

# Understanding oesophageal cancer



# About this booklet

This booklet is about oesophageal cancer. 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 is treated. It also has information about looking after yourself and getting support. We hope this booklet helps you deal with some of the questions or feelings you may have.

This information is written for people who have already been diagnosed with oesophageal cancer. We have more information about possible causes, risk factors and symptoms of oesophageal cancer at [macmillan.org.uk/oesophageal-cancer](https://www.macmillan.org.uk/oesophageal-cancer)

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

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the [contents list](#) to help you.

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

At the [end of the booklet](#), there are details of other organisations that can help.

There is also [space to write down questions and notes](#) for your doctor or nurse.

### Quotes

In this booklet, we have included quotes from people who have had oesophageal cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://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](tel:08088080000), 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats, including audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit [macmillan.org.uk/otherformats](https://macmillan.org.uk/otherformats) or call [0808 808 00 00](tel:08088080000).

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## Contents

About oesophageal cancer	<b>5</b>
Planning treatment for oesophageal cancer	<b>15</b>
Treating oesophageal cancer	<b>33</b>
After treatment for oesophageal cancer	<b>89</b>
Coping with oesophageal cancer	<b>101</b>
Money and work	<b>109</b>
Further information	<b>115</b>



# About oesophageal cancer

The oesophagus	6
What is cancer?	8
The lymphatic system	10
Types of oesophageal cancer	12
Your data and the cancer registry	13

# The oesophagus

The oesophagus (gullet) is part of the digestive system, which is sometimes called the gastro-intestinal (GI) tract. The oesophagus is a muscular tube that goes from the mouth down through the chest to the stomach.

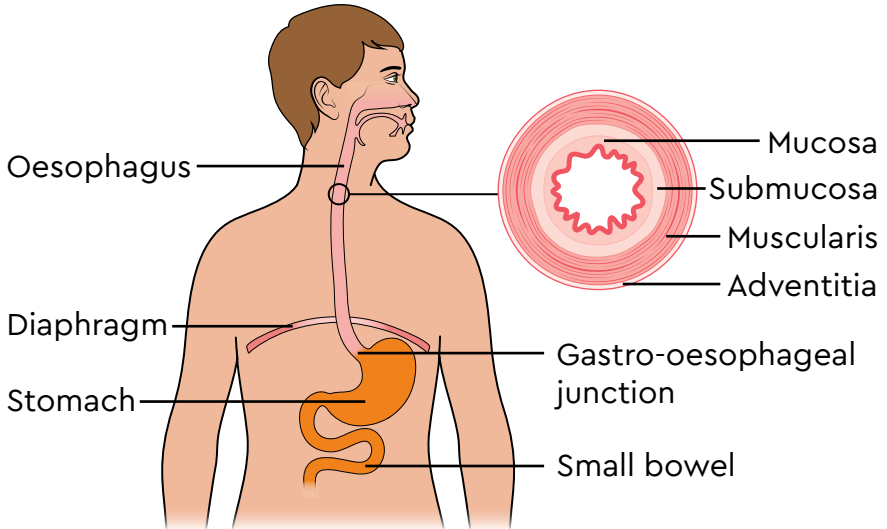
When you swallow food, the walls of the oesophagus squeeze together (contract). This moves the food down the oesophagus to the stomach. Most of the oesophagus is in the upper part of the chest above a layer of muscle called the diaphragm. The diaphragm sits below the lungs and helps you breathe.

The bottom part of the oesophagus is below the diaphragm. The place where the oesophagus joins the stomach is called the gastro-oesophageal junction (GOJ). There are [lymph nodes](#) close to the oesophagus.

The oesophagus has 4 layers:

- 1.** The mucosa is the inner layer. It is similar to the lining of the mouth. It is moist, to help food pass smoothly into the stomach.
- 2.** The submucosa contains glands that produce mucus (secretions). These keep the oesophagus moist.
- 3.** The muscularis is a layer of muscle. It pushes food down into the stomach.
- 4.** The adventitia is the outer layer. It attaches the oesophagus to nearby parts of the body.

## The oesophagus and surrounding organs





# What is cancer?

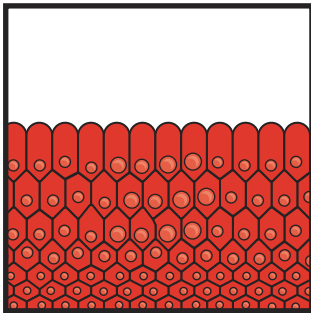
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

The instructions send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

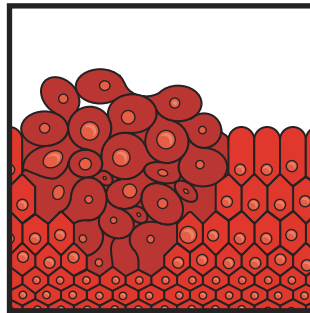
Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

## Abnormal cells forming a tumour



Normal cells



Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample to look for cancer cells. This is called a biopsy. Visit [macmillan.org.uk/biopsy](https://www.macmillan.org.uk/biopsy) to find out more.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body.

Cancer can spread from one place (the primary site) to another through the blood or [lymphatic system](#). When cancer spreads and grows somewhere else, it is called a secondary cancer or metastasis.

Cancer can start in any type of cell. This includes tissue or skin cells and cells that form the lining of the organs. It can also start in stem cells in the bone marrow. Stem cells make blood cells. Cancer that starts in stem cells does not cause a tumour. Instead, the stem cells create abnormal blood cells that behave differently from healthy blood cells.

# The lymphatic system

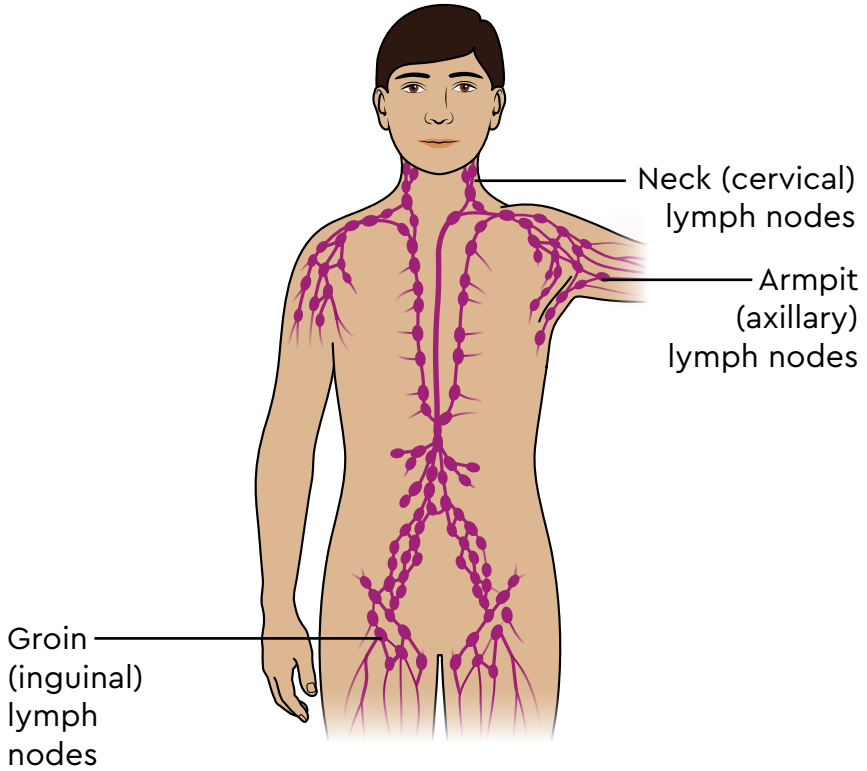
The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

## Lymph nodes and oesophageal cancer

Oesophageal cancer can sometimes spread to the lymph nodes close to the oesophagus. If you have surgery to remove oesophageal cancer, your surgeon will usually remove some lymph nodes to check for cancer cells.

## The lymphatic system



# Types of oesophageal cancer

Knowing the type of oesophageal cancer helps your cancer doctor plan your treatment.

There are 2 main types of oesophageal cancer:

- Squamous cell carcinoma develops in the thin, flat cells of the mucosa, which lines [the oesophagus](#).
- Adenocarcinoma develops from glandular cells and is often linked with Barrett's oesophagus. We have more information on our website at [macmillan.org.uk/barretts](http://macmillan.org.uk/barretts)

Cancer can develop anywhere in the oesophagus. Cancers in the upper or middle oesophagus are usually squamous cell cancers. Cancers in the lower oesophagus are usually adenocarcinomas. This includes cancers that develop in the gastro-oesophageal junction (GOJ). This is where the oesophagus joins the stomach.

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

- neuroendocrine cancers, including small cell cancer
- soft tissue sarcomas, such as gastro-intestinal stromal tumours (GISTs)
- oesophageal melanoma.

We have more information about these cancer types online at [macmillan.org.uk/cancer-types](http://macmillan.org.uk/cancer-types) The tests and treatments for these rarer types of oesophageal cancer are different from the ones we describe in this information. They are specific to each type of oesophageal cancer. Our cancer information specialists can give you more information. You can call them free on [0808 808 00 00](tel:08088080000).

# Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the [cancer registry](#) in your country to opt out.



# Planning treatment for oesophageal cancer

Finding out you have oesophageal cancer	16
Staging and grading	17
Treatment overview	20
How treatment is planned	26



# Finding out you have oesophageal cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. For example, you may have been diagnosed through screening. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with oesophageal cancer. We have more information about possible causes, risk factors and symptoms of oesophageal cancer at [macmillan.org.uk/oesophageal-cancer](https://www.macmillan.org.uk/oesophageal-cancer)

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment you will have. You might choose to spend some time reading about the cancer. Or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on [0808 808 00 00](tel:08088080000). They will be able to talk to you about what has happened and any worries you have.

# Staging and grading

Your cancer doctor needs information about the cancer to advise you on the best treatment for you. This includes the cancer:

- stage, which describes the cancer and whether it has spread
- [grade](#), which gives an idea of how quickly the cancer might grow and spread.

Your cancer doctor can use the results of your tests to try to identify the stage of the cancer. They will do this before your treatment is planned to help decide the best treatment for you. But they may not know the exact stage of the cancer until it has been removed with surgery.

Your healthcare team may describe the cancer using the:

- TNM staging system
- [number staging system](#).

## TNM staging system

The TNM staging system is the most commonly used staging system for oesophageal cancer.

T is for tumour, N is for nodes and M is for metastasis. It can help to review the information about [the oesophagus](#) when you read this to understand the staging:

- **T** describes how far the tumour has grown into the oesophageal wall.
- **N** describes whether the cancer has spread to the [lymph nodes](#).
- **M** describes whether the cancer has spread to other parts of the body (metastases).

