

Understanding

# Cancer of the Larynx

Caring for people with cancer

## Understanding

# Cancer of the Larynx

This booklet has been written to help you to 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 treatment and how it may affect you.

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.



|                               | Name | Telephone |
|-------------------------------|------|-----------|
| Head and neck surgeon         |      |           |
| Radiation oncologist          |      |           |
| Radiation therapist           |      |           |
| Medical oncologist            |      |           |
| Specialist nurse              |      |           |
| Speech and language therapist |      |           |
| Dietitian                     |      |           |
| Family doctor (GP)            |      |           |
| Emergency                     |      |           |



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- *Cancer in Ireland: A Summary, 1994–2007*, National Cancer Registry Ireland, 2009.
- *Squamous Cell Carcinoma of the Head and Neck: EHNS–ESMO–ESTRO Clinical Practice Guidelines for Diagnosis, Treatment and Follow-up. Annals of Oncology* 21 (Suppl 5): v184–v186, 2010.
- *Radiotherapy Versus Open Surgery Versus Endolaryngeal Surgery (with or without laser) for Early Laryngeal Squamous Cell Cancer*. P Dey et al. Cochrane Database of Systematic Reviews 2002, Issue 2.
- *Hyperfractionated or Accelerated Radiotherapy for Head and Neck Cancer*. B Baujat et al. Cochrane Database of Systematic Reviews, 2010.
- *Outcomes of Open Conservation Laryngectomy for Radiorecurrent Laryngeal Carcinoma: A Systematic Review and Meta-analysis of English-Language Literature*. V Paleri et al. Cancer. Feb 1, 2011.
- *Cetuximab for the Treatment of Head and Neck Cancer. National Institute for Clinical Excellence*, June 2008.
- *DeVita, Hellman and Rosenberg's Cancer: Principles & Practice of Oncology*. 8th edn, Lippincott Williams & Wilkins, 2008.
- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 1997. First published by the Irish Cancer Society in 2002.

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## Introduction

This booklet has been written to help you to understand more about cancer of the larynx (laryngeal cancer). The booklet is divided into 4 parts:

- **About laryngeal cancer** gives an introduction to cancer of the larynx.
- **Treatment and side-effects** looks at the different treatments used and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having laryngeal cancer.
- **Support resources** gives information on where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

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



### 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 want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email us at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). You can also visit a Daffodil Centre. See page 61 for more about Daffodil Centres.



Cancer Nurseline Freephone 1800 200 700

## About cancer of the larynx

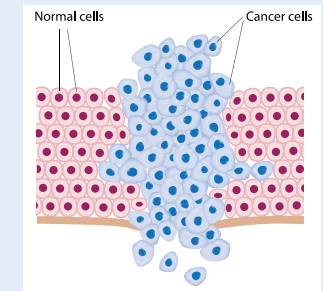


### What is cancer?

Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer starts in cells in the prostate gland, breast cancer starts in cells in the breast.

All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

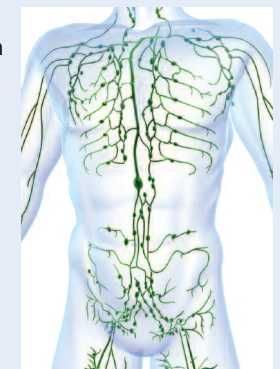
Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. These cells can then grow into a new tumour. This is called a metastasis or secondary tumour.



Cancer cells

### What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system

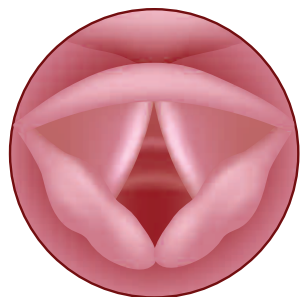


## To sum up

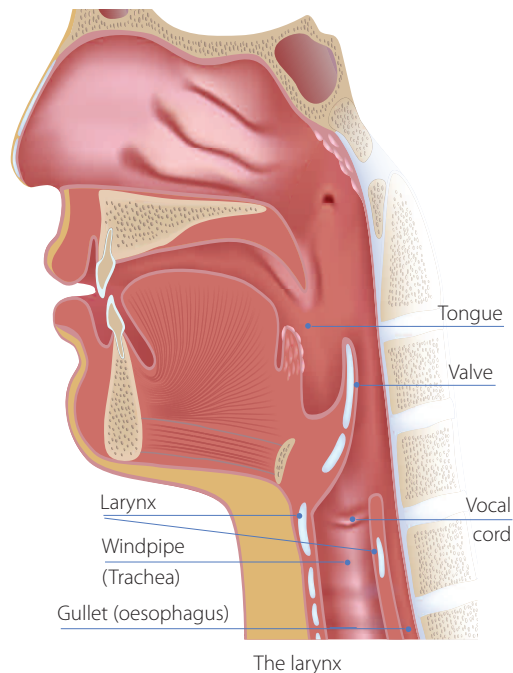
- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by your bloodstream or lymph vessels and form a tumour somewhere else. This is called a metastasis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



The vocal cords



The larynx

## 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.

## 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 our Cancer Nurseline on 1800 200 700.

## How common is laryngeal cancer?

Laryngeal cancer is a rare cancer. In Ireland, about 160 people are diagnosed with it each year. It is more common in men than women and becomes more common as you get older.

