noisy and you will be given earplugs to wear during it. 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.

Cancer Nurseline Freephone 1800 200 700

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 8-11. 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 onto 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 exactly the right place.

You usually need to stay in hospital for a few days when you have your biopsy. Some hospitals may do the surgery as a day case, which means you do not need to stay in hospital overnight.

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 28) 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 results

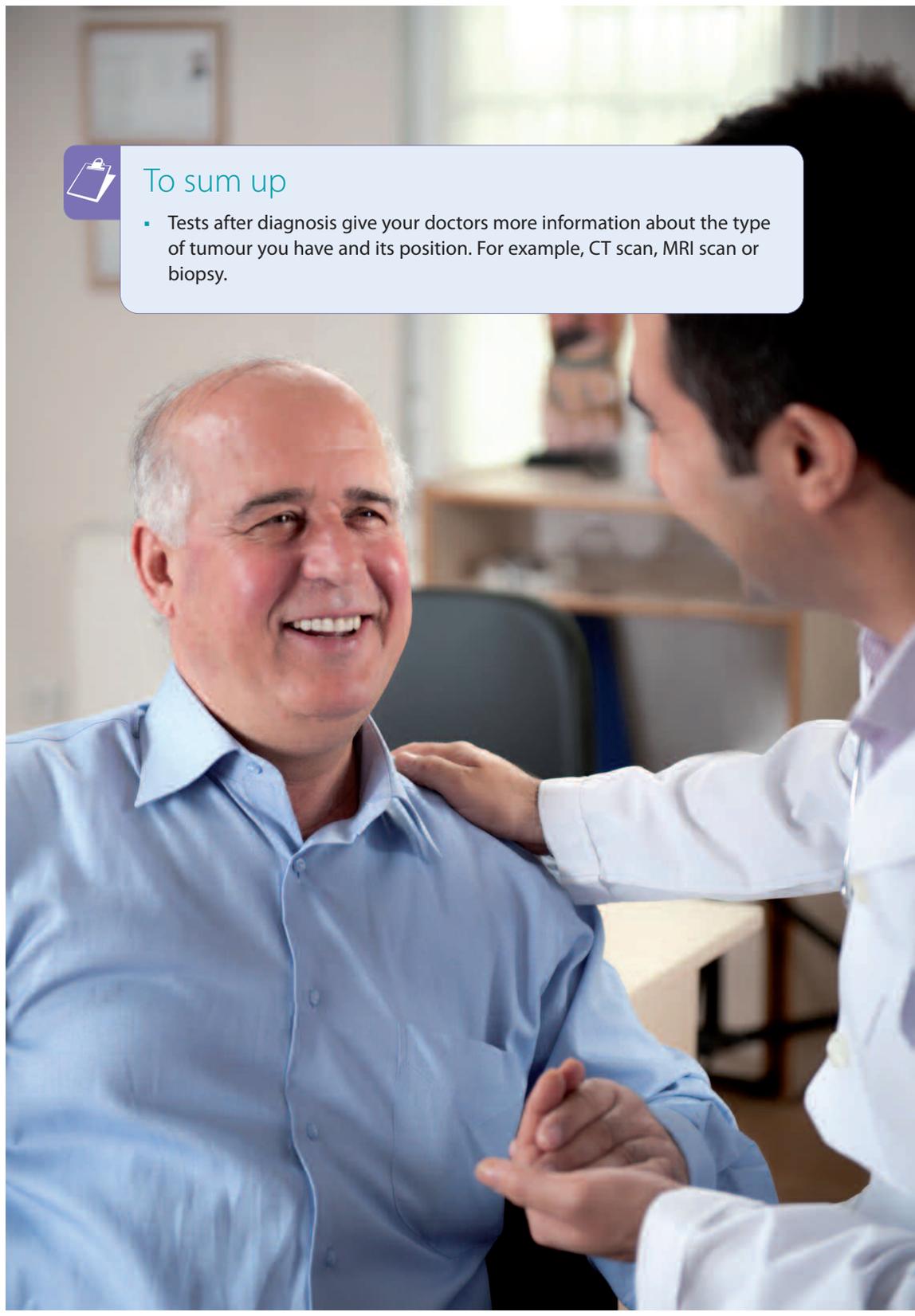
It may take some time for the test results to come back. This can be an anxious time. It may help to talk things over with the specialist nurse in the hospital or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk in confidence to one of our cancer nurses.





