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This booklet has been written to help you understand cancer of the larynx.

It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information contained in this booklet is an agreed view on this cancer, its diagnosis and management, and the key aspects of living with it.

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

Speech and language therapist
_________________________________________

_________________________________________

Hospital
_________________________________________

Phone
_________________________________________

Treatments
_________________________________________

If you like, you can also add:

Your name
_________________________________________

Address
_________________________________________
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Website: www.cancer.ie

The Irish Cancer Society is the national charity dedicated to eliminating cancer as a major health problem, and improving the lives of those living with cancer.

This booklet has been produced by the Nursing Services Unit of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment.

We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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Introduction

This booklet has been written to help you find out more about cancer of the larynx. We hope it answers some of the questions you may have about its diagnosis and treatment.

We cannot advise you about which treatment to choose. You can only make this decision, together with your doctor, when all your test results are ready. However, we can help you find out more about some of the methods used to treat this cancer and the side-effects that may occur when treatment is given.

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

If reading this booklet helps you, why not pass it on to your family and friends who might find it helpful too. The more they know about your illness the more they will be able to help you cope when you need them.
Reading this booklet

Read the sections of this booklet that are of interest to you only. Some of the information may not be relevant to your situation.

You may find that there is a lot of information to take in, but try not to worry. Sometimes it can be hard to concentrate, especially if you are feeling anxious or worried. Remember that you do not need to know everything about cancer of the larynx straight away. Read a section and when you feel relaxed and want to know more, read another section.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline at 1800 200 700, if you wish.
### What does that word mean?

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benign</td>
<td>Not cancer. Harmless.</td>
</tr>
<tr>
<td>Biopsy</td>
<td>The removal of a small amount of tissue from your body to find out if cancer cells are present.</td>
</tr>
<tr>
<td>Cell</td>
<td>Cells are the building blocks that make up your body. They are very small and can only be seen under a microscope.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Treatment with anti-cancer drugs.</td>
</tr>
<tr>
<td>Larynx</td>
<td>This is the voice box. It is a small organ in the front part of your neck attached to the windpipe. It contains your vocal cords and is also needed for swallowing and breathing.</td>
</tr>
<tr>
<td>Laryngectomy</td>
<td>An operation to remove your larynx.</td>
</tr>
<tr>
<td>Laryngoscopy</td>
<td>A test to examine your voice box using a thin flexible tube called a laryngoscope.</td>
</tr>
<tr>
<td>Nausea</td>
<td>Feeling sick or wanting to be sick.</td>
</tr>
<tr>
<td>Malignant</td>
<td>Cancer.</td>
</tr>
<tr>
<td>Metastasis</td>
<td>The spread of cancer from one part of the body to other tissues and organs.</td>
</tr>
<tr>
<td>Oncology</td>
<td>The study of cancer.</td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td>A doctor who specialises in treating cancer patients using chemotherapy.</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>The treatment of cancer using high high-energy X-rays.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td>A doctor who specialises in treating cancer patients using radiotherapy.</td>
</tr>
<tr>
<td>Staging</td>
<td>A series of tests that measure the size and extent of cancer.</td>
</tr>
<tr>
<td>Stoma</td>
<td>A permanent opening made in the lower part of your neck after a laryngectomy so that you can breathe.</td>
</tr>
<tr>
<td>Tracheostomy or laryngectomy tube</td>
<td>A special breathing tube that may be placed in your throat to help you to breathe.</td>
</tr>
<tr>
<td>Tracheoesophageal fistula</td>
<td>An opening between the trachea (windpipe) and the oesophagus (food pipe) so that air can move from the lungs to the mouth for speech.</td>
</tr>
</tbody>
</table>
What is cancer?

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

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

These abnormal cells can form a tumour. Tumours can either be benign or malignant. Benign tumours do not spread to other parts of the body so are not called cancer. Malignant tumours are made up of cancer cells that can spread and damage other tissues and organs. This may happen when a cell or group of cells breaks away and travels through the bloodstream or lymphatic vessels (which fight infection) to form a new tumour somewhere else in the body. This is called a metastasis or secondary tumour.

To sum up

- Cancer is a disease of the cells of the body.
- Cancer cells do not behave as normal and keep growing, even when there is no need.
- If a tumour is malignant, cells can break away and be carried in the bloodstream or lymph vessels to form a new tumour somewhere else. This is called a metastasis or secondary tumour.
The larynx

The larynx is also called the voice box. It is a small organ at the front part of the neck and attached to the windpipe. The larynx has three important functions:

■ It allows air breathed in through the nose and mouth to reach the lungs.
■ It acts as a valve that closes to prevent food and drink entering the windpipe when swallowing.
■ It contains the two vocal cords. These cords vibrate together when air is passed over them to produce the sound when speaking.

Cancer of the larynx

When cancer of the larynx occurs, the cells in a part of the larynx change and grow out of control to form a tumour. The tumour may develop near the vocal cords and affect the sound of your voice. In rare cases, cells may break away from it and spread to other parts of the body.
What causes cancer of the larynx?

The exact cause of cancer of the larynx is unknown, but research into possible causes of the disease is going on all the time. However, it has been found that people who smoke are at much higher risk of developing cancer of the larynx than people who don’t smoke.

Cancer of the larynx occurs mainly in middle-aged and older people. It is much more common in men than women. Cancer of the larynx, like other cancers, is not infectious and so cannot be passed on to other people.

If you feel you could be at risk:

- Go to your own family doctor and talk about your concerns. He or she will advise you what to do.
- If you smoke and would like support and advice about quitting, there is help available. See page 53 for more information.
Symptoms of cancer of the larynx

Most cancers of the larynx begin on one of the vocal cords. A very small tumour can prevent the two vocal cords meeting together and working properly, so a hoarse voice usually occurs very early in the disease. If you have a hoarse voice for longer than six weeks, you should go and see your doctor.

Sometimes cancer can start elsewhere in the larynx. Hoarseness may not occur straight away. The first symptom may be a change in the sound of your voice, a lump in your throat or neck or a feeling of not being able to breathe properly. You may also have discomfort or pain on swallowing.

If you do have any of the above symptoms, you must get them checked out by your doctor. However, all of these symptoms can occur in diseases other than cancer.

Symptoms of cancer of the larynx may include:

- Hoarse voice
- Change in the sound of your voice
- A lump in your throat or neck
- Difficulty in breathing
- Discomfort or pain on swallowing.
How does the doctor make the diagnosis?

Most people begin by visiting their doctor. If your doctor has concerns about you, he or she will refer you to an ear, nose and throat (ENT) specialist. He or she will ask you questions about your health before examining your throat.

To do this the doctor will ask you to sit on a chair. He or she will then spray local anaesthetic on the back of your throat. This will numb your throat. When you are ready the doctor will pass a small flexible instrument into the back of your throat or up your nose. Once you have been examined you can go home. The test is a little uncomfortable but is not painful.

Depending on the results of this test, you may need to come into hospital for a further examination and biopsy under general anaesthetic.

Laryngoscopy and biopsy

A laryngoscopy is a test where the doctor is able to look inside your larynx. He or she may take samples of tissues to look at under a microscope (biopsy). A thin flexible tube called a laryngoscope is used. A light on the end of the tube helps the doctor to see any abnormal areas or swelling. The test is carried out under general anaesthetic.

