

Lung Cancer – from diagnosis to recovery



Marie Keating
FOUNDATION

Making cancer less frightening by enlightening

About this booklet

The Marie Keating Foundation has developed this booklet because we recognise that lung cancer is the fourth most common cancer overall in Ireland.

More than 1,500 men and over 1,240 women are diagnosed with lung cancer each year in Ireland. Lung cancer is the leading cause of cancer death overall.

This booklet focuses on your journey after you have been diagnosed with lung cancer. It will give you advice and information if you are going through treatment and also when you are on the road to recovery. The first four chapters address issues before you start treatment.

Your experience will be unique to you. Still, the challenges you face may be similar to those faced by the thousands of lung cancer patients and survivors living in Ireland today.

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1. Lung cancer, the facts

More than 2,700 people are diagnosed with lung cancer in Ireland every year

The Irish figures

- More people die from lung cancer in Ireland (1,891 in 2017) than any other type of cancer.
- Lung cancer is the fourth most common cancer in Ireland.
- The incidence of lung cancer has been rising steadily over the past three decades.
- Lung cancer is expected to increase by 141 per cent in women and 61 per cent in men by 2030.
- Only 3 per cent of all new cases occur before the age of 50.

Survival

The net five-year survival rate for lung cancer is currently 20 per cent (about 20 people out of every 100). ‘Net survival’ means those who will be alive five years after diagnosis, but it does not include those who die from other diseases that they have alongside lung cancer.

If lung cancer is detected early, there is a much better chance of successful treatment. However, 35 per cent (more than three out of every 10) of women and 38 per cent (almost four out of 10) of men do not go for medical advice until lung cancer is at a late stage.

Causes and risk factors

Smoking

Smoking is the biggest risk factor associated with lung cancer. More than 90 per cent (nine out of 10) of lung cancers are caused by cigarette smoke. Not smoking or stopping smoking are the most important things you can do.

However, lung cancer can occur in people without any of the known risk factors.

Age

Lung cancer is more common in older people – 75 per cent (more than seven out of 10) of lung cancer cases are in people aged 65 and over.

Passive smoking

Breathing other people's cigarette smoke is a risk factor, but it is still much less dangerous than if you smoke yourself.

Chest problems

You are at an increased risk of lung cancer if you have:

- chronic bronchitis emphysema
- pneumonia
- tuberculosis.

Exposure to harmful substances

Radon natural gas can be found in the air or trapped in buildings. It increases the risk, especially in smokers. Other substances and environments that can increase your risk of lung cancer include:

- asbestos
- some chemicals
- being a painter
- burning coal indoors.

Family history

If there is a family history of lung cancer, it puts you at a higher risk of developing the disease.

Smoking and smoking cessation

10 tips to help you quit

1. Prepare to quit

Weigh up the pros and cons. Write down your reasons for quitting.

2. Make a date to quit

And stick to it.

3. Support

Ask your family and friends for help.

4. Change your routine and plan ahead

Replace or change activities that you usually associate with smoking.

5. Be active

Regular activity is good for your health and helps manage stress.

6. Think positively

You may have withdrawal symptoms once you quit smoking. These are positive signs that your body is recovering from the harmful effects of tobacco. They will disappear once your body gets used to the change.

7. Learn to deal with cravings

See below.

8. Remind yourself of benefits like saving money.

Tobacco is expensive and you will see the benefit of quitting in your pocket.

9. Watch what you eat

If you are worried about putting on weight, be careful about what you eat.

10. Take one day at a time

Remember, every day without smoking is good news for your health, your family and your pocket. If you slip up, all is not lost. Set a new date and start again.

Dealing with cravings – the 4 Ds

- **Delay** at least 3-5 minutes and the urge will pass.
- **Drink** a glass of water or fruit juice.
- **Distract** yourself. Move away from the situation.
- **Deep** breaths. Breathe slowly and deeply.

The symptoms of lung cancer

- Having a cough most of the time, or for a long time, or both.
- A change in a cough you have had for a long time.
- Being short of breath.
- Coughing up phlegm (sputum) with signs of blood in it.
- An ache or pain when breathing or coughing.
- Unexplained loss of appetite or tiredness (fatigue).
- Unexplained weight loss.

Some of these may not be caused by cancer, but it is vital to see your GP because knowing about lung cancer at an early stage could save your life.

Types of lung cancer

Lung cancer is divided into two main groups:

- small cell lung cancer (SCLC)
- non-small cell lung cancer (NSCLC).

Non-small cell lung cancer (NSCLC) is the most common.

The type of lung cancer you have helps your doctor decide which treatment you need. Cancer that starts in the lung is called primary lung cancer. If cancer spreads to your lungs from somewhere else in your body, this is secondary lung cancer.

Non-small cell lung cancer (NSCLC)

Almost nine out of 10 lung cancers are non-small cell lung cancer (NSCLC). There are four common types grouped together because they behave similarly and respond to treatment in the same way.

They are:

- adenocarcinoma
- squamous cell carcinoma
- large cell carcinoma
- undifferentiated non-small cell carcinoma.

Adenocarcinoma

This is the most common type of NSCLC and starts in the mucus-making gland cells in the lining of your airways.

Squamous cell cancer

This type of NSCLC develops in the flat cells that cover the surface of your airways. It tends to grow near the centre of the lung.

Large cell carcinoma

In NSCLC, the cancer cells are large and round under the microscope.

Undifferentiated non-small cell lung cancer

If your cancer cells look very undeveloped under the microscope, your doctor won't be able to tell which type of NSCLC you have. Undeveloped cancer cells are called undifferentiated cancers. So, your doctor might say you have undifferentiated NSCLC.

Small cell lung cancer (SCLC)

About 12 out of every 100 lung cancers diagnosed (12%) are SCLC. It is usually caused by smoking. These cancers tend to spread early on.

Rarer types of lung cancer

Mesothelioma

Mesothelioma is a rare cancer that starts in the covering of the lung (the pleura). In the early stages of mesothelioma, there are not many symptoms. When mesothelioma symptoms do develop, they are often caused by the cancer growing and pressing on a nerve or another body organ.

Neuroendocrine

Lung neuroendocrine tumours (NETs) are rare lung cancers that start in the neuroendocrine cells of the lung. They usually develop slowly over some years. There are neuroendocrine cells in most organs of our body, including the lungs. .

Advanced (metastatic) lung cancer

Advanced or metastatic lung cancer is when a cancer begins in the lung and spreads to another part of the body. Secondary lung cancer is when a cancer that started somewhere else in the body has spread to the lung.

Where a cancer starts is called the primary cancer. If some cells break away from the primary cancer they can move through the bloodstream or lymph system to another part of the body, where they can form a new tumour. This is called a metastatic cancer.

For example, if your cancer started in your bowel and has spread to your lung, the cells in the lung are made up of bowel cancer cells. This is important because the primary cancer tells your doctor which type of treatment you need.

Which cancers spread to the lungs?

Any primary cancer can spread to the lung.

Symptoms of secondary lung cancer

The most common symptom is feeling tired and unwell. Other symptoms include:

- a cough that doesn't go away
- shortness of breath
- ongoing chest infections
- loss of appetite and weight loss
- coughing up blood
- a build-up of fluid between the chest wall and the lung (a pleural effusion).

A build-up of fluid stops the lungs from expanding fully when you breathe and causes shortness of breath; chest aching; discomfort; and heaviness. Remember, these symptoms can also be due to other more common conditions. If you have any of them tell your doctor so that they can check them out.

Tests for secondary lung cancer

You may have one or more of the following tests:

- chest X-ray
- CT scan/MRI scan
- PET scan
- tissue biopsy.

2 Diagnosis of lung cancer

If your GP suspects you have lung cancer, they can refer you to the National Lung Cancer Rapid Access Service

Rapid access to services

Rapid Access Services provide investigations like CT scan and bronchoscopy. This service is organised so that you have to make as few trips to the hospital as possible.

Within two weeks of these investigations, you will be seen by a lung cancer team to have more tests to find out whether or not you have lung cancer.

Rapid Access Service is available in these hospitals	
Beaumont Hospital, Dublin	(01) 809 3484
Mater University Hospital, Dublin 7	(01) 803 2644/2295
James's Hospital, Dublin 8	(01) 416 2196
St. Vincent's University Hospital, Dublin 4	(01) 221 3702
Waterford Regional Hospital, Waterford	(051) 848 98
Mid-Western Regional Hospital, Limerick	(061) 585 637

Tests to diagnose lung cancer

Chest X-ray

If you have symptoms that could be caused by lung cancer, your doctor will arrange for you to have an X-ray.

X-rays can show up changes in the lungs that may be due to cancer but can also be caused by other lung conditions.

An X-ray



Cancer Research UK

Getting your results

Ask your doctor how long it will take to get your X-ray results. Waiting for test results can be a worrying time. It may help to talk to a close friend or relative about how you feel.

Chest X-rays alone cannot provide a definite diagnosis because they often cannot tell the difference between tumours and other abnormalities, like a lung abscess.

Sometimes, lung cancer has been found even when the X-rays appeared to be normal (a false-negative). Therefore, you may need more tests.

CT Scan

A computer tomography (CT) (previously called a CAT scan) scan is usually done after a chest X-ray. It uses X-rays and a computer to create detailed pictures of inside your body. The computer puts the pictures together to make a three-dimensional (3D) image. You usually have a CT scan in the X-ray (radiology) department.

Before having a CT scan, you may be given a drink or injected with a slightly radioactive dye. The dye is used to make the lungs show up more clearly on the scan. You may be asked to fast for your scan. If you have diabetes, do tell your doctor. The scan itself is painless and takes 10-30 minutes to complete.

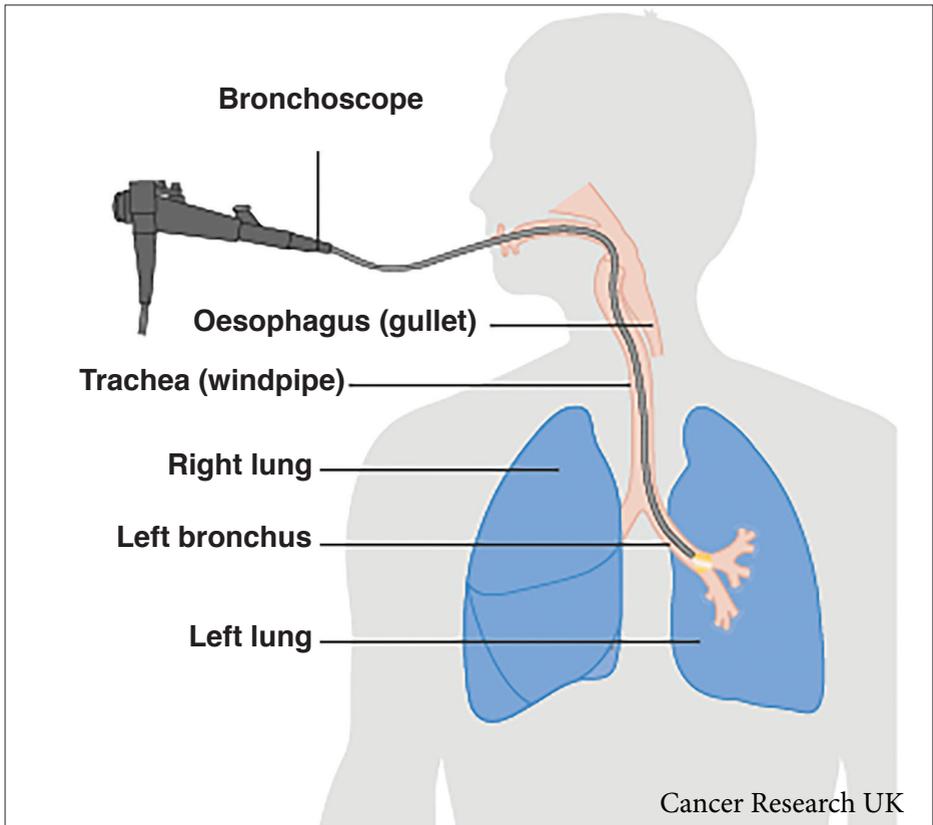
Bronchoscopy – general or local anaesthetic

During a bronchoscopy, a thin tube called a bronchoscope is used to examine your lungs and take a sample of cells. The bronchoscope is passed through your mouth or nose, down your throat, and into the airways of your lungs. The cells are then examined in a laboratory.

Under local anaesthetic

The bronchoscopy may be done under local anaesthetic. This means you should be able to eat and drink as normal beforehand. If you are having the bronchoscopy with a local anaesthetic, it may be uncomfortable, but you will be given a mild sedative beforehand to help you

A bronchoscopy



relax. The local anaesthetic will numb your throat. The procedure only takes a few minutes.

Under general anaesthetic

Sometimes, if the medical team need a larger sample from your lungs, your bronchoscopy may be done under a general anaesthetic. You will need to stop eating a few hours before the test and to stop drinking fluids two hours beforehand. Your doctor or nurse will tell you when to stop eating and drinking.

Having a bronchoscopy under a general anaesthetic means that the doctor can remove a larger sample of tissue (biopsy) or put a tube (stent) in place to keep your airway open.

Further testing

The combination of a chest X-ray, CT scans and a bronchoscopy can usually confirm or rule out a diagnosis of lung cancer.

You may still need more tests to find out exactly what type of lung cancer you have and to assess how far the cancer has spread (the ‘stage’ of the cancer).

Endobronchial ultrasound

The endobronchial ultrasound is a bronchoscopy test that uses an ultrasound. You might have this test if your doctor has seen an abnormal-looking area on your lung using an X-ray or CT scan.

An endobronchial ultrasound can show if you have lung cancer and the size of the tumour. It can also tell if the cancer has spread to other areas of the lung or outside the lung.

This test can also be done using local or general anaesthetic.

Sputum cytology

A sputum cytology involves taking a sample of your phlegm. This will then be checked under a microscope for the presence of cancerous cells.

Percutaneous transthoracic needle biopsy

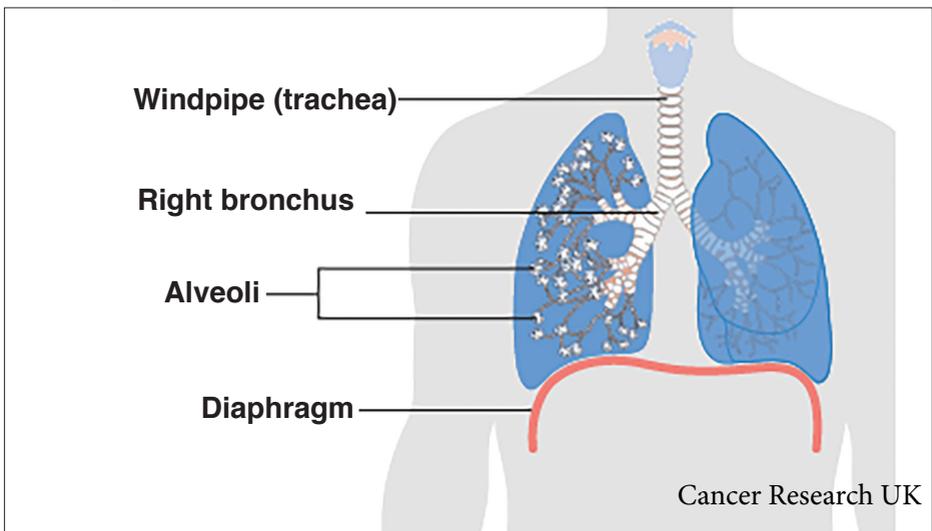
A 'percutaneous transthoracic needle biopsy' is a surgical biopsy that removes a sample of a suspected tumour. It is then tested at a laboratory for cancerous cells.

