

Understanding

Lung cancer and mesothelioma

Caring for people with cancer

Understanding

Lung cancer

This booklet has information on:

- Non-small cell and small cell cancer
- Mesothelioma
- Lung cancer treatments
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Family doctor (GP)

Lung specialist

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Hospital records number (MRN)



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Fast facts

What kind of treatment will I have? Page 35

Surgery: An operation to remove the cancer

Chemotherapy: Drugs intended to slow down and control the growth of cancer

Targeted therapies: Drugs that target cancer cells in different ways to stop or slow down their growth

Immunotherapy: Treatment that helps your immune system to fight cancer cells

Radiotherapy: Uses high-energy rays to kill cancer cells

Are there side-effects from treatment? Page 77

Any side-effects will depend on your cancer and the type of treatment you have. For example, following surgery, you may feel short of breath – but this will improve as the lung tissue heals.

You can read about the treatments to learn more about their side-effects and possible complications.

There are treatments to help with most side-effects so tell your doctor or nurse. Don't suffer in silence.

Clinical trials Page 76

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

We're here for you Page 118

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
 - Drop into a Daffodil Centre —
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
 - Email us: supportline@irishcancer.ie
- See page 118 for more about our services.

Reading this booklet



This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference. If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

We cannot give advice about the best treatment for you. Talk to your hospital team about your treatment and care – they know your medical history and your individual circumstances.



Support Line Freephone 1800 200 700

About lung cancer

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What is cancer?

- **Cancer is a disease of the body's cells**

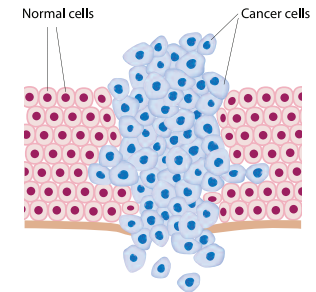
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

- **Cancers are named after the organ or cell where the cancer starts**

Lung cancer starts in cells in the lung.

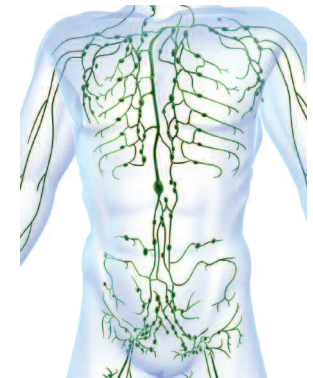
- **Cancers sometimes spread**

If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis. Metastatic lung cancer is still lung cancer, even if it is in another part of your body. It will be treated with lung cancer treatments.



What is the lymphatic system?

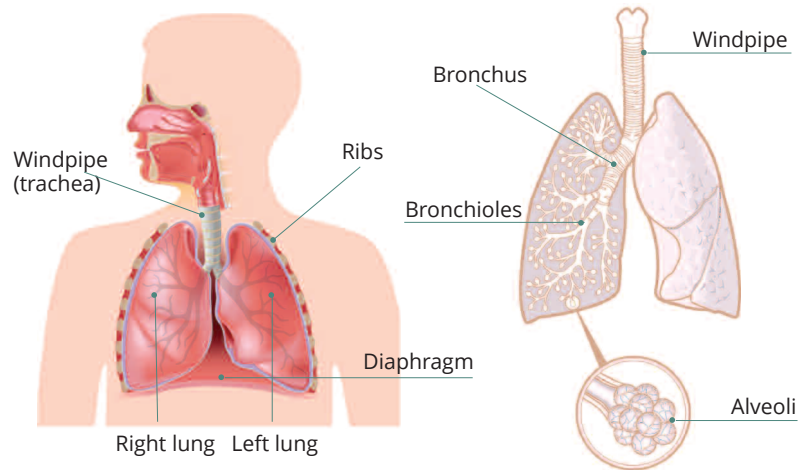
- The lymphatic system is part of our immune system, which protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the chest, neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes they can become swollen.



Support Line Freephone 1800 200 700

What are the lungs?

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



How do the lungs work?

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

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

What is lung cancer?

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

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

Lung cancers can be either primary or secondary. Primary is when the tumour starts to grow in the lungs first. Secondary is when cancer spreads to another part of the body. It still looks like lung cancer and will be treated as lung cancer.

Only primary lung cancer is discussed in this booklet.

What caused my lung cancer?

Smoking is the main cause of lung cancer. Unfortunately, in many cases, symptoms of lung cancer may not be easy to spot and are only found at a later stage.

If you want to know more about why cancer happens or to learn about other risk factors for lung cancer, see our website www.cancer.ie or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

How common is lung cancer?

About 2,500 cases of lung cancer are diagnosed in Ireland each year. It is the fifth most common cancer in men and women. Lung cancer usually affects people over the age of 50. The average age of diagnosis is about 70 years.

What are the types of lung cancer?

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

Non-small cell lung cancer (NSCLC)

Most lung cancers are of the non-small cell type. Some NSCLC cancers are linked to genetic changes (mutations) – which are not inherited. When these mutations occur in cells in the lungs, they affect the normal activity of the gene and lung cancer can develop. Mutations in the EGFR, KRAS, ROS1 and ALK genes are common in lung cancers – particularly in adenocarcinomas (see below).

There are four main types of NSCLC:

Adenocarcinoma: This is the most common type of lung cancer and is found in the mucous glands in the outer region of the lungs.

Squamous cell carcinoma: This cancer is found in squamous cells, which are flat cells that line the inside of the airways in the lungs.

Large cell carcinoma: This cancer may appear in any part of your lung. The cells are large and round when viewed under the microscope.

Not otherwise specified (NOS): This is when the doctors cannot be sure which type of non-small cell lung cancer it is.

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

Small cell lung cancer (SCLC)

About 1 in 7 of all lung cancers is the small cell type. Small cell lung cancer begins in cells around the bronchi (airways) called neuroendocrine cells (NETs). SCLC cells appear small and round when looked at under a microscope and tend to grow quickly. They often spread to lymph nodes and other organs such as your bones, brain, adrenal glands and liver. The cancer is usually caused by smoking. In fact, it is very rare for someone who has never smoked to have small cell lung cancer.

