



*Understanding*

# Cancer of the Larynx

*Caring for people with cancer*



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Open Monday to Thursday 9am–7pm; Friday 9am–5pm

## Understanding cancer of the larynx

This booklet has been written to help you understand more about cancer of the larynx. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and key aspects of living with it.

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



Specialist nurse	Tel:
Speech and language therapist	Tel:
Dietitian	Tel:
Family doctor (GP)	Tel:
Head and neck surgeon	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Medical oncologist	Tel:
Emergency	Tel:
Treatments	Review dates

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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## Introduction

This booklet has been written to help you understand about cancer of the larynx. It is also known as laryngeal cancer or cancer of the voice box. It describes what it is and how it is diagnosed and treated. We hope it answers some of your questions and encourages you to discuss them with your doctor and nurse too.

We cannot advise you about which treatment to choose. You can only make this decision along with your doctors when all your test results are ready. But we can tell you about some ways to treat this cancer and side-effects that may happen after treatment is given.

The booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



### Reading this booklet

Remember you do not need to know everything about laryngeal cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm.

## What does that word mean?

<b>Adjuvant treatment</b>	Treatment for cancer given soon after surgery.
<b>Alopecia</b>	Loss of hair or baldness. No hair where you normally have hair.
<b>Benign</b>	Not cancer. A tumour that does not spread.
<b>Biological therapies</b>	Treatment using your body's own immune system to fight cancer. There are several types. For example, monoclonal antibodies.
<b>Biopsy</b>	Removing a small amount of tissue from your body to find out if cancer cells are present.
<b>Cells</b>	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
<b>Chemotherapy</b>	Treatment using drugs that cure or control cancer.
<b>Fatigue</b>	Ongoing tiredness often not helped by rest.
<b>Larynx</b>	Your voice box. It is a small organ in the front part of your neck attached to your windpipe. It contains your vocal cords and is also needed for swallowing and breathing.
<b>Laryngectomy</b>	An operation to remove your larynx.
<b>Laryngectomy tube</b>	A hollow tube made of metal or plastic put into your windpipe at the stoma site. This makes sure that the stoma remains open and is suitable in size.
<b>Laryngoscopy</b>	A test that examines your voice box using a thin flexible tube called a laryngoscope.
<b>Malignant</b>	Cancer. A tumour that spreads.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

<b>Metastasis</b>	The spread of cancer from one part of the body to other tissues and organs.
<b>Neck stoma</b>	A permanent opening made in the lower part of your neck after a total laryngectomy to allow you to breathe.
<b>Oncology</b>	The study of cancer.
<b>Palliative care team</b>	A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They can also help you cope with any emotional distress.
<b>Prognosis</b>	The expected outcome of a disease.
<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients using radiotherapy.
<b>Radiotherapy</b>	The treatment of cancer using high-energy X-rays.
<b>Speech and language therapist</b>	A therapist who assesses and manages communication and swallowing difficulties.
<b>Staging</b>	A series of tests that measure the size and extent of cancer.
<b>Tracheostomy</b>	A small hole or opening directly into your windpipe (trachea) from your neck.
<b>Tracheostomy tube</b>	A special tube placed in your throat to help you breathe.
<b>Tracheoesophageal fistula</b>	An opening between your windpipe and oesophagus (gullet) made by your surgeon. A voice prosthesis may be placed in this opening to help you speak.
<b>Vocal cords</b>	Two bands of muscle inside your larynx. They vibrate together when air passes between them. The vibrations make the sound of your voice.

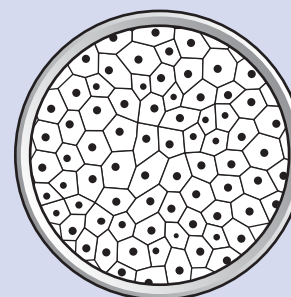
## About laryngeal cancer



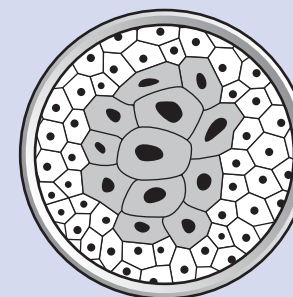
### What is cancer?

Cancer is a word used to describe a group of diseases. Each one has its own name. For example, skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

In your body, your organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing, even when there is no need.



Normal cells



Cancer cells growing

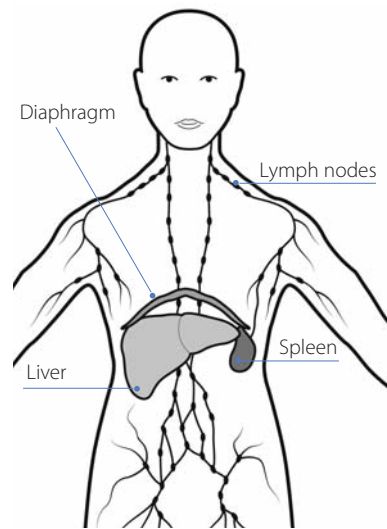
These groups of abnormal cells can form a lump or tumour. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of the body and so are not called cancer. Malignant tumours are cancer cells that can spread from where they first grew. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to form a new tumour somewhere else in your body. This is called a metastasis or secondary tumour.

## What is the lymphatic system?

Every day your body defends itself against infection in many ways. The lymphatic system is one way. Like your bloodstream it carries material around your body. It is made up a network of tiny tubes that pass through most of the tissues in your body. These tubes carry a clear watery fluid called lymph.

Along the network are hundreds of small glands shaped like beans. These are called lymph nodes and they remove unwanted material from the lymph like a sieve. They also help white blood cells called lymphocytes to protect your body against infection.

Lymph nodes are found in groups throughout your body, such as in your neck, armpits and groin. Sometimes you may notice these glands if they become swollen. More of these lymph nodes are found in larger groups in your chest and tummy (abdomen). Other parts of the lymphatic system include your spleen, thymus, tonsils and bone marrow. Lymph nodes can also spread cancer cells.



The lymphatic system

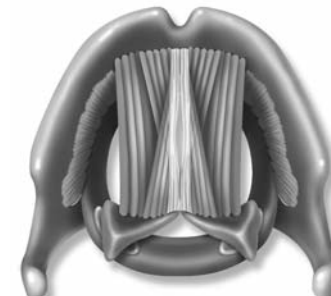


### To sum up

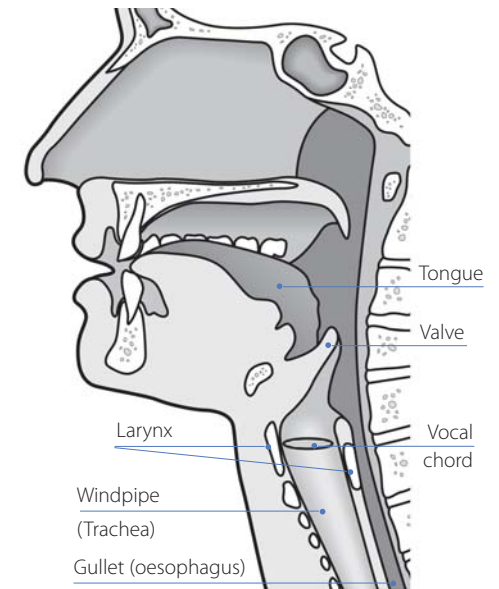
- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by the bloodstream or lymphatic system somewhere else. This is called a metastasis or secondary tumour.

## What is the larynx?

The larynx is also known as your voice box. It is a small organ in your neck that sits at the entrance to your windpipe (trachea). In men, it is often seen as the lump at the front of the neck and called the 'Adam's apple'.



The vocal cords



The larynx

The larynx allows the air you breathe to reach your lungs through your windpipe. It also acts as a valve to prevent food and drink from entering your airway when you swallow. The larynx also contains the vocal cords. When air passes through these muscles they vibrate. This allows you to make sound when you speak.

## What is laryngeal cancer?

Laryngeal cancer starts when the cells in your larynx change and grow in an abnormal way. They can form a single mass or tumour within your larynx. Most are found on or near your vocal cords and affect the sound of your voice. Less common are those above the vocal cords and rarer still are those below. In rare cases, cells may break away and spread to other parts of your body. For example, your lungs.

## How common is laryngeal cancer?

Laryngeal cancer is a rare cancer. In Ireland, about 139 people were diagnosed with it in 2009. It is more common in men than women and becomes more common as you get older.

## What causes laryngeal cancer?

The exact cause of laryngeal cancer is unknown. But there are certain things called risk factors that can affect your chances of getting the disease. Different cancers have different risk factors. Some things that can increase your risk of laryngeal cancer are:

- **Smoking:** Smoking is one the main risk factors for laryngeal cancer. It is thought that tobacco contains chemicals that can trigger changes in normal cells that can lead to cancer.
- **Drinking:** Drinking a lot of alcohol, especially spirits, is another main risk factor. Alcohol contains chemicals that can trigger changes in normal cells and lead to cancer. The effect of both smoking and drinking makes your risk even higher than average.
- **Age:** Your risk of laryngeal cancer increases with age. It occurs mainly in people over the age of 50.
- **Gender:** Laryngeal cancer is more common in men than women.
- **Exposure to substances in the workplace:** Some chemicals may increase your risk of laryngeal cancer. If you have been regularly exposed to high levels of wood dust, paint fumes or soot and coal dust over some years, you might have an increased risk.
- **Human papilloma virus:** If you are exposed to the human papilloma virus (HPV), your risk might increase. This virus is passed on by sexual contact.

»»» Drinking alcohol, especially spirits, and smoking tobacco are the main risk factors for laryngeal cancer.

Remember laryngeal cancer is not infectious and cannot be passed on to other people. If you feel you may be at risk, first talk to your family doctor (GP) about your concerns. He or she may advise you to visit a specialist.



### Giving up smoking and alcohol



If you smoke and would like support and advice about quitting, there is help available. You can call your GP or the National Smokers' Quitline on CallSave 1850 201 203. If you would like further personal support locally, call the Quitline and they will put you in touch with the HSE smoking cessation officer in your area. See page 51 for more information.

There is helpful information, advice and support on cutting down or giving up alcohol on the website [www.yourdrinking.ie](http://www.yourdrinking.ie). Or the HSE Infoline 1850 24 1850 can provide you with the best contact number for support in your local area.

### Can I be screened for laryngeal cancer?

Testing for laryngeal cancer when you have no symptoms is called screening. There is no national laryngeal cancer screening programme in Ireland at present. If you are concerned about laryngeal cancer, especially if you are a heavy drinker, smoker or ex-smoker, talk to your GP.



## What are the symptoms of laryngeal cancer?

The symptoms of laryngeal cancer can include any of the following:

- A hoarse voice for longer than 4 weeks
- Change in the sound of your voice
- A lump in your throat or neck
- Difficulty in swallowing
- A cough or feeling you cannot breathe properly
- Earache
- Blood in your spit after coughing

**Hoarseness:** Most laryngeal cancers begin on one of the vocal cords. A very small tumour can prevent the two vocal cords meeting together and working properly. So a hoarse voice usually occurs very early in the disease. If you have a hoarse voice for longer than 4 weeks, you should visit your GP.

