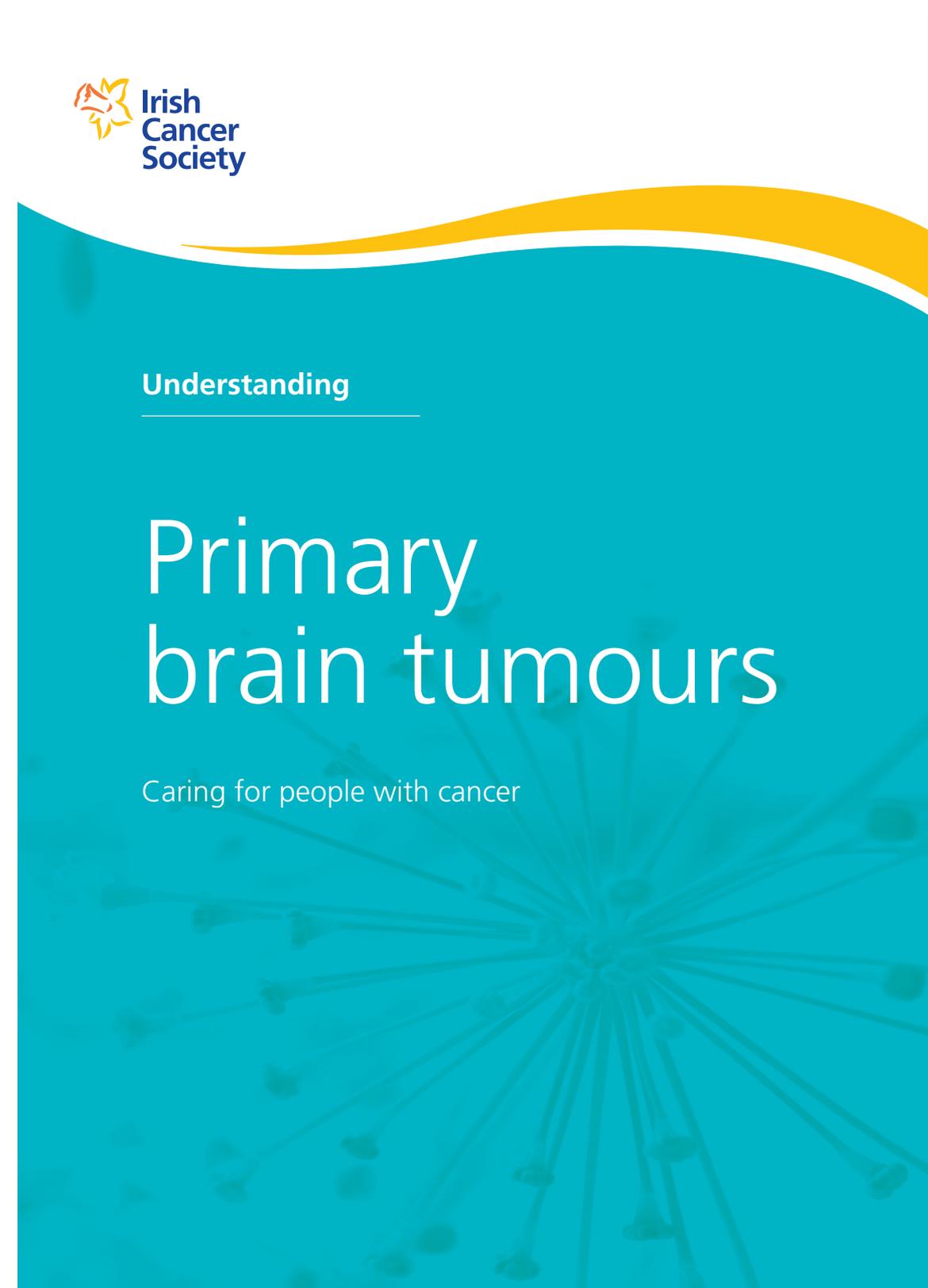


Understanding

Primary brain tumours

Caring for people with cancer



Understanding

Primary brain tumours

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

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

Useful numbers

Neurosurgeon (brain surgeon)

Neuro specialist nurse

Radiation oncologist

Radiation specialist nurse

Medical oncologist

Medical oncology specialist nurse

Neurologist

Epilepsy specialist nurse

Medical social worker

Family doctor (GP)

Emergency

Hospital records number (MRN)



Contents

About brain tumours	7
Preparing for your hospital appointments	21
Diagnosis and further tests	27
Treating brain tumours	37
Types of treatment	53
Managing side-effects and symptoms	77
After treatment	91
Coping and emotions	99
Supporting someone with a brain tumour	107
Support resources	113
What does the word mean?	126
Questions to ask your doctor	128



Fast facts

What kind of treatment will I have? Page 37

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

Are there side-effects from treatment? Page 77

There can be side-effects. This will depend on the type of tumour and the type of treatment. For example, radiotherapy side-effects can include tiredness, headaches and hair loss.

Read about the different treatments to learn more about their side-effects and possible complications.

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

Will I be OK? Page 34

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

Clinical trials Page 76

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

We're here for you Page 119

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

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 119 for more about our services.

Support Line Freephone 1800 200 700

Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About brain tumours

The central nervous system	9
About the brain	10
What is a brain tumour?	12
What causes brain tumours?	14
What are the types of brain tumours?	14
How might the tumour affect me?	17
How are brain tumours graded?	19



Support Line Freephone 1800 200 700

The central nervous system

The brain and spinal cord make up the central nervous system. The brain receives and processes information carried to it from nerves – controlling the senses (taste, smell, touch, sight and hearing), movement, breathing, heart rate, blood pressure, memory, personality and behaviour. The brain is protected by the skull (also called the cranium). Beneath the skull are three layers of membranes called meninges.