See page 39 for more about small cell lung cancer and its treatment. You can also contact our Support Line on 1800 200 700 or visit a Daffodil Centre if you have any questions that this booklet does not answer.

Other types of cancer affecting the lungs

Mesothelioma

Mesothelioma is a rare type of cancer that affects the lungs. This is a cancer of the cells in the protective linings that cover your lungs, known as the pleura. Usually this cancer occurs when someone has been exposed to a chemical called asbestos, often many years ago.

See page 15 for more on mesothelioma.

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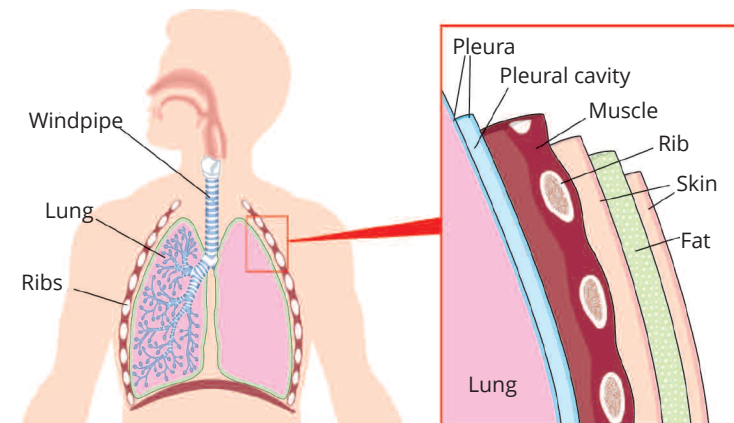
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What is mesothelioma?

- Mesothelioma is a cancer of the cells in the protective linings that cover your lungs, known as the pleura.
- Being exposed to asbestos in the past, often 20-50 years ago, is the main cause of mesothelioma.

Mesothelioma is cancer of your mesothelium. The mesothelium is a thin layer of tissue that forms the lining of several body cavities: the pleura (thoracic cavity), peritoneum (abdominal cavity) and pericardium (heart sac). Pleural mesothelioma, which affects the lining of your lungs, is the most common type of mesothelioma.



The layers lining your lungs (the pleura) are separated by a small amount of fluid, which helps them to slide over each other easily. This allows your lungs to get air in and out as you breathe. Mesothelioma causes the pleura to become hard or thicken. This makes it more difficult for your lungs to expand and contract as normal, making it harder for you to breathe.

Sometimes excess fluid builds up between the two layers. This is called pleural effusion. The build-up of fluid also makes it harder to breathe, and you will feel breathless.

Asbestos is a substance that was used mainly in insulation. It is now illegal to use it, but there may still be asbestos in older buildings. Asbestos shouldn't do any harm unless it releases its fibres, which can happen if it's broken or damaged, for example during construction.

Asbestos fibres can't be broken down if they're breathed in. They stay in your lungs and can cause mesothelioma, usually many years (10-60 years) after you've been exposed to the asbestos.

Diagnosing mesothelioma

Tell your family doctor (GP) about your symptoms and if you were exposed to asbestos. They may refer you to hospital or a rapid access lung clinic. These are consultant-led assessment and diagnostic services for patients with suspected lung disease. There are eight rapid access clinics located around the country; your GP will send you to your nearest one.

You will then have some tests, which may include a chest X-ray, CT scan and biopsy, thorascopy, bronchoscopy and mediastinoscopy – which are described on pages 25-30. You may also have a pleural aspiration, where the doctor will put a small needle and/or tube into the chest cavity to drain off some fluid. This fluid is then sent to the laboratory to test for cancer cells.



Treating mesothelioma

Mesothelioma can be difficult to treat as it is usually discovered when at a more advanced stage. The aims of most treatments are to control mesothelioma, keep you well and relieve symptoms. The following treatments may be offered:

Surgery

Surgery may be offered for early-stage mesothelioma to try to remove it. However, it can be difficult to get rid of it for good. For the majority of people, the aim of surgery is to try control the disease, relieve symptoms and to try keep you well for as long as possible. Chemotherapy and radiotherapy are usually offered after surgery.

Pleurodesis

The build-up of fluid between the pleura (pleural effusion) can be removed during a pleural aspiration. During this treatment, your doctor can put powdered medication into the pleura, causing scarring and often preventing further build-up of fluid. This is known as pleurodesis. It will help you feel less breathless.

Radiotherapy

Radiotherapy is the use of high-energy rays to control symptoms and shrink the tumour. You may have radiotherapy after surgery to stop or delay the cancer returning. This treatment is quick and is usually painless. Sometimes patients can experience pain after treatment. This is known as pain flare but it usually eases after a day or two.

See page 68 for more about radiotherapy and the side-effects of radiotherapy treatment.

Chemotherapy

Chemotherapy is the use of drugs to control the symptoms of cancer or slow down the growth of the tumour. You may have chemotherapy as well as surgery or radiotherapy. The doctors will assess and discuss with you if you are well and fit enough to have chemotherapy. See page 60 for more about chemotherapy and the side-effects of chemotherapy treatment.

Controlling symptoms

Mesothelioma can cause symptoms like breathlessness and pain. Let your medical team know if you have any symptoms so that they can help you. Some hospitals have pain specialists and breathlessness clinics. You should also be referred to the palliative care team, who are experts in managing symptoms.

See page 77 for more on how symptoms such as shortness of breath, cough, pain and fatigue may be relieved.



Diagnosis and tests

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Being diagnosed with lung cancer

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

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

However you feel, you are not alone.

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

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Survivor Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 124.

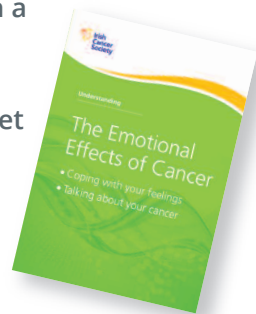
Support Line Freephone 1800 200 700

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the Emotional Effects of Cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have?

- Tests you may have include blood tests, breathing tests, CT scan, biopsy, PET scan, MRI scan, bronchoscopy, mediastinoscopy and thorascopy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The tests you have will give your doctors more information about your general health and about your cancer. Some tests may also be used to see how well your lungs are working and how you are responding to treatment.