**Difficulty in swallowing:** You might also have difficulty in swallowing. This can vary from feeling food is sticking in your throat to being unable to swallow food. You may have some pain or discomfort when swallowing food.

The above symptoms can also be caused by conditions other than cancer. Do visit your GP to get your symptoms checked out.



### To sum up

- The larynx is known as your voice box. You use it to breathe and make sounds.
- About 39 people were diagnosed with laryngeal cancer in Ireland in 2009.
- The cause of laryngeal cancer is unknown. Your risk increases with age, if you drink and smoke, or are infected with the virus HPV.
- The symptoms of laryngeal cancer include hoarseness, a change in the sound of your voice, a lump in your throat or neck, difficulty in swallowing or breathing problems.

## How is laryngeal cancer diagnosed?

Most people visit their GP first if worried about any symptoms. Your GP will check inside and outside your throat for any lumps or swellings and also your glands. Extra blood tests might be arranged to rule out other possible causes of your symptoms. Your GP may refer you to the hospital for further tests or ask you to see a specialist. This is usually an ear, nose and throat (ENT) specialist.

### At the hospital

The ENT specialist will ask you about your medical history and symptoms before examining you. You will have blood tests to check your general health and usually a chest X-ray. Other tests will be arranged, possibly for another day.

Tests may include:

- Nasendoscopy
- Fine needle aspiration
- Laryngoscopy and biopsy

**Nasendoscopy:** This test uses a thin flexible tube with a light at one end to examine the back of your mouth and throat. Your doctor puts the tube into your nose and down into your throat. Before the tube is put in, your throat is sprayed with local anaesthetic. This will numb your throat and make the test more comfortable for you. If your doctor sees an abnormal areas, he may take a sample of the tissues (biopsy). Once you have been examined, you can go home. The test is a little uncomfortable but not painful.

**Fine needle aspiration:** This is a quick, simple test done in the outpatient clinic. If your doctor feels a lump in your neck, he or she can take a sample of cells from it. This is done using a small needle that draws off liquid and cells into a syringe. The sample is then sent to the laboratory and checked for cancer cells.

**Laryngoscopy:** This is an exam of your larynx under general anaesthetic. A thin flexible tube called a laryngoscope is used this time. A light at one end of the tube helps your doctor to see any



abnormal areas or swelling. It is like a nasendoscopy but it allows your doctor to have a closer look at your larynx.

Before the test, you cannot eat or drink anything for a few hours. You may also be given a mild sedative to relax you before going to theatre. Once you are asleep, the laryngoscope is passed gently through your nose or mouth and into the back of your throat.

It will be at least 4 hours after the test before you can eat or drink again. Your throat will be numb after the anaesthetic and food or drink might go down the wrong way. Most people are able to go home the next day. You cannot drive for 24 hours after the test, so do arrange for someone to take you home. You might have a sore throat for a couple of days after the test, but it will soon clear up.

**Biopsy:** If your doctor sees any abnormal tissue during the laryngoscopy, he or she can take a biopsy. This is a small sample of the tissue. It is removed and sent to a laboratory and examined under a microscope. This helps your doctor to diagnose if cancer is present.

»»» Nasendoscopy, laryngoscopy and biopsy can help to diagnose laryngeal cancer.

### Further tests

If the biopsy shows that you have laryngeal cancer, your doctor may decide to do other tests. These tests will show if the cancer affects other tissues and organs. This is called staging. It will also help your doctor to decide on the best treatment for you.

These tests include:

- CT scan
- MRI scan
- PET scan (with CT)

**CT scan:** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. It can be used to check if the cancer has spread locally beyond the larynx or to other parts of your body. The scan itself is painless.

For a CT scan of your larynx, you might need to fast from midnight before the test or 4 hours beforehand. You may also be given a special drink to help show up parts of your body on the scan. It is important

to let the radiographer know if you are allergic to iodine or have asthma, before you take the drink or injection. The injection may make you feel hot all over for a few minutes.

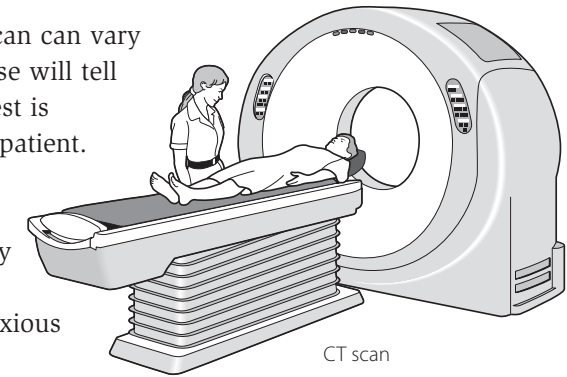
Preparation for a CT scan can vary but your doctor or nurse will tell you what to do. The test is usually done as an outpatient. Some people feel anxious about this test and are afraid they may feel claustrophobic during it. If you are anxious about this, contact the radiographer the day before.

They may be able to give you medication to relax you on the day.

**MRI scan:** This special scan uses magnetic energy to build up a picture of the larynx tissues inside your body. It does not hurt but can be very noisy. You will be given earplugs to wear during it. You might get an injection before the scan to show up certain parts of your body. During the scan you cannot wear metal jewellery. If you have any medical device like a pacemaker or metal piece in your body, you may not be suitable for the test. Usually you can go home afterwards.

**PET scan:** PET stands for positron emission tomography. It uses a low dose of radioactive sugar (glucose) to measure activity in your cells. A CT scan is usually done with the PET scan.

The day before the test you must avoid any strenuous physical activity. Also, avoid eating carbohydrate foods like bread, cereal, pasta, rice and potatoes. Do not take any drink or food containing sugar, like biscuits, cakes or fizzy drinks. It is best to



PET scan

avoid alcohol and caffeine as well. All these things can interfere with the results. Before the test, you may have to fast for 6 hours.

Once you are feeling relaxed, the glucose is injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the glucose, there will be more radioactivity where the cancer cells are located. After an hour, the scan is taken and can show if the cancer has spread to other tissues and organs. The scan itself may take up to 1 hour. Remember PET is safe to use and there are no side-effects.

Your doctor and nurse will give you more information about preparing for it.

### Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. Fear of the unknown can overwhelm everything. It may be frustrating as well, especially if new tests are ordered or scans redone. You may be anxious to start treatment straight away and afraid that delays are letting the cancer spread. But it is important that your doctor gets as much information as possible about your cancer before it is treated.

It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.



### To sum up

- Laryngeal cancer is diagnosed by nasendoscopy, laryngoscopy and biopsy.
- Further tests include CT, PET and MRI scans.

## What are the types of laryngeal cancer?

The most common type of laryngeal cancer is the squamous cell type. About 9 out of 10 laryngeal cancers are of this type. Squamous cells are flat skin-like cells that cover the surface of your epiglottis, vocal cords and other parts of your larynx.

Rarer types of laryngeal cancer are adenocarcinoma and sarcoma. If you would like more information on any type of laryngeal cancer, contact the National Cancer Helpline on 1800 200 700.

## What are the stages of laryngeal cancer?

Staging means finding out the size of the tumour and if it has spread to other tissues and organs in your body. Your doctor may arrange some tests to stage the cancer. Some of these tests are mentioned on page 14. This will help your doctor to plan the best treatment for you.

»»» Staging allows your doctor to plan the best treatment for you.

There are different systems used to stage cancer. One staging system is called TNM. This stands for tumour, node, metastasis. It refers to how deeply the tumour has grown into your larynx (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M).

The exact TNM system for laryngeal cancer will depend on which part of your larynx is affected. Your doctor or nurse can give you more details about the stage of your cancer.



### To sum up

- The most common type of laryngeal cancer is the squamous cell type.
- Staging finds out the size of the cancer and if it has spread.
- Staging helps your doctor to plan the best treatment for you.

## Treatment and side-effects

### How is laryngeal cancer treated?

The type of treatment you receive will depend on the stage of the cancer, your symptoms, where in the larynx it is found, your age and general state of health. Treatments for laryngeal cancer include:

- Radiotherapy
- Surgery
- Chemotherapy
- Biological therapy

These treatments may be used on their own or in combination.

**Radiotherapy:** Radiotherapy is now the most common treatment for laryngeal cancer. It involves using high-energy X-rays to kill the cancer cells. It is often used alone, especially for small, early stage cancers of the larynx. Depending on the size of the cancer, it may be given with chemotherapy (also called chemoradiation) or biological therapy. Sometimes radiotherapy may be used before or after surgery. See page 23 for more details about radiotherapy.

**Surgery:** Laser or endoscopic surgery can be used for small, early stage cancers of the larynx. You may need to have your larynx partially or completely removed if the cancer is large. Sometimes surgery is used to remove any cancer remaining after radiotherapy treatment. See page 30 for more details about surgery.

**Chemotherapy:** This is the use of drugs to kill or control the cancer cells. It can be used with radiotherapy or if the cancer returns after surgery or radiotherapy. It is sometimes used to help to shrink a large cancer before surgery or radiotherapy. See page 42 for more about chemotherapy.

**Biological therapy:** This treatment uses your body's own immune system to fight cancer. It is sometimes used in combination with radiotherapy. Newer types of biological therapies may be part of your treatment if you are on a clinical trial. See page 46 for more details about biological therapy.

>>> Your doctor will discuss your treatment options with you.

Laryngeal cancer is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with laryngeal cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

## Deciding on treatment

At this time you may be anxious about what is going to happen next. Do not be afraid to ask for more information.

**Treatment options:** Your doctor and nurse will explain your treatment options to you. Sometimes, depending on the stage of your cancer, you may have fewer choices.

Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and the answers you receive.

**Time to think:** When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You might want more time to think things through. But remember there is always time for you to consider what sort of treatment you want.

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

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

>>> No medical treatment will be given without your consent.

## Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:

- The type of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any major side-effects of the treatment

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 always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

## Individual treatment

You may notice that other people with laryngeal cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Do not be afraid to ask your doctor about your own treatment.

>>>

## Who will be involved in my care?

Some of the following health professionals may be involved in your care.

<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients using radiotherapy.
<b>ENT surgeon</b>	A doctor who specialises in ear, nose and throat surgery.
<b>Head and neck surgeon</b>	An ENT surgeon specially trained in cancer of the head and neck.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

<b>Head and neck nurse specialist</b>	A specially trained nurse who works in a special cancer care unit for those with head and neck cancers. She or he can support and reassure you and your family from diagnosis and throughout treatment.
<b>Speech and language therapist</b>	A therapist who can assess and treat any speech, voice, language and communication problems or swallowing problems.
<b>Dietitian</b>	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
<b>Radiation therapist</b>	A radiotherapist who specialises in giving radiotherapy and information about it to cancer patients.
<b>Physiotherapist</b>	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
<b>Medical social worker</b>	A person specially trained to help you and your family with all your social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of loss and change. They can give advice on benefits, entitlements and services available to you when you go home. For example, if you need Meals on Wheels, etc.
<b>Psychologist</b>	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
<b>Counsellor</b>	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
<b>Palliative care team</b>	This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.



## To sum up

- The main treatment for laryngeal cancer is radiotherapy. Surgery and chemotherapy may be used as well.
- A team of specialists will decide the best treatment for you.