The doctor carrying out the biopsy will use a CT scanner to guide a needle to the site of a suspected tumour. A local anaesthetic numbs the surrounding skin, the needle is passed through your skin and into your lungs. The needle will then be used to remove a sample of tissue for testing.

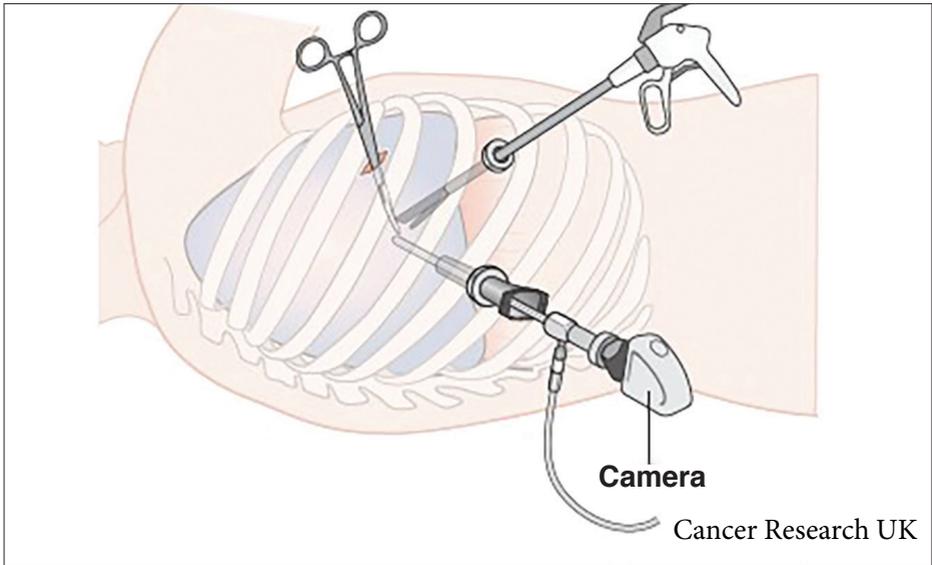
Thoracoscopy

A thoracoscopy is a procedure that allows the doctor to examine a particular area of your chest and take tissue and fluid samples.

The lungs and the alveoli



Lung biopsy thoracoscopy



You are likely to need a general anaesthetic before having a thoracoscopy. Two or three small incisions (cuts) will be made in your chest to pass a tube (similar to a bronchoscope) into your chest. The doctor will use the tube to look inside your chest and take samples. The samples will then be sent away for tests. After a thoracoscopy, you may need to stay in hospital overnight while any further fluid in your lung (or lungs) is drained out.

Mediastinoscopy

A 'mediastinoscopy' allows the doctor to examine the area between your lungs at the centre of your chest (mediastinum).

For this test, you will need to have a general anaesthetic and stay in hospital for a couple of days. The doctor will make a small cut at the bottom of your neck so that they can pass a thin tube into your chest.

The tube has a camera at the end, which enables the doctor to see inside your chest. They will also be able to take samples of your cells and lymph nodes at the same time. The lymph nodes are tested because they are usually the first place that lung cancer spreads to.

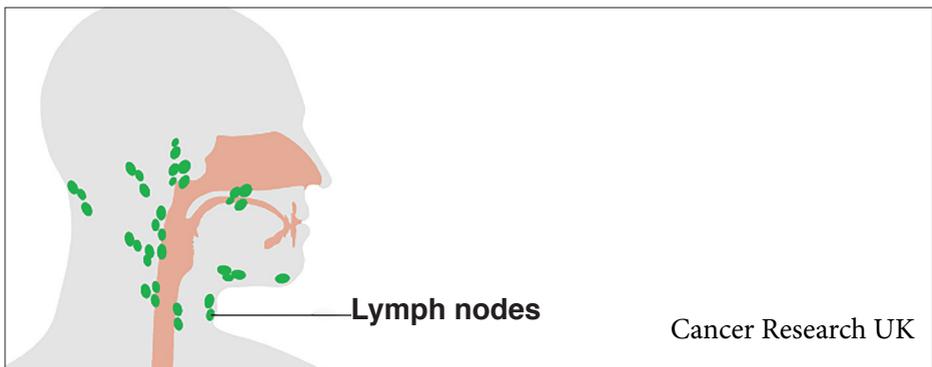
Positron emission tomography (PET) scan

A positron emission tomography (PET) scan is often used if the results of a biopsy are inconclusive, or if it is impossible to do a biopsy because of where the suspected tumour is.

A PET scanner is a new and expensive piece of technology. Only a limited number of hospitals and specialist centres have them so you may have to travel to have a PET scan.

PET scans study how a part of the body actually works. This is useful in diagnosing cancer because cancerous cells use more energy than healthy cells. PET scans can be used to study the energy profile of cells. Cancerous cells look like bright spots on the PET scan.

As with a CT scan, before having a PET scan, you will be injected with *The lymph nodes in the head and neck*



a slightly radioactive material. You will be asked to lie down on a table, which will be pushed into the PET scanner. The scan is painless and takes around 30 minutes to complete.

Tests to stage and grade lung cancer

The stage of a cancer means how big it is and whether or not it has spread. Knowing the stage of the lung cancer helps your doctor decide which treatment you need. You might need one or more tests to find the stage. The grade of cancer is the cell makeup. The classification for staging is called TNM:

TNM staging

TNM stands for :

- **Tumour**
- **Node**
- **Metastasis.**

Doctors use the TNM system to create a number staging system: with stages 1 to 4.

The **TNM** staging system describes:

- **T** – the size of a primary tumour
- **N** – if any lymph nodes contain cancer cells
- **M** – if the cancer has spread to another part of the body (there is metastasis).

The stage of a cancer tells you how big it is and whether or not it has spread. Knowing the stage helps your doctor decide which treatment you need. Your scans and tests will give some information about the stage of your cancer. But your doctor might not be able to tell you the exact stage until after you have surgery.

The TNM staging system is the most common way for doctors to stage non-small cell lung cancer. And it is sometimes used for small-cell lung cancer.

T – Tumour

Tumour describes the size of the tumour (area of cancer). This is a simplified description of the T stage.

TX

The main cancer (primary) can't be assessed. It doesn't show on scans, but there might be cancer cells present in sputum (spit) or in fluid taken from the lung.

T0

There is no sign of cancer.

Tis

There is an area of cancer cells contained within the inner lining of the lungs. There are 4 other categories – T1 to T4.

The other four categories of tumour – T1 to T4

T1	It is divided into T1a, T1b, and T1c according to the diameter of the cancer.
T1a	The cancer is 1cm or less at its widest part.
T1b	The cancer is between 1cm and 2cm across.
T1c	The cancer is between 2 and 3 cm across.

T2	T2 can mean different things. The cancer is between 3cm and 5cm across. Or the cancer has one or more of the following features: <ul style="list-style-type: none">• it involves the main airway (the main bronchus), but is not close to the area where the bronchus divides to go into each lung• it includes the inner lining of the chest cavity (the visceral pleura)• part or all of the lung has collapsed or is blocked due to inflammation. T2 is divided into T2a and T2b.
T2a	The cancer is between 3cm and 4cm.
T2b	The cancer is between 4cm and 5cm.

T3 T3 can mean different things.

- The cancer is between 5cm to 7cm, or
- there is more than one tumour in the same lobe of the lung.

Or the cancer has grown into one or more of these structures:

- the chest wall (the structures around the lungs, like ribs, muscles, cartilage, or the diaphragm)
- the nerve close to the lung (phrenic nerve)
- the outer covering of the heart (the pericardium).

T4 T4 can mean different things:

- The cancer is bigger than 7cm, or
- it is in more than one lobe of the lung.

Or it has spread into one or more of the following structures:

- the muscle under the lungs (the diaphragm)
- the area between the lungs in the middle of the chest (the mediastinum)
- the heart
- a major blood vessel
- the windpipe (trachea)
- the nerve that controls the voice box
- the food pipe (oesophagus)
- a spinal bone
- the area where the main airway divides to go to each lung.

N – Node

Node (N) describes whether or not the cancer has spread to the lymph nodes.

NX means that the lymph nodes can't be assessed.

N0 means that the lymph nodes don't contain cancer cells.

N1	N1 means there are cancer cells in lymph nodes within the lung or in lymph nodes in the area where the lungs join the airway (the hilum).
N2	N2 means there is cancer in lymph nodes: <ul style="list-style-type: none">• in the centre of the chest (mediastinum) on the same side as the affected lung, or• just under where the windpipe branches off to each lung.
N3	N3 means there is cancer in lymph nodes: <ul style="list-style-type: none">• on the opposite side of the chest from the affected lung, or• above the collar bone, or• at the top of the lung.

M – Metastasis

Metastasis (M) describes whether or not the cancer has spread to a different part of the body.

M0 and M1	There are 2 stages of metastasis – M0 and M1.
M0	The cancer hasn't spread to another lobe of the lung or any other part of the body.
M1	The cancer has spread to other areas of the body. It is split into: <ul style="list-style-type: none">• M1a• M1b• M1c.
M1a	This means one or more of the following: <ul style="list-style-type: none">• there is cancer in both lungs• there are areas of cancer around the heart or in the lining around the lung• there is fluid around the lung or heart that contains cancer cells – this is called a malignant pleural effusion or a pericardial effusion.
M1b	There is a single area of cancer outside the chest in an organ (like the liver or brain) or a lymph node.
M1c	There is more than one area of cancer in one or several organs.

Stage 1 cancer

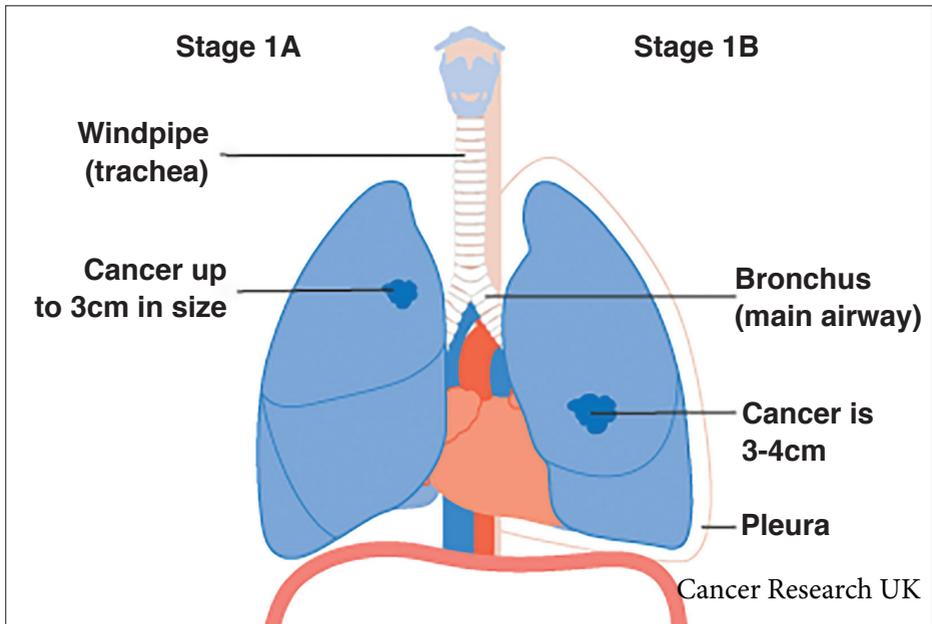
The stage of a cancer tells you how big it is and whether or not it has spread. It helps your doctor decide which treatment you need. It can also give some idea of your outlook (prognosis).

Stage 1 is part of the number staging system and means your cancer is small. It hasn't spread to your lymph nodes or other distant organs.

Stage 1 can be divided into 1A and 1B:

- Stage 1A means the cancer is 3cm or smaller.
- Stage 1B means the cancer is between 3cm and 4cm.

Stages of lung cancer: 1a and 1b



During Stage 1, cancer might also be growing into structures such as the:

- main airway of the lung (main bronchus)
- membrane covering the lung (visceral pleura), or
- cancer is making the lung wholly or partly collapse by blocking the airway.

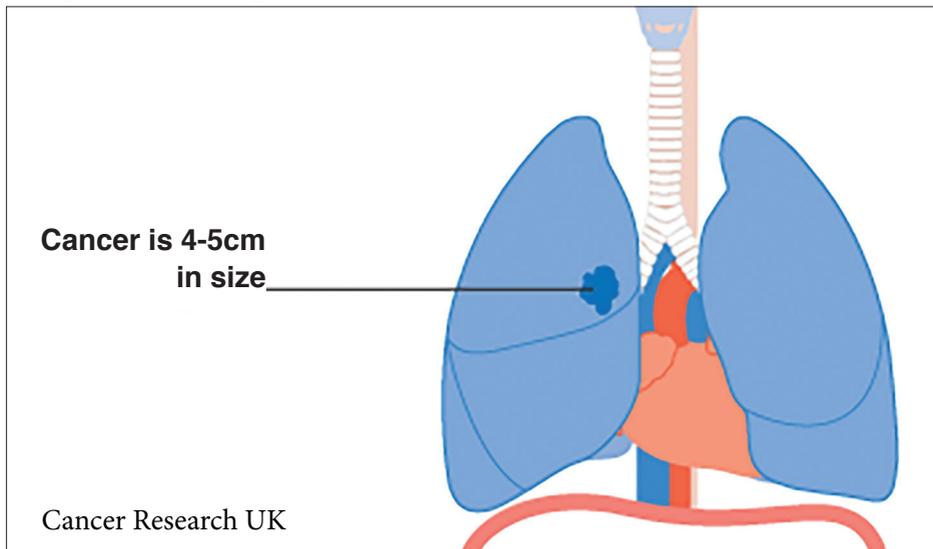
Stage 2

Stage 2 can be divided into stage 2A and 2B. Part of the affected lung might have collapsed.

