

Understanding

Lung cancer and mesothelioma

Caring for people with cancer

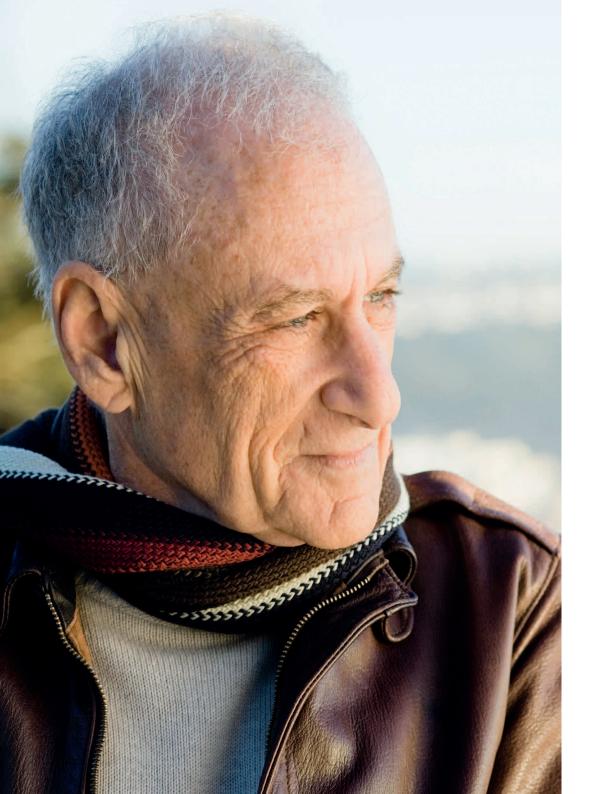
Understanding

Lung cancer and mesothelioma

This booklet has information on:

- Non-small cell and small cell lung cancer
- Mesothelioma
- Lung cancer treatments
- Treatment 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
Thoracic 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 43

Surgery: An operation to remove or help in the diagnosis and treatment of the cancer.

Chemotherapy: Treatment using drugs that kill or control cancer cells.

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

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

Radiotherapy: High-energy X-rays that kill cancer cells. Radiotherapy can try to cure cancer or help manage some of the symptoms of advanced cancer.

Are there side-effects from treatment? Page 59

Any side-effects will depend on your cancer and the type of treatment you have.

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 89

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you

Page 135

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 to speak to a nurse.
 Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 135 for more about our services.

Support Line Freephone 1800 200 700

Reading this booklet

This booklet is to help you throughout your treatment and afterwards. Keep it for reference. You may find different sections useful at different times in your illness. 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

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About lung cancer

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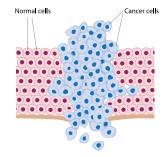


Email: supportline@irishcancer.ie



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
 For example, 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 tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.

What is the lymphatic system?

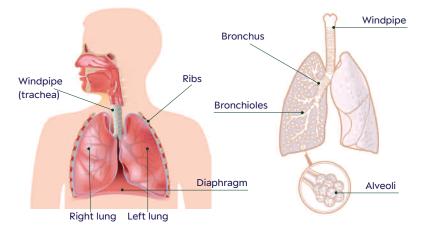
- The lymphatic system is part of our immune system. It helps to protect us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin, abdomen (tummy) and chest.



• If cancer cells spread into lymph nodes or cancer starts in the lymph nodes, they can become swollen.

What are the lungs?

The lungs are sponge-like organs in your chest. They allow our bodies to use oxygen by breathing. The right lung is slightly bigger and is made up of 3 areas called lobes. The left lung has 2 lobes. The area between your 2 lungs is called the mediastinum. It holds your heart, trachea (windpipe), oesophagus (food pipe) and many lymph nodes.



How do the lungs work?

Your lungs form part of the respiratory system, 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 2 airways called the right bronchus and left bronchus, which go to each lung. These divide into smaller tubes called bronchioles. Finally, the bronchioles become tiny air sacs called alveoli.

The alveoli allow oxygen from the air to pass into your bloodstream when you breathe in. The bloodstream carries oxygen to the cells in your body. The cells need oxygen to live and carry out everyday functions. Carbon dioxide is a waste gas made during cell activity, and 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 expel carbon dioxide out.

What is lung cancer?

Lung cancer is a condition that arises 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.

A cancer in your lungs can be either a primary or secondary cancer. The medical team need to find out which type it is to guide treatment.

Primary lung cancer: The tumour starts to grow in the lungs first.

Secondary cancer (metastatic or advanced disease): Lung cancer cells may break away from the cancer in your lung and form tumours in other parts of your body. For example, your other lung or your bones. This is called advanced, metastatic, or secondary cancer.

When lung cancer spreads to another part of the body, it still looks like lung cancer. Treatment can be more complex, but generally the type of treatments used are the same as for primary lung cancer.

Only primary lung cancer is discussed in this booklet.



What caused my lung cancer?

Smoking is the main cause of lung cancer, but non-smokers can get lung cancer too. Unfortunately, in many cases, lung cancer does not have any symptoms in the early stages, making it difficult to spot; in many patients symptoms are only apparent 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 2,700 cases of lung cancer are diagnosed in Ireland each year. Lung cancer usually affects people over the age of 50.

What are the types of lung cancer?

- Most lung cancers belong in 2 main groups: non-small cell lung cancer and small cell lung cancer.
- Diagnosis for each type of lung cancer is made by looking at a sample of the lung cells under a microscope.
- Each type of lung cancer behaves in different ways and requires different treatments.