## Radiotherapy

This is a treatment where high-energy X-rays are aimed at the cancer to cure or shrink it. It is a widely used treatment for laryngeal cancer. The X-rays are usually delivered through a machine called a linear accelerator. This is known as external radiotherapy. Radiotherapy works well for laryngeal cancers and even the most advanced form may still be cured with it.

The treatment can be given at different times:

**Radiotherapy alone:** If possible, your doctors will suggest radiotherapy rather than surgery because it can help you to keep your voice. The treatment is usually over 3 to 7 weeks during weekdays (Monday to Friday).

**Radiotherapy after surgery:** Your doctors may advise radiotherapy after surgery as it may help to reduce the risk of your cancer coming back.

**Radiotherapy with chemotherapy or biological therapy:** You may have radiotherapy and chemotherapy (chemoradiation) or biological therapy at the same time.

## Before radiotherapy

**Dental check-up:** It is important that you have a dental check-up before receiving any radiotherapy to your larynx. This is to make sure that any mouth infections are fully healed and your teeth are in good condition. Your dentist can also remove any teeth that need to be extracted. If you have dentures, they will be checked to make sure they do not cause trauma or infection. Radiotherapy to the head and neck can cause damage to bones in this area. This is known as osteoradionecrosis.

Your dentist will also give you advice on how to care for your mouth, your diet and any physiotherapy exercises that you may need during radiotherapy.

**Smoking and alcohol:** Your doctor might advise you not to smoke and drink alcohol at this time. The treatment might work less well and increase the side-effects if you smoke and take alcohol.

## Planning your treatment

Before radiotherapy, your doctor and other specialists plan how best to give you the treatment. They work out how much treatment you need with the least damage to normal cells.

You may need radiotherapy to your head or neck. The head is one of the most difficult parts of your body to keep steady during treatment. For this reason, a special mould (mask or shell) is made of your head for you to wear during treatment. When you wear the mould, it will be attached to the couch you are lying on during treatment. This makes sure that the radiation is aimed at the same area each day. The treatment area will be marked on the mould using ink.



Radiotherapy to the larynx

On your first visit to the radiotherapy unit, you lie on a couch and the person who makes the mould will explain how it is made. When the mould is ready, you lie under a machine called a simulator that takes X-rays of the area to be treated.

Treatment planning is a very important part of radiotherapy and may take several weeks. Before starting radiotherapy, you will be told how to look after your skin during and after treatment.

»»» Treatment planning is a very important part of radiotherapy and may take several weeks.

## Getting radiotherapy

Getting radiotherapy is quite straightforward. You will be asked to come for treatment every day during the week with a break at weekends. Your treatment may continue for 6 to 7 weeks. Each treatment session only takes a few minutes. The treatment does not hurt but you will have to lie still. How much treatment you receive will depend on the size and type of tumour. Your doctor will discuss this with you.

Each time you come for treatment, you will go into a radiotherapy room. The radiation therapist will help you put on the mould and ask you to lie in a certain position under a radiotherapy machine. Once you are ready, he or she will leave the room.

The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed-circuit camera. You can talk to the staff through an intercom if you wish.

If your mouth or throat becomes very painful, do let your doctor or nurse know as soon as possible. External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

»»» External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

## Will I get any side-effects?

Radiotherapy is given directly to the site of the cancer. In radiotherapy for laryngeal cancer, the areas likely to be affected are the mouth and throat. How severe these side-effects are will vary from person to person and depend on the amount of treatment you need. The effects of radiotherapy may be more severe if you have had surgery as well. Your doctor or nurse will explain how these effects can be managed before you start treatment.

The side-effects may include:

- Sore mouth and throat
- Dry mouth and throat
- Mouth infection
- Difficulty swallowing
- Poor appetite and weight loss
- Voice changes
- Skin changes
- Tiredness (fatigue)
- Hair loss

**Sore mouth and throat:** Radiotherapy to your larynx can cause a sore mouth and throat. This happens because the cells that line these areas are very sensitive to treatment. Your doctor will prescribe painkillers for you if your mouth or throat is painful. Do let your doctor or nurse know if they are working or not. Stronger painkillers can be prescribed for you instead. If you have an infection in your mouth or throat, you may need other medication as well. Do keep your teeth, gums and mouth very clean as this will help to control the soreness and reduce the risk of a mouth or throat infection.



### Tips & Hints – mouth care

- Gently brush your teeth with a small, soft toothbrush five or six times a day, especially after meals and before bedtime. It may be helpful to soften the brush in warm water before brushing.
- Use a mild fluoride toothpaste only.
- If you have dentures, remove them every night and if your gums are sore.
- Use special mouthwashes to keep your mouth clean, fresh and to ease mild soreness or pain.
- Only use mouthwashes recommended by your dentist, radiation therapist or nurse. Some mouthwashes contain alcohol and are too harsh.
- Sip cool water during the day. Add ice cubes to keep it cool.
- Avoid eating hot, spicy or very cold food and drink.
- Avoid food that might be hard to eat like crusty bread, crispy bacon, toast or crisps.
- Avoid alcohol (especially spirits) and tobacco as they can irritate the lining of your mouth and throat. They can also make side-effects more severe.
- If you need teeth pulled (extracted), tell your doctor.
- Visit your dentist at least every 6 months.



**Dry mouth and throat:** After a week or two of treatment you may notice that your mouth and throat feel dry all the time. Radiotherapy can cause the salivary glands to make less saliva than usual. The dryness in your mouth may last for several months after treatment and may be permanent. There are many types of artificial saliva available to help to keep your mouth moist. Special mouthwashes, toothpastes and gels can also help to relieve the discomfort and keep your mouth healthy. You may find that you have a lot of sticky mucus in your throat as well. If the mucus turns green or yellow, tell your doctor, as you may need medication.

**Mouth infection:** It is common to get a mouth infection like thrush during radiotherapy. If it happens, your doctor can prescribe an antifungal medication to take by mouth. Thrush can make your mouth sore and cause difficulty in swallowing. Your nurse and doctor will give you more advice and give painkillers if you need them.

**Difficulty in swallowing:** After a week or two of treatment your chest might feel tight and you may have difficulty in swallowing. It might feel like you have a lump in your throat all the time. Food or drink might seem to go down the wrong way, making you cough as you try to swallow.

It is best to put small amounts of food into your mouth and chew properly before you try to swallow. Eating soft foods mixed with liquid, such as thick soups or stews, can also help. If fluids go down the wrong way, you can use a special powder. By adding it to your drink, it makes the drink thicker and easier to swallow.

Talk to your speech and language therapist if you have difficulty swallowing. Your dietitian can also help. He or she can give you advice on the best foods to eat. Your doctor may also give you medication to take before meals to make swallowing easier. The discomfort will usually ease 5 to 8 weeks after you finish treatment.

If food is passing into your windpipe, you may have to stop eating by mouth until the area has healed. Your doctors may decide to use another way of eating. For example, PEG feeding. With PEG, a tube is put directly into your stomach through the skin on your tummy (abdomen). This can bypass your mouth and gullet. In fact, your

doctors might even decide to use this method before radiotherapy begins, if they think you might experience problems. PEG feeding can also be used if your mouth or throat is too painful for food and drink to pass through.

»»» Eating well can reduce the risk of getting a sore mouth or skin reactions and can speed up wound healing.

**Poor appetite and weight loss:** Radiotherapy can affect the taste buds in your mouth. You may notice that you have no taste or a metallic taste in your mouth. If this happens, you may lose interest in food and not eat as much as you did before treatment. Eating well can reduce the risk of getting a sore mouth or skin reactions and can speed up wound healing. Ask your nurse to refer you to a dietitian if you have a poor appetite. He or she will monitor your weight and give you advice on what to do. Your appetite should improve once treatment has ended. Call the National Cancer Helpline on 1800 200 700 and ask for a copy of the booklet, *Diet and Cancer*.

**Voice changes:** Radiotherapy to the larynx may cause the sound of your voice to change. Your voice may become quieter or sound hoarse. It may become sore for you to talk too. If you have a voice prosthesis such as a Blom-singer valve or are using an electrolarynx, you may notice that the quality of your voice is poor. This common effect of treatment is temporary. The quality of your voice should start to improve when you finish treatment. Talk to your speech and language therapist, who will explain this side-effect to you in more detail.

**Skin changes:** During radiotherapy the skin in the treated area may become red and sore. It may look a little like sunburn. A cream can be used to treat this problem. Remember to only use creams recommended to you by your nurse or radiation therapist. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. If you shave, use an electric razor only. Avoid all aftershaves, perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

**Tiredness (fatigue):** Feeling very tired can build up over the course of your treatment. It may be due to the treatment itself or because you have to travel distances to come for treatment. It helps to rest as much as you can. Also, cut down on the things you normally do while you are on treatment. See page 47 for more about fatigue.

»»» Rest as much as you can. Cut down on the things you normally do while you are on treatment.

**Hair loss:** Any hair within the treatment area will fall out. If you receive radiotherapy to your neck, the hair loss may be permanent or any future hair growth may be lighter than it was before treatment.

These or any other side-effects you develop will be monitored during treatment. Information will be given on how to prevent side-effects and medication will be prescribed if needed. If you have a problem that concerns you, talk to your doctor or nurse. Most of these side-effects should go away when treatment is over, but do let your doctor know about them if they continue.

If you would like more information on radiotherapy and its side-effects, call the National Cancer Helpline on 1800 200 700. Ask for a copy of the free booklet *Understanding Radiotherapy* or a DVD called *Radiation Therapy: A Patient Pathway*.



### To sum up

- Radiotherapy is a treatment using high-energy X-rays to cure or shrink cancer cells.
- The treatment does not hurt and lasts only a few minutes.
- Treatment may continue for 6 to 7 weeks, depending on the cancer.
- Side-effects of radiotherapy depend on the area being treated.



## Surgery

Surgery may be used to treat laryngeal cancer. The aim of surgery is to remove the part of the larynx with cancer cells in it. The type of surgery you have will depend on where in the larynx the tumour is found, its size and if it has spread to other parts of your body. Your age and general health will also be considered.

### Types of surgery

Your surgeon may need to remove part or all of your larynx. The types of surgery that are possible include:

- Laser surgery
- Endoscopic resection
- Partial laryngectomy
- Total laryngectomy

**Laser surgery:** This surgery is used for very small tumours on one vocal cord. Part of the vocal cord is removed using a laser. A laser is an intense beam of light that is aimed at the cancer cells to kill them. Any eating and drinking difficulties you have are short term and should clear up over time. But your voice is likely to remain hoarse.

**Endoscopic resection:** This surgery can be used for early stage laryngeal cancer. Your surgeon uses a small flexible tube with a light and camera at one end called an endoscope. During the surgery, your surgeon guides the endoscope into your larynx and pictures are taken. These pictures appear on a screen in the operating theatre so your surgeon can see your larynx in detail. Your surgeon removes any cancer cells using either a laser or surgical instruments. This surgery is done under general anaesthetic. You will not have a wound but may feel some soreness in your throat for a few weeks afterwards.