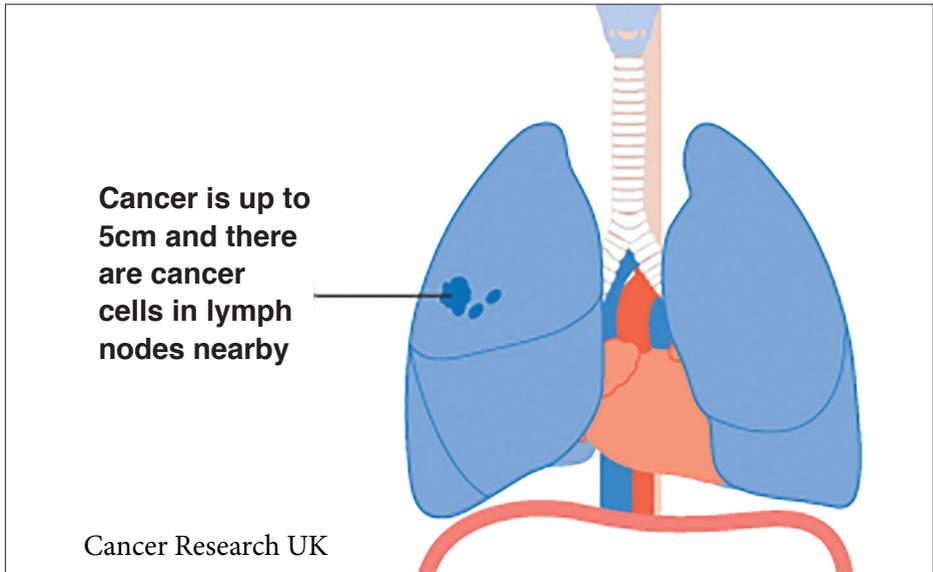
Stage 2A

Stage 2A means that the cancer is between 4cm and 5cm in size, but there are no cancer cells in any lymph nodes.

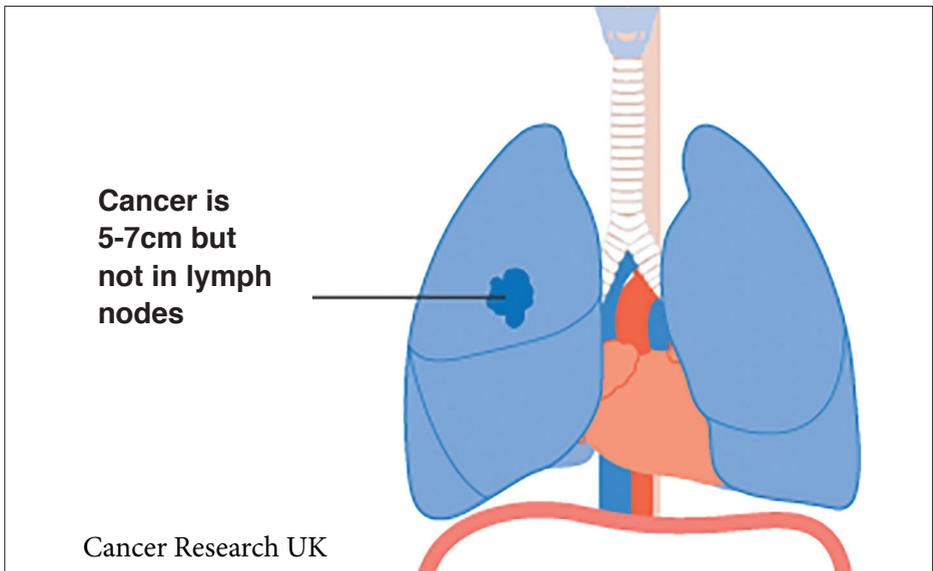
Lung cancer: stage 2A



Lung cancer: stage 2B, 1

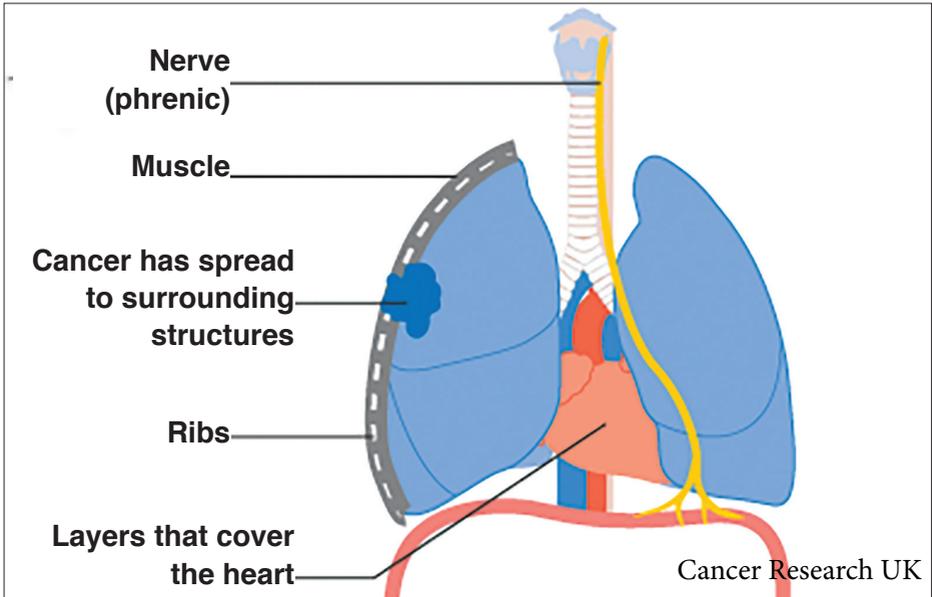


Or Lung cancer: stage 2B, 2

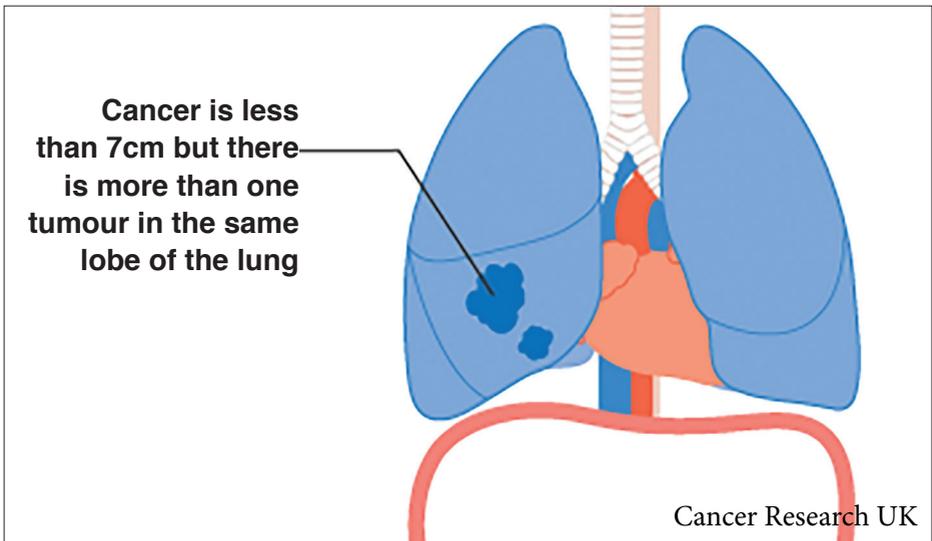


2 Diagnosis of lung cancer

Or Lung cancer: stage 2B, 3



Or Lung cancer: stage 2B, 4



Stage 2B

Stage 2B means that the cancer is up to 5cm in size, and there are cancer cells in the lymph nodes close to the affected lung.

Or it is between 5cm and 7cm, but there are no cancer cells in any lymph nodes.

Or the cancer is not in any lymph nodes but has spread into one or more of the following areas, the:

- chest wall (ribs, muscle or skin)
- nerve close to the lung (the phrenic nerve)
- layers that cover the heart (mediastinal pleura and parietal pericardium), or
- cancer is less than 7cm, but there is more than one tumour in the same lobe of the lung.

Stage 3

Stage 3 means your cancer is in more than one lobe of the lung, or it has spread to lymph nodes or nearby structures in the chest.

Stage 4

Stage 4 means your cancer has spread to your other lung or to a distant part of your body like the liver or bones.

Grades of lung cancer

Grading is a way of dividing cancer cells into groups based on how the cells look under a microscope. This gives you and your doctors an idea of how quickly or slowly the cancer might grow. It also shows whether or not the cancer is likely to spread.

There are two main types of lung cancer: non-small-cell lung cancer and small-cell lung cancer. Grading is not used for small-cell lung cancer.

Grades of non-small-cell lung cancer

Grade 1 – low grade

The cells look very like healthy cells. They tend to be slow-growing and are less likely to spread than higher-grade cancer cells. They are called low grade.

Grade 2 – moderate grade

The cells look more abnormal and are more likely to spread. This grade is also called moderately well-differentiated or moderate grade.

Grades 3 and 4 – poorly differentiated or high grade

The cells look very abnormal and not like healthy cells. They tend to grow quickly and are more likely to spread. They are called poorly differentiated or high grade.

3 Other tests for lung cancer

Scientists can look at lung cancer samples in the laboratory and search for gene changes (mutations) that change the way the cancer grows.

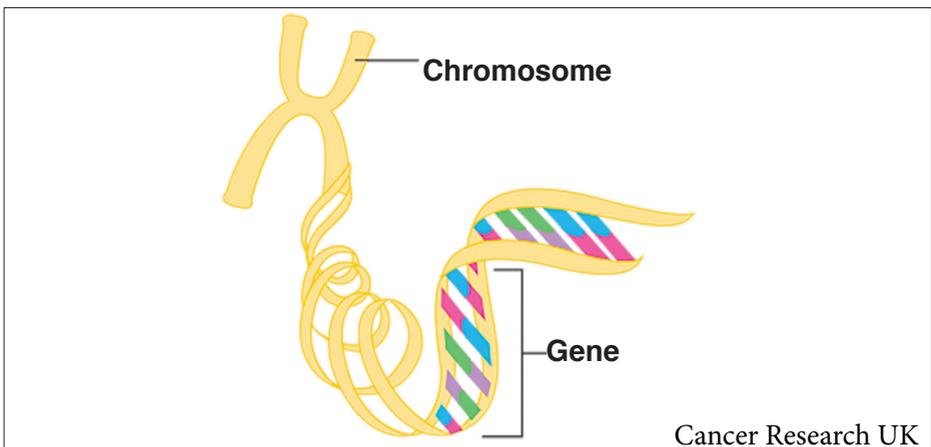
Doctors use this information to plan the best treatment based on the genetic type of cancer. This is called targeted cancer treatment or personalised therapy.

Gene changes in lung cancer

Some non-small cell lung cancers have changes in genes that make cancer grow and divide, like:

- the epidermal growth factor receptor (EGFR) gene
- the anaplastic lymphoma kinase (ALK) gene.

Gene mutation



Your doctor might test for one or more of these genes before you start treatment. To have these tests, your cancer must:

- be non-small-cell lung cancer that has spread into the area around the lung, or
- has spread elsewhere in the body (advanced cancer).

Sometimes you might have this test as part of a clinical trial.

About the genetic mutation test

Doctors look for gene mutations from a tissue sample and test them in the laboratory.

Another test that looks for gene changes in cells is the FISH test. FISH stands for fluorescence in-situ hybridisation.

Research has found that some targeted cancer drugs work well for some people with specific gene mutations in non-small cell lung cancer. These drugs change the way that cells work, and they help the body to control the growth of cancer.

Getting results of your genetic mutation test

Getting the results of your genetic tests could take a few weeks. Waiting for test results or for further tests can be very worrying. It may help to talk to a close friend or relative about how you feel.

Immunotherapy

You may have tests to see if you are suitable for other therapies, for example immunotherapy for non-small-cell lung cancer.

4 Treatment for non-small cell lung cancer (NSCLC)

NSCLC is the most common form of lung cancer and has better survival rates than small cell lung cancer

If you have NSCLC, a team of doctors and other professionals will discuss the best treatment and care for you. They are called a multidisciplinary team (MDT). Your treatment depends on:

- where your cancer is
- how far it has grown or spread (the stage)
- how abnormal the cells look under a microscope (the grade)
- your general health and level of fitness.

Treatment overview

The main treatments are:

- surgery
- chemotherapy
- radiotherapy
- radiofrequency ablation
- chemo-radiotherapy – chemotherapy with radiotherapy
- targeted cancer drugs
- immunotherapy
- symptom control treatment (palliative care).

4 Treatment for non-small cell lung cancer (NSCLC)

Your multidisciplinary team will discuss your treatment, its benefits and the possible side effects with you. You may have one or more of these treatments. This depends on the stage of your cancer and how well the treatment is working.

Chapter 2 describes the different stages of lung cancer.

Treatment for Stage 1

For Stage 1, surgery is the main treatment. Your surgeon might remove:

- part of your lung (a lobectomy)
- all of the lung (pneumonectomy).

You might have chemotherapy after your operation to lower the chance of your cancer coming back.

If you aren't fit enough for surgery you might have:

- radiotherapy
- radio-frequency ablation.

Radio-frequency ablation is used for some people with small lung tumours. It uses high energy radio waves to heat the tumour.

Treatment for Stage 2

Stage 2 is divided into stage 2A and 2B (see Chapter 2). Surgery is the main treatment. Your surgeon might remove:

- part of your lung (a lobectomy)
- all of your lung (pneumonectomy).

After surgery, you might have chemotherapy to lower the chance of your cancer coming back. Depending on the results of your surgery, you may require radiotherapy. If you aren't fit enough for surgery you might have:

- radiotherapy
- chemo-radiotherapy – chemotherapy with radiotherapy.

Treatment for Stage 3

There are several different possible treatments for Stage 3 lung cancer. You might have surgery if:

- your surgeon thinks they can remove all of the cancer
- you are well enough.

After surgery, you may have chemotherapy and radiotherapy. If you can't have surgery, you may have one or more of these treatments:

- radiotherapy or chemotherapy
- chemo-radiotherapy – chemotherapy and radiotherapy together
- immunotherapy.

You may then require surgery after one or more of these treatments.

Treatment for Stage 4

Stage 4 treatment aims to control the cancer for as long as possible and help with symptoms. You may have:

- chemotherapy
- immunotherapy
- targeted cancer drugs
- palliative care (symptom control treatment).

5 Treatment for small cell lung cancer

Small cell lung cancer (SCLC) is less common than non-small cell lung cancer

A team of doctors and other professionals will discuss the best treatment and care for you. They are called a multidisciplinary team (MDT). The treatment you have depends on:

- where your cancer is
- how far it has grown or spread (the stage)
- your general health and level of fitness.

Treatment overview

The main treatments are:

- chemotherapy
- radiotherapy
- surgery
- chemo-radiotherapy – chemotherapy with radiotherapy
- immunotherapy
- palliative care (symptom control treatment).

You may have one or more of these treatments. This depends on the stage of your cancer and also how well the treatment works.