Tests you may have after diagnosis include:

Blood tests

Blood tests can help to check your general health. They will be done regularly during your treatment. Note, there is no blood test to diagnose lung cancer.

CT scan (CAT scan) and biopsy

This is a type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat or drink) for a few hours before the test. You may also be given an injection or a special contrast drink to help show up parts of your body on the scan. **Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma.**



The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

Sometimes a small sample of tissue is taken from your lungs in a test called a CT-guided lung biopsy. The sample is taken using a thin needle and sent to a laboratory for analysis.

As well as having a CT scan of your lungs, your doctor may do a CT scan of your abdomen/pelvis. Some types of lung cancer can spread to the brain, so you may have an MRI scan (see page 30) of your brain.

Lung biopsy



A biopsy is when tissue samples are taken from your lung during surgery. The biopsy samples are sent to a laboratory where a doctor called a pathologist will look at them under a microscope. This can give information about the type of cancer and how fast it is growing (the grade). You will need to fast (not eat) before your biopsy. Also, tell the doctor if you are taking any blood-thinning medication.

PET scan

A PET scan can also show if the cancer has spread to other tissues and organs. A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

PET is safe to use and there are no side-effects. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

You will be slightly radioactive after the PET scan, so you will be advised not to have close contact with pregnant women, babies or young children for a few hours after a PET scan.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

Lung function tests

Your doctor will organise a range of breathing tests to see how well your lungs are working, and what treatments are possible. The main type of breathing test is a pulmonary function test (PFT), which is where you blow into a mouthpiece on a machine. The test is not painful and takes about 20 minutes.



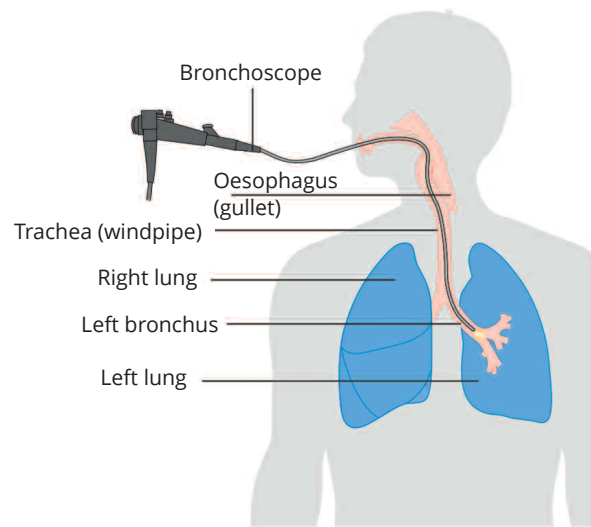
Bronchoscopy

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



Endobronchial ultrasound scan (EBUS)

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



Pictures courtesy of Cancer Research UK/Wikimedia Commons

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

The doctor can take biopsy samples from the lung or the nearby lymph nodes by passing a needle through the tube. This is called a transbronchial needle aspiration (TBNA). You will be given a sedative to help you relax. Or you may have the test under general anaesthetic. The test takes less than an hour and you can usually go home on the same day.

Endoscopic ultrasound scan (EUS)

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

A fine needle can also be passed along the endoscope tube so that biopsies can be taken from the lymph nodes. You may be sedated for an EUS or you may have a general anaesthetic. The test takes less than an hour and you can usually go home on the same day.

Mediastinoscopy

The mediastinum is the area in the middle of your chest containing your heart, large blood vessels, lymph nodes and oesophagus.

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

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

Thoracoscopy

This is a test to look at the membranes that line the lungs (pleura). A thoracoscope is used for this test. This is a flexible tube with a light and video camera attached to it. You will usually be put to sleep before having a thoracoscopy. Or you may be given a sedative to make you sleepy and relaxed. During the test, your surgeon will make a cut between two ribs and put the thoracoscope in. This allows them to see if the pleura appear normal. During a thoracoscopy, your surgeon can take biopsies of the tissue.



Picture courtesy of Cancer Research UK/Wikimedia Commons

MRI scan

This is a scan that uses magnetic energy to create a picture of the tissues inside your body. It can tell if cancer has spread beyond your lung. MRI scans are not often used for lung cancer unless the cancer is very close to the top of the lung, or other tests suggest an MRI is needed.

During the test you will lie inside a tunnel-like machine for 40-60 minutes. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs/headphones to wear. You might get an injection before the scan to show up certain parts of your body.

During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Waiting for test results



It usually takes over a week for all the test results to come back. Naturally, this can be an anxious time for you. It can be a good time for you to focus on a healthy lifestyle, which may improve your mental and physical wellbeing. See page 45 for more on waiting for treatment to start.

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

Staging lung cancer



- Staging cancer means finding out its size and if it has spread.
- Staging helps your doctor to decide the best treatment for you.
- Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis are usually done to help the doctor to stage your cancer. Staging describes how big the cancer is and where it is in your body. Knowing the stage of your cancer is very important, as it helps your doctor to decide the best treatment for you.

Staging non-small cell lung cancer

The staging system normally used is called TNM. This stands for:

Tumour (T)

The size of the tumour and how deeply the tumour has grown into lungs.

Nodes (N)

If there is cancer in your lymph nodes. N0 means no lymph nodes affected, N1 means lymph nodes near where the airways join the lungs are affected. N2 means lymph nodes in the centre of your chest or where your trachea enters your lung are affected. With N3, lymph nodes on the opposite side of your chest to where the tumour is, or near your collar bone, are affected.

Metastasis (M)

If the cancer has spread to other parts of your body. M1 means the cancer has spread and M0 means it hasn't.

Your doctor often uses this information to give your cancer a number stage – from 1 to 4.

In general, the lower the number, the less the cancer has spread.

What are the stages of lung cancer?

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

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

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

Staging allows your doctor to decide the best treatment for you.

Staging small cell lung cancer

Increasingly, doctors are using the TNM and number staging system to stage small cell lung cancer. However, some will describe your cancer as a limited stage disease or extensive stage disease.