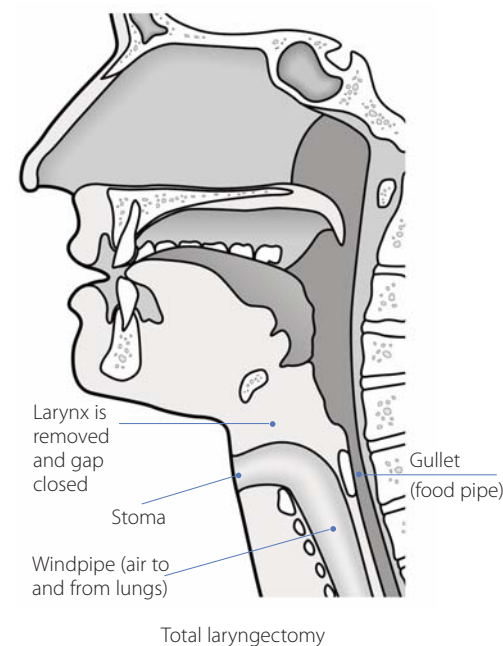
**Partial laryngectomy:** In this surgery part of your voice box (larynx) is removed. At least one vocal cord is kept and you will still be able to speak. But your voice might be quite hoarse or weak afterwards. Your surgeon will first make a temporary hole in your neck and place a tube in it for you to breathe through.

This breathing tube will help your larynx to heal and is known as a temporary tracheostomy. Once your larynx has healed, the tube is removed and the hole will heal. You may find eating and drinking difficult at first but they should improve gradually.

If the cancer is found above your vocal cords, an operation called a supraglottic laryngectomy is done. For this, you will also need a temporary breathing tube (tracheostomy) while the area is healing.

**Total laryngectomy:** You may need to have your entire larynx removed. This operation is called a total laryngectomy. In this case, you will no longer have a voice box and you will have to learn to speak in a different way. Your surgeon might also have to remove the lymph nodes in one or both sides of your neck. This is usually the first place where cancer cells are likely to spread.

When your larynx has been removed, there will be no connection between your mouth and your lungs. As a result, your surgeon will have to make a permanent opening in the lower part of your neck so you can draw air into your lungs and breathe. This opening is called a stoma. You should be able to eat and drink normally after a short period of time. This surgery is explained in detail in the next section.



### Getting ready for surgery

You will need some extra tests to make sure you are strong enough for surgery. These tests may include a heart test (ECG), chest X-ray and more blood tests. An anaesthetist may also examine you to make sure you are fit for surgery.

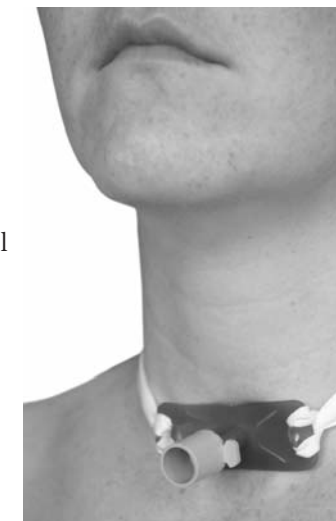
- **Exercises:** A physiotherapist or nurse will show you how to do special exercises. They will involve deep breathing and leg exercises. These will help to prevent you getting a chest infection or blood clot after your surgery.
- **Eating and drinking:** A dietitian and speech and language therapist will visit you before the surgery. They will explain how you will manage to eat and what to expect after surgery. You will not be allowed to eat anything from the night before your operation. Your nurse may give you a tablet before you go to theatre to relax you.
- **Preventing clots:** Depending on your surgeon or the hospital, you may get an injection of an anti-clotting drug before surgery. For example, heparin. You may also get a course of it afterwards. This is to prevent a clot forming in your legs after surgery as you will be less mobile for a few days. You will also be given special elastic stockings to wear.
- **Support at home:** If you live alone or have problems getting around the house, do get advice. Talk to your nurse or medical social worker on your ward as soon as you are admitted to the hospital. He or she can then arrange the community services that you may need after you leave hospital.
- **Speech and language:** A speech and language therapist will visit you and tell what to expect after surgery. He or she will also explain what communication options are available to you after surgery. Do ask as many questions as you can. Write them down on a piece of paper if you find them difficult to remember.

Your family or close friends will benefit from meeting the speech and language therapist as well. That way, you will all have some idea of what is going to happen. Your nurse or speech and language therapist can also arrange for you to meet someone who has had similar surgery.

### After the surgery

You may spend a short time in an intensive care unit or high-dependency unit after surgery. For the first couple of days your face may be swollen but this will soon disappear. When you wake up, you may notice a number of tubes attached to your body. They might look alarming but are normal after an operation like this.

- **Tracheostomy tube:** You may have a tracheostomy tube in the stoma to help you breathe. This tube will be held in place with tapes tied at each side of your neck.
- **Wound drains:** There may be tubes placed near the wound. These tubes will drain away fluid from your wound site.
- **Fluids:** A drip will be put into a vein in your arm. Through this you will be given fluids until you can be fed through the feeding tube.
- **Feeding tube:** A thin plastic tube may be passed either up your nose or through a small hole at the back of your stoma leading down into your stomach. This will be used for feeding.
- **Oxygen:** You will have an oxygen mask over the stoma when you first wake up. This will help to warm and moisten the air passing into your lungs.
- **Catheter:** You will have a small tube called a catheter to drain urine from your bladder into a bag. This will save you having to get out of bed to go to the toilet.



Tracheostomy tube

### Controlling pain

You are likely to have some pain after your surgery. But your nurse will give you painkillers and also medication to prevent you feeling or getting sick, if you need them. There are various ways to give painkillers. There may be a thin epidural tube in your back to help relieve any pain. Or you may be given a patient controlled analgesic (PCA) pump. Your nurse will show you how to use this.

Always ask for help if you have any pain or feel sick. Do not play down the amount of pain you have as being pain-free will help with healing and speed up your recovery. Mild discomfort or pain in your throat can last for several weeks or even months. Your doctor will give you a prescription for painkillers to take home with you, if you still need them.

**Eating and drinking**

You cannot eat or drink in the normal way until the wound in your throat and around the stoma has healed. During this time your nurses will give you fluids and food through the feeding tube.

Between 7 and 10 days after your surgery, you will be sent for a special X-ray to check that your throat has healed. Depending on the results of this X-ray, you may be allowed to resume eating and drinking. When you are ready, you will start by taking fluid and soft food. You may find swallowing a little difficult for the first few days but this will improve. Once you begin to drink and eat again the feeding tube will be removed.

**Communication**

You will still be able to communicate after the surgery. But as your voice box has been removed, you cannot make sounds or speak the way you did before. When you wake up after the surgery, you can communicate through writing, picture charts, facial expressions and mouthing, pointing or making gestures. If you have a mobile phone and can send text messages, this will be very useful. Your nurses will also make sure you have a call bell and pen and paper to hand at all times. Your hearing will not be affected.

It may be quite a shock when you realise you have no voice. You may feel angry and upset at yourself or the people closest to you. Try not to worry as these feelings are normal. They will become less upsetting as you feel better and learn to use a different method of speaking.

As soon as your wounds show signs of healing, the speech and language therapist will show you how to mouth words without making any sound. People will understand you more easily if you use your hands and facial expressions while mouthing words. Once you begin to eat again, you can start to work on your new voice.

See page 37 for more information on learning to speak again.

**Getting up and about**

A physiotherapist will visit you daily to help with your breathing and leg exercises. He or she will also show you how to cough. For the first few days after surgery your lungs will make more mucus than usual.

Until you learn how to cough up the mucus yourself, a nurse will remove it with a suction machine.

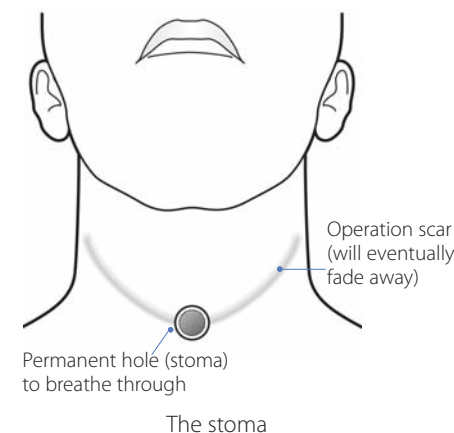
You will be shown how to do exercises to help loosen up any shoulder stiffness that can occur due to surgery. Even when you are in bed you will be encouraged to move your legs and do your deep breathing exercises at least once an hour. On the day after surgery, your nurses will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you feel stronger and more confident.

**Caring for your stoma**

After a few days the tracheostomy tube put into the stoma after surgery may be removed completely or changed to another type of tube. Every patient is different and your surgeon will decide if you have to wear a tube or not and for how long.

Keep the stoma clean and free from crusts, or the skin around the stoma may become sore. For a few days after surgery, your nurse will look after your stoma. He or she will also replace the tube as needed.

When you are feeling better, you will be shown how to do this on your own. You may feel anxious about how you will manage the stoma at first. Most people with a stoma learn how to look after it themselves, but help is always available if you need it. It might be helpful to have a relative or close friend with you when learning to look after the stoma.



»»» Do keep the stoma clean and free from crusts or the skin around the stoma may become sore.

On leaving hospital, your nurses will make sure you have all the equipment you will need. You will also get a prescription for further supplies from your pharmacy. If you have any problems at home, you can contact the speech and language therapist or cancer nurse specialist. It can also be arranged for your local public health nurse to visit you too.

## Recovery

The surgery for laryngeal cancer involves a big operation. You will need a lot of support from your doctors and nurses, family and friends. The recovery period can vary from patient to patient. Sometimes the wounds do not heal as quickly as you would like. This may cause a delay in getting back to normal eating and drinking. Remember it takes time to fully recover from this operation. Most people are ready to go home about 3 to 4 weeks after surgery, but some cases may take longer.



## To sum up

- The aim of surgery is to remove the part of the larynx with cancer cells in it.
- There are different types of surgery depending on where the tumour is located.
- Some surgical treatments include laser surgery, endoscopic resection, partial laryngectomy or total laryngectomy.
- If you have a total laryngectomy, you will no longer have a voice box. You will have to learn how to speak in a different way.
- With a total laryngectomy, you will have a permanent opening in your neck called a stoma through which you will breathe. Your nurses will show you how to care for it.

National Cancer Helpline 1800 200 700

## Learning to speak again

There are three ways to make a new voice after a laryngectomy. Your speech and language therapist will explain the options to you and guide you to the most suitable one. This will depend on the type of surgery you have had. It may also help to meet with someone who has had a laryngectomy. Your speech and language therapist can arrange this for you.

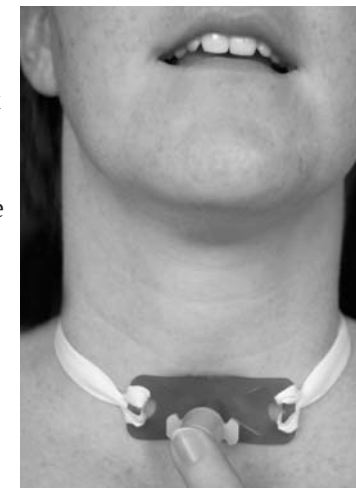
The voice options are:

- Tracheoesophageal speech
- Oesophageal speech
- Electrolarynx

## Tracheoesophageal speech

Tracheoesophageal speech can only be used if enough of your oesophagus has been left to provide a source of vibration. It is not suitable for everyone. Your speech and language therapist will give you more details.