Treatment for SCLC confined to one lung

This means your cancer is only in one lung. It may also be in lymph nodes nearby. The primary treatment for this type of small-cell lung cancer is chemotherapy. You usually then have radiotherapy to the chest.

If you are fit enough, you might have chemo-radiotherapy. This means that you have chemotherapy at the same time as radiotherapy.

If your cancer is at a very early stage, you might be able to have surgery to remove the part of the lung containing the cancer. This is called a lobectomy. But surgery isn't used very often for small-cell lung cancer. If you do have surgery, you usually have chemotherapy afterwards and may also have radiotherapy.

After treatment

After you finish treatment, you might have radiotherapy to your brain if the cancer in your lung has stopped growing and you are well enough. Radiotherapy to the brain is called 'prophylactic (preventive) cranial radiotherapy' (PCR). It aims to kill any cancer cells that might have spread to the brain but are too small to see on scans.

Treatment for extensive SCLC Extensive disease means your cancer has spread outside your lung. This could be either within your chest or to other parts of your body. It is also called advanced cancer.

Treatment aims to control the cancer for as long as possible and help with symptoms.

5 Treatment for small cell lung cancer (NSCLC)

If you are well enough, you usually have chemotherapy. If it works well, you might have radiotherapy to your lungs afterwards.

Palliative care (symptom control)

To control symptoms, you might also have treatments like:

- radiotherapy
- internal radiotherapy (brachytherapy)
- laser treatment
- freezing the tumour (cryotherapy)
- a rigid tube called a stent to keep the airway open
- light therapy (photodynamic therapy – PDT)
- tumour microwave ablation (high frequency microwave energy).

Side effects

Chemotherapy

Common chemotherapy side effects include:

- feeling sick
- loss of appetite
- losing weight
- feeling very tired
- lower resistance to infections
- bleeding and bruising easily
- diarrhoea or constipation
- hair loss.

Contact your doctor or nurse immediately if you have any signs of infection such as a temperature higher than 37.5C or generally feeling unwell. Infections can make you very ill very quickly.

Side effects depend on:

- which drugs you are taking
- how much of each medicine you have
- how you react.

Tell your treatment team about any side effects that you have.

Your team can help you manage any side effects.

Radiotherapy

Side effects tend to start a week after the radiotherapy begins. They gradually get worse during the treatment and for a couple of weeks after the treatment ends. But they usually start to improve over time. These side effects vary from person to person. You may not have all of these side effects:

- tiredness and weakness
- feeling or being sick
- reddening or darkening of your skin
- a sore mouth and throat
- breathlessness and cough
- difficulty swallowing
- loss of neck and chest hair.

Long term side effects of radiotherapy

Most side effects gradually go away in the weeks or months after treatment. But some side effects can continue or might start some months or years later:

- narrowing of the food pipe
- cough and breathlessness
- inflammation to the lining of the heart
- damage to the spinal cord.

Side effects of chemo with radiotherapy

Chemotherapy combined with radiotherapy is called chemo-radiation and this can make some side effects worse, like fatigue and weakness, nausea and weight changes.

6 Physical and emotional effects of lung cancer

Lung cancer and its treatments are likely to cause physical and emotional changes in your body

The cancer and the treatments might affect the way you feel about yourself. Treatments like surgery, chemotherapy, immunotherapy and radiotherapy can change the way your body looks, works or feels.

Physical effects

Managing breathlessness

Feeling short of breath can be hard to live with. It can make you feel exhausted, and as though everything is a struggle. Some days might seem harder than others. But some things can help you to cope.

What can cause breathlessness?

Colds and infections

If you are more breathless than usual and are coughing up coloured phlegm or have a temperature, you might have a chest infection. Some people with lung cancer can be more prone to infections.

Contact your GP or specialist nurse. You might need a course of antibiotics to clear up the infection. This may make your breathing easier.

Feeling anxious

Being anxious can make you feel more breathless. This can be very frightening and make you feel even more anxious.

If you feel panicky, try to slow your breathing down. Concentrate on breathing in and out slowly.

You can also learn about relaxation techniques using:

- YouTube
- books
- CDs
- DVDs.
- mindfulness.

Some support groups can lend you books and other resources or you might be able to borrow some from your local library.

Moving around

It can be easier to walk around if you can control your breathing.

If you use stairs, try matching your breaths to the steps you take. Don't rush. It's better to go upstairs slowly than rush up and have to stop and recover at the top.

Planning to make your life easier

You can help yourself by planning ahead. Make sure the things you need at home during the day are easy to get to.

Here are some ideas you can try out

- Move everything you need downstairs to avoid unnecessary trips up and down.
- Use a cordless phone or a mobile phone.
- Try using a trolley or bag on wheels to carry shopping or washing around.
- For household tasks, plan ahead and get everything you need together before you start.
- Pace yourself and allow rest times – you will get more done if you don't take on too much at once.

Eating and drinking

Swallowing and chewing can be difficult if you are feeling breathless.

Try some of the following tips:

- take smaller mouthfuls and chew your food slowly
- eat lots of small meals instead of a few large ones.
- avoid foods that are difficult to chew.
- keep a drink close by to sip through the day.

Remember that you can lose a lot of fluid in your breath, especially if you are breathing through your mouth. Make sure that you drink plenty of fluids. Being dehydrated can make saliva and phlegm stickier, thick saliva can also make it difficult to chew and swallow.

Asking for help

Many hospitals have specialist clinics for people who have breathing problems associated with their lung cancer.

Speak to your doctor or nurse about your breathlessness, you will be taught breathing techniques and much more about coping with breathlessness. You could have a chat with a physiotherapist or nurse who specialises in helping people with breathing problems.

Talking things through may help you to solve a few problems.

If you need oxygen

If you are very breathless, you can have oxygen tanks brought to you at home.

You can also get oxygen for when you are away on holiday or travelling.

Tiredness post-treatment

Fatigue for people with cancer might not go away even when you rest. It can go on for weeks, months or even years after you finish treatment. This is called chronic fatigue – chronic means long-lasting. Most people get back to their normal energy levels from between six months to one year after the end of cancer treatment. But it can take longer.

Fatigue is widespread in people with cancer. It can be the most troubling symptom. It affects between 70 and 80 out of every 100 people (70 to 80%). Many people say it's the most disruptive side effect of all.

In the past, doctors and nurses haven't always appreciated the long-term effects of fatigue on people with cancer. But there is now a lot of research into this area. Things are improving, and there are ways of relieving fatigue.

The first step is to tell your doctors and nurses about your fatigue. More than half of cancer patients with fatigue never tell their doctor about it. But if you tell your doctor or nurse, they can find ways of helping you.

This may involve:

- finding the causes of your long-term fatigue
- treating anaemia (low iron level)
- resting and saving energy
- exercising
- accepting support from other people
- sleeping well
- improving your diet
- keeping a diary of when you feel fatigued
- looking at the drugs you take.

Pain after treatment and diagnosis

About cancer pain

Pain affects people in different ways, let your doctor or nurse know if you have pain, even if it is mild. Help is available and not all cancers cause pain.

Causes and types of cancer pain

Cancer pain has different causes and there are different types of pain. Your pain can be controlled, and you can get support to help you manage your pain.

Treating cancer pain

There are many different ways of handling cancer pain and many different people who can treat it. A pain assessment can help you get the right treatment.

Support when you have pain

Getting support when you have pain can be very helpful. It's normal to feel upset, frightened or even depressed, but there are people who can help.

You might have questions for your doctor about cancer pain. Here are some things you might want to ask.

- What is causing my pain?
- How long will my pain last?
- How will you assess my pain?
- Are painkillers addictive?
- Does the pain mean that my cancer has got worse?
- Could the pain be related to something other than my cancer?
- Is there any research going on into cancer pain and its treatment?

Controlling chronic (long-term) pain

Chronic pain is also called persistent pain. It can be challenging to treat, but often regular painkillers or other pain control methods can successfully control it.

It is essential to take the painkillers that the doctor prescribes for you. Trying to put up with the pain can make it harder to control in the future.

People with chronic cancer pain might have times when their medicines do not control the pain. This is called breakthrough pain.

Tell your doctor or nurse if you're taking regular painkillers but still get pain at times. They can prescribe extra doses of painkillers for you to take when you need them.

There are lots of organisations, support groups and books to help you understand pain control and get the treatment you need. See page 111 for our list of Cancer Support Centres

Hair loss

Losing your hair due to cancer treatment can be challenging to cope with.

There are many practical ways to cope with hair loss:

- wigs – you can continue with your usual hairstyle or try something new
- hats – to protect your head from the sun and the cold
- scarves, bandanas or turbans – they are light and comfortable to wear.

6 Physical and emotional effects of lung cancer

Some turbans, scarves or headbands also have optional fringe or hair attachments.

You may decide not to wear anything on your head. Accessories, clothing and make-up can help draw attention away from hair loss.

Weight loss

Many people with cancer find there are times when they cannot eat as much as usual. Sometimes this leads to weight loss. It can be related to the cancer itself or to the side effects of different treatments.

Some people do not feel hungry. Others find food makes them feel sick. Some types of cancer make your body use up more energy, even if you are not very active. So, you may be eating well, but still lose weight.

Fortified milk

Make fortified milk by adding 2 to 4 tablespoons of dried milk powder to a pint (570ml) of full-fat milk and mixing it together. Keep it in the fridge and use it in drinks, on cereals and for cooking such as making soups or milk puddings.

Choose full-fat foods

When you are shopping, choose full-fat foods instead of 'diet' or 'light' foods.

Fry foods

Fry your foods in oil, ghee or butter.

Use fats

Use plenty of butter when making sandwiches. Add a dessert spoon of mayonnaise or salad cream to thick sandwich fillings like:

- tuna
- chicken
- egg
- cheese.

Add extra butter, margarine or oil to:

- bread and potatoes
- pasta
- cooked vegetables.

It can also help to do the following.

- Add extra cheese to sauces and extra paneer to curries.
- Add cream, sour cream, plain yoghurt, mascarpone or crème fraiche to sauces, soups and meat dishes.
- Grate cheese on top or drizzle some olive oil on soups.
- Add evaporated milk, condensed milk or cream to desserts and drinks.
- Have cream or ice-cream with desserts, or custard made with fortified milk.

Add pulses

Add whole or blended beans, lentils or peas to soups, curries and stews.

Sexuality

Physical and emotional changes after cancer and its treatment may affect your sexual confidence or ability to have sex. This could cause difficulties with a partner, delaying you getting back to having sex, or affect any new relationships. Concerns about your sex life and intimate relationships are normal. If you're not in a relationship, you may worry about how a new partner might react to body changes. People who have cancer do go on to have close and intimate relationships in the future.

Partners may also have concerns. Talking openly with each other can have a positive effect on your relationship and make you feel more comfortable with each other.

If difficulties with your sex life don't improve, talk to your doctor or specialist nurse. Try not to feel embarrassed – they're used to giving advice on intimate problems. They can also refer you to a sex therapist if needed.

Emotional effects

Managing anxiety and other feelings

Coping with body changes can make you anxious, but there are ways to handle this. Talking to family and close friends may help you to put things into perspective. Information from health professionals may also help to reassure you. You might find sharing your feelings with people going through a similar experience helpful. This could be through a support group or organisation, or an online forum. Writing down your feelings or setting goals to manage challenges can also be useful.

Other things that may help you to unwind include:

- exercises to relax your breathing or your body
- cutting down caffeine and alcohol
- getting enough sleep
- taking regular physical activity
- using imagery (visualisation) meditation or mindfulness
- complementary therapies like massage or aromatherapy.

If your body image concerns become overwhelming, it's important to get help. Your doctor can refer you to a counsellor or psychological therapist. They can help you to understand your feelings better and find ways of coping with them.

Rebuilding confidence

Cancer treatment can lead you to feel anxious, less confident, angry or sad. Some people think they are no longer the person they used to be or may just feel low at times. There are ways to get support. This includes talking about your feelings with people you trust. You can also talk to your doctor, nurse or other people going through a similar experience.

Before treatment, your doctor or nurse will explain what to expect afterwards. You'll need time to adjust. Be kind to yourself and accept help from loved ones.

Anxiety can cause physical symptoms and be difficult to cope with. Tell your doctor if these feelings don't improve so they can arrange for you to get the right support.

7 Palliative care

Palliative care aims to improve the quality of life of patients and their families who are dealing with a life-threatening illness

Palliative care is not just for end of life

Palliative care can be used at any stage of an illness if there are any troubling symptoms like pain or sickness.

It does this by:

- identifying problems early
- assessing and treating pain.

Palliative care also means evaluating and treating other problems including:

- physical
- psychological
- psychosocial
- spiritual.

The terms 'hospice care' and 'palliative care' are sometimes used interchangeably. Palliative care is the term generally used by those working in the health service. Palliative medicine is a recognised medical specialty in Ireland. A doctor specialising in this area is known as a Consultant Physician in Palliative Medicine or Palliative Care Consultant.

Specially trained nurses working in hospices, or as part of a specialist palliative care team in a hospital or in the community, are Clinical Nurse Specialists (CNS) in Palliative Care.

Hospice care

Hospice care aims to improve the lives of people whose illness is no longer curable. It helps them to live as fully as possible to the end. It seeks to relieve the physical symptoms of illness while equally addressing the patient's emotional and spiritual needs. Hospice care also provides support to families and those who are important to the patient. It also helps those bereaved.

Hospice care can be provided in various care settings, like:

- a hospice
- your home
- a hospital
- a nursing home.

End-of-life care

Not everyone means the same when they talk about 'end-of-life care'. The Irish Hospice Foundation uses this term to refer to all aspects of the care provided to a person with a life-limiting illness:

- from the time of diagnosis
- through the last months of life
- up to and including the final hours.

More information about hospice care in Ireland

Website: www.hospicefoundation.ie

Phone: (01) 679 3188

Email: info@hospicefoundation

The Irish Hospice Foundation runs a Hospice Friendly Hospitals Programme to make sure that, palliative care, end-of-life and bereavement care are central to mainstream care for people diagnosed with cancer and their families .

The programme aims to improve the standard of end-of-life care in hospitals. More than 40 public and private hospitals are now linked to the programme.

There are a number of end-of-life coordinators in position in hospitals across the country.

More information about end-of-life coordinators

Website: www.hospicefriendlyhospitals.ie

Phone: (01) 679 3188

Email: hfh@hospicefoundation.ie

Planning ahead: think ahead

The ‘Think ahead’ scheme can help you record and register your preferences about what you want if you are very ill or dying.

The ‘Think ahead’ scheme was devised by the National Council of the Forum on End of Life in Ireland.

The programme gives people control and choice. It can help you be responsible for what happens in the future.

Family members may want to prolong your life at all costs. That may not be what you want. There are lots of care preferences that you can consider.