Before the test, you will be asked not to eat or drink anything for a few hours. You may also be given a mild sedative. This will help you feel more relaxed going to theatre. When you are asleep, the laryngoscope is gently passed through your nose or mouth and into the back of your throat. The doctor can look through the
laryngoscope to check for any abnormalities. A small sample of tissue (biopsy) can be taken at the same time.

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

**Staging**

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

Further tests may include:  ■ CT scan  ■ MRI scan

**CT scan (CAT scan)**

This is a special type of X-ray that builds up a detailed picture of the inside of your body. A CT scan can be used to check if the cancer has spread locally beyond the larynx or to other parts of the body.

For some CT scans you may be asked not to eat or drink for four hours beforehand. For others, you may be given a special drink or
injection which helps show up certain parts of the body on the scan. It is important to let the radiographer know if you are allergic to iodine or have asthma, before you take the drink or injection. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. The scan does not hurt. This test is usually done as an outpatient.

**MRI scan**

This special type of scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but it can be noisy. You will be given earplugs to wear during the scan. You may have an injection before the scan to highlight certain areas of the body. You cannot wear metal jewellery during the scan and patients who have certain medical devices implanted are not suitable for the test. The doctor in the hospital will advise you. Most people can go home after the scan.

It will take about two weeks for all the test results to come back. This can be an anxious time for you. It may help to talk things over with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.

To diagnose cancer of the larynx, you will need:

- An examination of your throat using a laryngoscope.
- A sample of tissue taken from the larynx (biopsy).

Depending on the results of these tests you may need to have a:

- CT scan
- MRI scan
Types of treatment

Surgery, radiotherapy and, in a small number of cases, chemotherapy can be used for the treatment of cancer of the larynx. These treatments may be used on their own or in combination. The type of treatment recommended to you will depend on the type and size of the tumour, where it is in the larynx and whether it affects other tissues. Your doctor will also take into consideration your general state of health.

Surgery may be required if the tumour is large or to remove any tumour remaining after radiotherapy treatment. You may also need surgery if the tumour recurs after initial treatment using radiotherapy.

Radiotherapy is the most common form of treatment for people with cancer of the larynx. It can be used before or after surgery or on its own. Radiotherapy can also be used with chemotherapy. It may also be used to relieve symptoms such as pain or shortness of breath.

Chemotherapy may be used with radiotherapy or if the cancer recurs following surgery or radiotherapy. It is also used if the cancer has spread to other parts of the body, or to relieve symptoms such as pain or difficulty in swallowing.

You may notice that other people with cancer of the larynx are not getting the same treatment as you. Their cancer may not be at the same stage as yours, so their treatment needs will be different.

At this time you might be anxious about what is going to happen next. Do not be afraid to ask your doctor or nurse. You may want
Your doctor will be happy to talk to you about your treatment choices.

to use the fill-in page at the back of this booklet to write down your questions and the answers you receive. Your doctor will be happy to talk to you and tell you about your treatment choices.

**Surgery**

Surgery may be used to treat cancer of the larynx. Your doctor will decide if surgery is suitable for you or not. It will depend on:

- Where in the larynx the tumour is located
- The size of the tumour
- If it has spread to other tissues
- Your general health.

Before any operation, make sure you discuss things fully with your doctor. No operation or course of action can take place without your consent.

The aim of surgery is to remove the part of the larynx with cancer cells in it. There are several types of surgery that can be done. These include:

**Laser excision surgery**

This is used for very small tumours on one vocal cord. Part of the vocal cord is removed using a laser. Eating and drinking difficulties are short term and should resolve over time. However, your voice is likely to remain hoarse.

**Hemi-laryngectomy**

This is a partial laryngectomy. It involves the removal of one vocal cord. A special breathing tube (tracheostomy tube) may be placed...
in your throat during the operation. This is usually removed when your throat is fully healed. Eating and drinking will be difficult at first but should improve over time. But your voice will remain hoarse.

**Supraglottic laryngectomy**

This involves removing a tumour which lies above the vocal cords. A breathing tube may be placed in your throat during the operation, but should not be needed long term. This is usually removed when your throat is fully healed. Eating and drinking will be more difficult and your voice will be hoarse at first but should gradually improve.

**Total laryngectomy**

You may need your entire larynx removed. This operation is called a total laryngectomy. You will no longer have a voice box and you will have to learn to speak in a different way. Your surgeon may have to remove lymph glands near to the tumour, as this is the first place to which the cancer may have spread.

When the larynx has been removed, there will be no connection between your mouth and your lungs. Therefore, to enable you to draw air into your lungs
so that you can breathe, the surgeon will create a permanent opening called a stoma in the lower part of your neck. You should be able to eat and drink normally, but you will cough through the stoma. This surgery will be explained in detail in the next section.

**Getting ready for surgery**

To make sure you are fit for surgery some extra tests may be done. These may include a heart test (ECG), chest X-ray and some more blood tests. A physiotherapist will show you how to do deep breathing and leg exercises. These will help prevent you from getting a chest infection or a blood clot after your operation.

**Eating and drinking**

Before your operation a dietician will visit you. He or she will explain how you will manage to eat and what to expect following surgery.

**Support at home**

If you live alone or have problems getting around the house, 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 community services that you may need after you leave hospital.

**Speech and language**

A speech and language therapist will also see you before your operation. You will be told what to expect after the operation. He or she will also explain how you can communicate during the next few months. It’s a good idea to ask as many questions as you can. Write them down on a piece of paper if you find them difficult to remember.

Your family or close friends will benefit from meeting the speech and language therapist as well, so that they will have some idea of
what is going to happen. This would be a good time for you to meet someone who has had a similar operation. Your nurse or speech and language therapist will arrange this for you.

Other preparations
You will not be allowed to eat anything from the night before your surgery. Your nurse may give you a tablet before you go to theatre. This tablet will make you feel more relaxed and sleepy.

After your operation
You may spend a short time in an intensive care unit or high-dependency unit after your operation. You will be closely monitored for a day or two before returning to the ward. Your face may be swollen for the first couple of days but this will soon disappear. When you wake up, you will notice a number of tubes attached to your body. They might alarm you at first, but they are normal after an operation like this.

- You may have a tracheostomy tube in the stoma. The tube will be held in place with tapes tied at each side of your neck.
- There may be tubes inserted near the wound. These tubes will drain away fluid from your wound site.
- 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.
- A thin plastic feeding 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.
- 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.
A small thin tube called a catheter may be put into your bladder and urine drained off into a drainage bag. This will save you having to get out of bed to go to the toilet.

**Pain**

You may have some pain after surgery for cancer of the larynx. Your nurse can give you pain-killing injections. You can also have medicine to prevent you feeling or getting sick, if you need it. Always ask for help before the pain or sickness gets too bad. If the injections do not work, let your nurse know as they can be changed.

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

**Eating and drinking**

Until the wound in your throat has healed, you cannot eat or drink in the normal way. The nurses will continue to give you fluids and food through the feeding tube until the tissues inside the throat and around the stoma are healed.