**What's involved?:** An opening can be made between your windpipe (trachea) and your oesophagus (food pipe) so that air can move from your lungs to your mouth for speech. This small opening, called a fistula, can be made at the same time as your laryngectomy or at a later date. The fistula will allow air to pass into your oesophagus and up towards your mouth. Voice will be produced as the air passes through the top of your oesophagus, causing the muscle to vibrate.



Talking by covering the stoma with a finger

When the fistula has time to heal, your speech and language therapist will put in a one-way valve. This valve will prevent the backward flow of saliva and food from your oesophagus into your windpipe. It will also stop the fistula from closing over. Once the valve is put in, you can talk when the stoma is covered with a finger or thumb. This might take a little bit of practice at first.

**Protecting the valve:** The fistula is not a permanent opening. It will close over very quickly unless a valve is kept in place at all times. If the valve falls out, you should replace it with a clean valve or a thin rubber tube (catheter) straight away. This will all be explained and shown to you and you can practise it with your speech and language therapist before going home. Do contact your speech and language therapist or nurse if you are unsure when at home. If the fistula closes over, it will be 3 to 4 months before you can have an operation to make another one.

**Hands-free speech:** At a later stage, it may be possible to fit a device over the stoma to give you hands-free speech. This means you will not have to use a finger or thumb to close the stoma.

**Caring for the valve:** Before you go home, the speech and language therapist will teach you and your family how to care for the valve. Some valves last for 2 to 3 months once they are kept clean. In time, most people learn to change their own valve. There are long-term valves that last up to 6 months without changing. These valves are sometimes placed in the fistula at the time of surgery. But only a trained speech and language therapist can change long-term valves. There are also a number of valves to choose from. You will be advised about which one suits you best by your speech and language therapist and surgeon.

>>> Most people learn how to use their new voice within a few weeks.

**Time to learn:** The time it takes to produce your new voice varies from person to person. Most people learn how to use their new voice within a few weeks. Remember that your voice quality will sound different at first but your accent will remain the same.

It can help to have a positive attitude towards your new voice. Learning something new can often be a little strange and you may have good days and bad days. But it will be worth the effort. Do not be too hard on yourself and just go at your own pace. There is no set time in which you should learn to speak again. Practise a little every

day and you will soon learn to use the voice that best suits you. Your speech and language therapist is there to help and encourage you at all times.

As well as learning a new voice, you will need to allow yourself some time to get used to the sound of it and to make it your own. In time, you will learn to speak and feel at ease when speaking with family and friends.

## Oesophageal speech

This method of speech is not suitable if you have had most of your oesophagus removed. Oesophageal speech is made by pushing air from your mouth to your oesophagus (food pipe) with your tongue. The sound or voice comes from the top of your oesophagus when the air is released back to your mouth. This happens because the air vibrates as it passes through the muscles at the top of your oesophagus.

The voice will not sound the same as your old voice. It is usually deeper and not quite as clear. Remember it can take a lot of time to achieve a good level of speech. But it is easily understood and can sound very good with practice. Your surgeon or speech and language therapist will discuss this option with you.

## Electrolarynx

The electrolarynx is an artificial larynx. It is a hand-held device that looks like a microphone and about the same size. It has an on/off switch along with switches to control the pitch and volume. The device runs on batteries that are rechargeable and it comes with a recharger.

When turned on, it makes a vibrating sound like a voice. If the head of the electrolarynx is held against the skin of your neck when you mouth words, the sound is passed through your neck and up to your mouth in the same way as real voice. There is also the option of an oral adaptor, which is attached to the electrolarynx. This is a thin tube placed in your mouth which can vibrate in the same way.

The speech from an electrolarynx is clear but does not sound like your old voice. Indeed it may take some time to get used to it. Learning how to use the electrolarynx may take a while but your speech and language therapist is there to help you.

## Daily life after a laryngectomy

**Breathing:** After a laryngectomy, you can no longer breathe through your nose and mouth. You will breathe through the stoma in the front of your neck. The air breathed in through the stoma will go straight to your lungs and is not warmed or filtered by your nose or mouth. As a result, you will have to wear a stoma cover all the time. This will help to protect your lungs from infection, prevent you from breathing in dust and fumes and warm the air you breathe. It will also help to reduce the amount of mucus that comes out of the stoma.

There are many types of stoma cover available. Some options include:

<b>Foam bib</b>	This is a foam cover which ties around your neck.
<b>Base plate filter system</b>	This is a cover that sticks over your stoma. There is a foam filter in the middle that allows you to breathe. This may be used in valve speech with the outer valve that closes when you speak for hands-free speech.
<b>Buchanan bib</b>	This is a cotton bib with foam lining that can be worn around your neck. It is made to look like a false front of a vest or T-shirt. You can wear this under your clothes.

Your nurse and speech and language therapist will help you choose the stoma cover most suitable for you. You might need to wear a stoma stud as well. This is a simple device like a button to keep your stoma open.

**Coughing and sneezing:** When you cough and sneeze, it will sound different because the air comes straight from your stoma and not through your nose or mouth. This new cough may sound strange at

first but you and your family will soon get used to it. At first there may be more mucus than before your surgery. This is quite normal and usually becomes less of a problem as time goes on. You will soon learn to quickly cover your stoma when you feel the need to cough. Remember you will not be able to sniff or blow your nose, as there will be no air going to or from your nose and mouth. You will probably not feel the need to blow your nose, so do not worry about this.

**Swallowing:** When you start eating again, you may find that some foods are hard to swallow. Usually this improves once you have recovered from the surgery. But it may become a long-term problem if your food pipe has narrowed due to surgery or radiotherapy. If this happens, you will have to adapt to a new way of eating. Most people are able to manage by eating softer foods, such as thick soups or stews, or having a sauce or gravy with their meals. Eating smaller meals more often is also a good idea. Taking fluids with meals may help too. If you have a problem with swallowing, talk to your speech and language therapist, who can advise you.

**Body image:** It can take quite a while to come to terms with how you look after surgery. You may be worried about how people will react to you. It may even stop you from going out and meeting people. It is natural for people to be curious about the change in your appearance. But if they see that you have accepted the change, they will accept it too.

A well-groomed appearance can help. Fresh clean clothes and a good haircut or style can draw attention away from any physical changes. For women, make-up may help. There are many products available that will help disguise your stoma. For example, scarves, cravats, false jumper covers and necklaces. Talk to your speech and language therapist or someone who has had a laryngectomy. You can contact the National Cancer Helpline 1800 200 700 for more information.

**Bathing and showering:** Some people worry about bathing after a laryngectomy. There is no reason why you cannot bathe or shower but you must be careful that no water enters your stoma. Even the tiniest amount of water entering the stoma can cause a severe bout of

coughing. If you wish to take a shower, adjust the showerhead so that the water hits your body below the level of your stoma. There are also shower shields available. Your speech and language therapist will discuss this with you.

>>> You can bathe or shower but must be careful that no water enters the stoma.

**Swimming:** If you enjoy swimming, you can swim after a laryngectomy. But you will have to use a special swimming device called a larkel. This is a specially adapted snorkel. Before you resume swimming, you will have to do a special course on how to use a larkel safely. There is a training course available in the UK. For more details, contact the National Cancer Helpline on 1800 200 700.

**Taste and smell:** As you will no longer breathe or sniff through your nose, your sense of taste and smell may be reduced. Your sense of taste usually improves a little over time.

See page 59 for more about life after treatment.

## Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs travel through your bloodstream to almost every part of your body. Chemotherapy can be given with other treatments like surgery and radiotherapy.

### When is chemotherapy given?

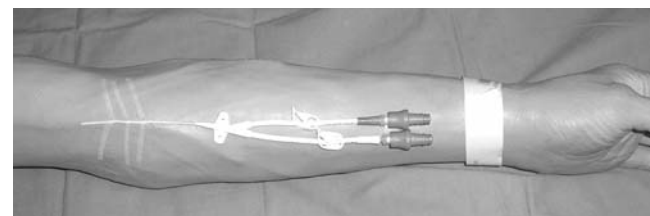
**Before surgery or radiotherapy:** Chemotherapy can help to shrink the cancer before surgery or radiotherapy.

**Chemoradiation:** You might have radiotherapy and chemotherapy at the same time. This is called chemoradiation. Your doctor may suggest that you have this type of treatment to try and cure your cancer instead of having your larynx removed. With this treatment there is a chance you can speak afterwards. Chemotherapy might also be given alongside radiotherapy to make the radiotherapy work better.

**Advanced cancer:** Chemotherapy is sometimes used to treat laryngeal cancer that is advanced or has returned after treatment with radiotherapy. In this case, it can relieve symptoms and may slow the growth of your cancer. If you have an advanced cancer that has not spread to another organ, but cannot be removed with surgery, you might have chemotherapy. This is to try to shrink the cancer so it can then be operated on.

### What drugs are used and how?

Chemotherapy is usually given into a vein as an injection or through an infusion or drip. Sometimes it is given as a tablet. Usually you receive the treatment as a day patient at the hospital. Your doctor will let you know how many courses you need. You will have a rest period between each course to allow your body to recover from the drugs.



Chemotherapy given into a vein

Chemotherapy drugs used for laryngeal cancer include:

- Cisplatin
- Fluorouracil (5-FU)
- Carboplatin
- Paclitaxel (Taxol®)

If you would like more information on any of these chemotherapy drugs, see the Irish Cancer Society website:

**[www.cancer.ie/cancerInfo/chemotherapydrugs\\_list.php](http://www.cancer.ie/cancerInfo/chemotherapydrugs_list.php)**

Some research studies called clinical trials are being done to find out if the drugs can improve the treatment results. Your doctor may ask you to take part in a trial. These studies are quite safe. See page 52 for more details.

>>> The side-effects of chemotherapy vary from person to person and depend on the drugs used.

## Side-effects of chemotherapy

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells. The side-effects can be short term or long term. In most cases the side-effects go away once the treatment ends or soon after. Your doctor or nurse can give you medication to stop most side-effects or make them easier to cope with.

The more common side-effects include:

- Infection
- Sore mouth
- Bruising
- Nausea and vomiting
- Loss of appetite
- Diarrhoea
- Hair loss
- Fatigue

**Infection:** Chemotherapy can make you more likely to get infections. This happens because the drugs can affect the bone marrow where white blood cells that fight infection are made. Regular blood tests will be done during treatment to check your blood count. If you feel shivery or unwell or have a high temperature of 38°C or higher, contact the hospital straight away. You may need a blood test and antibiotics.

>>> If you feel shivery or unwell or have a high temperature of 38°C or higher, contact the hospital straight away.

**Sore mouth:** Some drugs used to treat laryngeal cancer may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Keeping your teeth, gums and mouth very clean will reduce the risk of infection. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers or other medication to treat the infection if needed. There are also special mouthwashes, gels and toothpastes that can help.

**Bruising:** Chemotherapy can also affect the number of platelets in your blood. If you have fewer platelets (thrombocytopenia), you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily, as you might need a transfusion.

**Nausea and vomiting:** Not everyone feels sick (nausea) or gets sick with chemotherapy. It all depends on the drugs being given. But if you do, it can happen before, during or after treatment and may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick.