- How do you feel about your quality of life compared to the length of your life?
- If you are dying, do you want chemotherapy or radiotherapy?

If you are very ill, you are not going to recover, and you have very poor quality of life and a lot of suffering, you may feel you want to say: ‘Thus far and no further’.

If you can write down your preferences while you are still able to, it can save a considerable amount of conflict, heartache and hassle.

If you take part in the ‘Think ahead’ project, it means you will get the type of care that you want. It can make what is a tough time for everyone that bit easier.

Let people know your wishes

'Think ahead' lets you answer questions like:

- who would you like included in discussions about your medical condition or care?
- are there cultural preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

The 'Think ahead' form

- The form lets you say what your care preferences would be if you were so ill that you could not speak for yourself.
- It allows you to set out your preferences about the medical treatments that you do not want to receive in the future in case you cannot speak for yourself.
- It also allows you to name someone, called a 'Patient-Designated Healthcare Representative', who can speak on your behalf.

It would help if you spoke to a healthcare professional before completing the form. They may be the best person to give you the information you need when deciding about the care and treatment you would like.

You can print out a 'Think ahead' form to fill in your preferences here:
<http://www.thinkahead.ie/think-ahead-form-2/>

Interview: Learning to live with the new normal

Yvonne O’Meara works therapeutically with individuals, partners and their families when illness has entered their lives. She works with them through all stages of illness and into bereavement

When illness comes into a person’s life, it changes what was normal into a chaotic situation. The norms no longer exist.

“We try to establish a new norm within the disease irrespective of the stage of the disease,” says Yvonne O’Meara.

Ms O’Meara is a Systemic Psychotherapist and Psycho-Social Oncologist, at St James’s Hospital and in private practice.

“People do not change personality just because they have lung cancer. So, it is helpful to think about how they coped with life before the diagnosis and use those skills to help them handle the disease.

“Sometimes, the diagnosis of lung cancer leads people to decide they

“It is equally important to set long- and short-term goals for the future. This could be as simple as: ‘Next week, I’d like to be able to go to the grocery shop’; or ‘I’d like to be able to read my granddaughter her bedtime story’.”

**– Yvonne O’Meara
Systemic Psychotherapist
and Psycho-Social
Oncologist**

want to overhaul their life.”

“For example, if someone is overweight, they might feel now is the time to change the patterns of the past. Or they may previously have had a very healthy life, and they want to re-establish that,” says Ms O’Meara.

Lung cancer stigma

There is a stigma around lung cancer which is different to other cancers. If people have smoked, there is the ‘well it’s my own fault’ attitude. That brings its own complications.

“Equally if you haven’t smoked and you’ve got a lung cancer there can be a sense of unfairness or injustice. This makes the diagnosis difficult to stomach,” says Ms O’Meara.

Continuing to smoke

Family can become very upset and angry if a person diagnosed with lung cancer continues to smoke. They may ask: ‘Do they not love me enough to stop smoking? Are cigarettes more important than spending minutes longer with me?’

Equally, if the person with lung cancer stops smoking and their partner continues to smoke, that can be very challenging. Families need to talk about this. Sometimes the diagnosis can lead to most members of the extended family ceasing to smoke.

“Or people say I smoke because I am so stressed about this,” says Ms O’Meara.

Setting goals

Being able to focus on the present moment is a beneficial skill for everyone.

“It is equally important to set long- and short-term goals for the future. This could be as simple as: ‘Next week, I’d like to be able to go to the grocery shop’; or ‘I’d like to be able to read my granddaughter her bedtime story’,” says Ms O’Meara.

Some people may not want to do this and their wishes must also be respected.

Sometimes that goal can be having a good death. People feel better if they have control over what they do for the rest of the life that they have in this world. They may want to:

- plan their funeral
- make a will
- do a life story book.

Life story book

Some people who are terminally ill write a book about their life and tie it in with family photos.

“Often we go through life not knowing what someone’s favourite colour is; favourite ice-cream; favourite early childhood memory. This synopsis allows the family to put together a book. Sometimes the patient does it privately and arranges for the book to be given to their family after they have died. It can be a lovely thing to do,” says Yvonne.

Importance of exercise

Fatigue is one of the most significant side effects of any cancer diagnosis, so it is essential to use what energy we have wisely. Physical activity is key to restoring energy.

“Research has repeatedly shown that the endorphins exercise produces have a profound positive effect on cancer patients’ recurrence and longevity of life,” says Ms O’Meara.

“It may be the last thing you feel like doing. Especially since your breathing may be compromised, but you must work with the physiotherapy team to find the best way for you to exercise.”

Feelings and emotions

It is more productive to focus on relationships rather than tasks. What is really important? Is it going to the grocery store or reading a book with your granddaughter?

Prioritise your activities of daily living. Stay connected with people and if possible, develop a support group with others in the same boat. It is hugely beneficial, and the Marie Keating Foundation can put you in touch with people near you.

“It is also important to try and be yourself. Go back to being you. If you have pre-existing anxiety or depression, maybe now is the time to get psychological support for that,” says Ms O’Meara.

Dealing with fear

Most people diagnosed with lung cancer are fearful – no matter if they have been diagnosed with Stage 1 or Stage 4.

Someone diagnosed with Stage 1 lung cancer and who finishes their treatment may fear recurrence.

And someone diagnosed with Stage 4 lung cancer often fears how much time they have left.

“Fear is normal and rather than fighting it as people often try to do, acknowledge it, process it and accept that a degree of worry is part of life. If it becomes overbearing, it is helpful to get support. This could be with the Marie Keating Foundation support services, psycho-oncology or social work in your hospital setting,” says Ms O’Meara.

However, it is also important to realise that fear is normal. An anxiety diary can help you pinpoint triggers that make you fearful, for example, when you are going for a checkup.

“Try to become familiar with the things that trigger fear and to normalise it,” says Ms O’Meara.

Your hospital team know that people can be fearful. An excellent person to talk to at the hospital is your:

- nurse specialist
- social worker
- a psycho-social oncology department within the hospital.

Psycho-sexual side effects

One of the most significant side effects of cancer is fatigue. This can also affect people's psycho-sexual health. Meanwhile, chemotherapy affects your hormones. This can lead to a lack of desire for sex which can impact a relationship. This is very often not spoken about.

Carers and family

If you are a carer or you are part of this person's world, it is essential to respect where the person with cancer is at. It is important to communicate in a way that is open and honest, and that also respects their position. You need to listen to the person with cancer.

“This can be a real struggle for people. What the family member wants for the person with cancer may be very different to what the person with cancer wants,” says Ms O'Meara.

Carers and family need support so that they can, in turn, support the person with cancer. Everyone should try to be open, honest, and as relaxed as possible around people with cancer.

People can sense when they are being treated differently because of their illness. A distance between people can creep in that wasn't there before.

“It is important to talk about those changes in relationships. Sometimes the changes can be positive, and people get closer. But, sometimes people grow distant because they are not connecting in a way that is matching each other,” says Ms O'Meara.

Making lifestyle changes together

It can empower and strengthen relationships when people work together to improve their lifestyle.

This could include doing things together like:

- preparing healthy meals
- exercising
- doing yoga classes
- doing mindful-based things.

It is also essential to look at the whole family including children. You should be honest with them, as you would be with an adult, in an age-appropriate way. You can ask the social worker to help you do that. With children, you need to set aside a particular time to talk to them. Children need to know this is serious, this is different and that you need them to listen.

It is also important to keep it real for everybody in the family.

“It’s not real to go off to Disneyland on a whim, but if you ask the person who is sick what they want to do, often it’s just about spending time with family. Just being. The best outcome is when there is open communication. This is true irrespective of prognosis,” says Ms O’Meara.

If communication is difficult you can say something like: ‘Is there a way that we could reconnect because there are things that are important to talk about for me. Is that something that you feel that we could do?’

“It is not helpful for the person with cancer to try and protect their

partner from how they are feeling. Protection is inclusion – this means that to protect your partner, they need to know how you feel. You can protect yourself and others by telling them how you feel.

“I will often find that I meet the patient and they disclose that they don’t want to hurt or cause upset or further sadness to the family. Therefore, they conceal their emotions. Then I will meet the family separately, and they’ll say: ‘They’re not talking. They’re pretending everything is fine. I would love to have a conversation with them – I am dying inside, and nothing has been said’. It is essential to get everyone communicating together,” says Ms. O’Meara.

“It is never good to hold things in. But it is complicated. People who conceal things genuinely feel that they are holding it in for all the right reasons. Sometimes people think ‘I’m not going to talk about this because if I talk about it, it becomes real and I don’t want it to be real, so we’re not going to talk about it.’ We have to respect that person’s position and then it is about the family respecting that person’s position too,” said Ms O’Meara.

A little patience goes a long way

Being patient is a skill that is extremely important when presented with cancer. Being patient with the patient, being patient with each other, being tolerant, being kind. Some days are harder than others.

8 Interview: The role of surgery in lung cancer

Surgery is often the best chance for a cure for lung cancer, says cardiothoracic surgeon, Mr Ronan Ryan

Most people who have surgery for lung cancer have non-small cell lung cancer (NSCLC) – the most common type of lung cancer. However, a small number of people with small cell lung cancer (SCLC) – the less common lung cancer, are sometimes also suitable.

Early diagnosis is essential, and surgery is most successful when the cancer is still at Stage 1 and has not spread to other parts of the body.

Thankfully, lung cancer is diagnosed more quickly than it used to be.

“It is vital to get an early and accurate diagnosis and to get people to a surgeon in a reasonable time frame.”

– Ronan Ryan
Cardiothoracic surgeon

Rapid Access Lung Clinic

Unfortunately, if lung cancer has spread, surgery is unlikely to be of benefit. The HSE Rapid Access Lung Clinic (RALC) in your area is the key to early diagnosis. Early lung cancer can present with persistent symptoms like:

- a cough
- a change in a cough
- shortness of breath.

8 The role of surgery in lung cancer: Interview

If you have symptoms that may be cancer, your GP must refer you directly to the HSE Rapid Access Lung Cancer Clinic.

This will give you direct access to a consultant-led service for people with symptoms of lung cancer. It provides direct and rapid access to assessment and diagnosis for suspected lung cancer.

“It is vital to get an early and accurate diagnosis and to get people to a surgeon in a reasonable time frame,” says Mr Ryan. “Patients also need to be fit enough to undergo surgery. As surgeons, we are looking for someone who is early stage and reasonably fit.”

Different types of surgery

Lung cancer surgery involves removing part of the lung.

“The vast majority of lung cancer surgery is going to be a lobectomy – removing a lobe of the lung. There are three lobes on the right and two lobes on the left. They are all equal in size. We remove the lobe of the lung because you get better results in terms of survival and recurrence.

“If someone has very poor lungs and they have a tumour at the edge of the lung, in certain circumstances you can remove less than the lobe. But this is in less than 10 per cent of cases.

“On the other side of things, occasionally you’ll find that the whole of one lung – a pneumonectomy, will have to be performed to remove all the cancer. This would only be in 10%,” says Mr Ryan.

They do everything they can to avoid a pneumonectomy because the more lung they remove the:

- bigger the physiological trauma to the patient
- more ramifications after
- higher the risk of the operation.

Surgery is done using the minimal amount of incisions, although sometimes it is necessary to do open surgery. Minimally invasive surgery is most often done using Visual Assisted Surgery (VAS).

“Instead of making one big hole you put in a camera, and you have a couple of smaller incisions to do the operation through that,” says Mr. Ryan.

About half of the surgeries are now done through VAS.

“Robotic surgery for lung cancer is now becoming available in some hospitals. It is very similar to VAS except you use a surgical robot. The incisions are very similar, but there is probably even less pain involved,” says Mr. Ryan.

The advantage of the small incisions include:

- less muscle is divided
- it is easier for the patient to get up and walk around afterwards
- patients go home earlier
- there is a lower risk of pneumonia
- there is a lower risk of complications.

8 The role of surgery in lung cancer: Interview

“However, there are a good number of patients where a minimally invasive operation is not an option. This can be to do with the size of the tumour – you can’t get a big tumour out through a small hole. Or if a more complicated operation is needed that involves the ribs,” says Mr Ryan.

Open surgery may also be necessary if:

- there is a lot of scar tissue on the lungs
- people have had previous treatment for something else
- a person has had lots of bad pneumonias.

Preparing for surgery

People must stop smoking.

“It is never too late to stop smoking. Even a brief period off cigarettes, which is difficult for people at this stressful time, will help,” says Mr. Ryan.

It is also essential to stay active, try to eat a healthy diet and to cut down on alcohol.

Exercise and diet before surgery

Exercise and a proper diet can help to set people up for the operation so that they are also psychologically prepared. It is very beneficial if people can build up a bit of muscle mass, even for a couple of weeks before surgery. Overall fitness is important.

Even a short bit of pre-habilitation benefits the patient. It shows them how to:

- do exercises
- be generally fitter
- have a bit more muscle mass than they had previously.

The operation

“If they have reasonable lungs coming in, most people will notice the difference in their breathing, particularly just after the surgery. A few months later most people can live their daily lives and not be limited by their breathing.

“Most people tolerate the surgery very well. If they are people who like going hillwalking, they might notice that they get out of breath earlier. But in terms of living your life and doing whatever you want to do most people can tolerate having a lobe of the lung removed,” says Mr. Ryan.

The surgery takes a couple of hours, but this depends on the complexity of what needs to be done. You will usually be in hospital for five or six days. It takes about four weeks to recover from the surgery.

Some people are ready to go back to work after a couple of weeks, but others take 6-8 weeks before they are really back on their feet.

Risks of surgery

The risks of surgery are quite low. The risk of dying or having a severe life-altering complication is about 1-3 per cent (between one and three in every 100 people).

8 The role of surgery in lung cancer: Interview

Some patients will be at higher risk because they:

- are not fit
- have poor pulmonary (lung) function
- have another disease
- need more of their lung removed, and the risk is then higher.

Outcome and repeat surgery

The cure rate for lung cancer following surgery is high. About a quarter of people will be referred on to an oncologist for more treatment like chemotherapy.

About one in five people who have one episode of cancer in the lungs, which has been cured, will develop another lung cancer. About one in three of these people will be suitable for radical treatment including surgery.

“If they are young and they are fit and their pulmonary function is up to it, they can have another operation. If you get another early-stage cancer the results of surgery are just as good the second time as the first,” says Mr. Ryan.

9 Interview: ‘Rapid Access’ saves lives

Michael Byrne, who has recovered from lung cancer, first came in contact with the Marie Keating Foundation through a local cancer support centre in Waterford, the Solas centre



“The least little thing can upset you and a lot of that is the side effects of all the treatment you get. You have to say to people: ‘Whatever I say and whatever I do, it’s not me, it’s just what I am going through so please bear with me’.”

