

Understanding

# Cancer of the Lung

Caring for people with cancer

## Understanding

# Cancer of the Lung

This booklet has been written to help you understand more about lung cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on lung cancer, its treatment and how it may affect you.

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



Specialist nurse	Telephone
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Family doctor (GP)	Telephone
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Respiratory physician	Telephone
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Surgeon	Telephone
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Medical oncologist	Telephone
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Radiation oncologist	Telephone
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Radiation therapist	Telephone
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Medical social worker	Telephone
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Emergency telephone number:

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

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- *Cancer Factsheet: Lung*. National Cancer Registry Ireland, 2013.
- *Guidelines for the Diagnosis and Treatment of Lung Cancer*. Irish Thoracic Society Lung Cancer Subcommittee, All-Ireland Lung Cancer Working Group, 3rd edn, 2009.
- *Lung Cancer Rapid Access Service GP Referral Guidelines*. HSE/NCCP, 2011.
- *Cancer Nursing: Principles and Practice*. CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.
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## Introduction

This booklet has been written to help you understand more about lung cancer. This booklet is about primary lung cancer – this is cancer that starts in the lung. It should not be confused with secondary lung cancer, where a different type of cancer, which started in another part of your body, has spread to your lung. The treatment of secondary lung cancer is different.

This booklet is divided into 4 parts:

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

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

## Reading this booklet

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

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email us at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). The Nurseline is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 65 for more about Daffodil Centres.



Cancer Nurseline Freephone 1800 200 700

## About lung cancer

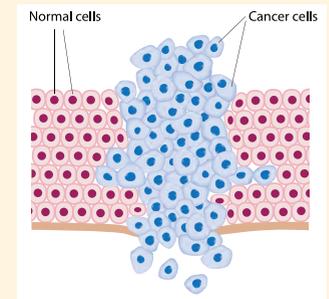


### What is cancer?

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

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

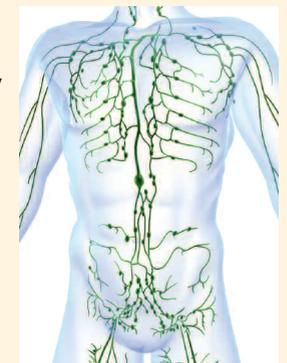
Tumours can be either benign or malignant. Benign tumours are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels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



Cancer cells

### What is the lymphatic system?

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



Lymphatic system



## To sum up

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

## What are the lungs?

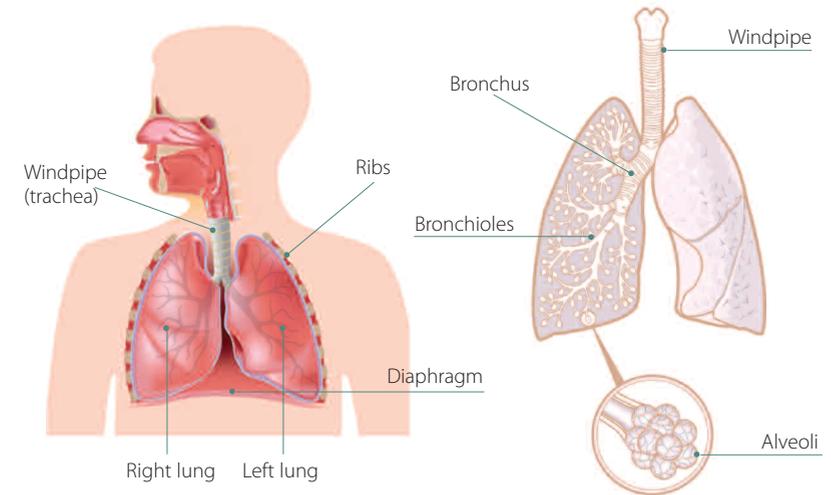
The lungs are a pair of organs found in your chest. They are shaped like cones. The right lung is slightly bigger and has three areas called lobes, while the left lung has two lobes. Between the two lungs is an area called the mediastinum. This contains your heart, trachea (windpipe), oesophagus (gullet) and many lymph nodes.

## How do the lungs work?

Your lungs form part of the respiratory system in your body, which allows you to breathe.

When you breathe in, you bring air into your lungs. The air passes from your nose or mouth down through your windpipe. From there it divides into two airways called the right and left bronchi, which go to each lung. These bronchi then divide into smaller tubes called bronchioles. Finally, the bronchioles become tiny air sacs called alveoli.

In the alveoli, oxygen from the air is passed into your bloodstream and carried to all the cells in your body. The cells need oxygen to live and carry out everyday functions. During cell activity, carbon dioxide is made. But as it is a waste gas your body must get rid of it. It does this by moving it from your bloodstream into the alveoli. When you breathe out, your lungs force carbon dioxide out.



## What is lung cancer?

Lung cancer is when the cells in your lung change and start to grow out of control. These cells increase to form a tumour. Many lung cancers start in the cells lining the bronchi. Cancers that start in the cells that make up the skin or the tissue lining of organs are called carcinomas. Lung cancers that start in the lining of the lung bronchi are called bronchogenic carcinomas.

When the tumour is malignant (cancerous), cells may break away from it and spread to other parts of your body.

Lung cancers can be either primary or secondary. Primary is when the tumour starts to grow in the lungs first. Secondary is when cancer has spread from somewhere else to your lungs. Only primary lung cancer is discussed in this booklet.

## What are the types of lung cancer?

The different types of lung cancer are recognised by looking at them under a microscope. Most lung cancers are divided into two main types: non-small cell lung cancer and small cell lung cancer. The two types behave in different ways and will need different treatments.

## Non-small cell lung cancer (NSCLC)

Most lung cancers are of the non-small cell type. There are three main types of this cancer:

- 1 **Squamous cell carcinoma:** These cells are found in the airways of your lung.
- 2 **Adenocarcinoma:** These cells are usually found at the edges of your lung where mucus is made.
- 3 **Large cell carcinoma:** These are large round cells that may appear in any part of your lung, and tend to spread quickly.

The cells in these subtypes can also differ in size, shape and chemical make-up.

## Small cell lung cancer (SCLC)

About 1 in 7 of all lung cancers is the small cell type. These cancers have small round cells that tend to grow quickly. They usually form large tumours and often spread to lymph nodes and other organs such as your bones, brain, adrenal glands and liver. This type of cancer often starts in the bronchi near the centre of your chest. It is usually due to smoking. In fact, it is very rare for someone who has never smoked to have small cell lung cancer. Another name for this type of cancer is oat cell. Small cell lung cancer is briefly discussed in this booklet. See page 20 for its treatment. You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you have any questions that this booklet does not answer.

## Other types of cancer affecting the lungs

A rare type of cancer that affects the lungs is mesothelioma. This is a cancer of the cells in the protective linings that cover your lungs, known as the pleura. Usually it happens when someone is exposed to a chemical called asbestos. Mesothelioma is not discussed in this booklet. For more information, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the factsheet *Mesothelioma and Asbestos* or download it from [www.cancer.ie](http://www.cancer.ie)

## How common is lung cancer?

About 2,200 cases of lung cancer are diagnosed in Ireland each year. It is the third most common cancer in men and women, excluding non-melanoma skin cancer.