Limited Stage (LS)

This usually means the cancer is in one lung and may be in nearby lymph nodes.

Extensive Stage (ES)

This means the cancer may have spread to the other lung, to more distant lymph nodes or to other parts of your body.

Asking about your prognosis



Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

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


If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on your prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treating lung cancer

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How is lung cancer treated?

- 
- Surgery, drug treatments and radiotherapy are the main treatments for lung cancer.
 - A team of healthcare professionals will be looking after you (multidisciplinary team).

Treating non-small cell lung cancer

The best treatment for your cancer will depend on:

- The type and size of the tumour
- Where it is in your lung
- If it has spread
- Your general state of health

You may have a combination of treatments.

The main treatments for non-small cell lung cancer are:

Surgery

If the non-small cell lung cancer is found in one lung only – or in one lung with only lymph nodes close to the tumour involved – it may be possible to remove all the tumour by surgery (see page 53). You may also have surgery to stage your cancer or to help manage your symptoms. See page 79 for more about symptom control.

Drug treatments

Systemic anticancer drug therapies are medications that spread throughout the body to treat cancer cells wherever they may be. They include chemotherapy, targeted drugs and immunotherapy. Systemic therapies are usually prescribed by a medical oncologist – a doctor who specialises in treating cancer with medication.

Chemotherapy: Chemotherapy, which uses drugs to kill cancer cells, has become increasingly more tailored to each patient based on their type of NSCLC. Chemotherapy can be given before or after surgery. Sometimes it is given together with radiotherapy. This is called chemoradiation. Chemotherapy can also be used to control cancer symptoms. See page 60 for more about chemotherapy.

Targeted therapies: These drugs target specific genetic mutations in cancers. Different targeted therapies work in different ways. The type used for lung cancer usually works by blocking the signals that tell cancer cells to grow and divide.

See page 65 for more details.

Immunotherapy: Immunotherapy treatment helps your immune system to work better to fight cancer cells. Immunotherapy can change special immune cells to help them attack the cancer directly. It can also change other parts of the immune system to make it more difficult for cancer cells to grow or spread. See page 67 for more details.

Radiotherapy

Radiotherapy can be used on its own or with other therapies to treat non-small cell lung cancer. It can also be used to control symptoms such as breathlessness or pain. Also, targeted radiotherapy treatments might be given to treat non-small cell lung cancer instead of surgery. See page 68 for more about radiotherapy.

Treating symptoms

You may have any of the treatment types described above to help control symptoms such as shortness of breath or fluid on the lungs. Other treatments you may have to control symptoms include laser treatment, cryotherapy, stenting and radiofrequency ablation (see panel and page 73). For more about symptom control see page 79.

Radiofrequency ablation (RFA) and microwave ablation (MWA)



These treatments use heat to treat very early-stage lung cancers for people who can't have or don't want to have surgery. They may also be used to relieve breathlessness if the tumour is blocking an airway. See page 73 for more information.

Treating small cell lung cancer

In small cell lung cancer, treatment will depend on the stage the cancer is at (limited or extensive) and your general health.

Chemotherapy with radiotherapy is the main treatment for limited disease small cell lung cancer.

Surgery is rarely used to treat small cell lung cancer.

Chemotherapy alone is the main treatment for extensive small cell lung cancer – where the cancer has spread outside your lung. The treatment aims to control the cancer and help with symptoms.

Radiotherapy may also be used to relieve symptoms such as pain or to shrink tumours that have spread to other parts of your body, such as your brain or bones.

Sometimes, if you have responded very well to chemotherapy, radiotherapy is used to reduce the risk of the cancer spreading to your brain. This is called prophylactic cranial irradiation.

Radiotherapy is used for the brain because most chemotherapy drugs cannot easily pass into the brain due to the brain's natural protective barrier, called the blood-brain barrier.

Specialist cancer centres

Lung cancer is treated in specialist cancer centres in Ireland – where there are rapid access centres for people with symptoms of lung cancer. Four of the centres are designated surgical centres for the treatment of lung cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis. This will depend on your diagnosis and your treatment plan. The staff at these centres have a lot of experience in managing patients with lung cancer.

Deciding on treatment

Multidisciplinary team

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



Understanding your treatment

Your doctor and nurse will explain your treatment options. You could use the fill-in page at the back of this booklet to write down your questions. Ask as many questions as you like. If you forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion

You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP can refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment

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

If you smoke, your medical team may advise you to try to stop smoking. See page 48 for advice.

Who will be involved in my care?



Surgeon A doctor who specialises in surgery and who can remove a tumour from your body.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Radiation oncologist A doctor who specialises in treating cancer patients using radiotherapy.

Radiation therapist A healthcare professional who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Advanced nurse practitioner A specialist nurse who has extra experience and skills in looking after patients in a specialty area such as lung cancer.

Oncology liaison nurse/Clinical nurse specialist A specialist nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family throughout your treatment.

Community palliative care team This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.

Medical social worker A healthcare professional trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

GP (family doctor) You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

Physiotherapist A therapist who treats injury or illness with exercises and other physical treatments.

Dietitian An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Community health services This includes family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Giving consent for treatment

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

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

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

Individual treatment



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

Waiting for treatment to start

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

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

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

You might like to make some lifestyle changes while you're waiting for treatment, such as improving your nutrition, reducing alcohol intake, increasing exercise and quitting smoking. This can help you prepare for your treatment and feel more in control.



How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well

Eating well when you have cancer can help you feel better. It can help to:

- Make you feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Help your recovery

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet *Diet and Cancer*. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it from our website www.cancer.ie



Keep active

Keeping active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning, but build up gradually.



Quit smoking

It is never too late to stop smoking. If you stop, it reduces your chance of the cancer coming back or another one developing. It also reduces your chance of developing other illnesses. Research shows that smoking can affect your cancer treatment. For example:



- Non-smokers have fewer or less severe side-effects during or after cancer treatment, such as infection after surgery
- Smoking can affect how well chemotherapy or radiotherapy work
- Quitting can help you to recover faster

You will have a better quality of life if you give up smoking

You may find it very stressful to quit smoking after a diagnosis of cancer, and you might need help to give up. If you would like support or advice on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Talk to your doctor or nurse about giving up and ask if there is a cessation officer in the hospital who can help and support you.