### Tumour

- **T1** means the tumour is in the inner layer (mucosa or submucosa) of the oesophagus. It has not grown outside of it:
  - **T1a** – the tumour is only in the mucosa.
  - **T1b** – the tumour has grown into the submucosa.
- **T2** means the tumour has grown into the muscle layer (muscularis) of the oesophagus.
- **T3** means the tumour has grown into the outer layer (adventitia) of the oesophagus.
- **T4** means the tumour has grown through the outer layer of the oesophagus and into nearby structures, such as the diaphragm or a blood vessel. Doctors sometimes put the letter 'a' or 'b' after this. This gives extra detail about where the tumour is.

### Nodes

- **N0** means there are no cancer cells in any nearby lymph nodes.
- **N1** means there are cancer cells in 1 to 2 nearby lymph nodes.
- **N2** means there are cancer cells in 3 to 6 nearby lymph nodes.
- **N3** means there are cancer cells in 7 or more nearby lymph nodes.

### Metastases

- **M0** means the cancer has not spread to other parts of the body.
- **M1** means the cancer has spread to other parts of the body, such as the lungs or liver.

## Number staging system

Another system used to describe the stage of the cancer is the number staging system. This is a combination of the TNM stages. It uses the numbers 1 to 4.

Your cancer doctor can explain number staging to you and how the number stage relates to the [TNM stage](#). There are different number staging systems, depending on whether the cancer is staged before or after surgery.

## Grading

Grading compares cancer cells under the microscope with normal cells:

- **Grade 1** means the cancer cells look similar to normal cells, usually grow slowly and are less likely to spread. Grade 1 is also called low grade or well differentiated.
- **Grade 2** means the cancer cells look more abnormal and grow slightly faster. Grade 2 is also called moderate or intermediate grade.
- **Grade 3** means the cancer cells look very different from normal cells, may grow more quickly and are more likely to spread. Grade 3 is also called high grade or poorly differentiated.

# Treatment overview

Oesophageal cancer can be treated with:

- [surgery](#)
- [chemotherapy](#)
- [radiotherapy](#)
- chemotherapy and radiotherapy ([chemoradiation](#))
- [immunotherapy](#)
- [targeted therapy](#).

The treatments can be used alone or together.

Your treatment for oesophageal cancer depends on:

- the type of oesophageal cancer you have
- where the cancer is in [the oesophagus](#) – in the upper, middle or lower oesophagus
- the [stage](#) and [grade](#) of the cancer
- your general health and level of fitness
- your personal choices.

You might have treatment to cure the cancer. If a cure is not possible, the aim of treatment is to control the cancer and help with the symptoms.

Your cancer doctor and specialist nurse will explain the treatments they think are best for you. They can help you make decisions about your treatment. If you do not understand something, it is important to ask them.

## Preparing for treatment

After being diagnosed with oesophageal cancer, you may be referred to a dietitian. You may have difficulty eating and may have lost weight. A dietitian can:

- give you support and advice on eating well
- help you stop losing weight.

This helps you prepare for treatment.

It may help to try eating softer foods such as soup, or jelly and custard. These may be easier to swallow. You may also find that eating small, soft meals 4 to 5 times a day is easier than 2 to 3 bigger meals. Blending foods you like may help you eat more. If you cannot swallow anything, tell your healthcare team straight away.

## Prehabilitation

Research suggests that making certain lifestyle changes before your treatment can help you cope better with side effects and improve your recovery.

Your healthcare team may suggest things you can do to improve your general health before treatment. This is sometimes called prehabilitation.

It can help reduce the risk of complications such as blood clots. We have more information at [macmillan.org.uk/blood-clots](https://www.macmillan.org.uk/blood-clots)

It can also help you to recover faster.

Prehabilitation can include:

- [stopping smoking](#) (if you smoke) at least 2 weeks before surgery or radiotherapy
- maintaining or gaining weight if you have lost weight due to difficulty eating
- doing gentle physical activity, such as regular short walks
- drinking less alcohol – [Drinkaware](#) has more information.

We have more information on keeping active and eating well in our booklets [Healthy eating and cancer](#) and [Physical activity and cancer](#).

## Treating early-stage oesophageal cancer

The treatment you are offered will depend on your individual situation. The cancer multidisciplinary team will meet and discuss the [treatment options](#) available to you. Your doctor will talk to you more about these.

If you have very early-stage oesophageal cancer, the cancer may be removed using an endoscope. This is called an [endoscopic mucosal resection \(EMR\)](#) or an [endoscopic submucosal dissection \(ESD\)](#).

These can be offered if the tumour is very small and only affecting the inner layer of the oesophagus.

For most cancers that have not spread beyond the oesophagus and lymph nodes, doctors recommend combining different types of treatment. How these are combined depends on the type of oesophageal cancer.

Most people diagnosed with squamous cell cancer receive chemotherapy and radiotherapy. This is called [chemoradiation](#). Some people may not need any further treatment.

For others, chemoradiation or chemotherapy alone may be used to shrink a cancer so that it can then be removed with an operation.

If you are diagnosed with oesophageal adenocarcinoma, you will usually need an operation. Before this, you will generally be offered either chemoradiation or chemotherapy, which is given both before and after the operation.

The main operation used to treat adenocarcinoma and squamous cell carcinoma in the oesophagus is called an [oesophagectomy](#). This is where a surgeon removes all or part of your oesophagus. This is a major operation, and you need to be well enough to have it. If you are unable to have an oesophagectomy, you may be offered chemoradiation or radiotherapy instead.

If you have had surgery, a pathologist will examine the tissue removed under a microscope. A pathologist is a doctor who studies cells and body tissues. If cancer cells are found in the removed tissue you may be offered further treatment after your operation. This may be chemotherapy. Or if you had chemoradiation before surgery, you may be offered immunotherapy treatment.



## Treating oesophageal cancer that has spread

Advanced stage oesophageal cancer is when the cancer has spread beyond the oesophagus. This may be to lymph nodes or other parts of the body, such as the liver, lungs or stomach.

If you have advanced squamous cell oesophageal cancer, you may have [chemotherapy](#) or [immunotherapy](#). These may be given on their own, or together.

If you have advanced adenocarcinoma of the oesophagus, you may have chemotherapy or immunotherapy. Or you may have a combination of both.

[Targeted therapy drugs](#) are sometimes used to treat advanced oesophageal cancer. Your cancer doctor can talk to you more about this.

You might be offered treatment as part of a [research trial \(clinical trial\)](#). Your cancer doctor can tell you if there are any suitable trials for you to take part in.

If you have difficulty swallowing, you may have 1 of the following treatments:

- Your cancer doctor may suggest putting a wire mesh tube, called a stent, into the oesophagus. This can help keep it open, so food can pass through more easily.
- External radiotherapy or internal radiotherapy (brachytherapy) can be used to help with swallowing difficulties.
- Laser therapy may be used to help with swallowing difficulties.
- You might have a treatment to help stretch the oesophagus.
- Your cancer doctor may recommend you have a feeding tube to make sure you are getting enough food. We have more information on feeding tubes and nutritional support at [macmillan.org.uk/tube-feeding](https://www.macmillan.org.uk/tube-feeding)

# How treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

## Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT reviews national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- a surgeon who specialises in stomach and gastrointestinal cancers
- a medical oncologist – a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer
- a clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer
- a gastroenterologist – a doctor who treats problems with the digestive system
- a clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment

- a dietitian – someone who gives information and advice about food and food supplements
- a radiologist – a doctor who looks at scans and x-rays to diagnose problems
- a pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

It may also include other healthcare professionals, including:

- a palliative care doctor or nurse – someone who helps with symptom control
- a physiotherapist – someone who gives advice about exercise and mobility
- an occupational therapist – someone who gives information, support and aids to help people with tasks such as washing and dressing
- a psychologist or counsellor – someone who can talk with you, and help you understand your feelings and find ways of coping with them.



## Talking about your treatment plan

After the MDT meeting, you will usually meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan.

It can help to write down your questions before you meet with them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your cancer doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than 1 meeting with your doctor or nurse to talk about your treatment plan.

## Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

### Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when 2 treatments work equally well.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away.

You could write a list of benefits and disadvantages for each treatment. When choosing a treatment, you may want to think about:

- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

Your doctor or nurse may give you printed information or show you videos about your treatment options. They may also show you web-based tools (decision-making aids) to help you make your decision.

We have more information in our booklet [Making treatment decisions](#).

## Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on [talking about your treatment plan](#). You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have so they can give you the best advice.

## Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about. We have more information about getting a second opinion at [macmillan.org.uk/second-opinion](http://macmillan.org.uk/second-opinion)





# Treating oesophageal cancer

Surgery	34
Chemotherapy	53
Radiotherapy	68
Targeted therapy and immunotherapy	82
Clinical trials – research	85

# Surgery

Surgery for oesophageal cancer is done by specialist surgeons. It is not available in all hospitals, so you may need to travel to a hospital further away to have the operation.

## Oesophagectomy

This is the main operation used to treat oesophageal cancer. In this operation, the part of the oesophagus containing the cancer is removed. The part of the oesophagus that is removed depends on the size and position of the cancer inside the oesophagus.

The surgeon removes the affected part of the oesophagus and the top of the stomach if the cancer:

- is in the lower part of the oesophagus
- has grown into the stomach.

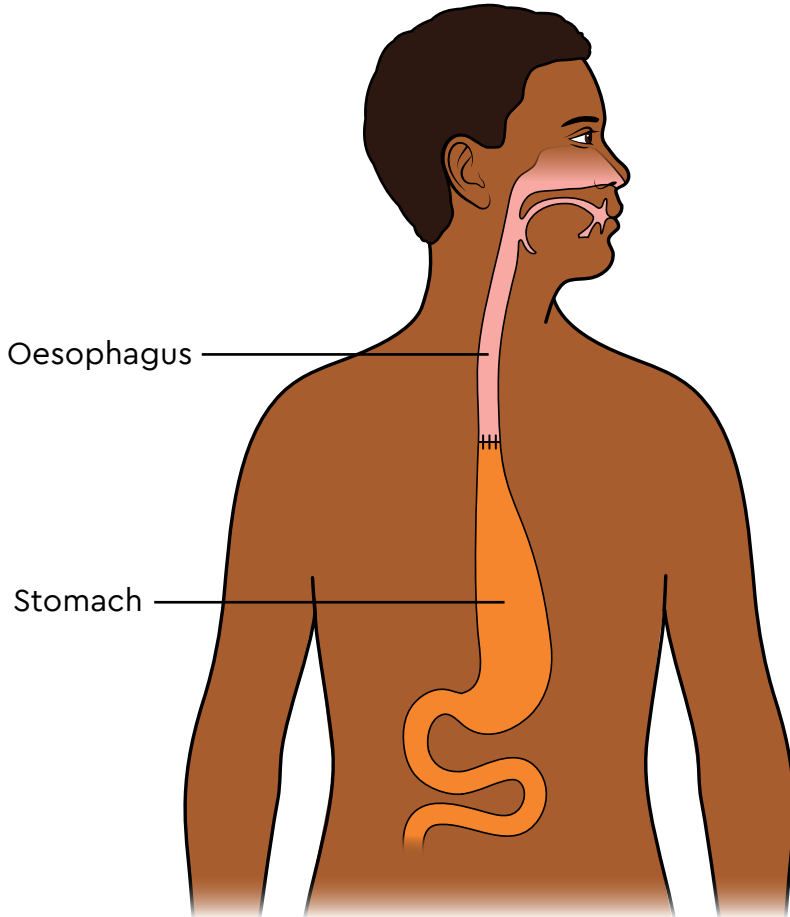
The surgeon then joins together the remaining parts of the oesophagus and stomach. This forms a tube that becomes the new oesophagus.