Between 10 and 14 days after your operation, you will be sent for a special X-ray to check that your throat has healed. Depending on the results of this X-ray, you may be allowed to resume eating and drinking again. When you are ready, you will begin by taking fluid and soft food. You may find swallowing a little difficult in the first few days. As soon as you begin to drink and eat again the feeding tube will be removed.
Communication

You will still be able to communicate after your operation. However, as your voice box has been removed, you will not be able to make sound or speak the way you did before.

When you wake up after your operation, you will be able to communicate through writing, picture charts, facial expressions, pointing or making gestures. The nurses will make sure you have a call bell and pen and paper to hand at all times. Your hearing will not be affected. It may be quite a shock when you realise you have no voice. You may feel angry and upset at yourself or the people closest to you. Try not to worry, as these feelings are normal. They will become less upsetting as you feel better and learn to use a different method of speaking.

As soon as your wounds show signs of healing, the speech and language therapist will show you how to mouthe 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 24 for more information on learning to speak again.

Getting up and about

A physiotherapist will visit you daily to help you with your breathing and leg exercises. He or she will also show you how to cough. For the first few days after your operation your lungs will produce more mucus than usual. Until you learn how to cough up the mucus yourself, a nurse will remove it with a suction machine.

You will be shown how to do exercises that will help loosen up any shoulder stiffness that can occur as a result of surgery. Even when you are in bed you will be encouraged to move your legs and do
your deep breathing exercises at least once an hour. On the day after surgery, the 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**

The tube inserted into the stoma following surgery may be removed completely or changed to another type of tube after a few days. Every patient is different and your surgeon will decide whether you have to wear a tube or not and for how long. It is important to keep the stoma clean and free from crusts or the skin around the stoma may become sore.

For a few days after your operation a nurse will change your dressings. He or she will also replace the tube as required. When you are feeling better, you will be shown how to do this on your own. You may feel anxious about how you will manage the stoma. 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.

On leaving hospital, the nurses will make sure you have an extra supply of dressings, etc. You will also get a prescription for further supplies from your chemist. If you have any problems at home, you can contact the speech and language therapist or cancer nurse specialist. It can also be arranged for your local public health nurse to see you too.

**Recovery**

Surgery for cancer of the larynx is a major operation. The recovery period can vary from patient to patient. Sometimes the wounds
does not heal as quickly as you would like. This may cause a delay in getting back to normal eating and drinking and learning to speak again. However, most people are ready to go home about three to four weeks after surgery.

Going home

On the day you go home, you will be given a date to come back for a check-up. If you have a worry or symptom before your check-up date, contact your doctor, speech and language therapist, cancer nurse specialist or hospital ward for advice.

To sum up

- The aim of surgery is to remove the entire tumour.
- You will have to learn a different method of speaking, if your larynx is removed.
- Most people are ready to go home three to four weeks after surgery.
Learning to speak again

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

The voice options are:
- Tracheoesophageal speech
- Artificial larynx
- Oesophageal speech.

Tracheoesophageal speech

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

An opening can be made between the trachea (windpipe) and the oesophagus (food pipe) so that air can move from the lungs to the mouth for speech. This small opening (fistula) may be created at the time of your laryngectomy or at a later date. The fistula will allow air to pass into the oesophagus and up towards the mouth. Voice will be produced as the air passes through the top of the oesophagus, causing vibration.

When the fistula has time to heal the speech and language therapist will insert a one-way valve into it. The valve will prevent the backward flow of saliva and food from the oesophagus into the trachea. It will also stop the fistula from closing over. Once you
have a valve inserted, you will be able to talk when the stoma is covered with a finger or thumb.

It is important to know that the fistula is not a permanent opening. It will close over very quickly unless a valve is kept in place at all times. If the valve falls out, you should replace it with a clean valve or a catheter (a thin rubber tube) straight away. Contact your speech and language therapist, nurse or hospital if you are not sure what to do.

If the fistula closes over, it will be three to four months before you can have an operation to create another one.

At a later stage, it may be possible to fit another type of valve 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. Before you go home, the speech and language therapist will teach you and/or your family how to care for the valve. Some valves last for two to three months once they are kept clean. In time, most people learn to change their own valve. There are long-term valves that last up to six months without changing. These valves are sometimes placed in the fistula at the time of surgery. However, only a trained speech and language therapist can change long-term valves.

There are a number of valves to choose from and you will be advised as to which one suits you best by the speech and language therapist and your surgeon.

The time it takes to learn a new voice varies from person to person. Most people learn how to use their new voice within a few weeks. It will help if you have a positive attitude towards the new voice. Learning something new is often 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, 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. The 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 to feel at ease when speaking with family and friends.

**Artificial larynx**

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

When turned on, it makes a vibrating sound similar to voice. If the head of the artificial larynx is held against the neck when mouthing words, the sound is passed through the neck and up to the mouth, in the same way as real voice. The speech 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 artificial larynx may take a while but your speech and language therapist will be there to help you.

**Oesophageal speech**

Oesophageal speech is produced by pushing air from the mouth to the oesophagus (food pipe) with the tongue. The sound or voice comes from the top of the oesophagus when the air is released back to the mouth. This happens because, as the air passes through the muscles at the top of the oesophagus, it vibrates.
The voice will not sound the same as your old voice. It is usually deeper and not quite as clear. It can take a lot of time to achieve a good level of speech. However, it is easily understood and can sound very good with practice. This method of speech is not suitable if you have had most of the oesophagus removed. Your doctor or speech and language therapist will discuss this with you.

**Non-voice changes following a laryngectomy**

**Breathing**

After a laryngectomy, you will no longer be able to 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 the lungs and is not warmed or filtered by the nose or mouth. You will have to wear a stoma cover all the time. This will help 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 foam cover which ties around your 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'.

- **Stoma stud:** This type of filter fits into your stoma. Some people with a laryngectomy simply wear a cotton bib with foam lining around their neck. It is made to look like a false front of a vest or T-shirt. You can wear this under your clothes. Your nurse and speech and language therapist will help you choose the stoma cover most suitable for you.
Coughing and sneezing
Coughing and sneezing will sound different because the air comes straight from the 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 you may produce more mucus than before your operation. This is quite normal and in most cases the mucus 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. You will not be able to sniff or blow your nose, as there will be no air going to or from the 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 difficult to swallow. In some cases this will improve once you have recovered from the effects of your operation. However, it may become a long-term problem if the food pipe has narrowed as a result of surgery or radiotherapy. If this occurs, 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. If you have a problem with swallowing, talk to your speech and language therapist. He or she may be able to help you.

The way you look
It can take quite a while to come to terms with the way you look after surgery. You may be worried about how people will react to you. It may stop you from going out and meeting people. People may be curious about the change in your appearance. However, if they see that you have accepted the change, they will accept it too.
A well-groomed appearance will help. Fresh clean clothes and a good haircut or style can draw attention away from any physical changes. For women, make-up may help. There are many products available that will help disguise the stoma. These include scarves, cravats, false jumper covers and necklaces. Talk to your speech and language therapist or someone who has had a laryngectomy. You can contact a volunteer by calling the Laryngectomy Association of Ireland. Call the National Cancer Helpline 1800 200 700 for more information.

