Understanding

Oesophageal cancer

Caring for people with cancer

Understanding

Oesophageal cancer

This booklet has information on:

- Treatment for oesophageal cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Oesophageal cancer coordinator

Specialist nurse

Family doctor (GP)

Medical social worker

Gastroenterologist

Surgeon

Medical oncologist

Radiation oncologist

Dietitian

Emergency

Hospital switchboard

Hospital records number (MRN)

Contents

Fast facts

Can my cancer be treated? Page 37

Yes. There are treatments that aim to cure oesophageal cancer, treatments to keep the cancer under control and treatments to help with side-effects. Your doctor will discuss with you what treatments will be of most benefit to you.

Will I be OK? Page 34

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, such as the type and stage of your cancer. Everyone is different, so it's best to ask your consultant about your own situation.

Will I get side-effects? Page 97

Most cancer treatments cause some side-effects, but these usually get better after treatment has ended. Problems with eating and drinking, such as having little appetite, swallowing difficulties and weight loss are common with oesophageal cancer. You may need to be fed through a tube for a time if you have problems eating.

Read about the different treatments to learn more about their possible side-effects. **There are treatments to help with most side-effects, so tell your doctor. Don't suffer in silence!**

What kind of treatment might I have? Page 55

Your treatment will depend on several factors such as the type of oesophageal cancer you have, its stage, which part of the oesophagus is affected and your general health.

Treatments include:

Endoscopic treatments: Minimally invasive procedures using an endoscope (tube with a camera and a light) that is passed through the mouth into the oesophagus

Surgery: An operation to remove the cancer

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

Targeted therapy drugs: Drugs that attack specific targets in the cancer to slow its growth

Radiotherapy: High-energy rays to destroy the cancer cells

You may also have other treatments to help with side-effects, such as difficulty swallowing.

Clinical trials Page 93

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

Ask your consultant if there are any trials suitable for you.

Helplines Partnership Member

Support Line Freephone 1800 200 700

We’re here for you

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

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre.
  Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 147 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don’t understand something, ask your doctor or nurse. You can also ask one of our cancer nurses.

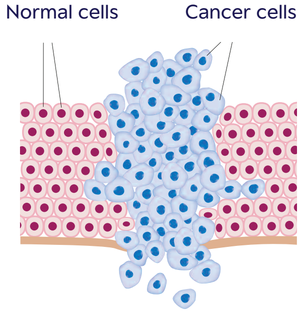
About our information

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.

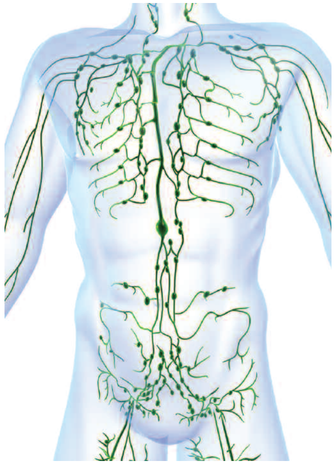
About oesophageal cancer

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**
  Oesophageal cancer starts in cells in the oesophagus.
- **Cancers sometimes spread**
  If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.

What is the lymphatic system?

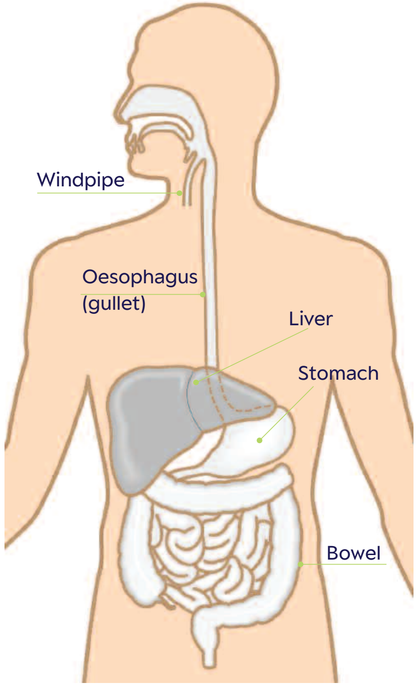


- The lymphatic system is part of our immune system, which protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, chest, armpit, groin and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

What is the oesophagus?

The oesophagus is part of the gastrointestinal tract within your digestive system.

The oesophagus is also called the gullet or food pipe. It is a long muscular tube that links your throat to your stomach. In adults it is about 25-30 cm long and runs behind your windpipe (trachea).



When you swallow food, the muscles in your oesophagus move the food down into your stomach. A muscle valve at the end of your oesophagus prevents food and fluid from going back up.

A valve at the top of your oesophagus stops food from going into your lungs.

The area where the oesophagus joins the stomach is called the gastro-oesophageal junction.

The wall of your oesophagus has 4 layers:

Inner layer or lining (mucosa): The lining of your oesophagus is moist so that food can pass easily into your stomach. It is made up of skin-like cells called squamous cells.

Submucosa: The gland cells in this layer produce secretions (mucus). Mucus helps to keep your oesophagus moist.

Muscle layer (muscularis): The muscles in this layer push the food down to your stomach.

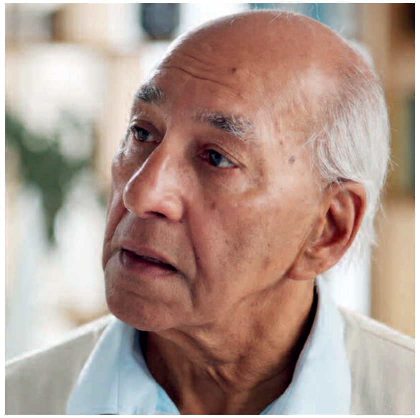
Outer layer (adventitia): The outer layer, which covers the oesophagus, attaching it to nearby parts of the body. Lymph nodes are also found near your oesophagus. For example, in your neck, the middle of your chest and where your oesophagus joins your stomach.

What is oesophageal cancer?

When cancer happens, the cells in the oesophagus change and grow in an abnormal way. Usually the tumour does not cause symptoms at first, or only causes heartburn symptoms, but as it grows it can cause difficulty with swallowing (dysphagia). This is because it narrows the oesophagus and makes food lodge or stick there. After that, it can be hard to swallow liquids. Other symptoms such as a fatigue, weight loss and a change in the voice may occur.

Cancer can develop anywhere in your oesophagus and there are different types. See page 12 for more about the different types.

What caused my cancer?



We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for oesophageal cancer, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

What are the types of oesophageal cancer?

A tumour can grow anywhere along your oesophagus. When diagnosing and treating cancer, doctors think of the oesophagus in 3 sections: upper, middle and lower.

Oesophageal cancers are usually named after the type of cell where the cancer first starts to grow. More than 9 in every 10 oesophageal cancers are squamous cell carcinomas or adenocarcinomas.

Squamous cell cancer

Squamous cells are skin-like cells that line your oesophagus. They are found mainly in the upper and middle of your oesophagus. This type of oesophageal cancer can be linked to smoking or alcohol intake.

Adenocarcinoma

Adenocarcinoma means a cancer that starts in the glandular cells that make mucus. This cancer usually starts in the lower part of your oesophagus. It is linked to acid reflux and Barrett's oesophagus.

Sometimes adenocarcinoma can cross the junction between the oesophagus and the stomach. This is known as a gastro-oesophageal junction tumour and may be treated as oesophageal cancer or as stomach cancer, depending on where the cancer is found.

Rarer types of oesophageal cancer

Neuroendocrine cancers: These are rare cancers that affect cells in the neuroendocrine system. Neuroendocrine cells make hormones that help to control many of the functions in your body.

Soft-tissue sarcomas: Rare cancers that start in soft tissues like fat and muscle. For example, gastrointestinal stromal tumours (GISTs).

Small cell cancers: More commonly happen in the lung, but rarely they can affect the oesophagus.

Undifferentiated: Cancer where the doctors cannot tell if the cancer started in the gland cells (adenocarcinoma) or skin-like cells (squamous cells).

Tests and treatments for these rarer types of oesophageal cancer are different from those included in this booklet. Your medical team will give you more information on your type of cancer or you can call our Support Line on 1800 200 700.

How common is oesophageal cancer?

Around 520 people are diagnosed with oesophageal cancer in Ireland each year.

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 parking).
- 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 aren't 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. Ask a friend or family member to go along for extra support.

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 medications. 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

It's important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Try not to be shy about asking questions. It is always better to ask than to worry.

What tests will I need?

Will I have to stay in hospital for the tests?

How long will I have to wait for the test results?

At what stage is my cancer?

What type of treatment do I need?

Will treatment affect my fertility?

What type of surgery do I need? Why is this one better for me?

What are the expected benefits of treatment?

How successful is this treatment for my cancer?

How long will treatment last?

What are the risks and possible side-effects of treatment?

How long will it take me to get over the effects of treatment?

Do I have to eat special foods?

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

What support services are available to help me?

Diagnosis and tests

Being diagnosed with oesophageal cancer

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

- **Upset and overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **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 oesophageal cancer coordinator or clinical nurse specialist. 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.
- Go to your local cancer support centre. For more information, see page 154.
- The Oesophageal Cancer Fund (OCF) provides support and information. OCF organises patient support meetings and their peer-to-peer service can connect you with a person who has experienced oesophageal cancer by phone, in person or online. Call 086 069 7328, email info@ocf.ie or visit **www.ocf.ie**

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 cancer and to ask for the help and support you need.

What tests will I have?

- Tests you may have include blood tests, CT scan, endoscopic ultrasound, PET scan, MRI scan and occasionally a laparoscopy.
- You may have heart and lung function tests to help with treatment planning.
- The tests will tell your medical team more about your cancer and help them to plan the best treatment for you.

The following tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment. Tests you may have include:

CT scan (CAT scan)

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. 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.

Blood tests

Blood tests can check your general health, including how well your kidneys and liver are working. They can also check the level of different blood cells and monitor your response to certain treatments.

- Full blood count (FBC): Checks the number of different types of blood cells in your blood
- Kidney function tests (urea and electrolytes) check how well your kidneys are working
- Liver function tests (LFT) check your liver's health

Routine blood tests will be done throughout chemotherapy treatment. A blood test called a micronutrient screen can check levels of vitamins, minerals and other essential nutrients to see if you have a deficiency.

Tumour marker blood tests may be done to monitor your response to chemotherapy.

Lung function tests

Lung (pulmonary) function tests can see how well your lungs are working – normally before neo-adjuvant chemotherapy (chemotherapy given before surgery) and again before surgery. For a pulmonary function test (PFT), you blow into a mouthpiece on a machine. PFTs are not painful and take about 20 minutes.

Heart tests

These tests can see how well your heart is working. They may be used to check your general health or to see if treatment has affected your heart. For example, some chemotherapy drugs can affect the muscles of the heart (this is usually temporary).

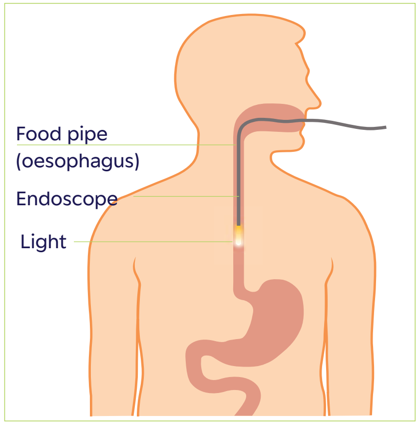
The 2 main types of test are:

- **ECG:** Sensors are attached to your skin that can pick up the signals produced by your heart when it beats.
- **Echocardiogram ('Echo' scan):** This is a type of ultrasound that can produce a moving image of your heart at work and nearby blood vessels to give information about your heart function.