Lung cancer usually affects people over the age of 40. The average age of diagnosis is about 70 years.

## What causes lung cancer?

Smoking is the cause of most lung cancers. There are also other risk factors that can increase the chance of getting lung cancer.

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

## Smoking and lung cancer

Cigarette smoking causes more than 8 out of 10 lung cancers. The risk increases with the amount of time you have smoked. Smoking a large number of cigarettes and smoking from a young age also increase the risk of lung cancer. Low tar cigarettes do not reduce your risk. Inhaling other people's cigarette smoke, known as passive smoking, increases the risk of lung disease and cancer too. But the risk is still much less than if you smoke yourself. Those who smoke pipes and cigars have a lower risk of lung cancer than cigarette smokers, but they are at a much greater risk than non-smokers.

## Other lung cancer risk factors

**Chemicals:** If you are exposed to certain chemicals in your workplace or elsewhere, in rare cases it might lead to cancer. These chemicals include asbestos, uranium, metal dust and fumes, nickel, paints, diesel exhaust, nitrogen oxides, etc. These risks are higher if you smoke as well. Air pollution may be a cause in some countries where it is particularly bad. Research studies are looking at this problem at present.

**Radon gas:** Radon is a radioactive gas found naturally in the soil. It leaves the soil and rises into the air, sometimes through cracks and holes in the foundation of your house. Radon is harmless when it escapes into

the air and is diluted. But if your home traps it inside, it can build up and cause harm. At high concentrations, it may increase your risk of developing lung cancer. Because it is colourless, odourless and tasteless, it can only be measured using special equipment.

**Family history:** It is believed that at least one faulty lung cancer gene can be passed down in families (inherited). If you have a parent, brother or sister with lung cancer, your risk of lung cancer is doubled.



### To sum up

- Lung cancer is a common cancer.
- There are two main types of lung cancer: Non-small cell lung cancer and small cell lung cancer.
- Cigarette smoking causes more than 8 out of 10 lung cancers. Exposure to chemicals or radon gas and a family history of lung cancer also increase the risk of developing the disease.

## Being diagnosed with lung cancer

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

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

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

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

- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie)

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to other people going through the same thing. Join our online community at [www.cancer.ie/community](http://www.cancer.ie/community)

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

### Telling people about your diagnosis



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

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

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can email the nurses at [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie). Ask for a copy of our booklet *Who Can Ever Understand? Talking About Your Cancer*. This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

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

## What tests will I have?

After you have been diagnosed with lung cancer, your doctor may want to do tests to find out more about your cancer and your general health.

Tests you may have include:

- Bronchoscopy
- Mediastinoscopy
- Thoracoscopy
- Biopsy
- Endobronchial ultrasound scan (EBUS)
- Endoscopic ultrasound scan (EUS)
- Bone scans
- MRI scan
- CT scan
- PET-CT scan
- Lung function tests
- Blood tests

**Bronchoscopy:** This test uses a small tube with a camera at one end. You will be given a sedative drug into a vein before the test to make you feel relaxed and sleepy, and a local anaesthetic will be sprayed onto the back of your throat. The tube goes through your nose or mouth and then down into your airways and your lungs. Here photos and samples from the lung tissue (biopsies) can be taken.



**Mediastinoscopy:** The mediastinum is the area in the middle of your chest containing your heart, large blood vessels and oesophagus.

A mediastinoscopy allows your surgeon to examine the area and the lymph nodes found there. This is to check if the cancer has spread.

Your surgeon will first make a small cut at the base of your neck. Then a thin flexible tube is put in. The tube has a light and a camera so the surgeon can look for any abnormal areas. Samples (biopsies) of this tissue can also be taken. These will then be looked at under a microscope to see if the cancer has spread.

A mediastinoscopy is done under general anaesthetic so you may need to stay overnight in hospital. The test itself takes about 20–30 minutes. Before the test you cannot eat or drink for a few hours.

**Thoracoscopy:** This is a test to look at the membranes that line the lungs. These are called pleura. An instrument called a thoracoscope is used. This is a flexible tube with a light and video camera attached to it.

You will usually be put to sleep before having a thoracoscopy. Or you may be given a sedative to make you sleepy and relaxed. During the test, your surgeon will make a cut between two ribs and put the thoracoscope in. This allows him or her to see if the pleura appear normal. During a thoracoscopy, your surgeon can take biopsies of the tissue.

**Lung biopsy:** A biopsy is when tissue samples are taken from your lung during surgery. The biopsies are sent to a laboratory where a doctor called a pathologist will look at the samples under a microscope. This can give information about the type of cancer and how fast it is growing (the grade).

**Endobronchial ultrasound scan (EBUS):** An EBUS is a special type of bronchoscopy that uses an ultrasound scan to take pictures inside and outside the lungs.

With an EBUS the bronchoscope tube has a small ultrasound probe on the end. The probe makes sound waves that are changed into pictures by a computer. The pictures can show how big the tumour is, and whether any nearby lymph nodes are enlarged.

The doctor can take biopsy samples from the lung or the nearby lymph nodes by passing a needle through the tube. This is called a transbronchial needle aspiration (TBNA).

You will be given a sedative to make you feel sleepy and relaxed during the test. Or you may have a general anaesthetic to put you to sleep. The test takes less than an hour and you can usually go home on the same day.

**Endoscopic ultrasound scan (EUS):** This is very similar to an EBUS but the tube with the ultrasound probe goes down your oesophagus (gullet) to give images of the area around the heart and lungs, to show if any of the lymph nodes in the centre of the chest are enlarged.

A fine needle can also be passed along the endoscope tube so that biopsies can be taken from the lymph nodes. You may be sedated for an EUS or you may have a general anaesthetic.

The test takes less than an hour and you can usually go home on the same day.

**Bone scan:** Bone scans can check for signs that lung cancer has spread to the bones.

Before the scan, you will have an injection of a very small amount of a mildly radioactive substance, or radionuclide, usually into your arm.

You will then have to wait for up to 3 hours for the radionuclides to travel through your body.

When the radionuclides have passed through your body, you'll be asked to lie down on an X-ray table. A camera will then scan your entire body. Abnormal bone absorbs more radioactivity than normal bone, so these areas will show up on the scan as areas of activity known as 'hot spots'.

The scan lasts for up to an hour and you'll be able to go home immediately afterwards. The amount of radioactivity used in these scans is very low and safe and will disappear from your body within a few hours.

**MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. It can tell if a cancer has spread beyond your lung. MRI scans are not often used for lung cancer unless the cancer is very close to the top of the lung.

An MRI scan does not hurt, but you may feel a bit uncomfortable while the pictures are being taken. It is also noisy but you will be given earplugs to wear during it. You might have an injection before the scan to highlight certain areas of your body.

During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. The scan takes about 30 minutes, although it may take longer. You do not need to stay in hospital after an MRI scan.