Non-small cell lung cancer (NSCLC)

Most lung cancers are non-small cell lung cancer (NSCLC).

There are 4 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.

Some NSCLCs have genetic changes (mutations) that aren't 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 can happen in lung cancers – particularly in adenocarcinomas and in patients who have had little or no exposure to smoking.

Small cell lung cancer (SCLC)

- Small cell lung cancer (SCLC) accounts for about 1 in 7 of all lung cancers in Ireland.
- It begins in cells around the bronchi (airways) called neuroendocrine cells.
- The cells appear small and round when examined under a microscope and tend to grow quickly.
- **SCLC** is an aggressive cancer with the potential to grow and spread rapidly.
- **SCLC** often spreads to lymph nodes and other organs such as your bones, brain, adrenal glands and liver.

See page 47 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 lung cancer that most commonly affects the cells in the protective linings that cover your lungs, known as the pleura. Usually this cancer occurs after exposure to a chemical called asbestos. Asbestos use is now banned in the Western world. Mesothelioma tends to occur many years after exposure to asbestos.

See the next section for more on mesothelioma.

About mesothelioma

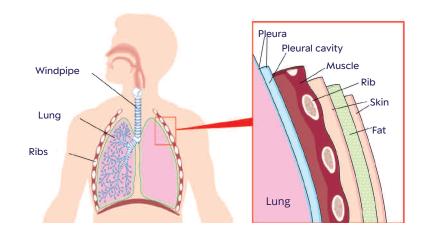
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What is mesothelioma?

Mesothelioma is cancer of the mesothelium. The mesothelium is a thin layer of tissue that lines many cavities in the body. These include 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 that line your lungs are called the pleura. They are separated by a small amount of fluid, which helps them to slide over each other easily.

Mesothelioma causes the pleura to thicken and become hard. This makes it more difficult for your lungs to expand and contract as normal, making it more difficult for you to breathe.

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

Support Line Freephone 1800 200 700

Treating mesothelioma

Mesothelioma can be difficult to diagnose and treat.

The aim with most treatments is to control mesothelioma, keep you well and relieve symptoms.

The following treatments may be used:

Surgery

The aim of surgery, in many cases, is to obtain tissue to reach a diagnosis and to try to relieve symptoms. Surgery may be offered for early-stage mesothelioma to try to remove it, but this is rare. It can be difficult to get rid of it for good. For most patients, chemotherapy and radiotherapy treatments are normally offered after surgery.

Pleurodesis

Mesothelioma can cause a build-up of fluid between the pleura (pleural effusion). This fluid can be removed during a pleural aspiration. During this treatment, your doctor can put medication into the pleura. The medication causes the surfaces of the pleura to become sticky and bond together. This seals the space between the pleura and can help to prevent further build-up of fluid. This procedure is known as pleurodesis (see page 96). It will help you to 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 prevent or delay the cancer returning. This treatment is usually well tolerated, but sometimes patients can experience pain after treatment. This is known as pain flare, but it usually eases after a day or two.

See page 81 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 cancer. You may have chemotherapy as well as surgery or radiotherapy. The doctors will assess if you are fit enough to have chemotherapy and discuss this with you.

See page 70 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 91 for more on how symptoms such as shortness of breath, cough, pain and fatigue may be relieved.



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Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.



Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as carparking).
- Dress in warm comfortable clothes and shoes sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you are not fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. It's best to have support from a friend or family member, if possible.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- · Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- · A referral letter or GP letter, if you got one
- · Your GP's name and contact details
- Your medical history remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- Your phone and your phone number
- Contact details of the person to call in an emergency
- · Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave, if required

After the appointment

 Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Support Line Freephone 1800 200 700



Diagnosis and further tests

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Being diagnosed with cancer

Hearing that you have cancer will 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
- Angry that this is happening to you

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 Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. 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 142.

However you feel, you are not alone.

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 or need a little time to adjust. 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 illness 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 thoracoscopy.
- Other tests after diagnosis can help your healthcare team decide on the best treatment for you.

The tests you have will give your doctors more information about your general health and about the 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.

CT 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 or have the injection, the radiographer will ask you some health questions. Let them know if you are allergic to any foods or medications.

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 a CT scan of your lungs, your doctor may do a CT scan of your abdomen/pelvis and/or brain. Some types of lung cancer can spread to the brain, so you may have an MRI scan of your brain (see page 36).

Lung biopsy

The small pieces (samples) of tissue taken from your lung during a bronchoscopy, EBUS, CT scan or surgery are called biopsies. The biopsy samples are sent to a laboratory where a doctor called a pathologist will look at them under a microscope. The pathologist can usually get information from your biopsy sample about your type of cancer and how fast it is growing. 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 show if the cancer has spread to other tissues and organs in your body. Before you have the scan, a low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The PET scan uses the radiotracer to 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) and drink only plain unflavoured water for a few hours.

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 the scan.

Drink plenty of fluids and empty your bladder regularly after the scan; this can help flush the radiotracer from your body.

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

Lung function tests

Your doctor will organise a range of breathing tests to check how well your lungs are working and to see 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. Cardiopulmonary exercise testing (CPET) assesses how your lungs and heart respond to exercise, using an exercise bike.



Bronchoscopy

This test uses a small tube with a camera at one end. You will have a sedative drug injected 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. Photos and samples (biopsies) from the lung tissue will be taken during the procedure.