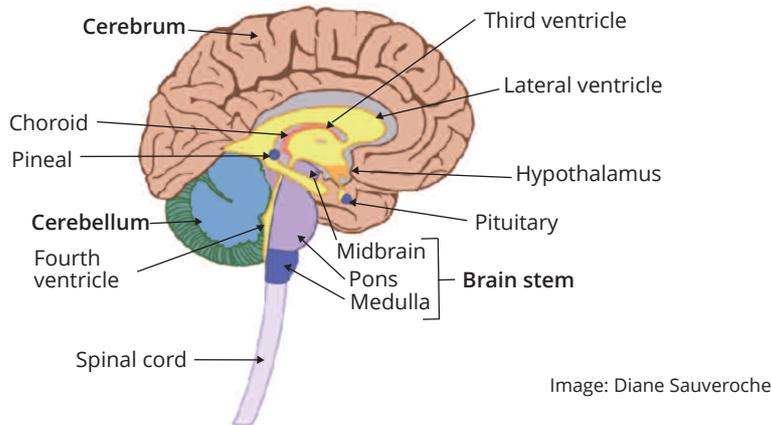
The spinal cord contains bundles of nerves that carry messages between the brain and the rest of the body. It communicates movements and sensations between the brain and the rest of the body through a network of nerves called the peripheral nervous system (PNS). The spinal cord is protected inside the bones of the spine (vertebrae).

Both the brain and spinal cord are bathed in a fluid called the cerebrospinal fluid (CSF), which is produced by cells within the brain.



About 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 3 main parts of the brain are the:

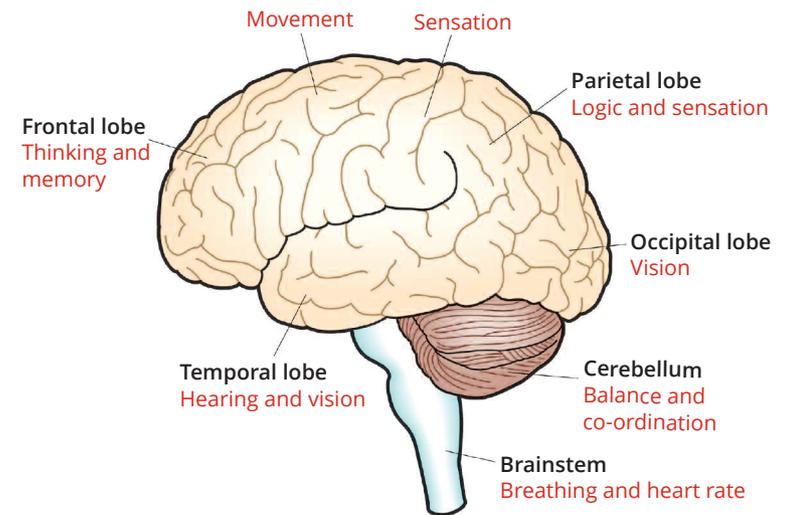
- **Cerebrum** • **Cerebellum** • **Brainstem**

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

Each cerebral hemisphere is divided into four areas, known as lobes. Each lobe controls different activities. This means that depending on where it is found in the brain, a tumour can affect different activities and cause different symptoms:

- The **frontal lobe** controls thinking, planning, problem solving, emotions, behaviour and some body movement.

- The **parietal lobe** helps us process information associated with taste, touch, smell, vision and hearing. It also helps with logic and speech.
- The **temporal lobe** controls memory and understanding. It also helps us process what we see and hear.
- The **occipital lobe** helps us understand what we see.



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

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

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

Types of brain cells

The brain is made up of two types of cell:

Nerve cells (neurons)

Nerve cells form a network that carries messages back and forth between the brain and the rest of the body.

Glial cells

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

What is a brain tumour?

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

A brain tumour will cause symptoms either when it presses on the brain or if it invades (grows into) the brain tissue. The symptoms will depend on which area of the brain is affected (see diagram on 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.



How are brain tumours classified?

Brain tumours can be classified as benign (not cancerous) or malignant (cancerous). However they are often classified as low grade or high grade or by their location within the brain.

Benign tumours often grow slowly and are unlikely to spread. They can affect how the brain works and may need urgent treatment. They can come back after treatment and sometimes they become malignant.

Malignant tumours can be slow or fast growing (see grading brain tumours, page 19). They sometimes spread within the brain or spinal cord.

What is a primary brain tumour?

Primary brain tumours develop 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 in the covering layers of the brain cause pressure on brain tissue and tumours that develop from cells within the brain invade brain tissue.

What is a secondary brain tumour?

Sometimes diseased cells from another part of the body – such as breast cancer cells or lung cancer cells – spread to the brain and begin to grow there. This is called a secondary or metastatic brain tumour and is treated with breast or lung cancer treatments.

To find out more about metastatic (secondary) tumours, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

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

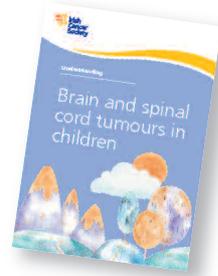
How common are primary brain tumours?

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

Children and brain tumours



About 45 children are diagnosed with brain tumours each year in Ireland. We have a separate booklet about brain tumours in children. Call our Support Line on 1800 200 700 or visit a Daffodil Centre to ask for a free copy of *Understanding brain and spinal cord tumours in children*.



What causes brain tumours?

We don't know exactly what causes brain tumours, but there are things called risk factors that can increase your chance of getting a tumour. Sometimes brain tumours can result from rare genetic conditions, but this is not common. Having a risk factor does not mean you will get a brain tumour. If you want to learn more about the risk factors for brain tumours, see our website www.cancer.ie, call our Support Line or visit a Daffodil Centre.

What are the types of brain tumours?