If the cancer is in the upper or middle part of the oesophagus, the surgeon removes this part of the oesophagus. They then pull up the stomach and join it to the remaining part of the oesophagus.

You will usually need to stay in hospital for about 2 weeks after surgery to the oesophagus. Some people may stay longer.

Your cancer doctor will talk with you about the operation. It is important to discuss the operation with them before it happens. It may help to make a list of questions you want to ask.

## Oesophagectomy



## Surgery to the lymph nodes

During the oesophagectomy, the surgeon removes a small area of healthy tissue around the oesophagus. This is called a margin. They also remove some of the nearby lymph nodes within the margin. This is called a lymphadenectomy.

A pathologist is a doctor who looks at cells or body tissue under a microscope to diagnose cancer. They look at the lymph nodes under a microscope to check if there are any cancer cells.

Removing the lymph nodes helps reduce the risk of the cancer coming back. It also helps the doctors know more about the [stage of the cancer](#).

## Having an oesophagectomy

Depending on where the cancer is in the oesophagus, there are different types of surgery. The 2 main ways a surgeon can do your operation are a trans-thoracic or a trans-hiatal oesophagectomy. But some people may have [keyhole surgery](#).

### Trans-thoracic oesophagectomy

The surgeon makes cuts in the tummy (abdomen) and chest to remove the part of the oesophagus that contains the cancer. This is also called a 2-stage oesophagectomy. Sometimes they also make a cut in the neck, which is called a 3-stage oesophagectomy.

## Trans-hiatal oesophagectomy

This type of oesophagectomy is not used very often. The surgeon makes cuts in the tummy and neck to remove the part of the oesophagus that contains the cancer.

After surgery to the oesophagus, the stomach will be in a higher position in the body than it was before. It will be above, instead of below, the sheet of muscle (diaphragm) that divides the chest from the tummy. The stomach will also be smaller. This is because the surgeon has shaped it into a tube to replace the part of the oesophagus they removed. This will affect [how much you can eat and drink](#).

Sometimes, it is not possible to join the stomach to the remaining part of the oesophagus. In this case, the surgeon uses a part of the large bowel (colon) to replace the part of the oesophagus they removed. Your cancer doctor will explain this in more detail if they think they might use this type of surgery.

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. If this happens, your cancer doctor will talk to you about other treatment options.

### Keyhole surgery (minimally invasive surgery)

The surgeon does this operation through a few small cuts in the tummy (abdomen), rather than 1 large opening. It is sometimes called laparoscopic surgery. The surgeon puts fine tubes with a camera and light on the end through the cuts. This lets them see and work inside the body. Depending on the part of the oesophagus they need to reach, they might work in different areas of the body. A thoracoscopy looks inside the chest, and a laparoscopy looks inside the tummy.

You may be able to have part, or all, of your operation by keyhole surgery. Your surgeon can tell you whether this is suitable for you.

During the operation, the surgeon may decide 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.

Surgeons sometimes use robotic surgery to treat oesophageal cancer. The surgeon uses controls to move robotic arms that hold the surgical instruments. Having robotic surgery can reduce side effects for some people and may mean they spend less time in hospital.

## Possible risks of surgery

Your surgeon will explain the possible risks of oesophagectomy before you have the operation. You will have tests to check your heart and lungs, to make sure you are well enough to have it.

Some of the possible complications of surgery to the oesophagus may be life-threatening. You will usually have a short stay in the intensive care unit after surgery so you can be carefully monitored. Possible risks include:

- a leak in the join between the oesophagus and stomach
- a chest infection or pneumonia
- bleeding
- problems with the wound healing.

It is important to have the information you need about any possible risks before the operation. If you have questions, you can talk to your surgeon or specialist nurse.

After this type of operation, you will be in hospital for a few weeks. At first it may feel like you are improving quite quickly. But it may take a few months before you recover and can go back to your normal activities.



## Before your operation

Before your operation, you will have tests to make sure you are well enough. These are usually done a few weeks before surgery at a pre-operative assessment clinic. They include tests on the heart and lungs.

Your surgeon and a specialist nurse will talk to you about the operation. You may meet the doctor who gives you the anaesthetic (anaesthetist) when you are at a clinic. Or you may meet when you go into hospital for the operation.

If you think you might need help when you go home after your operation, tell your specialist nurse as soon as possible. For example, tell them if you might need help because you live alone or are a carer for someone else. Your healthcare team can help organise support before you go home.

You usually go into hospital on the morning of your operation. Or you may go in the night before.

The nurses give you special elastic stockings (TED stockings) to wear during and after the operation. These help prevent blood clots in your legs.

Before surgery, it is important to make sure you have all the information you need. The operation can be complex, so you may want to ask questions. Talk to your surgeon or specialist nurse if there is anything you do not understand.

## Enhanced recovery programme

Many hospitals now have enhanced recovery programmes. This aims to reduce your time in hospital and speed up your recovery. It also involves you more in your own care. For example, you will get information about exercises you can do to help you get fitter before surgery. You will also get information about exercises to do after your operation.

It also makes sure any arrangements needed for your return home are organised in advance.

Your cancer doctor will tell you if an enhanced recovery programme is suitable for you.



## After your operation

You will probably be cared for in the intensive care unit, or a high-dependency unit, for a few days after your operation. You may be kept asleep for a longer period of time after your operation. Your breathing will be supported using a machine called a ventilator. This is 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. You will probably feel quite tired, and may not remember much about the first day or 2 after your operation.

### Drips and drains

You may have some drips and drains attached to your body for a few days after surgery. These include the following:

- A central venous catheter – this is called a CVC or central line. It is a thin, flexible tube that is put into a large vein in the neck, upper chest or groin. It can stay in place for up to a week. It is used to give you fluids and medicines until you can eat and drink again. It can also be used to take blood samples without a needle.
- A nasogastric tube – this is a fine tube that goes up the nose and down into the stomach or small intestine. It drains fluid, so you do not feel sick.
- Chest drains – these are tubes put into the chest during the operation. They drain away any air or fluid that may have collected around the lungs. The fluid drains into a bottle. If it is uncomfortable, tell your cancer doctor or a nurse.
- A feeding tube – this is called a jejunostomy. It is a thin, flexible tube that goes into the small bowel through a small cut in the abdomen. It is used to give you food and nutrients until you can eat again.

- An abdominal drain – this is a tube that is put into the abdomen to help drain fluid and prevent swelling.
- A urinary catheter – this is a tube that is put into the bladder to drain urine into a collecting bag. It can be removed as soon as you can get up and walk around.

The nurses will get you out of bed and moving around as soon as possible after the operation. This helps reduce the risk of complications after surgery, such as blood clots and infections. The nurses can help you manage your drips and drains while walking.

A physiotherapist or nurse will teach you deep breathing exercises to help keep your lungs clear. They will also show you how to do regular leg movements to prevent blood clots forming in your legs.

A physiotherapist can also show you how to clear your lungs of any fluid that may have built up because of your operation.

## **Pain**

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

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

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

When you no longer need the epidural or PCA, you have painkillers as tablets or liquids.

It is important to tell your healthcare team if you are still in pain. Mild discomfort or pain in your chest can last for several weeks. You will get some painkillers to take home with you.

### **Your wound**

You will probably have a dressing covering your wound. This will be removed after the first few days.

How long the wound takes to heal depends on the operation you had. The surgeon may have closed your wound with glue or stitches that dissolve and do not need to be removed. If you do not have stitches that dissolve, they are usually removed about 7 to 10 days after your operation.

Tell a nurse or your cancer doctor straight away if your wound becomes hot, painful or leaks any fluid.

### **Eating and drinking**

You will not usually have anything to eat for the first 48 hours after surgery. When you are fully awake, you may have small sips of clear fluids. The amount of fluids you have is slowly increased.

After a few days, when you can drink enough, you will start having small amounts of soft foods, and then normal food in smaller portions. This means the new joins that were made during surgery have some time to heal.

In some hospitals you may have tests to check there are no leaks in the new join.

This might be a CT scan. We have more information about CT scans on our website. Visit [macmillan.org.uk/ct-scan](https://www.macmillan.org.uk/ct-scan)

You will usually go home with your feeding tube still in, to make sure you get enough food and nutrients and do not lose weight.

Before leaving hospital, your nurse or dietitian will show you how to use your feeding tube. If you have someone taking care of you at home, they can learn how to use it too. You will meet the dietitian regularly as an outpatient to check how well you are eating. When you are eating and drinking enough, the tube can be removed.

## Starting to recover from surgery

You will still be recovering for some time after you go home. Try slowly building up the amount of physical activity you do. Gentle exercise, such as regular walks, builds up your energy levels. You can increase the amount you do as you feel better. Everyone is different, and some people take longer than others to recover.

Avoid lifting heavy things like shopping, or doing vacuuming or gardening, for at least 8 weeks. This gives your wound time to heal.

Some insurance policies give specific time limits for not driving after surgery. Contact your insurance company to tell them you have had an operation. Most people are ready to drive about 4 to 6 weeks after their operation. Do not drive unless you feel in full control of the car.

We have more information in our booklet [Going home from hospital](#), which explains how to get support after you get home.

## **Outpatient appointment**

Before you leave hospital, you will be given an appointment for your check-up at an outpatient clinic. You may also be given contact details for your specialist nurse. The appointment is a good time to talk about any problems you have after your operation.

If you have any problems before this appointment, you can contact your cancer doctor, specialist nurse or ward nurse for advice.