If you're on blood-thinning medication

If you're on blood-thinning medication (anti-coagulants), you may be advised to stop taking the medication for a time before certain tests. Make sure to tell your nurse so that they can advise you. Don't stop taking any medication unless your medical team tells you to.

Endoscopic ultrasound (EUS)



An ultrasound probe is passed through a tube into your body through your mouth. This probe makes sound waves that allow your doctor to see the tissues inside your oesophagus and nearby areas. This can help your doctor assess the size and depth of the tumour. They can also check if nearby lymph nodes are enlarged due to cancer or infection.

A sample of the lymph nodes can be taken and examined under a microscope to check for signs of cancer. An EUS is usually done under sedation and you can usually go home the same day. If your doctor recommends you have a general anaesthetic, you may have to stay in hospital overnight.

PET CT scan

A PET CT scan is a combination of a CT scan and a PET scan. It can show if the cancer has spread to other tissues and organs. Before the scan, you may have to fast (not eat) for a few hours.

A low dose of radioactive sugar is injected into your arm. An hour or so later you will have a scan. The radioactivity can highlight cancer cells in your body. During the scan, you will lie on a table that moves through a scanning ring. The scan can last up to an hour. You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

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

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

MRI scan

Sometimes you will have an MRI scan if your doctors want to have a closer look at areas outside the oesophagus, such as the liver.

MRI uses magnetic energy to create a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine for 30-60 minutes, depending on the number of pictures being taken. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious.

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

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

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

Laparoscopy

You may have this test if your doctor needs more information after other tests have been done. A laparoscopy is a small operation that is performed under general anaesthetic. A mini telescope is passed through a small cut in your abdomen (tummy) so that your doctor can see the organs close to your oesophagus and check the lining of your abdomen for cancer. Your doctor may make another cut in the tummy if a small sample of tissue (biopsy) needs to be taken and checked for cancer.

During the test, carbon dioxide gas is passed into your abdominal cavity. This can give you uncomfortable wind and/or shoulder pains for 3 or 4 days. Walking about or taking sips of peppermint water often eases the pain.

After a laparoscopy you will have 1 or 2 stitches at the wound site. Usually they dissolve as your wound heals. Once the effect of the anaesthetic wears off, you will usually be able to go home. Your doctor will discuss this test with you if you need it.

Waiting for test results

It usually takes a week or 2 for all the test results to come back. Naturally, 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.

Staging oesophageal cancer

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

The tests you have after diagnosis help the doctor to give your cancer a stage and a grade.

- Staging describes where the cancer is in your body, its size and whether it has spread beyond the area it started
- Grading describes the cancer cells – what they look like and how they might grow

Knowing the stage of your cancer helps your doctor to decide the best treatment for you.

How is oesophageal cancer staged?

The TNM staging system is often used. It describes:

T – Tumour

The size of the tumour and how far it has grown into the lining of the oesophagus. Doctors put a number next to the T to describe the size and spread of the cancer.

N – Nodes

This describes whether the cancer has spread to the nearby lymph nodes and how many nodes are affected. N0 means there is no cancer in the nodes. If cancer has spread to the lymph nodes (positive nodes) the N will have a number to describe how many lymph nodes are affected. NX means the doctors cannot tell if the nodes are affected.

M – Metastasis

This describes if the cancer has spread to another part of the body, such as the liver or lungs. The M may have a number next to it. This gives extra information about where the cancer has spread to.

What are the stages of oesophageal cancer?

Your doctor often uses the TNM information to give your cancer a number stage – from 0 to 4. A higher number, such as stage 4, means a more advanced cancer. Some stages are further divided into stage A and B.

Stage 0: This means the cancer is at a very early stage. Cancer cells are found in the lining of your oesophagus but are completely within the lining. This stage is also known as carcinoma in situ.

Stage 1: This also means the cancer is at an early stage. The cancer cells are found only in the surface layers of the lining of your oesophagus. Or it may be found in only a small part of your oesophagus. There is no sign of it spreading anywhere.

Stage 2: Here the cancer has spread to the muscle layer of your oesophagus or to nearby lymph nodes. But it has not spread to any other organs. If the cancer has not spread to nearby lymph nodes, it is stage 2A. If the cancer has spread to nearby lymph nodes, it is stage 2B.

Stage 3: In this stage the cancer has spread beyond the wall of your oesophagus. It may also have spread to nearby lymph nodes and other tissues next to your oesophagus. But there are no signs of it spreading to other parts of your body.

Stage 4: This means the cancer is advanced and has spread to your lymph nodes and other parts of your body. For example, your liver, lungs or stomach. Cancer in another part of your body is called metastatic oesophageal cancer.

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

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 always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

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

If you decide you want information on your prognosis:

- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on your prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to go with you, if you would like some support.
- Be careful with online information. It may be hard to understand or 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.
- 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 or nurse 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 may help you.

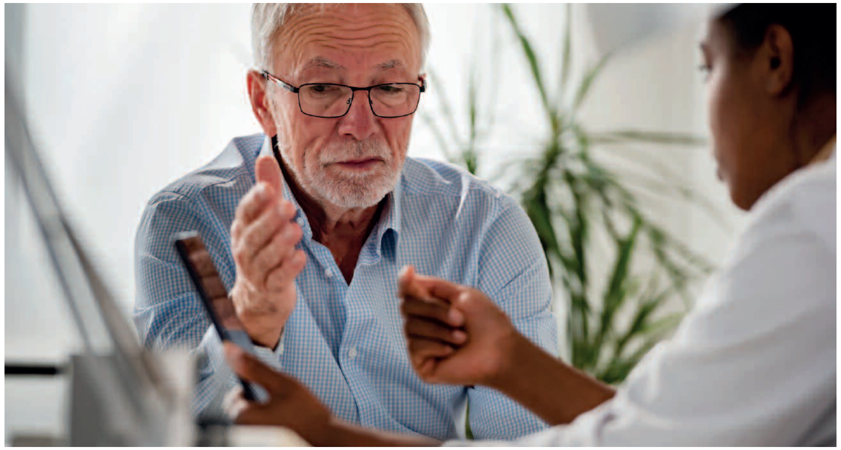
Treating oesophageal cancer

How is oesophageal cancer treated?

- The main treatments for oesophageal cancer are endoscopic treatments, surgery, radiotherapy, chemotherapy, targeted therapies and immunotherapy.
- Many people will also receive additional treatments such as nutritional therapy.
- You may have a combination of treatments.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment you have will depend on:

- The type of oesophageal cancer you have
- The size of the tumour
- Where it's found
- If it has spread to your lymph nodes or other parts of your body
- Your symptoms
- Your age and general health



Types of treatment

Endoscopic treatments

For early-stage cancers, you may have treatment using an endoscope – this is a tube with a camera on the end that goes into your oesophagus through your mouth. Instruments – a knife or wire loop – are used to remove the cancer.

Surgery

If the cancer is found in only a small section of the oesophagus, it may be possible to remove the entire tumour along with the affected part of the oesophagus and lymph nodes. Often you will have chemotherapy or chemoradiation (chemotherapy and radiotherapy together) to reduce the size of the tumour before surgery. See page 57 for more about surgery.

Radiotherapy

Radiotherapy is often used to reduce the size of a tumour. Making the tumour smaller can make it easier to remove with surgery or can help to improve symptoms, such as difficulty swallowing.

Radiotherapy can be used on its own or with chemotherapy. Chemotherapy helps the radiotherapy to work better.

Radiotherapy can also help to relieve pain and may be used after surgery to prevent cancer coming back. See page 76 for more on radiotherapy.

Chemotherapy

Chemotherapy may be used alone or with radiotherapy. It can help to reduce the size of the tumour before surgery or to prevent it from coming back after surgery. It may be used to control the cancer if it has spread to other organs or if it recurs after surgery or radiotherapy. It may also be used to relieve symptoms. See page 85 for more about chemotherapy.

Other cancer drugs

Targeted therapy and immunotherapy drugs can stop cancer cells growing or spreading. They may be given if the cancer has spread to nearby tissues or other parts of the body. Immunotherapy may also be given after your primary treatment to reduce the risk of the cancer coming back. HER2-directed therapy is a type of targeted therapy that targets a protein called HER2 that encourages cancer cells to grow. See page 91 for more details.

Nutritional therapy – feeding tubes and supplements

If you have difficulty swallowing and cannot eat enough food, you may have a feeding tube fitted for a time. This will help you to get the nutrition you need. See page 61 for more information. You may also have treatment to relieve swallowing difficulties (dysphagia). The most common treatments are stenting and dilation (see page 110).

Supportive care

A team of healthcare professionals will support you before, during and after your treatment. This supportive care may include physiotherapy, psychological support, social work support with practical matters and help with managing any symptoms. Always talk to your hospital team if you need help with anything.

Specialist cancer centres

Oesophageal cancer is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with oesophageal cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan.

Who will be involved in my care?

Usually a team of healthcare professionals will be involved in your treatment and care.

Gastroenterologist: A doctor who specialises in treating diseases of the digestive system.

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

Oesophageal cancer coordinator/oncology liaison nurse/clinical nurse specialist: Specially trained nurses who work in a cancer care unit. They give information and reassurance to you and your family from diagnosis throughout your treatment.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment. In some hospitals, ANPs run acute oncology clinics for people who need help with side-effects or other problems during their treatment. Ask your doctor or nurse if there is an acute oncology clinic in your hospital.

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

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

Radiation therapist: A specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

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.

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

Speech and language therapist: A therapist who treats speech and swallowing difficulties.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Occupational therapist: A therapist who specialises in helping people who are ill or with disabilities learn to manage their condition and their daily activities, such as washing and dressing, housework, parenting, work and leisure activities.

Medical social worker: A person trained to help you and your family with your social issues and emotional and practical needs. They can also give advice on social welfare benefits, applying for a medical card, other financial matters and practical supports and services available to you.

Pharmacists: 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.

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 make decisions.

Community health services: These include 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. They can also 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.

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.

Deciding on treatment

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists who look after your type of cancer. The team can include surgeons, medical oncologists, radiation oncologists, specialist nurses, pathologists and radiologists. The team will meet to discuss your test results and your suggested treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in page at the back of this booklet for your questions and answers.

If you do 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 your treatment, if you are unsure when it is first explained to you.

Second opinion

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

Accepting treatment

You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse 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.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form stating 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.

Tailored treatment

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

Waiting for treatment to start

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

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

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

While you're waiting for treatment, you might like to focus on your own health and wellbeing. This can help you prepare for your treatment and feel more in control.

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain 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 as well as possible.

Eat well

Eating well when you have cancer can help you feel better. 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 if you have not already been referred to one. They can advise you about the best diet for you. You can also read our booklet ***Understanding diet and cancer.*** To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it from our website **www.cancer.ie**

Stay active

If you are able, it can really help to be 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.

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, chest 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. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Avoid alcohol

It's best to avoid alcohol. Alcohol may interact with some chemotherapy drugs. It may also make certain side-effects worse, such as a sore mouth or nausea. Excess alcohol can put a strain on your liver if you are having chemotherapy. Alcohol is a carcinogen, which means it can increase the risk of developing certain cancers. Ask your consultant or specialist nurse if you have any questions about alcohol and your treatment.

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. 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

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

Use your support network

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

Try relaxation and stress management techniques

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

Accept change in your life

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

Know that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. There is help and support available if you are finding it hard to cope. Call into your nearest Daffodil Center or call our Support Line on 1800 200 700.

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.

Types of treatment

Surgery

- Surgery aims to remove the tumour and the surrounding lymph nodes.
- There are different types of surgery, depending on the size of the tumour and where it is found.

Surgery is the most common treatment for oesophageal cancer that has not spread outside the oesophagus. It is mainly done when the tumour is found in one section of your oesophagus only.

The aim of surgery is to remove all the cancer cells in the oesophagus and any cells that may have spread to surrounding lymph nodes. The type of surgery you have will depend on:

- The type of tumour
- Where the cancer is
- The size of the tumour
- Your general health

Sometimes your surgeon will only find out the exact size and position of the tumour during surgery. If this happens, your treatment plan may change. Your doctors may recommend a different type of surgery or another treatment.

If the tumour is attached to nearby tissues and organs, radiotherapy and/or chemotherapy before surgery can shrink it and make it easier to remove.

Endoscopic treatments

For early-stage cancers, you may have treatment using an endoscope – this is a tube with a camera on the end that goes into your oesophagus through your mouth. Instruments – a knife or wire loop – are used to remove the cancer.

- **Endoscopic mucosal resection (EMR)** removes small cancers on the inner layer of the oesophagus
- **Endoscopic submucosal dissection (ESD)** removes slightly bigger cancers that affect the layer below the mucosa, called the submucosa

You may have another treatment called radiofrequency ablation (RFA) after EMR or ESD to reduce the risk of the cancer coming back. RFA uses heat energy (from radiowaves) to destroy cancer cells. The radiofrequency device is passed down the oesophagus (gullet) using an endoscope.

You will usually have a spray to numb your throat and you may have a sedative to make you feel relaxed and sleepy.

Surgery to remove all or part of the oesophagus

There are many types of oesophageal surgery. Your surgeon may remove the whole oesophagus or just the part that has cancer.

Because the oesophagus is a long tube going from one body part to another, the surgery can be done in different ways. Your surgeon may need to make a cut (incision) or cuts in your chest, tummy (abdomen) or neck to remove the tumour, depending on where it is.

Depending on factors including the location of the tumour and your health and fitness, the operation may be performed using open surgery, keyhole surgery or robotic surgery.

Oesophagectomy

The part of your oesophagus with cancer is removed along with lymph nodes and nearby soft tissues. The surgeon pulls up your stomach and joins it to the remaining part of your oesophagus. Rarely it's not possible to join your stomach to the remaining part of the oesophagus. In this case, a section of your bowel (colon) will be used to replace part of the oesophagus.

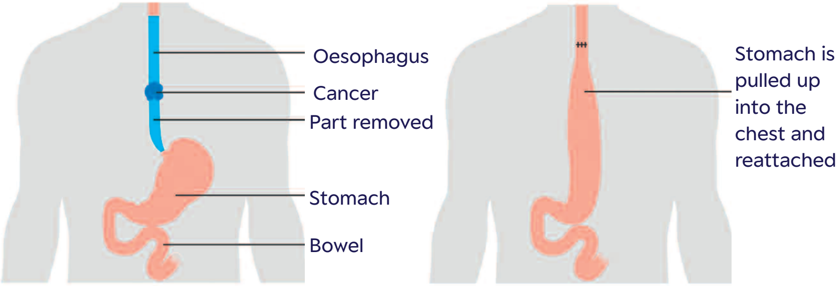


Image courtesy of Cancer Research UK / Wikimedia Commons

Oesophago-gastrectomy or extended total gastrectomy

If the cancer has spread to your stomach, the upper part of your stomach can be removed, as well as the affected part of your oesophagus. This is called an oesophago-gastrectomy. The intestine or colon may be used to create a new connection so that you can swallow and digest food after your oesophagus is removed.

If more of the stomach is involved than the oesophagus, sometimes the whole stomach is removed and the remaining oesophagus is joined to the small bowel (called an extended total gastrectomy).

Pharyngolaryngo-oesophagectomy (PLO)

This is an operation to remove the uppermost part of the oesophagus and the voicebox (larynx) to treat cancers found very high up in the oesophagus and in the pharynx (throat).

Removal of lymph nodes (lymphadenectomy)

During the surgery your surgeon will take out some of the lymph nodes from around your oesophagus. This is called a lymphadenectomy. If the lymph nodes contain cancer, removing them can help to stop it spreading and may help guide further treatment. The removed lymph nodes will be looked at under a microscope to give your doctor more information about the stage of your cancer.

Getting ready for surgery

Extra tests

You will have tests to make sure you are fit for surgery. These might include a chest X-ray, heart tests (ECG and echocardiogram), breathing tests (pulmonary function tests), and blood tests to check your liver and kidneys.

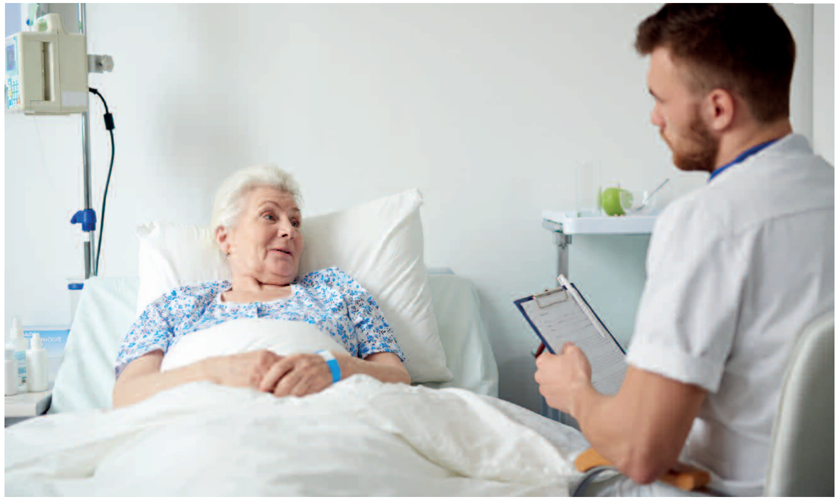
Smoking

Giving up smoking as soon as possible before your operation will improve your breathing and reduce the risk of a chest infection after surgery. See page 51 for where to get support.

Your diet

A dietitian will visit you and explain how best to manage eating before your surgery. Your dietitian or doctor will also talk to you about:

- How to make swallowing easier, if you're having trouble with this
- Ways to prevent further weight loss and keep up your strength
- What dietary/eating changes to expect after surgery



Feeding tube

If swallowing becomes very difficult, you may not be able to eat enough food. You may need to be fed by a tube for a while. The tube may go into your stomach through your nose (nasogastric tube) or into your small intestine through your nose (nasojejunal tube). Alternatively, it may go through an opening made in your abdomen into the stomach (gastrostomy tube) or small intestine (jejunostomy tube).

You will be fed liquid supplements high in protein and energy through the tube. Your family and friends may find it helpful to meet with the dietitian too. That way, they can learn about any changes to your diet.

Deep breathing and leg exercises

A physiotherapist will show you how to do deep breathing and leg exercises. These exercises will help to prevent a chest infection or blood clot after surgery. You will be given special elastic stockings to wear that can also prevent a blood clot in your legs. Your nurse may also give you an injection of heparin to prevent blood clots.

Feeling anxious

It's normal to feel anxious about having surgery. Talk to your nurse or doctor, especially if there's something you're worried about or don't understand.

Community services

If you live alone or have problems getting around at home, talk to your nurse or the medical social worker on your ward. Do this as soon as you are admitted to the ward. That way, they can organise any community services you may need after you leave hospital. For example, the public health nurse or home help.

Before surgery

You cannot eat anything for a few hours before your surgery. Your doctor or nurse will tell you when you should have your last meal.

After surgery

- For a few days you will be in the intensive-care or high-dependency unit.
- You may be fed through a tube in your small intestine until you can eat normally again.
- Having an operation for oesophageal cancer is major surgery, however most people can go home after 10-14 days.
- Possible side-effects of surgery include poor appetite, feeling full and uncomfortable after eating only small amounts, weight loss, nausea and vomiting (see page 71).

Drips, drains and tubes

After your operation, you will usually spend at least 2–5 days in an intensive-care unit or high-dependency unit. At first you may be put on a machine called a ventilator that helps you to breathe until the anaesthetic wears off. When you wake up, you might notice some tubes attached to your body. They might look alarming but are normal after an operation like yours.

- **Intravenous (IV) drip:** A drip will be put into a vein in your arm. You will be given fluids through the drip until you are able to take fluids by mouth again.

- **Drains:** One or more thin tubes called drains will be attached to you near your wound. These help to drain blood and fluid from the operation site to let your wound heal.
- **Nasogastric tube:** A thin plastic tube may be placed in your nose leading to your stomach and small intestine to drain off gastric (stomach) fluids. This will stop you feeling sick and promote healing.
- **Urine tube:** A thin flexible tube called a catheter may be put into your bladder to drain urine into a bag. This will save you having to get out of bed to go to the toilet. Also, your nurses can check how much fluid you are passing.
- **Chest drain:** These drainage tubes are inserted into your chest during the surgery. They drain any fluid around your lungs into a bottle beside your bed.
- **Feeding tube:** You may have a small feeding tube placed directly into your small intestine. This is called a jejunostomy or JEJ tube. The tube is put in through your belly wall during surgery. It can be used to give you all the calories, protein and nutrients you need until you are ready to eat and drink again. Some medications may be safely given through the tube.
- **Epidural:** You may have a thin tube called an epidural in your back. This is to help relieve any pain you might have.

What happens after surgery?

A team of doctors, nurses, physiotherapists and dietitians will work towards your full recovery. They will help with any problems you have after surgery.

Staying upright

While you are recovering, both in hospital and at home, you shouldn’t lie completely flat. Your upper body will be kept upright. At home you can use pillows or put a wedge under the head of the mattress to raise it up. A selection of wedge-shaped pillows can be purchased on the internet.

Pain

You may have some pain after surgery, especially when you cough or try to move, but most patients are very comfortable with the epidural pain relief. If needed, you will be given painkillers to ease any pain.

You may have a patient-controlled analgesia pump (PCA). This sends pain medication into your blood when you press a button. A nurse will show you how to use it.

It can help to take your painkillers before getting out of bed or before other activities. If your medicine isn't controlling your pain, tell your doctor or nurse. Always ask for help before the pain gets too bad.

Nausea (feeling sick) and vomiting

You might feel sick (nausea) or vomit after surgery. Your doctors and nurses can give you medicine to prevent this, if needed. Let your team know if you are suffering from nausea or vomiting. It is important to get this under control.

Breathing and coughing

A physiotherapist will visit you regularly after surgery to help you with breathing and leg exercises. Doing these exercises regularly will help to prevent a blood clot in your legs or lungs. You should move your legs and do deep breathing exercises at least once an hour, even when you're in bed.

Your physiotherapist will also help you to clear any build-up of mucus (sputum) in your chest to help to prevent an infection. You will also feel more comfortable if you can breathe easily. If you're in pain you may not feel able to do your breathing or leg exercises, so let your nurse or doctor know if you need medication to help with pain. The physiotherapist can also show you other exercises to help loosen up any shoulder stiffness due to surgery.

Wound/infection

Your medical team will keep a close eye on your wound to make sure you're healing well. They will also check the wound and tubes regularly for signs of infection. Let your nurse know if you have any redness or leakage at the wound or tube sites or if you feel hot or unwell.

Starting to eat and drink again

For the first few days after your operation, you will usually not have anything to eat by mouth until your surgeon is happy that the operation site has healed satisfactorily.

If you had a feeding tube inserted during your surgery, you will be fed through this from the day after surgery to meet your nutritional requirements. Once the surgeon is happy, you will start on fluids by mouth first and this will then be increased gradually over a number of days.

When you are managing fluids, you can start to eat small amounts of soft food. Eat slowly and chew your food well to help you to feel more confident with swallowing. Your dietitian will be there to support you and advise you on what foods to eat, to make sure you’re getting enough calories and nutrients.

Once you begin to eat and drink reasonable amounts, you will just be fed by tube at night. This may continue when you go home. You, along with your family or a friend, will be trained on how to manage your feeding tube before you go home.

Weight loss

It's normal to lose some weight after surgery. This usually improves in time, although you may not get back to the weight you were before surgery. The dietitian and other members of the team will help you to manage your weight and support you with any eating problems.

Moving around

On the day after surgery, your nurses and physiotherapists will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you feel stronger. Soon you will be able to go for walks on your own.

How long will it take for me to recover?

Every person is different, so the recovery period can vary. If your wound does not heal as quickly as expected, it may delay you getting back to normal eating and drinking.

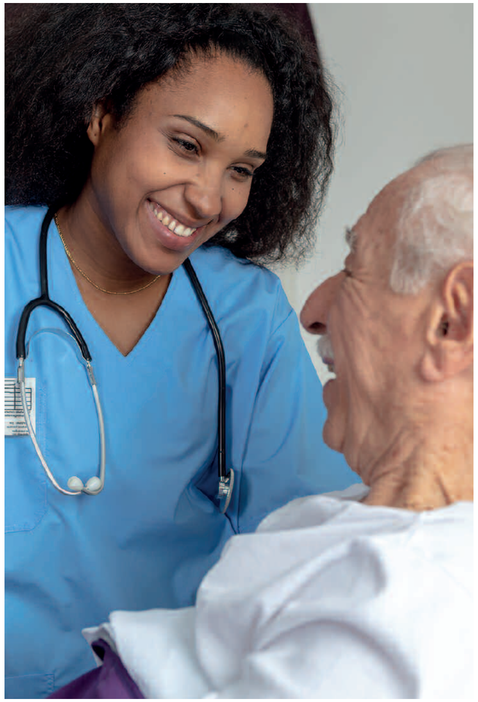
Most people are ready to go home 10–14 days after surgery. But you will feel very tired at times and will need plenty of rest. You may feel weak and lacking in energy for at least 3 months or up to a year afterwards.

For at least 3 months, avoid strenuous activity like vacuum cleaning or lifting heavy bags of shopping. Also avoid bending over from the waist. If you need to pick up something from the floor or tie your shoes, bend from the knees and crouch down. You will not be able to drive for 6–8 weeks after surgery. Your doctor and nurse will discuss this with you.

Before you go home you will be given a date to come back for a check-up. It is usually about 4–6 weeks later.

Tube feeding at home

If you need to continue with tube feeding at home, training will be arranged for you before you go home. Your family members can also learn how to use the tube. Your dietitian will order the tube equipment and give you and the public health nurse all the information you need.



Even if you are no longer being fed through the feeding tube, the tube may be left in place when you go home. It will need to be flushed through regularly to prevent blockages. Your nurse will show you how to do this.

The feeding tube will be removed following a review of your weight, food intake and symptoms. If you are going for further treatment such as chemotherapy following your surgery, you may be advised to keep your feeding tube in place until your treatment is complete.

Heartburn/reflux

These symptoms are common after oesophageal cancer surgery, as valves that keep acid inside your stomach are opened up at the time of surgery. This means that when you have a full stomach tube you are more likely to feel reflux (such as after meals) and you may also have reflux when you lie flat or bend over. It can help to sleep in a more upright position, by using pillows or a wedge under the mattress.

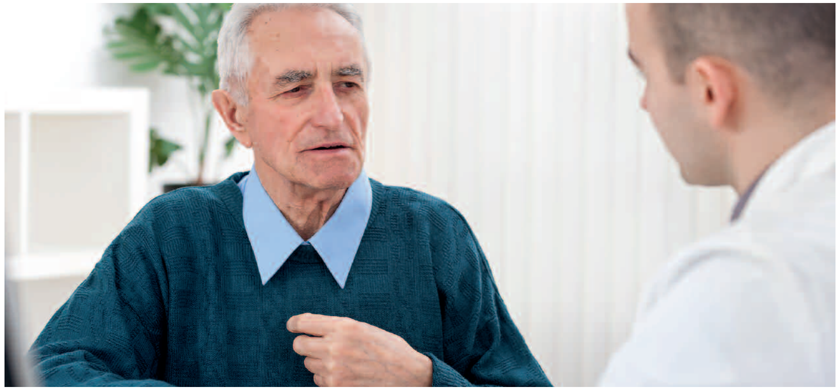
People who have had an oesophagectomy should take a regular antacid medication (proton pump inhibitor) to prevent acid reflux, even if they are not experiencing reflux symptoms.

People who have had their stomach removed may benefit from other medications to help manage heartburn symptoms related to bile refluxing – you can discuss this with your team at your follow-up appointments.

Managing side-effects after surgery

You will be given contact numbers so you can reach the healthcare team if you have a problem. Contact your cancer nurse coordinator as soon as possible if you:

- Have nausea (feel sick)
- Are vomiting or are coughing up saliva (spit)
- Have a cough, shortness of breath, pain or hoarseness
- Have a problem with the feeding tube
- Have difficulty swallowing
- Have diarrhoea for more than 24 hours or feel unwell
- Are worried about your wound
- Have pain that does not get better with over-the-counter painkillers



It's normal to experience some of these symptoms after surgery, but you should let the hospital know so they can advise you. If you have any other symptom that is causing you concern before your check-up date, contact your cancer nurse coordinator for advice. See page 121 for more about follow-up.

If you're feeling sick, your medical team can give you medicine to help with this.

Will I be able to eat and drink normally again?

It may take a while before you get back to normal eating and drinking. It depends on the type of surgery you have and the time it takes for your wounds to heal. You might experience:

- Feeling full and uncomfortable after eating only small amounts
- Having little or no appetite
- Weight loss
- Nausea
- Feeling tired or needing to lie down after eating
- A change in your bowel habit e.g. diarrhoea or constipation

Eating difficulties often last for a few months after surgery. Getting better can be a slow process. But there are things you can do to help reduce these problems. See below for more information.

Dietary advice

The hospital dietitian will help you with any eating difficulties and advise you on how to have the best possible diet, including if you need any nutritional supplements. Eating well will help your strength and energy levels to improve. Your wounds may heal faster and further weight loss may be prevented. Many people find that the natural desire to eat is reduced after this kind of surgery. If this is the case it can be helpful to try to schedule meals throughout the day rather than waiting until you feel hungry.

Dumping syndrome

Dumping syndrome can happen after oesophageal cancer surgery. It happens when food, particularly high-sugar or high-fat food, travels too quickly into the small intestine. It can cause various symptoms. Slowing down the movement of food from your stomach to the intestine can help to avoid dumping syndrome.

Early dumping syndrome usually happens 30 to 60 minutes after a meal. It causes symptoms such as tummy pain, bloating, stomach rumbling, nausea and diarrhoea. It can also cause fatigue, flushing, sweating and heart palpitations.

Late dumping syndrome usually happens 1 to 3 hours after a meal. It can make you feel very tired, weak, confused, hungry, irritable or faint. It can also cause sweating and palpitations.

Hints and tips: Dumping syndrome

- **Avoid too much fluid at mealtimes** – fluid with meals can cause food to travel into the small intestine faster. If possible, avoid drinking liquids 30 minutes before and after meals.
- **Eat slowly, chewing foods well.**
- **Don't skip meals.** Eat small and frequent meals throughout the day.
- **Eat high-protein foods.** These are foods like meat, fish, cheese, eggs, beans and lentils. Adding protein to meals slows down the absorption of sugar into the bloodstream.
- **Choose higher fibre, slow-release carbohydrates.** For example, oats, basmati or brown rice, wholemeal or granary breads, lentils, beans, chia or flax seeds, wholegrain pasta and potatoes with skins on. Limit white bread, pasta and shortgrain rice.
- **Cut down on sugary foods** like sweets, chocolate and sugary drinks.
- **Rest for 15-30 minutes after a meal.**

For most people, dumping syndrome settles after a while.

Let your doctor, nurse or dietitian know if dumping syndrome continues to be a problem. They will be able to give you more advice.

The Irish Cancer Society has a medical needs toilet card that you can show at shops and other public places to get urgent access to a toilet. Get one from a Daffodil Centre or by calling our Support Line on 1800 200 700.

Feeling full

Feeling full and uncomfortable after eating only small amounts is common. This is related to the reduced size of the remaining stomach, and changes in the signals between the gut and brain after the surgery.

Hints and tips: Feeling full after eating small amounts

- **Eat small portions** – half portions at the most
- **Try to wait 30 minutes after eating before having a drink**
- **Eat slowly**
- **Do not lie down flat after eating**
- **Take anti-sickness medication** if advised by your doctor
- **Eat small meals 3 times a day and try adding 2-3 small snacks,** so that you are eating little and often. See pages 103-107 for ideas on how to eat well.

Reduced appetite

You may not feel like eating much. A poor appetite is very common after surgery. This is thought to be related to a reduction in hunger hormone levels, particularly in the first few months after surgery. It is very important that you try to eat as well as you can despite this. Try to eat small amounts regularly, every 2-2.5 hours, rather than waiting to feel hungry. Try not to skip meals or snacks. The dietitian can support and help you if you lose your appetite. They can also give you advice about the best foods to eat and other tips to help. See page 100 for more advice on coping with a loss of appetite.

Weight loss

Most people who have surgery will lose weight afterwards. But usually this settles down after 6-12 months. Most likely, you will not get back to the weight you were before your illness.

If you are worried about weight loss, or you feel that it is impacting your physical fitness, stamina or activity levels, discuss this with the team at your next clinic appointment.

Radiotherapy

- Radiotherapy uses high-energy rays to kill cancer cells.
- You normally have treatment every week day for a number of weeks.
- Most side-effects affect the area of the body being treated with radiotherapy.
- Side-effects usually improve soon after treatment ends, but some can be long-lasting.

Why is radiotherapy given?

The aim of radiotherapy is to destroy cancer cells with as little damage as possible to normal cells. Radiotherapy can be given:

Before surgery: To reduce the size of the tumour and make it easier to remove. It may also improve swallowing. You may have both chemotherapy and radiotherapy, as chemotherapy makes the cancer cells more sensitive to radiotherapy. This is called chemoradiation.

You may have a feeding tube inserted before your treatment to keep up your nourishment.

After surgery: Radiotherapy can be used if there is a risk some cancer cells have been left behind after surgery or a risk that the cancer may return.

Relieving symptoms: Radiotherapy can be used on its own to relieve symptoms such as pain or difficulty in swallowing. This is called palliative radiotherapy.

Radiotherapy can be given in two ways:

External beam radiotherapy

The radiation comes from machines that aim rays directly at your tumour or the tumour site. The machines are called linear accelerators.

Internal radiotherapy (brachytherapy)

Occasionally, radiotherapy is given by putting a radioactive source inside your body on or near your tumour. Internal radiotherapy is also known as brachytherapy (“brack-ee-thera-pee”). See page 83 for more about brachytherapy.

Occasionally, external radiotherapy is followed by brachytherapy when treating oesophageal cancer.

Planning external radiotherapy

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells. You will have a scan to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

Getting radiotherapy

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

The treatment normally takes several minutes. It doesn't hurt but you will have to lie very still, which can be uncomfortable. Most people receive radiotherapy as outpatients, travelling to the radiotherapy unit each week day, with a break at weekends.

Radiotherapy is normally given in special cancer treatment centres, so you may have to attend a different department or hospital from where you had surgery. If you are having chemotherapy and radiotherapy together, your team will coordinate your treatment.

> External beam radiotherapy does not make you radioactive. It is safe for you to mix with family and friends, including pregnant women and children.

How much radiotherapy do I need?

The course can be several treatments over a number of days or weeks (5 to 6 weeks) or between 1 and 10 doses for palliative treatment.

For more information on radiotherapy and possible side-effects, read our booklet ***Understanding radiotherapy***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Will I get any side-effects?

Radiotherapy is given directly to the site of the cancer. The areas that are most likely to be affected by treatment are your throat and chest.

How severe side-effects are will vary from person to person. It depends on the amount of treatment you need and the exact part of the oesophagus needing treatment. The effects of radiotherapy may be more severe if you have had surgery as well. Your doctor, nurse or radiation therapist will explain how these effects can be managed before you start treatment.

Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long term or may even be permanent.

The side-effects may include:

- Sore mouth and throat
- Difficulty swallowing
- Pain below your ribs in your upper abdomen
- Poor appetite and weight loss
- Feeling sick (nausea)
- Voice changes
- Feeling very tired (fatigue)
- Hair loss in chest area

Sore mouth and throat

Radiotherapy to the oesophagus can make your throat and oesophagus inflamed. This happens because the cells that line these areas are very sensitive to treatment.

If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible.

Your doctor will prescribe painkillers if you need them.

If you have an infection in your mouth or throat, you may need to be treated with antibiotics or other medication. See page 102 for tips to help with a sore mouth and throat.

Difficulty swallowing

After a week or 2 of treatment, your chest might feel tight, and you might have difficulty swallowing. It may feel like you have a lump in your throat all the time. Food or drink may seem to go down the wrong way, making you cough as you try to swallow. Tell your medical team if you have difficulty swallowing. They can arrange for you to get advice from a dietitian or speech and language therapist to help you cope. They may also give you medication to take before meals to make swallowing easier.

Occasionally, a procedure can be performed using endoscopy (camera test) to relieve the problem or to provide nutritional support with a feeding tube if swallowing has become very difficult. The discomfort will usually ease 5–8 weeks after your treatment ends. See page 108 for more about swallowing difficulties and tips to help you.

Pain

Sometimes radiotherapy to the oesophagus can cause pain when swallowing or pain in your chest. If you are in pain, your doctor can prescribe painkillers. Take them regularly so that the pain can be controlled. The pain normally goes away 4–6 weeks after treatment has ended.

Poor appetite and weight loss

If the part of your oesophagus nearest your mouth is treated with radiotherapy, it can affect the taste buds in your mouth. You may get a loss of taste or a metallic taste in your mouth. If this happens, you may lose interest in food and eat less than you did before treatment. Remember that eating well can speed up wound healing.

Ask your nurse to refer you to a dietitian if you have a poor appetite. They will watch your weight and give you advice. Your appetite should improve once treatment is over. See pages 103-107 for more on eating well and page 100 for tips to help with poor appetite.

Mouth and jaw problems

Radiotherapy can increase your risk for dental issues such as cavities, gum disease, tooth sensitivity, jaw stiffness, mucositis (mouth sores) and osteoradionecrosis (ORN). See page 111 for more about mouth and jaw problems.

Feeling sick (nausea)

You might feel sick during treatment. Let your doctor know, as they can prescribe medication to prevent or reduce nausea. See page 101 for more about nausea.

Voice changes

Sometimes radiotherapy to the oesophagus may cause your voice to change. Your voice may become quieter or sound hoarse. It may even become sore for you to talk. This common effect of treatment usually doesn't last long. The quality of your voice should start to improve about 2 to 3 weeks after treatment. If your voice is becoming more hoarse or not improving, it is important to speak to your doctors about this.

Skin changes

The skin in the area treated with radiotherapy may become red and sore. It may even look like sunburn. Only use creams advised by your nurse or radiation therapist. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. If you shave, only use an electric razor. It is best to avoid all aftershaves, perfumed creams or powders.

Feeling very tired (fatigue)

Tiredness can build up over the course of your treatment, so you may feel more tired towards the end of your treatment or after treatment is finished. Tiredness can be a side-effect of the radiotherapy or it can happen because of the demands of a busy treatment schedule, especially if you're travelling long distances for treatment. See page 112 for more about fatigue.

Hair loss in treated area

Any hair in and around the treatment area will fall out, for example chest hair. The hair loss is usually temporary, but it may be thinner when it grows back.

Cough and shortness of breath

You may develop a cough and some shortness of breath with radiotherapy. Sometimes this side-effect may not appear until several months after your treatment. If it happens, you should tell your doctor as soon as possible.

Brachytherapy (internal radiotherapy)

Occasionally, radiotherapy is given by putting a radioactive source inside your body for a few minutes. This can help to slow down the growth of cancer cells. Different doses can be given but often a high dose rate is given for a very short time.

Treatment

Your doctor will first spray the back of your throat with local anaesthetic. A fine tube is then placed in your oesophagus through your nose. Then your doctor will take an X-ray to help them plan the treatment.

Once the planning has been done, the radioactive source will be put into the tube. It will travel to the area to be treated, gives the treatment and then returns safely to the machine. The planning X-ray lasts about 1 hour and the treatment itself takes about 10 minutes.

Once the tube is removed, you can go home. No radioactivity will be left in your body so it is safe for you to mix with family and friends. Usually, only 1 or 2 treatments are needed.

Side-effects

The treatment may cause nausea and soreness when swallowing. These may happen a few days after treatment and last for a few days. Your doctor can prescribe medication to help with swallowing and to ease any nausea and soreness. You will not have any hair loss with this treatment.

If you feel unwell or have any other side-effects or symptoms – during or at any time after treatment – tell your doctor, nurse or radiation therapist.

Chemotherapy

- Chemotherapy uses drugs to kill cancer cells.
- Possible side-effects of chemotherapy include the risk of infections, sore mouth, feeling sick or vomiting, hair loss, tiredness and poor appetite.
- Side-effects normally go after treatment ends.

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

When is chemotherapy given?

Chemotherapy drugs may be given:

Before surgery: Chemotherapy may be given before planned surgery. The aim of this treatment is to reduce the size of the tumour and to kill any cancer cells that may have spread from the tumour into the bloodstream. This type of treatment aims to reduce the risk that the cancer can spread to other organs or return in the longer term after surgery.

With radiotherapy: Chemotherapy is often given with radiotherapy, usually before surgery or if surgery isn't possible. This is called chemoradiation. You may have to go to 2 different departments to get the different treatments.

After surgery or radiotherapy: This is given to kill any cancer cells left behind or to prevent them coming back.

To relieve symptoms: If cancer has spread beyond your oesophagus, chemotherapy can help to shrink and control it. The aim of treatment is not to cure the cancer but to improve your symptoms and quality of life.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (by drip or pump). It may also be given as tablets that you take at home.

You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as PICC lines, ports and Hickman lines.

Most chemotherapy treatments are given in the oncology day ward.

What kinds of drugs are used?

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

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 written information 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. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depend on the amount of chemotherapy you are given and the drugs used. Ask your doctor or nurse if you're worried about side-effects or have any questions.

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

Risk of infection: Chemotherapy can reduce the number of white blood cells in your blood. White blood cells help fight infection. If the number of white blood cells is low, you are more likely to get infections. Watch out for signs of infection. These signs include feeling shivery and unwell, having a high temperature, having a cough or sore throat, or pain passing urine. If this happens, call the number you have been given straight away.

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.

Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

Constipation and diarrhoea: Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Tell your medical team if you have constipation or diarrhoea. They can advise you on what to do and give you medications to help, if needed.

Skin and nail changes: Skin may become dry, flaky and itchy. Use a moisturiser recommended by your doctor or nurse to keep the skin soft. Nails may become dark, yellow or brittle. Don't try to treat them yourself. It is important to report any changes to your doctor or nurse.

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. They are usually treated with medication to thin your blood.

Sore mouth: 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. Keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after every meal, using a soft toothbrush. See page 102 for more tips to help with a sore mouth.

Bleeding and bruising: Chemotherapy can stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums, or if you notice tiny red spots under your skin that can look like a rash. You may need a platelet transfusion.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). There are treatments that work well to prevent nausea and vomiting. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects. There are some tips to help you manage nausea on page 101.

Numbness or pins and needles in your hands and feet (peripheral neuropathy): Some drugs can affect your nerve endings. Tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet and ask how this side-effect can be managed.

Hair loss (alopecia): Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemotherapy. Scalp cooling may be available to reduce the chance of hair loss during chemotherapy – if you are interested, ask your oncologist if it is available and suitable for you.

Hand–foot syndrome: Some chemotherapy can cause hand-foot syndrome. This is pain, swelling and redness of your hands and/or your feet. It can look like sunburn, where your skin begins to peel as well. Use a moisturiser recommended by your doctor or nurse to keep the skin soft. It can help to avoid friction and heat, so do not rub your skin or put pressure on it. Ice packs may help. Tell your nurse or doctor if you notice this side-effect. They can give you medication and creams to help and may change your treatment.

Fatigue: Fatigue (extreme tiredness) is very common and can make you feel weak. For more information see page 112.

Poor appetite: It is best to eat as well as you can while on chemotherapy to keep up your strength. Eating smaller amounts more often can help. If you don't feel like eating during treatment, ask to see a dietitian who can give you specific dietary advice. See page 100 for tips to help with poor appetite. For more information on diet, you can read our booklet on ***Diet and cancer***. 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. Our nurses can also tell you about our 'Eating Well' group online information sessions with an oncology dietitian.

Other side-effects

If you notice any side-effects or you feel unwell, tell your doctor or nurse straight away. They will tell you what to do.

Other cancer drugs – Targeted therapies and immunotherapy

Targeted therapy and immunotherapy drugs can be used for some types of oesophageal cancer. They are often given along with chemotherapy.

Targeted therapies: These drugs target certain parts of the cancer cells that make them different from other cells. For example, if your cancer cells have a lot of a protein called HER2, a targeted therapy drug called trastuzumab can attach to the HER2 proteins and stop the cancer cells from dividing and growing.

Some targeted therapies are given into a vein, as an infusion or an injection. Others may be given as tablets that you can take at home. Side-effects of targeted therapies include flu-like symptoms, such as fever and chills, weakness, nausea, vomiting, cough diarrhoea and headache, an increased risk of infection and fatigue (tiredness).

Find out more about side-effects

There's more information on possible side-effects of cancer drugs in our booklet ***Understanding chemotherapy and other cancer drugs***. Call our Support Line or visit a Daffodil Centre for a free copy. You can also read or download it on our website, **www.cancer.ie**

Immunotherapy: Immunotherapy treatment is designed to boost your own immune system to fight cancer. Cancer cells often disguise themselves in your body so that the immune system doesn't recognise them as bad cells. Immunotherapy works by helping the immune system to recognise and attack the bad cells caused by cancer. It can help to control the cancer and stop it from spreading.

Side-effects can occur at any time during or even after treatment is finished. Some side-effects are caused by the immune system - stimulated by immunotherapy - attacking healthy organs. This can result in inflammation in different parts of the body. For example: colitis (inflammation of the bowel), causing diarrhoea and tummy pain; pneumonitis (inflammation of the lung), which can cause shortness of breath or a cough; inflamed skin, causing rash or dryness.

If you do experience side-effects, it is important to tell your doctor or nurse straight away.

Clinical trials

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

Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of, or as well as, the standard treatment you may get a new trial drug or be treated with a new pathway (e.g. different types of nutrition, exercise physiotherapy, or follow-up plans). 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 treatment pathways and 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 cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

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

Treating cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic, secondary or stage IV (4) cancer. Your cancer may be in more than one part of your body when it is first diagnosed.

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

Often metastatic cancer is treated with chemotherapy, targeted therapies or immunotherapy. There may also be treatments that you can have as part of a clinical trial (see page 93).

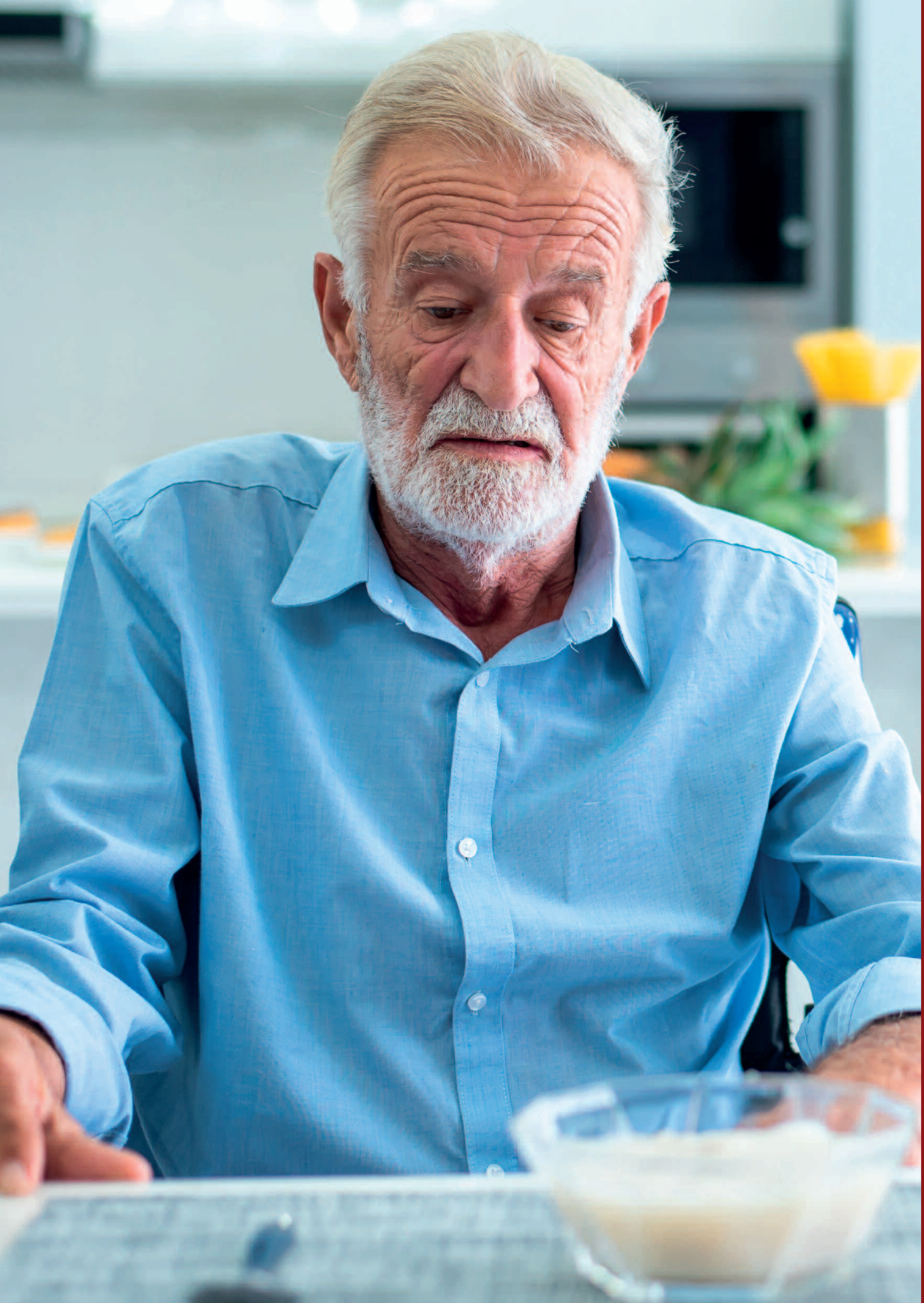
You can also have treatment to help with any symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of metastatic cancer.

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

Palliative care

Palliative care helps you to manage your physical symptoms and improve your quality of life, by providing physical, psychosocial and spiritual care. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to manage symptoms and complications earlier in your illness. Palliative care teams work both in hospitals and in the community and sometimes visit patients at home. The palliative care team may work along with your treating team.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Your family doctor (GP), public health nurse or the hospital can refer you to palliative care. Palliative care is a free service for all patients with cancer.



Managing side-effects and symptoms

Eating difficulties

Some cancer treatments can make it harder to eat well. For example, you may feel sick or not have much appetite. Your doctors, nurses and the dietitian at the hospital will help you with any eating difficulties and advise you on the best foods to eat so that you get as much nutrition as possible from the food you eat and keep your weight and strength up. The tips in this section may help too.

Advice for friends and family

Sharing food can be an enjoyable experience, so it can be hard to adjust if your loved one has a new eating pattern after their treatment. For example, eating much smaller amounts or avoiding certain foods. They may feel they are upsetting you if they have to refuse food, eat at different times or don’t eat very much. Try to support and reassure them as they get used to these changes.

Hints and tips: Poor appetite

- **Take small meals and snacks 4/5 times a day**, about every 2-2.5 hours.
- **Plan times to eat each day so that you are eating regularly,** even if you don't feel hungry.
- **Eat what you want.** If your appetite is small, the most important thing is to eat something.
- **Use a smaller plate for meals.** Large portions can be off-putting.
- **Eat slowly and chew your food well.**
- **Choose drinks that give some nutrition,** such as milk, milkshakes, milky coffee and build-up drinks.
- **Don't drink while you're eating or take only small sips,** as drinking might make you full.
- **Eat together if you can** and make mealtimes relaxing and enjoyable.
- **Take regular exercise, if you can,** as it may help your appetite. Fresh air can help too.
- **Ask your doctor about medications to help other problems,** like constipation, nausea, pain or other side-effects of treatment, if they affect your appetite.
- **Tell your doctor if you're feeling fatigued, anxious or depressed,** as this can also affect your appetite.
- **Supports are also available for people who have long-term changes in appetite after treatment.** The Oesophageal Cancer Fund has portion-control cards that can make eating out easier. The wallet-sized cards explain to restaurant staff that you need a smaller portion for medical reasons.

Hints and tips: Feeling sick (nausea)

- **Talk to your GP or medical team if you're feeling sick or if you feel dehydrated.** There are medicines to help.
- **Eat before you get hungry,** as hunger can make nausea worse.
- **If you are sensitive to the smell of cooking, try using ready meals or avoid being in the kitchen while food cooks.** If you have a friend or family member, ask them to help with cooking.
- **Eating little and often may help.** Eat slowly and chew food well.
- **Have sips of fluids regularly to avoid getting dehydrated between meals.** Try to choose drinks that give some nutrition such as milk, milkshakes, hot chocolate or milky coffees. Have clear liquids such as water if other drinks make you feel sick.
- **Take plenty of nourishing fluids** if you miss a meal or 2.
- **Rest after your meals.**
- **Try the following foods and drinks,** as they might help:
  - Cold, bland foods like yogurt, boiled potatoes, rice, noodles, breakfast cereal or cheese
  - Dry food like toast, scones, crackers or breakfast cereals
  - Herbal teas like mint
  - Foods containing ginger, such as ginger ale or tea, ginger nut biscuits, ginger cake or fresh ginger in hot water
- **Some people find the following foods make nausea worse:**
  - Fatty, greasy or fried foods
  - Spicy foods
  - Very sugary foods
  - Foods with a strong smell, like onions and garlic
- **Eat foods that you like or are able to tolerate.** When your nausea improves, try other foods for variety (if you can tolerate them).
- **Some people find relaxation exercises, acupuncture or meditation helps.** Check with your doctor if you're thinking of acupuncture, to make sure it's safe for you.

Hints and tips: Sore mouth or throat

- **Take sips of fluids like water or milk often.** Drink through a straw if your mouth is painful.
- **Eat soft, moist food** like omelettes, scrambled eggs, mashed potatoes, cream soups, natural yogurt, milkshakes, stews, puddings.
- **If you need to liquidise or puree meals, ask to be referred to a dietitian to make sure your nutritional intake is adequate.**
- **Take care with foods that might make a sore mouth or throat worse:**
  - Pickled, salty or spicy foods
  - Rough food, like crispy bread, dry toast or raw vegetables
  - Alcohol and tobacco
  - Citrus juices, like orange, lemon, lime, grapefruit or pineapple
  - Mouthwashes that contain alcohol, or acidic ones.
- **Avoid very hot food or very cold foods and drinks.** You may find it easier to have foods and drinks at room temperature.
- **Ask your doctor or nurse about mouthwashes, gels and medications to help with your sore mouth.** Only use products they recommend.
- **Try rinsing your mouth with a homemade mouthwash** made with 1 teaspoon of baking soda (sodium bicarbonate) and 1 teaspoon of salt to 1 pint/half a litre of warm water.
- **Ask your doctor and nurse for painkillers if your mouth is painful.** They may prescribe some antiseptic or local anaesthetic gels or lozenges.
- **Keep your teeth, gums and mouth clean to control soreness and prevent infection.** Clean your teeth after every meal, using a soft toothbrush.
- **If you have dentures, remove them** if your mouth is sore.

Making the most of your diet

If you can only eat small amounts or if you have lost weight, it's a good idea to make the most of your appetite to eat nutritious, high-energy (high-calorie) foods and drinks. Avoid diet or low-fat foods.

Eating well will help you to feel better and have more energy. A good nourishing diet may also prevent further weight loss and help you to recover more quickly from the effects of treatment. If you have problems eating, talk to your dietitian. They will advise you on an eating plan most suitable for you. For example, a build-up diet, which is high in protein and calories.

Tips to get more calories

- **Add butter or olive oil** to soups, mashed and baked potatoes, sauces, cooked vegetables, rice.
- **Add whipped cream or full-fat yogurt** to desserts, puddings and fruit.
- **Add cream** to soups, sauces, custards, cereals. It can also be added to mashed potatoes and puréed vegetables.
- **Add cheese or vegetarian/vegan alternatives** to casseroles, potatoes, vegetables, omelettes, sandwiches.
- **Sauté or fry foods** if you can tolerate them.
- **Add sauces or gravies** to your food.
- **Add ground almonds or other nuts** to porridge, cereals or desserts.
- **Add hummus, guacamole, nut butter or cream cheese** to sandwiches or as a snack with crackers.

Tips to get more protein

- **Try to eat protein food at every meal,** spread over the day, rather than only at one meal.
- **Eat more hard and soft cheeses.** Add them to food where possible.
- **Use full-fat milk as a nutritious drink.** Use it to also make smoothies and in cooking whenever possible.
- **Add high-protein milk or yogurt** to drinks, fruit and cereals.
- **Add chopped hard-boiled eggs** to salads, vegetables, casseroles.
- **Add nuts, seeds and wheat-germ to your food.** Add to casseroles, salads, breads, biscuits.
- **Add chopped meat or fish** to vegetables, salads, casseroles, soups, baked potatoes.
- **Add hummus** to sandwiches and salads or have with crackers.

Food safety

Some patients may have a low white cell count due to their cancer or treatment. This can mean your immune system doesn’t work as well to fight off infections like food poisoning. It is best to avoid undercooked or raw meat, fish and eggs and unpasteurised or ‘live’ dairy products such as milk, cheese and yogurts. For more about food safety, see our booklet ***Understanding diet and cancer.***

Nourishing drinks

Drinks that give some nourishment include full-fat milk, fresh or frozen yogurt, milkshakes, ice-cream, build-up drinks (nutritional supplements), chocolate drinks, smoothies, yogurt drinks, malt drinks or milky coffee made with full-fat milk.

Fortified milk

This high-protein, high-calorie milk can be used for milky drinks such as lattes, smoothies and milkshakes. It can also be used to make soup stock or in porridge and cereal.

- Add 3-4 tablespoons of skimmed milk powder to 1 pint of full-fat milk. You can usually find skimmed milk powder beside the baking items in the supermarket.
- Mix well with whisk or in blender. Store in the fridge for up to 3 days.

Alternatively you can buy high-protein milk in supermarkets.

Build-up drinks

Build-up drinks have a balanced mix of nutrients for when it’s hard for you to eat food. Talk to your doctor or dietitian about suitable ones for you. Your doctor can give you a prescription for these drinks.

Build-up meal ideas

Breakfast ideas

- Scrambled, poached, boiled or fried egg with bread and full-fat spread or butter
- Avocado on toast
- Porridge with full-fat milk/cream and tinned fruit, for example, prunes, peaches, pears
- Full-fat yogurt, oats and fruit, topped with nuts or seeds
- Toast with peanut or another nut butter or jam and butter/full-fat spread
- Fried bread or French toast (bread dipped in beaten egg and fried)
- Cheese and spinach omelette
- Granola or muesli with milk or yogurt with nuts

Lunch ideas

- Meat, chickpea or lentil-based soup – add cream or coconut milk to normal soup to add calories
- Sandwich or roll filled with chicken, egg mayonnaise, tuna, nut butter, hummus, sliced meat or non-meat alternative. Have mayo or butter/full fat spread to add calories
- Baked beans on toast – butter the toast and add cheese for extra calories and protein
- A mixed salad with meat, cheese or vegan protein. Add avocado and seeds for extra protein, healthy fats and nutrients
- Macaroni cheese with tomato and bacon/non-meat alternative

Dinner ideas

- Roast or fried meat or fish – salmon and other oily fish like mackerel and sardines are particularly nutritious
- Vegetarian or vegan burger or sausages
- Pasta with creamy sauce or tomato and vegetable sauce with plenty of cheese or other protein
- Casseroles and stews – add meat, beans or lentils for extra protein and nutrition
- Shepherd's pie or vegetarian/vegan alternative using soya mince, beans or lentils

Add butter, cream or olive oil to any vegetables you have with your dinner. For example, creamed spinach, buttered carrots or sweetcorn. Fry or roast potatoes or sweet potatoes, or add butter or cream to mashed or boiled potatoes.

Dessert ideas

- Fresh fruit salad with cream or ice cream
- Bananas and cream
- Fruit pie and custard
- Rice pudding

Snack ideas

- Olives, nuts and seeds
- Dips made with cheese or yogurt, guacamole, cheese and chive dip, hummus
- Cheese – for example, mini cheese portions, cheese slices
- Breakfast cereal/porridge with lots of toppings – cream, jam, stewed or tinned fruit, nuts and seeds
- Toast with sardines, baked beans or nut butter
- Hot chocolate or milky coffee made with full-fat milk
- Ice cream/milkshakes
- Fruit bread or scones with butter or full-fat spread and jam
- Quiche
- Sandwiches or jacket potatoes filled with tuna, chicken or eggs with mayonnaise, cheese, smoked or tinned salmon
- Smoothies made with yogurt or full-fat milk
- Full-fat yogurt or fromage frais. For example, Greek-style yogurt. Add seeds or dried fruit.

Swallowing difficulties (dysphagia)

Difficulty swallowing can be caused by the tumour itself or if the oesophagus is narrowed after surgery or radiotherapy.

If you have difficulty swallowing, with food becoming stuck in the oesophagus, tell your medical team as soon as possible. Several treatments are available to help you to maintain your nutrition if you have swallowing difficulties. This can include temporary dilatation, the use of a feeding tube, oesophageal stent, or radiation treatment. More information is provided on page 110.

If you find fluids are going down the wrong way, you may also need to see a speech and language therapist who can assess your swallow and recommend safe foods and fluids for you to eat and drink. Sometimes, people may need to use a thickener, which they can add to their fluids to make them safer to swallow.

The dietitian at the hospital can give you advice on eating. They can advise you on ways to make foods easier to swallow and ways to get the most nutrition possible into your diet.

If you want tips and recipe ideas, ask your medical team for our booklet ***Understanding diet and cancer*** or the booklet ***Eating Well with Swallowing Difficulties*** (from Breakthrough Cancer Research). Or call our Support Line for copies.

Hints and tips: Difficulty swallowing

- **Ask your dietitian for advice about how to make eating easier** and if you need to take supplements or eat special foods, such as liquidised or pureed foods.
- **Eat foods that you can swallow comfortably.**
- **Put small amounts of food in your mouth and chew well** before swallowing.
- **Finely chop, mince, mash or liquidise your food.**
- **Have sips of liquid between mouthfuls** to help you to swallow.
- **Eat your favourite foods but soften them** with sauces and gravies, where possible.
- **Try eating soft, liquid foods** like soups, milkshakes, custards, natural yogurt. But vary them so you don’t get bored. Make sure soups have potato, lentils, vegan or vegetarian meat alternatives, tender or minced meat or fish in them for extra nourishment.
- **Eat small, frequent meals.**
- **Sit up for all your meals if possible.** Try to remain seated upright for 20–30 minutes after eating.
- **Take build-up drinks,** which are high in calories and protein. Your dietitian can advise you about these and your doctor can prescribe them.
- **Drink at least 6 to 8 cups of fluid each day.** All fluids count. For example, water, milk, juice, tea and coffee.

Treatments for swallowing difficulties

Sometimes, the cancer can cause the oesophagus to be narrowed. If you continue to have problems with swallowing, your doctor may suggest one or more of the following treatments. Sometimes they may need to be repeated.

Oesophageal dilatation

Oesophageal dilatation is a treatment that stretches and widens a narrowed area in your oesophagus so food and drink can pass through again. It uses an instrument called a dilator and it can be done quickly under general or local anaesthetic.

The dilatation may last only a short time and may need to be repeated a few weeks or months later. A different type of dilator might be used instead. Your doctor and dietitian can advise you on the best consistency of food to take after the dilatation.

Oesophageal stent

Another way to make swallowing easier is to put a hollow tube called a stent into your oesophagus. The stent is usually made of plastic or flexible wire mesh. It is put in under local or general anaesthetic like during an endoscopy. Once in place, it expands to keep your oesophagus open so you can swallow more easily.

Once you are awake, you can usually start taking fluids. Gradually you will be given small amounts of soft food to eat. Your dietitian will advise you on the type of foods you should eat. You will need to chew your food thoroughly before swallowing so the stent does not get blocked. Foods that are soft and moist are generally the most suitable. It is often best to avoid bread or large pieces of meat. But you may need to blend your food too. Having drinks with your food and after food can help to keep the stent clean.

Your treating team and the dietitian will advise you about eating and your diet if you have either of these treatments.

Mouth and jaw problems

Chemotherapy and radiotherapy can increase your risk for dental issues such as cavities, gum disease, tooth sensitivity, jaw stiffness, mucositis (mouth sores) and osteoradionecrosis (ORN). ORN is a rare but serious side-effect where the bone in your jaw starts to die. This happens because your jaw bone can have less blood supply and not heal so well after radiotherapy, so any damage to your jaw bone may cause problems.

Hints and tips: Mouth and jaw problems

- **Keep your teeth in good condition and treat any tooth decay (cavities) quickly.**
- **If a tooth has to be taken out after radiotherapy or chemotherapy, you should see a dentist who is used to dealing with patients who have had cancer treatment,** as they will take extra precautions to avoid infection.
- **Avoid smoking and drinking alcohol,** as these increase the risk of ORN.
- **Tell your doctor or dentist immediately if you develop any problems with your teeth or gums,** or notice swelling, pain, stiffness, heaviness or numbness of your jaw.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Fatigue usually 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 blood transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you advice to help.

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 ***Understanding 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 130).
- **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 complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for 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**

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. There is no set time for you to be ready to have sex again. It varies from person to person. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

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.

Our booklet ***Understanding sex, sexuality and cancer*** has more advice. It's available to read on our website **www.cancer.ie**. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

Sex after surgery

It may be some weeks before you will feel well enough to have sex after surgery. If you have surgery to remove the tumour, this may change the way you feel about your body. If you have a feeding tube in place, it may also affect your body image. You may also have concerns about the way your partner will react. Try to talk to your partner about the way you are feeling.

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. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

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

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

Asking for advice

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

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. This may be temporary or permanent. It depends on the type and amount of chemotherapy drugs you have and on the area being treated by radiotherapy.

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 if this is an option for you.

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

Cancer and complementary therapies

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

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

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

What's the difference between complementary and alternative therapies?

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

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

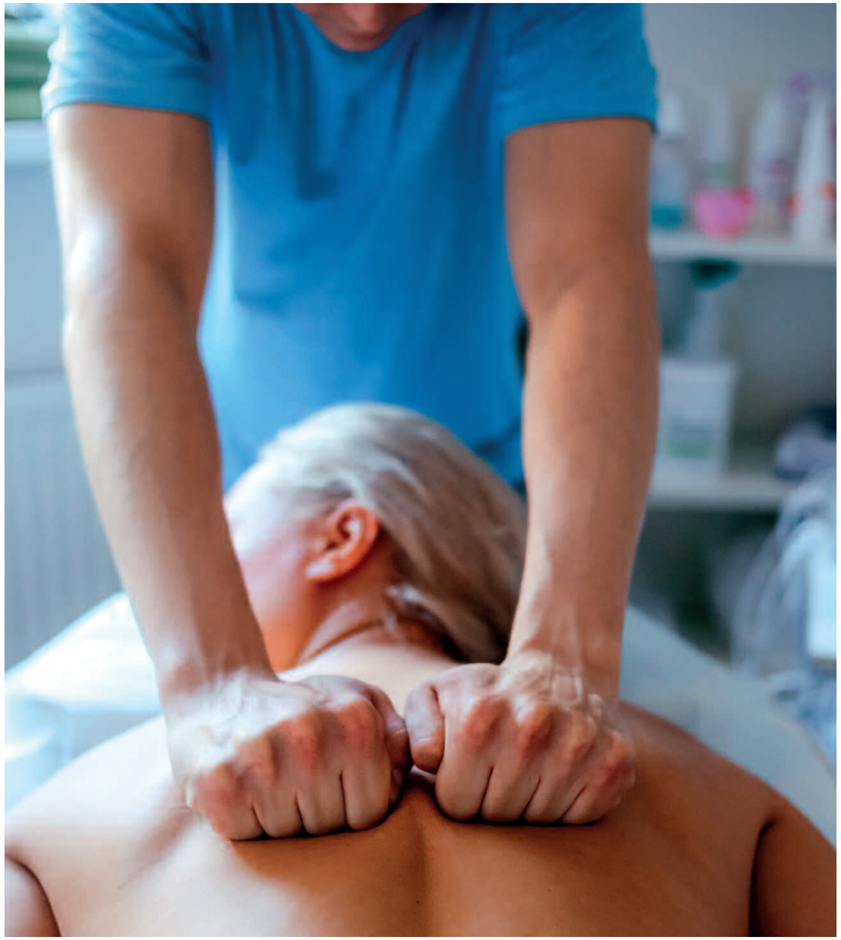
Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

Integrative care

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

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

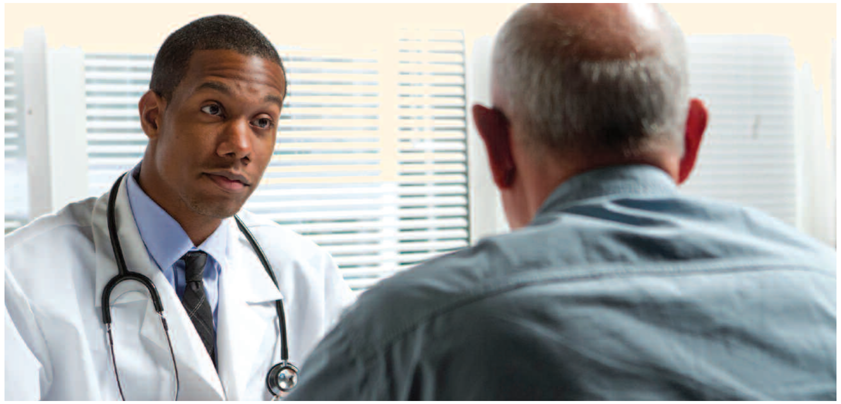
What follow-up will I need?

Once your treatment for cancer is over, your doctor may recommend that you have regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood tests and/or scans or camera tests.

Some people who have had treatment for cancer of the oesophagus experience ‘late effects’. These are side-effects that happen sometime after treatment. Your doctor will monitor you for these. Late effects can include issues with swallowing, food getting stuck, changes in eating or digestion, nutritional issues, breathlessness, reduced exercise tolerance, pain or low mood. If you have any symptoms that are bothering you, it is important that you discuss these with your doctor during your follow-up appointment. You can also meet with the dietitian to discuss any eating problems you might have. If your mobility has not improved or you have trouble breathing, the physiotherapist can help you.

Follow-up protocols vary at different hospitals. Speak to your doctor about which follow-up plan is best for you.

It's important to attend your follow-up appointments so your doctor can help with any side-effects that you may have and 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. The doctor will also check for signs of the cancer coming back (recurrence). These can include difficulty swallowing food, vomiting, abdominal pain, chest pain, unexpected or excessive weight loss or new onset hoarseness of voice.



Tell your doctor or nurse how you have been since your last appointment, including if you're having any symptoms 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 what you wanted to say.

If you are between appointments 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.

Worry about the cancer coming back

It's very common to worry about cancer coming back and it can be hard to live with this fear. Although you may feel anxious before your follow-up appointments, staying in touch with your medical team can help you feel more in control. On the other hand, some people may prefer to have less frequent follow-up appointments if they are feeling well. Speak to your doctor about what is best for you. It's also important to get support if you're feeling anxious. Joining a support group, such as those run by the Oesophageal Cancer Fund, or having some counselling (see page 130), may help. Often people find their worries lessen as time goes on.

Life after treatment

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

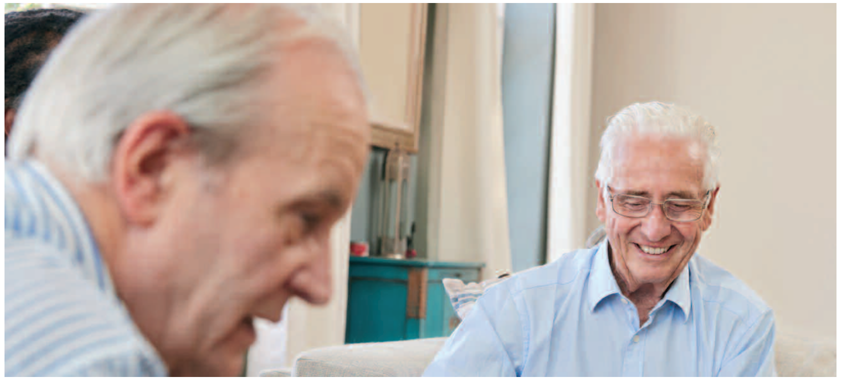
- Fear of cancer coming back and worrying about every small symptom
- Loneliness without the company and support of your medical team and fellow patients
- Stress at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- 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

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

You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 131 for other ways to get emotional support.

Ups and downs in your recovery

You may have symptoms and ups and downs in your recovery. This doesn't mean you aren't making progress. The important thing is to get support if you are having difficulties, including medical advice from your GP or hospital team and emotional support, such as counselling (see page 130). See page 97 for more on coping with side-effects and symptoms.



After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or have started maintenance therapy. This workshop 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 or ask your specialist nurse or doctor to refer you to a LACES workshop.

Living a healthy lifestyle

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

- Feel better
- Heal and recover faster
- Cope better with any side-effects
- Keep up your energy and strength
- 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 what your treatment options are.

Planning ahead

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

Planning ahead might include:

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

Who can help me plan?

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

Irish Hospice Foundation

Think Ahead Planning Pack

Coping and emotions

How can I cope with my feelings?

There are many different reactions to getting a cancer diagnosis. There is no right or wrong way to feel and there is no set time to have any particular emotion.

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

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

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

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

Anxiety and depression

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

All cancer centres in Ireland have a psycho-oncology multi-disciplinary team who can offer specialist support. Your medical team, cancer support centre or Daffodil Centre nurse can refer you to this team if needed.

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 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 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, 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."

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 154 for more about 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 local cancer support centres have activities and groups where you can meet other people affected by cancer. The Oesophageal Cancer Fund organises patient support meetings and can connect you with a person who has experienced oesophageal cancer. Call 086 069 7328 or visit **www.ocf.ie**

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

Talk things through: It can be a great relief to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

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

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

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.

You and your family

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

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.

Changing relationships

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

Talking to children and teenagers

Saying nothing

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

How to tell your children

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

Our cancer nurses can also support you if you have children and aren't sure what to say to them.

Supporting someone with cancer

How you can help

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 the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities. Here are some things that can help to make life a little easier:

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at some local cancer support centres. Talk to your GP or see page 130.

Find out about support for carers

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

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet has a section on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre or download it at **www.cancer.ie**

Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information. Our booklet, ***Caring for someone with cancer***, has lots of information on:

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

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

Support resources

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 medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with your illness if you are worried about money.

Irish Cancer Society Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis/returning to work**
- **Housing and homelessness issues**

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 an Irish Cancer Society Welfare 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 Welfare Officers or other supports might be of help.

Medical expenses

Medical expenses that you might have to pay include:

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

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

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

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

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

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

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

Benefits and allowances

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

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

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 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 photocopy completed forms before posting them.

If you have money problems

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

Call the MABS Helpline 0818 072 000 for information.

If you are finding it hard to cope financially, contact the 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 151 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 **Welfare and supports** 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 website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Team may also be able to help (see page 144).

Irish Cancer Society services

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

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team (see page 144)

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.

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 this service, please go to **https://www.cancer.ie/Support-Line-Video-Form**

You can also email us at any time on supportline@irishcancer.ie

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 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie. You can also learn about different treatments by watching our patient education videos at **www.cancer.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 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 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 1800 200 700.

Transport Service

We provide patient travel 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 radiotherapy patients attending University Hospital Cork and the Bons Secours Hospital, Cork for treatment.
- Travel2Care is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50km one way to a national designated cancer centre or approved satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these services please contact your hospital healthcare professional, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Night Nursing

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

For more information, please contact the healthcare professional who is 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, 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 Freephone our Support Line or call into your nearest Daffodil Centre for a free copy 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 one-to-one counselling 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/local-support**

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.

What does that word mean?

Abdomen The part of your body that lies between your chest and hips. Also known as your tummy.

Adjuvant Treatment given soon after surgery.

Alopecia Loss of hair or no hair where you normally have hair.

Anaemia A shortage of haemoglobin in your red blood cells. This causes fatigue, weakness and shortness of breath.

Anastomosis The area where two parts of the gastrointestinal tract are joined together (for example, the oesophagus and the stomach).

Benign Not cancer. A tumour that does not spread.

Biopsy Removing a small amount of tissue from your body to find out if cancer cells are present.

Cells The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Dilatation Stretching or widening. Can be used to help open up the oesophagus to help you to swallow.

Dysphagia Difficulty in swallowing.

Intestine Another word used to describe the bowel. The intestine/bowel absorbs nutrients and fluid from the food you consume.
The stomach leads to the small intestine which is about 7m (22ft) long.
The small intestine/bowel is connected to the large intestine/bowel.
The large intestine is also called the colon.

Malignant Cancer - A tumour that can spread.

Metastasis The spread of cancer from one part of the body to other tissues and organs.

Nausea Feeling sick or wanting to be sick.

Neo-adjuvant Treatments such as chemotherapy and radiotherapy given before surgery.

Oncology The study of cancer.

Notes/Questions

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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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The Irish Cancer Society is a registered charity, number CHY5863.

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

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

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