**CT scan:** This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The scan itself is painless and takes 10-30 minutes. You might be asked not to eat (fast) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.



As well as having a CT scan of your lungs, your doctor may decide to do a CT scan of your brain too. Some types of lung cancer can spread to the brain.

**PET-CT scan:** This is a combination of two types of scan: a CT scan, which takes a series of X-rays, and a positron emission tomography (PET) scan, which uses a low dose of radioactive sugar to measure activity in your cells. The amount of radiation is very small and won't harm you or make you radioactive.

Using the two types of scan together can give your doctor detailed information about your cancer and can show if it has spread to other tissues and organs.

Before the scan you won't be able to eat for around 6 hours. The radioactive sugar is first injected into a vein in your arm and travels to all the cells in your body. You then rest for about an hour and a half to allow your cells to absorb the radioactivity. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. The scan is taken after the radioactive sugar has had time to be absorbed.

The scan itself is painless and takes about 30 minutes.

Preparations for a PET-CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should be able to go home afterwards.

**Lung function tests:** Your doctor will organise a range of breathing tests to see how well your lungs are working. This is important if he or she decides to remove the tumour by surgery or give you radiotherapy later. The two main types of test are:

- **Pulmonary function tests (PFTs):** PFTs are breathing tests to check how well your lungs work. You blow into a mouthpiece on a machine. PFTs are not painful and take about 20 minutes.
- **Cardiopulmonary exercise stress test or CPET:** CPET measures your heart rate and breathing during exercise. You will be asked to do some exercise – such as riding an exercise bike – while breathing through a mouthpiece. You don't have to be fit to do the test. It lasts for about 40 minutes, but you will only be exercising for around 10 minutes.

**Blood tests:** You will usually have a range of blood tests taken. For example, a full blood count will tell if your blood has the right number of blood cell types. This test will also be done often if you are later treated with chemotherapy, as chemotherapy drugs can affect your bone marrow, where your blood cells are made. Other blood tests can spot problems in different organs such as your kidneys, liver and bones.

### Waiting for test results



It usually takes about a week for all the test results to come back. Naturally, this can be anxious time for you. You may also be keen to start your treatment as quickly as possible and worry about having to wait.

It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.



### To sum up

After being diagnosed with lung cancer, you will likely have further tests such as bronchoscopy, mediastinoscopy, thoracoscopy, endobronchial ultrasound scan (EBUS), MRI/ PET scans, lung function tests and blood tests.

## Staging lung cancer

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

### How is lung cancer staged?

There are different ways to describe the stages of cancer. The staging system normally refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor often uses this information to give your cancer a number stage – from 0 to 4. In general, the lower the number, the less the cancer has spread. A higher number, such as stage 4, means a more serious cancer. Some stages are further divided into A and B. Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

### What are the stages of lung cancer?

**Stage 1:** The cancer is inside the lung (localised) and has not spread to nearby lymph nodes.

**Stage 2 and 3:** The cancer may be larger in size and/or may affect the nearby lymph nodes or surrounding tissue.

**Stage 4:** The cancer has spread to a distant part of the body such as the liver, bones or the brain.



## Treatment and side-effects

### How is lung cancer treated?

#### Non-small cell lung cancer

The best treatment for your cancer will depend on:

- The type and size of the tumour
- Where it is in your lung
- If it has spread or not
- Your general state of health

You may have a combination of treatments. The main treatments for non-small cell lung cancer are:

**Surgery:** If the non-small cell lung cancer is found in one lung only – or in one lung with only lymph nodes close to the tumour involved – it may be possible to remove all the tumour by surgery (see page 24). You may also have surgery to stage your cancer or to help manage your symptoms. See page 38 for more about symptom control.

**Radiotherapy:** Radiotherapy can be used on its own or with other therapies to treat non-small cell lung cancer. It can also be used to control symptoms such as breathlessness or pain. Also, advanced radiotherapy treatments might be given to treat non-small cell lung cancer instead of surgery. See page 29 for more about radiotherapy.

**Chemotherapy:** Chemotherapy can be given before or after surgery. Sometimes chemotherapy is given together with radiotherapy. This is called chemoradiation. Chemotherapy can also be used to control symptoms. See page 33 for more about chemotherapy.

**Radiofrequency ablation (RFA) and microwave ablation (MWA):** These treatments use heat to treat very early stage lung cancers for people who can't have surgery or don't want to have surgery. They may also be used to relieve breathlessness if the tumour is blocking an airway. See page 36 for more information.

**Biological therapies:** These drugs work with in your body to fight cancer. Different biological therapies work in different ways. The type used for lung cancer usually work by blocking the signals that tell cancer cells to grow and divide. See page 36 for more details.

## Treating symptoms

You may have surgery or other types of treatment to help control symptoms such as shortness of breath or fluid on the lungs. Treatments include radiotherapy, chemotherapy, laser treatment, cryotherapy, stenting and radiofrequency ablation. For more about symptom control see page 38.

## Treatment for small cell lung cancer

In small cell lung cancer, chemotherapy is the main treatment. It is not unusual for doctors to give treatment to prevent the small cell lung cancer from spreading as a precaution, even if the signs of spread haven't shown up on your scans yet.

The chemotherapy is given to help you live longer with better control of your symptoms. Usually two or three drugs are used.

Treatment may include radiotherapy as well. Giving radiotherapy together with chemotherapy (chemoradiation) or after chemotherapy may improve the results of treatment.

Radiotherapy may also be used to relieve symptoms such as pain or to shrink tumours that have spread to other parts of your body, such as your brain. Sometimes, if you have responded very well to chemotherapy, radiotherapy is given to your brain to reduce the risk of the cancer spreading there. This is called prophylactic cranial irradiation. Radiotherapy is used for the brain because most chemotherapy drugs cannot pass into the brain. This is because of the brain's natural protective barrier, called the blood-brain barrier.

Surgery is rarely used to treat small cell lung cancer. But if the tumour is very small and found in one lung only, surgery may be possible. If this applies to you, your doctor will discuss it with you in more detail.

## Who will be involved in my care?

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

<b>Surgeon</b>	A doctor who specialises in surgery and who can remove a tumour from your body.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients using radiotherapy.
<b>Radiation therapist</b>	A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.
<b>Oncology liaison nurse / Clinical nurse specialist</b>	A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family throughout your treatment.
<b>Medical social worker</b>	A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.
<b>GP (family doctor)</b>	You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.
<b>Palliative care team</b>	This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.

<b>Physiotherapist</b>	A therapist who treats injury or illness with exercises and other physical treatments.
<b>Dietitian</b>	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
<b>Psycho-oncology team</b>	These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
<b>Psychologist</b>	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
<b>Counsellor</b>	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
<b>Community health services</b>	This includes family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

## Deciding on treatment

**Multidisciplinary team:** A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a thoracic surgeon, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

**Treatment options:** Your doctor and nurse will explain your treatment options to you. Ask as many questions as you like, no matter how small or trivial you think they are. All questions are

important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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

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

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

>>> If you smoke, your doctor may advise you to try to stop smoking. See page 45 for advice.