## **Eating**

You probably will not feel like eating very much for a while, and you may lose some weight. You may feel full after eating small amounts. Some foods might make you feel sick, or give you indigestion or diarrhoea. It is important to try to eat, even if you do not feel like it.

Over time, you will start to manage bigger portion sizes and different foods. If you continue to have problems, it can help to write down what is happening so you can limit or avoid certain foods. If you continue to have problems with food, talk to your cancer doctor or dietitian.

We have more information in our booklet [Eating problems and cancer](#).

## Indigestion

Indigestion or reflux is a backward flow of digestive juices into the oesophagus. You may have it after oesophagus surgery. This can cause pain and inflammation of the lining of the oesophagus. Your GP or cancer doctor can prescribe antacid medicines to help with this.

Avoid fizzy drinks, alcohol and spicy foods, as these may make your symptoms worse. Lying down may also make symptoms worse. After eating and drinking, try to stay sitting up for at least an hour. When you lie down to sleep, try using pillows to raise your head slightly.

Indigestion can also be caused by wind trapped in the digestive system. You can reduce wind by drinking peppermint water. You can buy this from a pharmacy.

## Preventing weight loss

To start with, you may find it hard not to lose weight. Your body will use lots of calories to help it recover from surgery and you may not be eating as much as you normally would. But in time, most people find they stop losing weight.

You will usually meet a dietitian, who will talk with you about the effects of surgery on your diet. They will give you advice about eating a balanced diet and building up your weight. To gain weight, you need to add more energy (calories) and protein to your diet. You can do this by:

- eating high-calorie foods, such as crisps, cakes, biscuits and pastries
- adding more calories to your food by using things like cream, butter or cheese
- having nutritious, high-calorie and high-protein food supplements – these are available on prescription as liquids or powders.

We have more information in our booklet [The building-up diet](#).



## Dumping syndrome

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

There are 2 types of dumping syndrome – early and late. Late dumping syndrome is more common after an [oesophagectomy](#).

### Early dumping syndrome

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

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

### Late dumping syndrome

This usually happens a few hours after eating a meal, or when you have missed a meal. You may suddenly feel faint, sick and shaky. The problem is caused by low blood sugar levels.

## Controlling early or late dumping syndrome

For most people, the symptoms of dumping syndrome slowly reduce over time. If the symptoms do not stop, tell your cancer doctor or dietitian. If your symptoms continue or are severe, your cancer doctor may give you medicine to help.

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

- eat slowly
- eat small, frequent meals
- drink fluids slowly between meals, rather than at mealtimes – try to leave 15 to 30 minutes between eating and drinking
- eat foods that are high in protein, such as fish, meat and eggs
- eat foods that are high in starchy carbohydrates, such as pasta, rice, bread and potatoes
- avoid having foods or drinks that have a lot of added sugar, such as sugary cereals, sweet drinks and desserts – if you have them, eat slowly and only have small amounts
- rest for 15 to 30 minutes straight after eating a meal.

We have more information about nutritional support and diet problems after surgery on our website. Visit [macmillan.org.uk/tube-feeding](https://www.macmillan.org.uk/tube-feeding)

## Surgery for early-stage oesophageal cancer

Some very early-stage oesophageal cancers are only in the inner layer of the oesophagus. Only a small number of people are diagnosed with very early-stage oesophageal cancer.

Early-stage oesophageal cancers can be treated using the following treatments:

- Endoscopic mucosal resection (EMR) – this removes small cancers on the inner layer of the oesophagus called [the mucosa](#).
- Endoscopic submucosal dissection (ESD) – this can remove slightly larger cancers that may be growing into the layer of tissue below the mucosa, called [the submucosa](#).

The doctor passes an endoscope through the mouth and into the oesophagus, so they can see the cancer. They then inject a small amount of fluid into the layer of cells below the cancer. The fluid lifts the cancer up from the muscle layer in the oesophagus. This makes it easier to remove the cancer. The doctor does this using suction and a small knife or wire loop called a snare.

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

Your cancer doctor may recommend further treatment after an EMR or ESD. This is to reduce the risk of the cancer coming back. For example, they may suggest you have a treatment called radiofrequency ablation (RFA).

You do not usually have a general anaesthetic for EMR or ESD but you may be given medicine to numb the throat. Some people may be given medicine to make them drowsy (sedative). Your doctor or nurse will talk to you about the preparation and recovery for this type of surgery.

**“ The surgery went very well and I had a full pathological response, meaning that I was cancer free after surgery. ”**

Ali, diagnosed with oesophageal cancer



Having chemotherapy through a cannula

# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It may be used on its own, or with [surgery](#), [radiotherapy](#), [immunotherapy](#) or [a targeted therapy drug](#).

Chemotherapy for [adenocarcinoma](#) may be given:

- both before and after surgery (perioperative chemotherapy)
- with radiotherapy (chemoradiation)
- on its own as palliative treatment
- with immunotherapy or targeted therapy (as palliative treatment).

Chemotherapy for [squamous cell carcinoma](#) may be given:

- on its own before and after surgery (perioperative chemotherapy)
- with radiotherapy (chemoradiation)
- on its own as palliative treatment
- with immunotherapy or targeted therapy (palliative treatment).

## Perioperative chemotherapy

When chemotherapy is used both before and after surgery, it is called perioperative chemotherapy. This treatment shrinks the tumour to make surgery more effective. It also reduces the chance of the cancer coming back. You usually have chemotherapy for 2 to 3 months before the operation, and again for 2 to 3 months after it.

## Chemoradiation

This is when you have chemotherapy at the same time as [radiotherapy](#). Chemoradiation may be given before surgery to help shrink the tumour. This is called neo-adjuvant treatment. Or it can be used as the main treatment without the need for surgery afterwards. This is called definitive chemoradiation.

Chemotherapy makes the cancer cells more sensitive to radiotherapy. Combining both treatments is more effective than having either treatment on its own. Your cancer doctor or specialist nurse will explain what your course of chemoradiation involves. We have more information at [macmillan.org.uk/chemoradiation](http://macmillan.org.uk/chemoradiation)

## Palliative chemotherapy

Chemotherapy can be used as the main treatment:

- if the cancer cannot be removed by surgery
- to control cancer that has spread to other parts of the body (advanced cancer).

You may have more than 1 course of chemotherapy. It can help control the cancer and reduce symptoms.

Some people may have targeted therapy or immunotherapy treatment as well as chemotherapy, including:

- trastuzumab, a targeted drug used for some people with adenocarcinoma
- nivolumab (Opdivo®), an immunotherapy treatment used for some people with adenocarcinoma or squamous cell carcinoma
- pembrolizumab (Keytruda®), an immunotherapy treatment used in advanced oesophageal cancer for both adenocarcinoma and squamous cell carcinoma.

## Chemotherapy drugs used to treat oesophageal cancer

The chemotherapy drugs most commonly used are:

- carboplatin, oxaliplatin, or cisplatin
- fluorouracil (5FU), or capecitabine
- paclitaxel or docetaxel.

Other chemotherapy drugs such as trifluridine-tipiracil hydrochloride (Lonsurf®) or irinotecan may also be used.

Usually, you have a combination of 2 or more drugs. The drugs you have will depend on whether you have an adenocarcinoma or a [squamous cell carcinoma](#). The treatments are sometimes named after the initials of the drugs included.

Common combinations for both types are:

- carboplatin and paclitaxel
- cisplatin and 5FU or capecitabine
- oxaliplatin and capecitabine (XELOX).

Other common combinations used for adenocarcinoma of the oesophagus are:

- 5FU, leucovorin, oxaliplatin and docetaxel (FLOT)
- oxaliplatin, 5FU and leucovorin (FOLFOX).

We have more information on our website about the chemotherapy drugs mentioned here. Visit [macmillan.org.uk/treatments-and-drugs](https://www.macmillan.org.uk/treatments-and-drugs)





**“ Chemotherapy was tough, but with the support of family, friends, and hospital staff, we managed it. The feeling of sickness generally subsided around 5 days after my chemotherapy session, allowing me to rest as normal during the following week. ”**

Ali, diagnosed with oesophageal cancer

## How chemotherapy is given

You usually have chemotherapy treatment in a chemotherapy day unit. This means you can go home on the same day.

After each session, you 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 talk to you about this and tell you how many cycles you are likely to have.

You have the chemotherapy drugs given into a vein (intravenously) or as tablets. Oesophageal cancer is sometimes treated with a combination of both.

Chemotherapy into a vein can be given through:

- a cannula – a short, thin tube put into a vein in the back of the hand ([see photo](#))
- a PICC line – a thin tube put into a vein near the bend of the elbow
- a central line – a plastic tube put into a large vein in the chest
- an implantable port (portacath) – a disc that is put under the skin on your chest or arm and goes into a vein in your chest.

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

Some chemotherapy drugs can be given continuously for several days. The drug is given through a small, portable pump that is attached to a central line 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 in our booklet [Understanding chemotherapy](#).

## DPD testing before treatment (5FU)

Before starting this treatment, you should have a blood test. This test checks for gene changes that affect how your body produces DPD. DPD is an enzyme that helps the body break down 5FU.

If you have low DPD levels or no DPD (DPD deficiency), you have more risk of serious or life-threatening side effects from 5FU. To reduce your risk, your doctor may give you:

- a lower dose of 5FU to start with
- a different type of chemotherapy.

Having low DPD levels does not usually cause any symptoms. Without a test, you will not know whether your DPD levels are low. Testing finds most people who are affected, but not all. Your doctor, nurse or pharmacist can give you more information about your risk of DPD deficiency, before you start treatment.

## Side effects

Chemotherapy drugs may cause unpleasant side effects. But these can usually be well controlled with medicines and usually go away once treatment has finished. Not all drugs cause the same side effects and some people have very few. You can talk to your cancer doctor or specialist nurse about what to expect from your treatment.

The main side effects are described here, as well as some ways to reduce or control them. Always tell your cancer doctor, specialist nurse or pharmacist about any side effects you have.

## Risk of infection

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

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

**It is important to follow any specific advice your cancer treatment team gives you.**

Your white blood cell count will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

## **Anaemia (low number of red blood cells)**

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. 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**

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

## Feeling tired (fatigue)

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

We have more information in our booklet [Coping with fatigue \(tiredness\)](#).

## Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss, including eyelashes and eyebrows. Others may only have some hair loss or thinning. Some people may also lose other body hair such as leg, arm, underarm and pubic hair. It depends on the chemotherapy drugs you are having. Your doctor or nurse can tell you more about what to expect. If you lose your hair, it will start to grow back once your chemotherapy has finished. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

We have more information in our booklet [Coping with hair loss](#).

## Feeling sick

Some chemotherapy drugs can make you feel sick (nausea) or possibly be sick (vomit). Your cancer doctor will prescribe anti-sickness (anti-emetic) drugs to prevent this. Anti-sickness drugs work better when you take them regularly. Tell your doctor or nurse if your anti-sickness drugs are not helping, as there are several different types you can take. Some anti-sickness drugs can make you constipated. Let your doctor or nurse know if this happens.

If you feel sick, take small sips of fluids and eat small amounts regularly.

## Loss of appetite

This treatment can affect your appetite. Don't worry if you do not eat much for 1 or 2 days. But if your appetite does not come back after a few days, or if you are losing weight, tell your doctor, nurse or pharmacist. They can give you advice. They may give you food or drink supplements. Or they may suggest changes to your diet or eating habits to help.

## Sore mouth and throat

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

Contact the hospital straight away on the 24-hour number if:

- a sore mouth is affecting how much you can drink or eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

If you are having continuous treatment through a pump, it is important to contact the hospital without delay if your mouth becomes sore.

## Changes to your taste

Some foods may taste different or have no taste. Try different foods to find out what tastes best to you. You may also get a bitter or metallic taste in your mouth. Your doctor, nurse or pharmacist can give you advice. It might help to try:

- sucking sugar-free sour or boiled sweets
- eating cold foods
- eating sharp-tasting fresh fruit.

Taste changes usually get better after treatment ends.

We have more information about coping with changes to taste.

Visit [macmillan.org.uk/mouth-problems](https://www.macmillan.org.uk/mouth-problems)

## Diarrhoea

Some chemotherapy drugs can cause diarrhoea. Diarrhoea may be severe depending on what treatment you have.

Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. Tell your hospital team if you have diarrhoea, or if it is getting worse. Your doctor may prescribe drugs to control it. It is important to take them exactly as they tell you.

Try to drink at least 2 litres (3½ pints) of fluid each day if you have diarrhoea. It can help to avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods.

If you are taking capecitabine tablets at home, it is important to tell your doctor or nurse if you have diarrhoea.



## **Numb or tingling hands or feet (peripheral neuropathy)**

This treatment may affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. This is called peripheral neuropathy. You might find it hard to do fiddly tasks such as fastening buttons or tying shoelaces.

If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug. The symptoms usually improve slowly after treatment ends. But for some people they continue and are a long-term side effect of treatment.

## **Hand-foot (palmar-plantar) syndrome**

This treatment can affect the palms of your hands and the soles of your feet. This is called palmar-plantar or hand-foot syndrome.

If you have white skin these areas may become red. If you have black or brown skin, these areas might get darker.

The skin on the palms of your hands and the soles of your feet may:

- be sore
- be painful, tingle, or swell
- peel, crack or blister.

If you have any of these symptoms, contact the hospital straight away on the 24-hour number. They can give you advice. This is especially important if you have any broken skin or if walking is difficult. They can prescribe creams and painkillers to help.

You can care for your hands and feet by:

- keeping your hands and feet cool by washing in cool water
- gently moisturising your hands and feet regularly
- wearing gloves to protect your hands and nails when working in the house or garden
- wearing loose cotton socks and avoiding tight-fitting shoes and gloves.

## Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- throbbing pain or swelling in a leg or arm
- reddening of the skin in the area – if you have black or brown skin, this can be harder to notice, but the skin might become darker
- suddenly feeling breathless or coughing.

Always call **999** if you have:

- chest pain
- difficulty breathing.

A blood clot is serious, but it can be treated with drugs called anticoagulants. These thin the blood. Your doctor, nurse or pharmacist can give you more information about preventing and treating blood clots.

## Effects on the heart

5FU can affect how the heart works. You may have tests to check how well your heart is working. These may be done before, during and after treatment.

You may develop heart problems even if these test results are normal. Very rarely, 5FU causes heart failure or a heart attack. The risk of this happening is very low. It happens to less than 1 in 100 (1%) of people who have 5FU. But it is important that you know about it.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- breathlessness
- dizziness
- changes to your heartbeat
- swollen feet and ankles.

Always call **999** if you have:

- chest pain, pressure, heaviness, tightness or squeezing across the chest
- difficulty breathing.

## **Fertility**

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your doctor before you start treatment.

## **Changes to periods**

If you have periods, these may become irregular or stop while you are having this treatment. They might return after treatment, but this does not always happen. Your menopause may start sooner than it would have done. Your doctor, nurse or pharmacist can give you more information.

# Radiotherapy

Radiotherapy uses high-energy rays called radiation to treat cancer. It destroys cancer cells in the area where the radiotherapy is given.

Some normal cells in the area being treated can also be damaged by radiotherapy. This can cause side effects. As the normal cells recover, the side effects usually get better.

Radiotherapy is always carefully planned by a team of experts. They will plan your treatment so it does as little harm as possible to normal cells.

Radiotherapy can be given in the following 2 ways:

- [External beam radiotherapy](#) is given from outside the body (externally) by a radiotherapy machine. The machine aims high-energy x-rays at the area of the body being treated. This is the most common way of giving radiotherapy for oesophageal cancer.
- [Internal radiotherapy](#) is when a radioactive material is placed inside the body to treat the cancer. There are different types of internal radiotherapy. Internal radiotherapy is sometimes used to treat oesophageal cancer.

Radiotherapy is always carefully planned by a team of experts. They will plan your treatment, so it does as little harm as possible to normal cells.

We have more information about radiotherapy in our booklet [Understanding radiotherapy](#).



Planning radiotherapy

## External beam radiotherapy

External beam radiotherapy is usually given with chemotherapy to treat oesophageal cancer. This is called [chemoradiation](#)).

For early-stage oesophageal cancer, you might have chemoradiation:

- before surgery, to shrink the tumour
- instead of [surgery](#), with the aim of curing the cancer.

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

## Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. Some people may have an MRI or a PET scan. During the scan, you need to lie in the position that you will be in for all your radiotherapy treatments.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They are made in the same way as a tattoo. The marks help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them or already have a tattoo in the treatment area, tell your radiographer. They can discuss this with you.

You will not get any results from the CT scan. The results go to a planning computer, which works out the precise dose and area for your treatment.

## Radiotherapy mask

If the treatment area is in the top part of your [oesophagus](#), you may have a mask made of your head and neck. A mask is sometimes called a mould, head shell or cast. It is made to hold your head and neck still and in exactly the right position. This helps make your treatment as accurate and effective as possible. The mask fits tightly but should not be uncomfortable. You can breathe normally while you are wearing it.

If the treatment area is in the lower part of the oesophagus, you usually need to lie with your arms supported above your head. You may have markings made on your skin to help the radiographers position you accurately for treatment. If you are worried about them, talk to your radiographer.

We have more information about masks for radiotherapy on our website. Visit [macmillan.org.uk/radiotherapy-masks](https://www.macmillan.org.uk/radiotherapy-masks)





## Feeding tube

Sometimes, radiotherapy can lead to difficulty swallowing. Usually this gets better within a few months of finishing treatment. You will usually meet a dietitian or speech and language therapist (SLT), if you need to, before treatment starts. They can tell you about the effects treatment may have on swallowing and what can help.

You may have a feeding tube put into the stomach before the radiotherapy starts. This helps make sure you are getting enough to eat. There are different types of feeding tube:

- nasogastric feeding tubes are put into the nose and passed down the oesophagus into the stomach
- gastrostomy feeding tubes are passed through the skin into the stomach.

Liquid food can be given through the tube. You can go home with it in place. You, or any carers, can be shown how to manage the feeding tube at home with support from a dietitian or community nurse.

Your cancer doctor can talk to you about whether you might need a feeding tube.

We have more information about feeding tubes on our website. Visit [macmillan.org.uk/tube-feeding](https://www.macmillan.org.uk/tube-feeding)



## Having radiotherapy treatment

Radiotherapy is normally given as a number of short, daily treatments in a hospital radiotherapy department. A radiotherapy machine ([see photo](#)) aims high-energy rays at the area of the body being treated. You might hear this type of radiotherapy being called [external beam radiotherapy](#).

You usually have radiotherapy as an outpatient. You sometimes have it during a hospital stay. Usually, each appointment takes about 10 to 30 minutes. Your radiotherapy team will explain how many treatments you will have and when you will have them. Your course of treatment may last up to a few weeks.

The person who operates the machine is called a radiographer. They give you information and support during your treatment.

At the beginning of each session, the radiographers will make sure you are in the correct position. They will tell you how long your treatment will take. When everything is ready, they leave the room and the treatment starts. The treatment itself is not painful. It does not make you radioactive. You will not be a risk to anyone during the course of your treatment.

The radiographers can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions.

## Side effects of radiotherapy

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. Sometimes side effects get worse for a time during and after you have finished radiotherapy before they get better.

Your cancer doctor, specialist nurse or radiographer will tell you what to expect. They will give you advice on what you can do to manage side effects. If you have any new side effects or if side effects get worse, tell them straight away.

### Skin changes

The skin in the area that is treated may:

- become dark or red, depending on your skin type
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice on taking care of your skin. If your skin becomes sore or itchy, or changes colour, tell them straight away. They can give you advice and treatments if needed.

Skin reactions should get better within 4 to 6 weeks of treatment ending.

During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with soap and water and gently pat it dry
- avoid rubbing the skin
- avoid very hot things, for example heating pads
- avoid cooling pads, but these may be helpful in some situations so speak to your team about using these first
- avoid wet shaving
- avoid hair-removing creams or products, including wax and laser treatment
- follow your radiotherapy team's advice about using moisturisers and deodorants
- protect the treated area from the sun.

## **Sore throat and difficulty swallowing**

Towards the end of treatment, radiotherapy can make your throat or oesophagus painful. You may not be able to swallow properly for a while. It can help to eat soft foods until the pain improves. Difficulty swallowing and pain can last for a few weeks after radiotherapy finishes. Your cancer doctor or radiographer can give you medicines to help.

If swallowing is painful, it may mean you are not able to eat enough. If this happens, you may need to speak with a dietitian. They can talk to you about how you can supplement your diet with high-calorie, nutritious drinks.



## Dry mouth

Sometimes, radiotherapy to the upper oesophagus reduces the amount of spit (saliva) the salivary glands make. This does not usually last long, but for some people it may be permanent. It may make your mouth dry, which can make eating difficult.

## 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 give you advice on ways to build up your diet and maintain or gain weight. We have more information in our booklets [The building-up diet](#) and [Eating problems and cancer](#).

## Feeling sick

Radiotherapy and chemotherapy can cause you to feel sick (nausea) and be sick (vomit). This can usually be treated with anti-sickness drugs (anti-emetics). Your cancer doctor can give you these.