**Loss of appetite:** It is often hard to eat due to the cancer and side-effects of treatment. But do try to eat as well as you can to keep your strength up. It is best to eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite too. Your dietitian will also give you advice. A helpful booklet on what to eat is called *Diet and Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

**Diarrhoea:** The drugs may also affect the cells lining your bowel. If you get diarrhoea, drink lots of clear fluids to prevent dehydration. Do tell your doctor or nurse if you have diarrhoea for more than 24 hours. There is medication that can stop this side-effect of treatment. It might help to talk to a dietitian who can offer more advice too.

**Hair loss (alopecia):** The amount of hair loss depends on the drugs you are given. It can vary from person to person. You may notice that your hair just thins out a little bit. If you do lose your hair, it will happen quite quickly. You may get a tingling sensation for a day or two beforehand. Try not to worry as your hair will grow again when treatment stops. You might like to wear a wig or hairpiece when this happens or you may prefer a hat, turban or scarf. Contact the National Cancer Helpline 1800 200 700 for more advice or a copy of the factsheet on *Hair Loss and Cancer Treatment*.

**Feeling very tired (fatigue):** It is normal to feel tired during treatment. Sometimes it can be due to fewer red blood cells (anaemia) after chemotherapy. This tiredness can last for some weeks after treatment is over. If this happens, take things easier and rest more if you can.



Ask your family or friends to help you at work or at home. Do tell your doctor and nurse if fatigue is a problem for you. See page 47 for more about fatigue. You can also call the National Cancer Helpline 1800 200 700 for a free copy of the booklet *Coping with Fatigue*.

**Other side-effects:** If you have a side-effect or symptom from those listed above and it concerns you, tell your doctor or nurse straight away. They will give you suitable advice. For more information on chemotherapy, contact the National Cancer Helpline on 1800 200 700. Ask for a copy of the free booklet *Understanding Chemotherapy* or the DVD *A Guide to Chemotherapy*. For advice on what foods to eat if you have poor appetite, nausea, vomiting or diarrhoea, ask for a copy of the booklet *Diet and Cancer*.



### To sum up

- Chemotherapy is a treatment using drugs to control laryngeal cancer.
- It can be given directly into a vein as an injection or through an infusion (drip).
- The side-effects vary from person to person and depend on the drugs used.
- Most side-effects are well controlled with medication.

## Biological therapy

Biological therapies use your body's own immune system to prevent cancer cells growing. Your immune system includes your lymph nodes, tonsils, spleen, bone marrow and white blood cells. These all help to protect you from infection and disease.

Biological therapy changes the activity of substances made naturally in your body. They target the cancer cells directly and so are often called targeted therapies. They block the growth of cancer cells by interfering with molecules needed for the cancer to grow.

The most common biological therapy used for laryngeal cancer is cetuximab (Erbix<sup>®</sup>). Cetuximab is a type of drug known as a

monoclonal antibody. Monoclonal antibodies lock onto specific proteins on cancer cells and trigger the immune system to attack and kill the cancer cells.

Cetuximab is often given with radiotherapy if your chemotherapy treatment is not working or cannot be used for whatever reason. You receive the drug in a drip that goes into a vein. Other biological therapies are also being used in clinical trials for laryngeal cancer. See page 52 for more about clinical trials.

### Side-effects of biological therapy

The side-effects will depend on which biological therapy you receive. Some side-effects include fatigue, diarrhoea, skin reactions, flu-like symptoms or sore eyes. Your doctor and nurse will discuss any possible side-effects before you start treatment. Do ask them for further advice if any occur.



### To sum up

- Biological therapies use your body's immune system to prevent cancer cells growing.
- There are different types of biological therapies. For example, monoclonal antibodies.
- A drug commonly used is cetuximab (Erbix<sup>®</sup>).
- Some side-effects include fatigue, diarrhoea, skin reactions, sore eyes and flu-like symptoms.

## How can I cope with fatigue?

Fatigue is a common symptom of cancer and described as an overwhelming tiredness. Often it is not relieved by rest. You may also find it hard to concentrate or make decisions. The reason for your fatigue can sometimes be hard to identify. It may be caused by anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are things you can do to help.

For many patients, treatment may help by relieving symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, get some regularly. For example, a 30-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



### Tips & Hints – fatigue

- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Save your energy for doing the things you most enjoy.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.



- Use relaxation techniques to get to sleep. For example, gentle exercise, relaxation tapes, etc.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

## Will treatment affect my sex life and fertility?

### Sex and sexuality

Coming to terms with the fact that you have cancer can take quite a while. Your emotions will be turned upside down. It can be hard to relax too when you have a lot of worries on your mind. You may also be feeling tired from the effects of tests and treatment. As a result, you may lose the desire for sex. This is quite normal when you are concerned about recovering from cancer.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

### Effects of treatment

**Surgery:** Depending on the type of surgery you have, it may be some time before you can resume an active sex life. If you have had your larynx removed, this may change the way you feel about your body. You may also have concerns about the way your partner will react. Try to talk to your partner about the way you are feeling. Your fears may be unfounded and talking will help ease your anxiety.

You will not be able to hold your breath during sexual climax after a laryngectomy. This may take away some of the pleasure of sex for you. But it is possible to still enjoy sex by using different positions.

You may also have a small problem with noisy breathing from your stoma. This breathing will be less noticeable if you wear a stoma cover. If you need more help, do talk to your doctor, nurse or speech and language therapist.

**Chemotherapy:** If you are receiving chemotherapy and you or your partner are fertile, it is best to use a reliable method of contraception during treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in children conceived during or just after treatment. Many doctors believe it is better for you or your partner not to get pregnant for 2 years after your chemotherapy ends. This time gives your body a chance to get over the effects of the cancer and its treatment.

#### Asking for advice

If you have any queries about how treatment may affect your sex life, do ask your doctor. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor is well used to these matters and will give you advice.

#### Infertility

Your fertility may be affected by some of the treatments. For example, chemotherapy. Sadly, you may not be able to have a child in the future. If this is the case, do talk to your partner about your feelings. Also, discuss your worries about infertility with your doctor. He or she can tell you if there are any options open to you at this time. It may be possible to freeze your eggs or sperm before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital, Dublin provides a service where eggs or sperm can be frozen for later use. Talk to your doctor about this service or call the National Cancer Helpline 1800 200 700 for more information.

Dealing with infertility may not be easy, depending on your age and if you have had children or not. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener.

## What follow-up do I need?

No matter what type of cancer treatment you get, you will still need to come back for regular check-ups once it is over. This is called follow-up. At first these visits to your specialist will be quite often, sometimes every 3 to 6 months, especially for the first 2 years. The visits are likely to continue for up to 5 years. The follow-up may involve having a physical exam, blood tests, chest X-rays and ultrasound and chest CT scans.

The visit also gives you a chance to talk about any side-effects of treatment or symptoms you might have. If you are feeling a bit low or depressed, do mention this to your doctor at these visits. If you are between check-ups and have a symptom or problem that is worrying you, let your doctor know. Make an appointment to see him or her as soon as possible.



### Should I quit smoking?

If you have a total laryngectomy you will not be able to smoke after surgery. This is because there will be no connection between your mouth and your lungs.

It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example, it can reduce how well chemotherapy or radiotherapy works. It can also make their side-effects worse. Sometimes it may cause rarer side-effects such as breathing and heart problems. This is because radiotherapy can make body organs like the lungs more sensitive to tobacco smoke.

### How can I quit?

Like many others, you may find giving up smoking hard. But with the right information and support you can do it. If you would like advice or support on quitting, call the National Smokers' Quitline on CallSave 1850 201 203. It is open Monday to Saturday from 8am to 10pm.

If you would like further personal support locally, the helpline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see [www.giveupsmoking.ie](http://www.giveupsmoking.ie)

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



## Research – what is a clinical trial?



Research into new ways of treating laryngeal cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

### Phases of research

There are many stages or phases when research is being done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

### Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called informed consent. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For more information, call the National Cancer Helpline 1800 200 700 or visit our website: [www.cancer.ie](http://www.cancer.ie)

## Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Many people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

### Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

### Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

## Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy can often be restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.

Most doctors do not believe that such treatments can cure or control cancer.



### If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, do talk to your doctor or nurse.

Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies. A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline 1800 200 700.

## Coping and emotions

### How can I cope with my feelings?

There are many reactions when told you have laryngeal cancer. Reactions can often differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

#### Common reactions include:

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



Sometimes a diagnosis of laryngeal cancer can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

#### Shock and disbelief

*'It can't be me.' 'Has there been a mistake?' 'Cancer happens to other people, not me.'*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

## Fear and uncertainty

*'I'm going to die.'  
'Will it be painful?'  
'Will I become a  
different person?'*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers can be cured or controlled with modern treatments.

Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, nurse or medical social worker, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

## Loss of control

*'I can't cope with  
this.' 'I'll never get  
through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

## Sorrow and sadness

*'I used to be so  
healthy.' 'I had so  
many plans.' 'I've let  
my family down.'*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

## Denial

*'I'm fine, really.'  
'I don't have cancer.'*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

## Anger

*'Why me? I always  
took care of my  
health.' 'Why did  
this happen now?'*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for allowing

cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

### Resentment

*'How can you talk – you don't have to deal with cancer.'*  
*'How come I'm not getting better?'*

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker

than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

>>> Don't bottle up your feelings – express them.

### Blame and guilt

*'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'*

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed

going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

### Withdrawal and isolation

*'I just need to be on my own.'*

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may

want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline 1800 200 700.

### Life after treatment

Remember it can take at least a year for life to get back to normal. You can still feel tired and lacking in energy for many months after treatment has ended. You may not be ready to lead as active a life as you did before and it is better not to fight these feelings. Instead, allow your body the time it needs to recover. There are many things you can do to speed up your recovery and have a good quality of life in the future.

**Social life:** After treatment for laryngeal cancer, you may find it difficult to go out and meet people. But you may feel depressed and lonely if you stay in the house all the time. When you feel strong enough, set yourself small goals for getting out and about. For example, start by going to the local shop with a relative or friend. After you have done this a few times, go to the shop on your own. Gradually your confidence will return and you can go out and enjoy yourself.

**Back to work:** You might be able to go back to work once you have recovered from surgery or when your treatment is over. After a laryngectomy, whether you go back to work or not depends on the kind of work you did in the past. You will not be able to lift heavy weights and a dusty atmosphere may cause problems with your stoma. Talk to your employer about your concerns. It may be possible to change to a position more suitable for you.

**Understanding what you say:** Another concern you may have is whether people will be able to understand you or not. Nowadays there are speech amplifiers available that can help. These can be used in one-to-one conversations if you are speaking to a number of people at once or if talking on the telephone. An electrolarynx is often very useful too. They give your voice more volume and are clear on the telephone. They also save your voice if you are feeling tired or unwell. Talk to your speech and language therapist about the different aids that are available to help you. He or she will advise you on the one best suited to your needs.

## How can my family and friends help?

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



## How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing.

So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with your own feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

### Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy.

## How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.



Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting them down. These are all natural feelings to have at this time.

### Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

### Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a free copy, call the National Cancer Helpline on 1800 200 700.

## Caring for someone with laryngeal cancer

Looking after someone who has had treatment for laryngeal cancer may not be easy. How well they are when discharged from hospital depends on the type of treatment they have had.