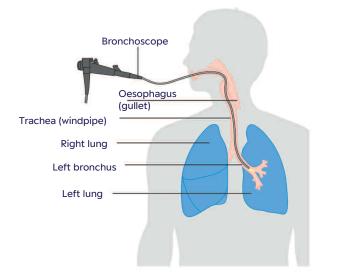


Endobronchial ultrasound scan (EBUS)

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

An EBUS is different to a normal bronchoscopy because 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 procedure is called a trans-bronchial needle aspiration (TBNA). You will be given a sedative to help you relax before the EBUS. 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.



Picture courtesy of Cancer Research UK/Wikimedia Commons

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 any enlarged lymph nodes in the centre of the chest.

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 tube is inserted into your chest following along the outside of your airway. 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. The samples 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.

Surgical thoracoscopy

This is a test to look at the membranes that line the lungs (pleura). A thoracoscope is the instrument used for this test, which is a long tube with a camera. You will have a general anaesthetic for this operation.

During the operation, your surgeon will make a cut

between two ribs and put the thoracoscope in. This allows them to see if the pleura appear normal.

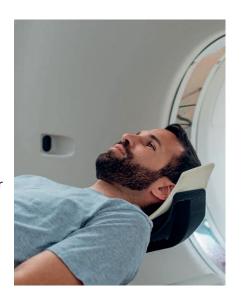
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The surgeon can also take biopsies (tissue samples) of the lining of the inside of the chest and / or the lymph nodes. They can perform a pleurodesis, if needed (see page 96).

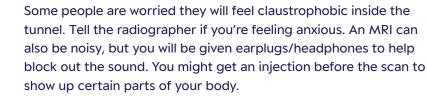
MRI scan

This is a scan that uses magnetic energy to create a picture of the tissues inside your body. An MRI scan may need to be done to see if the 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 scan is needed.

During the test you will lie inside a tunnel-like machine for 40-60 minutes.



7 8 9 SKIN MARKER



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.

Waiting for test results

It usually takes up to 2 weeks for all the test results to come back. This can be an anxious time for you. It may help to talk things over with 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.

You might also like to focus on your own health, which may improve your mental and physical wellbeing. See page 53 for more on waiting for treatment to start.



Staging lung cancer

- Staging cancer means finding out where it is, 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 your diagnosis are usually 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 healthcare team to decide the best treatment for you.

Staging non-small cell lung cancer

A cancer stage is a way to describe the extent of the cancer at the time you are first diagnosed. The staging system normally used is called the TNM system. This stands for:

Tumour (T)

Describes the tumour size and where it is located in the lungs.

Nodes (N)

Whether there is cancer in the lymph nodes:

- NO: No lymph nodes are affected.
- N1: Some lymph nodes near where the airways join the lungs are affected.
- N2: Some lymph nodes in the centre of the chest or where the trachea enters the lung are affected.
- N3: Some lymph nodes on the opposite side of your chest to where the tumour is, or near your collarbone, are affected.

Metastasis (M)

Whether the cancer has spread to other parts of the body:M0: The cancer has not spread.M1: The cancer has spread.

Number stage

The medical team uses the information from the TNM staging system to decide what stage your cancer is. The stages range from 1 to 4. In general, the lower the number, the less the cancer has spread.

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

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:

- Get the information 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 it may be 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. It is also important to know that lung cancer care in Ireland is excellent, with outcomes ahead of many other countries. Be guided by your doctors, who want the best for you, and be cautious of claims of miracle cures in overseas countries.
- 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.

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.

Support Line Freephone 1800 200 700



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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 (the 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 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 61). You may also have surgery to stage your cancer or to help manage your symptoms. See page 91 for more about symptom control.

Drug treatments

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

Chemotherapy

Chemotherapy involves the use of drugs to kill or control cancer cells. Your specialist doctor will prescribe your chemotherapy based on the type of NSCLC that you have.

Chemotherapy can be given before or after surgery. Sometimes it is given together with radiotherapy. This is called concurrent chemoradiation. Chemotherapy can also be used to control cancer symptoms. See page 70 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 76 for more details.

Immunotherapy

Immunotherapies are treatments that help your body's own immune system to find and attack 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 78 for more details.

Radiotherapy

Radiotherapy can be used on its own or with other therapies to treat NSCLC. It is often used to control symptoms such as breathlessness or pain. Targeted radiotherapy treatments can sometimes be used to treat NSCLC instead of surgery. See page 81 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 to control symptoms include cryotherapy, stenting and radiofrequency ablation. For more about symptom control see page 91.

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 86 for more information.

Treating small cell lung cancer

The best treatment for small cell lung cancer (SCLC) will depend on the stage the cancer is at (limited or extensive – see page 39) and your general health. Chemotherapy with radiotherapy is the main treatment for limited stage SCLC.

Surgery is only used to treat SCLC in very select cases. Chemotherapy is the main treatment for extensive stage SCLC – where the cancer has spread outside your lung. Immunotherapy may be added to chemotherapy as part of the treatment of extensive stage SCLC in some cases. 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.

Support Line Freephone 1800 200 700

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. 4 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, respiratory physician, specialist nurse, radiologist, oncologist (cancer doctor) and pathologist will meet as a team 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 56 for advice.

Who will be involved in my care?

Thoracic surgeon A doctor who specialises in surgery of the chest and who can remove a tumour from your body.