**Bathing and showering**

Some people worry about bathing after a laryngectomy. There is no reason why you cannot bathe or shower, but you must be careful that no water enters the stoma. The smallest 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 the stoma. There are also shower shields available. Your speech and language therapist will discuss this with you.

**Swimming**

If you enjoy swimming it is possible to swim after a laryngectomy. You will have to use a special swimming device called a larkel. This is a specially adapted snorkel. Before you start swimming again, you will have to do a special course on how to use a larkel safely. There is a training course available in the UK. For more details, contact the Laryngectomy Association of Ireland by calling the National Cancer Helpline 1800 200 700.

**Taste and smell**

As you will no longer breathe or sniff through your nose, your sense of taste and smell may be reduced. The sense of taste usually
improves over time. The loss of smell may be permanent. However, there are training methods available to teach you how to smell. Discuss this with your speech and language therapist.

**Lifting**
You may find that you are not able to lift heavy weights following surgery for cancer of the larynx. The back muscles normally work with the larynx to create pressure within the chest to allow heavy lifting. This is no longer possible after a laryngectomy.

**Numbness**
A certain amount of numbness may persist in the area around the neck wounds, but this should not bother you too much.

Apart from these changes, which you should adapt to quickly, you should be able to do what you always did prior to the operation. If there is something else that is worrying you talk to your doctor, nurse or speech and language therapist. They will be able to help you.
Radiotherapy

This is a treatment where high-energy X-rays are directed at a cancer to cure or shrink it. For cancer of the larynx the X-rays are usually delivered through a machine called a linear accelerator or cobalt machine. This is known as external radiotherapy.

Adjuvant radiotherapy

This treatment is given following surgery for cancer of the larynx, particularly if the cancer had also been present in the lymph glands.

Planning your treatment

Before radiotherapy, your doctor and other specialists plan how best to deliver your treatment. They work out how to give you the right amount of treatment for the cancer with the least effect to normal cells.

You may need to have radiotherapy to your head or neck. The head is one of the most difficult parts of the body to keep steady during treatment. Therefore, a mould (mask) of your head is made for you to wear during treatment. When you are wearing the mould it will be attached to the couch you are lying on during treatment. Wearing the mould will ensure that the radiotherapy is delivered to the same area each day. The areas for treatment will be marked on the mould using ink.

On your first visit to the radiotherapy department, you will be asked to lie on a couch and the person who makes the mould will explain what they are going to do. When the mould is ready, the next part of treatment planning will take place. You will be asked
to lie under a simulator that takes X-rays of the area to be treated. Treatment planning is a very important part of radiotherapy and may take several weeks.

Before starting radiotherapy, you will be told how to look after your skin during and after treatment.

**Getting radiotherapy**

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

Each time you go for treatment, you will go into a radiotherapy room. The therapy radiographer will help you to put on the mould and ask you to lie in a certain position under a radiotherapy machine. When you are ready, he or she will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiographer will be able to see you all the time through a closed-circuit camera. You can talk to the radiotherapy staff through an intercom if you need to.
External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

**Will I get any side-effects?**

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

The side-effects may include:

**Sore mouth and throat**

Radiotherapy to the larynx can cause a sore mouth and throat, as the cells that line these areas are very sensitive to treatment. It is most important that you keep your teeth, gums and mouth very clean, as this will help to control the soreness and reduce the risk of a mouth or throat infection.

Clean your teeth after each meal. Use a very soft toothbrush. If you have dentures, remove them if your gums are sore. There are special mouthwashes that you can use. These will help keep your mouth clean and ease mild soreness or pain. Only use mouthwashes recommended by the radiographer or nurse looking after you. Your nurse will show you how to use them properly.

If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers if you need them. If you have an
infection in your mouth or throat, you may need to be treated with other medication.

Avoid eating hot, spicy or very cold food and drink. Alcohol (especially spirits) and tobacco can irritate the lining of the mouth and throat. It is best to avoid them during treatment and for a few weeks afterwards. Your doctor will probably recommend that you give up alcohol and smoking completely.

**Dry mouth and throat**

After a week or two of treatment you may notice that your mouth and throat feel dry all the time. Radiotherapy may cause the salivary glands to produce less saliva than usual. The dryness in your mouth may last for several months after treatment and may be permanent. There are many types of artificial saliva available, which will help to keep your mouth moist. You may find that you have a lot of sticky mucus in your throat as well. If the mucus turns green or yellow, tell your doctor. He or she may want to treat you with medication.

**Difficulty in swallowing**

You may notice after a week or two of treatment that your chest feels tight and you have difficulty in swallowing. It may feel like you have a lump in your throat all the time. Food or drink may seem to go down the wrong way, making you cough as you try to swallow.

Put small amounts of food into your mouth and chew properly before you try to swallow. You may find it helpful to eat soft foods combined with liquid, such as thick soups or stews. If fluids go down the wrong way, there is a powder available which, when added to your drink, makes it thicker and easier to swallow. Talk to your speech and language therapist if you have difficulty
swallowing. A dietician may also be able to help. He or she will give you advice on the best foods to eat. Your doctor may also give you medicine to take before meals to make swallowing easier. The discomfort will usually ease five to eight weeks after you finish treatment.

**Poor appetite and weight loss**

Radiotherapy can affect the taste buds in your mouth. You may notice that you have a loss of taste or a metallic taste in your mouth. If this happens, you may lose interest in food and not eat as much as you did before your operation. Eating well can reduce the risk of getting a sore mouth or skin reactions and can speed up wound healing. Ask your nurse to refer you to a dietician if you have a poor appetite. He or she will monitor your weight and give you advice on what to do. Your appetite should improve once treatment has ended.

**Voice changes**

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

**Skin changes**

During radiotherapy the skin in the treated area may become red and sore. It may look like sunburn. A cream can be used to treat this problem. Only use creams recommended to you by your nurse.
Rest as much as you can. Cut down on the things you normally do while you are on treatment.

Feeling very tired

Feeling very tired can build up over the course of your treatment. It may be due to the treatment itself or because you have to travel distances to come for treatment. Rest as much as you can. Cut down on the things you normally do while you are on treatment.

Hair loss

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

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

To sum up

- Radiotherapy is the treatment of cancer using high-energy X-rays.
- You will not feel any pain while you are getting treatment. Each session only takes a few minutes.
- Treatment may continue for six to seven weeks, depending on the cancer.
Chemotherapy is a treatment using drugs that cure or control cancer. These drugs can be used on their own or in combination.

The decision to give you chemotherapy or not will depend on the type and size of the tumour, and if the cancer has spread to other parts of the body. Chemotherapy can be given before and after radiotherapy or surgery. Usually it may be given through an intravenous infusion (drip). The side-effects of chemotherapy can vary from person to person and depend on the drugs used. However, side-effects can be controlled very well with medication.

Before any chemotherapy is given, your doctor will discuss your treatment options with you. If you would like to find out more about chemotherapy and its side-effects, there is a booklet available called *Understanding Chemotherapy*. Call the National Cancer Helpline 1800 200 700 for a copy.
Follow-up

Whatever treatment you receive for your cancer, once it is over you will need to come back for regular check-ups. At first these will be quite often. Follow-up visits may include seeing your doctor and having some tests such as X-rays, scans and blood tests. These check-ups will continue for a number of years but will become less frequent. If you are between check-ups and have a symptom or problem that worries you, let your doctor know. Make an appointment to see him or her as soon as possible.