The brain is made up of different types of cells. Tumours are usually named after the cells in which they begin. For example, an astrocytoma starts in astrocyte cells. Gliomas are the most common type of malignant brain tumour. Doctors will give the tumour a grade, usually numbered 1 to 4, which will help describe how fast the tumour is expected to grow. (See page 19 for more about brain tumour grades)

Types of primary brain tumours

Gliomas	Most adult brain tumours start in the glial cells. Glial cells are glue-like cells that keep the brain together.
Astrocytoma	This is the most common type of glioma. It develops in cells called astrocytes. There are four grades: Grade 1 or pilocytic astrocytoma – slow growing, usually benign Grade 2 or low-grade diffuse astrocytoma – slow growing, can become a higher grade Grade 3 or anaplastic astrocytoma – malignant, can grow quickly and spread Grade 4 or glioblastoma multiforme (GBM) – malignant, aggressive, most common type of glioma in adults
Oligodendroglioma	Develops in oligodendrocyte cells. Can be low grade or high grade
Mixed glioma	More than one type of tumour is involved. For example, gliosarcoma is a mixture of glioblastoma and sarcoma
Ependymoma	Rare. Slow growing. Starts in the ependymal cells lining the fluid-filled spaces in the brain (ventricles) and the spinal cord

Types of primary brain tumours

Non-glial tumours	Start in areas outside the brain tissue, such as in the nerves, the covering of the brain (meninges) or glands, such as the pituitary or pineal gland
Meningioma	Common. Starts in the meninges. Most are grade 1. Most are benign. Can cause serious symptoms if it grows and presses on the brain or spinal cord or grows into the brain tissue
Central nervous system (CNS) lymphoma	Rare form of lymphoma. Starts in the brain and can spread to the spinal fluid and eyes
Pituitary gland tumours	Most develop in the gland tissue and are called adenomas. Most are benign. Grow slowly. Don't usually spread
Pineal tumours	Can be slow or fast growing. The most common are called germinomas (germ cell tumours)
Medulloblastoma	Starts in the cerebellum. Not common in adults. Can be fast growing and can spread within the brain and spinal cord
Craniopharyngioma	Rare. Benign. Starts near the pituitary gland. Does not usually spread
Vestibular schwannoma (VS)	Also called acoustic neuromas. Usually benign. Begins in cells on the vestibular nerve, which helps control hearing and balance.

How might the tumour affect me?

The effects of brain tumours vary. Symptoms can be caused by:

- **The size of the tumour**
A tumour can cause pressure to build up inside the skull
- **The part of the brain affected**
The brain is the control centre of the body. Different parts of the brain control different things. The effects that may happen are related to what the affected part of the brain controls.

You may not get all or even any symptoms. It will depend on your own diagnosis - the type of tumour you have, the location and its size. Ask your medical team about this. If you do have symptoms, treatment may improve them.



Physical effects

- Headaches
- Seizures (fits)
- Difficulty swallowing
- Difficulty speaking
- Difficulty walking or unsteadiness
- Dizziness
- Sight problems, such as double vision, tunnel vision or blurred vision, or hearing problems
- Weakness on one side of your body
- Loss of feeling, pain or numbness in part of your body
- Bowel or bladder control problems
- Loss of smell
- Sickness
- Uncontrolled eye movements
- Tiredness, drowsiness or loss of consciousness

Thinking and remembering effects

- Memory difficulties
- Problems with reading or writing
- Difficulty thinking normally
- Hearing voices in your head
- Difficulty understanding

Behaviour effects

- Changes in your personality or behaviour

Hormone-related effects

- Weight gain
- Infertility
- Mood changes
- High blood pressure
- High blood sugar levels (diabetes)

How are brain tumours graded?

The tumour will be given a grade based on how the cells look compared to normal cells. This is usually a number from 1 to 4. Grading refers to how a sample of cells from the tumour looks under a microscope. It gives an indication as to how fast the tumour will grow.

Grade 1 tumours are described as low-grade or benign. Usually, they grow slowly and do not spread to other parts of the brain.

Grade 2 tumours also grow relatively slowly (low grade) but in time some may spread to other parts of the brain or become malignant.

Grade 3 or 4 tumours are described as high grade or malignant. They grow more quickly and are more likely to spread into normal brain tissue.

Tumours that arise from the covering layers of the brain (meninges) are also graded – usually with a number from 1 to 3. Most of these tumours are grade 1 and they are usually cured by surgery.

Sometimes a low-grade tumour can become a higher-grade tumour. How a tumour behaves also depends on the type of tumour you have (see page 15). It is common for higher-grade tumours to return some time after treatment. This is known as a recurrence.

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.

Seizures



Seizures (fits) are a common symptom of some types of brain tumours. If you have seizure activity, anti-convulsant drugs may be prescribed to try to prevent the seizures. See page 81 for more about treating seizures.

Driving after diagnosis

If you usually drive and have been diagnosed with a brain tumour, you will most likely need to stop driving until well after your treatment has ended. Ask your doctor or specialist nurse about your situation. Visit the Road Safety Authority (RSA) website RSA.ie or the National Driver Licence Service website at ndls.ie to read or download the Medical Fitness to Drive Guidelines.



Preparing for your hospital appointments

Before your appointment	23
What to take to your appointment	23
Before leaving the appointment	24
After the appointment	25
Cancelling your appointment	25

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.

Before your appointment

- **Write down a list of questions and things you would like to discuss.**
- **Know where you are going and plan your journey** (build in extra time for unexpected delays).
- **Dress in warm comfortable clothes and shoes** – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- **Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you are not fasting.** This can make it easier for the nurse or doctor to find a vein.
- **Check with the hospital if it is okay to bring someone with you.** Ask a friend or family member to go along for extra support.



What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- **Your medical card**, if you have one
- **Your private health insurance details**, if you have insurance
- **The appointment letter from the hospital**, if you got one
- **A referral letter or GP letter**, if you got one
- **Your GP's name and contact details**
- **Your medical history** – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- **Your list of questions**
- **A notebook and pen to take notes.** (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- **A list of your medications or the medication itself** – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- **Be aware of when your prescription is due**, so you can ask for a prescription before you leave, if needed
- **Medications and any medical supplies** you may need that day, in case you are delayed
- **A light snack and drink if you are likely to have to wait for some time.** (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- **Your phone and your phone number**
- **Contact details of the person to call in an emergency**
- **Your glasses and hearing aid**, if you use them
- **A book or something to listen to** (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave, if required

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

Note

If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.



Diagnosis and further tests

Being diagnosed with a brain tumour	29
Telling people about your diagnosis	29
Tests after diagnosis	30
Asking about your prognosis	34

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
- **Angry** that this is happening to you

'However you feel,
you are not alone.'