Respiratory physician/consultant A doctor who specialises in diagnosing, treating and preventing conditions affecting the respiratory (breathing) system.

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 Oncology trained health professional, qualified in the planning, treatment and post-treatment care of cancer patients.

Radiologist A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET and also undertakes biopsies under image-guidance.

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. They give information and reassurance to you and your family throughout your treatment.

Medical social worker A healthcare professional trained to help you and your family with your social, emotional and practical needs. 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) While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can 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.

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), community welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Palliative care team

This team is experienced in managing pain and other physical symptoms throughout your cancer journey. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

Individual treatment

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

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.

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 focus on your health and wellbeing while you're waiting for treatment. For example, eating well and staying active.

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on cancer treatments, including what to expect and how to manage side-effects.



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 as well as possible can help you during your treatment. It can help you to:

- Keep up your energy and strength
- · Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with side-effects of treatment
- · Reduce your risk of infection and other complications
- Recover faster



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 on our website **www.cancer.ie**

Keep active

If you are able, it can really help to stay active before, during and after your treatment. Keeping up or increasing your activity levels 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 – build up gradually.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

 Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, infections



- Smoking can reduce how well
 radiotherapy and some other anti-cancer treatments work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chance of further illness

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

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

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. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

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.

Be aware 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 is used to remove 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. If the cancer has spread to the lymph nodes it helps your doctors to decide if you need any other treatments.

Before your surgery you may have an assessment at a preadmission clinic (PAC). You will have tests like a heart test (ECG) and lung tests (PFT and occasionally CPET). See page 33 for more on lung function (breathing) tests.

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

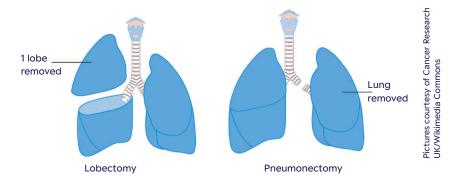
- The type of tumour
- The size of tumour
- Where it is found in your lung
- If it has spread to other areas in your body
- The results of your lung function (breathing) and cardiac (heart) tests
- Your general health and fitness for treatment
- Your own wishes

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: Removal of a lobe of your lung. The removal of 2 lobes of your lung is called a bi-lobectomy.

Pneumonectomy: Removal of your entire lung. 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. Your surgeon will carefully assess this beforehand to ensure that you will still be able to breathe properly with just one lung.



Sleeve resection: This is more technically challenging and involves removing the part of the lung with the cancer in it while preserving the remaining part of the lung, by reconstructing the airway and / or pulmonary arteries – it's termed a parenchymal sparing resection. It is a preferred option to a pneumonectomy if possible and is the treatment of choice in high-volume cancer centres.

Lymphadenectomy (removal of the lymph nodes): During your surgery, the surgeon should remove a minimum number of the lymph nodes that are located close to and within the lung. This is in case they contain cancer cells that may have spread from the lung tissue. The minimum number of lymph nodes to be removed can vary. It depends on the location of the tumour. **Wedge or sub-lobar resection:** A section of a lobe of your lung is removed. This operation is only suitable when the cancer is less than 2cm in size and it is found on the periphery (edge) of the lung, with no evidence of cancer within any of the lymph nodes in the lung or chest. You should also have specific lymph nodes removed to assess and ensure accurate staging.

Segmentectomy resection: Removes slightly more of the lung than a wedge resection, in a way that follows the blood and airway supply of that segment or part of the lung. It is also very important that an appropriate number and location of lymph nodes are removed to ensure accurate staging.

Important things to consider while waiting for your surgery

Stop smoking

If you are a smoker, it is important that you try to stop smoking at least 4 weeks before your surgery. Not smoking reduces your risk of developing complications after surgery. Please see page 56 for advice on how to get support to stop smoking.

Avoid alcohol

Excessive alcohol consumption should be avoided for at least 4 weeks before your surgery. The low-risk guidelines are less than 17 standard drinks for males and less than 11 standard drinks for females spread out over a week. A standard drink is a half pint of beer, a small glass of wine or a single measure of spirits.

Food and activity

It is important that you try to eat well and be physically active while you are waiting for surgery. You can ask your medical team about this.

See page 53 for more on waiting for treatment to start.

Getting ready for surgery

You will have to fast (not eat anything) for a number of hours before your surgery. The medical / nursing staff will give you advice about when you need to start fasting. They will also tell you about what will happen on the day you come to hospital for your surgery.

On the day of your surgery

- You may be admitted to the hospital on the morning of your surgery.
- You will be instructed what medications to take the morning of your surgery.
- You will meet a doctor and nurse who will prepare you for theatre. You will be given surgical stockings to wear and you may also be given an injection of heparin (blood thinner) to prevent a clot developing in your legs after surgery.
- After your surgery, you will be assigned a bed on the surgical ward.

How is surgery done?

There are 2 main ways of doing surgery for lung cancer:

Keyhole surgery: The surgeon removes the cancer 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: The surgeon will make a cut (incision) in your chest to open it up by spreading the ribs so that the cancer can be removed. You will have a larger scar afterwards. Open surgery is generally done for more advanced or technically complex cancer surgery.

After surgery

You will generally stay in a high dependency unit (HDU), where the staff will keep you under close observation for a day, or you may go straight to the ward, depending on the complexity of your operation and your general health.