Email: supportline@irishcancer.ie

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

Don't keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.



Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day


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



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Surgery

- 
- Surgery means removing a tumour.
 - Surgery can often cure early-stage lung cancer.
 - There are different types of surgery for lung cancer.
 - You may have radiotherapy or chemotherapy after surgery.

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

Before your surgery you may have an assessment at a pre-admission clinic (PAC). You will have tests like a heart test (ECG) and lung tests (PFT and CPET). See page 27 for more on lung function (breathing) tests.

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

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

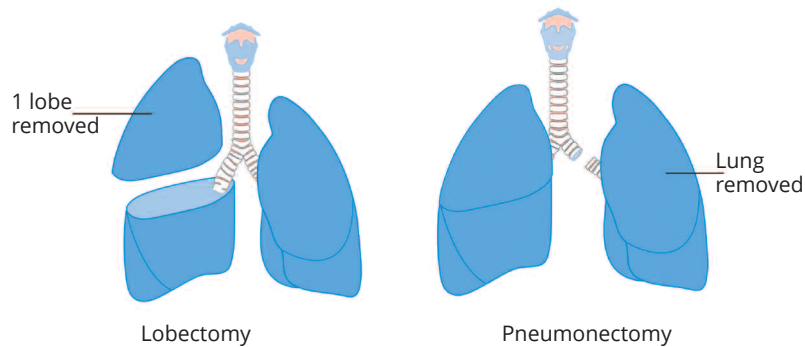
Support Line Freephone 1800 200 700

Types of surgery

The type of surgery you have will depend on the size of the tumour, where it is and your general health. The main types of surgery are:

Lobectomy: This is when a lobe of your lung is removed. Removal of 2 lobes is called bi-lobectomy.

Pneumonectomy: Here an entire lung is removed. During surgery, your surgeon will usually remove lymph nodes near the tumour, as this is where the cancer will usually spread to first. Sometimes patients worry they will be unable to breathe properly after surgery because part of their lung will be removed. But you will still be able to breathe with just one lung.



Lymphadenectomy (removal of the lymph nodes): During your surgery, the surgeon might take out some of the lymph nodes that are located close by. This is in case they contain cancer cells that may have spread from the lung tissue. The number of lymph nodes removed can vary from person to person.

Wedge resection or segment resection (segmentectomy): A small section of a lobe of your lung is removed. A segment resection removes slightly more of the lung than a wedge resection.

Getting ready for surgery

You will not be allowed to eat anything from the midnight before surgery. You may be given an injection of heparin (blood thinner) and surgical stockings to wear to prevent a clot developing in your legs after surgery.

How is surgery done?

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

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

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



After surgery

You may stay in an intensive care or high dependency unit (HDU) where the staff will keep you under close observation for a day or two, or you may go straight to the ward.



Drips, drains and tubes

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

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

Pain

You may have some pain after surgery for lung cancer. Your nurse can give you medicine to control the pain and prevent you feeling or getting sick. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help if you have any pain or feel sick.

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



Reduced bowel movements

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

Exercising

You will be asked to move your legs in bed and do deep breathing exercises at least once an hour to avoid clots. On the day after surgery, your nurses will help you out of bed and take you for a short walk. As you get better, you will be able to go for longer walks on your own.

Shortness of breath

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

Incentive spirometer

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



Weakness

Surgery for lung cancer is a major operation. It may take weeks or even months to get your strength back. The recovery period varies from patient to patient. The muscles of your chest and the arm of the affected side may become weak too. The physiotherapist will show you exercises to help rebuild muscle strength. You will help your recovery if you spend a short time each day doing the exercises at home.

Going home

Most people are ready to go home 3-5 days after video-assisted thoracoscopic surgery and 5-7 days after open surgery. Before you go home you will have an X-ray to make sure your lung is working properly. Your wound will be checked for any signs of infection – which include redness or swelling, the wound site feeling warm or discharge from the wound. You may also have a fever. Tell your nurse or doctor if you have any of these symptoms after you go home.

Help at home

If you live alone or have problems getting around the house, talk to your nurse or medical social worker on your ward as soon as you are admitted to the hospital. That way they can help put in place any community services that you may need after you leave hospital.


You will be given a date to come back for a check-up, usually about 2-3 weeks after your surgery. Your doctor will check how you are and will discuss any biopsy or other test results. Your doctor will also talk to you about any further treatment you may need. For more about follow-up, see page 93.

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

Drug therapies

You may be given one type of systemic drug therapy at a time or a combination of systemic therapies may be given at the same time. The three main categories of drug therapies are: chemotherapy, targeted therapy and immunotherapy.

Chemotherapy

- 
- Chemotherapy uses drugs to kill cancer cells.
 - Chemotherapy can cause a range of side-effects.
 - Side-effects normally go after treatment ends.

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

Chemotherapy drugs may be given:

- Before surgery or radiotherapy to shrink the cancer to make it easier to remove surgically and reduce the risk of it coming back. This is called neo-adjuvant treatment.
- At the same time as radiotherapy to make treatment work better (chemoradiotherapy).
- After surgery to reduce the risk of the cancer coming back. This is called adjuvant treatment.
- As a treatment on its own to slow or control the cancer.

The decision about treating your cancer with chemotherapy will depend on the type and size of the tumour, your general wellbeing and if the cancer has spread to other parts of your body.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. For example, you may have treatment 1 day every 3 weeks. Or another common cycle is you get treatment on day 1 and 8 in a 3-week cycle, but nothing on days 2 to 7 and days 9 to 21. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment, but it's usually between 4 and 6 cycles.

How is chemotherapy given?

Chemotherapy is usually given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump).

Sometimes it is given through a PICC line (peripherally inserted central catheter), which is a thin, flexible tube that is put into a vein in your arm and then put into (threaded through) a vein in your chest. Chemotherapy may also be given through an implantable port (sometimes called a portacath). This is a thin, soft, plastic tube that is put into a vein. It has an opening (port) under the skin on your chest.