To sum up

- Tests after diagnosis give your doctors more information about the type of tumour you have and its position. For example, CT scan, MRI scan or biopsy.



Treatment and side-effects

How are brain tumours treated?

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.

Your doctor will explain to you if the treatment is expected to cure or control the tumour. He or she 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 22 for more details on surgery.
- **Radiotherapy:** Radiotherapy is the use of 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 30 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 34 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 are drugs used to treat the symptoms of a brain tumour. Steroids work by reducing inflammation and swelling. See page 37 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 will be prescribed to try to prevent the seizures from happening. See page 38 for more information.

You may be referred to palliative care for help in treating your symptoms. The palliative care team are experts in managing symptoms of cancer and other illnesses. For more about palliative care, see page 46.

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. Clinical trials study the effect of using new drugs or treatments to treat diseases. Or they can look at what happens when existing drugs or treatments are used in new combinations. See page 37 for more about clinical trials.

Specialist centres

In Ireland, brain tumours are treated in specialist cancer centres. The staff at these centres have expertise and experience in managing patients with various types of brain tumours. As a result, you may be transferred to another hospital 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 brain tumours. For example, neuroradiologists, neurosurgeons, medical oncologists and radiation oncologists, neuropathologists and clinical nurse specialists and other healthcare professionals.

The team will meet to discuss your test results and your suggested treatment plan. They will review your care during your treatment and change your treatment plan if necessary.

Treatment options: Your doctor and nurse will explain your treatment options to you. Ask as many questions as you like, no matter how small or trivial you think they are. If you forget a question or you want more explanations, you can ask one of our cancer nurses by calling 1800 200 700.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. 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 is 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 doctor 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 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 informed of the benefits and risks.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying 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
- 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.

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.

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 cancer using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer 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. She or he 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.



To sum up

- 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.

Surgery

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 28 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 he or she thinks 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

Before surgery

Your surgical team and specialist nurse will tell you about your surgery and what to expect. Discuss your surgery fully with your surgical team 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 Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse in confidence.

Tests before surgery

You will need some extra tests to make sure you are strong enough for surgery. These extra 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.

Smoking

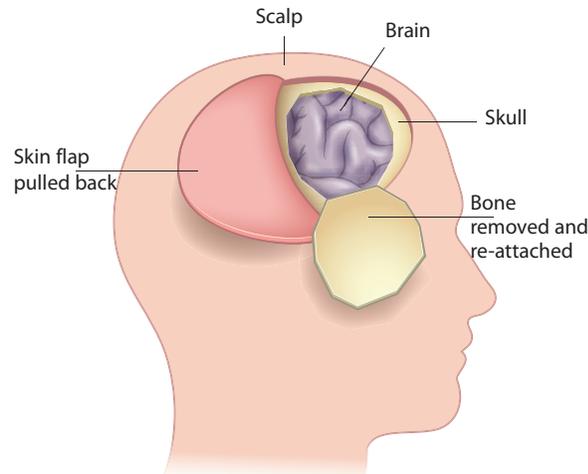
If you are a smoker, you will be advised to give up smoking before your operation. This will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 45 for advice.

What are the types of brain surgery?

Craniotomy

A craniotomy is an operation where a piece of the skull is removed to make an opening 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. 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 with you 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 fluorescence helps the surgeon to see where the cancerous (malignant) tissue 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 he or she removes 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.