## Giving consent for treatment

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again.

Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

### Individual treatment

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

## Surgery

The aim of curative surgery is to remove the part of your lung containing the tumour and any nearby lymph nodes. The lymph nodes will then be checked for cancer cells. Knowing if the cancer has spread to the lymph nodes also helps your doctors decide if you need any other treatment.

Before your surgery you will have an assessment at a pre-admission clinic (PAC). You will have tests like a heart test (ECG) and lung tests (PFT and CPET). See page 16 for more on lung function (breathing) tests.

The following factors will help your doctor decide if you are suitable for surgery:

- Your type of tumour
- The size of tumour
- Where it is found in your lung
- If it has spread to other tissues
- The results of your lung function (breathing) and cardiac (heart) tests
- Your general health

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## Types of surgery

The type of surgery you have will depend on the size of the tumour and where it is. There are three main types of surgery available:

- 1 **Wedge resection or segment resection (segmentectomy):** A small section of a lobe of your lung is removed. A segment resection removes slightly more of the lung than a wedge resection.
- 2 **Lobectomy:** This is when a lobe of your lung is removed. Removal of 2 lobes is called bi-lobectomy.
- 3 **Pneumonectomy:** Here an entire lung is removed.

During surgery, your surgeon will usually remove lymph nodes near the tumour, as they are usually the first places where the cancer spreads.

Sometimes patients worry they will be unable to breathe properly after surgery because part of their lung will be removed. But you will still be able to breathe with just one lung.

## Getting ready for surgery

You will not be allowed to eat anything from the midnight before surgery. You may be given an injection of heparin and surgical stockings to wear to prevent a clot developing in your legs after surgery. Before you go to theatre your nurse may give you medication to make you feel more relaxed and sleepy.

## How is surgery done?

There are two main ways of doing surgery for lung cancer: keyhole surgery and open surgery.

**Keyhole surgery** means the cancer is removed through 2-4 small cuts between the ribs, guided by a tiny camera. People often recover more quickly from keyhole surgery than from open surgery and the scars are smaller. Video-assisted and robotic-assisted thoracoscopic surgery (VATS and RATS) are types of keyhole surgery used for lung cancer. They are not suitable for every patient.

**Open surgery** means that the surgeon will make a cut (incision) in your chest to open it up by spreading the ribs so that he or she can do the operation to remove the cancer. You will have a larger scar afterwards.

## After surgery

After surgery you will be closely monitored in the intensive care unit (ICU), the cardiothoracic high-dependency unit (HDU) or on the ward. When you wake up, you will notice a number of tubes attached to your body. They may look alarming but they are normal after an operation like this.

- There will be 1 or 2 plastic tubes (chest drains) near your wound site. These are to help your lung re-expand and drain away fluid from your chest cavity.
- A drip will be put into a vein in your arm. Through this you will be given fluids until you can drink again.
- You will be wearing an oxygen mask or nasal oxygen prongs. These will give you extra oxygen to help you breathe.
- A small thin tube called a catheter may be put into your bladder to drain your urine into a bag. This means you don't have to get out of bed to go to the toilet.
- There may be a tube in your back (epidural or paravertebral catheter) or at your wound site to deliver pain medication.

All of these tubes and drains will be taken out as you get better. You will have regular chest X-rays to make sure your lungs are working properly.

## Side-effects of surgery

Side-effects of surgery for lung cancer include:

- Pain and feeling sick
- Reduced mobility
- Weakness
- Reduced bowel movements
- Shortness of breath

**Pain and feeling sick:** It is common to have some pain after surgery for lung cancer. Some patients also feel sick. Your doctor will prescribe medicine to relieve your pain or sickness.

There are lots of different ways to relieve pain. You may have a combination of methods to keep your pain under control. For example, epidural, tablets, injections, patches or suppositories, or you may have a patient controlled analgesia pump (PCA). A PCA sends pain medication into your blood when you press a button. A nurse will show you how to use it to reduce your pain. Always ask for help before the pain or sickness gets bad. Being pain free will help you to recover better, so if

the pain relief is not working, let your nurse know so that your medication can be increased or changed.

You may need to take painkillers for 6-8 weeks after surgery, or even longer. Your doctor will give you a prescription for painkillers to take home with you if you need them. Your GP can give you repeat prescriptions if necessary.

**Reduced bowel movements:** The anaesthetic used during your operation slows down the movement of your bowel. As a result, it takes a few days before you can return to eating and drinking. You will quickly be able to take sips of water again. The amount of fluids you can take will then be increased. Most people can manage a light meal within 1 or 2 days of surgery. You will be monitored to make sure your bowel habits get back to normal.

**Reduced mobility:** To help with your mobility after surgery, you will be encouraged to move your legs and do deep breathing exercises at least once an hour and to follow any other exercise programme you have been given. The nurses and physiotherapist will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better.

**Shortness of breath:** Some patients may feel short of breath because they have less lung tissue to supply their body with oxygen. Usually, this gets better as the lung tissue re-expands and heals after surgery. A physiotherapist will show you how to cough and turn in the bed. The physiotherapist will also show you how to do breathing exercises and use equipment such as an incentive spirometer or an exercise bike. By doing the exercises, you will help to re-expand the remaining lung tissue, increase your lung capacity and get rid of excess fluid and air in your lung.

**Incentive spirometer:** An incentive spirometer is a device that tries to exercise your lungs and improve your breathing. When you breathe in with your mouth over a mouthpiece it makes a ball in a tube rise up. The physiotherapist will ask you to try to keep the ball up at the top of the tube for a few seconds by holding your breath. Gradually you can change the settings on the device to increase the level of exercise.

**Weakness:** Surgery for lung cancer is a major operation. It may take weeks or even months to get back your old strength. The recovery period varies from patient to patient.

The muscles of your chest and the arm of the affected side may become weak too. The physiotherapist will show you special exercises to help rebuild muscle strength. You will help to speed up your recovery if you spend a short time each day doing the exercises at home.

### Going home

Most people are ready to go home 5–7 days after surgery. Before you go home you will have an X-ray to make sure your lung is working properly. Your wound will be checked to make sure it is healing and there is no infection. Signs of infection include redness or swelling around the wound, the wound feeling warm or discharge from the wound. You may also have a fever. Tell your nurse or doctor if you have any of these symptoms after you go 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. That way he or she can help put in place any community services that you may need after you leave hospital.

You will be given a date to come back for a check-up, usually about 2–3 weeks after your surgery. Your doctor will check how you are and will discuss any biopsy or other test results. Your doctor will also talk to you about any further treatment you may need. For more about follow-up, see page 50.

**>>> If you have a worry or symptom before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.**



### To sum up

- The aim of curative surgery is to remove the part of your lung containing the tumour.
- Surgery may be of benefit when the tumour is found in one area of your lung and there are few or no lymph nodes affected.
- The types of surgery include a wedge or segment resection, lobectomy or pneumonectomy.
- The side-effects of surgery can include pain and feeling sick, reduced bowel movements, reduced mobility, weakness and shortness of breath. Not all patients will get these problems.
- Regular breathing exercises will build muscle strength in your lung after surgery.
- Most people are ready to go home 5–7 days after surgery.

## Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells. With lung cancer radiotherapy may be given to try to cure early cancer or after surgery to reduce the risk of cancer coming back. Radiotherapy is also used to control symptoms when lung cancer has spread to other parts of the body (palliative radiotherapy).

Radiotherapy can be given in two ways: externally and internally. With external beam radiotherapy, the radiation comes from machines that aim rays directly at your tumour or the tumour site.

With internal radiotherapy, the radiation source is placed inside your body in special applicators on or near your tumour. It is possible to have both external and internal radiotherapy.

### Planning your treatment

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

In external radiotherapy an important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area to be treated. You may have extra scans or X-rays taken but this is to plan your treatment only. The treatment field or area will then be marked carefully on your skin with tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.



CT simulator

### Getting your radiotherapy treatment

You will usually get your radiotherapy treatment around 10 days after the planning appointment. Radiotherapy is normally given in special cancer treatment centres, usually hospitals or clinics. As a result, the centre may be some distance from the hospital where you received surgery or chemotherapy.

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

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

External radiotherapy does not make you radioactive. It is safe for you to mix with family and friends. Pregnant women or children are not at risk.



External radiotherapy

>>> External radiotherapy does not make you radioactive.

### How much radiotherapy do I need?

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

### Stereotactic radiotherapy

Stereotactic radiotherapy is a very precise, high dose radiotherapy treatment. It is usually used to treat cancer at an early stage. It is not available in all hospitals because specialist equipment and skills are needed. The radiation is aimed at your tumour from many different points. This means that less of your healthy tissue is exposed to radiation, so there are fewer side-effects than with the usual type of radiotherapy.

**Planning your treatment:** Planning for stereotactic radiotherapy usually takes 1-2 hours. The specialist uses a CT scanner to work out how to shape the radiotherapy beam so it fits your tumour exactly. As you breathe in and out the tumour will move too. This is called tumour motion. A special device or box placed just below your breast bone during the CT can track the rise and fall of your chest and the tumour motion as you breathe. This is called 4-dimensional CT scanning.

It is very important that you stay still during your treatment. To help you do this, the radiation technician will make a mould for you to lie in during your treatment. To make the mould, you will lie on a vacuum pac, which is like a plastic mattress full of air. The air is then sucked out of the vacuum pac so that it moulds around your body. Each time you receive your treatment, you will be put into this mould.

**Having your treatment:** You will normally have 3-8 fractions (treatments), depending on where the tumour is. This means you will have to go to the hospital a number of times. Each session will last about an hour. The treatment itself does not take very long. But it will take a little while to get you into the right position in your mould.

When you are in the right position, your upper chest will be covered with a thin sheet. The box that traces your breathing will be put on your breast bone. The box helps the radiation beam to target the tumour accurately by following the movement of your chest as you breathe – you do not need to keep still by holding your breath.

You will not feel anything but may hear a beeping sound. This is normal and means the treatment is happening.

During the treatment the radiation therapist will watch you on a television screen and will talk to you through an intercom.

For more information on radiotherapy treatments, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, *Understanding Radiotherapy*, or download it from [www.cancer.ie](http://www.cancer.ie)

### Internal radiotherapy (brachytherapy)

With lung cancer, internal radiotherapy is sometimes used to reduce the size of a tumour that is blocking an airway and making it hard to breathe. See page 38 for more information.

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

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

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

- Difficulty swallowing or sore throat
- Weight loss
- Cough and shortness of breath
- Skin changes
- Feeling very tired
- Feeling sick or vomiting

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

Most side-effects go away once treatment is over, but do let your doctor know about them if they continue. Your medical team will explain your treatment and any possible side-effects to you. For more information, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, *Understanding Radiotherapy*, or the DVD, *Radiation Therapy: A Patient Pathway*.



### To sum up

- Radiotherapy is when high-energy rays are used to kill cancer cells.
- Radiotherapy is painless and each session only takes a few minutes.
- Side-effects of radiotherapy to the lung include difficulty swallowing, sore throat, weight loss, cough or breathing problems, skin changes, tiredness and feeling sick.

## Chemotherapy

Chemotherapy is a treatment using drugs to kill cancer cells. Chemotherapy may be given:

- Before surgery to make the tumour smaller (neoadjuvant treatment).
- After surgery to help prevent cancer spreading or coming back (adjuvant treatment).
- To control cancer that has spread or come back.
- With radiotherapy to improve the results of treatment. This is called chemoradiation.

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 your body.

### How often do I need chemotherapy?

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

### How do I get chemotherapy?

Chemotherapy may be given directly into a vein as an injection or through an intravenous infusion (drip). Some drugs may also be given as tablets.

Usually your chemotherapy will be given in the oncology day ward and you will be able to go home the same day.

### What kinds of drugs are used?

There are several chemotherapy drugs used to treat lung cancer. Most patients with lung cancer who need chemotherapy will get a combination of two or three drugs. For example, cisplatin or carboplatin along with another drug such as gemcitabine, etoposide, paclitaxel or pemetrexed. Your doctor or nurse will discuss your treatment and any possible side-effects with you.

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

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

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

Most side-effects can be helped with medication. In most cases the side-effects go away when the treatment ends or soon after.

Side-effects may include:

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

**Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 43.

**Changes in kidney function:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination, swelling of the hands and feet (oedema), or headaches, as these can be signs of kidney damage.

**Bruising/bleeding:** Chemotherapy can stop your bone marrow from making enough platelet cells. With fewer platelets you may bleed or bruise very easily. You will have regular blood tests to count the

number of platelets in your blood. Tell your doctor or nurses if you have any bruising or bleeding you can't explain, such as nosebleeds, blood spots or bleeding gums.

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

**Nausea (feeling sick) or vomiting (getting sick):** If you feel sick it can happen during or after treatment and may last for several hours. Always take any anti-sickness medication you are given, even if you don't feel sick, as it can stop the sickness from happening in the first place.

**Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

**Other side-effects:** For information on chemotherapy and fertility, see page 49.

>>> If you have other symptoms that concern you, or feel unwell, tell your doctor or nurse straight away. He or she will tell you what to do.

### More information

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



### To sum up

- Chemotherapy is a treatment using drugs to kill cancer cells.
- The drugs can be given in tablet form, directly into a vein as an injection, or through an infusion (drip).
- The side-effects vary from person to person and depend on the drugs used.
- Most side-effects are well controlled with medication.
- Common side-effects include: anaemia, nausea, fatigue, bruising and changes in kidney function.

## Radiofrequency ablation and microwave ablation

Radiofrequency ablation (RFA) and microwave ablation (MWA) use heat to destroy cancer cells.

You'll be given a local anaesthetic and sedation before treatment begins. In some cases, a general anaesthetic is used instead. Your doctor will place a small needle-like probe into the lung tumour through your chest. This is usually done using a CT scanner to make sure the probe is in the right place. Radiowaves or microwaves are then passed down the probe into the tumour to heat and destroy the cancer cells.