If you need to talk to someone, or if you want support or advice, ask to speak to the specialist nurse on your healthcare team or the medical social worker at the hospital. They can help you and your family to cope with difficult feelings and advise you about practical matters. You can also talk to one of our nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700.

Telling people about your diagnosis



Telling people about your diagnosis can be difficult. While telling friends and family might help to get the support you need, you may like a little time to adjust to your situation. You may prefer not to tell them straight away. You may also worry about how they will react. For example, they may fuss over you or be upset.

Call our Support Line on 1800 200 700 if you would like to talk things over. Or drop into your local Daffodil Centre for emotional support and to get information about talking about your illness.

Tests after diagnosis

- You may have a neurological examination, brain MRI, CT scan and a biopsy.
- The tests will tell your medical team more about your tumour and help them to decide on the best treatment for you.

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



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

Neurological examination

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

Brain MRI scan

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

During the scan you cannot wear metal jewellery, hair clips or a prosthesis. If you have medical devices in your body, like a pacemaker or metal pin, you may 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 it is important that you keep as still as possible during this test. Normally it takes between 10 and 30 minutes.

Other tests

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

Biopsy

A biopsy means removing a small piece of the tumour so that it can be examined under a microscope. A biopsy is the only sure way to find out what type of brain tumour you have and how fast it is growing (the grade). For more about the types and grades of brain tumours see pages 15–19. The information from the biopsy can help your doctor to plan your treatment.

You may have a biopsy as part of an operation (surgery) to remove all or part of your tumour. You may have a biopsy and then go on to have other treatments such as radiotherapy and chemotherapy. Before the biopsy you will have an MRI or CT scan to show where the tumour is. The biopsy is done under general anaesthetic. During the operation the surgeon uses a fine needle to remove a sample of the tumour through a small hole in your skull.

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

After the operation, a pathologist examines the sample in the laboratory. The laboratory tests may take 1-2 weeks to complete. If a sample of tumour is sent for genetic profiling (see page 34) it will take longer for your test results to come back.



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

Waiting for test results



It usually takes 3-5 days for the first results to come back. However, it can take several weeks for more detailed genetic profiling (see below) to be done. This will not usually delay treatment. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a nurse.

Pathology report



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

Genetic profiling



Samples of your tumour may be sent to a special laboratory to get information on your DNA and to check if any genetic changes have occurred. This is called genetic or DNA profiling (also described as testing for biomarkers or molecular markers). It can give your doctor more detailed information about:

- How the tumour may develop
- Which treatment or treatments are likely to work for you.

If you have genetic profiling, the tumour sample may be sent abroad for testing, so it may take some weeks 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.

Asking about your prognosis

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

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

Should I ask about my prognosis?

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



If you decide you want information on your prognosis:

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



Treatment overview

How are brain tumours treated?	39
Deciding on treatment	41
Who will be involved in my care?	43
Giving consent for treatment	47
Waiting for treatment to start	48
How can I help myself?	49

How are brain tumours treated?

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

The treatment you have will depend on:

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

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

Surgery

Surgery aims to remove as much of the tumour as is safely possible. If the whole tumour cannot be removed, surgery can help to relieve symptoms. Surgery is not always possible, depending on where the tumour is in the brain and how big it is. See page 55 for more details on surgery.

Radiotherapy

Radiotherapy uses high-energy X-rays to kill tumour cells. Radiotherapy may be given instead of surgery, if surgery is not possible. Or you may have radiotherapy after surgery to control the tumour. See page 65 for more about radiotherapy.

Chemotherapy

Chemotherapy is the use of 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 71 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, such as steroids or anti-convulsants.

- **Steroids:** Steroids work by reducing inflammation and swelling. See page 81 for more details.
- **Anti-convulsants:** Seizures (fits) are a common symptom of some types of brain tumours. If you have seizure activity, anti-convulsant drugs may be prescribed to try to prevent the seizures from happening. See page 81 for more information.

Sometimes a brain tumour cannot be removed or controlled any more. If this happens, you can still have treatment to ease difficult symptoms. You will have supportive care (sometimes called palliative care) from a specialist doctor or nurse who is an expert at managing symptoms. For more on this, see page 97.

Other treatments



New ways of treating brain tumours are being developed all the time. Your doctor will advise you about any other treatments that may help you. You may be offered a different treatment as part of a clinical trial. See page 76 for more about clinical trials.

Specialist centres



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

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of tumour. For example, surgeon, medical oncologist, radiation oncologist, radiologist, pathologist, nurse specialist and other healthcare professionals. The team will meet to discuss your test results and your suggested treatment plan.

Understanding your treatment



Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in page at the back of this booklet for your questions and answers.

Time to think

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

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or your GP can refer you to another specialist for a second opinion if you feel this would be helpful. Getting a second opinion will not affect the care you will receive.

Accepting treatment

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

Who will be involved in my care?

Usually, a team of doctors and healthcare professionals will be involved in your treatment and care. Your team may include some of the following:

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

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



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

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

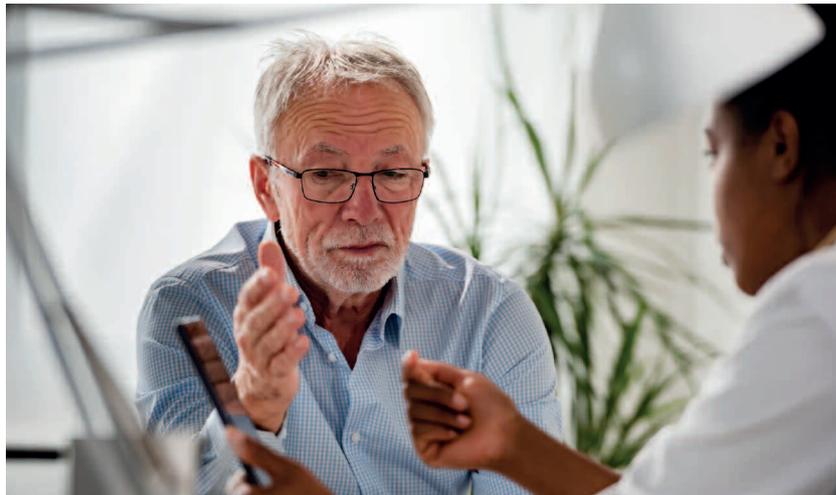
Radiation therapist A specialist who gives radiotherapy and advises patients about their radiotherapy treatment.