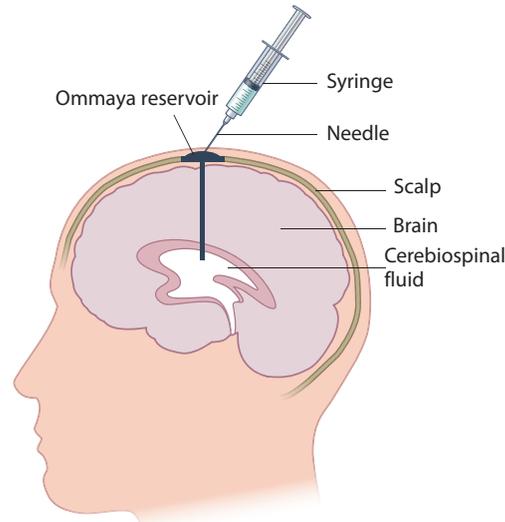
The fluid build-up can cause pressure inside the brain. A special tube called a shunt can be put in to drain away the fluid and relieve the

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 approximately 1 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.

Drips and drains

It is normal to have tubes and drips attached to you after your surgery. For example:

IV fluids/drip: You will need to fast before your surgery and for some time afterwards. A drip giving fluids into your vein (IV) can prevent you from becoming dehydrated. Other medications like steroids or antibiotics can also be given through the drip.

Urinary catheter: A catheter is a small tube placed in your bladder which drains urine into a bag. This means you won't have to get out of bed to go to the toilet. The tube is usually removed a few days after surgery.

Wound drain: A small plastic tube may be placed beside your wound and stitched into place. This collects any excess blood or fluid from your wound and prevents further swelling. Drains are normally removed a few days after surgery.

Pain/nausea

It is normal to have some pain after your surgery, although it is often not as painful as you might expect after such a big operation. Always tell your nurses and doctors if you feel the pain relief medication is not helping. There are several different types of painkillers that can be used. If you feel nauseated (like you might vomit) you will be given drugs to relieve this symptom.

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.

Getting up and about

On the day after surgery your nurses will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better. Even when you are in bed you will be encouraged to move your legs and do deep breathing exercises at least once an hour. A physiotherapist may also visit you if you need extra help.

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.

The pathology 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

It will take time for you to return to your usual level of energy after your surgery. Healing requires extra rest.

The amount of time required to recover after brain surgery is different for each person and depends 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

Often people go home 2-5 days after surgery, but it varies from person to person. 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 can be 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.



To sum up

- Surgery is one of the main treatments for brain tumours.
- You will have several tubes and drains in after surgery. For example, a drip or catheter.
- Most patients go home after 2 to 5 days, but this varies from patient to patient.

Radiotherapy

Radiotherapy is the use of 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 is the type of radiotherapy used for brain tumours. This means the radiation comes from machines that aim X-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 any tumour cells have spread.

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.

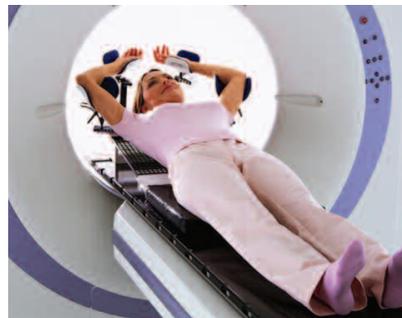


Planning your treatment

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.

Planning your treatment and preparing for it can take some time. It can be anything from one day to several weeks.

Simulation: Your first visit to the radiotherapy unit will involve a planning session called simulation. This involves using a CT scanner to pinpoint the area to be treated. The treatment area will be planned and the dose of radiation will be decided.



Your doctors might also use your previous scans to help them plan your treatment. When you are lying in the treatment position, you may need more tests, such as up-to-date MRI or CT scans. See page 14 for more about MRI/CT scans.

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 can be made from either clear plastic (Perspex) or thermoplastic, which prevents you from moving. Sometimes you may have to visit the mould room several times before your treatment can start. The number of visits depends on the type of mask you need.