Some chemotherapy drugs can be given orally as a tablet or capsule.

Usually your treatment will be given in the chemotherapy day care unit.

What kinds of drugs are used?

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

Support Line Freephone 1800 200 700

Understanding your drug treatment



It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

What are the side-effects of chemotherapy?

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

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

Infection: Chemotherapy drugs make you more likely to get infections by suppressing your immune system. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough, or pain passing urine.

Fatigue: Fatigue is very common. It can make you feel tired and weak. For more information see page 87.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting – talk about this with your doctor or nurse.

Anaemia: Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. You may require a blood transfusion. Regular blood tests to measure your red cell count will be done during treatment.

Bleeding and bruising: Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding.

Mouth and throat problems: Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.



Hair loss (alopecia): Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemo.

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

Skin and nail changes: Skin may become dry, flaky and itchy. Nails may become dark, yellow or brittle.

Peripheral neuropathy: Some drugs can affect your nerve endings. They may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. Tell your doctor or nurse if you experience this.

Changes in kidney and liver function: Some drugs can irritate or damage kidney or liver cells.

Allergy: On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath.

Blood clots: Chemotherapy and having cancer can both increase your risk of developing blood clots.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. Make sure you have details of who to contact if you are worried.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website www.cancer.ie for tips on coping with different side-effects.



Targeted therapies

- Targeted therapies target certain parts of cancer cells that make them different from other cells.
- Side-effects depend on the drugs being used and vary from person to person.

Targeted therapies are drugs that target certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

Different targeted therapies work in different ways. Targeted therapies can work to:

- Block or turn off chemical signals that tell the cancer cell to grow and divide
- Change proteins within the cancer cells so the cells die
- Stop new blood vessels growing to feed the cancer cells
- Carry toxins to the cancer cells to kill them

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

Different types of targeted therapies may be used to treat lung cancer. Examples of targeted therapies used for people with EGFR mutated non-small cell lung cancer are erlotinib (Tarceva®) and osimertinib (Tagrisso®). ALK-mutated lung cancer is treated with alectinib (Alecensa®) or brigatinib (Alunbrig®). Most targeted drugs are given in tablet or capsule form.

Support Line Freephone 1800 200 700

New developments in targeted therapies

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 76). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Side-effects of targeted therapies

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include:

- Skin rash
- Changes in your nails
- Higher risk of getting an infection
- Vision changes (blurred vision, double vision, flashing lights)
- Diarrhoea or constipation
- Loss of appetite
- Feeling sick
- Feeling very tired (fatigue)

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you.

For more information on targeted therapies and their side-effects, or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.



Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells.

Our immune system is often not good at recognising or clearing cancer cells from our body. Sometimes cancer cells find a way of hiding from the immune system, allowing cancer to develop or spread. Immunotherapy treatments can change special immune cells to help them attack the cancer directly. They can also change other parts of the immune system to make it more difficult for cancer cells to grow or spread.

Checkpoint inhibitors



The newest class of systemic treatments are immune checkpoint inhibitors.

A T-cell is a type of lymphocyte (white blood cell) that can be distinguished from other lymphocytes by the presence of a T-cell receptor on the surface of the cell.

The receptor, or protein complex, can turn on an immune response while other proteins turn it off. These are called checkpoints. Cancer cells sometimes find ways to use these checkpoints to hide from the immune system. They do this by making high levels of proteins to switch off T-cells, when the T-cells should really be attacking the cancer cells.

Checkpoint inhibitors work by blocking the proteins that stop the immune system from killing cancer cells. When checkpoint inhibitors block these proteins, this turns the immune system back on and the T-cells are able to find and destroy the cancer cells.

Side-effects of immunotherapy

Because immunotherapy acts on the immune system, it can cause inflammation in any part of your body.


Depending on the drugs used, side effects can include:

- Diarrhoea
- Skin rash
- Tiredness
- Shortness of breath

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects.

For more information or for a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Radiotherapy

- 
- Radiotherapy uses high-energy rays to kill cancer cells.
 - You normally have treatment every weekday for a number of weeks.
 - Side-effects affect the area of the body where the radiotherapy is aimed.
 - Side-effects normally go once your treatment is over, but some can last a long time or develop later on.

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage as possible to normal cells.

Radiotherapy may be given:

- After surgery to destroy small amounts of the cancer that may be left. This is called adjuvant treatment.
- With chemotherapy to make the treatments work better.
- Before surgery to shrink the cancer, making it easier to remove. This is called neo-adjuvant treatment.

With lung cancer, radiotherapy may be given to try to cure early cancer or after surgery to reduce the risk of cancer coming back. Radiotherapy is also used to control symptoms when lung cancer has spread to other parts of the body (palliative radiotherapy).

Radiotherapy can be given in two ways – externally and internally:

External beam radiotherapy: This is the most common type of radiotherapy. The radiation comes from machines which aim rays directly at your tumour or the tumour site. The machines are called linear accelerators.

Internal radiotherapy (brachytherapy): The radiation source is placed inside your body in special applicators on or near your tumour.

You may have both external and internal radiotherapy.

Standard external radiotherapy

Planning your treatment

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

You will have a CT scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting your treatment

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

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



The treatment normally takes several minutes and is painless. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each day.

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

How much radiotherapy do I need?

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

Stereotactic radiotherapy

Stereotactic radiotherapy is a very precise type of external radiotherapy. It is usually used to treat cancer at an early stage. With stereotactic radiotherapy, the radiotherapy beams are aimed at your tumour from many different points. Only a small area is targeted with a high dose of radiotherapy. This means that less of your healthy tissue is exposed to radiation, so there may be fewer side-effects than with the standard type of radiotherapy.

Stereotactic radiotherapy does not make you radioactive. It is safe to be around people, including pregnant women and children.

Planning your treatment

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

It is very important that you stay still during your treatment. To help you do this, the radiation technician will make a mould for you to lie in during your treatment. Each time you receive your treatment, you will be put into this mould.