Drips, drains and tubes

- There will be 1 or 2 plastic tubes (chest drains) near your wound site. They are there to help your lung to 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.
- After open surgery, you may have a small thin tube called a catheter to drain urine from your bladder into a bag. This means you don't have to get out of bed to pass urine.
- 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. You may be given a PCA (patient controlled analgesia) pump after you operation. The PCA releases a set amount of pain relief when you press a button. Your nurse will show you how to use it. It is important that you use this as you need it in order to remain comfortable in the period after your surgery. The pump has a safety mechanism, so you will not get too much medication. It is important that your pain is controlled so that you can walk around, breathe deeply, eat, drink and sleep well. 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.

Eating and drinking

You will be encouraged to drink and eat as soon as it is safe to do so. The nursing staff will tell you when it is safe to do so. You will start taking sips of water and progress towards solid food.

The nursing and medical staff will tell you if you need to make any changes to your diet after your surgery.

Reduced bowel movements

The anaesthetic and pain medication used during and after your operation slow down the movement of your bowel. As a result, you may not return to normal eating and drinking for 1 or 2 days. You will be able to take sips of water very soon. Your fluid intake will increase and most people can manage a light meal within 1 or 2 days of surgery, depending on the type of operation you have had. You will be monitored to make sure your bowel habits get back to normal.

Exercising

Moving about after your surgery is an important part of your recovery.

You will be asked to move your legs in bed and do deep breathing exercises at least once an hour to help to prevent clots from developing. You will be encouraged to move once it is safe to do so. The morning after your surgery the nurses will help you out of bed and take you for a short walk. You should aim to go for at least 2 short walks on the day after your surgery and sit out for a minimum of 4 hours, with rests in between as you need. This helps to improve your circulation and to reduce the risk of chest infection and other post-operative complications. 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 your body adapts 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 full 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 1-2 days after robotic surgery, 2-4 days after video-assisted thoracoscopic surgery and 5-7 days after open surgery. Before you go home you will have a chest 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 coming 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. They can help put in place any community services that you may need after you leave hospital. It is best to mention this to the nurse during your admission as it can take time to set up these services.

Once your surgical results are back, your MDT will meet to plan further treatment or follow-up. Generally, a cancer nurse specialist, who you will know, will contact you to update you on the outcome of the MDT meeting. You will be given a date to come back for a check-up, usually about 6 weeks after your surgery. Your doctor will check how you are and will discuss any biopsy or other test results with you. Your doctor will also talk to you about any further treatment you may need. For more about follow-up, see page 109.

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

Drug therapies

If needed, 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 3 main categories of drug therapies are: chemotherapy, targeted therapy and immunotherapy.

Chemotherapy

- · Chemotherapy uses drugs to kill or control cancer cells.
- · Chemotherapy can cause a range of side-effects.
- Side-effects normally go or lessen after treatment ends.
- The doctor who specialises in prescribing chemotherapy drugs is known as a medical oncologist.

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 or together with other drug treatments such as immunotherapy to slow or control the cancer.

The medical oncologist's decision to offer you chemotherapy treatment will be based 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. Another common cycle is that you get treatment on day 1 and day 8 in a 3-week cycle, but no treatment on days 2 to 7 and days 9 to 21. The number of treatments and cycles can vary depending on a few factors including the type of cancer you have, how well it is responding to treatment and how well you are tolerating the chemotherapy. Patients usually receive between 4 and 6 cycles of chemotherapy.

How is chemotherapy given?

Chemotherapy is most commonly given as an injection directly into a vein, 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 can also be given through an implantable port (sometimes called a portacath). This 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 are prescribed to be taken orally, either as a tablet or as a capsule.

Your chemotherapy treatment will usually be given in the chemotherapy day unit.

What kinds of drugs are used?

There are a number of different chemotherapy drugs used to treat lung cancer. Your doctor or nurse will discuss your treatment with you. You may either receive one chemotherapy drug or a combination of a few chemotherapy drugs.

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 know the name of your drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for information about the drug and possible side-effects.

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 sideeffects go away when the treatment ends or soon after. Side-effects may include:

Increased risk of infection

Chemotherapy drugs can 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 sore throat, or experiencing a burning feeling when passing urine.

Avoiding infections

If you have a high temperature or feel unwell (even with a normal temperature), it is very important to call the hospital straight away - never delay. Check with your hospital about the temperature advice to follow.

Bleeding and bruising

Chemotherapy can stop your bone marrow from making enough platelets. Platelets help your blood to clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

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 will have regular blood tests to measure your red cell count during treatment. You may need a blood transfusion to treat your anaemia.

Fatigue

Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 101.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will usually grow back after you stop chemotherapy.



Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). Always take any anti-sickness medication you are given, even if you don't feel sick, as it can help to prevent the sickness from happening in the first place.

Constipation and diarrhoea

Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor can give you medication to help with these side-effects, if necessary.

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.

Blood clots

Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

Other side-effects

Other side-effects include headaches, a loss of appetite and an itchy rash or dry skin. For the effects of chemotherapy on fertility see page 105. If you have any other side-effect or symptom that concerns you, tell your doctor or nurse straight away. They will give you advice. For more information on the side-effects of chemotherapy 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. You can also look at our website **www.cancer.ie** for tips on coping with different side-effects.

Targeted therapies

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 help 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

Tissue samples taken from your tumour are tested in a laboratory to see if your lung cancer will respond to a targeted therapy or therapies. This is known as molecular testing. The tests check for mutations (or abnormal changes) in specific genes. They also check to see if the cancer cell is making certain proteins. Tests can be done on blood taken with a blood test, but this is rare. While molecular testing is routinely performed to determine whether treatment with a targeted therapy is possible, targetable mutations are only detected in a minority of cases.