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.

Advanced nurse practitioner (ANP) ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

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



Medical social worker A person trained to help you and your family with your social, emotional and practical needs. 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 physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care team is available in most hospitals.

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 These are specialists in psychological care and support. Usually the team includes psychiatrists, clinical psychologist, social workers 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 welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

GP (family doctor) While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Pharmacists - in hospital and in your local pharmacy dispense chemotherapy and other medication. They can give you advice about your medications, such as how to take them, side-effects, and possible interactions with other drugs, food and drink, and supplements such as herbs and vitamins.



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 are different. Do not be afraid to ask your doctor about your treatment.

Giving consent for treatment

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

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



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

Waiting for treatment to start

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

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

If you are worried, talk to your doctor or specialist nurse. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk things over with a nurse in confidence.

You might like to focus on your health and wellbeing while you're waiting for treatment. For example, eating well and staying active.



Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

How can I help myself?

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

Eat well

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

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



Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also pick up our booklet *Diet and Cancer* at a Daffodil Centre.

Keep active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

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



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning – build up gradually.

Support Line Freephone 1800 200 700

Quit smoking

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

- Non-smokers are likely to have fewer or less severe side-effects during treatment. For example, chest infections
- Smoking can reduce how well chemotherapy or radiotherapy work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chance of further illness



If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit www.QUIT.ie or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Get information about your tumour and treatment

Understanding your brain tumour and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

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

Use your support network

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



Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. See our *Understanding complementary therapies* booklet.

Accept change in your life

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

Know that there will be ups and downs

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

Try to cope day by day

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

Types of treatment

Surgery	55
Radiotherapy	65
Chemotherapy	71
Clinical trials	76

Surgery

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

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



Your surgeon will also take a sample of your tumour (biopsy) during surgery. This will be tested by a doctor called a pathologist to give more information about your tumour. Knowing as much as possible about your tumour will help your medical team decide on the best possible treatment plan for you. See page 33 for more about pathology reports.

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

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

Worries and fears



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

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

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery and what to expect. Discuss it fully with them so that you know exactly what is going to be removed and how it may affect you afterwards. If there is anything that you don't understand, ask again. Your doctor or nurse will be happy to answer your questions. It is natural to feel very anxious about having surgery. Let your doctor or nurse know if you are feeling very anxious. It may help to talk things through again.

Tests before surgery

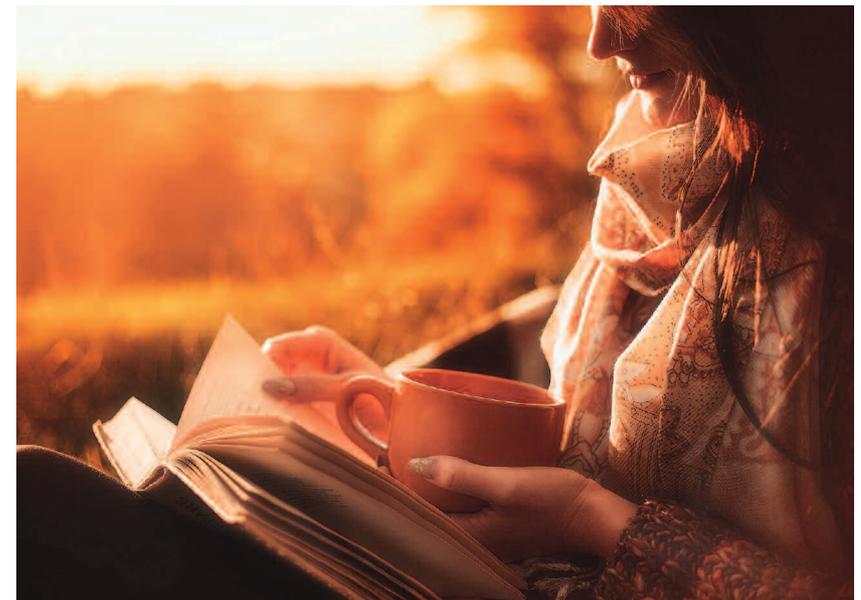
You will need some extra tests to make sure you are strong enough for surgery. These tests are usually done a few days before your operation. Tests may include a chest X-ray, heart test (ECG), breathing/lung tests and some more blood tests.

Steroids

You may be given a course of steroids before surgery, if you are not already taking them. They help to reduce any swelling in the brain caused by the tumour. Always take steroids exactly as your doctor has prescribed them. You may need to take them for a while after your operation. See page 79 for more about steroids.

Smoking

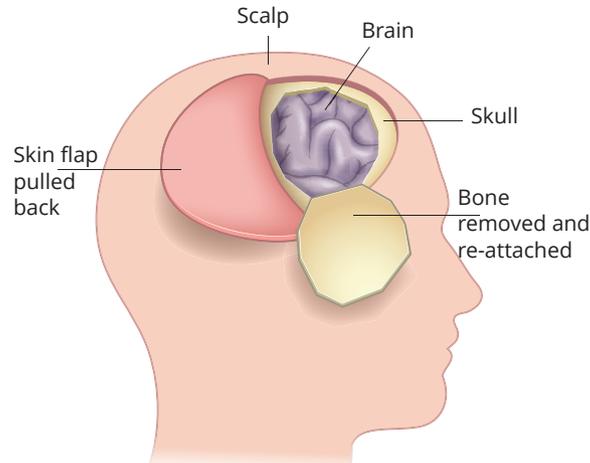
If you are a smoker, you will be advised to give up smoking before your operation. This will improve the quality of your breathing and reduce the risk of a chest infection after surgery. See page 51 for advice.



What are the types of brain surgery?