Having your treatment

You will normally have 3-8 treatments, depending on where the tumour is. Each session will last about an hour. You will not feel anything during your treatment but may hear a beeping sound. Your radiation therapist will watch you on a screen and talk to you through an intercom. For more information on radiotherapy treatments, call our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the booklet, *Understanding Radiotherapy*, or download it from www.cancer.ie

Internal radiotherapy (brachytherapy)

With lung cancer, internal radiotherapy is sometimes used to reduce the size of a tumour that is blocking an airway and making it hard to breathe. See page 80 for more information.

For some internal radiotherapy you may have to stay in hospital for a few days, or in some cases you can receive it in the radiotherapy unit as an outpatient.

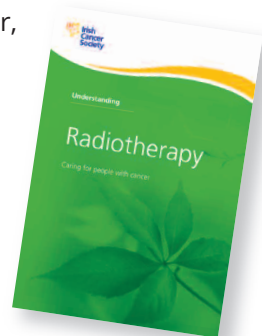
What are the side-effects of radiotherapy?

Radiotherapy is given directly to the site of the cancer so side-effects are usually related to the part of your body being treated. When lung cancer is being treated, the most common side-effects are:

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

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

Most side-effects go away once treatment is over, but do let your doctor know about them if they continue. Your medical team will explain your treatment and any possible side-effects to you. For more information, contact our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklet, **Understanding Radiotherapy**, or download it from our website, www.cancer.ie



Radiofrequency ablation and microwave ablation

Radiofrequency ablation (RFA) and microwave ablation (MWA) use heat to destroy cancer cells. They are sometimes used to treat very early-stage lung cancers, or for someone who is not medically fit for surgery. You'll be given a local anaesthetic and sedation before treatment begins. In some cases, a general anaesthetic is used instead. Your doctor will place a small needle-like probe into the lung tumour through your chest. This is usually done using a CT scanner to make sure the probe is in the right place. Radiowaves or microwaves are then passed down the probe into the tumour to heat and destroy the cancer cells.

It is common for people to have some pain or discomfort and to feel tired after RFA or MWA. You'll usually need to stay in hospital overnight for these treatments. RFA and MWA can be repeated if necessary. These treatments are not available in every treatment centre.



Treatment for cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed.

If your cancer has spread it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There are a range of treatment options for most advanced cancers, and new treatments are being developed all the time.

Often metastatic cancer is treated with chemotherapy, immunotherapy or targeted therapies. There may also be treatments that you can have as part of a clinical trial (see page 76).

Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

You can also have treatment to help with any symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of metastatic cancer.

Email: supportline@irishcancer.ie

Palliative care



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

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You don't need medical insurance.



Clinical trials

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

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

Because the drugs are still in trial, you'll be very closely monitored for unexpected side-effects and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*.

It's available for download on our website, www.cancer.ie. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at www.cancertrials.ie



Managing side-effects and symptoms

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How can my symptoms be relieved?

Some of the most common symptoms of lung cancer are:

- Blocked airway
- Shortness of breath (dyspnoea)
- Fluid on the lungs
- Cough
- Pain
- Fatigue

These symptoms can come and go and they may be either mild or severe. If you have symptoms that are troubling you, it is important to let your doctor or nurse know. They should be able to give you treatment to help. Depending on the stage of your cancer, you may also have help from the palliative care team. Members of the palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness and pain. Palliative care also offers emotional support and comfort to patients and their families. See page 74 for more on advanced cancer.



Blocked airway

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

Laser therapy

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

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

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

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

Stenting

Stenting is a treatment that uses a mesh tube, which can hold your airway open and relieve any breathing difficulties caused by the tumour blocking or narrowing your lung airways. Stents are usually put in under a general anaesthetic. The stent can stay in your lung permanently and shouldn't cause you any problems.

Internal radiotherapy

Sometimes a special type of internal radiotherapy called endobronchial radiotherapy or brachytherapy can help. This is when a source of radiation is put close to or inside the tumour.

Internal radiotherapy may be given if the tumour is blocking one of your airways, causing your lung to collapse, or if you find it hard to breathe.

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

Cryosurgery

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



Chemotherapy (see page 60), external radiotherapy (see page 69) and ablation treatments (see page 73) may also be used to relieve a blocked airway.

Shortness of breath (dyspnoea)

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

Discuss this problem with your doctor, GP or nurse. He or she can decide what to do. It may be possible to relieve the problem that is causing the shortness of breath. For example, you may have extra fluid on your lung that is making it hard for you to breathe in a relaxed way. By removing this fluid your lung can re-expand and your breathing becomes easier (see below for details).

Another way to relieve the shortness of breath can be through breathing exercises. For example, by using an incentive spirometer (see page 58 for more).

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

Fluid on the lungs (pleural effusion)

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

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

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

Hints & Tips – shortness of breath



- Ask the physiotherapist or nurse to show you some breathing exercises that will help to strengthen the muscles you use to breathe. Follow any exercise plan they recommend.
- The physiotherapist can also show you ways to sit that will increase the amount of air you can take into your body.
- You may find that you sleep better in a comfortable chair than in a bed.
- Avoid doing things that increase your shortness of breath, such as bending over and climbing flights of stairs. Take your time getting dressed and wear clothes and shoes that are easy to put on.
- Anxiety can make a breathing problem seem much worse. Finding ways to manage your anxiety may help. For example, learning relaxation techniques such as mindfulness or breathing exercises.
- If you are anxious and upset, ask to speak to a counsellor about your feelings – it may help. See page 102 for more about counselling.

Cough

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

Hints & Tips – coughing



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

Email: supportline@irishcancer.ie

Pain

For many patients with lung cancer, pain is one of the main symptoms that prompts them to go to their doctor in the first place. A lung tumour can cause mild to severe pain in your chest by pressing on nearby tissues and organs. Pain can also be caused by the tumour spreading to other parts of your body, such as your bones. The pain may be constant or present only now and then.

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

You may be referred to the palliative care team who are experts in managing symptoms, including pain. See page 75 for more about palliative care.



Hints & Tips – pain



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

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.



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

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

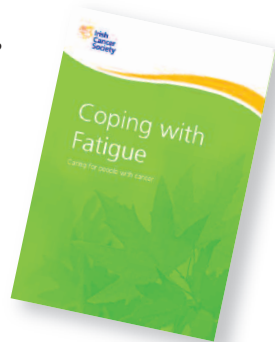
Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

Hints & Tips – fatigue



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

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



Email: supportline@irishcancer.ie

Will treatment affect my sex life?