If your relative or friend has had a total laryngectomy, it may take several months before they have fully recovered from surgery and can speak again. They may not be able to eat the foods they used to eat. Radiotherapy on its own or after surgery can be very tiring and have side-effects. As radiotherapy is normally given as an outpatient, most of the care after treatment will be given in your home.

### What you can do:

- **Seek information:** Find out as much as you can about the illness and its treatment. If there is something you do not understand, ask again. Write your questions down if you wish. Ask the nurses if you can come along while they are cleaning the stoma if your relative or friend has had a laryngectomy. The nurse will explain the routine to you and how best to look after the stoma. This will help you to get used to the look of the stoma and become familiar with how to keep it clean.
- **Planning:** Plan as much as you can ahead of the discharge date. Ask to speak to a social worker about the community services that are available. Use whatever help there is. If equipment is needed, make sure you have some supplies at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

- **Accept help:** You may feel tired with all the worry and extra work. It can be very straining as you try to adapt to a new way of life. When people offer you help with transport to the hospital, shopping, housework or gardening, accept it.
- **Time for yourself:** Try to set aside some time for yourself each week and do something you really enjoy.
- **Encourage your relative or friend:** At first your relative or friend may feel very tired. But as soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life. Do remember that most people go on to make a full recovery from laryngeal cancer and live full and enjoyable lives.

Call the National Cancer Helpline on 1800 200 700 if you would like more information and advice.

## Support resources

### Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Cancer support groups and centres
- Irish Cancer Society helpline nurses



**Medical social worker:** The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on benefits, entitlements and services available when you go home.

**Cancer nurse specialists:** Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These nurses along with other members of your medical team work together to meet your needs.

**Psycho-oncology services:** In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

**Family doctor (GP):** You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

**Community health services:** When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the social worker in the hospital before you go home or at your local health centre.

**Cancer support groups and centres:** Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with laryngeal cancer. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet.

**Irish Cancer Society:** The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information or practical advice about your financial matters. For example, getting a mortgage or travel insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

>>> Remember there are many people ready to help you.

## Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

## Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

## Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

## Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You may have to pay a prescription charge of 50c per item up to a limit of €10 per family.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

## GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your

after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

## Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €120 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

## Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance, e.g. MRI scan, PET scan. Sometimes it might take 24–48 hours to get approval from your health insurer.

## Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



For a free copy of *Social Welfare Support: A Guide for Cancer Patients*, contact the National Cancer Helpline 1800 200 700.

## Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

## Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

## Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits,

like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

### **Carer's Allowance**

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

### **Carer's Benefit**

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

### **Carer's Leave**

By law you may be entitled to unpaid temporary leave from your

employment. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

### **Appliances**

For patients who have medical cards most appliances are free of charge. For example, if you receive chemotherapy and suffer from hair loss, you are entitled to 1–2 free or subsidised wigs or hairpieces every year.

### **Travel to hospital**

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

See page 77 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society.

## Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you.

Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

### For social welfare queries, contact:

Dept of Social Protection – Information Service	Tel: 1850 662 244
Oisín House	Leaflet line: 1890 202 325
212–213 Pearse Street	Email: <a href="mailto:info@welfare.ie">info@welfare.ie</a>
Dublin 2	Website: <a href="http://www.welfare.ie">www.welfare.ie</a>

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

**HSE infoline:** 1850 241 850 **Email:** [info@hse.ie](mailto:info@hse.ie) **Website:** [www.hse.ie](http://www.hse.ie)

**[HSE East Coast Area**  
[Co Wicklow, South East Dublin]  
Southern Cross House  
Southern Cross Business Park  
Boghall Road  
Bray  
Co Wicklow  
Tel: 01 201 4200

**HSE Northern Area**  
[North Dublin]  
Swords Business Campus  
Balheary Road  
Swords  
Co Dublin  
Tel: 01 813 1800

**HSE South Western Area**  
[Co Kildare, West Wicklow, South Dublin]  
Oak House  
Millennium Park  
Naas  
Co Kildare  
Tel: 045 880 400

**HSE Midland Area**  
[Counties Laois, Offaly, Longford,  
Westmeath]  
Head Office  
Arden Road  
Tullamore  
Co Offaly  
Tel: 057 932 1868

**HSE Mid-Western Area**  
[Counties Clare, Limerick, Tipperary North]  
Head Office  
31/33 Catherine Street  
Limerick  
Tel: 061 483 286

**HSE North Eastern Area**  
[Counties Cavan, Monaghan, Louth and  
Meath]  
Head Office  
Navan Road  
Kells  
Co Meath  
Tel: 046 928 0500

**HSE North Western Area**  
[Counties Donegal, Sligo, Leitrim and  
West Cavan]  
Head Office  
Manorhamilton  
Co Leitrim  
Tel: 071 982 0400 / 1850 636 313

**HSE South Eastern Area**  
[Counties Carlow, Kilkenny, Wexford,  
Waterford, South Tipperary]  
Head Office  
Lacken  
Dublin Road  
Kilkenny  
Tel: 056 778 4100

**HSE Southern Area**  
[Counties Cork and Kerry]  
Head Office  
Wilton Road  
Cork  
Tel: 021 454 5011

**HSE Western Area**  
[Counties Galway, Mayo and  
Roscommon]  
Head Office  
Merlin Park Regional Hospital  
Galway  
Tel: 091 751 131

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

### Citizens Information Board (formerly Comhairle)

Ground Floor, George's Quay House, 43 Townsend Street, Dublin 2

Tel: 01 605 9000; Locall 1800 777 121

Email: [info@ciboard.ie](mailto:info@ciboard.ie); Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social Protection). Copies are available from the Dept of Social Protection. Tel: 01 874 8444. Email: [info@welfare.ie](mailto:info@welfare.ie). Website: [www.welfare.ie](http://www.welfare.ie)
- *Entitlements for People with Disabilities* (published by Comhairle). Copies are available from the Citizens Information Board. Tel: 01 605 9000 / 1890 777 121. Email: [info@ciboard.ie](mailto:info@ciboard.ie) Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)



## If you have financial worries...

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.



There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 77 for more details. You can also call the National Cancer Helpline 1800 200 700 for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 78 for contact details.

## Irish Cancer Society services

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Daffodil Centres providing cancer information
- Cancer support groups
- Peer-to-peer support
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets
- Financial support
- Care to Drive transport project



## Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a message board on our website (**www.irishcancer.ie**) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

## Daffodil Centres providing cancer information

Daffodil Centres are located in a number of Irish hospitals. They were set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give enquirers a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

## Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 78 for more details.

## Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. The Irish Cancer Society can put you in touch with someone who has been trained to give you emotional and practical support. All volunteers have had a personal experience of cancer and understand the emotional and physical impacts of the disease. If you would like to make contact with a volunteer, please call the National Cancer Helpline 1800 200 700.

## Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) if you are seriously ill at home. The night nurse can also give support to your family. You can find out more about this service from a member of the homecare team, your GP or local public health nurse. Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms.

## Oncology liaison nurses

The Society funds oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

## Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Society.

## Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.

The Travel2Care scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

**Travel2Care:** If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society.

**Financial Aid:** For this kind of help, contact the social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society.

See our website for more information: [www.cancer.ie](http://www.cancer.ie)

## Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected and trained. You, the patient, are collected from your home, driven to your appointment and brought back home again.

If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.





## Useful organisations

### Irish Cancer Society

43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
National Cancer Helpline: 1800 200 700  
Email: [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### Cancer Research Ireland

Website: [www.cancer.ie/research/why.php](http://www.cancer.ie/research/why.php)

### The Carers Association

Market Square  
Tullamore  
Co Offaly  
Tel: 057 932 2933  
Email: [info@carersireland.com](mailto:info@carersireland.com)  
Website: [www.carersireland.com](http://www.carersireland.com)

### Citizens Information Board

Ground Floor  
George's Quay House  
43 Townsend Street  
Dublin 2  
Citizen Information Service:  
1890 777 121  
Tel: 01 605 9000  
Email: [info@ciboard.ie](mailto:info@ciboard.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

### Dept of Social Protection – Information Service

Oisín House  
212–213 Pearse Street  
Dublin 2  
Tel: 1850 662 244  
Email: [info@welfare.ie](mailto:info@welfare.ie)  
Website: [www.welfare.ie](http://www.welfare.ie)

### HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital  
Parnell Square  
Dublin 1  
Tel: 01 807 2732  
Website: [www.rotunda.ie](http://www.rotunda.ie)

### Health Promotion HSE

Website: [www.healthpromotion.ie](http://www.healthpromotion.ie)

### Irish Clinical Oncology Research Group

Website: [www.icorg.ie](http://www.icorg.ie)

### Irish Nutrition & Dietetic Institute

Ashgrove House  
Kill Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 280 4839  
Email: [info@indi.ie](mailto:info@indi.ie)  
Website: [www.indi.ie](http://www.indi.ie)

### Money Advice and Budgeting Service (MABS)

Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 01 812 9350  
Freefone 1890 283 438  
Email: [helpline@mabs.ie](mailto:helpline@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

## Health insurers

### AVIVA Health

(formerly VIVAS Health)  
PO Box 764  
Togher  
Cork  
Tel: 1850 717 717  
Email: [info@avivahealth.ie](mailto:info@avivahealth.ie)  
Website: [www.vivahealth.ie](http://www.vivahealth.ie)

### Quinn Healthcare (formerly BUPA)

Mill Island  
Fermoy  
Co Cork  
Locall: 1890 700 890  
Email: [info@quinn-healthcare.com](mailto:info@quinn-healthcare.com)  
Website: [www.quinn-healthcare.com](http://www.quinn-healthcare.com)

### Voluntary Health Insurance (VHI)

IDA Business Park  
Purcellsinch  
Dublin Road  
Kilkenny  
CallSave 1850 44 44 44  
Email: [info@vhi.ie](mailto:info@vhi.ie)  
Website: [www.vhi.ie](http://www.vhi.ie)

## National support groups

### ARC Cancer Support Centres

Dublin and Cork (see page 80 and 81).