Examples of the most commonly detected genetic mutations in nonsmall cell lung cancer (NSCLC) include:

EGFR-positive lung cancer: There is an unusual change in the epidermal growth factor receptor (EGFR) gene that can cause cancer cells to grow.

ALK-positive lung cancer: There is an abnormal change in a gene called anaplastic lymphoma kinase (ALK).

ROS-1 positive lung cancer: There is an abnormal change in the ROS-1 gene causing cancer cells to grow.

Your medical oncologist will prescribe the most suitable targeted therapy for whichever mutation is found in your cancer.

Most targeted drug therapies come in tablet or capsule form.

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 89). 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 can 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.

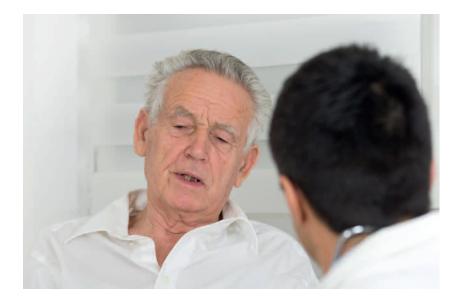
For more information on targeted therapies and their side-effects, or a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

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 to hide 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.

You might need to have tests to find out whether immunotherapy is likely to work for you. These tests look for changes in certain proteins, genes or chromosomes. For example, a test called the PDL-1 test can see if your cancer has a high amount of a protein called PDL-1, which plays a role in the body's immune system. Cancers that have a high amount of PDL-1 might respond well to certain immunotherapy drugs.



Your doctor will tell you if there are immunotherapy treatments for your type of cancer. You may also be offered a new immunotherapy treatment as part of a clinical trial (see page 89)

Checkpoint inhibitors

Checkpoint inhibitor drugs are a type of immunotherapy. Immune checkpoints are a normal part of the immune system. Their role is to stop an immune response from destroying healthy cells. However, cancer cells can find ways to use these checkpoints to avoid detection by your own immune system, in particular, white blood cells called T-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.

How is immunotherapy given?

Most immunotherapies are given intravenously (through a vein).

Immunotherapy is usually given in a course of treatment, with a rest period between treatments, for example once every 2 or 3 weeks. This course can last weeks or months depending on your cancer, the type of immunotherapy, how well your cancer is responding and how well you tolerate it.

You may have a combination of immunotherapy treatments or have other treatments too, such as targeted therapies or chemotherapy.

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 and tell you about any likely side-effects.

Side-effects from immunotherapy drugs can sometimes be serious. Your doctor will discuss this in detail with you, before and during treatment.

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.
- There are different types of radiotherapy. The length of radiotherapy treatment can vary.
- Side-effects mainly 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:

- On its own, to try to cure early-stage lung cancer.
- Before surgery to try to kill the cancer cells, and make the tumour easier for the surgeon to remove. This is called neo-adjuvant treatment.
- After surgery to destroy any cancer cells that may be left and to reduce the risk of cancer coming back. This is called adjuvant treatment.
- With chemotherapy to make the treatments work better. This is called concurrent chemoradiation.
- To reduce the risk of small cell lung cancer spreading to the brain. This is called prophylactic cranial irradiation.
- To control symptoms such as shortness of breath, bleeding and pain, when lung cancer has spread to other parts of the body (palliative radiotherapy).

Radiotherapy can be given in 2 ways – externally and internally:

External beam radiotherapy: This is the most common type of radiotherapy. The radiation treatment is delivered from special machines that aim radiation beams directly at your tumour or the tumour site. These machines are called linear accelerators.

Internal radiotherapy: 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 planned precisely 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 radiation therapist will accurately plan your treatment and mark your skin using tiny tattoo dots or washable dots to show the area to be treated. The doctor who specialises in prescribing radiotherapy treatment is called a radiation oncologist. The radiation oncologist works closely with other professionals, including radiation therapists and medical physicists to carefully calculate and plan the doses of radiation.

Getting your treatment

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

The radiation therapist gives the daily radiotherapy treatment. They will position you 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.

How much radiotherapy do I need?

The length of the course can vary. You may have several treatments over a number of weeks (often 4-6 weeks), but it varies depending on factors such as the type of radiotherapy and the aim of treatment. For treatment to relieve your symptoms, the course is usually shorter, often over a few days, rather than weeks.

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

Stereotactic radiotherapy

Stereotactic radiotherapy is a very precise type of external radiotherapy. It is often used to treat early-stage cancer.

During this treatment, 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 sideeffects 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 stereotactic radiotherapy usually takes 1-2 hours. A radiation therapist uses a CT scanner to work out how to shape the radiotherapy beam so that it fits your tumour exactly. As you breathe in and out, the tumour will move too. This is called tumour motion. The radiation therapist will monitor your breathing before and during the CT scan with specialist equipment that 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 are comfortable and in the same position for each treatment. The radiation therapist will work with you to decide on the best position for you.

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)

Internal radiotherapy is sometimes used to reduce the size of a tumour that is blocking an airway, to make it easier for you to breathe. See page 94 for more information.