– Michael Byrne
Lung cancer
survivor

9 Lung cancer survivor: Interview

Michael Byrne reckons that if he had not given up cigarettes a few years before his diagnosis of lung cancer, he would no longer be alive.

This is because he would have put his nagging cough down to the everyday effects of cigarettes and wouldn't have bothered to go to his GP.

“Pay attention to your body and get any symptoms checked,” says Michael.

Michael is also grateful that his GP referred him on using the HSE Rapid Access Lung Cancer Clinic. This meant he was seen and diagnosed quickly.

Michael has made a full recovery and is now back to his passion of playing music – he plays six or seven instruments.

“I like every kind of music except heavy opera. I've played with a group called Caípeen in Jurys hotel in Waterford. And I've also done sessions in a local pub,” says Michael.

After Michael's GP sent him to the Rapid Access Clinic, he had a bronchoscopy (where a fibre-optic cable is passed into the windpipe to view the lungs). He was not surprised when he was diagnosed with Stage 1 lung cancer.

Surgery

Because his cancer was confined to the lung, Michael was suitable for surgery and had one lung removed.

Chemotherapy

“The hardest part was the chemotherapy. The 11 weeks of intravenous chemotherapy were grand, but what nearly finished me off altogether was the tablet form. We only discovered afterwards that I had five ulcers, and they caused all the havoc. The intravenous chemotherapy would go straight into my bloodstream, but the tablets were going through my digestive tract.

“I was sitting on the toilet from 7 o’clock at night to 7 in the morning with a basin in my hand. My wife was crying outside the door. That was the toughest part,” says Michael.

Michael became anxious during and after his treatment.

“I hadn’t a clue what was going on in my head. It was like my head was in a washing machine, and I just couldn’t think. I was fearful of everything and I was thinking of everything that could go wrong.

“I went to the Solas centre in Waterford, and that is how I came in contact with the Marie Keating Foundation.

“They worked with Solas to deliver a free six-week programme for men, who had cancer like myself, who were trying to live the new normal. The programme is called “Survive and Thrive”. I joined the Solas Men’s Club and it started a gardening project.

“The hardest part was the chemotherapy. The 11 weeks of intravenous chemotherapy were grand, but what nearly finished me off altogether was the tablet form,”

– Michael Byrne

“At that time Bloom was on and the Marie Keating Foundation had a show-garden there. One of our members was there and asked them what they did with their display plants when Bloom was over.

“They said they normally gave them to charity. They hadn’t yet decided in the charity for that year, so they sent all the plants and flowers down to the Men’s Club for our Solas garden in Waterford,” says Michael.

Giving back

They had a big opening day for the garden and some members of the Marie Keating Foundation attended. Michael told them if he could ever help out with the Foundation, he would love to do so. The Foundation later contacted him about a woman who had just had surgery for lung cancer.

“She was in an awful state. She’d had a lung removed and she had only 25 per cent capacity in the other lung. The Marie Keating Foundation asked me if I’d have a little chat with her even though everyone’s experience is unique. I was happy to do so,” says Michael.

Michael has found that even though it can be difficult, it is important to stay as positive as possible.

“But the first thing you must realise is that you have to come to terms with the cancer yourself and I told myself: ‘I have this, but I am going to fight it no matter what’.

“It’s an awful shock for your family as well. They are going through everything you’re going through. If not a little bit more.

“If you are lucky enough to have good family and friends, you need to acknowledge that to yourself. There are some people there who have no one belonging to them. I’d hate to be that way myself. You need someone to lean on.

“I had my wife who was a tower of strength. It is hard for family because they know in their heart and soul, they cannot do anything for you. That’s tough.

“The least little thing can upset you and a lot of that is the side effects of all the treatment you get. You have to say to people: ‘Whatever I say and whatever I do, it’s not me, it’s just what I am going through so please bear with me’,” says Michael.

Michael felt really down at times.

“I was sitting in the chair for 11 hours a day looking out the window, that is how bad I was. But then I got counselling and availed of some other treatments at Solas, like Reiki, and they kind of got me back to realising I was not on my own. I thought I was the only one in the world who felt like this.”

Advice for someone newly diagnosed

“If people are going to go for lung cancer treatment, I would advise them if they can to put on a few pounds in weight. Start eating before you start getting the chemo because you are going to lose weight. You are going to be on different types of medication. You may not even want to look at food, but you do have to get it into your stomach,” says Michael.

He says it is also essential to drink all the water you can while you are on medication because it helps to flush out all the toxins.

“Normally I could go from one end of the week to the other without drinking water, but when I was going through treatment, I had to drink it.

“And another thing, if you are in the house on your own, for god’s sake have a radio or some sort of entertainment on. Because otherwise the mind starts playing tricks and you want to keep your mind occupied as much as you can.

“It is also important to exercise every day, even just for 5 or 10 minutes.

“Don’t just sit down and start looking at walls. You need a kind of routine and if you can, try and change that routine every day. Even if you have no transport and it is a bad day, get an umbrella and go into town on the bus and get a cup of coffee. Do something different.

“If you do just one thing the whole time, it will bring you down. Be as active as you can. I sat down for the bones of a year and I am suffering for it now because everything tightened up on me. Now I am doing a good bit of walking, but it was a big fight to try and get those muscles going. I am 66 years of age, so a few things are starting to seize up more quickly,” says Michael.

10 Supportive personnel

Specialists involved in lung cancer care aim to provide a high-quality and efficient service for anyone affected by lung cancer

Lung cancer specialists, regularly submit information on the results they are achieving and other information to the National Cancer Control Programme. The role of this Programme is to improve cancer care and services in Ireland.

Lung cancer care team

The lung cancer care team in most cancer hospitals includes:

- respiratory physicians
- lung histopathologists (doctors who diagnose and study disease by interpreting cells and tissue samples)
- cardiothoracic surgeons (see the interview with Mr Ronan Ryan in this booklet)
- radiation oncologists
- medical oncologists
- radiology staff who specialise in cancer
- lung cancer nurse specialists
- physiotherapists
- occupational therapists.

Public Health Nurse

Most specialist cancer hospitals have a community oncology nursing programme in place. This allows them to liaise with community health organisations who provide services for people receiving cancer therapy.

A Public Health Nurse may come to your home to assess your needs. The Public Health Nurse or the Community Registered Nurse can help you with wound care and other aspects of your treatment.

Cancer Support Services

There are a number of Cancer Support Centres that offer counselling and other services to cancer patients and their families. A list of these is available on page 111.

Siel Bleu Ireland – an exercise programme

Siel Bleu is a not-for-profit organisation that provides exercise programmes to older adults and patient groups. Siel Bleu Ireland is the first organisation set up to promote exercise among older adults and patient groups in Ireland.

It designs programmes that benefit all adults, at any age, and at any stage of their lives. They promote the autonomy and wellbeing of older people and people with chronic disease. They aim to make sure that everyone is able, and has the self-confidence needed, to live an independent and happy life.

See <http://www.sielbleu.ie/>

11 Diet and nutrition

A healthy lifestyle can give you more control over your health and help you to improve it

A healthy diet can also help you manage the effects of lung cancer and its treatment. Staying a healthy weight and having a healthy diet can reduce your risk of many health problems, including:

- heart disease
- diabetes
- some cancers.

Many people with lung cancer not only lose weight but also find it challenging to eat and drink. This is because of the tumour and the impact of cancer treatment. You may also have difficulty preparing and taking in meals and drinks.

It can help to eat energy and protein-rich meals and snacks. It is also important to keep your diet varied so that you meet your vitamin and mineral needs. It can help to eat small frequent meals and snacks.

If you have problems swallowing, you may need to mash up or liquidise your food. Talk to a qualified dietitian if:

- your tumour or side effects of medication make it difficult for you to eat easily
- you're having difficulty eating enough and you're losing weight.

The dietitian can help if you're making changes to your diet, or if you have other health problems affected by your diet, like diabetes.

How can I eat more healthily?

A healthy diet doesn't need to be boring. It's good to eat lots of different foods to make sure you get a range of nutrients. First, make small changes that you are comfortable with, like eating a new fruit and veg each week. Most people should be able to get all the nutrients they need by eating a balanced diet without taking supplements.

Eat small amounts regularly

If you lose your appetite or it is difficult to eat, try eating small amounts regularly instead. Try three small meals and three small snacks a day. Eat at least five to seven servings of fruit and vegetables each day.

Eat starchy foods at each meal		
• Potatoes	• Bread	• Pasta
• Rice	• Sweet potato	• Plantain

Choose wholegrain and other high-fibre options where possible. These give you energy and help you feel full if you are trying to lose weight.

Include some protein-rich foods		
• Fish	• Meat	• Eggs
• Nuts	• Beans.	

Dairy foods

Eat dairy foods or non-dairy sources of calcium. If it is difficult to keep the weight on, choose full-fat milk instead of semi-skimmed and mix grated cheese or cream into foods like mashed potato and soups.

Non-dairy sources of calcium include:

- soy products with added calcium
- green leafy vegetables
- fish where you eat the bones.

Keep high-energy snacks within easy reach

Get extra calories and protein throughout the day		
• Cheese and crackers	• Biscuits	• Cakes
• Nuts	• Crisps	• Dried fruit
• Peanut butter on toast.		

Cut down on salt

Eat less than 6g of salt each day. Look out for hidden salt in processed foods and takeaways. Avoid adding salt when you cook.

Drink less alcohol

Ask your team about alcohol. If you drink alcohol, stay within the low-risk alcohol guidelines:

- a man should drink no more than 17 standard alcoholic drinks a week
- a woman should drink 11 standard alcoholic drinks a week at most.

12 Physical activity before, during and after treatment

Physical activity is essential for general health and wellbeing and can help you to stay a healthy weight by using extra energy that the body would otherwise store as fat

What type of activity should I do?

The type of physical activity you do isn't critical – the main thing is to get active. If you find an activity you enjoy, and that fits into your life, you'll be more likely to keep doing it. The following tips may help.

Everyday exercise

Walking, swimming, cycling and gardening are all excellent exercise. You can do simple things, like getting off the bus one stop earlier or using stairs rather than a lift.

Exercise from the bed or chair

You can even exercise from your chair or bed. Try lifting and stretching your arms and legs – this can help improve your movement and muscle strength.

Counting steps

If you're trying to be more active, an exercise programme like walking may help. Counting your steps per day can also be useful.

Try a variety of activities or sports so that you don't get bored and make sure you set some goals for yourself. You may prefer to exercise with a friend or in a group.

How much physical activity should I do?

This will depend on many things, including:

- the stage of your cancer
- any treatments you are having
- your fitness levels.
- what is acceptable and manageable for you.

Even if you can't do a lot of physical activity, a small amount can still help. Take things at your own pace and don't do too much. Rest when you feel you need to.

Ask for advice from your doctor, nurse or physiotherapist. Aim to be physically active up to five times a week. Start gently for short periods, like 10 to 15 minutes, and gradually increase the amount as you become fitter. If you can, build up to include 30 minutes of moderate exercise three to five days a week. Moderate activity means your heart should beat faster, but you should still be able to talk. This would be about the level of a brisk walk. While 30 minutes may seem like a lot, remember you can reach this amount by being active for 10 minutes, three times a day.

Being physically active is safe

It's safe for people with lung cancer who are having treatment to be physically active. But it might be a good idea to speak to your GP, nurse or hospital doctor before you start any exercise plan. This is particularly important if you have other health problems, like heart disease or problems with your joints or muscles.

Your doctor or nurse can talk to you about exercising safely. You could also ask to be referred to an exercise programme or a physiotherapist for further advice. Exercise programmes for cancer patients are being set up around Ireland as part of the HSE wellness programme. Referral can be made by your doctor or healthcare professional to info@exwell.ie

Exercise safely

Be careful to avoid falls, especially if your cancer has spread to the bones.

Wear clothing and trainers that fit well, and don't exercise on uneven surfaces.

Don't exercise if you feel unwell

Don't exercise if you feel sick, or have any pain, sickness or other unusual symptoms. Stop if you get any of these symptoms while exercising.

And make sure to drink plenty of water.

Interview: Getting fit for surgery

While we are all familiar with rehabilitation, St James’s Hospital in Dublin has introduced a pre-habilitation programme for people scheduled to undergo surgical treatment for cancer

The pre-habilitation programme introduced by St James’s Hospital recently aims to reduce the number of days surgical patients spend in hospital and to generally improve their outcome.

Sarah Moore is the physiotherapist running the pre-habilitation programme.

“Surgery can put many stresses and demands on your body. It is like a marathon and you’d never not train for a marathon so why would you not train for surgery?” says Ms Moore.

“Those who did the [exercise] classes were in hospital for 4.5 days less than those who didn’t.”

**– Sarah Moore
Physiotherapist**

Fitter people do better after surgery

Recent research shows that people who are fit and strong before they have surgery will generally do better after surgery. They will have fewer complications and a shorter hospital length of stay. Even a two-week fitness programme before surgery can benefit the patient significantly.

The St James’s hospital pre-habilitation course takes place in the gym in the physical health department.

“Since July of 2019 we have had classes on every day. Patients can come every day if they want to or if they live a bit further away, they might just come once or twice a week. It is a structured exercise class with a couple minutes of a warmup and then we do high intensity exercise for half an hour. We also do stretching exercises and a cool down. The programme is open to cancer patients who are having surgery and a lot of those would be lung cancer patients,” says Ms Moore.

People need to start attending the classes at least two weeks before surgery to get the benefit.

If you are not a patient at St James’s you can still attend a physiotherapist near you and explain that you are going for an operation and would like to do exercises to prepare for it. The physiotherapist will assess your fitness and give you advice about how to prepare for the operation. You could then go to your own local gym and carry out the programme or even do it at home.

Community organisations like Siel Bleu can also help you develop a suitable exercise programme. Siel Bleu is a not-for-profit organisation that provides exercise programmes to patient groups and older adults (<http://www.sielbleu.ie/>)

Results of new programme

“I analysed the first four months of the programme – July to end of October. Within the lung cancer surgery group, there was a significant difference between those who attended the classes and those who didn’t. Those who did the classes were in hospital for 4.5 days less than those who didn’t,” said Ms Moore.

However, these are preliminary figures and don't take all circumstances into account. For example, the people who chose to do the course may have been fitter to begin with. And during that period, the average hospital stay for other patients was unusually long. Nevertheless, the results are promising.

During the pre-habilitation course, patients learn to use the different machines in the gym and spend five minutes on each one – a total of 30 minutes. The machines used include:

- bike
- rower
- treadmill
- cross trainer
- stepper.

“We put heart rate monitors on people and get them exercising up to 80 per cent of their heart rate max. That is quite high and higher than most of them would be used to, but research shows that it is safe and effective.

“We also do strengthening exercises during that circuit, two for the arms and two for the legs and use free weights. We do some chest clearance exercises at the end – these are especially important post-operatively,” says Ms Moore.

Social contact is very helpful

A lot of patients say they really appreciate the social aspect of the classes. Ms Moore assesses and measures them on the anxiety and depression scale.

12 Physical activity: Interview

“A lot of them will come back with quite high levels of anxiety, not so much depression. You would expect this in people who have been diagnosed with cancer and are waiting to go for surgery.

“I have been getting one of the clinical psychologists to give a talk once a month. It has got great feedback and is called ‘Dealing with the psychological impact of cancer’,” says Ms Moore.

People love being in the classes and it puts them in great form.

“It is such a nice thing to see, people who are going for big surgery relaxing. Some of them are not working and are sitting at home worrying so they really like the social aspect. The social side is a huge thing for patients. And they feel more prepared for their surgery,” says Ms Moore.

It is really good for people to meet others going through the same things as themselves.

“A lot of them have the same surgeons and just talking about their diagnosis helps and takes the stigma out of the situation too. They feel like they’re just normal people whereas a lot of them have been thinking ‘why did it happen to me?’. But when they’re in the class, they see other normal people who are in a similar situation.”

“We can also prepare them for being up out of bed as soon as possible after surgery so they know: ‘I am going to get up and walk three times on day one’,” says Ms Moore.

13 Relationships and family life

You might find that your plans get interrupted, or your priorities change after a diagnosis of lung cancer.

If you have side effects from lung cancer or your treatment your usual family role might change for example tiredness may affect you.

Lung cancer is your disease, but it also affects everyone who loves and cares for you. Your loved ones experience lung cancer in a very real way.

Your loved ones' challenges may not show up on a lab chart or test result, but they are often equally important. Your diagnosis can leave them feeling helpless and confused. They, too, experience the treatments, the doctor visits, interrupted sleep, sadness, fear and grief.

While some relationships remain unchanged, you and your loved ones may have to work to find the 'new normal'. This means deciding what information you want to share and with whom, and how to best approach these conversations.

Have a confidante

You may benefit from having people around whom you can trust with thoughts and concerns. Who is that person for you?

Ask for help

Asking for help may be difficult. But family and friends can listen, prepare a meal, run errands or drive you to an appointment – whatever you might need.

Look for support

A lot of people may have similar experiences to yours. Openly or anonymously, you may use an online forum or in-person support group to discuss your thoughts through the treatment process.

There is a list of cancer support centres at the back of this booklet, look for a support group near you. The Marie Keating Foundation provides programmes for those who have completed treatment and come out the other side. These include the free programmes:

- ‘Survive and Thrive’ – a six-week programme
- ‘Positive Living’ – running twice a month during the current Covid Pandemic.

Be understanding

Your family and friends may also be worried and tired. Put yourself in their shoes and consider seeking support together. It may help everyone cope during this time.

Adjusting takes time

People find that they go through stages of adjusting and develop new ways of thinking about life and relationships after a cancer diagnosis.

Lung cancer – From diagnosis to recovery

You might find some of these ideas can help:

- learn more about lung cancer together
- talk about things
- get all the support you need as a family
- get help with practical matters like work, money or household tasks
- develop a wider support network including other family, friends or health professionals.

You may also need to find ways to manage or treat your side effects – ask for help.

Talking to your partner

If you have a partner or are starting a new relationship, try talking to them about how you're feeling. Talking could help you both feel better and reduce any worries you have about what each other is thinking.

Psychosexual counselling

The emotional and physical effects of a cancer diagnosis and of treatment for cancer can be difficult for both you and your partner. They can cause stress and strain in some relationships.

14 Coping with the financial implications of lung cancer

There are many different financial supports for those who are ill – even if you don't have full PRSI cover

Benefits if you are sick or have a disability

There are several social welfare payments for people who are sick or have a disability. The two main ones are:

- Illness Benefit – intended for those with a short-term illness
- Invalidity Pension – a long-term payment.

Illness Benefit and Invalidity Pension are both social insurance payments based on your PRSI contributions. Payments are made either by the Department of Social Protection or the Health Service Executive (HSE). To qualify for a social welfare payment because you are sick or have a disability, you must be certified as sick or disabled by a doctor.

You may not have enough PRSI contributions for some social welfare disability payments. If this is so, you may qualify for a similar social assistance payment. However, you must pass a means test.

Partial Capacity Benefit

This scheme allows you to return to work (if you have reduced capacity to work) and continue to receive a payment from the Department of Social

Protection. To qualify for Partial Capacity Benefit, you must be getting either Illness Benefit (for a minimum of six months) or Invalidity Pension.

Disability Allowance

This is a long-term social assistance payment for those aged 16-66 with a disability expected to last at least one year.

Supplementary Welfare Allowance

If you are sick and do not qualify for any payment you may be eligible for Supplementary Welfare Allowance. Generally, social welfare payments are made up of a personal payment for you and extra amounts for your dependent spouse, civil partner or cohabitant and your dependent children.

Other payments and benefits

If you are getting a social welfare payment you may qualify for additional financial support because of your illness or disability. For example, under the Supplementary Welfare Allowance Scheme, you can apply for a Heating Supplement, if you have exceptional heating expenses due to ill-health or infirmity.

You may also be eligible for:

- the Long Term Illness Scheme
- a Medical Card
- a GP Visit Card.

Apply to your Local Health Office in the Health Service Executive.

Driving and home benefits

There are concessions for disabled drivers and passengers and local authority grants to adapt your home.

Tax benefits

There are also tax benefits available to people that are sick or have a disability.

Carer's payment

If someone is providing you with full-time care, they may qualify for a carer's payment.

Medical Card application form

Your illness may mean you are entitled to a Medical Card. Your Medical Social Worker or GP will advise you and can help you to apply for a Medical Card online if appropriate at:

- <https://www.mymedicalcard.ie/>

Medical card forms
Phone: HSE customer care team, Call Save 1890 252 919
Website: https://www.mymedicalcard.ie/

People who hold a Medical Card are entitled to a range of Health Services free of charge.

Call the HSE customer care team at Call Save 1890 252 919 for any other questions you have about Medical Cards. They can also post an application form to you, or help you in filling in the form or making your application.

If you don't have a Medical Card

Everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is an €80 a night charge up to a limit of €800 in 12 months. Higher rates apply for semi-private or private care.

If you do not have a Medical Card, you may have to pay some inpatient and outpatient hospital charges. You may be entitled to some community care and personal social services.

Mortgages, loans, pensions and insurance

Mortgages and loans

You may be experiencing short-term payment difficulties with your mortgage, due to your illness, and you may be worried about losing your home. Talk to your lender or talk to MABS, the State's free money advice service (see below).

MABS – Money Advice and Budgeting Service

Free money advice and budgeting service (MABS)
Phone: 0761 07 2000
Website: www.mabs.ie

14 Coping with the financial implications of lung cancer

MABS is the State's money advice service, guiding people through dealing with problem debt for more than 20 years.

MABS is free, confidential and independent.

MABS has a dedicated confidential, free, and independent mortgage arrears service. It is a state-funded service for mortgage debt advice and referral.

You can call MABS on 0761 07 2000 for independent information, advice and referral.

If you are unable to make payments on other loans, you can contact MABS for help on this too. It is the same phone number 0761 07 2000.

You can also send an email to helpline@mabs.ie if you have any queries. MABS does not offer financial advice on investments or on specific financial products. Remember also that MABS does not give out money.

Pensions

You may be worried about taking a break from paying into a private or occupational pension scheme. For information on your scheme, contact:

- the trustees in an occupational (workplace) pension scheme
- the provider in a private scheme.

They will tell you if the scheme allows you to take a break and how this may affect your final pension pay-out.

The Department of Social Protection can tell you how a break in employment may, or may not, affect your final state pension. See more information on their website at:

- www.welfare.ie/en/Pages/home.aspx

Health insurance

You may have private health insurance. If you do, before you attend hospital, check with your insurer what cover you have for inpatient and outpatient services.

Taking out health insurance

If you take out health insurance when you are ill, the health insurance company may not cover you for existing or previous illnesses for some years. The amount of time you have to wait before you are covered for pre-existing conditions varies from company to company.

Travel insurance

It can be tough for people who have cancer to get travel insurance. This can apply if you have had cancer in the past or if you are receiving treatment at present.

Before you look for insurance, ask your doctor for a letter to say you are fit to travel. Before you book your tickets, check the cost of travel insurance as it may be so expensive that you cannot afford the trip.

When asked, you must give the travel insurance company all the information they need about current and past illnesses. They will use this information to decide how much of a risk you are and how much they

14 Coping with the financial implications of lung cancer

will charge. They may refer you to a special phone line that will ask you questions to medically screen you.

You must give the insurance company all the relevant information. Otherwise, if you later make a claim, they may say the policy is invalid and refuse to pay out on it.

The Travel Abroad Scheme (TAS)

The HSE operates the TAS scheme. It provides an option for treatment in another EU–EEA member state or Switzerland for treatments that are not available in Ireland, or not available within the normal time necessary to receive it in Ireland.

The Citizens Information Service

The Citizens Information Service can also give you free advice on:

- savings and investments
- pensions
- loans and credit
- debt
- insurance
- banking.

Citizens' Information Service
Phone: 0761 07 4000
Website: www.citizensinformation.ie/en/

15 Returning to work after cancer treatment

You cannot set in stone when you will return to work after being treated for lung cancer – everyone’s experience will be different

Unfortunately, some people who have had lung cancer may feel under financial pressure to return to work before they really feel fit enough.

If possible, agree on a flexible plan with your employer where you can fit in medical appointments and treatment and possibly work flexi-hours or part-time. It can give you confidence and help you return to work more easily if you can make these arrangements before your cancer treatment.

You may also need to return to a less physically demanding or stressful work until you are fully recovered.

‘Reasonable accommodation’ at work

The law requires your employer to take reasonable steps to accommodate your needs while you are ill. They must make ‘reasonable accommodation’. This might be some modification to the way your work is organised including the:

- tasks or structure of your job or workplace
- working time arrangements.

15 Returning to work after cancer treatment

It's a good idea to arrange a conversation with your employer at least a couple of weeks before you plan to return to work. This will give you enough time to discuss and identify any adjustments that you need to be able to return to work.

Every person with lung cancer is different, and employers should not make assumptions about your fitness or about what reasonable adjustments will or won't be needed.

Ask your employer to arrange a smooth return and avoid situations where you come back to a mountain of work. Also, check that your employer has told your colleagues that you are returning. If your colleagues don't already know about the nature of your illness, it is up to you if you want them to be told. You should agree with your employer whether you tell them, or if someone else should do it.

If you feel it will be helpful, ask your union representative (if you are a member of a union) to help you make arrangements about sick leave and returning to work.

Returning to work after cancer treatment

Returning to work after cancer, or while still undergoing treatment, can be a daunting prospect. By planning a phased return and knowing what to expect, the transition will be smoother.

Marie Keating Foundation booklet on returning to work

- <https://www.mariekeating.ie/back-to-work-after-cancer/>

16 Talking to children about lung cancer

Children can sometimes feel left behind but it is important to be honest and open with them in an age-appropriate way

Cancer has a significant impact on everyone, but the focus of medical professionals and family members can often, of necessity, be on supporting the person diagnosed with cancer. Children can sometimes feel left behind. It can be hard for children to know where to turn. They may not know how to express their feelings, or who to talk to.

It is natural to want to protect children from difficult news but being honest and open with them about cancer is usually best. Children often know if there is a severe change that affects their family. Telling them about cancer means they can ask questions. It will also help to stop them from misunderstanding what is going on.

Take time to prepare yourself before speaking with your children. Make sure you understand everything and think about questions they may ask.

Tips for talking to children

Choose a time and place when you all feel comfortable. It's best to tell your children at an age-specific time and in a language understood by them.

What they need to know and their reactions depend on their age, but some tips will help:

- be honest
- use simple language
- find out what they know
- correct misunderstandings
- repeat information for younger children.

It may be useful for teachers, other parents or nursery staff to be aware of the situation. With teenagers, it's usually best to talk this through with them first. If you're concerned about how your child is coping, ask your doctor or nurse for advice about counselling or psychological services.

CLIMB® Programme for Children

CLIMB programme for children

- <https://www.purplehouse.ie/climb-programme-for-children/>

The CLIMB (Children's Lives Include Moments of Bravery) programme is aimed at children aged between five and 11 years. It is run by Cancer Support Centres around Ireland. This six-week programme is designed especially for children of primary school-going age (5-11 years) who have a parent or a significant adult who has been diagnosed with cancer.

The CLIMB programme is free. If you would like to register a child, contact your nearest Cancer Support Centre (there is a list at the back of this booklet). Register your interest and your children will be booked in.

Jigsaw – young people’s mental health

Jigsaw, the National Centre for Youth Mental Health

- www.jigsaw.ie

Jigsaw, the National Centre for Youth Mental Health, offers services to children dealing with any mental health issues.

Barnardos

Barnardos for children from 0-18 years of age

- www.barnardos.ie

Barnardos works with children from 0-18 years of age in a variety of different ways. This depends on the individual child’s age and stage of development. Their work supports children to achieve their milestones and develop resilience to help them overcome any challenges they may face.

Rainbows

Children’s peer support programme

- www.rainbowsireland.ie

Rainbows is a peer- support programme to assist children who are grieving a death or separation in their family.

17 How the Marie Keating Foundation can help you

The Marie Keating Foundation’s aim is “making cancer less frightening by enlightening”

The Marie Keating Foundation is a leading voice in cancer awareness and support for both men and women in Ireland.

We provide information on all the key cancers, including:

- lung cancer
- prostate cancer
- bowel cancer
- breast cancer
- cervical cancer
- throat cancer
- skin cancer
- testicular cancer.

We do not receive any Government funding, and all of our community services are provided free of charge.

Marie Keating Foundation Comfort Fund

We provide financial help to people who are receiving treatment for any kind of cancer and who find themselves in financial difficulty as a result. A diagnosis of cancer can lead to:

- increased medical costs like consultant fees and expensive medications
- additional expenses from activities like increased travel to medical appointments that may be some distance from home
- increased utility bills due to extra time at home while recovering from treatment
- reduction in earnings where a patient and their family members have to take time off work.

Many people can find themselves overwhelmed by these costs, and this adds to the stress associated with their cancer diagnosis. We hope to reduce that burden. Each year, the Marie Keating Foundation allocates a specific budget for people who are undergoing treatment for cancer, but who are financially struggling. The fund accepts applications on behalf of men, women and children. This fund has been operating successfully since 2004.

How does the Comfort Fund work?

The Marie Keating Foundation works in partnership with health care professionals, mainly Medical Social Workers (MSWs) and Clinical Nurse Specialists (CNSs). The Marie Keating Foundation does not accept applications directly from patients.

17 How the Marie Keating Foundation can help you

Applications must be made by the healthcare professional involved directly in your care. If you do not know who this is, ask in the centre where you are receiving treatment and they will refer you. The Comfort Fund only provides 'one-off' assistance. The Foundation will consider only one application per patient.

Survive and Thrive

The Marie Keating Foundation provides workshops and seminars to help cancer survivors adapt to the 'new normal'. The workshops and the seminars cover issues that cancer survivors often face including:

- coping with emotions
- fatigue and other side effects
- changing nutritional needs
- dealing with feelings and change
- managing stress and physical activity
- dealing with uncertainty
- self-management with individual action plans.

Sometimes the courses are for men or women only, and sometimes they are mixed. Attendees are welcome to bring a friend or family member to support them through the course or day.

All courses and seminars are free, but places are limited, and registration is essential. If you would like to apply for an upcoming class or seminar, please contact the Marie Keating Foundation, on 01 628 3726 or email info@mariekeating.ie. or visit www.mariekeating.ie/events Please say which course or seminar you are applying for.

Positive Living

Being diagnosed with metastatic cancer can be an emotional time that can lead a person to have many fears and questions and moments of anger and confusion. At a time where a person needs the most support, some people with metastatic cancer can find that it is tough to find.

The Marie Keating Foundation has launched its Positive Living programme. It is designed to support people with metastatic cancer. When you have metastatic cancer you have your own emotional, physical, and practical needs separate from other cancer patients.

This programme includes monthly meetings that are led by a health professional. They provide resources and support for people with metastatic cancer. Common themes explored in the programme include:

- working with your medical team and managing side effects
- coping with the emotional impact of metastatic cancer
- sexuality and relationships
- altered body image
- positive appearance and well-being
- using mindfulness to cope
- physical activity
- stress management
- diet and nutrition.

17 How the Marie Keating Foundation can help you

The aim of the programme is to help men and women who have meta-static cancer to live their best lives. It does this by providing specialised supports and connecting them with:

- experts in their local community
- other people affected by similar circumstances who they can relate to on a personal level.

We hope that through the course, participants will be able to look ahead and plan for the future.

‘Making Moments Matter’



Every year the Marie Keating Foundation runs a number of national awareness campaigns to increase awareness of early signs and symptoms and improve early detection. Every November, the Foundation runs a campaign on lung cancer to mark International Lung Cancer Awareness Month.

One of these was called Making Moments Matter which focused on the importance of extra time for anyone on a lung cancer journey. Seven ambassadors shared their stories and included those who had lost someone to lung cancer, survivors and those living with advanced lung cancer.

Karen McDonnell bravely shared her story of lung cancer survival as part of the campaign. Karen had been diagnosed with lung cancer twice in the same lung but is living proof that early detection can make a huge difference. You can read more of Karen's story, and those of our other ambassadors by visiting www.mariekeating.ie/making-moments-matter

Contact us

All courses and seminars are free to attend, but places are limited, and registration is essential. If you would like to find a course that is suitable for you, please contact:

- The Marie Keating Foundation
- Phone: 01-628 3726
- Email: info@mariekeating.ie
- www.mariekeating.ie/events

18. Useful organisations, contacts and supports

National organisations and supports See also www.mariekeating.ie			
Name	Location	Phone	Email and/or website
Citizens Information Board	43 Townsend St, Dublin 2, D02 VK65	0761 07 4000	info@ciboard.ie www.citizensinformation.ie
Family Carers	Nationwide	1800 240 724	info@familycarers.ie http://familycarers.ie/
Hospice Friendly Hospitals	Nationwide	01- 679 3188	hfh@hospicefoundation.ie www.hospicefriendlyhospitals.ie
Irish Brain Tumour Support Group	St Luke's Hospital, Dublin 6	01-406 5163	www.braintumoursupport.ie
Irish Cancer Society	Head office, 43/45 Northumberland Road, Dublin 4	01-231 0500 1800 200 700	support@irishcancer.ie www.cancer.ie
Irish Hospice Foundation	32 Nassau Street, Dublin 2, D02 YE06	01-679 3188	info@hospicefoundation.ie www.hospicefoundation.ie

Support groups and centres – National organisations continued			
Name	Location	Phone	Email and/or website
Irish Nutrition & Dietetic Institute	Ashgrove House, Kill Avenue, Dun Laoghaire, Co Dublin	01-280 4839	info@indi.ie www.indi.ie
LARCC (Lakelands Area Retreat & Cancer Centre)	Multyfarnham, Mullingar, Co Westmeath.	044-9371971 1850 719 719	http://cancersupport.ie/ info@cancersupport.ie
Lymphoedema Ireland	C/O The Irish Cancer Society, 43/45 Northumberland Road, Dublin 4	Freefone 1800 200 700 087-693 4964	info@lymphireland.com http://lymphireland.com/
Marie Keating Foundation	Unit 9 Millbank Business Park, Lucan, Co Dublin	01-628 3726	info@mariekeating.ie www.mariekeating.ie
Medical card application		Call Save 1890 252 919	https://www.mymedical-card.ie/
Money Advice and Budgeting Service (MABS)	Nationwide	0761 07 2000	helpline@mabs.ie www.mabs.ie
St Luke's Breast Cancer Support Group	St Luke's Hospital, Dublin 6	01-406 5163	http://stlukesnetwork.ie/patients/patient-support/support-groups-and-programmes.html

Useful organisations, contacts and supports

Support groups and centres – National organisations continued			
Name	Location	Phone	Email and/or website
Think Ahead Planning For death and dying	32 Nassau Street, Dublin 2	01-679 3188	info@hospicefoundation. ie http://hospicefoundation. ie/
Health insurers			
AVIVA Health (formerly VIVAS Health)	1 Park Place, Hatch Street, Dublin 2.	1850 45 35 25	www.aviva.ie/health
Laya Healthcare (formerly Quinn)	Eastgate Road, Eastgate Business Park, Little Island, Co. Cork	021-202 2000	www.layahealthcare.ie
LEINSTER			
ARC Cancer Support Centre	Arc House, 65 Eccles Street, Dublin 7	01-830 7333	info@arccancersupport.ie http://arccancersupport.ie/
ARC Cancer Support Centre	557-559 South Circular Road, Dublin 8	01-707 8880	info@arccancersupport.ie www.arccancersupport.ie
Arklow Cancer Support Centre	8 St. Mary's Road, Arklow, Co Wicklow	040-235 90	arklowcancersupport@ gmail.com http://arklowcancersup- port.ie/

Regional support groups and centres – Leinster continued			
Name	Location	Phone	Email and/or website
Balbriggan Cancer Support Group	Unit 23, Balbriggan Business Park, Co Dublin	01-841 0116 087-353 2872	www.balbriggan.info/balbriggan-cancer-support-group/
Brain Tumour Ireland	8 Kilgobbin Lawn, Stepside, Co Dublin		info@braintumourireland.com https://braintumourireland.com/
Canteen Ireland – support for young people with cancer	4 Carmichael Centre, North Brunswick Street, Dublin 7	01-872 2012	info@canteen.ie www.canteen.ie
Cois Nore Kilkenny Cancer Support Centre	8 Walkin Street, Kilkenny, Co Kilkenny	056-775 2222	https://coisnore.ie/
Cuisle Centre	Block Road Portlaoise Co Laois	057-868 1492	info@cuislecancersupport-centre.ie www.cuislecentre.com
Dochas Offaly Cancer Support	Teach Dóchas, Offaly Street, Tullamore, Co Offaly	057-932 8268	info@dochasoffaly.ie www.dochasoffaly.com

Useful organisations, contacts and supports

Support groups and centres – Leinster continued			
Name	Location	Phone	Email and/or website
Éist Cancer Support Centre Carlow	The Waterfront, Mill Lane, Carlow	059-913 9684 085-144 0510	info@eistcarlowcancersupport.ie www.eistcarlowcancersupport.ie
Gary Kelly Cancer Support Centre	George's Street, Drogheda, Co Louth	041-980 5100	info@gkcancersupport.com www.gkcancersupport.com
Greystones Cancer Support	La Touche Place, Greystones, Co Wicklow	01-287 1601	info@GreystonesCancerSupport.com http://www.greystonescancersupport.com/
Hope Cancer Support Centre	22 Upper Weafer Street, Enniscorthy, Co Wexford	053-923 8555	info@hopesupportcentre.ie www.hopesupportcentre.ie
Lakelands Area Retreat & Cancer Centre	Ballinalack, Mullingar, Co Westmeath	044-937 1971; Callsave 1850 719 719	info@larcc.ie www.larcc.ie

Support groups and centres – Leinster continued			
Name	Location	Phone	Email and/or website
Rathdrum Cancer Support Centre	St Anne's, Rathdrum, Wicklow.	087-691 7675	rathcan@gmail.com
Tallaght Cancer Support Group	1-2 Main Street, Tallaght, Dublin 24	086-400 2736 086-400 2703	ctallaght@yahoo.ie http://tallaghtcancersupport.com/
Wicklow Cancer Support Centre	Unit 2, Rear of Butlers Medical Hall Pharmacy, Abbey Street, Wicklow	0404-32696	wicklowcancersupport@gmail.com
CONNAUGHT			
Athenry Cancer Care	Social Service Centre, New Line, Athenry, Co. Galway	091-844 319 087-412 8080	athenrycancercare@gmail.com http://athenrycancercare.ie/
Ballinasloe Cancer Support Centre	Society Street, Ballinasloe, Co Galway	090-964 5574 087-945 2300	http://ballinasloecancersupport.ie/
Cancer Care West	Inis Aoibhinn, University Hospital Galway, Costello Road, Galway	091-545 000	info@cancercarewest.ie www.cancercarewest.ie

Useful organisations, contacts and supports

Support groups and centres – Connaught continued			
Name	Location	Phone	Email and/or website
Cara Iorrais Cancer Support Centre	2 Church Street, Belmullet, Co Mayo	097-20590	caraiorrais@gmail.com www.caraiorrais.com
Galway East and Midlands Cancer Support Centre	Le Chéile, Brackernagh, Ballinasloe, Co Galway	090-964 2088	info@egmcancersupport.com www.egmcancersupport.com
Gort Cancer Support Group	Garrabeg, Gort Co Galway	091-648 606 086-172 4500	info@gortcancersupport.ie www.gortcancersupport.ie
Mayo Cancer Support Association	Rock Rose House, 32 St Patricks Avenue, Castlebar, Co Mayo	094-903 8407	info@mayocancer.ie www.mayocancer.ie
Roscommon Cancer Support Group	Vita House Family Centre, Abbey Street, Roscommon	090-662 5898	lauramullooly@vitahouse.org https://roscommoncancersupport.ie/
Sligo Cancer Support Centre	44 Wine Street, Sligo, Co Sligo	071-917 0399	scsc@eircom.net http://www.sligocancer-supportcentre.ie/
Tuam Cancer Care Centre	Cricket Court Dunmore Road Tuam, Co Galway	093-285 22	support@tuamcancer-care.ie www.tuamcancercare.ie

Lung cancer – From diagnosis to recovery

Support groups and centres – Munster			
Name	Location	Phone	Email and/or website
MUNSTER			
CARE Cancer Support Centre	14 Wellington Street, Clonmel, Co Tipperary	052-618 2667	caresupport@eircom.net https://cancercare.ie/
Circle of Friends Cancer Support Centre	4, 6 & 7 Station House, Station Road, Tipperary Town	087-3412600	circleoffriendstipp@gmail.com www.circleoffriendscancer-support.com/
Clare Cancer Support Sláinte on Chláir:	Kilnamona, Ennis, Co Clare	1850 211 630 087-691 2396	admin@clarecancersupport.com www.clarecancersupport.com
Cork ARC Cancer Support House	Cliffdale, 5 O'Donovan Rossa Road, Cork	021-427 6688	info@corkcancersupport.ie www.corkcancersupport.ie
Cork Brain Tumour Support Group	Chemotherapy Department of Cork University Hospital, Cork	087-146 5742	https://www.brain-tumoursupport.ie/irish-support-groups/cork/
Cunamh Bons Secours Cancer Support Group	Bon Secours Hospital, College Road, Cork	021-480 1676	http://www.cunamh.ie/
Kerry Cancer Support Group	124 Tralee Town House Aptmnts, Main Street, Tralee, Co Kerry	066-719 5560	kerrycancersupport@eircom.net www.kerrycancersupport.com

Useful organisations, contacts and supports

Support groups and centres – Munster continued			
Name	Location	Phone	Email and/or website
Midwestern Cancer Support Centre	University Hospital Limerick, Dooradoyle, Limerick	061-482 900	http://www.midwestern-cancercentre.ie/support.htm
Recovery Haven	5 Haig's Terrace, Tralee, Co Kerry	066-719 2122	reception@recoveryhavenkerry.com www.recoveryhavenkerry.com
South Eastern Cancer Foundation Solas Centre	Solas Cancer Support Centre, Williamstown, Waterford.	051-304 604	info@solascentre.ie https://solascentre.ie/
Suimhneas Cancer Support Centre	2 Clonaslee, Gortland Roe, Nenagh, Co Tipperary	067-37403	suaimhneascancersupport@eircom.net
Suir Haven Cancer Support Centre	Clongour Road, Clongour, Thurles, Co Tipperary	0504-211 97	suirhaven@gmail.com
West Cork Cancer Support	'The Bungalow' at Bayview Gories, Goureebeg, Bantry, Co. Cork	027-53 891 083-198 8580	westcork@corkcancer-support.ie
Youghal Cancer Support Group	29 Friar St, Youghal-Lands, Youghal, Co Cork	024-91654	https://www.facebook.com/youghalcs/

Lung cancer – From diagnosis to recovery

Ireland's eight Designated Cancer Centres			
Hospital Group	Cancer Centre	Phone	HSE Region
RCSI	Beaumont University Hospital www.beaumont.ie/oncology	Main switch: 01-809 3000	HSE Dublin – North East
Ireland East	Mater University Hospital www.mater.ie	Main switch: 01-803 2000	HSE Dublin – North East
	St Vincent's University Hospital www.stvincents.ie	Main switch: 01-221 4000	HSE Dublin – Mid Leinster
Dublin Midlands	St James's University Hospital www.stjames.ie	Main switch: 01-410 3000	HSE Dublin – Mid Leinster
South/Southwest	Cork University Hospital www.cuh.hse.ie	Main switch: 021-492 2000	HSE South
	Waterford Regional Hospital www.hse.ie/eng/services/list/3/acutehospitals/hospitals/waterford/	Main switch: 051-848 000	HSE South
Saolta University	Galway University Hospital www.saolta.ie/hospital/university-hospital-galway	Main switch: 091-524 222	HSE West
	Satellite: Letterkenny General Hospital www.hse.ie/go/LGH/	Main switch: 074-912 5888	
Midwest	University Hospital Limerick www.hse.ie/eng/services/list/3/acutehospitals/hospitals/ulh/hospitals/uhl/	Main switch: 061-301 111	HSE West

The Keating Family



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