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

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching, caressing and holding each other can help you to stay physically close.

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



There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery.

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

Contraception

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

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

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

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this may be an option for you.

Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to talk through your feelings with someone who is a good listener or with a professional counsellor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and meditation.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies and to tell them if you're using or considering using any over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care



Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

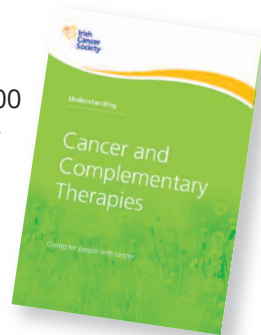
Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet *Understanding cancer and complementary therapies*, or download it from our website www.cancer.ie



After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need to have regular check-ups. This is called follow-up. The follow-up may involve having a physical examination, lung function and blood tests, X-rays and scans. At first you will see your consultant every 3-6 months but these check-ups will become less frequent over time.

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



It's important to attend your follow-up appointments as they will allow your doctor to check for signs of the cancer coming back (recurrence) and to help with any side-effects that you may have. He or she can also check for signs of new side-effects that may develop after you have finished treatment. It is better to be aware of these as early as possible so that suitable treatment can be given.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary. If you become suddenly unwell and can't contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

Life after treatment

While you may feel relieved that your treatment is over and a new phase in your life is set to begin, it can take some time to adjust to life after cancer treatment. It is usual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- **Fear of cancer coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Guilt, or shame, for having smoked** – thereby blaming yourself for getting lung cancer. You may also find it difficult to deal with the stigma in society centred around your smoking
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**
- **Relief** that treatment is over and a new phase in your life can begin

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 103 for other ways to get emotional support.

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of cancer returning or a new cancer

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting vaccinations as recommended

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website www.cancer.ie for tips and publications on healthy living.



What if the cancer comes back?

If cancer does come back, it can often be treated again. Your cancer doctor will advise you on what your treatment options are.

Planning ahead

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive.** This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will.**
- **Sorting out financial affairs.**
- **Talking about what you want** to your family, friends, carers and healthcare providers.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie



Coping and emotions

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How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

A cancer diagnosis can be hard on you - mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

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



Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Free one-to-one counselling is available at some local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline @irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 124 for more about cancer support services.

'Counselling has helped me with every part of my life.'

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

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

Survivor Support: Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.



Talk things through:

It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so.

You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

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

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

'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Email: supportline@irishcancer.ie

Positive feelings



In time, some people say they can find positive things in their cancer experience.

They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

'I am very happy and content ... even though I have to live with this.'

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Understanding the Emotional Effects of Cancer* can help to you find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.

Changing relationships



You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.



Supporting someone with cancer

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Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website www.cancer.ie or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at our affiliated cancer support centres. Talk to your GP or see page 102.

Find out about support for carers

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

How to talk to someone with cancer

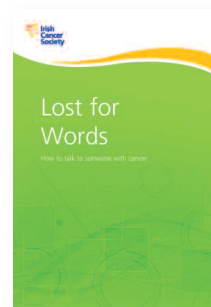


When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*.

The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative.

You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie



Support for you



Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, *Caring for Someone with Cancer* has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website www.cancer.ie



Email: supportline@irishcancer.ie

If a loved one has cancer and you smoke


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



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Money matters

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- If you have cancer you may not be able to work for a time. You may also have extra expenses.
 - You may have to pay for some of your cancer treatment.
 - You might be entitled to certain social welfare payments.
 - There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with your illness if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

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

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

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

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

If you don't have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment to check you're covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.



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

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0761 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

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

If you have money problems

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

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 121 for more details of our Volunteer Driver Service and the Travel2Care fund.

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

More information

Go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer*. This explains:

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



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

Irish Cancer Society services

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

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information.

The Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on supportline@irishcancer.ie or visit our Online Community at www.cancer.ie

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



Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- End-of-life services
- Chemotherapy group education sessions
- Lifestyle and cancer prevention
- Emotional support
- Local cancer support groups and centres
- Practical entitlements and services
- Living with and beyond cancer

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support



Speak to someone who has been through a diagnosis similar to yours. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to www.cancer.ie and search 'Find Support'.

Patient travel and financial support services



We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

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

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Publications and website information



We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Support Line for free copies of our publications.

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

Local cancer support services

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

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses



- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



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

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at www.cancer.ie/cancer-information-and-support/cancer-support/find-support

What does that word mean?

Adjuvant treatment	Treatment given soon after surgery when a diagnosis of cancer is made.
Alopecia	Baldness. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository (into your back passage) to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
Biopsy	The removal of a small amount of tissue from your body to find out if cancer cells are present.
Bronchoscopy	A test where your doctor can look inside your lung airways using a thin flexible tube called a bronchoscope. It is like a small telescope that can take pictures like a camera.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Drugs intended to slow down and control the growth of cancer.
Malignant	Cancer. A tumour that spreads.
Mediastinum	The area in the middle of your chest containing your heart, large blood vessels and oesophagus (gullet). Your lungs are on either side of it.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.

Nausea	Feeling sick or wanting to be sick.
Neo-adjuvant	Treatment given before surgery to reduce the size of the tumour.
Oncology	The study of cancer.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy rays.
Staging	A series of tests that measure the size, location and extent of cancer.



Questions to ask your doctor

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

What tests do I need?

What type of lung cancer do I have? Where is it exactly?

How long will I have to wait for test results?

What stage is my cancer at? Has it spread?

What type of treatment do I need?

How successful is this treatment for my cancer?

Are there other treatment options? Why is this one best for me?

What side-effects or after-effects will I have?

How long will my treatment take?

Do I have to stay in hospital for my treatment?

Is there anything I can do to help myself during treatment?

Who do I contact if I have a problem when I go home?

What support services are available to help me cope with my cancer?

Join the Irish Cancer Society team

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

Support people affected by cancer

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

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

Share your experiences

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

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

Raise money

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

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

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

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

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