For some internal radiotherapy treatments, you may have to stay in hospital for a few days. Sometimes 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
 Cough and shortness of breath throat

• Loss of appetite

Feeling very tired

Skin changes

Weight loss

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 sideeffects 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 tell your doctor 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 cancer. They can also be used when lung surgery may not be a suitable treatment option.

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, secondary or advanced cancer. The cancer may be in more than one part of your body when it is first diagnosed. If it has spread, it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. There is 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 89).

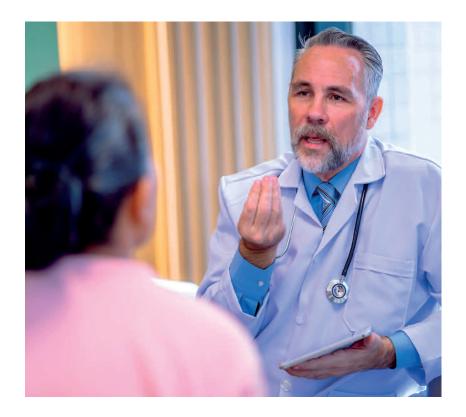
Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

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.

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.



Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing tumours or reducing side-effects. They can also help improve a person's quality of life, when living with a diagnosis.

Patients with tumours are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

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

Trials often investigate very specific features of a particular type of tumour or treatment, so you may not be suitable for a trial. 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 to

read or 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)
- Cough
- Pain
- Fatigue
- Fluid on the lungs

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 symptoms of advanced cancer, such as breathlessness and pain. Palliative care also offers emotional support and comfort to patients and their families. See page 88 for more on palliative care.



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:

Tumour debulking

In some patients, thoracic surgeons can use a number of techniques to remove large amounts of tumour blocking airways to try and improve breathing. This is usually done as part of a treatment approach that would include radiotherapy, to try and prevent the tumour growing back for as long as possible.

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 airways. Stents are usually put in under a general anaesthetic. The stent can stay in your lung permanently if needed. Stents do have a number of side-effects, but they can improve symptoms in some patients.

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 70), external radiotherapy (see page 82) and ablation treatments (see page 86) 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, by 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. They 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 68 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.

Shortness of breath will usually improve 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. This can be done under local or general anaesthetic. Pleurodesis involves putting medication (usually a sterile medical 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. This enables you to be in control of managing the fluid and so managing the breathlessness.

Hints and tips: Shortness of breath

- Ask the physiotherapist or nurse to show you 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. Try learning relaxation techniques such as mindfulness or breathing exercises to help manage your anxiety.
- If you are anxious and upset, ask to speak to a counsellor about your feelings – it may help. See page 118 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 and tips: Coughing



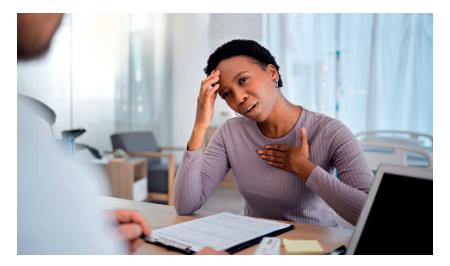
- Drink plenty of fluids, such as water and fruit juice, if you are coughing up a lot of phlegm. This will loosen it and make it easier to cough up.
- Ask your doctor or nurse to recommend a good cough mixture.
- Tell your doctor if your cough is dry and irritating. You may not be coughing up any phlegm. 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 88 for more about palliative care.

Hints and 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.
- Take your painkillers as advised, even if you don't have pain at a particular time. They will help to keep your pain under control.
- Even though the 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.
- 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 very common with cancer. Usually fatigue starts to improve 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.

Our booklet **Coping with fatigue** has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**

Hints and tips: Fatigue



- Ask your doctor about exercising. Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- Plan your days: Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- Ask for help at work or at home with any jobs that you find tiring.
- Try to eat a well-balanced diet. Eat little and often if your appetite is poor. Our booklet *Diet and Cancer* has tips to help.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 118).
- If you are not sleeping well, have a good bedtime routine and try relaxation techniques. Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- Short naps (less than an hour) and rest periods can be helpful, as long as they don't stop you from sleeping at night. Try to keep naps to the earlier part of the day.
- Try complementary therapies like meditation, acupuncture or massage, if your doctor says they're safe for you.

Will treatment affect my sex life?

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



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 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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy 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, even if your periods stop. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

Many specialists recommend that you wait for up 2 years after treatment before trying to start a family or to have more children. This 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 nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Email: 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. They 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.



Dealing with infertility can bring feelings of sadness, anger and loss of identity. It can help to share your concerns 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 and counselling.

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 illness and the sideeffects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your diagnosis.

Integrative care

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

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. 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 follow-up, which means you will have regular check-ups with your cancer specialist. The follow-up visit may involve having a physical exam, blood tests and scans. At the end of your treatment, your follow-up plan will be discussed. It's likely that you will be seen by your specialist cancer team every 3–6 months. These check-ups will become less frequent over time. Make sure you are clear on your post-treatment plan and have a contact number of your specialist cancer team to contact if you have any queries.

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. It can help 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 so your doctor can check for signs of the cancer coming back (recurrence) and 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.

After-treatment workshops

You might like to join our free **Life and Cancer – Enhancing Survivorship (LACES)** workshops when you have completed treatment or have started maintenance therapy. Developed in partnership with the National Cancer Control Programme, LACES covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

Life after treatment

It can take some time to adjust to life after treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- Fear of the tumour coming back and worry 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
- 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 treatment 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 119 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
- · Cope better with the side-effects of treatment
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

It's also important to have any vaccines recommended for you. For example, flu and pneumonia. Some vaccinations may not be suitable if you've had cancer treatment, so check with your doctor which you should have and make sure you get them.