## Hair loss

When radiotherapy is used to treat oesophageal cancer, it can affect hair in the area being treated. If you have hair on your chest, some of it may fall out. We have more information in our booklet [Coping with hair loss](#).

## Tiredness (fatigue)

Radiotherapy can make you feel tired. In some people, this continues for several months after treatment finishes. During treatment, you will need to rest more than usual, especially if you have to travel a long way for your treatment each day. But gentle exercise, such as short walks, can help with energy levels. After treatment finishes, try to slowly increase your activity. You may find our booklet [Coping with fatigue \(tiredness\)](#) helpful.

## Late effects of radiotherapy to the oesophagus

Sometimes radiotherapy for oesophageal cancer can cause long-term side effects. These are side effects that:

- start during treatment but do not go away
- develop months or years after treatment finishes.

Most people do not get late effects. But if you notice any symptoms, always tell your cancer doctor or specialist nurse.

### Difficulty swallowing

Radiotherapy can cause some damage to the tissue in the oesophagus. This can make it difficult to swallow. You may be offered treatment to stretch the oesophagus to make swallowing easier.

We have more information about treating swallowing problems for oesophageal cancer on our website. Visit [macmillan.org.uk/swallowing-problems](https://macmillan.org.uk/swallowing-problems)

### Effects on the lungs

The lungs may become inflamed, or the tissue can become scarred (fibrosis). If you have a cough or are short of breath, tell your cancer doctor or specialist nurse.

We have more information about breathlessness in our booklet [Managing breathlessness](#).

## Effects on the heart

Radiotherapy can cause heart problems if the heart area is being treated. If you were told the radiotherapy may affect your heart, you can reduce the risk by making healthy lifestyle choices.

We have more information in our booklet [Heart health and cancer treatment](#).

## Effects on the spleen

Chemoradiation may damage the spleen if it is used to treat tumours that are close to the stomach. The spleen is an organ in the upper part of the abdomen, on the left-hand side. It helps us to fight infection and removes old and damaged blood cells from the bloodstream. Your doctor may talk to you about the need for immunisations and long-term antibiotics after your treatment.

We have more information about the late effects of cancer treatment. Visit [macmillan.org.uk/late-effects-of-treatment](http://macmillan.org.uk/late-effects-of-treatment)



## Internal radiotherapy (brachytherapy)

Brachytherapy uses radioactive implants such as seeds, pellets, wires or plates that are put near or inside the tumour. The radioactivity only affects tissue that is very close to the implant. This means the tumour is treated, but healthy areas around it get much less radiotherapy. Areas of the body that are further away are not affected at all.

The implants are left in place for 10 to 30 minutes, depending on the radiation dose being given.

Brachytherapy is not suitable for everyone. It is usually only given if the cancer has come back in the oesophagus after external radiotherapy or chemoradiation. Sometimes brachytherapy is given to help control the cancer and improve symptoms such as difficulty swallowing.

We have more information about difficulty swallowing.  
Visit [macmillan.org.uk/swallowing-problems](http://macmillan.org.uk/swallowing-problems)

Internal radiotherapy is given through a nasogastric (NG) tube. A thin, flexible, plastic tube is placed up the nose, down the back of the throat, and into the stomach. A machine then sends radioactive pellets into the tube.

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

Internal radiotherapy can cause some pain when you swallow. This may start a few days after treatment starts, but usually goes away a few weeks after treatment finishes. Your cancer doctor can recommend liquid medicines to help.

## Chemoradiation

Some people have [chemotherapy](#) at the same time as radiotherapy. This is called chemoradiation or chemoradiotherapy. Chemoradiation is used to treat squamous cell and adenocarcinoma of the oesophagus. The chemotherapy drugs can make cancer cells more sensitive to radiotherapy. This can help the radiotherapy work better.

These chemotherapy drugs include:

- fluorouracil (5FU)
- capecitabine
- cisplatin
- carboplatin
- paclitaxel.

Chemoradiation can be used:

- before surgery, to shrink the tumour
- instead of surgery, with the aim of curing the cancer
- instead of surgery if you are not well enough or choose not to have surgery
- as part of a [clinical trial](#).

We have more information about these chemotherapy drugs on our website. Visit [macmillan.org.uk/treatments-and-drugs](https://www.macmillan.org.uk/treatments-and-drugs)



# Targeted therapy and immunotherapy

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy drugs. Each type targets something in or around the cancer cell that is helping it grow and survive.

Immunotherapy drugs use the immune system to find and attack cancer cells.

## Targeted therapy drugs

Targeted therapy drugs are sometimes used to treat advanced oesophageal cancer.

Sometimes a targeted therapy drug called trastuzumab is given with chemotherapy to treat advanced oesophageal cancer.

Trastuzumab only works for people with an oesophageal cancer that:

- is an [adenocarcinoma](#)
- has high levels of a protein called HER2.

Doctors can test tissue taken at a biopsy or during surgery to find out if the cancer cells have high levels of HER2.

Trastuzumab attaches to the HER2 proteins on the surface of the cancer cells. This stops the cancer cells from dividing and growing.

Trastuzumab is given as a drip (infusion) every 3 weeks. If it works well, your cancer doctor may decide to keep giving it after your chemotherapy finishes. The side effects of trastuzumab are usually mild.

## Immunotherapy drugs

If the cancer was in the area where the oesophagus joins the stomach, you may be offered an immunotherapy drug called nivolumab. Nivolumab targets and blocks a protein (receptor) called PD-1 on the surface of T cells, which are part of the immune system. It also blocks another protein called PD-L1.

This helps the immune system to find and attack the cancer cells. Some people have tests on the cancer cells to check the levels of PD-L1. The results can tell your doctor how likely this type of immunotherapy drug is to be helpful. Immunotherapy drugs can still work for you even if results do not show high levels of PD-L1.

You may be given nivolumab if you have already had chemoradiation and surgery. It is given to help reduce the risk of cancer coming back. Your cancer doctor can tell you more about whether nivolumab might be helpful in your situation.

Some people with advanced cancer of the oesophagus may be offered another immunotherapy drug called pembrolizumab, along with chemotherapy. This will depend on the treatments you have had before and the levels of PD-L1 that are found on the cancer cells. Your cancer doctor can tell you more about whether this might be suitable for you.

You have pembrolizumab, along with chemotherapy, as a drip (infusion) into a vein. A nurse will give them to you in the chemotherapy day unit.

## Other targeted therapies for oesophageal cancer

If you have [squamous cell carcinoma or adenocarcinoma](#), you may be offered a newer type of treatment. This is called histology independent therapy (HIT). The HIT drugs currently available in the UK through the NHS are:

- larotrectinib
- entrectinib.

They may be used to treat people with a cancer that has a gene change called NTRK gene fusion. The drugs come as capsules you can take at home.

We have more information about HITs on our website and in our leaflet [Understanding histology independent therapies \(HITs\)](#).

We have more information about targeted therapies on our website. Visit [macmillan.org.uk/targeted-therapy](https://www.macmillan.org.uk/targeted-therapy)

# Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit [macmillan.org.uk/clinical-trials](https://www.macmillan.org.uk/clinical-trials)

## Taking part in a clinical trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before [you agree \(consent\)](#) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.



Taking a blood sample





# After treatment for oesophageal cancer

After treatment

90

# After treatment

After your treatment has finished, you will have regular follow-up appointments. Depending on what treatment you had, you may have an endoscopy or a scan as part of your follow-up care. The appointments are a chance to talk to your cancer doctor or specialist nurse about any worries or problems you have.

During your appointment, your cancer doctor or specialist nurse may examine you and check any recent blood test results. They will ask you:

- how you are feeling
- if you are having problems eating
- about any symptoms you have.

If you have any problems or new symptoms between appointments, tell your doctor or specialist nurse as soon as possible.

Some healthcare teams use holistic needs assessments (HNAs) to plan your care. These assessments give you the chance to think about your concerns. These might be:

- physical
- emotional
- practical
- financial
- spiritual.

We have more information in our booklet [Holistic Needs Assessment: Planning your care and support](#).

Your team may write your care plan based on the assessments. A care plan should give information about the support you are getting and other services that may be useful. You should have a copy of the care plan, and you can update it whenever you need to. You can use it at follow-up appointments, or when you see your GP or another doctor.

These treatment summaries, assessments and care plan are not used everywhere, but more hospitals are starting to use them.

You might feel very anxious before your appointments. This is natural. It can help to get support from family members, friends, your specialist nurse or a support organisation. We have a list of [useful organisations](#) at the end of the booklet. You can also talk to one of our [cancer support specialists](#).

## **Eating after treatment for oesophageal cancer**

It can take a few months to recover from treatment for oesophageal cancer. And it may take up to a year to adjust to the changes in your digestive system.

You may have a soft diet while you are still in hospital. You are normally advised to keep to this diet for a few weeks. This can help the oesophagus to heal. It also helps to eat small amounts more often instead of larger meals.

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 having your usual diet again.

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

We have more information in our booklets [Eating problems and cancer](#) and [The building-up diet](#).

**“ I went to see a specialist upper GI dietitian. She showed me how to get lots of good calories into a small amount of food and how to deal with getting enough fluid and food into the system. ”**

Lizzy, diagnosed with oesophageal cancer

## Indigestion

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

- Try to eat slowly.
- After eating, try not to lie down for about 30 to 60 minutes.
- When you lie down, do not lie completely flat.
- Use extra pillows or raise the head of your bed.

## Feeling full quickly

You may feel full very quickly when eating. This is because your stomach is smaller. This can happen if you have had part of the stomach removed. It can also happen if the stomach has been reshaped to replace a part of the oesophagus that has been removed. Try to:

- eat smaller meals more often, rather than large ones
- chew food well
- eat slowly
- have drinks between meals rather than with a meal, so the fluid does not make you feel full too quickly.

## Diarrhoea

Diarrhoea is fairly common after any operation for oesophageal cancer. It should start to get better as you begin to eat more normally. If you have diarrhoea, it is important to make sure you are getting enough fluids. Try to drink at least 2 litres (3½ pints) of fluids every day. It can help to avoid:

- alcohol
- caffeine
- high-fat foods
- high-fibre foods.

If the diarrhoea is severe (more than 4 times a day) talk to your cancer doctor, specialist nurse or dietitian.

## Eating after radiotherapy or stenting

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

- Keep to a soft food diet.
- Sit upright when you are eating, to help move food down.
- If you have a stent, avoid foods that may block it, or that you may find difficult to swallow. These include raw fruit and vegetables, tough meat and crusty bread.
- If you use a powdered food supplement, such as Complan®, make sure it is thoroughly mixed.
- Eat slowly and have sips of water between each mouthful to help wash food down.