### CanTeen Ireland

Young Peoples' Cancer Support Group  
Carmichael Centre  
North Brunswick Street  
Dublin 7  
Tel: 01 872 2012  
Freefone: 1800 200 700  
Email: [canteen@oceanfree.net](mailto:canteen@oceanfree.net)  
Website: [www.canteen.net](http://www.canteen.net)

### I've Got What?!

[Support for young adults affected by cancer]  
c/o Cross Cause Charity Shop  
Blackrock  
Co Louth  
Tel: 086 339 5690

## Connaught support groups & centres

### Athenry Cancer Care

Social Service Centre  
New Line  
Athenry  
Co Galway  
Tel: 091 844 319 / 087 412 8080

### Ballinasloe Cancer Support Centre

Society Street  
Ballinasloe  
Co Galway  
Tel: 090 964 5574 / 087 945 2300  
Email: [ballinasloecancer@yahoo.co.uk](mailto:ballinasloecancer@yahoo.co.uk)

### Cara Iorrais Cancer Support Centre

2 Church Street  
Belmullet  
Co Mayo  
Tel: 097 20590  
Email: [caraiorrais@gmail.com](mailto:caraiorrais@gmail.com)

### CD's Helping Hands

Lakeview Point  
Corporate Park  
Claregalway  
Co Galway  
Tel: 091 799 749  
Email: [info@cdshelpinghands.ie](mailto:info@cdshelpinghands.ie)  
Website: [www.cdshelpinghands.ie](http://www.cdshelpinghands.ie)

### Gort Cancer Support Group

The Hawthorn  
Ennis Road  
Gort  
Co Galway  
Tel: 086 312 4220

### Inis Aoibhinn – Cancer Care West

Costello Road  
University College Hospitals Galway  
Tel: 091 545 000  
Email: [info@cancercarewest.ie](mailto:info@cancercarewest.ie)  
Website: [www.cancercarewest.ie](http://www.cancercarewest.ie)

### Mayo Cancer Support Association

Rock Rose House  
32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407  
Email: [mayocancersupport@eircom.net](mailto:mayocancersupport@eircom.net)  
Website: [www.mayocancer.ie](http://www.mayocancer.ie)

### Roscommon Cancer Support Group

Vita House Family Centre  
Abbey Street  
Roscommon  
Tel: 090 662 5898  
Email: [vitahouse@eircom.net](mailto:vitahouse@eircom.net)

### Sligo Cancer Support Centre

44 Wine Street  
Sligo  
Tel: 071 917 0399  
Email: [scsc@eircom.net](mailto:scsc@eircom.net)  
Website: [www.sligocancersupportcentre.ie](http://www.sligocancersupportcentre.ie)

**Tuam Cancer Care Centre**

Cricket Court  
Dunmore Road  
Tuam  
Co Galway  
Tel: 093 28522  
Email: support@tuamcancercare.ie  
Website: www.tuamcancercare.ie

**Leinster support groups & centres****ARC Cancer Support Centre**

ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**ARC Cancer Support Centre**

ARC House  
559 South Circular Road  
Dublin 8  
Tel: 01 707 8880  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**Arklow Cancer Support Group**

25 Kingshill  
Arklow  
Co Wicklow  
Tel: 085 110 0066  
Email: arklowcancersupport@gmail.com

**Balbriggan Cancer Support Group**

74 Castleland  
Parkview  
Balbriggan  
Co Dublin  
Tel: 086 164 2234

**Bray Cancer Support & Information Centre**

36B Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Email: bcsc@iol.ie  
Website:  
www.braycancersupport.ie

**Cuisle Centre**

Cancer Support Group  
Block Road  
Portlaoise  
Co Laois  
Tel: 057 868 1492  
Email: cuislecentre@eircom.net  
Website: www.cuisle.com

**Dóchas – Offaly Cancer Support**

Teach Dóchas  
Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: dochasoffaly@eircom.net  
Website: www.dochasoffaly.ie

**Dundalk Cancer Support Group**

Philipstown  
Hackballs Cross  
Dundalk  
Co Louth  
Tel: 086 107 4257

**Éist – Carlow Cancer Support Group**

5 Mount Clare Court  
Carlow  
Tel: 085 144 0510

**Gary Kelly Support Centre**

George's Street  
Drogheda  
Co Louth  
Tel: 041 980 5100 086 195 9864  
Email: services@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support**

La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email: info@greystonescancersupport  
Website:  
www.greystonescancersupport.com

**HOPE**

Enniscorthy Cancer Support & Information Centre  
22 Upper Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: mary@hopesupportcentre.ie

**Lakelands Area Retreat & Cancer Centre**

Ballinalack  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Little Way Cancer Support Centre**

4 Woods Way  
College Road  
Clane  
Co Kildare  
Tel: 045 902 996  
Email: littlewayclane@eircom.net  
Website: www.littlewaycancersupport.com

**Little Way Cancer Support Centre**

8 Stanhope Street  
Athy  
Co Kildare  
Tel: 059 863 3725

**Manorhamilton Cancer Support Group**

(Leitrim)  
Tel: Maura Farry 071 985 6220

**Rathdrum Cancer Support Centre**

34 Main Street  
Rathdrum  
Co Wicklow  
Tel: 087 292 8660  
Email: rathcan@gmail.com

**Stillorgan Cancer Support**

c/o Marsham Court  
Stillorgan  
Co Dublin  
Tel: 01 288 5725

**Tallaght Cancer Support Group**

Millbrook Lawns  
Tallaght  
Dublin 24  
Tel: 087 217 6486

**Wicklow Cancer Support Centre**

1 Morton's Lane  
Wicklow  
Tel: 087 691 4657 / 0404 32696

**Munster support groups & centres****Cancer Information & Support Centre**

Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 485 163  
Website: www.midwesterncancercentre.ie

**CARE – Cancer Support Centre**

14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 618 2667  
Email: cancersupport@eircom.net  
Website: www.cancercare.ie

**Cork ARC Cancer Support House**

Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: karen@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**Kerry Cancer Support Group**

Acorn Centre  
47 Liosdara  
Oakpark  
Tralee  
Co Kerry  
Tel: 066 719 5560 / 087 230 8734  
Email: kerrycancersupport@live.ie  
Website: www.kerrycancersupport.com

**Listowel Cancer Support Group**

Bedford  
Listowel  
Co Kerry  
Tel: 068 21741 / 087 237 0766

**Recovery Haven**

5 Haig's Terrace  
 Tralee  
 Co Kerry  
 Tel: 066 719 2122  
 Email: recoveryhaven@gmail.com  
 Website: www.recoveryhaven.com

**Sláinte an Chláir: Clare Cancer Support**

Tír Mhuire  
 Kilnamona  
 Ennis  
 Co Clare  
 Tel: 1850 211 630 / 087 691 2396  
 Email: admin@clarecancersupport.com  
 Website: www.clarecancersupport.com

**South East Cancer Foundation**

7 Sealy Close  
 Earlsclourt  
 Waterford  
 Tel: 051 876 629  
 Email: infosecf@eircom.net  
 Website: www.secf.ie

**Suimhneas Cancer Support Centre**

2 Clonaslee  
 Gortland Roe  
 Nenagh  
 Co Tipperary  
 Tel: 067 37403  
 Email: suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**

Clongour Road  
 Thurles  
 Co Tipperary  
 Tel: 0504 21197  
 Email: suirhaven@gmail.com

**Youghal Cancer Support Group**

161 North Main Street  
 Youghal  
 Co Cork  
 Tel: 024 92353

**West Cork Cancer Support**

Community Work Department  
 HSE Skibbereen  
 Co Cork  
 Tel: 027 53485 / 086 862 5417

**Ulster support groups & centres****Cootehill Community Centre Support Group**

Cootehill  
 Co Cavan  
 Tel: 087 622 0000

**Éist – East Inishowen Cancer Support Group**

c/o Serenity House  
 2 Montgomery Terrace  
 Moville  
 Co Donegal  
 Tel: 074 938 2874

**Gary Kelly Support Centre**

Monaghan  
 Tel: 086 195 9864 / 041 980 5100

**Living Beyond Cancer**

Oncology Day Services  
 Letterkenny General Hospital  
 Letterkenny  
 Co Donegal  
 Tel: 074 912 5888 (Bleep 674)

**Solace – Donegal Cancer Support Centre**

St Joseph's Avenue  
 Donegal Town  
 Tel: 074 974 0837  
 Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

**Useful contacts outside Republic of Ireland****Action Cancer**

Action Cancer House  
 1 Marlborough Park  
 Belfast BT9 6XS  
 Tel: 028 9080 3344  
 Email: info@actioncancer.org  
 Website: www.actioncancer.org

**Aetna IntelliHealth**

[Drug and medicines information]  
 Website: www.intelihealth.com

**American Cancer Society**

Website: www.cancer.org

**Cancer Network Buddies**

Website: www.cancerbuddiesnetwork.org

**Cancer Research UK**

Tel: 0044 20 7242 0200  
 Website: www.cancerresearchuk.org  
 Website: www.cancerhelp.org.uk

**Healthtalkonline**

Website: www.healthtalkonline.org

**Macmillan Cancer Support (UK)**

89 Albert Embankment  
 London SE1 7UQ  
 Tel: 0044 207 840 7840  
 Email: cancerline@macmillan.org.uk  
 Website: www.macmillan.org.uk  
 Website: www.cancerbackup.org.uk

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
 77–81 Lisburn Road  
 Belfast BT9 7AB  
 Tel: 028 9069 9202  
 Email: cancerinfo@belfaststrust.hscni.net  
 Website: www.cancerni.net

**National Association of Laryngectomee Clubs (UK)**

Lower Ground Floor  
 152 Buckingham Palace Road  
 London SW1W 9TR  
 Tel: 0044 020 7730 8585  
 Website: www.laryngectomy.org.uk

**National Cancer Institute (US)**

Website: www.nci.nih.gov

**Royal Marsden Hospital Foundation NHS Trust**

Website: www.royalmarsden.org

**Ulster Cancer Foundation**

40/42 Eglantine Avenue  
 Belfast BT9 6DX  
 Tel: 048 906 63281  
 Website: www.ulstercancer.co.uk



## Helpful books

### Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
- *Social Welfare Support: A Guide for Cancer Patients*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



### C: Because Cowards Get Cancer Too...

John Diamond  
Vermilion, 1999  
ISBN 978-0091816650

### Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir  
Class Publishing, 2002  
ISBN 1-85959-068-3

### The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment

Judith McKay, Nancee Hirano & Myles E Lampenfeld  
New Harbinger, 1998  
ISBN 1-57224-070-9

### Looking Forward: The Speech and Swallowing Guidebook for People with Cancer of the Larynx or Tongue

Jack E Thomas & Robert L Keith  
Thieme Publishing Group, 2004  
ISBN 978-1588902948

### Explaining cancer to children

#### The Secret C: Straight Talking About Cancer

Julie A Stokes  
Winston's Wish, 2000  
ISBN 0-95391-230-2

#### Why Mum? A Small Child with a Big Problem

Catherine Thornton  
Veritas, 2005  
ISBN 1-85390-891-6

### Helpful DVDs

#### Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.  
Website: [www.cancer.ie](http://www.cancer.ie)

#### A Guide to Chemotherapy

HSE/Mid-Western Cancer Centre/ICS, 2008  
Call 1800 200 700 for a copy.

## Questions to ask your doctor

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

- How long will it take to get the test results?
- What stage is my cancer at?
- What type of treatment will I need?
- Will the treatment cure my cancer?
- Will I be able to speak after treatment?
- Are there other treatment options? Why is this one best for me?
- 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 get?
- Is there anything I can do to help myself during treatment?
- Will treatment affect my fertility?
- How often will I need check-ups?
- Will I need more tests after treatment?
- What if the cancer comes back?

## Your own questions

1 \_\_\_\_\_

Answer \_\_\_\_\_

2 \_\_\_\_\_

Answer \_\_\_\_\_

3 \_\_\_\_\_

Answer \_\_\_\_\_

4 \_\_\_\_\_

Answer \_\_\_\_\_

5 \_\_\_\_\_

Answer \_\_\_\_\_

6 \_\_\_\_\_

Answer \_\_\_\_\_

7 \_\_\_\_\_

Answer \_\_\_\_\_



## Notes



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Anne Murphy, Clinical Nurse Specialist

Martina Nash, Medical Social Worker

## Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline 1800 200 700.

### Would you like to be a patient reviewer?

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

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

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

## Would you like to help us?

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

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

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

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.