It is common for people to have some pain or discomfort and to feel tired after RFA or MWA. You'll usually need to stay in hospital overnight for these treatments. RFA and MWA can be repeated if necessary.

## Biological therapies (targeted therapies)

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

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

Some treatments fit into more than one of these groups:

Doctors can now test tissue taken from your tumour to see if your lung cancer will respond to a particular biological therapy. This is called mutation testing.

Different types of biological therapies may be used to treat lung cancer.

Examples of biological therapies used for people with non-small cell lung cancer are erlotinib (Tarceva®), gefitinib (Iressa®) and crizotinib (Xalkori). Some drugs are given in tablet form. Others are given into a vein through a drip.

## Side-effects

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

Side-effects of biological therapies depend on the drugs being used and vary from person to person.

Common side-effects include:

- Skin changes (dry skin, rash, sun sensitivity)
- Higher risk of getting an infection
- Vision changes (blurred vision, double vision, flashing lights)
- Diarrhoea or constipation
- Loss of appetite
- Feeling sick
- Feeling very tired (fatigue)

Your doctor and nurse will explain the treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you are having any symptoms that are troubling you.

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

## New biological therapies

New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 46). Ask your doctor if there are any biological therapies available to treat your cancer or any trials that are suitable for you.



## To sum up

- Biological therapies work with your body to fight cancer.
- The drugs can be given by tablet or into a vein through a drip.
- Some side-effects include small allergic reactions, skin rash, diarrhoea, nausea and loss of appetite.

## How can my symptoms be relieved?

Some of the most common symptoms of lung cancer are:

- Blocked airway
- Shortness of breath (dyspnoea)
- Fluid on the lungs
- Cough
- Pain
- Fatigue
- Blocked vein (superior vena cava obstruction)

These symptoms can come and go and they may be either mild or severe. If you have symptoms that are troubling you, it is important to let your doctor or nurse know. He or she should be able to give you treatment to help. Depending on the stage of your cancer, you may also have help from the palliative care team. The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness and pain. Palliative care also offers emotional support and comfort to patients and their families. See page 51 for more on advanced cancer.

### Blocked airway

In some cases lung cancer can block your windpipe (trachea) and cause breathing problems, infections or a collapsed lung. The following treatments can help:

#### Internal radiotherapy

Sometimes a special type of internal radiotherapy called endobronchial radiotherapy or brachytherapy can help. This is when a source of radiation is put close to or inside the tumour. Internal radiotherapy may be given if the tumour is blocking one of your airways, causing your lung to collapse, or if you find it hard to breathe.

First, a thin tube called an applicator is put inside your lung for a short while using a bronchoscope. The tube is then linked to another tube that is attached to a machine. When the machine is switched on, it causes the source of radiation to pass inside the tube in your lung. This way of opening up the airway is often done in one session.

#### Laser therapy

Laser therapy aims to reduce the size of a tumour that is causing a blockage. The laser beam is powerful and can cut away at the tumour like a surgical knife. The laser also seals off blood vessels so there is little bleeding afterwards. It may not destroy the entire tumour, but it can relieve your symptoms.

You will be given a general anaesthetic if you are having laser therapy. Once you are asleep, your doctor will put a tube called a bronchoscope down your throat and into your lungs. The laser tube then goes down inside the bronchoscope. The laser beam is turned on and burns away as much of the tumour as possible.

Laser therapy is very safe and most people have no side-effects. Usually you are allowed home the next day unless there has been an infection below the blockage. In this case, it may be relieved with antibiotics and physiotherapy.

If the tumour grows back, the laser therapy can be repeated. You can also have chemotherapy or radiotherapy to slow the growth of the tumour and give you relief.

#### Stenting

Stenting is a treatment that uses a mesh tube, which can hold your airway open and relieve any breathing difficulties caused by the tumour blocking or narrowing your lung airways.

Stents are usually put in under a general anaesthetic. The stent can stay in your lung permanently and shouldn't cause you any problems.

#### Cryosurgery

Cryosurgery, or cryotherapy, uses extreme cold to freeze and destroy cancer cells. An instrument called a cryoprobe is placed close to the tumour through a bronchoscope tube. Liquid nitrogen flows through the probe to freeze the tumour. This treatment can be repeated if the tumour grows back.

Chemotherapy (see page 33), external radiotherapy (see page 29) and ablation treatments (see page 36) may also be used to relieve a blocked airway.

### Shortness of breath (dyspnoea)

Shortness of breath can be very uncomfortable and distressing. You may find that it makes you feel anxious and stops you from doing things that you like to do. This symptom may be caused by your tumour or because of treatment. For example, you may have had part of your lung removed or you may have developed a chest infection while on chemotherapy.

Discuss this problem with your doctor or nurse. He or she can decide what to do. It may be possible to relieve the problem that is causing the shortness of breath. For example, you may have extra fluid on your lung that is making it hard for you to breathe in a relaxed way.

By removing this fluid your lung can re-expand and your breathing becomes easier (see below for details). Another way to relieve the shortness of breath can be through breathing exercises. For example, by using an incentive spirometer (see page 27 for more).

Other ways of helping to ease shortness of breath could include a blood transfusion if you have a low red blood cell count or antibiotics if you have a chest infection. Your doctor may organise oxygen therapy at home for you if they feel it will help.

### Fluid on the lungs (pleural effusion)

Fluid may build up between the linings of your lung. This is known as a pleural effusion and can cause you to feel short of breath. Your doctor may take a sample of this fluid using a small needle or may decide to drain the fluid. This can be done by putting a small tube into your chest under local anaesthetic. The tube can then be removed once all the fluid has stopped draining.

Any shortness of breath is likely to get better after the fluid is drained. If the drainage has improved your symptoms and if the fluid starts to build up again, your doctor may decide to do a pleurodesis. Pleurodesis may be done under local or general anaesthetic.

Pleurodesis involves putting medication (usually a sterile talc) into your chest through the chest tube to make the linings of your lung to stick together. This prevents fluid building up again. Or sometimes a tube (catheter) may be put under your skin and threaded into the pleural effusion. This can be left there for the long term. A vacuum bottle or bag attached to the tube can then be used to drain the fluid as needed.



### Tips & Hints – shortness of breath



- Ask the physiotherapist or nurse to show you some breathing exercises that will help to strengthen your muscles used in breathing. Follow any exercise plan they recommend.
- The physiotherapist can also show you ways to sit that will increase the amount of air you can take into your body.
- You may find that you sleep better in a comfortable chair than in a bed.
- Avoid doing things that increase your shortness of breath, such as bending over and climbing flights of stairs. Take your time getting dressed and wear clothes and shoes that are easy to put on.
- Anxiety can make a breathing problem seem much worse, so a quiet setting can really help. Listen to relaxation tapes too.
- If you are anxious and upset, ask to speak to a counsellor about your feelings – it may help.