Getting your radiotherapy treatment

On the day of your first treatment, you will come to the radiotherapy unit. The radiation therapists will help you onto the treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

How long does treatment take?

Treatment normally takes several minutes and is painless. External radiotherapy is usually given during outpatient visits to the hospital.

How much radiotherapy do I need?

The dosage and length of treatment can vary between patients, even between those with the same type of tumour. The course can be several treatments over a number of days or weeks (up to 6 weeks), or between 1 and 15 doses for palliative treatment.

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 31 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 radiosurgery (see opposite page 33).

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. How severe these side-effects are will vary from person to person and depend on the amount of treatment received. The radiotherapy staff will advise you about how to deal with any side-effects.

When the brain is being treated, the most common side-effects are:

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

Most side-effects clear up after a few weeks. These short-term side-effects are more common towards the end of treatment and may last for a few weeks after your course of radiotherapy has ended. Longer-term side-effects may happen some time after treatment and can sometimes be permanent. Longer term side-effects are less common.

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



To sum up

- Radiotherapy is the use of high-energy X-rays to kill tumour cells.
- It can be used alone or with other treatments like surgery or chemotherapy.
- A lot of careful planning is needed before radiotherapy. A special mask will be made to keep your head still during treatment.
- Any side-effects you get will depend on which part of your body is being treated and the number of treatments you get.
- Side-effects include tiredness, headaches and hair loss.

Chemotherapy

Chemotherapy is the use of drugs designed to kill tumour cells.

Chemotherapy drugs may be given:

- After surgery
- Before, with or after radiotherapy

Different chemotherapy drugs may be used to treat brain tumours. The drugs can be given on their own or in combination with each other. They are either given in tablet form or injected into your bloodstream.

Your medical oncologist (doctor who specialises in using drugs to treat cancer) 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.

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 own treatment. This includes where and how often you will receive it and any possible side-effects. Do 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. Do tell him or her about the way you are feeling during your chemotherapy, as there are treatments to ease most side-effects.

>>> Most side-effects can be eased with medication.

Common side-effects include:

Infection: Chemotherapy drugs 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 temperature, having a cough, or pain passing urine.

Bruising / bleeding: Chemotherapy can stop your bone marrow from making enough platelet cells. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood. Tell your doctor or nurses if you have any bruising or bleeding that you can't explain. This includes nosebleeds, bleeding gums, blood spots or rashes on the skin.

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 40.

Hair loss (alopecia) or hair thinning: Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the amount of chemotherapy you have and your own reaction to it.

Nausea (feeling sick) and vomiting (getting sick): If you feel sick it can happen during or after treatment and may last for several hours. 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 or diarrhoea: Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Numbness or tingling in hands and feet (peripheral neuropathy): Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. You may find it hard to pick up objects or button up your clothes.

Sore mouth: Some drugs can cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside your cheeks.

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 42.

If you have any other side-effect or symptom that concerns you tell your doctor or nurse straight away. He or she will give you advice.

More information

For more information on the side-effects of chemotherapy or a free copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Chemotherapy is the use of 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 with each other. They are given in tablet form or injected into your bloodstream.
- The side-effects of chemotherapy vary from person to person and depend on the drug being used.



Clinical trials



Clinical trials are research studies that try to find new or better ways of treating or diagnosing diseases.

Patients with brain 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.

When a drug is being used in a clinical trial it has already been carefully tested to make sure it is safe to use in a clinical trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

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, pain medication 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 or anti-convulsants.

Steroids

Steroids are often given with brain tumours. These drugs do not treat the tumour but they can reduce the swelling around the tumour.

Steroids can help you to feel better by reducing 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.

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. A seizure is caused by a burst of electrical activity in the brain.

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.

Coping with seizures

It is quite common for someone with a brain tumour to have a seizure (fit).

There are different types of seizures. Symptoms depend on what type of seizure it is. Symptoms can 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



Coping with 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 to ensure their safety

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 be confused.