Craniotomy

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



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

Having a craniotomy when you're awake

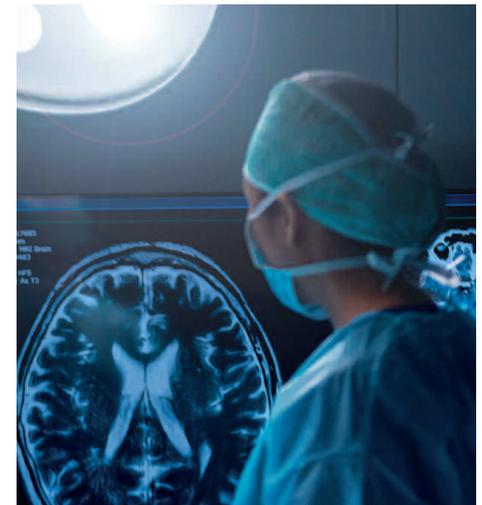
Some people have a craniotomy while they are awake. If you are awake, the surgeon can talk to you and do checks during the surgery to make sure the surgery isn't affecting your brain functions, like speech or movement. They can stop operating if they need to. A neurophysiologist or a speech and language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

Fluorescence guided surgery (5-ALA)

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

Stereotactic surgery

Stereotactic surgery uses scans and computer technology to give a 3D image of the brain. This helps the surgeon to target the affected area very accurately and decide on the best way to do the surgery. It allows your surgeon to remove safely as much abnormal tissue as possible. It ensures the least amount of damage is done to normal brain tissue, even if the tumour is very small or is deep within the brain.



Transsphenoidal surgery

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

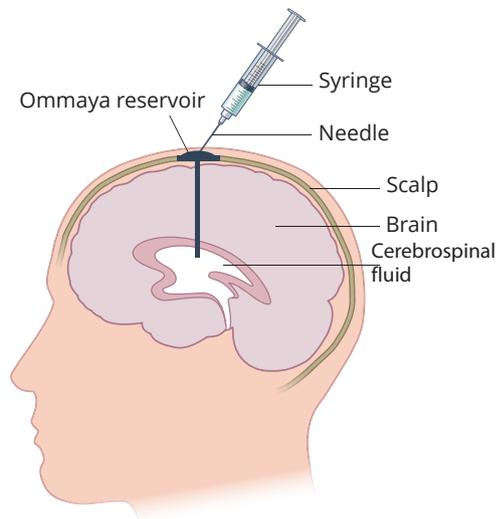
Shunting

Shunting is a type of surgery to remove fluid from the brain. Some tumours can cause a blockage which means cerebrospinal fluid (CSF) builds up in the brain. This collection of fluid is 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

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

After surgery

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

You will have neurological tests such as reflex checks and verbal interaction 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 on the first day after their surgery.



Tubes

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

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

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

Drains: Small tubes will drain any extra fluid from your surgery site, helping it to heal.



Pain and sickness

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

Eating and drinking

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

Exercising

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

Clips/sutures

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

Going home

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

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

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

Email: supportline@irishcancer.ie

Help at home

If you live alone or have problems getting around the house, talk to your nurse or medical social worker. They can help to organise any community services you may need. This may include visits from an occupational therapist or public health nurse. 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 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.

Email: supportline@irishcancer.ie

Radiotherapy

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

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

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

External beam radiotherapy

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



Planning your external radiotherapy treatment

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

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

Making the mask and using it

You will need a plastic mould or mask fitted before treatment is given. Marks are put on the mask to show where treatment will be given. The mask keeps your head still. It can be made from clear plastic (Perspex) or thermoplastic – so you can breathe and speak through it. The mask is fixed to the table while the treatment is given. It can make you feel uncomfortable and confined to start, but many people find that they get used to it. Tell the therapist or nurse if you are feeling anxious. They may help you with breathing or relaxation techniques.



Getting your treatment

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

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

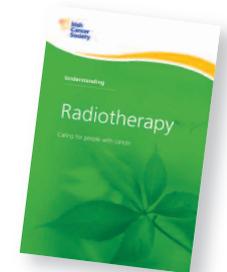
How much radiotherapy do I need?

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

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

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

For more information on radiotherapy, see our booklet *Understanding Radiotherapy*.



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 (SRT)

Stereotactic radiotherapy (SRT) is a very precise type of radiotherapy. With SRT, 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 66 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.

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

Stereotactic radiotherapy is not suitable for all tumours. It will depend on things such as the size and location of the tumour. Your doctor will discuss this with you. This treatment is not available at all hospitals.



Side-effects

Stereotactic radiotherapy treatment has fewer side-effects than standard radiotherapy, mainly because the area being treated is smaller. But you may feel tired afterwards.

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

Stereotactic radiosurgery

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

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

Side-effects of radiotherapy to the head

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

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

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

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

Proton beam therapy

Your doctors may recommend proton therapy, which is suitable for some types of brain and spinal cord tumours. Proton therapy is a type of radiotherapy. It uses protons, which are small parts of atoms, rather than high-energy X-rays. With this type of radiotherapy, a dose of high-energy protons is targeted directly at the tumour.

Proton therapy is not yet available in Ireland (as of mid 2023), but in certain cases your doctor may recommend that you have proton therapy overseas – mostly the UK and Germany. This can be funded under the HSE Treatment Abroad Scheme. If proton therapy is an option for you, your healthcare team will discuss this with you and give you all the details you need to avail of the treatment.



New treatments

New types of treatments are being developed all the time. Your doctor will talk to you about any other treatments that may be suitable for you.

Chemotherapy

- Chemotherapy is a treatment that uses drugs to kill tumour cells.
- Chemotherapy can be given after surgery or before, with or after radiotherapy.
- The drugs can be given on their own or as part of a combination of drugs.

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. Chemotherapy can be given on its own or as part of a combination of drugs. It is either given in tablet form or through a drip into your bloodstream (intravenously).

Your medical oncologist (doctor who specialises in using drugs to treat tumours) will decide the type, schedule and dose of your chemotherapy. They will base this on things such as your general health and the grade, size and location of the tumour.

Temozolomide is the chemotherapy drug most often prescribed to treat glioma brain tumours.

Sometimes doctors may not be sure how effective chemotherapy will be. If this is the case, your doctor and specialist nurse will talk to you about the possible advantages and disadvantages of chemotherapy in your situation.