### Cough

Cough is another common symptom of lung cancer. An irritating cough can really affect your quality of life. You may complain of not being able to sleep, shortness of breath and pain. It is important to find out the cause of the cough. The tumour, a chest infection or bronchitis may cause the cough. Treatment with radiotherapy or antibiotics may help.



## Tips & Hints – coughing



- Drink plenty of fluids, such as water and fruit juice, if you are coughing up a lot of phlegm. This will loosen it and make it easier to cough up.
- Ask your doctor or nurse to recommend a good cough mixture.
- Tell your doctor if your cough is dry and irritating. You may not be coughing up any phlegm. He or she may give you medicine to reduce or stop the cough.
- Avoid situations that make your cough worse, such as a smoky atmosphere or sudden changes in temperature. Make sure you have fresh air wherever you are sitting. Open a window or use a fan to create a light breeze.

## Pain

For many patients with lung cancer, pain is one of the main symptoms that prompt them to go to their doctor in the first place.

A lung tumour can cause mild or severe pain in your chest by pressing on nearby tissues and organs. Pain can also be caused by the tumour spreading to other parts of your body, such as your bones. The pain may be constant or present only now and then.

Your doctor will try to find out what is causing the pain. Surgery, radiotherapy and chemotherapy can all help to ease pain. There are also a lot of good painkillers available. Your doctor will decide which painkiller is best suited to the type of pain you have. If the medication does not kill the pain, tell your doctor or nurse. A specialist who manages pain and other symptoms may also be able to help you. He or she can arrange for you to try out different painkillers to find out what suits you best. There are also other ways to treat pain, such as nerve blocks and epidural injections. If you need more information, ask your doctor or nurse.



## Tips & Hints – pain

- If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain you are in. There is no need to suffer in silence or play down the amount of pain you have.
- Describe the pain as clearly as you can. Is it a dull pain? A sharp sudden pain? A pain that is always there or one that comes over you in waves? Is it mild or severe? Do you wake up in pain during the night? It may help to write down the times you get the pain and what makes it better or worse. You could show this record to your doctor or nurse – it may help to explain your problem.
- If you only have pain from time to time, take the painkillers when you need them. But if the pain is there most of the time or all of the time, take your painkillers regularly. This is most important to keep your pain under control.
- Even though your pain may be well controlled most of the time, you may notice that the pain is worse at night and wakes you up. Discuss this with your doctor or nurse. You can get extra medication to help with this 'breakthrough pain'.
- If you have constipation (a side-effect of painkillers), take a laxative every day. Drink plenty of clear fluids such as water to keep your bowel habit regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.
- If you are feeling sick (a side-effect of painkillers), your doctor may give you anti-sickness tablets. Take them 30 minutes before your painkillers. The nausea often improves as you get used to your medication.

## Fatigue

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

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

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)

- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

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

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

### >>> Tips & Hints – fatigue



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

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

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

### Blocked vein (superior vena cava obstruction (SVCO))

The superior vena cava is a large vein in the chest. If your cancer or lymph nodes affected by the cancer press on the superior vena cava it can stop the blood flowing through the vein. This is called superior vena cava obstruction (SVCO).

Symptoms of SVCO can develop quite quickly and include swelling of your face and neck, a feeling of fullness in your face when you bend over, breathlessness, headaches and dizziness. Contact the hospital if you have any of these symptoms.

Radiotherapy usually works well to shrink the cancer and improve the symptoms of SVCO. You may also have chemotherapy, or surgery to insert a small tube (a stent) into the vein to keep it open.

### Should I stop smoking?

It is never too late to stop smoking. If you stop, it reduces your chance of the cancer coming back and another one developing. It also reduces your chance of developing other illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example:

- It can cause more pain after surgery.
- It can increase the risk of infection after surgery.
- It can lead to complications with the general anaesthetic.
- It can reduce how well chemotherapy or radiotherapy works.
- It can make the side-effects of chemotherapy and radiotherapy worse. It can also cause rarer side-effects such as breathing and heart problems.

### How can I stop smoking?

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. The Quitline is open Monday to Friday 10am to 7pm and Saturday 10am to 1pm.

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

Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital and ask to see the smoking cessation officer while you are in hospital.

### If a loved one has cancer and you smoke



Smoking can damage not only your own health but also the health of those around you. This can be a greater problem if your loved one has cancer. If you smoke around them, you are increasing their risk of the cancer returning or another one developing. This could cause them great worry and may even bring conflict. Try to support your loved one by not smoking in their company or consider giving it up.

## Clinical trials

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

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

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

Your doctor can tell you if there are any trials suitable for you.

### More information

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

Cancer Nurseline Freephone 1800 200 700



## Cancer and complementary therapies



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

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

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

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

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

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

### More information

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



## Will treatment affect my sex life and fertility?

### Sex and sexuality

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

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

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

There is no set time for you to be ready to have sex again. It varies from person to person. If you have had surgery it may be some weeks before you will feel well enough to have sex again. Your doctor will advise you if you can have sex while on radiotherapy. Once you return to your usual routine your interest in sex should return too. To begin with you may feel more comfortable enjoying other forms of closeness such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

### Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during treatment and for some time afterwards.

For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

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

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

### Asking for advice

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

### Fertility

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

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

## What follow-up will I need?

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

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

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

## Staying healthy after treatment

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

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

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

A healthy lifestyle includes:

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

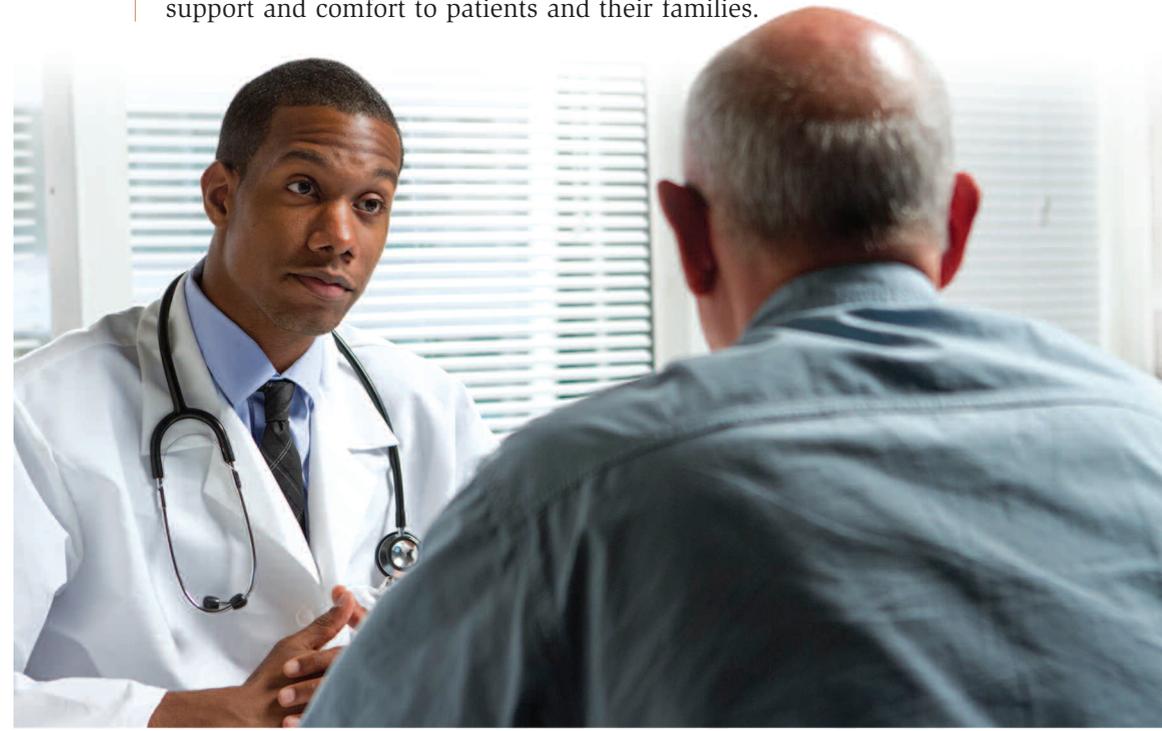
If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website [www.cancer.ie](http://www.cancer.ie) for tips and publications on healthy living.