How to help

- Keep calm – speak quietly and reassure the person
- Protect the person 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 when you have a brain tumour can be caused by many things, including:

- The tumour itself
- Tests and treatments
- Not eating well
- Low levels of red blood cells
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Usually fatigue improves once treatment is over, but it can carry on for some people. It is important to tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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.

Cancer Nurseline Freephone 1800 200 700

**Tips & 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 like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

Will treatment affect my sex life and fertility?**Sex and sexuality**

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. There is no right or wrong way to feel about your sexuality and sex life.

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. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

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. If you have had surgery it may be some weeks before you will feel well enough to have sex again. Your doctor will advise you if you can have sex while on radiotherapy. Once you return to your usual routine your interest in sex should return too. To begin with you may feel more comfortable enjoying other forms of closeness such as touching, caressing and holding each other.

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. 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 time gives your body a chance to recover from the effects of the cancer 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 queries about how treatment may affect your sex life, you can ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor and nurse are well used to taking about these matters and will give you advice. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

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. If this is the case, discuss your worries about infertility with your doctor before treatment starts.

He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

Dealing with infertility may not be easy, depending on your age and if you have had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener. You can call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.



Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.



Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments are things like chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments... Before you decide to change your treatment or add any methods of your own, talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects.

More information

If you want to know more about the different complementary and alternative therapies read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie



What follow-up do I need?

After your treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. Follow-up may involve having a physical exam, blood tests and scans. At first these visits will be quite often.

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, or if you are 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 what you wanted to say.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor or nurse know. Make an appointment to see him or her as soon as possible.

Driving and brain tumours

If you have been treated for a brain tumour, you will have to wait for a period of 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



Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:

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

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications on healthy living.

How can I stop smoking?



Like many others, you may find giving up smoking hard. If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. The Quitline is open Monday to Friday 10am to 7pm and Saturday 10am to 1pm. If you would like further personal support locally, the Quitline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see www.quit.ie

Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

Email: cancernurseline@irishcancer.ie

What if my 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

The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea. Palliative care also offers emotional support and comfort to patients and their families.

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

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 cancer. You do not need medical insurance.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have a brain tumour. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

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

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It is not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.



Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may be anxious about upsetting or worrying your friends or family. 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 and help you to make decisions and cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. You can also contact the nurses by email: cancernurseline@irishcancer.ie

Ways to get support



Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 61 for more about cancer support services.

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.

Join a support or educational group. Many people find it very reassuring to talk to other people with cancer, who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer. There are also some specialist groups, which have information and support for people with a particular type of cancer. For example, Brain Tumour Ireland.

Get one-to-one support. The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more information on Survivor Support.

Get online support. There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support from each other. Visit 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 concerns. 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.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have unpleasant side-effects, many people are able to adjust to life during treatment.

Email: cancernurseline@irishcancer.ie

How can I help myself?



Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Use your support network. Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends. Don't keep your worries or any 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.

Gather information about your cancer and treatment. Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Eat well. Try to eat as well as you can. Have lots of different types of foods with plenty of fresh fruit and vegetables.

Get some exercise. Exercising is a great way to boost your mood and sense of well-being. Exercise can improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

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.

Try complementary therapies. Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 43 for more information on complementary therapies.

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 is normal to have bad days. Get help if you are finding it hard to cope.

Keep busy. Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

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.

Express yourself. Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

Practical planning. It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it might be helpful for you, as it can give you the chance to be able to plan and deal with any practical concerns or worries you may have in your personal life.

If your cancer is advanced, you can look at our advanced cancer web pages on our website www.cancer.ie for more help with planning ahead. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

Positive emotions



A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

How can my family and friends help?

Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say or how best to help. You may find it difficult to talk about their cancer. Or you may be afraid of upsetting your friend or relative by saying or doing the wrong thing.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline and 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



Talking to children and teenagers

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children, or that you're letting them down. You may worry about the emotional impact your illness will have on your children, especially older children, who may already be struggling with the difficult changes that adolescence can bring. These are all natural feelings to have at this time.