You may have chemotherapy after surgery or before or after radiation therapy. Chemotherapy may also be given along with radiation therapy (chemoradiation).

Support Line Freephone 1800 200 700

Chemotherapy with radiotherapy (chemoradiation)

For some tumours (usually high-grade gliomas), radiation therapy is combined with chemotherapy (chemoradiation). Usually, you will take chemotherapy tablets while having radiotherapy. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy. Having both treatments may cause more side-effects than having just one. Your doctor and nurse will explain how the treatments work and the possible side-effects. They may also give you antibiotics, to reduce the risk of getting a chest infection. Usually you will stop the chemotherapy drug for a time when you finish radiotherapy, and then restart chemotherapy for up to 6 cycles.

Types of chemotherapy drugs



Different drugs are used in different situations. Your doctor or nurse will explain the drugs before you start treatment. The main drugs used to treat primary brain tumours are temozolomide (Temodal®), lomustine (CCNU) and carmustine (BCNU).

Understanding your drug treatment

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

If you know the name of the drug or drugs used in your chemotherapy, visit the Health Products Regulatory Authority's website at www.hpra.ie for more information about the drug and possible side-effects. If you have any questions or need any more information, you can our Support Line on 1800 200 700.

Where will I have my treatment?

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



What are the side-effects of chemotherapy?

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

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

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

Increased risk of infection

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

Avoiding infections



If you have a high temperature, or feel unwell (even with a normal temperature), it is very important to call the hospital straight away - never delay. Check with your hospital about the temperature advice to follow.

Bleeding and bruising

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

Anaemia

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

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 84.

Hair loss (alopecia)

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

Nausea and vomiting

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

Constipation and diarrhoea

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

Mouth and throat problems

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

Other side-effects

Other side-effects include headaches, a loss of appetite and an itchy rash or dry skin. For the effects of chemotherapy on fertility see page 88. If you have any other side-effect or symptom that concerns you tell your doctor or nurse straight away. They will give you advice.

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



Clinical trials

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

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

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

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



More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*. You can see a list of current trials at www.cancertrials.ie

Managing side-effects and symptoms

How can my symptoms be relieved?	79
How is swelling treated?	79
How are seizures treated?	81
How can I cope with fatigue?	84
Will treatment affect my sex life?	86
Will treatment affect my fertility?	88
Complementary therapies	89

How can my symptoms be relieved?

Let your doctor or nurse specialist know if you have side-effects or symptoms that are troubling you. There are treatments that can help. For example, medication for pain or drugs to stop you getting sick. Surgery, radiotherapy and chemotherapy can all be given to help with some of the symptoms caused by brain tumours. You may also be given steroids (see below) or anti-convulsants (see page 81).



How is swelling treated?

Steroids

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

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

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



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

Email: supportline@irishcancer.ie

How are seizures treated?

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

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

Anti-convulsants

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

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

If you are having seizures, it is important to stop driving. See www.rsa.ie for guidelines.

Seizures: advice for carers

Although it can be upsetting to see your loved one having a seizure, seizures usually pass quite quickly. After a seizure, it may take a short while before the person feels back to normal again.

It's important for them to rest until they have fully recovered.



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

Convulsive seizures

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

How to help

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

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

Do not:

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

Partial seizures

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

How to help

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

When should I call an ambulance?

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

How can I cope with fatigue?

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



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

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

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

Our booklet *Coping with Fatigue* has more advice. Call our Support Line on 1800 200 700 or call into a Daffodil Centre for a free copy.

Tips and Hints — fatigue

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



Will treatment affect my sex life?

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



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

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. They may suggest visiting a therapist who can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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

Sometimes people worry about infecting others. Your illness is not contagious. It cannot be passed on to a partner during sex.

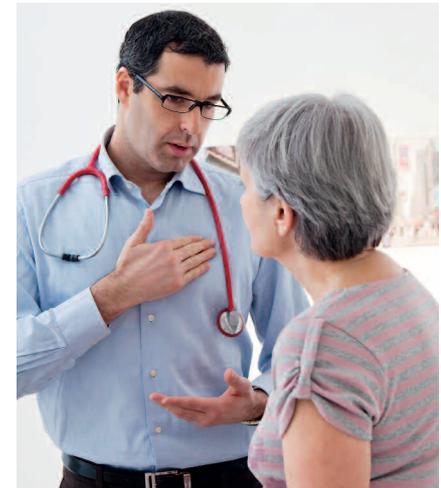
Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment, even if your periods stop. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy. Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or to have more children. This gives your body a chance to recover from the effects of the tumour and its treatment.

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so there's no need to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a nurse in confidence.



Will treatment affect my fertility?

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

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



Complementary therapies

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

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

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

Integrative care

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

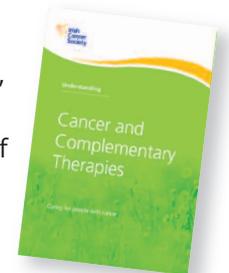
What's the difference between complementary and alternative therapies?

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

Alternative therapies are used **instead of** standard medical care. Modern medical treatments are very effective. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our complementary therapies booklet.





After treatment

What follow-up will I need?	93
Life after treatment	94
Living a healthy lifestyle	96
What if the brain tumour comes back?	97
Palliative care	97
Planning ahead	97

What follow-up will I need?

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

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

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

Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget anything. It's important to go to your follow-up appointments. They give your doctor the chance to:

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

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

Driving after brain tumour treatment



If you have been treated for a brain tumour, you will have to wait for some time before you are allowed to drive again. The amount of time depends on the treatment you have had, the type of brain tumour, and any symptoms you may be experiencing. Visit the Road Safety Authority website www.rsa.ie to read or download the Medical Fitness to Drive Guidelines.

If you're between check-ups and have a symptom or problem that's worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment, if necessary. Go to your GP or the hospital emergency department if you become suddenly unwell and you can't contact the hospital team.

Life after treatment

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



Feelings you may have include:

- **Fear of tumour coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues

- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**

You can also call our Support Line or visit a Daffodil Centre to talk things over with a nurse in confidence. See page 104 for other ways to get emotional support.