## How is advanced cancer treated?

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

If your cancer is advanced it can still be treated. The aim of treatment is usually to try to control the cancer rather than to cure it. Your doctor may advise different chemotherapy drugs or biological therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 46). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment can help you to live longer with better control of your symptoms. See pages 38-45 for more on controlling symptoms. Your doctor will discuss the best treatment option for you with the healthcare team. Your doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer. Palliative care also offers emotional support and comfort to patients and their families.





## Coping and emotions

### How can I cope with my feelings?

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

#### Common reactions include:

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

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

#### Anxiety and depression

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

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

#### Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Our cancer nurses can give you details of where free counselling is available and also provide confidential advice, support and information on any aspect of cancer. You can also contact the nurses by email:

**cancernurseline@irishcancer.ie**

## Ways to get support



**Find out about cancer support services in your area.** There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 67 for more about cancer support services.

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

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

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

**Talk things through.** It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital. To speak to one of our cancer nurses in confidence visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700.

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

## Learning to cope

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

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

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

### How can I help myself?

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

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

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

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

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

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

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

**Try complementary therapies.** Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 47 for more information on complementary therapies.

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

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

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

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

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

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

## Positive emotions

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

## How can my family and friends help?

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

### How to talk to someone with cancer



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

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

## Talking to children and teenagers

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

### Saying nothing

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

### How to tell your children

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



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

### Further information and support

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

## Advice for carers

Caring for someone with lung cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Other people may need more support and care.

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

### Looking after your loved one

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

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

**Talk to the dietitian:** If your relative or friend has had major surgery, talk to the dietitian before the discharge date. He or she will give you useful advice on the best foods and how to prepare them.

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

Our booklet *Caring for Someone with Lung Cancer* has lots of information on giving medical, practical and emotional care to someone with lung cancer. It also has support for you and tips to help you cope. For a free copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet from our website, [www.cancer.ie](http://www.cancer.ie)



## Looking after yourself

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

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

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

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

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

**Find carers support organisations or local cancer support services:** Find out about groups and organisations especially for carers of people with cancer, which can provide practical help and support for you as a carer. Many local cancer support centres have services for carers too.

## Life after cancer

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

Feelings you may have include:

- **Fear of cancer coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with concerns such as finances, work and family issues that may have been on hold during your treatment
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**

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

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 54 for other ways to get support.

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



## Support resources

### Coping with the financial impact of cancer

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

#### Medical expenses

Medical expenses that you might have to pay include:

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

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

**If you have a medical card**, you will probably have very little to pay for hospital and GP care or your medication. Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

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

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

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

## Benefits and allowances

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

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

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

Always have your PPS number to hand when you are enquiring about entitlements and benefits. It's also a good idea to keep a photocopy of any forms or correspondence.

## If you have financial difficulties

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some help with travel costs. See page 66 for more details of our Volunteer Driving Service and the Travel2Care fund. You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

## More information

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

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

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

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

## Irish Cancer Society Services

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

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

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am - 6pm and Friday 9am - 5pm. You can also email us on [cancernurseline@irishcancer.ie](mailto:cancernurseline@irishcancer.ie) or visit our Online Community at [www.cancer.ie](http://www.cancer.ie)
- For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: [remote@slis.ie](mailto:remote@slis.ie)
- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

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

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

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



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

## Local cancer support services

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

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

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

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

Cancer Nurseline Freephone 1800 200 700

## Helpful books

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

You may find the following helpful:

### Treatment and side-effects

*Understanding Chemotherapy*

*Understanding Radiotherapy*

*Understanding Cancer and Complementary Therapies*

*Diet and Cancer*

*Coping with Fatigue*



### Coping and emotions

*Understanding the Emotional Effects of Cancer*

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

*Who Can Ever Understand? Taking About Your Cancer*

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

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

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



## What does that word mean?

<b>Adjuvant treatment</b>	Treatment given soon after surgery when a diagnosis of cancer is made.
<b>Alopecia</b>	Baldness. No hair where you normally have hair.
<b>Anti-emetic</b>	A tablet, injection or suppository to stop you feeling sick or vomiting.
<b>Benign</b>	Not cancer. A tumour that does not spread.
<b>Biopsy</b>	The removal of a small amount of tissue from your body to find out if cancer cells are present.
<b>Bronchoscopy</b>	A test where your doctor can look inside your lung airways using a thin flexible tube called a bronchoscope. It is like a small telescope that can take pictures like a camera.
<b>Cells</b>	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
<b>Chemotherapy</b>	Treatment using drugs to cure or control cancer.
<b>Malignant</b>	Cancer. A tumour that spreads.
<b>Mediastinum</b>	The area in the middle of your chest containing your heart, large blood vessels and oesophagus (gullet). Your lungs are on either side of it.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
<b>Metastasis</b>	The spread of cancer from one part of your body to other tissues and organs.
<b>Nausea</b>	Feeling sick or wanting to be sick.
<b>Neo-adjuvant</b>	Treatment given before surgery to reduce the size of the tumour.
<b>Oncology</b>	The study of cancer.
<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients using radiotherapy.
<b>Radiotherapy</b>	The treatment of cancer using high-energy rays.
<b>Staging</b>	A series of tests that measure the size, location and extent of cancer.

## Questions to ask your doctor

Here is a list of questions you might like to ask your doctor. 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 tests do I need?
  
- What type of lung cancer do I have? Where is it exactly?
  
- What type of treatment do I need?
  
- How successful is this treatment for my cancer?
  
- Are there other treatment options? Why is this one best for me?
  
- What side-effects or after-effects will I have?
  
- 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?
  
- Do I need to use contraception during my treatment? What will happen if I, or my partner, become pregnant?
  
- Should I eat special foods?

## Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

## Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

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## Would you like more information?

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

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



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at [reviewers@irishcancer.ie](mailto:reviewers@irishcancer.ie)

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

## Would you like to help us?

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

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Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

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