## What increases my risk of 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. Having a risk factor doesn't mean you will definitely get cancer. And sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of laryngeal cancer are:

- **Smoking:** Smoking is the main risk factor for laryngeal cancer. It is thought that tobacco contains chemicals that can trigger changes in normal cells that can lead to cancer.
- **Alcohol:** 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.
- **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.

Remember laryngeal cancer is not infectious and cannot be passed on to other people.

»»» Smoking tobacco is the main risk factor for laryngeal cancer, followed by drinking a lot of alcohol, especially spirits.



### To sum up

- The larynx is known as your voice box. You use it to breathe and make sounds.
- Laryngeal cancer is a rare cancer. About 160 people are diagnosed with it in Ireland every year.
- The cause of laryngeal cancer is unknown. Your risk increases if you smoke, if you drink a lot of alcohol or if you are older than 50.

## Being diagnosed with laryngeal cancer

Hearing that you have laryngeal cancer can be a huge shock. You may be feeling:

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

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

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

- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)
- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to other people going through the same thing. Join our online community at <http://www.cancer.ie/community>

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



## Telling people about your diagnosis

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



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

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help you to find ways to talk about your cancer and to ask for the help and support you need.

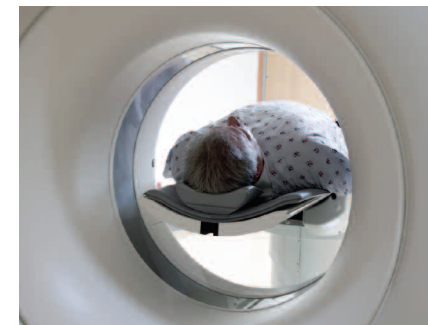
## What tests will I have?

After being diagnosed with laryngeal cancer, your doctor may want to do more tests to find out more about your cancer and your general health.

Tests you may have include:

- **X-rays:** X-rays use high-energy rays to take pictures of the inside of your body. You may have a chest X-ray to check your heart and lungs.
- **Microlaryngoscopy:** This test allows your surgeon to examine your larynx more clearly. A thin metal tube with a light on the end (laryngoscope) is passed down your throat. A microscope can be attached to the end of the tube to magnify the larynx to make it easier to examine. You'll have a general anaesthetic for this test.
- **CT scan (CAT scan):** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. During the scan you will lie on a table which passes through a large doughnut-shaped machine. It is painless and takes between 10 and 30 minutes. For a CT scan of your larynx, you might be asked not to eat (fast) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan.

Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.



- **MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people feel anxious about this and are afraid they may feel claustrophobic during it. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. It can also be noisy, but 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 in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home after the scan.
- **PET scan:** PET uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours.
- **Blood tests:** You may have blood tests to check your general health.



## Waiting for test results



It usually takes about 2-3 weeks for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

## Staging laryngeal cancer

The tests that you have after you have been diagnosed with laryngeal cancer can help the doctor to stage your cancer. Staging means finding out the size of the cancer and if it has spread to other parts of your body. Staging is very important, as it helps your doctor to plan your treatment.

### How is laryngeal cancer staged?

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor often uses this information to give your cancer a number stage – from 0 to 4.

In general, the lower the number, the less the cancer has spread. A higher number, such as stage 4, means a more serious cancer. Some stages are further divided into A and B.

**Stage 1:** The cancer cells are in one part of the larynx. The vocal cords can move normally.

**Stage 2:** The tumour has grown from where it started into another part of the larynx.

**Stage 3:** The cancer has spread throughout the larynx but not outside it. One of the vocal cords can't move.

**Stage 4:** The cancer has spread outside the larynx into the lymph nodes and surrounding tissues. It may have spread to other parts of the body.