After-treatment workshops



You might like to join our *Life and Cancer – Enhancing Survivorship (LACES)* programme when you have completed treatment or have started maintenance therapy. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

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

Living a healthy lifestyle

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

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

A healthy lifestyle includes:

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



It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had treatment, so check with your doctor which you should have and make sure you get them.

What if the brain tumour comes back?

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

Palliative care



Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer.

Planning ahead

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

Planning ahead might include:

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

Who can help me plan?

Think Ahead is a planning pack with different sections and easy-to-read forms. You can fill in your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie



Coping and emotions

How can I cope with my feelings? 101

Ways to get emotional support 104

You and your family 105

How can I cope with my feelings?

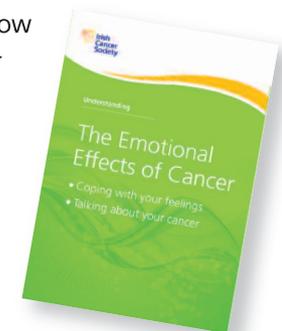
There are many different reactions to getting a diagnosis of a brain tumour. There is no right or wrong way to feel and there is no set time to have any particular emotion.

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

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

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

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



Support Line Freephone 1800 200 700

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Your healthcare team may refer you to psycho-oncology services, if they are available in your hospital. These services can help you to cope with your feelings. Medical social workers and other trained staff can also offer support to you and your family.



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

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

Counselling

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

To find out more about counselling and counselling services in the community, call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre.

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

Positive feelings

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

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



Ways to get emotional support

Find out about support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 125 for more about support services.

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

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology support services if they are available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Call our Support Line to find out more.

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

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

You and your family

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

Changing relationships

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



Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. We also have a booklet on talking to children of different ages that will help explain your illness.





Supporting someone with a brain tumour

How you can help	109
Support for you	111
Talking to your loved one about their illness	111

How you can help

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

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

Learn about brain tumours

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Call our Support Line for free copies of our information booklets.



Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at many local support centres. Talk to your GP or see page 122.



Find out about support for carers

Find out about groups and organisations for carers. Many local support centres have services for carers too. Brain Tumour Ireland has support groups throughout Ireland (see www.braintumourireland.com).

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

Support for you



Our nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, *Caring for someone with cancer*, has lots of information on:

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

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie



Talking to your loved one about their illness

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

Our booklet *Caring for someone with cancer* has a section on how to talk 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 from our website.



Support resources

Money matters	115
Irish Cancer Society services	119
Local cancer support services	125

Money matters

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

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

Practical and financial advice from the Irish Cancer Society



We provide individualised financial and practical advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**
- **Public supports**
- **Community supports**
- **Legal entitlements**

We can also act as advocates for patients and their families, for example when discussing your diagnosis with your employer or your financial provider.

Call our Support Line on 1800 200 700 or visit a Daffodil Centre to access any of these supports.

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Email: supportline@irishcancer.ie

Benefits and allowances

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

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

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0818 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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



If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 123 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

Money and finances

Go to www.cancer.ie and see our **Managing money** page for information on:

- **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**

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Support Line Freephone 1800 200 700

Irish Cancer Society services

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

- **Support Line**
- **Daffodil Centres**
- **Telephone interpreting service**
- **Peer Support**
- **Psychological support services**
- **Patient travel and financial grants**
- **Night nursing**
- **Publications and website information**
- **Support in your area**
- **Practical support and financial solution services (see page 115)**

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on Microsoft Teams platform. To avail of the service, please go to <https://www.cancer.ie/Support-Line-Video-Form>

You can also email us any time on supportline@irishcancer.ie; or visit our Online Community at www.cancer.ie.



Daffodil Centres

Daffodil Centres in 13 hospitals nationwide are staffed by cancer nurses and trained volunteers. They provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.



This is a walk-in service. For opening hours and contact details for each of the Daffodil Centres, go to www.cancer.ie and search 'Daffodil Centres'. You can also email daffodilcentreinfo@irishcancer.ie

Who can use the Daffodil Centres?

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

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

Telephone Interpreting Service

Speak to our Support Line and Daffodil Centre nurses in your own language through our telephone interpreting service.

Call Freephone 1800 200 700 or visit a cancer nurse in a Daffodil Centre and we will connect you to an interpreter.

Peer Support Programme

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.



To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Psychological Support Services

The Society funds professional one-to-one counselling. The services we provide are:

- **Remote counselling nationwide**, by telephone or video call.
- **In-person counselling sessions** in Cancer Support Centres around the country.

Counselling is available for the patient, family members, and close friends.

For more information, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them.

For more information about what's available near you, contact your nearest Daffodil Centre, or call our Support Line on Freephone 1800 200 700.



Patient travel and financial grants

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- The Irish Cancer Society **Volunteer Driver Service** is available mainly to patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for radiotherapy patients attending University Hospital Cork and the Bons, Cork for treatment.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite. Travel2Care is made available by the NCCP.

To access any of these supports, please contact your hospital healthcare professional, call Freephone 1800 200 700, or contact your nearest Daffodil Centre.



Irish Cancer Society Night Nursing

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



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

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website www.cancer.ie to see our full range of information and download copies. You can also Freephone our Support Line or call into your nearest Daffodil Centre for a free copy of any of our publications.

To find out more about the Irish Cancer Society's services and programmes:

- Visit us at www.cancer.ie
- Call our Support Line on Freephone 1800 200 700
- Email our Support Line at supportline@irishcancer.ie
- Contact your nearest Daffodil Centre
- Follow us on Facebook
- Follow us on Twitter
- Follow us on Instagram

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, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling through many local support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **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 lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to www.cancer.ie and search 'Find support'.



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) A computer aided X-ray that shows up tissue mass as well as bone.

Cyst A sac filled with fluid or semisolid material

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 to help 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. 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?

Join the Irish Cancer Society team

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

Support people affected by cancer

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

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

We would love to hear your comments or suggestions.

Please email reviewers@irishcancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4, D04 VX65

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