Saying nothing

You may feel it is best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It is best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.



The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It is also available on our website www.cancer.ie.

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Advice for carers

Caring for someone with a brain tumour can be difficult at times. Some patients manage well and need little practical support from family and friends, while others may need more support and care. It might take a few months before they are fully recovered and can care for themselves.

Coping with both the practical and emotional issues of treatment can also be hard. Here are some things that can help to make life a little easier.

Looking after your loved one

Learn about brain tumours: Learn more about brain tumours, any possible side-effects and the emotional effects they can cause. This will help you to understand how you can support your relative or friend.

Find out about managing seizures: You may have to look after your loved one during and after a seizure. See page 38 for more information.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Use whatever help there is. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Stay in touch with your own friends and get out when you can, even if you sometimes do not feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it is just a walk to the shops. This will give you something to look forward to each day. Ideally, you should also try to organise a longer break, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: Give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Join a self-help or support group: Find out about self-help groups, especially for carers of people with cancer. There are a number of voluntary organisations in the country that provide help and support for you as a carer. They can offer a variety of practical supports and give advice. Your GP, public health nurse or specialist palliative care service can inform you of local groups too.

Life after a brain tumour

Being told your treatment has been successful is wonderful news. But it can take some time for you 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 the 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 concerns such as finances, work and family issues that may have been on hold during your treatment
- **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/coping

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 48 for other ways to get support.



Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like medication, car-parking, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or you are unemployed, this may cause even more stress. It may be hard for you to deal with cancer 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
- 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 care or your medication. 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 do not 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 is important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection 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:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 07 4000
- Department of Social Protection – Tel: 1850 662 244

Always have your PPS number to hand when you are enquiring about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them and keep a copy at home.

If you have financial difficulties

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 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 in certain cases give some help with travel costs. See page 60 for more details of our Volunteer Driving Service and the Travel2Care fund. You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information please see our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. 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.

For a free copy of the booklet, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. The booklet is also available on our website: www.cancer.ie

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:

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

Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am - 6pm and Friday 9am - 5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

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

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

Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. 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 across the country to ensure cancer patients have access to confidential support, including counselling. See the next page for more information.

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 NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
- **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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 the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

Our **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 or call our Cancer Nurseline for a free copy of our publications.



If you would like more information on any of the above services, call our Cancer Nurseline 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 counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, psychologists, cancer nurses and counsellors
- **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, reflexology and acupuncture
- **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.

To find your nearest cancer support centre call our Cancer Nurseline on Freephone 1800 200 700 or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Cancer Nurseline Freephone 1800 200 700

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, cancer treatments, and coping. For free copies call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.



You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

Understanding the Emotional Effects of Cancer

Lost for Words: How to Talk to Someone with Cancer

Who Can Ever Understand? Talking About Your Cancer

Talking to Children about Cancer: A Guide for Parents

A Time to Care: Caring for Someone Seriously Ill at Home

Managing the Financial Impact of Cancer. A Guide for Patients and their Families

What does that word mean?

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

Metastasis	The spread of cancer from one part of your body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Oncology	The study of cancer.
Pathologist	A doctor who specialises in the examination of tissues/cells in the laboratory to determine their exact nature.
Pathology	The study of tissues/cells to determine their exact nature.
Primary	The area in which the tumour first started.
Prognosis	The assessment of the future course and probable outcome of a patient's condition.
Shunt	A device/catheter that is inserted in order to remove excess fluid from the brain or the tumour.
Tumour	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?

Your own questions

1 _____

Answer _____

2 _____

Answer _____

3 _____

Answer _____

4 _____

Answer _____

5 _____

Answer _____



Notes

A large, light blue rounded rectangular area intended for taking notes.



Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you feel you would like more information or someone to talk to, please call our Cancer Nurseline on 1800 200 700.

Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, research and education. This includes patient information booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

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