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

## Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

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

It is not always easy to answer a question about life expectancy, as the answer is based on a 'typical' experience. Experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

**If you decide you want information on your prognosis:**

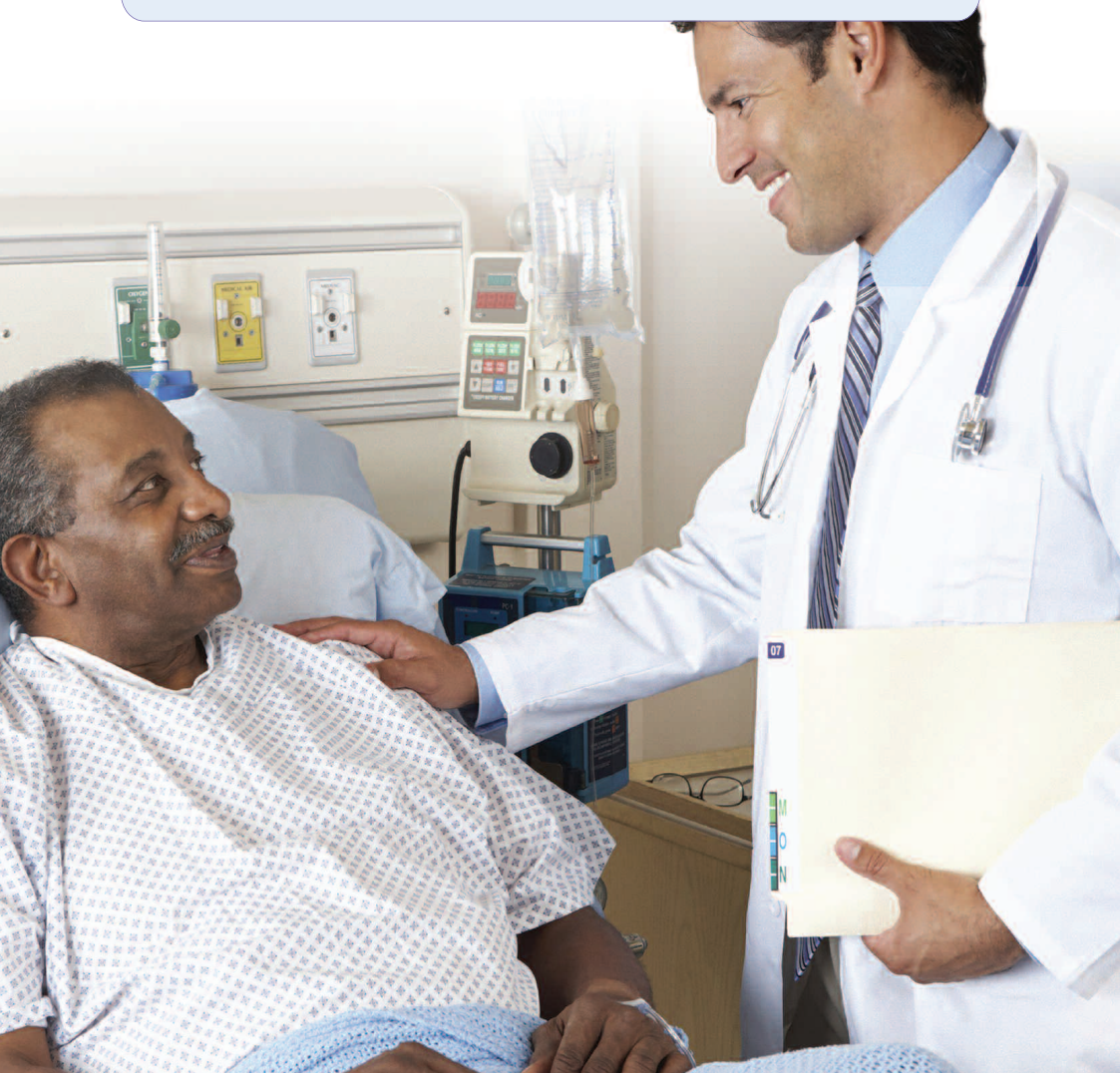
- **Think about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can sometimes be hard to understand what the figures you find online mean without an expert like a doctor to help. The information may not really apply to your situation or your particular cancer type.
- **Accept that you will need some time to think** about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.





## To sum up

- You may need to have tests such as a CT scan or PET scan.
- These tests can help to stage the cancer.
- Staging cancer means finding out its size and how far it has spread in the body.
- Staging allows your doctor to decide the best treatment for you.
- You may want to ask about the likely outcome (prognosis) for your cancer.



# Treatment and side-effects

## How is laryngeal cancer treated?

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

- Radiotherapy
- Surgery
- Chemotherapy
- Biological therapies

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

**Radiotherapy:** Radiotherapy is 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 (stage 1 and 2) cancers of the larynx. Depending on the size of the cancer, it may be given before or after surgery or in combination with chemotherapy or biological therapy.