Fatigue

Many people complain of fatigue from time to time even if not ill. For most people it is nature’s way of telling them to slow down and take some rest. Fatigue is a common symptom of cancer and often described as an overwhelming tiredness. You may find it difficult to concentrate or make decisions.

The reason for your fatigue can be hard to identify. Fatigue may be caused by anxiety when a diagnosis of cancer is made and the additional stress caused by treatment. You may feel very tired if you are having radiotherapy, especially if you have had surgery as well. Even if you find it hard to identify the reasons for your tiredness, there are things you can do that may help.

What you can do

- Surgery or other types of treatment may relieve symptoms such as pain and shortness of breath for many patients. If you require radiotherapy or chemotherapy, ask your doctor before you start
treatment about what side-effects you can expect. Always let your doctor know about side-effects before they get too bad. In most cases there is medication that you can take which will make you feel better.

- If you feel worried and find it hard to sleep at night, tell your doctor or nurse. He or she may be able to help. Try talking to your close family or friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to relax.

- Take part in some physical exercise if your illness allows you. For example: a 10-minute walk three days a week might be a realistic goal and will boost your morale when you achieve it.

- You may notice that you have lost weight. This may be due to the cancer, the effects of surgery or the treatment you are getting. Sometimes when you are feeling weak and tired, you may lose interest in your food. Ask for help in preparing your meals. Eat small meals often. Drink lots of clear fluids such as water and fruit juice.

- Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy. For more advice, there is a booklet called Understanding Fatigue available. If you would like a copy, call the National Cancer Helpline 1800 200 700.
Will treatment affect my sex life?

For some people sex is an important part of their lives, for others it is less so. The impact of having cancer and its treatment can affect your sex life. Coming to terms with the fact that you have cancer can take some time. Your emotions will be turned upside down. Indeed it can be hard to relax when you have worries on your mind. You may also feel tired from the effects of treatment. As a result you may lose interest in sex. This is quite normal when you are concerned about your health.

If you have a supportive partner, you may find that talking to him or her eases your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship. You should not feel guilty or embarrassed to talk to your nurse or doctor either. He or she can offer you advice and refer you for specialist counselling, only if you think that would be helpful.

There is no set time for you to be ready to have sex again. It varies from person to person. However, there is no medical reason why you cannot have sex, if you are getting chemotherapy or radiotherapy. However, radiotherapy can sometimes cause side-effects such as a sore throat, weight loss and fatigue. If receiving chemotherapy, you may also experience fatigue. More advice is available in a booklet called Understanding Chemotherapy from the Irish Cancer Society.

Following surgery

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

You will not be able to hold your breath during sexual climax following a laryngectomy. This may take away some of the pleasure of sex. It is possible to enjoy sex more by using different positions. You may also have a small problem with noisy breathing from the stoma. The breathing will be less noticeable, if you wear a cover over your stoma. If you need more help, talk to your doctor or nurse.

**Research – what is a clinical trial?**

Research into new ways of treating cancer of the larynx is going on all the time. Some studies are looking at new drugs and new drug combinations, while others are looking into new ways to stop or slow the spread of cancer. The best time to give chemotherapy and radiotherapy is also being investigated. Other studies are trying out two or more doses of radiotherapy a day to see if this improves the outcome of treatment.

Your doctor may suggest that you try a new form of drug or radiotherapy treatment. Doctors can only improve the treatment of cancer by trying new treatments on carefully selected groups of patients. These are called **clinical trials**. Sometimes, several
hospitals take part in the same clinical trial. The more people who take part in a trial the more useful the findings will be.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been explained to you, so that you understand what the trial is about. This is known as informed consent. You will also need time to think about it and discuss it with your family and friends. If you decide not to take part, you will be given the best treatment currently available.

If you would like to find out more about clinical trials, there is a booklet available. Call the National Cancer Helpline 1800 200 700 for a copy. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind.

Cancer and complementary therapies

Cancer treatments in Ireland are based on scientific and medical research, which means the response to treatment can be predicted. You may hear about the following types of treatments or therapies. It is important to know what they are and how they might help you.

Conventional therapies

Conventional therapies are the treatments which doctors use most often to treat people with cancer. These consist of surgery, radiotherapy, chemotherapy and hormone treatments. All these treatments have been tested in clinical trials and safely involved patients over a long period of time.
Complementary therapies

Complementary therapies are treatments that are sometimes given with conventional treatment. They include:

- Therapies such as psychotherapy, relaxation and visualization.
- Therapies which many people find helpful such as gentle massage, aromatherapy, and reflexology.

Many people who have cancer find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be able to cope better with the physical side-effects of cancer and often distressing emotions that cancer can bring.

Alternative therapies

Alternative therapies are generally viewed as treatments that are used instead of conventional treatments. Most doctors believe that such treatments cannot control or cure cancer. It is possible to spend large amounts of money and time on treatments that may result in more harm than good to the patient with cancer. Such therapies include alternative diet therapy, megavitamin therapy and some herbal medicines.

If you are thinking of going for treatment with either a complementary or alternative practitioner, it is important that you discuss this with your cancer specialist or GP.

You should also ensure that the practitioners you are planning to visit are properly qualified and will charge a fair price for your treatment. There is a booklet available on complementary therapies which you may find helpful. If you would like more information call the National Cancer Helpline 1800 200 700.
How to cope with your feelings

You might feel numb and shocked when told that you have cancer. You can feel swamped with many different emotions ranging from disbelief to anger. At first the news may be very hard to take in. It may all seem ‘unreal’. All these feelings are normal and to be expected. It does not mean that you are not coping. Rather they are part of the process you must go through in coming to terms with your illness. Your family and friends may also be feeling the same way and need time to get used to it too.

Reactions differ from one person to another – there is no right or wrong way to feel.

Shock and disbelief

‘I can’t believe it.’ ‘It can’t be true.’

Shock is often the first reaction when a diagnosis of cancer is made. Most people think, ‘It’ll never happen to me.’ It will take a while for the news to sink in. At this stage you may be getting a lot of information about your illness. You may ask the same questions over and over again or seem to accept the news calmly. These are common reactions to a diagnosis of cancer. Because you don’t quite believe what is happening, you may not want to talk about your illness, especially to your close family and friends.

Fear and uncertainty

‘Am I going to die?’ ‘Will I be in pain?’

For most people when told they have cancer, the first question is ‘Am I going to die?’ Cancer is a very scary word.
It brings to mind many stories – most of them untrue. In fact nowadays many cancers can be cured. When cure is not possible the cancer can be controlled for a number of years using modern treatments. There are new treatments being developed all the time.

Another common fear is that cancer is always painful. This is not true. Some cancers cause no physical pain at all. If you are in pain there are many drugs that can control it. Other methods of pain relief include radiotherapy and nerve blocks.

Being concerned about your future is a normal way to feel, however. But it can be hard for your doctor to predict the outcome of your treatment. Not knowing can make you feel anxious. The more you find out about your illness and its treatment, the less anxious you will be.

The real facts about cancer and its treatment are not as frightening as you might imagine. Talk to your doctor about your concerns; he or she should be able to help you. Discuss what you have found out with your family and friends, as they are probably worried too.