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 your treatment options.

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 enables people to concentrate on their illness and its treatment knowing that their wishes and desires are clearly documented should a need arise.

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.
- Talking about what you want to your family, friends, carers and healthcare providers.

Hospice

Think Ahead Planning Pack

Sorting financial affairs

Who can help me plan?

Think Ahead is a planning pack with different sections and easy-to-read forms. You can fill in 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.

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

Being diagnosed with cancer 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.

The Irish Cancer Society funds free professional one-to-one counselling, remotely or in person at many 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

Counselling has helped me with every part of my life. I feel I have a future now.

Positive feelings

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

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 142 for more about local cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are 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 healthcare team can refer you to psycho-oncology services if they're available at your hospital.

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.

You and your family

Every family deals with illness 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 illness and to ask for the help and support you need.

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 and find out how they feel. If you find it hard, ask another family member or friend to talk to them.

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.



Supporting someone with cancer

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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 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 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. The Irish Cancer Society funds one-to-one counselling for friends and family members remotely or in person at many local cancer support centres. Talk to your GP or see page 118.

Find out about support for carers

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

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**



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 illness. Or you may be afraid of saying the wrong thing. Often what people 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 **Caring for 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**





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Money matters

- 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 car parking during hospital visits, 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 cancer if you are worried about money.



Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- Understanding your welfare entitlements
- · Advice on accessing extra childcare
- Telling your boss about your diagnosis

We can tell you about the public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having a Practical and Financial Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Practical and Financial Officers might be of help.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to 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 tests or 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: 0818 074 000
- Department of Employment Affairs and Social Protection Tel: 0818 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 keep a copy of completed forms, so take a photo or photocopy them before posting.

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 0818 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 139 for more details of our Transport 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.

Money and finances

Go to **www.cancer.ie** and see our Managing money page for information on:

- 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

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.



Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Transport Service

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at www.cancer.ie/community.



Night Nursing

information

Publications and website

• Support in your area

Practical and financial

solutions (see page 132)

The Support Line service also offers video calls for those who want a face-to-face chat

with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of the service, please go to https://www.cancer.ie/Support-Line-Video-Form

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

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

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – just call in if you want to talk or need information on any aspect of cancer including:

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

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am–5pm, or contact your nearest Daffodil Centre.

Tell us, in English, the language you would like. You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.

We will connect you to an interpreter.

The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre. For more information on Peer Support search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our Patient Education Workshops, call our Support Line on Freephone 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on Freephone 1800 200 700, or contact your nearest Daffodil Centre.



Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure cancer patients and their families have access to high-quality, confidential support in a location that's convenient to them.

For more information about what's available near you, visit www.cancer.ie/local-support, contact your nearest Daffodil Centre, or call our Support Line on Freephone 1800 200 700.

Transport Service

We provide transport and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatment. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre or satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.



Night Nursing

We provide end-of-life care for cancer patients in their own homes. 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 night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the healthcare professional looking after your loved one.

We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.

Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

To find out more about the Irish Cancer Society's services and programmes:

- Visit us at www.cancer.ie
- Call our Support Line on Freephone 1800 200 700
- Email our Support Line at supportline@irishcancer.ie
- Contact your nearest Daffodil Centre
- Follow us on:
 - Facebook X Instagram LinkedIn

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, their partners, families and carers, during and after treatment, many of which are free. For example:

- Professional counselling. The Irish Cancer Society funds free one-to-one counselling remotely and through many local support services
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- Special exercise programmes
- Stress management and relaxation techniques, such as mindfulness and meditation
- Complementary therapies like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management 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 go to **www.cancer.ie** and search 'Find support'.



What does that word mean?

Adjuvant treatment: Treatment given soon after surgery for cancer to reduce the risk of cancer recurrence.

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 can spread around your body.

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 X-rays.

Staging: A series of tests that measure the size, location and extent of cancer.

Thoracic surgeon: Doctor who specialises in surgery of the chest.



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?

Notes / questions

Acknowledgments

This booklet has been produced by the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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- National Cancer Strategy 2017-2026, National Cancer Control Programme
- Cancer in Ireland 1994-2020: Annual statistical report of the National Cancer Registry
 (2022)
- National Clinical Guideline No16 Diagnosis, staging and treatment of patients with lung cancer, National Cancer Control Programme Guideline Development Group 2017
- Lung Cancer Rapid Access Service GP Referral Guidelines. HSE/NCCP, 2012.
- Cancer Nursing: Principles and Practice, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 8th Ed (2018).
- ERAS guidelines Batchelor TJP, Rasburn NJ, Abdelnour-Berchtold E, Brunelli A, Cerfolio RJ, Gonzalez M, Ljungqvist O, Petersen RH, Popescu WM, Slinger PD, Naidu B.
- Guidelines for enhanced recovery after lung surgery: recommendations of the Enhanced Recovery After Surgery (ERAS®) Society and the European Society of Thoracic Surgeons (ESTS). Eur J Cardiothorac Surg. 2019 Jan 1;55(1):91-115. doi: 10.1093/ejcts/ezy301. PMID: 30304509.

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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 Peer 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 Support Line 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





Our cancer nurses are here for you:

- Support Line Freephone 1800 200 700
- Email supportline@irishcancer.ie
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie