

A practical guide to understanding cancer

UNDERSTANDING OESOPHAGEAL CANCER (CANCER OF THE GULLET)



About this booklet

This booklet is about oesophageal cancer (cancer of the gullet). It is for anyone who is having tests for oesophageal cancer or has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains what oesophageal cancer is and how it may be treated.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

We have included quotes from people who have had oesophageal cancer, which you may find helpful. Some quotes are from David, who is on the cover of this booklet. Others are from our Online Community (macmillan.org.uk/community) and people who have shared their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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THE OESOPHAGUS AND OESOPHAGEAL CANCER

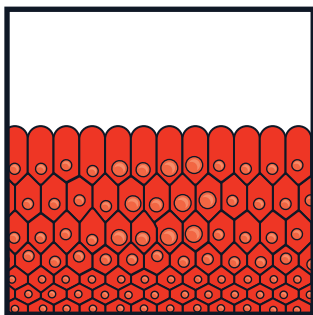
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What is cancer?

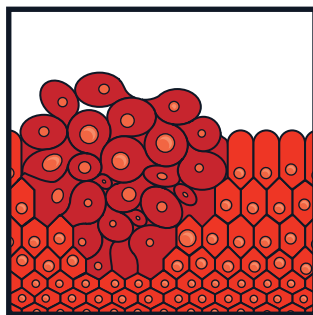
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

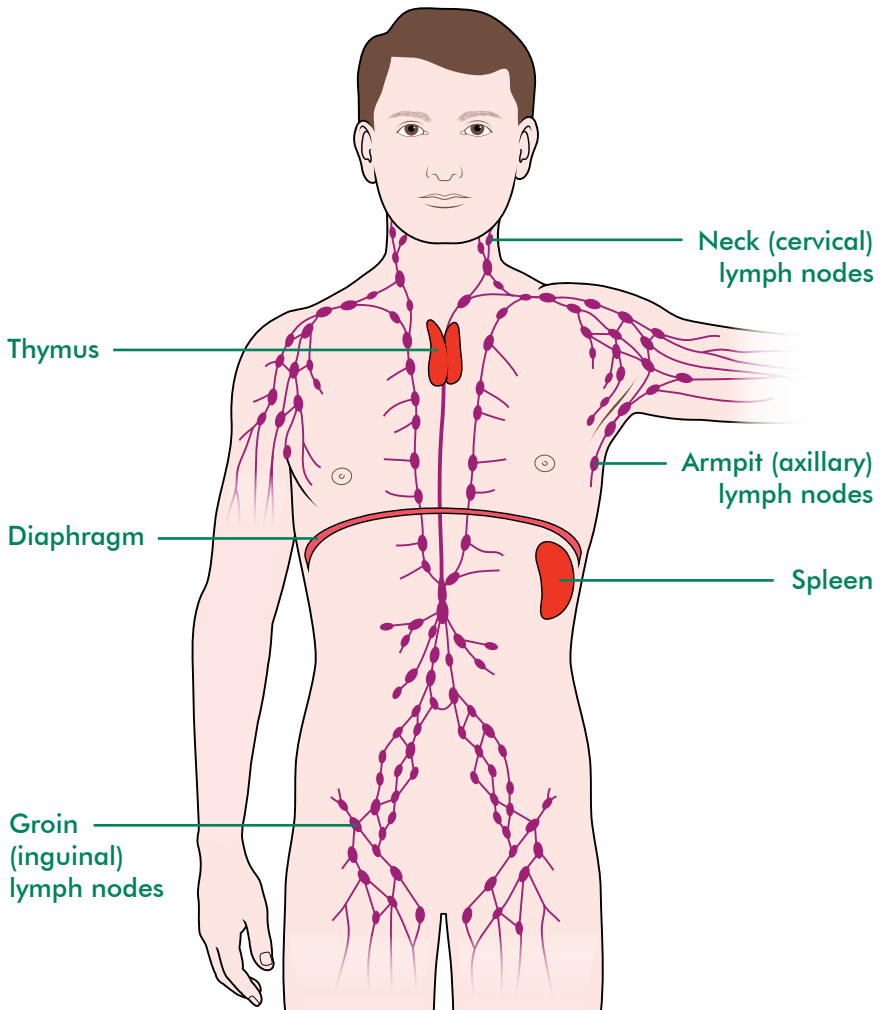
A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 8 to 9). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.

The lymphatic system

The lymphatic system helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body.

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection lymph nodes often swell as they fight the infection.

The lymphatic system



The oesophagus

The oesophagus is also called the gullet or food pipe. It is part of the digestive system, which is sometimes called the gastro-intestinal tract (GI tract). The oesophagus is a muscular tube about 25cm (10in) long. It connects your mouth to your stomach.

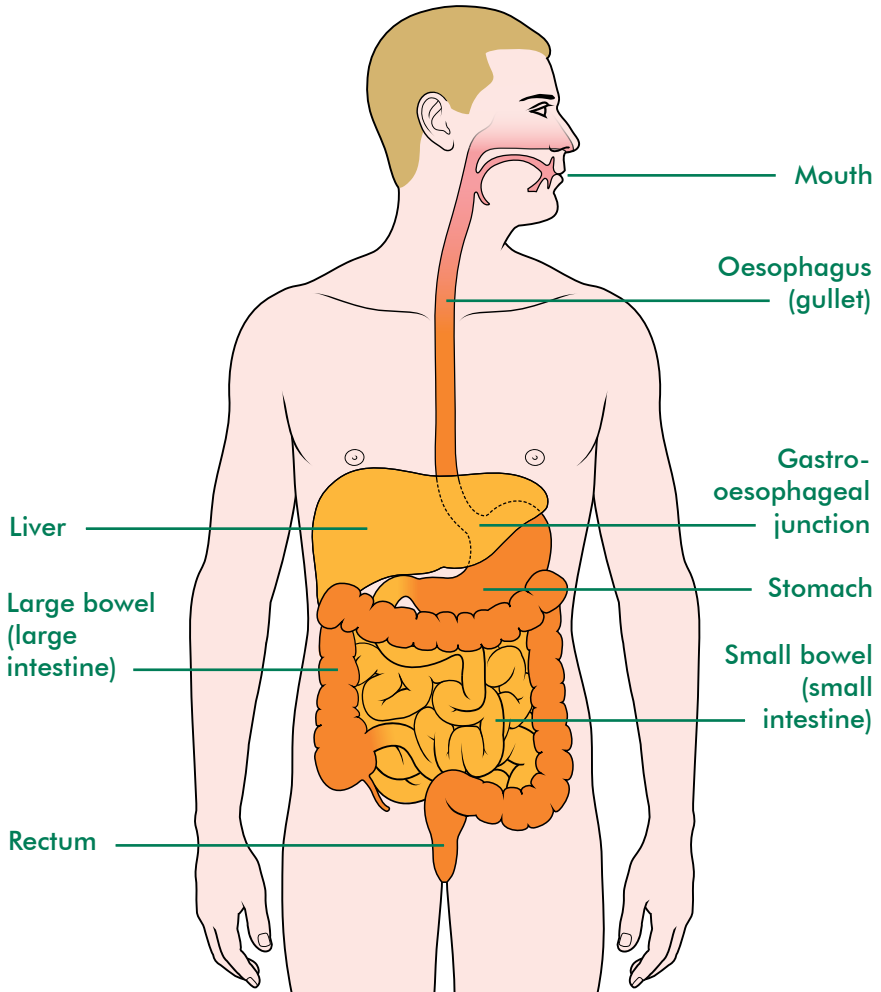
When you swallow food, the walls of the oesophagus squeeze together (contract). This moves the food down the oesophagus to the stomach.

The upper part of the oesophagus is behind the windpipe (trachea). The windpipe is the tube that connects your mouth and nose to your lungs, so you can breathe. There are several lymph nodes close to the oesophagus (see page 8). The area where the oesophagus joins the stomach is called the gastro-oesophageal junction.

The oesophagus has four layers:

- **The mucosa** is the inner layer. It is moist to help food pass smoothly into the stomach.
- **The submucosa** contains glands that produce mucus (secretions). This keeps the oesophagus moist.
- **The muscularis** is the muscle layer. It pushes food down to the stomach.
- **The adventitia** is the outer layer. It attaches the oesophagus to nearby parts of the body.

The oesophagus and surrounding organs



Causes and risk factors

Oesophageal cancer is becoming more common in Europe and North America. In the UK, around 8,750 people are diagnosed with it each year.

We do not know exactly what causes oesophageal cancer. But we know that certain things called risk factors can increase a person's chances of developing it. Having one or more risk factors does not mean you will definitely get oesophageal cancer. Equally, if you do not have any risk factors, it does not mean you won't get oesophageal cancer.



Long-term acid reflux

Oesophageal cancer is more common in people who have long-term acid reflux. This is when stomach acid flows back up into the oesophagus. It can happen in people with conditions such as gastro-oesophageal reflux disease (GORD).

Acid reflux can damage the lining of the oesophagus and can lead to a condition called **Barrett's oesophagus**. This is when abnormal cells develop in the lining of the lower oesophagus. It is not a cancer, but a small number of people (less than 1%) with Barrett's oesophagus may go on to develop cancer. It is known as a pre-cancerous condition.

We have more information about Barrett's oesophagus on our website.

Obesity

Being overweight may increase your risk of developing oesophageal cancer. This may be because long-term acid reflux is more common in people who are overweight.

Gender

Oesophageal cancer is more common in men than in women.

Age

The risk of developing oesophageal cancer increases as you get older. It is less common in people under 45.

Smoking

The longer a person smokes and the more tobacco they smoke, the more likely they are to develop oesophageal cancer. All types of smoking are harmful, but it is more damaging to smoke cigarettes than a pipe or cigars. You also have an increased risk of oesophageal cancer if you use betel quid (paan or pan). Smoking shisha may also increase your risk.

Alcohol

Drinking a lot of alcohol over a long period of time increases your risk of developing oesophageal cancer. People who drink alcohol and also smoke may have a greater risk. Your risk increases if you drink more than 14 units of alcohol a week.

Diet

Eating lots of red and processed meats (such as sausages, ham and burgers) may increase your risk of developing oesophageal cancer. Eating lots of fresh fruit and vegetables may help to reduce the risk.

Some evidence suggests that drinking very hot drinks may increase the risk of developing oesophageal cancer. This is because hot drinks may damage the lining of the oesophagus.

Previous cancer treatment

Radiotherapy to the chest area can increase your risk of developing oesophageal cancer. This is very rare.

Other rare medical conditions

- **Achalasia** is a condition where the muscle that controls the opening between the oesophagus and the stomach does not relax properly. People with achalasia have a higher risk of developing oesophageal cancer.
- **Tylosis** is a rare inherited skin condition. People with tylosis have a high risk of developing oesophageal cancer.

Oesophageal cancer is not usually caused by an inherited faulty gene. So it is unlikely that your children will develop oesophageal cancer if you have it.

Oesophageal cancer is not infectious and cannot be passed on to other people.

Signs and symptoms

The most common symptoms of oesophageal cancer include:

- difficulty swallowing – feeling that your food is sticking in your throat or chest
- food coming back up before reaching the stomach (regurgitation)
- being sick (vomiting)
- pain in your throat or in the middle of your chest when swallowing
- indigestion or heartburn that does not go away
- a cough
- a hoarse voice
- dull pain or discomfort behind the breastbone or in the back, for example between the shoulder blades
- weight loss.

These symptoms can be caused by other conditions, but you should always have them checked out by your doctor.

If you have symptoms that do not improve within a few weeks, it is important that your GP refers you to a specialist. They can arrange tests to find out what the problem is.





DIAGNOSING OESOPHAGEAL CANCER

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How oesophageal cancer is diagnosed

You usually start by seeing your GP, who will examine you. You may have blood tests to check your general health. If your GP is unsure what the problem is or thinks you may have cancer, they will refer you to a hospital for a test called an endoscopy (see below) and specialist advice and treatment. If a cancer is suspected, you should be seen at the hospital within two weeks.

At the hospital

Your first appointment at the hospital may be for an endoscopy. If the endoscopy shows that you might have cancer, you will then see a specialist. They will ask you about your general health and any previous medical problems. They will also examine you. You may have blood tests and a chest x-ray to check your general health. In some hospitals, you will be seen by a specialist nurse before seeing a doctor.

Endoscopy

The doctor or a specialist nurse will put a thin, flexible tube (endoscope) into your oesophagus. There is a tiny light and camera on the end of the tube. This helps the doctor or nurse to see any abnormal areas. If necessary, they can take a small sample of tissue (biopsy) to examine under a microscope. This can usually confirm whether there is a cancer. The biopsy is not painful.

You will usually have an endoscopy in the hospital outpatient department, but sometimes you will need to stay in hospital overnight. You will be asked not to eat or drink anything for at least four hours before the procedure. Your doctor or nurse will also give you instructions about any medicines you are taking.

When you have the endoscopy, you will be asked to lie on your side on a couch. A local anaesthetic may be sprayed on to the back of your throat. Or you may have a sedative to make you feel sleepy and reduce any discomfort. This is usually injected into a vein in your arm. Sometimes you have both an injection and the spray. The doctor or nurse passes the endoscope down the oesophagus to examine it.

An endoscopy can be uncomfortable, but it should not be painful. Tell your doctor if you have any chest pain during or after the procedure.

The local anaesthetic spray to the back of your throat can take an hour to wear off. You should not try to swallow anything during this time. You may need to stay in hospital until you are able to swallow and drink fluids safely again. After a few hours, the effect of the sedative will wear off and you will be able to go home. You should not drive for several hours after the test and should arrange for someone to travel home with you.

Some people have a sore throat afterwards. This is normal and should get better after a few days. If it doesn't, let your doctor at the hospital know.

'After suffering swallowing difficulties for 15 months or so, I finally went to my GP. The results of the biopsies confirmed that it was oesophageal cancer. The recommended treatment was to be more tests and then chemotherapy, followed by an operation.'

David

Further tests

If the first tests suggest that you have oesophageal cancer, your specialist may want to do some further tests. This is to confirm the diagnosis and see whether the cancer has spread to any other part of the body. This process is called staging (see pages 28 to 29). It may take a few weeks. The results of these tests will help you and your doctor decide on the best treatment.

You may have more tests even if no cancer was found, or if the results were unclear. Sometimes these tests may be repeated during and after treatment to check on your progress.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture (see page 22), and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30 to 90 minutes. You should be able to go home after the scan.



Having a CT scan

Endoscopic ultrasound (EUS)

This is like an endoscopy (see pages 20 to 21), but the tip of the endoscope has an ultrasound probe on it.

Ultrasound uses sound waves to build up a picture of the area. It allows the doctors to get a deeper view of the wall of the oesophagus and surrounding areas. This may give them a better idea of the size and depth of the tumour. They may also be able to see whether nearby lymph nodes are enlarged.

A sample of tissue (a biopsy) can be taken to be examined under a microscope.

You may have a slightly stronger sedative than for a gastro-intestinal endoscopy. This is because an EUS may take longer and you need to lie very still during this test. If you are given a stronger sedative, it will take a little longer to recover.

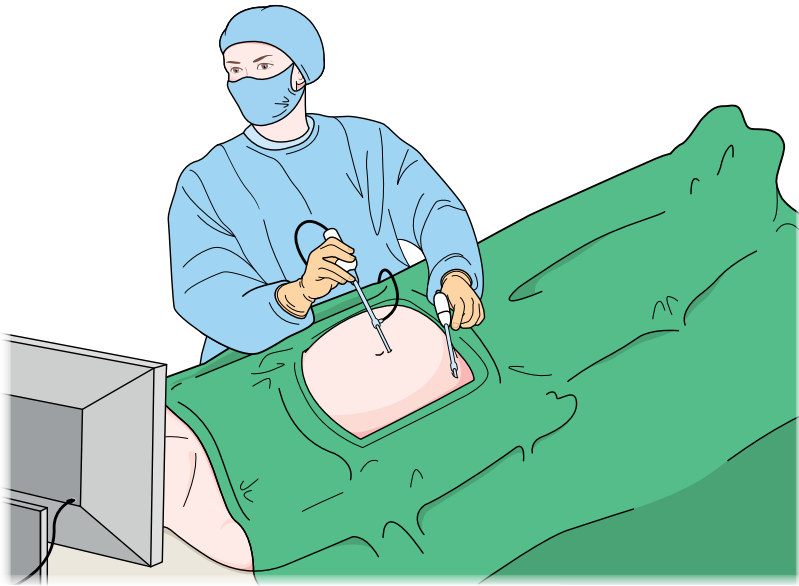
Laparoscopy

This is a small operation, which is done under a general anaesthetic. If your doctor has enough information from other tests, you may not need a laparoscopy. Your doctor will discuss the test with you if they think it will be helpful.

The surgeon makes a cut about 2cm long near the tummy button (navel). They then carefully insert a thin tube with a tiny video camera on the end (laparoscope) into your tummy (abdomen). The surgeon uses the laparoscope to look at the lining of your tummy and the organs nearby. The surgeon may take a biopsy. To do this, they will make another small cut and insert an instrument to take the sample.

When the effects of the anaesthetic have worn off, you will be able to get up. You sometimes need to stay in hospital overnight. You will have one or two stitches in your tummy where the cuts were made.

A laparoscopy



Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 121 to 127 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**. To find details about the cancer registry in your area, see page 123.

Types of oesophageal cancer

Knowing which type of oesophageal cancer you have helps your doctor to plan your treatment.

There are two main types of oesophageal cancer:

- **Squamous cell carcinoma** develops in the thin, flat cells of the mucosa (see page 10), which lines the oesophagus
- **Adenocarcinoma** develops from glandular cells and is often associated with Barrett's oesophagus (see page 13).

A cancer can develop anywhere along the length of the oesophagus. Cancers in the upper oesophagus are nearly always squamous cell cancers. Most cancers in the middle of the oesophagus are also squamous cell cancers. Most cancers in the lower oesophagus are adenocarcinomas. This includes those in the junction where the oesophagus joins the stomach.

Over 95 in 100 (95%) oesophageal cancers are squamous cell carcinomas or adenocarcinomas.

There are other, rarer types of oesophageal cancer. These include:

- poorly differentiated neuroendocrine cancer
- small cell cancer
- soft tissue sarcomas, such as gastro-intestinal stromal tumours (GISTs).

The tests and treatments for these rarer types of cancer are different from the ones we describe in this booklet.

Our cancer information specialists can give you more information. You can call them on **0808 808 00 00**.

Staging

The stage of a cancer describes its size and whether it has spread beyond the area where it started. Staging systems are constantly being updated to help doctors plan the best treatment and help give an idea of the likely outcome. This means they are becoming more detailed and complicated.

Your doctors will describe your cancer using either the TNM staging system or the number staging system.

TNM staging

This system gives precise information about the stage of the cancer.

T – Tumour

This describes 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 lymph nodes. The N may have an X or a number next to it. This gives extra information about the nodes that were examined.

If cancer cells have spread to the lymph nodes, the nodes are said to be positive.

M – Metastasis

This describes whether 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.

Number staging

Another system used to describe the stage of the cancer is the number staging system. Your doctor can explain your number staging to you and how the number stage relates to the TNM stage.



TREATING OESOPHAGEAL CANCER

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Treatment overview

The treatment you have will depend on several things. These include the type of oesophageal cancer you have, its stage, where it is in the oesophagus and your general health.

It is important you understand why your doctors have suggested a particular treatment for you. They will discuss the treatment options with you, and together you can decide on your treatment plan.

Oesophageal cancer can be treated with surgery (see pages 40 to 54), chemotherapy (pages 55 to 67) or radiotherapy (pages 68 to 75). The treatments can be used alone or in combination.

Treatment may be given to cure the cancer. If a cure is not possible, the aim of treatment is to control the cancer and relieve symptoms.

When planning treatment, the doctors consider the oesophagus in three sections: upper, middle and lower.

Diet before treatment

You should see a hospital dietitian soon after you have been diagnosed. They will give you advice to help you prepare for the treatment ahead.

Many people with oesophageal cancer have difficulty eating. You may be losing weight. While you are waiting for treatment, it is important to eat as well as possible, using food supplements if needed. Your GP can prescribe these for you. Increasing the amount of calories you have will help to slow down weight loss. This is very important to help you to cope better with the treatment and maintain your physical fitness and strength.

If you are finding swallowing difficult, you may have to change the consistency of your food. Small, soft, regular meals are better than two or three larger meals each day. Foods like soup, ice cream, jelly and custard are easy to swallow. You can also use a food blender to blend foods you like, to help you eat more. If you are not able to swallow anything, you should tell the hospital straight away.

Treating early-stage oesophageal cancer

The treatment you are offered will depend on your individual situation.

You may be offered a type of surgery which is done through an endoscope if you have a very early-stage oesophageal cancer. This is where the tumour is very small and has not spread to the surrounding area. The surgery may be an endoscopic mucosal resection (EMR) (see page 46) or an endoscopic sub-mucosal dissection (ESD).

An EMR may also be offered if there are very abnormal cell changes to the lining of oesophagus (precancerous changes).

Your doctor will discuss with you which type of operation might be best for you.

If you have an early-stage oesophageal cancer that has not spread and you are well enough, you may be offered surgery to remove the cancer. You may be offered chemotherapy before the operation. You may have the chemotherapy together with a course of radiotherapy. This is called chemoradiotherapy.

For some people, the tumour may have spread nearby (locally advanced) or may be too large to do an operation. In this case, you may be offered a course of chemoradiotherapy. This can sometimes shrink the tumour enough for it to be removed in an operation.

If you are not able to have surgery for any other reason, you may be offered chemoradiotherapy instead.

If you are not fit enough to have chemotherapy, you might be offered radiotherapy alone.

Treating advanced-stage oesophageal cancer

Advanced-stage oesophageal cancer is when the cancer has spread to lymph nodes and other parts of the body, such as the liver, lungs or stomach. If you have advanced oesophageal cancer, or are not fit enough to have other treatments, you may be offered chemotherapy. This can help control the cancer and improve symptoms. Some people may be given radiotherapy to help relieve symptoms such as pain.

In some situations, you might be offered treatment as part of a research trial (see pages 79 to 80). Your doctor will be able to tell you if there are any trials you might be able to enter.

If you have swallowing difficulties, putting a tube into the oesophagus to keep it open can help. This is called stenting. Other treatments that may be used to help with this are stretching the oesophagus and laser treatment. These are described on pages 95 to 96.

How treatment is planned (MDT)

In most hospitals, a team of specialists called a multidisciplinary team (MDT) will meet to plan your treatment.

This multidisciplinary team will include:

- **a surgeon** who specialises in oesophageal cancer
- **a medical oncologist**, who is a doctor who specialises in chemotherapy
- **a clinical oncologist**, who is a doctor who specialises in radiotherapy and chemotherapy
- **a gastroenterologist**, who is a doctor who specialises in diagnosing and treating problems with the digestive system
- **a nurse specialist** who can provide information and support
- **radiologists**, who help to analyse x-rays and scans
- **pathologists**, who are doctors who specialise in studying tissue samples and cells
- **a dietitian** who can advise you if you have problems with eating, drinking or weight loss.

It may also include other healthcare professionals, such as a palliative care doctor or nurse (who specialises in symptom control), a physiotherapist, an occupational therapist, and a psychologist or counsellor.

The MDT will take a number of factors into account when advising you on the best course of action, including your general health, the type and size of the tumour, and whether it has begun to spread.

The benefits and disadvantages of treatment

You may be frightened of having cancer treatments because of their side effects. Although treatments for oesophageal cancer can cause side effects, you will be given help to control and manage these.

Treatment can be given for different reasons. The potential benefits will vary depending on your individual situation. Your doctor can tell you if the main aim of treatment is to try to cure the cancer, to control the cancer for a time, or to reduce symptoms and improve your quality of life. They can also tell you the possible side effects of each treatment and whether these are likely to be temporary or permanent.

Treatment decisions

If different treatments are equally effective for the type and stage of cancer you have, your doctors may offer you a choice. Some people find it hard to make a decision. If you are asked to make a decision, make sure you have enough information about the different options. Ask about what is involved in each treatment and about possible side effects before you decide what is right for you.

Remember to ask questions about anything you do not understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages with your doctor or specialist nurse, or you could call our cancer support specialists on **0808 808 00 00**.

Our booklet **Making treatment decisions** has more information to help you make difficult decisions. You can order it at **be.macmillan.org.uk** or by calling our cancer support specialists.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

'Write down any questions you need answers to, so you don't forget to ask the doctor. Make sure you understand all you are told and if not, ask again!'

Christine, Online Community member



Surgery

If the cancer is at an early stage, you may have surgery with the aim of curing the cancer. There are different types of operations used to treat oesophageal cancer. The operation you have will depend on the size and position of the tumour. You may need to stay in hospital for a few weeks for some types of surgery.

Your doctor will talk with you about the best type of surgery for your situation. It is important to discuss the operation with your doctor before it happens. It may help to make a list of any questions you want to ask.

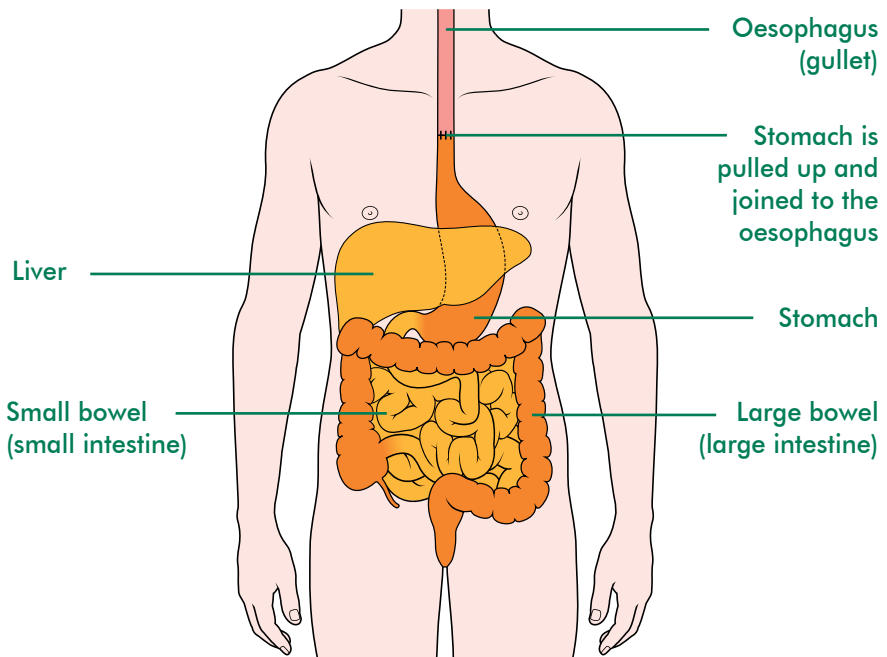
Types of surgery

There are two main types of operation:

Oesophagectomy

The part of the oesophagus containing the cancer is removed. This operation is used when the cancer is only in the oesophagus. The stomach is then pulled up and joined to the bottom of the oesophagus.

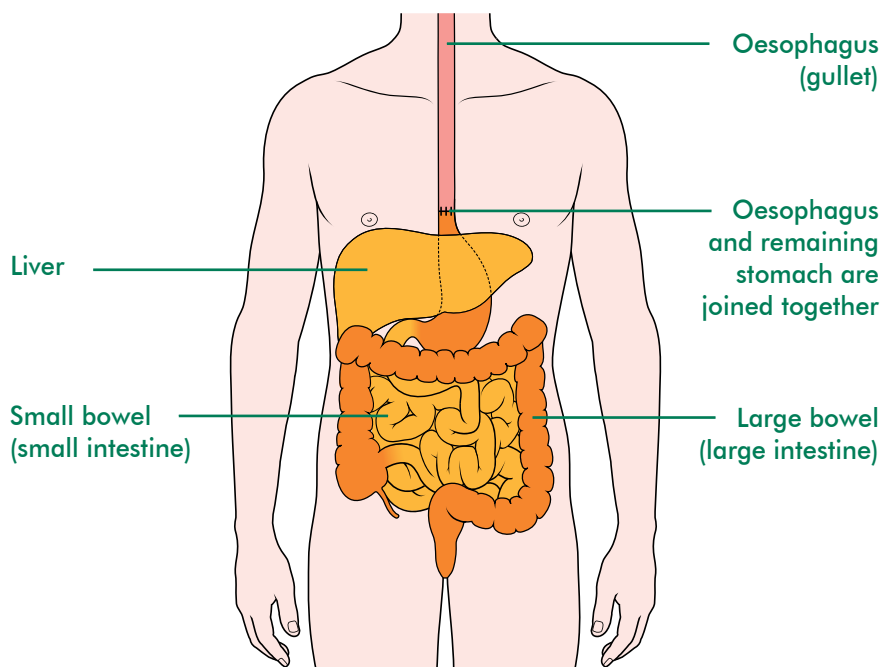
An oesophagectomy



Oesophago-gastrectomy

If the cancer is in the lower part of the oesophagus, or if it has grown into the stomach, you will need to have the top of your stomach removed, together with the affected part of the oesophagus. The oesophagus and remaining stomach are then joined together.

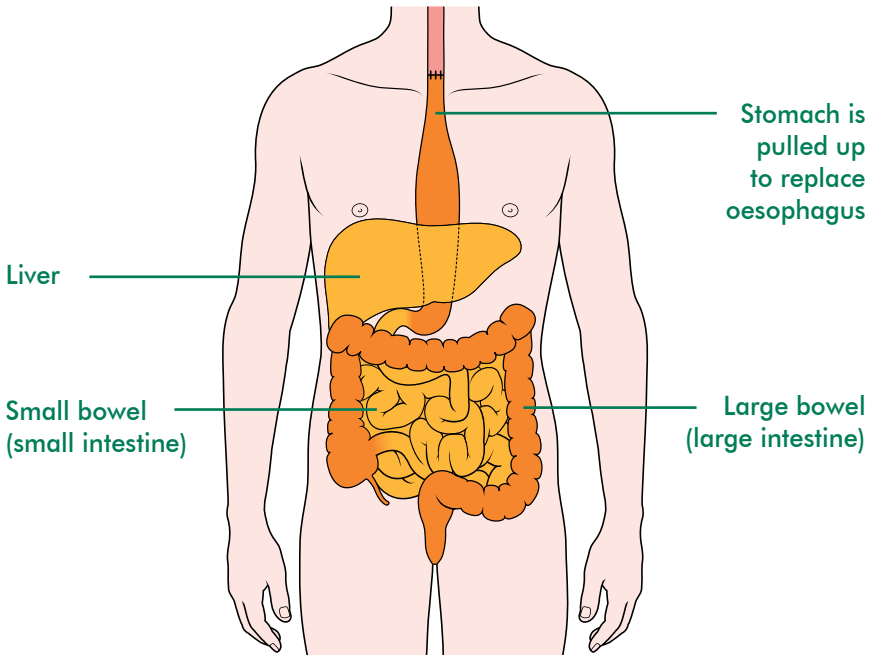
An oesophago-gastrectomy



Total oesophagectomy

Rarely, the whole oesophagus needs to be removed. This is called a total oesophagectomy. Your stomach will be pulled up into your neck to replace the removed oesophagus.

A total oesophagectomy



Surgery to the lymph nodes

During your operation, the surgeon will remove a small area of healthy tissue around the oesophagus. They will also remove some of the nearby lymph nodes. This is called a lymphadenectomy. A pathologist will look at the lymph nodes under a microscope to see if they contain cancer cells. Removing the lymph nodes helps reduce the risk of the cancer coming back. It also helps the doctors find out the stage of your cancer (see pages 28 to 29).

How the operation is done

Depending on where the cancer is in the oesophagus, your surgeon will use one of these two main techniques:

- **Trans-thoracic oesophagectomy** – Cuts are made in the tummy (abdomen) and chest so that the affected part of the oesophagus can be removed. This is also called a two-stage oesophagectomy. Sometimes a third cut is made in the neck, which is called a three-stage oesophagectomy.
- **Trans-hiatal oesophagectomy** – Cuts are made in the tummy and neck to remove the affected part of the oesophagus.

After these operations, your stomach will be higher than it was before. It will be above, instead of below, the sheet of muscle (diaphragm) that divides the chest from the tummy. Your stomach will also be smaller. This is because it has been shaped into a tube to replace the oesophagus, which has been removed. This will affect your eating and drinking (see pages 85 to 87).

Sometimes it is not possible to join your stomach to the remaining part of the oesophagus. In this case, a section of your large bowel (colon) will be used to replace part of the oesophagus. Your doctors will explain this in more detail if they think this type of surgery may be used.

Sometimes, during the operation, the surgeon finds that the tumour cannot be removed. This may be because the tumour has spread or gone through the wall of the oesophagus to nearby parts of the body.

Possible risks of surgery

Your surgeon will explain the possible risks with this type of surgery before you have your operation. You will have tests to check your heart and lungs, to make sure you are fit enough to have it.

Some of the possible complications of this type of operation may be life-threatening. You may need to stay in the intensive care unit for a period of time after surgery (see page 49). Other risks include getting a chest infection or pneumonia, bleeding, or problems with the wound healing properly. It can take a while to recover from the operation. It is important to discuss these risks with your surgeon before agreeing to have the surgery.

Keyhole surgery

Some people may be able to have part or all of their operation by keyhole surgery (also called minimally invasive surgery). Your surgeon can tell you whether this is suitable for you. In this operation, small cuts are used rather than larger cuts. The surgeon uses a special instrument called a thoracoscope to look through and work inside the chest. A laparoscope is used for the inside of the tummy.

During the operation, the surgeon may decide that keyhole surgery is not suitable. They will then do standard surgery instead. Keyhole surgery should only be done by experienced and specially-trained surgical teams.

Endoscopic mucosal resection (EMR)

Very early-stage oesophageal cancers that are just in the inner lining of the oesophagus (the mucosa), can sometimes be treated using endoscopic mucosal resection (EMR). For this procedure, you have an endoscopy (see pages 20 to 21) so the doctor can see the abnormal area clearly.

The cancer is then raised from the muscle layer of the oesophagus so it can be removed. The doctor either injects fluid into the layer of cells below the cancer or uses gentle suction to do this. Your specialist will explain how they do EMR.

The most common side effects of EMR are bleeding and narrowing of the oesophagus. There is a very small risk of a tear in the wall of the oesophagus (called a perforation).

Your doctor may recommend further treatment after EMR, to destroy any cancer cells that might be left. They may use a treatment called radiofrequency ablation (RFA) in this situation – see page 77.

Before your operation

You will have certain tests to prepare you for surgery. These tests are usually done a few days or weeks before the operation, at a pre-assessment clinic.

You will usually be admitted to hospital on the morning of your operation. A member of the surgical team and a specialist nurse will discuss the operation with you. You will also meet the doctor who will give you the anaesthetic (the anaesthetist). It is a good idea to talk to your nurse or doctor about any concerns or ask any questions that you have about the operation.

If you have been having problems with eating and have lost weight, you may be given extra help and support with your diet. This is to help prepare you for the operation.

You will be given special elastic stockings called TED stockings to wear during and after the operation. This is to prevent blood clots forming in your legs.

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of chest problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice. You may also find it helpful to read our booklet **Giving up smoking**. You can order it at **be.macmillan.org.uk**

Enhanced recovery programme

Some hospitals have an enhanced recovery programme. This aims to reduce your time in hospital and speed up your recovery. It involves you more in your own care. You will be given information about diet and exercise before surgery. Arrangements will also be made for when you need to go home. Your doctor will tell you if an enhanced recovery programme is suitable for you and if it is available.



After your operation

Most people will be nursed in the intensive care unit or a high-dependency unit for a few days after their operation. You may be kept asleep for longer on a machine called a ventilator, to help your heart and lungs recover after the operation. If you are woken up earlier, a ventilator may be used to help you to breathe for a few hours.

Pain

You will probably have some pain and discomfort after the operation. Your doctor or nurse will explain how your pain will be controlled.

You may have painkillers into the space around your spinal cord. You have these through a very fine tube placed into your back during surgery. The tube connects to a pump, which gives you a continuous dose of painkillers. This is called an epidural.

Another way to control pain is through patient-controlled analgesia (PCA). A painkiller is given through a pump that allows you to give yourself an extra dose of pain relief if you need to.

It is important to tell the staff caring for you if you are still in pain. Mild discomfort or pain in your chest can last for several weeks, so they will give you some painkillers to take home with you.

Drips and drains

You may have several drips and drains attached to your body for a few days after surgery.

These include:

- **An intravenous (IV) drip** – This is used to give you fluids until you are able to eat and drink again.
- **A nasogastric (NG) tube** – This is a fine tube that passes down your nose into your stomach or small intestine. It allows any fluids to be removed, so that you do not feel sick. This allows the area operated on to heal.
- **Chest drains** – These are tubes put into your chest during the operation. They drain away any fluid that may have collected around the lungs. The fluid drains into a bottle. Tell your doctor or nurse if the drains are uncomfortable.
- **Abdominal drain** – A tube may be put into your tummy (abdomen) to help drain off fluid and prevent swelling.
- **Urinary catheter** – Sometimes a tube is put into your bladder to drain your urine into a collecting bag. This will be removed as soon as you are up and walking about.

You will be encouraged to get out of bed and move around as soon as possible. This helps reduce the risk of complications after surgery, such as blood clots and infections. Your nurses will help you manage your drips and drains while walking.

You will be taught deep breathing exercises to help keep your lungs clear. You will also be taught regular leg movements to prevent blood clots forming in your legs. A physiotherapist or nurse will help you with this.

A physiotherapist will help you clear your lungs of any fluid that may have built up as a result of your operation.

Eating and drinking

You will only be allowed sips of liquid until your doctor is happy that the join in the oesophagus is healing. You will usually be able to drink normally after a few days.

You may be scared to swallow at first. You may also have a bad taste in your mouth. Mouthwashes can help with this. Your surgeon may suggest you have a special type of x-ray to make sure the join between the oesophagus and stomach has fully healed.

Some surgeons will put a small feeding tube (a jejunostomy tube) directly into the small bowel during surgery. You can be fed through this while you are not able to eat or drink. The tube is put into the middle part of the small bowel (the jejunum), through a small cut made in the tummy. The feeding tube may be used when you are at home, for you to have feeds overnight. This might be part of an enhanced recovery programme. When you are eating well enough to no longer need extra support, the tube will be removed. This is usually after four to six weeks.

We have more information about feeding tubes in the section of our website (macmillan.org.uk) about eating problems.

'It was a slow process of learning to eat again. I had a feeding tube for a month after the operation, and my diet was anything soft with calories to start with. I am allowed as many calories as I can swallow – quite a change from always watching my weight!'

Lizzy

Gradually, you will be able to eat and drink small amounts normally again. Your dietitian will give you support and advice. You will probably lose quite a lot of weight in the first few weeks after your operation. Try not to worry about this too much. The weight loss is normal and should slow down once you begin eating well (see pages 85 to 87). Losing weight does not mean that your cancer has come back.

You may also have some diarrhoea for a while. This can usually be controlled with medicine if it continues.

When you can eat more, you will be advised to eat slowly and chew food well or have a soft diet. You will need to eat smaller meals more often, about six to eight times a day. A dietitian will support and advise you on any changes you need to make. They will tell you how to increase your calorie intake, if you need to gain weight.

We have a booklet called **The building-up diet** for people who may be finding it difficult to maintain their weight. It has suggestions on how to get more energy and protein in your diet. You can order it at **be.macmillan.org.uk** or by calling our cancer support specialists on **0808 808 00 00**.

Dumping syndrome

The stomach normally stores food and releases it into the bowel in a gradual and controlled way. After an operation to remove part of your oesophagus, food can travel more quickly through the digestive system. This can cause symptoms known as dumping syndrome.

There are two types: early dumping syndrome and late dumping syndrome. Late dumping syndrome is more common after an oesophagectomy (see page 41).

Early dumping syndrome

This can happen within 30 minutes of eating a meal. You may feel dizzy and faint, and your heart may beat faster. These symptoms may last for about 10 to 15 minutes. Some people also have tummy cramps and diarrhoea. The symptoms happen when food enters your bowel more quickly. This draws fluid into the bowel from the surrounding organs and tissues, causing your blood pressure to drop.

Many people find that early dumping syndrome gets better on its own in time. Symptoms can get less severe and happen less often after a few months.

Late dumping syndrome

This usually happens a few hours after meals, or when a meal has been missed. You may suddenly feel faint, sick and shaky. The problem is caused by low blood sugar. If you feel the symptoms coming on, taking glucose tablets may help you feel better.

For most people, the symptoms of dumping syndrome become less severe and happen less often in time. Tell your doctor or dietitian if it continues to be a problem. If your symptoms continue or are severe, your doctor may prescribe a medicine to help, such as octreotide.

You can help prevent or reduce the chances of having early or late dumping syndrome if you:

- eat slowly
- eat small, frequent, dry meals
- drink fluids between meals, rather than at mealtimes
- eat foods that are high in protein (such as fish, meat and eggs) and high in starchy carbohydrates (such as pasta, rice, bread and potatoes)
- avoid eating foods that are high in added sugar, such as sugary cereals
- rest for 15 to 30 minutes straight after meals.

We have more information on our website about nutritional support and diet problems after surgery.

Going home

Before you leave hospital, you will be given an appointment to attend an outpatient clinic for your post-operative check-up. The appointment is a good time to discuss any problems you may have after your operation. If you have any problems before this appointment, you can contact your hospital doctor, specialist nurse or ward nurse for advice.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs disrupt the way cancer cells grow and divide but they also affect normal cells.

When chemotherapy is given

Chemotherapy is often given before an operation to remove an oesophageal cancer. This is sometimes called neoadjuvant chemotherapy. It can shrink the tumour, making it easier to remove. If there is a possibility that the cancer has spread somewhere else in the body, having chemotherapy before surgery may increase the chance of controlling it.

Chemotherapy can sometimes be given after surgery, to reduce the chances of the cancer coming back. It works by destroying any cancer cells that might be left behind after the operation. This is called adjuvant chemotherapy.

You may also have chemotherapy if the cancer has spread to other parts of the body. It aims to shrink the tumour to improve symptoms and quality of life. This is called palliative chemotherapy. In some people, the chemotherapy will help. For others, the chemotherapy will not shrink the cancer and they will have the side effects of treatment with little benefit.

It is important to discuss the benefits and side effects of chemotherapy with your cancer specialist. If you have cancer that has spread, and you decide that you do not want to have chemotherapy, your doctor can prescribe other medicines to help control your symptoms.

The drugs used

The chemotherapy drugs most commonly used are:

- fluorouracil (5FU) or capecitabine (Xeloda®)
- cisplatin, oxaliplatin (Eloxatin®) or sometimes carboplatin
- paclitaxel (Taxol®) or docetaxel
- epirubicin.

Other chemotherapy drugs may also be used.

Usually you have a combination of two or more drugs. The drugs you have will depend on whether you have an adenocarcinoma or a squamous cell carcinoma (see page 27). Common combinations are:

- cisplatin with either 5FU or capecitabine (a tablet form of 5FU)
- carboplatin and paclitaxel.

Other common combinations used to treat adenocarcinoma of the oesophagus are:

- the ECF regimen (epirubicin, cisplatin and 5FU)
- the EOX regimen (epirubicin, oxaliplatin and capecitabine).

Having chemotherapy



How chemotherapy is given

You usually have chemotherapy treatment in a chemotherapy day unit. It is given by injection into a vein (intravenously).

There are videos about chemotherapy on our website. They show people having treatment. You can watch these videos at **[macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)**

Chemotherapy can be given through:

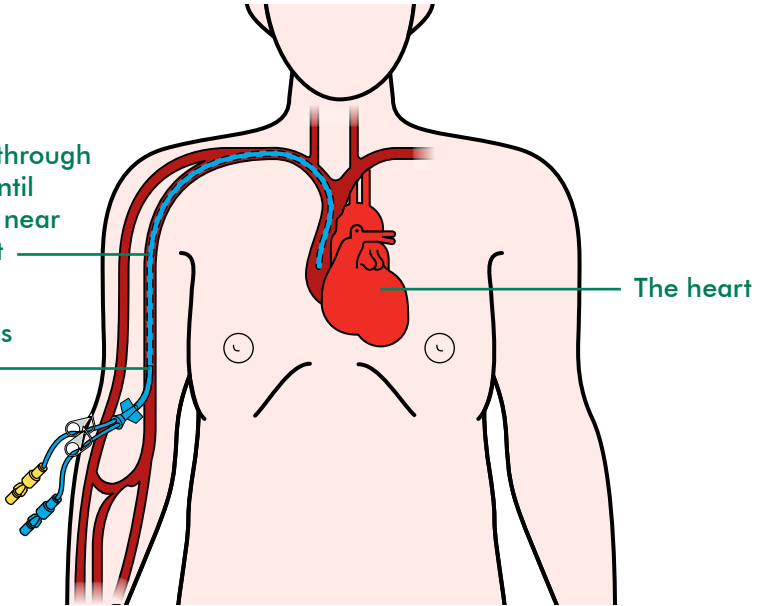
- a cannula – a short, thin tube put into a vein in the back of your hand
- a PICC line – a thin tube put into a vein near the bend of your elbow (see diagram opposite)
- a central line – a plastic tube put into a large vein in your chest (see diagram opposite).

Sometimes chemotherapy is given as tablets. If you have tablets, your nurse will explain how to take them at home.

A PICC line

The line is threaded through the vein until the end is near your heart

Line comes out here

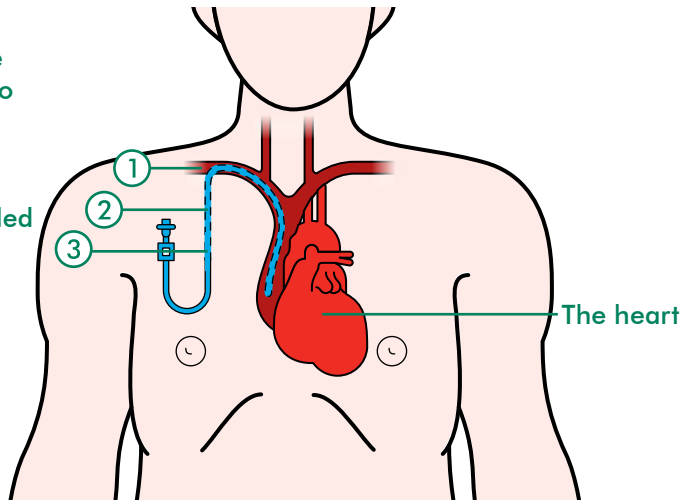


A central line

① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here



Chemotherapy is usually given as a session of treatment. After each session, you will usually have a rest period of a few weeks. This allows your body to recover from the side effects. The treatment and the rest period make up a cycle of treatment. Your specialist will discuss this with you and tell you how many cycles you are likely to have.

Sometimes chemotherapy can be given to you continuously for several days. It is given through a small, portable pump that is attached to a central or PICC line. The pump controls how much of the drug is given. You can go home with the pump. This means you can spend less time in hospital.

We have more information about chemotherapy on our website and in our booklet **Understanding chemotherapy**. You can order this from **be.macmillan.org.uk** or call our support line on **0808 808 00 00**.

Possible side effects

We explain the most common side effects of this treatment here. We also include some less common side effects.

You may get some of the side effects we mention, but you are unlikely to get all of them. If you are also having treatment with other cancer drugs, you may have some side effects that we haven't listed here. Always tell your doctor, nurse or pharmacist about any side effects you have.

Your doctor can give you drugs to help control some side effects. It is important to take them exactly as your nurse or pharmacist explains. This means they will be more likely to work for you. Your nurse will give you advice about managing your side effects. After your treatment is over, most side effects start to improve.

Risk of infection

Chemotherapy can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F) or over 38°C (100.4F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection, such as:
 - feeling shivery
 - a sore throat
 - a cough
 - diarrhoea
 - needing to pass urine often.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more chemotherapy. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you can't explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.



**'When I ran out of energy,
I had to stop and recharge.
I had to plan my days – if I
was doing anything one day,
the next day had to be a day
of rest.'**

Lizzy

Feeling sick

You may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

'I had a few side effects, nausea and sickness mainly, which didn't help with eating and drinking to keep my strength up. But there were good days.'

Lizzy

Loss of appetite

This treatment can affect your appetite. Don't worry if you don't eat much for a day or two after treatment. But if your appetite does not come back after a few days, tell your nurse or dietitian. They will give you advice. They may give you food or drink supplements.

Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Changes to your taste

You may get a bitter or metal taste in your mouth. Sucking sugar-free sweets may help with this. Some foods may taste bad or have no taste. Try different foods to find out what tastes best to you. Taste changes usually get better after treatment finishes. Your nurse can give you more advice.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect).

If you do experience hair loss, your hair should start to grow back within about 3 to 6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Numb or tingling hands or feet (peripheral neuropathy)

Some chemotherapy drugs can affect the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but for some people they may never go away. Talk to your doctor if you are worried about this.

Diarrhoea

Some chemotherapy drugs can cause diarrhoea. This often starts several days after treatment. If you are taking chemotherapy tablets or capsules at home, it is important to let your doctor or nurse know if you have diarrhoea, as your treatment may need to be interrupted. They can prescribe medicine to help. Try to drink at least two litres (three and a half pints) of fluids every day. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

Sore hands and feet

This is sometimes known as palmar-plantar, or hand-foot, syndrome. It is usually temporary and improves when the treatment is finished. Your doctor may prescribe creams or a vitamin called pyridoxine (vitamin B6), which some people find helpful. It can also help to keep your hands and feet cool, and to avoid tight-fitting clothing, such as tight socks, shoes and gloves.

Blood clot risk

Cancer and treatment with chemotherapy can increase the risk of a blood clot. Symptoms of a blood clot include:

- pain, redness or swelling in a leg or arm
- breathlessness
- chest pain.

If you have any of these symptoms, contact a doctor straight away.

A blood clot is serious, but can be treated with drugs that thin the blood. Your doctor or nurse can give you more information.

Changes in the way the heart works

Some chemotherapy drugs can affect the way the heart works. You may have tests to see how well your heart is working before, during and sometimes after treatment. Your specialist can explain more about this.

If you have pain or tightness in your chest, feel breathless or notice changes to your heartbeat at any time during or after treatment, tell a doctor straight away. These symptoms can be caused by other conditions, but it is important to get them checked by a doctor.

We have more information about the side effects above and how to cope with them on our website and in our booklets

Understanding chemotherapy and **Side effects of cancer treatment**. There are also videos about many side effects at macmillan.org.uk/cancerinformationvideos

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy can be given in two ways:

- **External beam radiotherapy** – This aims high-energy x-rays at the affected area using a large machine. This is the most common way of giving radiotherapy for oesophageal cancer.
- **Internal radiotherapy** – A radioactive material is put into, or close by, the tumour. It is also known as brachytherapy (see pages 74 to 75). It is not often used to treat oesophageal cancer.

External beam radiotherapy

External beam radiotherapy is usually given in combination with chemotherapy to treat oesophageal cancer. This is known as chemoradiotherapy (see page 76) and may sometimes be given instead of surgery with the aim of curing the cancer. It is also sometimes given before an operation to shrink the tumour.

If the cancer is more advanced, you may have radiotherapy on its own to shrink the tumour and help control symptoms.

You have the treatment in the hospital radiotherapy department. Each treatment takes 10 to 15 minutes. It is usually given every day from Monday to Friday, with a rest at the weekend. Your doctor will discuss your treatment and the possible side effects with you.



Having radiotherapy

Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it is as effective as possible. It is planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you will be asked to have a CT scan, which takes x-rays of the area to be treated (see page 22).

You may need some small marks made on your skin. These help the radiographer (who gives you your treatment) position you accurately and show where the rays will be directed. These marks must stay on throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are very small, and will only be done with your permission. It may be a little uncomfortable while they are done.

Your doctor or nurse specialist can tell you more about what will happen in your radiotherapy planning session. We also have information about this in our booklet

Understanding radiotherapy.

Treatment sessions

At the beginning of each session, the radiographer will position you carefully on the couch and make sure you are comfortable. You will be alone in the room during your treatment. But you can talk to the radiographer, who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Possible side effects of external radiotherapy

Radiotherapy can cause general side effects, such as feeling sick (nausea) and tiredness (fatigue). It is also likely to make the inside of your oesophagus inflamed. This can cause temporary soreness when you swallow. These side effects can be mild or more troublesome. This depends on the dose and length of your radiotherapy treatment.

It is not unusual to feel worse before you start to feel better. Some people can find this a very difficult time. You may feel low or even depressed for a while. Your clinical oncologist can advise you about what to expect and what can help with the side effects.

These side effects should disappear gradually once your course of treatment is over, but it is important to tell your doctor if they continue.

Radiotherapy does not make you radioactive and it is perfectly safe for you to be with other people, including children, throughout your treatment.

Skin

During your radiotherapy, you will need to take extra care of the skin in the area that is being treated. This is because the area being treated sometimes gets dry and irritated, or the treatment may cause a skin reaction.

Before your treatment starts, the staff in the radiotherapy department will give you advice on how to look after your skin.

We have more information on our website about managing skin reactions.

If you swim, you will need to ask your specialist team whether you should avoid swimming until after your treatment has finished. They will also tell you when you can go swimming again after your treatment.

Sore throat and difficulty swallowing

Radiotherapy can make your throat very sore towards the end of the treatment. You may not be able to swallow properly for a while. The soreness can last for a few weeks after radiotherapy ends. Your doctor will prescribe medicines to help. The pain may affect your ability to eat enough, so you may need to see a dietitian. They can talk to you about how you can supplement your diet with high-calorie, nutritious drinks.

Some people have a feeding tube put into their stomach before the radiotherapy starts. The tube may either be put into the nose and passed down the oesophagus (called a nasogastric tube) or through the skin (called a gastrostomy tube). Liquid food can be given through the tube. Your doctor can talk to you about whether you might need this. They can give you information about the type of tube to be used. You will also have support from a dietitian. A speech and language therapist can help you with any swallowing difficulties you may have.

We have more information about feeding tubes and how they are used in the section of our website on eating problems.

Dry mouth

Sometimes, radiotherapy to the upper end of the oesophagus may reduce the amount of saliva (spit) your salivary glands produce. This effect may be temporary but sometimes can be permanent. It may make your mouth dry, which can make eating difficult.

We have more information about how to cope with a dry mouth on our website.

Loss of appetite

During radiotherapy, you may not feel like eating very much. But it is important to try to maintain your weight. Your dietitian can advise on ways to build up your diet and maintain or gain weight. We have information on how build up your diet on our website and in our booklet **The building-up diet**. You can order our booklets at **be.macmillan.org.uk** or by calling **0808 808 00 00**.

Feeling sick

Radiotherapy and chemotherapy can cause you to feel sick (nausea) and be sick (vomit). This can usually be treated well with anti-sickness drugs (anti-emetics). Your doctor can prescribe these. We have more information about coping with nausea on our website.

Hair loss

When radiotherapy is used to treat oesophageal cancer, men may find that some of the hair on their chest falls out.

Tiredness (fatigue)

Radiotherapy can cause tiredness. In some people, this continues for several months after treatment. During your treatment, you will need to rest more than usual, especially if you have to travel a long way each day. But it is good to do gentle exercise, such as walking, when you feel able to. Once your treatment is over, try to gradually increase your activity and balance rest periods with gentle exercise. This will help build up your energy levels.

Internal radiotherapy (brachytherapy)

To give brachytherapy, a radioactive source is placed into the cancer. This gives a high dose of radiotherapy to the tumour. As the radiation does not travel far, your surrounding organs will be much less affected. The source is left there for a set period of time. The time will depend on the amount of radiation that is being used. It can range from 10 to 30 minutes. This means that treatment can be focused directly at the tumour, over a short time. It is used instead of a course of external radiation, which is given to a wider area over a longer period of time. Brachytherapy is usually used when the cancer is advanced, to help control symptoms.

There are two ways of giving internal radiotherapy. It can be given:

- through an endoscope – this is a tube placed through your mouth and down your throat until the tip is in your stomach (see pages 20 to 21)
- through a nasogastric (NG) tube – this is a thin, flexible, plastic tube that goes up your nose, down the back of your throat and into your stomach.

Your doctor can explain more about how this treatment is given.

Internal radiotherapy causes temporary soreness when you swallow. This may develop a few days after treatment and last for a few days. Your doctor will recommend liquid medicines to help.

You may need to stay in hospital for a few days for your treatment. Your doctor will be able to tell you when you can have visitors.

Children or pregnant women should not visit you while you are having this type of radiotherapy. The hospital staff will talk to you about this.

We have more information about radiotherapy and its side effects in our booklet **Understanding radiotherapy** and on our website. You might also find it helpful to watch our video at [macmillan.org.uk/radiotherapy](https://www.macmillan.org.uk/radiotherapy)



Chemoradiotherapy

Chemotherapy and radiotherapy can be given at the same time. This is called chemoradiotherapy or chemoradiation. Certain chemotherapy drugs make the cancer more sensitive to radiotherapy. These include fluorouracil (5FU), cisplatin and docetaxel.

Chemoradiotherapy is used for squamous cell carcinoma and adenocarcinoma.

Chemoradiotherapy can be used instead of surgery. You may also have it before an operation to shrink the tumour. You may be given chemoradiotherapy as part of a clinical trial (see pages 79 to 80).

Giving chemotherapy and radiotherapy together can make the side effects of treatment worse. It also may not be suitable for everyone, for example people who have other health problems. Your doctor or specialist nurse will give you more information about chemoradiotherapy and the possible side effects.

Other treatments

Radiofrequency ablation (RFA)

RFA uses heat to destroy cancer cells. It is used to treat pre-cancerous changes to the cells in the oesophagus (Barrett's oesophagus – see page 13). It is sometimes used after endoscopic mucosal resection (EMR) (see page 46). RFA uses a probe called an electrode to apply an electrical current (radiofrequency) to the tumour. The electrical current heats the cells to high temperatures, which destroys (ablates) them. The area that has been treated gradually shrinks and becomes scar tissue. Some people may need to be treated more than once.

We have more information about radiofrequency ablation on our website (macmillan.org.uk).

Targeted therapy

Targeted therapies are sometimes called biological therapies. They interfere with the way cancer cells grow.

Trastuzumab (Herceptin®) is a type of targeted therapy called a monoclonal antibody. It works by attaching to a receptor called HER2 on the surface of certain cancer cells. This stops the cancer cells dividing and growing. Herceptin is only suitable for people with oesophageal cancers that have high levels of HER2 receptors.

Herceptin is mainly used to treat breast cancer. But it can also be used to treat some advanced oesophageal cancers, found in the area where the oesophagus joins the stomach (the gastro-oesophageal junction – see pages 10 to 11). If a person with advanced oesophageal cancer has not had any treatment before, they may be offered trastuzumab in combination with chemotherapy.

Other targeted therapy drugs may also be used to treat oesophageal cancer. We have more information about targeted therapies on our website. You may be asked to take part in a clinical trial (see opposite).



Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Current research

Your cancer specialist will be able to tell you about research trials that are in progress. Our website **macmillan.org.uk** has links to databases with details of research trials.



'I am now on the road to recovery, doing physiotherapy – callisthenics, etc – to rebuild my strength and stamina.'

David



AFTER TREATMENT

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Follow-up

After your treatment has finished, you will have regular check-ups and possibly scans if you have any new symptoms. You will probably have check-ups for several years, but you will have them less often as time goes on.

Many people find that they get anxious before their appointments. This is natural, and it may help to get support during this time from family, friends or one of the organisations listed on pages 121 to 127.

These appointments are a good opportunity to discuss with your doctor any concerns or problems you may have. If you notice any new symptoms between check-ups, or are worried about anything, contact your doctor or specialist nurse for advice. You can be seen earlier if you need to be.

Our booklet **Life after cancer treatment** has some useful advice on how to keep healthy and adjust to life after cancer treatment is over. You can order a copy at be.macmillan.org.uk or by calling us on **0808 808 00 00**.

'It has been a tough time. I am suffering side effects and have lost confidence. But even now, my Macmillan nurse is always there at my check-ups to see how I am doing and ask how the girls are.'

Mohamed

Changes to eating after treatment

It can take a few months to recover from treatment, and up to a year to adjust to the changes in your digestive system.

After surgery, you can start to eat as soon as your doctor says you can. This can be up to a week after your operation. You will usually start with a soft diet while you are still in hospital. You will normally be advised to stay on this for a few weeks. This will help keep your oesophagus open as it heals.

Gradually, you will be able to start eating solid foods again. It will help if there are no large lumps of food. Try to chew everything well. You may worry about eating solid foods at first. This should get easier as you become more used to a normal diet again.

Your dietitian will talk to you about your diet and give you advice to help you recover from treatment. If you have any worries or concerns after you have gone home, contact the dietitian or your specialist nurse for advice.

Indigestion

You may have indigestion. If you do, the following tips can help:

- Try to eat slowly.
- Try not to lie down for about 30 to 60 minutes after eating.
- Do not lie completely flat.
- Use extra pillows or raise the head of your bed.

Feeling full quickly

If you have had part of your stomach removed, you will feel full very quickly. This is because your stomach is smaller. Try to:

- eat smaller meals more often, rather than large ones
- chew food well and eat slowly.

Diarrhoea

Diarrhoea is fairly common after any operation for oesophageal cancer. It might help to:

- cut out certain foods that are high in fibre, such as fruit, vegetables and cereals
- have less milk in your diet.

Changes after radiotherapy or stenting

If you have had radiotherapy, or have had a tube (stent) fitted in your oesophagus (see page 95), these tips may help:

- Keep to a softer diet.
- Avoid foods that may block the tube or that you may find difficult to swallow, such as raw fruit and vegetables, tough meat or crusty bread.
- If you use any powdered food supplement, such as Complan[®], make sure it is very thoroughly mixed.
- Eat slowly and have plenty to drink during and after meals.

These changes may make you feel embarrassed and frustrated. You may find it hard to eat with others. Your speech and language therapist and dietitian will help you learn to cope with any changes.

Try talking with your family and friends about how you are feeling. You can also talk to your specialist nurse. They will understand what you are going through. They may be able to help or put you in touch with other people who have experienced similar difficulties.

The Oesophageal Patients Association (see page 122) can give you recipes and ideas to make your meals more interesting.

We also have some booklets that you may find helpful – **Eating problems and cancer**, **The building-up diet** and **Recipes for people affected by cancer**. You can order these at be.macmillan.org.uk or by calling us on **0808 808 00 00**.

If you have difficulties with swallowing again after treatment, it does not necessarily mean that the cancer is coming back. This can be caused by the treatment itself. Contact your hospital doctor or nurse for advice.

'I went to see a dietitian, which helped a lot. She gave me lots of simple but invaluable tips. She showed me how to get lots of good calories into a small amount of food. I finally started to put on some weight and got more energy from the food I was eating.'

Lizzy

Beginning to recover

Treatment can be very hard on your body. It may be some time before you are feeling fit and well again. Some people have treatment side effects that gradually improve over time, while others may have ongoing effects.

You may have a range of other more general side effects, such as trouble sleeping or feeling weaker and more tired than usual.

Maintaining a healthy lifestyle can help your body recover more quickly and return to normal. It may help to prevent the cancer from returning. It will also help to reduce the risk of illnesses such as heart disease and strokes.

Positive lifestyle changes

Some people want to make changes to their lifestyle after cancer. You might choose to make just a few changes, or completely change the way you live. It does not have to be very difficult or expensive.

Living a healthy lifestyle can sometimes seem like a lot of hard work and as if you will be denying yourself all of the pleasures in life. However, it is about making small, achievable changes to the way you live that will improve your health and well-being.

Your healthy lifestyle will be individual to you. What is right for you may not be right for someone else. A healthy lifestyle can include having a well-balanced diet, getting some exercise, reducing stress and being involved in your healthcare.

You will need to think about any side effects of treatment when planning changes to your diet and exercise. Do not try to do too much too soon.

If you are thinking about making some major changes to your lifestyle, it is a good idea to discuss your plans with your doctor or specialist nurse.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Stopping smoking has many health benefits and reduces your risk of other diseases, such as heart disease and strokes. Our booklet **Giving up smoking** has more information and tips to help you quit. You can order it at **be.macmillan.org.uk**

Get physically active

Exercise does not have to be strenuous. You can start gently and build up the amount of physical activity you do. Whatever your age or physical health, there will be some kind of exercise you could try. Some examples are walking, hiking, cycling and swimming. Activities like gardening, dancing and playing sport are also good to try. We can send you more information about exercise after cancer treatment.

Reduce stress

There are lots of ways to reduce the stress in your life. You could make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate or pray, or to start a new hobby or an evening class. You may find it helpful to write a journal or online blog.

Get involved in your healthcare

Being involved in your healthcare means taking your medications as directed, always going for follow-up appointments and being aware of symptoms of a possible recurrence. We can send you more information about getting involved in your healthcare.

Getting help and support

Different people can help you during and after treatment.

Practical help

If you need help at home during or after treatment, a nurse or hospital social worker may be able to arrange this. If you have children, the social worker may arrange help with childcare. We have information about organising childcare that you may find helpful.

A social worker or benefits adviser can tell you about benefits you may be able to claim and can help with other costs.

If you need help with a wound, the district nurses can visit you at home to help with this.

Emotional help

It is common to have different and sometimes difficult feelings after cancer treatment (see pages 100 to 103). But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family and friends often helps.

If you think you may be depressed, or feel helpless or anxious a lot of the time, talk to your cancer specialist or nurse. They can refer you to a psychologist or counsellor who specialises in emotional problems that can affect people with cancer. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and tell you about services in your area.

Complementary therapies

Some people find that using complementary therapies helps them to relax or cope with treatment side effects. Some hospitals or support groups may offer therapies such as relaxation or aromatherapy.

Our booklet **Cancer and complementary therapies** has more information about the different types of complementary therapy. You can order it at **be.macmillan.org.uk** or by calling us on **0808 808 00 00**.

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. You can call us or visit our website (**macmillan.org.uk/inyourarea**) for information about support groups in the UK. Your clinical nurse specialist may also be able to tell you if there are any local support groups that might be helpful.

Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experience, ask questions and get advice based on your cancer experience.

Our Online Community (**macmillan.org.uk/community**) is a social networking site where you can talk to people on our forums, write blogs, make friends and join support groups.

'I wrote a sort of diary and marked down what I could do and how long it would take me. I wrote down positive achievements, and new things tried and accomplished. I began to see that I was improving month on month, sometimes even week on week.'

Lizzy



DIFFICULTY SWALLOWING

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Advanced cancer

If the cancer has spread from where it first started in the oesophagus, it is called advanced cancer. The cancer may be advanced when it is first diagnosed, or it may have come back after treatment. This is called a recurrent cancer.

Often, the biggest problem people with advanced oesophageal cancer have is difficulty swallowing.

If you have advanced oesophageal cancer, you may still be offered chemotherapy (see pages 55 to 67), radiotherapy (see pages 68 to 75) and targeted therapies (see pages 77 to 78). These treatments will not be able to cure the cancer, but may be able to shrink the tumour. This may control it for a time and improve symptoms, such as difficulty swallowing, and quality of life.

Treating swallowing problems

If you find swallowing difficult because the cancer is blocking your oesophagus, there is a lot that can be done to help make it easier.

Your doctor may also suggest one or more of the following treatments. The treatments may need to be repeated.

Stenting

A wire-mesh tube (called a stent) can be put into the oesophagus using an endoscope. The procedure is similar to an endoscopy (see pages 20 to 21). The tube helps keep the oesophagus open and should help you eat more comfortably.

It is important to be careful with your diet to make sure the tube does not become blocked. Drinking fizzy drinks after eating can help keep the tube clean and clear.

You can get more information on diet from the Oesophageal Patients Association (see page 122).

If stenting is not possible, other treatments you might have are stretching (dilatation) or laser treatment.

Stretching (dilatation)

The doctor stretches the oesophagus using a tube. This is to make more space for food and fluid to pass through. Stretching is often done after radiotherapy or surgery.

It is a simple and quick procedure, and may be done under a general or local anaesthetic. You may need to have the procedure more than once.

Laser treatment

Laser treatment can sometimes be used to remove enough of the tumour to allow food to pass down the oesophagus. The doctor will burn away some of the tumour using a powerful beam of light. The procedure is similar to having an endoscopy (see pages 20 to 21). It takes about 15 minutes.

Laser treatment is usually given under sedation with a local anaesthetic. You can go home the same day. Sometimes you may have a general anaesthetic.

It may take two or three sessions of laser treatment to clear your oesophagus enough for you to be able to swallow normally. You may need further treatments after four to six weeks. You are unlikely to feel any pain after the procedure. But there may be some temporary swelling, so you may find swallowing more difficult at first. You may also have some discomfort in your tummy (abdomen). If you have any pain, tell your doctor or nurse.

A treatment called argon plasma coagulation (APC) can be used to make swallowing more comfortable. Your specialist can tell you more about this and whether it might help.





YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them.

Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups**. You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**.

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**



Relationships

The experience of cancer may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have an effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who have been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse. Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other.

Our booklet **Cancer, you and your partner** has more information that may help. We also have booklets for men and women about sexuality and cancer. You can order our booklets at **be.macmillan.org.uk** or by calling us on **0808 808 00 00**.

Family and friends

Your family and friends may not always understand if you are not feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

Our booklet **Talking to children and teenagers when an adult has cancer** includes discussion about sensitive topics. There's also a video on our website that may help, at **macmillan.org.uk/talkingtochildren**



'I am unable to return to work yet and live on Employment Support Allowance (ESA). The Macmillan Welfare Rights Officer has been really helpful.'

David

WORK AND FINANCIAL SUPPORT

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Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation as it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also more information at macmillan.org.uk/work

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled. There are two different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don't qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called Universal Credit. This benefit is for people below retirement age who are out of work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least three months and expect them to last for at least nine months. PIP replaces an older benefit called Disability Living Allowance (DLA) for adults.

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least six months. If you are terminally ill, and may be expected to live for less than six months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than six months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We've just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 125).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at macmillan.org.uk/gettingfinancialhelp useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 124 to 125.

Our booklets **Insurance** and **Travel and cancer** may also be helpful.





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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support**. There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**. If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00**

to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Oesophageal cancer support organisations

Barrett's Oesophagus Campaign

Tel 020 8346 0171

Email [info@](mailto:info@barrettscampaign.uk)

barrettscampaign.uk

www.barrettscampaign.uk

An organisation set up to promote research into Barrett's oesophagus. Provides support and advice to Barrett's oesophagus sufferers and their relatives and friends. Raises awareness of the condition to encourage early detection.

CORE

Tel 020 7486 0341

Email info@corecharity.org.uk

www.corecharity.org.uk

Core is a charity committed to fighting all digestive conditions. Funds vital research. Provides expert information for people affected, their families and their carers. Promotes awareness and discussion about digestive health.

Ochre

Tel 0141 942 7739

Email [committee@](mailto:committee@ochrecharity.org.uk)

ochrecharity.org.uk

www.ochrecharity.org.uk

A national cancer charity set up to help promote awareness of oesophageal cancer. It encourages research into the causes of oesophageal cancer, develops information about the condition and offers advice and support to patients and their families.

The Oesophageal Patients Association

Tel 0121 704 9860

Email enquiries@opa.org.uk
www.opa.org.uk

An organisation made up of people who have had, or still have, oesophageal cancer. Publishes useful information about the condition and offers advice and support to their families.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151

Email

info@cancerblackcare.org.uk
www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus

Northern Ireland

Helpline 0800 783 3339

(Mon to Fri, 9am to 1pm)

Email

nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531

(Mon to Fri, 9am to 5pm)

Email

info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801

Email

enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Tenovus

Helpline 0808 808 1010

(Daily, 8am to 8pm)

Email

info@tenovuscancercare.org.uk

www.tenovuscancercare.org.uk

org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration Service

Tel 020 7654 8000

Email enquiries@phe.gov.uk

www.ncr.nhs.uk

Tel (Ireland) 021 4318 014

www.ncri.ie (Ireland)

Scottish Cancer Registry

Tel 013 1275 7777

Email nss.csd@nhs.net

[www.isdscotland.org/](http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry)

Health-Topics/Cancer/

Scottish-Cancer-Registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500

Email

general.enquiries@wales.nhs.uk

www.wcisuwales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028

Email nicr@qub.ac.uk

www.qub.ac.uk/nicr

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300

Email bacp@bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955

Email info@ukcp.org.uk

www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Equipment and advice on living with a disability

British Red Cross

Tel 0344 871 11 11

Textphone 020 7562 2050

Email information@redcross.org.uk

www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

Email enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

Helpline 0300 999 0004

(Tues to Thurs, 10am to 4pm)

Email helpline@dlf.org.uk

www.dlf.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674

(Mon, Tues, Wed and Fri, 9am to 5pm, Thurs, 10am to 5pm)

Textphone 028 9031 1092

**[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Department for Work and Pensions (DWP) Personal Independence Payment (PIP) Helpline

0345 850 3322

Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)

Carer's Allowance Unit
Tel 0345 608 4321

Textphone 0345 604 5312
(Mon to Thurs, 8.30am to 5pm,
Fri, 8.30am to 4.30pm)
www.gov.uk/browse/benefits

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Support for carers

Carers Trust

Tel 0300 772 9600

(Mon to Fri, 9am to 5pm)

Email info@carers.org

www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline

(England, Scotland, Wales)

0808 808 7777

(Mon to Fri, 10am to 4pm)

Helpline (Northern Ireland)

028 9043 9843

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

Support for older people

Age UK

Helpline 0800 678 1174

(Daily, 8am to 7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Advanced cancer and end-of-life care

Hospice UK

Tel 020 7520 8200

Email info@hospiceuk.org

www.hospiceuk.org

Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

Marie Curie

Helpline 0800 090 2309

(Mon to Fri, 8am to 6pm,
Sat, 11am to 5pm)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline 01962 712 690

Email [rosie@](mailto:rosie@naturaldeath.org.uk)

naturaldeath.org.uk

www.naturaldeath.org.uk

Offers independent advice on aspects of dying, funeral planning and bereavement.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.

YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for student input.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up-to-date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Mohan Hingorani, Clinical Oncologist; Professor Muntzer Mughal, Consultant Surgeon and Head of Upper Gastrointestinal Services at the University College Hospitals; Dr Ganesh Radhakrishna, Clinical Oncologist; Claire Sedgwick, Upper GI Clinical Nurse Specialist; and Dr Hamid Sheikh, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

British Medical Journal. BMJ Best Practice. Oesophageal cancer – step by step management. bestpractice.bmj.com/best-practice/monograph/1029/treatment/details.html. Last updated: Dec 20, 2016.

European Society for Medical Oncology (ESMO). Oesophageal cancer: ESMO Clinical Practice Guidelines 2016. esmo.org/guidelines/gastrointestinal-cancers/oesophageal-cancer

National Institute for Health and Care Excellence (NICE). [nice.org.uk/guidance/conditions-and-diseases/cancer/oesophageal-cancer](https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/oesophageal-cancer)

National Institute for Health and Care Excellence (NICE). Oesophageal cancer, interventional procedures. pathways.nice.org.uk/pathways/gastrointestinal-cancers#content=view-node%3Anodes-oesophagus

Uptodate. Epidemiology, pathobiology and clinical manifestations of oesophageal cancer. Last updated: Feb 10, 2017.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community

A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money

Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money

Big or small, every penny helps.
To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my: Visa / MasterCard
/ CAF Charity Card / Switch /
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Signature

Date / /

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- ☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

This booklet is about oesophageal cancer (cancer of the gullet). It is for anyone who is having tests for oesophageal cancer or has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of oesophageal cancer, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit **macmillan.org.uk/otherformats** or call our support line.

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