**Denial**

‘There’s nothing really wrong with me.’ ‘I haven’t got cancer.’

Many people cope with their illness by not wanting to talk about it. If that is the way you feel, try not to worry. Tell your family and friends that you would prefer not to talk about your illness, at least for the time being.

Sometimes, however, it is the other way round. You may find it is your family and friends who are denying your illness. They appear
to ignore the fact that you have cancer. They may play down your worries and symptoms and keep changing the subject. If this upsets or hurts you because you want them to support you, try telling them. Start perhaps by saying that you do know what is happening but it will help if you can talk to them about your illness.

**Anger**

‘Why me of all people?’ ‘And why right now?’

Anger can hide other feelings such as fear or sadness and you may vent your anger on those closest to you. You may also feel angry towards the doctors and nurses who are caring for you. If you have a religious belief, you may feel angry with your God.

It is easy to see why you may be deeply upset by many aspects of your illness, and there is no need to feel guilty about your angry thoughts or irritable mood. Relatives and friends may not always be aware that your anger is really directed at your illness and not against them. If you can, it may be helpful to tell them this at a time when you are not feeling so angry. Or if you would find that difficult, perhaps you could show them this section of the booklet.

If you are finding it difficult to talk to your family, tell your nurse or doctor. He or she may be able to help you.

**Blame and guilt**

‘If I hadn’t…this would never have happened.’

Sometimes people blame themselves or others for their illness, or wonder why it should have happened to them. This may be because we often feel better if we know why something has happened. As doctors rarely know exactly what has caused cancer, there is no reason for you to blame yourself.
**Resentment**

‘It’s all right for you, you haven’t got to put up with this.’

Understandably, you may be feeling resentful and miserable because you have cancer, while other people are well. Similar feelings of resentment may crop up from time to time during the course of your illness and treatment for a variety of reasons. Relatives too can sometimes resent the changes that the patient’s illness makes to their lives.

It is usually helpful to bring these feelings out into the open, so that they can be aired and discussed. Bottling up resentment can make everyone feel angry and guilty.

**Withdrawal and isolation**

‘Please leave me alone.’

There may be times during your illness when you want to be left alone to sort out your thoughts and feelings. This can be hard for your family and friends who want to share this difficult time with you. Let your family know that whilst you do not feel like talking about your illness at the moment, you will talk to them about it when you are ready.

Sometimes depression can stop you wanting to talk. It may be an idea to discuss this with your doctor who may prescribe a course of antidepressant drugs. He or she may decide to refer you to a doctor who specialises in managing the emotional problems of cancer patients. It is common for patients with cancer to feel depressed, so there is no need to feel you are not coping if you ask for help.

There is a booklet available *Who Can Ever Understand?* If you would like a copy, call the National Cancer Helpline 1800 200 700.
If you are a relative or friend

It can be hard to know what to say when someone close to you is diagnosed with cancer. It may seem best to pretend that everything is fine and carry on as normal. You may not want to add to the person’s worry by seeming afraid or by saying the wrong thing.

Sadly, denying strong feelings like this can make it even harder to talk openly together and can lead to the person feeling very lonely. Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say about his or her illness. Don’t say too much – let them do most of the talking.

You may not think you are doing much by just listening. In fact you are being very helpful. By listening carefully you allow the person to share their feelings and it helps you to better understand their concerns.

As well as having to come to terms with the fact that they have cancer, your partner may have to cope with a change in their appearance and learning to speak again. They may also need further treatment.

Try not to be upset if your friend or relative is cross or irritable. These feelings are completely normal. Try to be as patient as you can. Encourage them to talk. Above all let them know that you are there if they want to talk or need help. In time, with patience and understanding, life will begin to be normal again.

A booklet, Lost for Words, is available from the Irish Cancer Society, which you may find helpful. Call the National Cancer Helpline 1800 200 700 for a copy.
Looking after someone with cancer of the larynx

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

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

What you can do:

- Find out as much as you can about the illness and its treatment. If there is something you do not understand ask again. Write your questions down if you want to. Ask the nurse if you can come along while dressings are being changed if your relative or friend has had a laryngectomy. The nurse will explain the routine to you while changing the dressing and the tube. This will help you to get used to the look of the stoma and you will become familiar with how to keep it clean.

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

- You may feel tired with all the worry and extra work. It can be very straining as you try to adapt to a new way of life. When people offer you help with the garden, transport to the hospital
or shopping, accept it. Try to set aside some time for yourself each week and do something you really enjoy. If you are worried or upset you may find it helpful to talk to a volunteer in the Laryngectomy Association of Ireland. See page 69 for more information.

- At first your relative or friend may feel very tired. 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.

It is important to remember that most people go on to make a full recovery from cancer of the larynx and live full and enjoyable lives.
Talking to children

How much you tell children will depend on how old they are. Very young children don’t understand illness and need a very simple account as to why their parent or friend has had to go to hospital. Slightly older children will need to be told more. A simple story talking about good cells and bad cells may help. Every child needs to know what will happen while you are in hospital. Who will look after them, prepare their meals and take them to school? They also need to be reassured that your illness is not their fault. Whether they show it or not, children feel they may somehow be to blame and may feel guilty. Most children over 10 years of age can grasp fairly detailed explanations of what is wrong.

Adolescents can understand much more. They may have special needs in learning to cope with the situation. They may be torn between concern for you and trying to become more independent. An open honest approach is usually the best way for all children. You may find that your children rebel or turn quiet. This may be their way of showing their feelings. Even very young children can sense when something is wrong, so don’t keep them in the dark. They may think that things are much worse than they are.

There is a useful booklet available called What do I tell the children? – A guide for a parent with cancer. If you would like a copy, call the National Cancer Helpline 1800 200 700.
What you can do

Many people feel helpless when they are first told they have cancer. They think there is nothing they can do other than hand themselves over to the doctors and hospital. This is not true. There are many things that you can do at this time.

If you and your family understand your illness and its treatment you will be better able to cope.

- Always ask for information that is personal to you from your own doctors.
- Follow your doctor’s instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Write down the answers if you prefer.
- Let your doctor know if you have any problems or worrying side-effects. He or she can decide what to do to help you. If you say nothing, a small problem can become more serious.
- At times you may not be able to do the things you used to take for granted. But as you begin to feel better, you can set yourself some simple goals and slowly build your confidence again. Take one step at a time. Many people talk about ‘fighting their cancer’. This can help some people feel more in control of what is happening to them. You can do this by becoming more involved in your illness, like asking questions and getting information.
- Try to eat as well as you can. Eat little and often, including lots of different types of foods with plenty of fresh fruit and vegetables.
- Think about joining a ‘support group’. The Laryngectomy Association of Ireland was formed to meet the needs of patients, families and professionals who care for people with a
laryngectomy. These groups allow you to talk through your feelings with others who have had treatment for cancer. See page 69 for more information.

- Join a relaxation class or listen to relaxation tapes.
- There is help available if you smoke and would like to quit. The Irish Cancer Society Quitline offers support and assistance for smokers. You can talk to a specially trained stop-smoking counsellor who will help you prepare a plan and support you during this time. Call the Quitline 1850 201 203 (for the cost of a local call from anywhere in the country) weekdays 9.30 am – 5 pm for more information. Some hospitals have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.
- Take some regular exercise. Take it easy at first, building up the amount you do, as you feel stronger.
- Some people find it helpful to talk to a counsellor, if feeling very anxious or sad.

If the idea of changing your diet or taking exercise does not appeal to you, don’t do it. Just do whatever suits you. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby.
Who can help?

The most important thing to remember is that there are people ready to help you and your family throughout treatment and afterwards. The speech and language therapist is there to support and advise you on all aspects of living with a laryngectomy. The medical social worker in your hospital can also help in many ways. He or she provides support and counselling to the patients and their families and can give advice on benefits, entitlements and services available when you go home.

Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These nurses, along with other members of your medical team work together to meet your needs.

When you go home there are a variety of community health services available from your local health centre. These centres are staffed with GPs, public health nurses (who can visit you at home), welfare officers and home-help organisers. All these people can provide advice and support to you and your family.

You can get more information on the services available either from the medical social worker in the hospital before you go home or at your local health centre.

The Irish Cancer Society Helpline nurses will be happy to discuss any concerns you or your family may have, at any stage of your illness. They can give you more information about any of the services outlined above and can also let you know about support
services in your area. A useful booklet called *Directory of Cancer Care Services in Ireland*, is available free of charge from the Irish Cancer Society. For a copy call the National Cancer Helpline 1800 200 700.

**Life after treatment**

Many patients are delighted when their treatment ends and when told they no longer have cancer. However, some patients have to come to terms with the changes in lifestyle that occur after a diagnosis of cancer of the larynx. Most people are surprised at how long it takes to recover from treatment or a major operation. It is important to know that it can take at least a year for life to get back to normal. You can still feel tired and lacking in energy for many months after treatment has ended.

You may not be ready to lead as active a life as you did before and it is better not to fight these feelings, but allow your body the time it needs to recover. There are things that you can do to speed up the process of recovery and ensure that you have a good quality of life in the future.

**Anxiety**

You may find that you miss the regular contact with the people who looked after you while you were in hospital. You may be worried about the cancer coming back or trying to cope with the after-effects of surgery or other treatment. This anxiety can be overwhelming at times. It may help to talk about your feelings.

Try talking to your partner or a close friend. If you find this difficult, someone who has had the same illness may be able to
help. The Laryngectomy Association of Ireland is a support group for people who have had cancer of the larynx. It provides patients and relatives with information, advice and emotional support at time of diagnosis and throughout treatment.

Tell your doctor if you have a problem that is worrying you. If you are still anxious and upset, ask to speak to a counsellor about your feelings. It may help.

**Sadness and depression**
The whole experience of cancer may make you feel sad. Trying to adapt to a new way of life after diagnosis and treatment for cancer of the larynx may be difficult at first. You may have to cope with a change in your appearance and learn a new method of speech. You may blame yourself for having had cancer and cut yourself off from the rest of the world. You may wonder will life ever be the same again and feel very sad.

Sometimes strong feelings of sadness can turn into depression. If you think you are depressed, speak to your doctor. He or she may prescribe a course of antidepressant drugs or refer you to a doctor who specialises in the emotional problems of people with cancer.

**Lack of energy**
You may continue to feel quite tired after treatment ends. Do not be in a rush to get back to a normal routine at work. Just do as much as you feel comfortable with. Ask for help around the house or at work. Try to build rest periods into your day. Do not allow yourself to get overtired. If you are going out somewhere special have a rest before you go out. Save your energy for doing things you especially enjoy. As time goes on your energy levels should improve.
Smoking
There is help available, if you smoke and would like to quit. The Irish Cancer Society Quitline offers support and assistance for smokers. You can talk to a specially trained stop smoking counsellor who will help you prepare a plan and support you during this time. Call the Quitline 1850 201 203, weekdays 9am – 5pm. Some hospitals also run stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

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

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

Another concern you may have is whether your colleagues or customers will be able to understand you. There are speech amplifiers available which are helpful. These can be used in
one-to-one conversations, if you are speaking to a number of people at once or if you are talking on the telephone. Artificial larynxes (electro-larynges) are often very useful – they give your voice more volume and are clear on the telephone. They also save your voice if you are feeling tired or unwell.

Talk to your speech and language therapist about the different aids that are available to help you. He or she will advise you on the one best suited to your needs.
**Health cover**

Health cover falls into two categories – cover for medical card holders and for all other categories. At the end of this section there are some useful telephone numbers and addresses for further help.

**Hospital cover**

At present everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €45 a day charge up to a maximum of €450 in any 12 consecutive months. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

**Outpatient cover**

If you go to the outpatients or A&E department of a public hospital, without being referred there by a GP, you may be charged €45. There is no charge if you are referred by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E department first.

**Medical card**

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances.

Every person aged 70 or over has a right to a medical card and no means test is required. For most people, eligibility for a medical card is dependent on a means test. Financial guidelines are set out each year and these are available from your local health board or clinic. If your means are above but close to the guidelines, you
should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses, you may be granted a medical card. Also you may be eligible for a medical card as an individual because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

**Drugs Payment Scheme**

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a maximum of €78 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local health board office. You can also register for this scheme by filling in a registration form at your pharmacy.

**Private healthcare cover**

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, BUPA and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. It is advisable to check the level of cover provided by your insurance company, both for inpatient and outpatient services, before attending hospital.

**Benefits and Allowances**

**Disability benefit**

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

**Disability allowance**
You may qualify for Disability Allowance if you are not eligible for Disability Benefit and not able to work for at least a year. Disability Allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. You must have a means test and be medically suitable for this allowance. To be medically suitable, you should have an illness that has continued or may continue for at least one year. This means that you are unlikely to be able to work for at least a year due to your illness. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

**Invalidity pension**
This is a pension paid instead of a Disability Benefit or Allowance, if you are unable to work in the long term. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over 60 and have a serious illness or incapacity.

Your eligibility for this pension will also depend on your PRSI contributions. You are allowed a free travel pass and certain extra benefits, such as bottled gas, telephone rental, fuel allowance and...
assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Carer’s allowance
This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. There are a number of benefits with this scheme such as a free travel pass for the carer, free television licence, and home energy allowance. A free telephone rental has been extended to carers giving full-time care. There is also a contribution towards respite care. This is a means-tested allowance. For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. Application forms are available from your social welfare office or from the Carer’s Allowance Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Appliances
For patients who have medical cards most appliances are free of charge.

Travel to hospital
Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some health boards provide transport services to hospitals for outpatient appointments and day centres. Sometimes the health board may assist with transport costs for a person who has to travel a long distance to a hospital. In general, people who do not have medical cards may be charged for the service. However, the practice varies between
health boards and is often dependent on personal circumstances. Charges may be waived in certain cases, e.g. hardship, etc.

**Further information**

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

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

**For social welfare queries contact:**

Information Service  
Dept of Social and Family Affairs  
Áras Mhic Dhiarmada  
Store Street  
Dublin 1  
Tel: 01 874 8444  
Leaflet line: 1890 202 325  
Email: info@welfare.ie  
Website: www.welfare.ie

If you have queries about health and social services, contact the health board in your area.
Information is also available from your local Citizens Advice Centre. A list of these centres is available from

**Comhairle (formerly the National Social Services Board)**
7th Floor
Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000
Citizen Information: 1890 777 121
Email: comhairle@comhairle.ie
Website: www.comhairle.ie

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

*Directory of Cancer Care Services in Ireland* (published by the Irish Cancer Society). For a free copy call National Cancer Helpline: 1800 200 700. Email: helpline@irishcancer.ie

*Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local health board office. Tel: 01 671 4711 for local health board numbers. Website: www.doh.ie

*Guide to Social Welfare Services* (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie

*Entitlements for People with Disabilities* (published by Comhairle). Available from Comhairle. Tel: 01 605 9000. Email: comhairle@comhairle.ie
Irish Cancer Society services

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

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with family doctors and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your family doctor or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge for up to seven nights to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service by talking to a member of the homecare team, your family doctor or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

National Cancer Helpline

The Cancer Helpline gives confidential information, support and guidance to people concerned about cancer. It is a freefone service.
The specially trained nurses who staff the helpline have access to the most up-to-date facts on cancer-related issues, using a computerised directory and library of resources. The nurses can provide information to anyone enquiring about treatment, counselling and other support services. They can also help you to make contact with the various support groups that are available. The National Cancer Helpline 1800 200 700 operates weekdays from 9am – 5pm.

**Counselling**

Coping with a cancer diagnosis can be devastating. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the Cancer Helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

**Cancer support groups**

The Irish Cancer Society funds a range of support groups for people with specific cancers. The Laryngectomy Association of Ireland provides patients and relatives with information, advice and emotional support from time of diagnosis and for as long as it is needed.

**Cancer information booklets**

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

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial assistance to patients in need. Requests for this kind of help should be directed through your social worker, family doctor or public health nurse.

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

Irish Cancer Society
5 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

The Laryngectomy Association of Ireland
Irish Cancer Society
5 Northumberland Road
Dublin 4
National Cancer Helpline
1800 200 700
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Comhairle (formerly National Social Services Board)
7th Floor, Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000
Email: comhairle@comhairle.ie

Dept of Social and Family Affairs – Information Service
Áras Mhic Dhiarmada
Store Street
Dublin 1
Tel: 01 874 8444
Email: info@welfare.ie
Website: www.welfare.ie

Health Promotion Unit
Dept of Health and Children
Hawkins House
Hawkins Street
Dublin 2
Tel: 01 671 4711

Health insurers

BUPA Ireland
Mill Island
Fermoy
Co Cork
Local: 1890 700 890
Fax: 025 42122
Email: choices@bupa.ie
Website: www.bupa.ie

Voluntary Health Insurance (VHI)
VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie
## Cancer support centres

**ARC Cancer Support Centre**  
ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: info@arccancersupport.ie  
Website: [www.arccancersupport.ie](http://www.arccancersupport.ie)

**Bray Cancer Support & Information Centre**  
36B Main Street  
Bray  
Co Wicklow  
Tel: 286 6966  
Email: bcsc@iol.ie  
Website: [www.braycancersupport.ie](http://www.braycancersupport.ie)

**Cancer Information & Support Centre**  
Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 482 615

**Cork ARC Cancer Support House**  
Clifflade  
5 O’Donovan Rossa Road  
Cork  
Tel: 021 434 6688

**Donegal Cancer Support Group**  
Clar  
Co Donegal  
Tel: 074 974 0837

**The Gary Kelly Support Centre**  
Georges Street  
Drogheda  
Co Louth  
Tel: 041 980 5100  
Fax: 041 980 5101  
Email: info@garykellycentre.org  
Website: [www.garykellycentre.org](http://www.garykellycentre.org)

**Greystones Cancer Support**  
La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601

**HOPE**  
Enniscorthy Cancer Support & Information Centre  
6 Church Street  
Enniscorthy  
Co Wexford  
Tel: 054 38555

**Lios Aoibhinn Cancer Support Centre**  
St Vincent’s University Hospital  
Herbert House  
St Anthony’s  
Herbert Avenue  
Dublin 4  
Tel: 01 277 3545
Understanding cancer of the larynx

The LARCC Centre
Ballinalack
Mullingar
Co Westmeath
Tel: 044 71971
Email: info@larcc.ie
Website: www.larcc.ie

Mayo Cancer Support Association
Rock Rose House
32 St Patrick’s Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Slánú Cancer Help Centre
Birchall
Oughterard
Co Galway
Tel: 091 550050
Email: info@slanu.ie
Website: www.slanu.ie

Sligo Cancer Support Centre
2A Wine Street
Sligo
Tel: 071 70399
Email: scsg@tinet.ie

South East Cancer Foundation
Pairc Clinic
Lismore Park, Waterford
Tel: 051 590881

The Tuam Cancer Care Centre
30 Temple Jarlath Court
High Street
Tuam, Co Galway
Tel: 093 28522
Email: info@tuamcancercare.ie

Turning Point – Positive Health Centre
23 Crofton Road
Dun Laoghaire
Co Dublin
Tel: 01 280 7888
Email: turningpoint@eircom.net
Website: www.turningpoint.ie
Useful addresses outside Ireland

**American Cancer Society**
1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

**CancerBACUP**
3 Bath Place
Rivington Street
London EC2A 3JR
Tel: 0044 207 739 2280
Website: www.cancerbacup.org.uk

**Cancerlink**
89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Website: www.cancerlink.org

**National Cancer Institute (US)**
Website: www.nci.nih.gov

**The Ulster Cancer Foundation**
40–42 Eglantine Avenue
Belfast 9BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

**University of Pennsylvania Cancer Center**
Website: www.oncolink.com
Helpful books

Clan Newsletter
Available from: The National Association of Laryngectomee Clubs (NALC)
6 Rickett Street
Fulham
London SW6 IRU
Tel: 0044 207 381 9993
Website: www.nalc.uk.com

Cancer at Your Fingertips
Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1-85959-036-5

Challenging Cancer: Fighting Back, Taking Control, Finding Options
(2nd edn) Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1-85959-068-3

Cancer: What Every Patient Needs to Know
Jeffrey Tobias
Bloomsbury, 2001

What You Really Need to Know about Cancer
Dr Robert Buckman
Pan, 1997

Understanding Cancer
Gareth Rees
Family Doctor Publications, 2002

For more useful information please read the Directory of Cancer Care Services in Ireland. For a copy, call the National Cancer Helpline 1800 200 700.
Frequently asked questions

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

- What are the treatment options?
- What type of treatment do I need? Why is this one better for me?
- How successful is this treatment for my cancer?
- What side-effects or after-effects will I get?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- Is there anything I can do to help myself during treatment?
- How will you make sure that I am still clear of cancer?
- Will I need more tests after the treatment is finished?
Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer
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We hope that this booklet has been of help to you. If you have any suggestions as to how it could be improved, we would be delighted to hear from you. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If, after reading this booklet or at any time in the future, you feel you would like more information or someone to talk to, please phone our Cancer Helpline Nurses on Freephone 1800 200 700.

Would you like to help us?
The Irish Cancer Society relies entirely on voluntary contributions
The Irish Cancer Society is the national charity dedicated to eliminating cancer as a major health problem, and improving the lives of those living with cancer.