## Starting to recover

Treatment can be very hard for the body to cope with, and it may be some time before you are feeling well again. You might have treatment side effects that slowly improve over time, or you may have ongoing effects.

You may have general side effects such as trouble sleeping or feeling tired, rather than more specific side effects.

Having a healthy lifestyle can help your body recover more quickly, and may help stop the cancer coming back. It also helps reduce the risk of illnesses such as heart disease and strokes.

### Stop smoking

If you smoke, stopping is one of the healthiest decisions you can make. Smoking increases the risk of smoking-related cancers and heart disease. The NHS has [stopping smoking services](#) that can help you stop smoking.

### Eat healthily

Eating a wide variety of foods will give you more energy and help your recovery. A well-balanced diet usually includes 5 portions of fresh fruit and vegetables a day and foods that are high in fibre. But if you have had surgery or a stent, your healthcare team may advise you to avoid certain fruits and vegetables. Your dietitian and specialist nurse can tell you what may be suitable in your situation. It can help your general health to eat less:

- red and processed meat
- salt
- pickled or smoked food.



## Drink less alcohol

It is recommended that you drink no more than 14 units of alcohol a week, and have a few alcohol-free days a week. 1 unit is:

- half a pint of ordinary-strength beer, lager or cider
- a small glass (125ml) of wine
- a single measure (25ml) of spirits.

## Keep active

Keeping active helps build up your energy levels. It also helps reduce stress and the risk of other health conditions.

Our booklets [Healthy eating and cancer](#) and [Physical activity and cancer](#) may be helpful.

You can order our booklets and leaflets for free.  
Visit [orders.macmillan.org.uk](https://orders.macmillan.org.uk) or call 0808 808 00 00.



## Share your experience

When treatment finishes, you might find it helps to talk about your experience and share your thoughts, feelings and advice with other people.

We can help you share your story. Visit [macmillan.org.uk/shareyourstory](https://macmillan.org.uk/shareyourstory)

Or you may want to share your story on the Online Community at [macmillan.org.uk/community](https://macmillan.org.uk/community)

## Get help and support

Different people can help you during and after treatment. Your specialist nurse or GP can explain what services may be available to help. They may be able to refer you to one. You may be able to get other types of help and support by contacting services yourself.

### 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.

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

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

## Emotional support

It is common to have many different [emotions](#) after cancer treatment. But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family members and friends often helps.

If you think you may be depressed or if you feel helpless or anxious a lot of the time, talk to your cancer doctor, specialist nurse or GP. They can refer you to a psychologist or counsellor who specialises in the emotional problems people with cancer often have.

Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call us on [0808 808 00 00](tel:0808 808 00 00).

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

Lizzy, diagnosed with oesophageal cancer

## Complementary therapies

Some people find complementary therapies help them relax or cope with treatment or side effects. Some hospitals or support groups offer therapies such as relaxation or aromatherapy. Our booklet [Cancer and complementary therapies](#) has more information.

## Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. Find out more at [macmillan.org.uk/localsupportgroups](http://macmillan.org.uk/localsupportgroups)

## 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 and ask questions, get advice or just read about other people's experiences.

Our Online Community is a social networking site where you can:

- talk to people in our chat rooms
- write blogs
- make friends
- join support groups.

Visit [macmillan.org.uk/community](http://macmillan.org.uk/community)



# Coping with oesophageal cancer

Advanced oesophageal cancer	102
Treating swallowing problems	103
Your feelings	105
Relationships	106

# Advanced oesophageal cancer

Cancer that started in the oesophagus and has spread to other parts of the body is called advanced oesophageal cancer. The cancer may be advanced when it is first diagnosed. Or it may have come back after treatment. This is called recurrent cancer.

The main problem for people with advanced oesophageal cancer is difficulty swallowing.

If you have advanced oesophageal cancer, you may be offered treatment such as [chemotherapy](#), [radiotherapy](#) or [targeted therapies](#).

These treatments will not cure the cancer, but they may be able to shrink it. This may control it for a time and improve symptoms, such as difficulty swallowing.

# Treating swallowing problems

If you find swallowing difficult because the cancer is blocking your oesophagus, your doctor may suggest 1 or more treatments. The treatments may need to be repeated.

Radiotherapy that is given internally may also be used to help with swallowing problems. We have more information about [internal radiotherapy](#).

## Stenting

Your cancer doctor may suggest putting a wire mesh tube into the oesophagus using an endoscope. The tube is called a stent. Having a stent put in is similar to having an endoscopy. We have more information on endoscopies at [macmillan.org.uk/endoscopy](http://macmillan.org.uk/endoscopy)

The stent helps keep the oesophagus open, so food can pass through more easily. This makes eating more comfortable. To stop the stent from getting blocked, you may have to [avoid certain types of food](#). Having fizzy drinks after eating can also help keep the tube clean and clear.

After having a stent placed, you may have some pain for a few days. Your doctor or nurse will give you painkillers.



## Stretching (dilatation)

Instead of stenting, your surgeon may offer stretching or dilatation treatment. Using an endoscope, the surgeon passes a small dilator or expanding balloon into the oesophagus. This stretches the oesophagus and makes more space for food and fluid to pass through. Stretching may be done after [radiotherapy](#) or [surgery](#).

It is a simple and quick procedure. It may be done under a general anaesthetic, which means you are not awake when you have the procedure. Or you may have medicine to make you feel relaxed and sleepy (sedation). You may need to have the procedure more than once. There is a small risk that stretching the oesophagus may cause it to tear. If this happens, you will be treated in hospital.

## Laser treatment

Laser treatment is sometimes used to improve swallowing difficulties. Laser treatment is a powerful beam of light. It can destroy some of the cancer that is blocking the oesophagus. This helps food pass through the oesophagus more easily.

Laser treatment is not widely available in the UK, and you may have to travel to have it. Your cancer doctor can tell you whether laser treatment might be suitable for you.

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

# Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website at [macmillan.org.uk/emotions](https://www.macmillan.org.uk/emotions) and in our booklet [How are you feeling? The emotional effects of cancer](#).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on [0808 808 00 00](tel:08088080000) and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups) Or talk to other people on our Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

There is more information on [these pages](#) about other ways we can help you.

# Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships at [macmillan.org.uk/relationships](https://macmillan.org.uk/relationships) and in our booklets:

- [Talking about cancer](#)
- [Cancer and relationships: support for partners, families and friends.](#)

## If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website at [macmillan.org.uk/supporting-someone](https://macmillan.org.uk/supporting-someone) and in our booklet [Talking with someone who has cancer.](#)

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website at [macmillan.org.uk/carers](https://macmillan.org.uk/carers) and in our booklet [Looking after someone with cancer.](#)

## Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet [Talking to children and teenagers when an adult has cancer](#).

**“ It is so important to talk because it’s healthy and helps you to process what is happening to you physically and mentally. Talking to people who have been there was very helpful for me. ”**

Anne, diagnosed with oesophageal cancer



# Money and work

Help with money and benefits

110

Work

112

# Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to.

We also have information for carers on our website at [macmillan.org.uk/carers](http://macmillan.org.uk/carers) and in our booklet [Looking after someone with cancer](#).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- [gov.uk](http://gov.uk) if you live in England or Wales
- [socialsecurity.gov.scot](http://socialsecurity.gov.scot) if you live in Scotland
- [nidirect.gov.uk](http://nidirect.gov.uk) if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. You can get information about benefits and other types of financial help from [Citizens Advice](#) if you live in England, Scotland or Wales, or [Advice NI](#) if you live in Northern Ireland.

Our booklet [Help with the cost of cancer](#) has lots more information.

## Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line.

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our money advisers may be able to help. You can call them on [0808 808 00 00](tel:08088080000).

We have more information about travel insurance in our booklet [Travel and cancer](#). Our Online Community forum on [Travel insurance](#) may also be helpful. Visit [macmillan.org.uk/community](https://macmillan.org.uk/community)

You can order our booklets and leaflets for free.  
Visit [orders.macmillan.org.uk](https://orders.macmillan.org.uk) or call [0808 808 00 00](tel:08088080000).





# Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets [Work and cancer](#), [Working while caring for someone with cancer](#) and [Self-employment and cancer](#) have more information that may be helpful. You can also find out more about your employment rights in our booklet [Your rights at work when you are affected by cancer](#).

There is also lots more information online at [macmillan.org.uk/work](http://macmillan.org.uk/work)

You can order our booklets and leaflets for free.  
Visit [orders.macmillan.org.uk](http://orders.macmillan.org.uk) or call [0808 808 00 00](tel:08088080000).







**MACMILLAN**  
**SUPPORT**

# Further information

About our information	116
Other ways we can help you	118
Other useful organisations	122
Your notes and questions	140

# About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

## Order what you need

You may want to order more booklets or leaflets like this one. Visit [orders.macmillan.org.uk](https://orders.macmillan.org.uk) or call us on [0808 808 00 00](tel:08088080000).

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

## Online information

All our information is also available online at [macmillan.org.uk/information-and-support](https://macmillan.org.uk/information-and-support) You can also find videos featuring 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
- interactive PDFs
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk) or call us on [0808 808 00 00](tel:08088080000).

## The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit [macmillan.org.uk/ourinfo](https://www.macmillan.org.uk/ourinfo)



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on [0808 808 00 00](tel:08088080000). Or visit [macmillan.org.uk/support-line](https://macmillan.org.uk/support-line) to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to [macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call [0808 808 00 00](tel:08088080000) and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## **Macmillan Information and Support Centres**

Our Information and Support Centres are based in hospitals, libraries and mobile centres.

Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at [macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres) or call us on [0808 808 00 00](tel:08088080000).



## **Help with money worries**

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

### **Financial advice**

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

### **Help accessing benefits**

You can speak to our money advisers for more information. Call us free on [0808 808 00 00](tel:08088080000). Visit [macmillan.org.uk/financialsupport](https://macmillan.org.uk/financialsupport) for more information about benefits.

## **Help with work and cancer**

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

## 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 is why we help bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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](https://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](https://macmillan.org.uk/community)

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

## Macmillan healthcare professionals

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.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## Oesophageal cancer support organisations

### Barrett's UK

Tel **0777 156 7009**

[www.sites.google.com/site/barrettsoesophagusuk](http://www.sites.google.com/site/barrettsoesophagusuk)

Barrett's UK provides support specifically for those with Barrett's oesophagus and acid reflux. The website has useful information, including leaflets you can download.

### Guts UK

Tel **0207 486 0341**

[www.gutscharity.org.uk](http://www.gutscharity.org.uk)

Used to be called CORE. Set up to increase research into all digestive conditions. Provides expert information for people affected, their families and carers. Promotes awareness and discussion about digestive health.