See page 20 for more details about radiotherapy.

**Surgery:** Laser or endoscopic surgery can be used for small, early stage cancers of the larynx (stage 1 or 2). 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 24 for more details about surgery.

**Chemotherapy:** This is the use of drugs to kill 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 37 for more about chemotherapy.

**Biological therapy:** This treatment works with your body's own immune system to fight cancer. It is usually used to treat later stage laryngeal cancer. It is usually used in combination with radiotherapy. You may also be treated with a biological therapy as part of a clinical trial. See page 40 for more details about biological therapy.

## Specialist cancer centres

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

**Multidisciplinary team:** A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. They will meet to discuss your test results and your suggested treatment plan.

**Treatment options:** Your doctor and nurse will explain your treatment options to you. Ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

**Time to think:** When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

**Second opinion:** You might also find it reassuring to have another medical opinion to help you to 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.

>>> If you smoke your doctor may advise you to try to stop smoking. See page 47 for advice.

## Giving consent for treatment

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

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

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

## Individual treatment

You may notice that other people with 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 treatment.

## Who will be involved in my care?

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

|   |   |
|---|---|
| <b>Radiation oncologist</b>                                     | A doctor who specialises in treating cancer using radiotherapy.   |
| <b>Radiation therapist</b>                                      | A specialist who gives radiotherapy and advises cancer patients about their radiotherapy treatment.   |
| <b>ENT surgeon</b>  | A doctor who specialises in operating on the ear, nose and throat.  |
| <b>Head and neck surgeon</b>                                    | An ENT surgeon who specialises in operating on the head and neck, including the larynx  |
| <b>Medical oncologist</b>                                       | A doctor who specialises in treating cancer using chemotherapy and other drugs.   |
| <b>Oncology liaison nurse/<br/>Head and neck clinical nurse</b> | A specialist nurse who works in a cancer care unit for people with head and neck cancers, including cancer of the larynx. She or he can give you and your family information and reassurance throughout your treatment. |
| <b>Speech and language therapist</b>                            | A specialist trained in the assessment and treatment of swallowing, voice and communication difficulties.   |
| <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>Physiotherapist</b>  | A therapist who treats injury or illness with exercises and other physical treatments.  |

|                                  |   |
|----------------------------------|---|
| <b>Medical social worker</b>     | A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.          |
| <b>GP (family doctor)</b>        | You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or tell them if you are finding it hard to cope.   |
| <b>Psycho-oncology team</b>      | A group of specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.   |
| <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>Community health services</b> | These include family doctors, public health nurses (who can visit you at home), community occupational therapists and physiotherapists, welfare officers and home help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services. |
| <b>Palliative care team</b>      | This team is trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. Most general hospitals have a specialist palliative care team.                  |

### Waiting for treatment to start

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

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks doesn't usually affect how well the treatment works. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

If you are worried, tell your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

## Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. It is a widely used treatment for laryngeal cancer.

The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. The radiation comes from machines which aim rays directly at your tumour or the tumour site.

Radiotherapy may be given at different times and for different reasons:

**Radiotherapy alone:** If possible, your doctor may suggest radiotherapy or laser surgery rather than open surgery because it can help you to keep your voice.

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

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

**Palliative radiotherapy:** If your cancer is advanced, radiotherapy can also be used to control and relieve symptoms you may have. See page 47 for more about advanced cancer.

### Planning your treatment

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

With external radiotherapy to your head or neck you need to have a special mould (mask or shell) made of your head for you to wear during treatment. This makes sure that your head is still and the radiation is aimed at the same area each day. The treatment area will be marked on the mould using ink.

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. You may have extra scans or X-rays taken but this is to plan your treatment only. The dose of radiation will be decided and tightly controlled for your treatment.

**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.

### Getting your radiotherapy treatment

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

The treatment normally takes several minutes. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible.



Radiotherapy to the larynx



Most people receive external radiotherapy as outpatients, travelling to the radiotherapy unit each day, with a break at weekends.

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

### How much radiotherapy do I need?

How much treatment you receive will depend on the size and type of tumour. The course can be several treatments over a number of days or weeks (3 to 7 weeks) or between 1 and 10 doses for palliative treatment.

### What are the side-effects of radiotherapy?

Radiotherapy is given directly to the site of the cancer. Therefore, side-effects are usually related to the part of your body being treated.

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

- Sore mouth and throat
- Difficulty swallowing
- Dry mouth and throat
- Voice changes
- Thick sticky saliva (mucus)
- Mouth infection
- Poor appetite and weight loss
- Loss of taste
- Skin changes, such as skin irritation or darkened skin tone
- Tiredness (fatigue)
- Hair loss in the treated area
- Breathing problems

How severe these side-effects are will vary from person to person, depending on the amount of treatment received.

Most side-effects develop during or shortly after your treatment and get better within a few weeks. These are known as early or acute side-effects. Late side-effects develop some time after treatment. Late side-effects may be long-term or even permanent.

Most side-effects improve or disappear after treatment. Let your doctor know if they continue.

For more information on the side-effects of radiotherapy or a copy of the booklet *Understanding Radiotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from our website [www.cancer.ie](http://www.cancer.ie)



### Tips & Hints – mouth care

- Brush your teeth regularly with a small, soft toothbrush, 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.



### To sum up

- Radiotherapy is a treatment using high-energy X-rays to kill cancer cells.
- The treatment only lasts a few minutes.
- Treatment may continue for 3 to 7 weeks, depending on the cancer.
- Side-effects of radiotherapy usually affect the area being treated and usually improve or disappear after treatment.

## 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 the tumour is, 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 / Pharyngolaryngoesophagectomy (PLO)

**Laser surgery:** This surgery is mainly used for stage 1 and 2 cancers. 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 may remain hoarse, unless the tumour is very small.

**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:** With this surgery, the affected part of your larynx is removed. Your surgeon will first make a temporary hole in your neck and place a tube in it for you to breathe through. Having the breathing tube will help your larynx to heal after surgery.

It is known as a temporary tracheostomy. With partial laryngectomy at least one vocal cord is kept so you will still be able to speak. But your voice might be quite hoarse or weak afterwards.

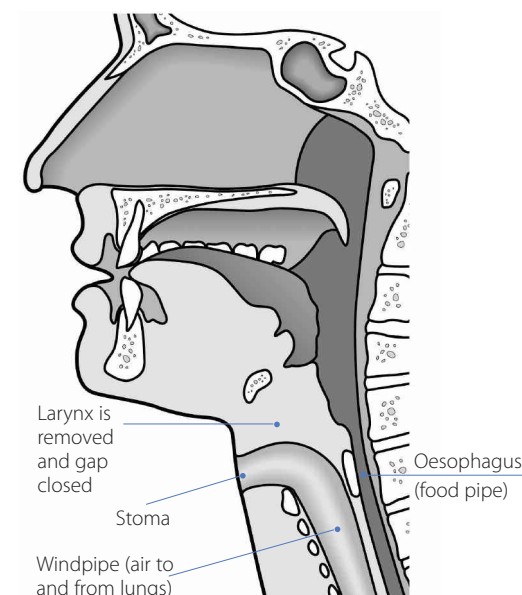
Once your larynx has healed, the temporary tracheostomy tube is removed and the hole will heal. You may find eating and drinking difficult at first but this should improve gradually. During this time you may need a feeding tube placed in your nose to help maintain your nutrition. This is called a nasogastric tube.

If the cancer is found above your vocal cords, an operation called a supraglottic laryngectomy is done. For this, you may 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. Depending on how far your cancer has spread, you may have an operation to remove your larynx and the upper part of your oesophagus. This is called pharyngolaryngoesophagectomy (PLO).

If your larynx is removed you will no longer have a voice box and you will have to learn to communicate in a different way. You will now breathe through your neck instead of your mouth and nose. While this may sound strange or frightening, most people adapt well to this new way of breathing.

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 spread.



Total laryngectomy



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 by mouth again once your wound has fully healed. 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. On the day of your operation your nurse may give you a tablet before you go to theatre to relax you.

- **Exercises:** A physiotherapist or nurse will show you how to do 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.
- **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. You will also be given special elastic stockings to wear. This is to prevent a clot forming in your legs after surgery as you will be less mobile for a few days.
- **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 therapy:** The speech and language therapist will explain what communication options will be available to you after surgery. He or she may advise you to bring a pen and paper or tablet device to the hospital with you, to help you communicate after your surgery.

Ask the speech and language therapist as many questions as you can. Write them down if you think you may forget something.

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. Most people find it very helpful to meet with someone who has been through a similar experience, as they can give reassurance and invaluable advice on how to adjust after surgery.

## After the surgery

You may spend a short time in an intensive care unit or high-dependency unit after surgery. Or you may be cared for on the ward. 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. In the days after your operation the tubes will be removed as they are no longer needed.

**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.



Tracheostomy tube

- **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 means you won't have to get out of bed to go to the toilet.

## 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. A PCA pump sends pain medication into your blood when you press a button. Your nurse will show you how to use this. Always ask for help if you have any pain or feel sick. Being pain-free will help with healing and speed up your recovery, so if your pain relief is not working let your nurse know so that your medication can be increased or changed.

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 by mouth 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 until you are ready to eat through your mouth. The feeding tube may be in your nose or in the stoma in your throat.

One to two weeks after your surgery, you will be sent for an X-ray to check that your throat has healed. Depending on the results of this X-ray, you may be allowed to start eating and drinking again. At first you will have fluid. Then you will start to eat 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 if your voice box has been removed, you will not be able to make sounds or speak the way you did before. When you wake up after the surgery, you can communicate through writing, a tablet or computer, picture charts, facial expressions and mouthing, or by pointing and making gestures. If you have a mobile phone you can communicate by writing text messages. 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 frustrated, angry and upset at yourself or at the people closest to you. Try not to worry as these feelings are normal. You should feel better once you get used to communicating in a different way. Your medical team will be very used to caring for patients in your situation and they will give you lots of support and advice.

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 32 for more information on learning to speak again.

## Getting up and about

A physiotherapist will visit you daily to help with breathing, neck and shoulder and leg exercises. For the first few days after surgery your lungs will make more mucus than usual. The physiotherapist will show you how to cough to help bring up the mucus. 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 happen due to surgery, or you may be given neck exercises. It is very important to follow any exercise plan you are given.

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

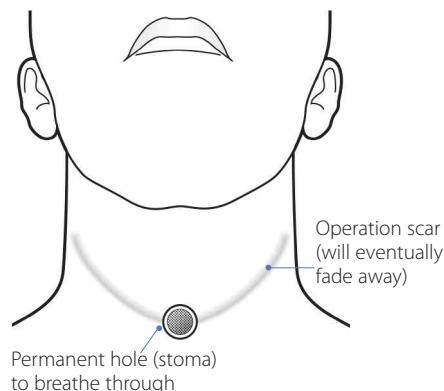
If you have a tracheostomy tube put into the stoma after surgery, it may be removed completely or changed to another type of tube after a few days. Every patient is different and your surgeon will decide if you have to wear a tube or not and for how long.

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. You may have a lot of secretions or phlegm initially after the surgery but this will reduce by the time you go home.

When you are feeling better, you will be shown how to look after the stoma yourself. Using a small freestanding, table-top mirror can make it easier to see what you are doing. 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.**



### Going home

The surgery for laryngeal cancer involves a big operation. You will need a lot of support from your doctors and nurses, family and friends. 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.

It takes time to fully recover from this operation. Most people are ready to go home about 3 to 4 weeks after surgery, but it may take longer, particularly if you have had radiotherapy.

On leaving hospital, your nurses will make sure you have all the equipment you will need. For example you will need a suction machine and a nebuliser at home. This will be ordered by the hospital and you will be shown how to use it.

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 clinical nurse specialist. It can also be arranged for your local public health nurse to visit you too.

You will be given a date to come back for a check-up, usually about 2-3 weeks after your surgery, or longer if you are having other treatments. Your surgeon will check how you are and discuss any test results with you. For more about follow-up see page 45.



### To sum up

- The aim of surgery is to remove the part of the larynx with cancer cells in it.
- 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.

## Learning to speak again

There are three main 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 pharynx 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 puncture or fistula, can be made at the same time as your laryngectomy or at a later date. The puncture 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.

When the puncture has had time to heal, your speech and language therapist will put in a one-way valve called a voice prosthesis. This valve will prevent the backward flow of saliva and food from your oesophagus into your windpipe. It will also stop the puncture from closing over.



Talking by covering the opening with a thumb

Once the voice prosthesis is put in, you can talk when the opening is covered with a finger or thumb. This might take a little bit of practice at first. Your speech and language therapist will support you in learning to talk with the prosthesis and will show you how to care for it.

**Protecting the valve:** The puncture 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 you are at home. If the puncture closes over, it will be 6 months to a year 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 voice-prosthesis valve. Some valves last for 3 to 6 months if they are kept clean, depending on the type. In time, most people learn to change their own valve.

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. While your new voice won't sound the same as your previous voice, you and your friends and family will become used to it. 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 or cheek when you mouth words, the sound is passed through your neck or cheek to your mouth. 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. 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.

Some people use a range of methods to communicate after their surgery, for example electrolarynx, mouthing, writing, and speaking with a prosthesis. You will adapt to whatever works best and is most comfortable for 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:

**Foam bib:** This is a bib with a foam lining that is worn around the neck.

**Base plate filter system:** 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.

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 to make you feel better and may draw attention away from any physical changes. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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.

**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 have to do special training on how to use a larkel safely. There is a training course available in the UK.

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

Larkels are only available with a prescription from your doctor or surgeon. Check with your insurance provider to see if the cost is covered by your policy. For more details, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

**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.

## Chemotherapy

Chemotherapy is a treatment using drugs to kill cancer cells. The doctor who specialises in chemotherapy is called a medical oncologist.

### When is chemotherapy given?

Chemotherapy drugs may be given at different times and for different reasons:

- Before surgery or radiotherapy to shrink the cancer and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- At the same time as radiotherapy to make the treatment work better (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 will be able to speak afterwards.
- To try to control advanced cancer and relieve symptoms, or for cancer that has returned after radiotherapy.

Chemotherapy may also be used if surgery isn't possible.



## How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles will depend on the type of cancer you have and how well it is responding to treatment.

## How do I get chemotherapy?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). Some drugs may also be given as tablets. Usually your chemotherapy will be given in the oncology day ward and you will be able to go home the same day.

## What kinds of drugs are used?

There are several chemotherapy drugs used to treat laryngeal cancer. Your doctor or nurse will discuss your treatment with you. Chemotherapy drugs can be used on their own or in combination with each other.

## Side-effects of chemotherapy

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication. The side-effects usually go away when the treatment ends or soon after.

Side-effects may include:

- **Infection.** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, running a high temperature, having a cough, or pain passing urine.
- **Anaemia.** Chemotherapy can cause the bone marrow to make fewer red blood cells. Fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment.

- **Bleeding and bruising.** Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the number of platelets in your blood.
- **Nausea and vomiting.** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.
- **Sore mouth and mouth ulcers.** There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Hair loss (alopecia) or hair thinning.** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **Diarrhoea.** Chemotherapy can cause diarrhoea (loose or watery bowel movements).
- **Peripheral neuropathy.** Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. He or she will tell you what to do.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from our website [www.cancer.ie](http://www.cancer.ie).



## To sum up

- Chemotherapy is a treatment using drugs kill cancer cells.
- The drugs can be given in tablet form, 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 therapies

Biological therapies work with your body. They can help to fight cancer, stop it spreading or control side-effects from other cancer treatments.

Different types of biological therapies work in different ways. For example:

- **Cancer growth inhibitors** block the chemical signals that trigger cancer cells to divide and grow.
- **Monoclonal antibodies** trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
- **Angiogenesis inhibitors** interfere with the blood supply to the cancer cells.
- **Immunotherapy** boosts your body's immune system to fight cancer.

Some treatments fit into more than one of these groups.

A monoclonal antibody drug called cetuximab (Erbix<sup>®</sup>) is an example of a biological therapy used for some people with cancer of the larynx.

### Side-effects

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy.

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include flu-like symptoms, tiredness, headaches and skin changes, such as rashes. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 41). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.

For more information on biological therapies and their side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

## Clinical trials

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

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

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

### More information

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

## How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well

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

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

### >>> Tips & Hints – fatigue



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

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.

## Will treatment affect my sex life and fertility?

### Sex and sexuality

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

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

>>> There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Your doctor will advise you if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex again with your partner.

### Contraception

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

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

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

## Asking for advice

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

## Fertility

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

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

## Cancer and complementary therapies

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

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

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

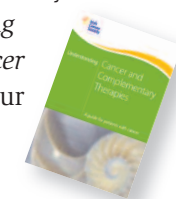
**Alternative therapies:** Alternative therapies are generally treatments that are used **instead of** standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

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

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

## More information

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



## What follow up will I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests, X-rays and scans. The doctor may also want to look inside your throat using a thin, flexible telescope (fibre-optic endoscope), which is inserted into your nose or your stoma.

At first you will see your consultant around every 3 months but these check-ups will become less frequent over time.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say.

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

## Staying healthy after treatment

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

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

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back.

A healthy lifestyle includes:

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

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

## Should I quit smoking?

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. 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.

## How can I stop smoking?

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

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

## How is advanced cancer treated?

Advanced cancer is when cancer has spread to another part of your body. Cancer that has spread to another part of your body can also be called metastatic or secondary cancer. Your cancer may be advanced when it is first diagnosed. Or it may have come back some time after you were first treated. This is called recurrence.

If your cancer is advanced it can still be treated. The aim of treatment is usually to try to control the cancer rather than to cure it. If the cancer is locally advanced (still close to the larynx) you may have surgery to try to remove it. Your doctor may advise different chemotherapy drugs or biological therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 41). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment can help you to live longer with better control of your symptoms. Your doctor will discuss the best treatment option for you with the healthcare team. Your doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer.



## Palliative care

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

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

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

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

## Coping and emotions

### How can I cope with my feelings?

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

#### Common reactions include:

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

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also read or download it on our website [www.cancer.ie](http://www.cancer.ie)

### Anxiety and depression

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

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

### Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings,





worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

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

## Ways to get support

**Find out about cancer support services in your area.** There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 63 for more about cancer support services.

**Join a support or educational group.** Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

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

**Get online support.** There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit [www.cancer.ie/community](http://www.cancer.ie/community) to join the Irish Cancer Society online community.

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

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

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

## Learning to cope

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

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

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

## How can I help myself?

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

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

**Involve your family and close friends.** Don't keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed.

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

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

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

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

**Try complementary therapies.** Complementary therapies are treatments like acupuncture, yoga and aromatherapy. They are given as well as your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 44 for more information on complementary therapies.

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

**Know that there will be ups and downs.** Sometimes people feel that they have to be brave or positive all the time, but it is normal to have bad days. Get help if you are finding it hard to cope.

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

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

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

**Practical planning.** It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it might be helpful for you, as it can give you the chance to be able to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website [www.cancer.ie](http://www.cancer.ie) for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

## Positive emotions



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

## How can my family and friends help?

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

## How to talk to someone with cancer



When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is a good listener. When a person has had treatment for laryngeal cancer they may find talking difficult, due to losing their voice box or other treatment. They may need extra time to get their message across. Be patient with your loved one and try to help them to find a way to communicate that suits them, perhaps by writing things down on paper or using a mobile phone or tablet.

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

## Talking to children and teenagers

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

### Saying nothing

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

### How to tell your children

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



The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It is also available on our website [www.cancer.ie](http://www.cancer.ie).

## Advice for carers

Caring for someone who has had treatment for laryngeal cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

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

### Caring for someone with cancer

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

**Plan as much as you can ahead of the discharge date:** Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

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

### Support for you, as a carer

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



## Looking after yourself

**Share worries:** You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Stay in touch with your own friends and get out when you can, even if you sometimes do not feel like it. You can also chat to our cancer nurses in confidence by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

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

**Have little treats:** If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

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

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

**Find carers support organisations or local cancer support centres:** Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

Email [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

## Life after cancer

Being told that your treatment has been successful is wonderful news. But it can take some time for your body to recover and for you to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

### Feelings you may have include:

**Fear** of cancer coming back and worrying about every small symptom

**Loneliness** without the company and support of your medical team and fellow patients

**Stress** at having to deal with concerns such as finances, going back to work and family issues that may have been on hold during your treatment

**Isolation or guilt** if your family and friends expect you to get back to normal before you are ready

**Anxiety and self-doubt** about sexual and romantic relationships

**Anger** at what has happened and the effect on you and your loved ones

### Depression or sadness

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 50 for other ways to get support.

Cancer Nurseline Freephone 1800 200 700





## Support resources

### Coping with the financial impact of cancer

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

#### Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

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

**If you have a medical card**, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

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

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

**If you do not have a medical card** you will have to pay some of the cost of your care and medication.

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

## Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

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

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

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

## If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some help towards travel costs. See page 62 for more details of our Volunteer Driving Service and the Travel2Care fund.

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

## More information

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

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

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

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

## Irish Cancer Society Services

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

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

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)

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

- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.



- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 63 for more information
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our **publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications.



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

## Local cancer support services

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

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, psychologists, cancer nurses and counsellors
- **Special exercise programmes**, like the Irish Cancer Society's Strides for Life walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

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

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

Cancer Nurseline Freephone 1800 200 700

## Helpful books

The Irish Cancer Society has a wide range of information on preventing cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: [www.cancer.ie](http://www.cancer.ie).

You may find the following helpful:

### Treatment and side-effects

*Understanding Chemotherapy*

*Understanding Radiotherapy*

*Understanding Cancer and Complementary Therapies*

*Diet and Cancer*

*Coping with Fatigue*



### Coping and emotions

*Understanding the Emotional Effects of Cancer*

*Lost for Words: How to Talk to Someone with Cancer*

*Who Can Ever Understand? Taking About Your Cancer*

*Talking to Children about Cancer: A Guide for Parents*

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

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



## What does that word mean?

|                             |   |
|-----------------------------|---|
| <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 plastic tube 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 specialist trained in the assessment and treatment of swallowing, voice and communication 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.                    |

## Questions to ask your doctor

Here is a list of questions that you may want to ask. There is also some space for you to write down your own questions if you would like. 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?

## Join the Irish Cancer Society team

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

### Support people affected by cancer

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

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

### Share your experiences

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

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

### Raise money

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

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

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

## Did you like this booklet?

We would love to hear your comments and suggestions.

Email [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)

## More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

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