### Heartburn Cancer UK

Tel **0125 633 8668**

[www.heartburncanceruk.org](http://www.heartburncanceruk.org)

Raises awareness about persistent heartburn, gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus. Provides information and support for people affected.

## **Oesophageal Patients Association**

Helpline **0121 704 9860**

[www.opa.org.uk](http://www.opa.org.uk)

An organisation made up of people who have had, or still have, oesophageal or stomach cancer. Produces information and offers advice and support to people with oesophageal or stomach cancer and their families.

## **General cancer support organisations**

### **Black Women Rising**

[www.blackwomenrisinguk.org](http://www.blackwomenrisinguk.org)

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

### **Cancer Black Care**

Tel **0734 047 1970**

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

### **Cancer Focus Northern Ireland**

Helpline **0800 783 3339**

[www.cancerfocusni.org](http://www.cancerfocusni.org)

Offers a variety of services to people affected by cancer in Northern Ireland.

### **Cancer Research UK**

Helpline **0808 800 4040**

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### **Macmillan Cancer Voices**

[www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices)

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

### **Maggie's**

Tel **0300 123 1801**

[www.maggies.org](http://www.maggies.org)

Has a network of centres in many 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.

### **Penny Brohn UK**

Helpline **0303 3000 118**

[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

## Tenovus

Helpline **0808 808 1010**

[www.tenovuscancercare.org.uk](http://www.tenovuscancercare.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.

## General health information

### Drinkaware

[www.drinkaware.co.uk](http://www.drinkaware.co.uk)

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

### Health and Social Care in Northern Ireland

[www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)

Provides information about health and social care services in Northern Ireland.

## **NHS.UK**

[www.nhs.uk](http://www.nhs.uk)

The UK's biggest health information website. Has service information for England.

## **NHS 111 Wales**

[111.wales.nhs.uk](http://111.wales.nhs.uk)

NHS health information site for Wales.

## **NHS Inform**

Helpline **0800 22 44 88**

[www.nhsinform.scot](http://www.nhsinform.scot)

NHS health information site for Scotland.

## **Patient UK**

[www.patient.info](http://www.patient.info)

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

## Stop smoking services

### NHS Smokefree Helpline (England)

Tel **0300 123 1044**

[www.nhs.uk/better-health/quit-smoking](http://www.nhs.uk/better-health/quit-smoking)

Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

### Quit Your Way (Scotland)

Tel **0800 84 84 84**

[www.nhsinform.scot/quit-your-way-scotland](http://www.nhsinform.scot/quit-your-way-scotland)

Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

### Help Me Quit (Wales)

Tel **0808 278 6119**

Text 'HMQ' to **80818**

[www.helpmequit.wales](http://www.helpmequit.wales)

Offers information, advice and support on stopping smoking in English and Welsh.

### Stop Smoking NI (Northern Ireland)

[www.stopsmokingni.info](http://www.stopsmokingni.info)

Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.



## Counselling

### British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**

[www.bacp.co.uk](http://www.bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

## Emotional and mental health support

### Mind

Helpline **0300 123 3393**

[www.mind.org.uk](http://www.mind.org.uk)

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans

Helpline **116 123**

Email [jo@samaritans.org](mailto:jo@samaritans.org)

[www.samaritans.org](http://www.samaritans.org)

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**

[www.adviceni.net](http://www.adviceni.net)

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317**

[www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

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

### Citizens Advice

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

#### England

Helpline **0800 144 8848**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

#### Scotland

Helpline **0800 028 1456**

[www.cas.org.uk](http://www.cas.org.uk)

## Wales

Helpline **0800 702 2020**

[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)

## Civil Legal Advice

Helpline **0345 345 4345**

Textphone **0345 345 4345**

[www.gov.uk/civil-legal-advice](http://www.gov.uk/civil-legal-advice)

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

## Disability and Carers Service

Tel **0800 587 0912**

Textphone **0800 012 1574**

[www.nidirect.gov.uk/contacts/disability-and-carers-service](http://www.nidirect.gov.uk/contacts/disability-and-carers-service)

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

## GOV.UK

[www.gov.uk](http://www.gov.uk)

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

## **Jobs and Benefits Office Enquiry Line Northern Ireland**

Helpline **0800 022 4250**

Textphone **0800 587 1297**

[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.

## **Law Centres Network**

[www.lawcentres.org.uk](http://www.lawcentres.org.uk)

Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

## **Local councils (England, Scotland and Wales)**

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

### **England**

[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)

### **Scotland**

[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)

### **Wales**

[www.gov.wales/find-your-local-authority](http://www.gov.wales/find-your-local-authority)

### **Money Advice Scotland**

[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)

Use the website to find qualified financial advisers in Scotland.

### **NI Direct**

Tel **0800 232 1271**

Text ADVICE to **0798 440 5248**

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

[www.nidirect.gov.uk/make-the-call](http://www.nidirect.gov.uk/make-the-call)

Has information about benefits and public services in Northern Ireland. You can also use the Make the Call service to check if you or someone you care for may be entitled to extra benefits.

### **Northern Ireland Housing Executive**

Tel **0344 892 0902**

[www.nihe.gov.uk](http://www.nihe.gov.uk)

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

### **StepChange Debt Charity**

Tel **0800 138 1111**

[www.stepchange.org](http://www.stepchange.org)

Provides free debt advice through phone, email, the website and online through live chats with advisers.

### **Unbiased.co.uk**

[www.unbiased.co.uk](http://www.unbiased.co.uk)

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

## **Equipment and advice on living with a disability**

### **British Red Cross**

Tel **0344 871 11 11**

[www.redcross.org.uk](http://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 **0330 995 0400** (not an advice line)

[www.disabilityrightsuk.org](http://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.

### **Living Made Easy**

[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)

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

### **Motability Scheme**

Tel **0300 456 4566**

[www.motability.co.uk](http://www.motability.co.uk)

The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

## Scope

Helpline **0808 800 3333**

Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.

[www.scope.org.uk](http://www.scope.org.uk)

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for Disabled people.

## Support for young people

### Young Lives vs Cancer

Tel **0300 330 0803**

[www.younglivesvscancer.org.uk](http://www.younglivesvscancer.org.uk)

Provides clinical, practical, financial and emotional support to children with cancer and their families in the UK.

### Teenage Cancer Trust

Tel **0207 612 0370**

[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

### Youth Access

[www.youthaccess.org.uk](http://www.youthaccess.org.uk)

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting [youthaccess.org.uk/find-your-local-service](http://youthaccess.org.uk/find-your-local-service)

## **Support for older people**

### **Age UK**

Helpline **0800 678 1602**

[www.ageuk.org.uk](http://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.

## **LGBT-specific support**

### **LGBT Foundation**

Tel **0345 330 3030**

[www.lgbt.foundation](http://www.lgbt.foundation)

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### **OUTpatients**

[www.outpatients.org.uk](http://www.outpatients.org.uk)

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.



## Support for carers

### Carers Trust

Tel **0300 772 9600**

[www.carers.org](http://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 **0808 808 7777**

[www.carersuk.org](http://www.carersuk.org)

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

## **Advanced cancer and end of life care**

### **Hospice UK**

Tel **0207 520 8200**

[www.hospiceuk.org](http://www.hospiceuk.org)

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

### **Marie Curie**

Helpline **0800 090 2309**

[www.mariecurie.org.uk](http://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 **0196 271 2690**

[www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

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

## **Bereavement support**

### **Cruse Bereavement Support**

Helpline **0808 808 1677**

[www.cruse.org.uk](http://www.cruse.org.uk)

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

## **Cancer registries**

The cancer registry is 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 a cancer registry in each country in the UK. They are run by the following organisations:

### **England – National Disease Registration Service (NDRS)**

[www.digital.nhs.uk/ndrs/patients](http://www.digital.nhs.uk/ndrs/patients)

### **Scotland – Public Health Scotland (PHS)**

[www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview](http://www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview)

### **Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)**

Tel **0292 010 4278**

[www.phw.nhs.wales/wcisu](http://www.phw.nhs.wales/wcisu)

### **Northern Ireland – Northern Ireland Cancer Registry (NICR)**

Tel **0289 097 6028**

[www.qub.ac.uk/research-centres/nicr/AboutUs/Registry](http://www.qub.ac.uk/research-centres/nicr/AboutUs/Registry)





## 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, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Chris Jones, Clinical Lecturer and Honorary Speciality Registrar in Clinical Oncology.

With thanks to: Laura Askins, Senior Specialist Dietitian; Dr Lubna Bhatt, Consultant Oncologist; Jeanette Collings, Macmillan Support and Information Radiographer; Mike Hallissey, Consultant Surgeon; Rebekah Hart, Upper GI Clinical Nurse Specialist; Pauline McCulloch, Macmillan Clinical Nurse Specialist; Christopher Peters, Clinical Senior Lecturer and Consultant Upper GI and General Surgeon; Dr Ganesh Radhakrishna, Consultant Clinical Oncologist; Dr Keith Siau, Consultant Gastroenterologist; Dr Amen Sibtain, Consultant Clinical Oncologist; and Rachel White, Specialist Oncology Dietitian.

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

We welcome feedback on our information. If you have any, please contact **[informationproductionteam@macmillan.org.uk](mailto:informationproductionteam@macmillan.org.uk)**

## Sources

Below is a sample of the sources used in our oesophageal cancer information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

European Society for Medical Oncology. Oesophageal Cancer: ESMO clinical practice guidelines for diagnosis, treatment and follow up. 2022. Available from [www.esmo.org/guidelines/guidelines-by-topic/gastrointestinal-cancers/oesophageal-cancer](http://www.esmo.org/guidelines/guidelines-by-topic/gastrointestinal-cancers/oesophageal-cancer) [accessed July 2023].

National Institute for Care and Health Excellence. Oesophago-gastric cancer: assessment and management in adults NICE guideline [NG83]. 2018. Available from [www.nice.org.uk/guidance/ng83](http://www.nice.org.uk/guidance/ng83) [accessed July 2023].

## Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer.

They are 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 are here 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.

### 5 ways you can help someone with cancer

#### 1. Share your cancer experience

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

#### 2. 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.

#### 3. 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?

#### 4. Raise money

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

#### 5. Give money

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



## Please fill in your personal details

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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 / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

## Do not 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 would rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)



**This booklet is about oesophageal cancer.  
It is for anyone who has been diagnosed with  
oesophageal cancer. It also has information about  
emotional, practical and financial issues.**

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The booklet explains what oesophageal cancer is and how it is treated. It also has information about looking after yourself and getting support. It may also be useful for your family and friends.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call [0808 808 00 00](tel:0808808000) or visit [macmillan.org.uk](https://www.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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats) or call our support line.

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