MACMILLAN
CANCER SUPPORT

UNDERSTANDING OESOPHAGEAL CANCER

> ‘Just talking to someone about what you're going through helps. Telephone the Macmillan help line or talk to a friend or relative. You will feel better afterwards.’

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

How to use this booklet

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 on page 3 to help you.

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

On pages 138 to 148 there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had oesophageal cancer, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Clint, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

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

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

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

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Buff

ABOUT OESOPHAGEAL CANCER

The oesophagus

The oesophagus is part of the digestive system, which is sometimes called the gastro-intestinal tract (GI tract). The oesophagus is a muscular tube. It connects your mouth to your stomach.

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

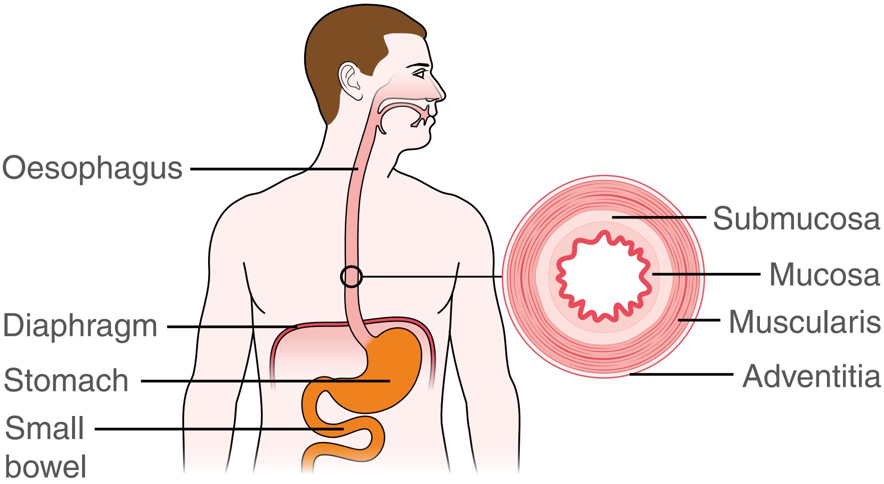
The upper part of the oesophagus is behind the windpipe (trachea). The windpipe is the tube that connects your mouth and nose to your lungs so you can breathe. Below your lungs is a layer of muscle called the diaphragm. It helps you to breathe. Most of your oesophagus sits above the diaphragm in your chest.

The bottom part of the oesophagus is below the diaphragm. The place where the oesophagus joins the stomach is called the gastro-oesophageal junction. There are lymph nodes (see pages 10 to 11) close to the oesophagus.

The oesophagus has four layers:

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

The oesophagus and surrounding organs

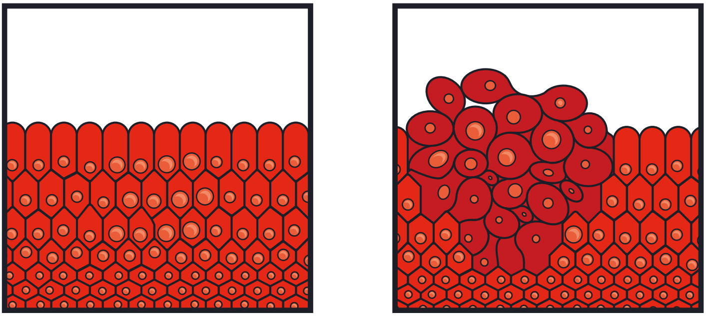


What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

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 of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see pages 10 to 11). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The lymphatic system

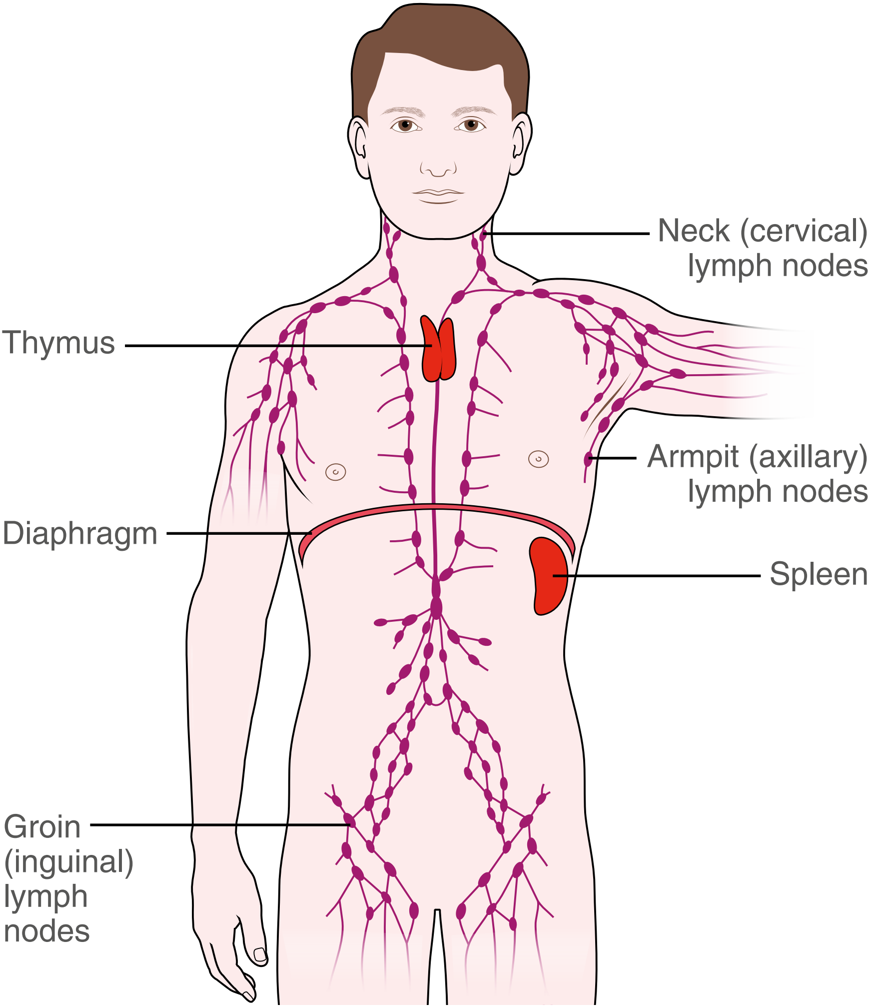
The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

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 you have helps your cancer doctor plan your treatment.

There are two main types of oesophageal cancer:

- squamous cell carcinoma – this develops in the thin, flat cells of the mucosa, which lines the oesophagus
- adenocarcinoma – this develops from glandular cells and is often linked with Barrett's oesophagus (see page 14).

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 area where the oesophagus joins the stomach (see pages 6 to 7).

Most oesophageal cancers are either squamous cell carcinoma or adenocarcinoma. But there are other, rarer types of oesophageal cancer. These include:

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

The tests and treatments for these rarer types of oesophageal cancer are different from the ones we describe in this information. Our cancer information specialists can give you more information. You can call them free on **0808 808 00 00**.

Risk factors and causes

In the UK, around 9,000 people are diagnosed with oesophageal cancer each year.

We do not know exactly what causes oesophageal cancer. But certain things called risk factors can increase the chance of developing it. Having a risk factor does not mean you will get oesophageal cancer. And if you do not have any risk factors, you may still get oesophageal cancer.

Cancer is not infectious and cannot be passed from one person to another.

Long-term acid reflux

When too much stomach acid flows back up into the oesophagus, it is called acid reflux or gastro-oesophageal reflux disease (GORD). It causes heartburn and food to come back up into your mouth. GORD is a common problem. People with GORD have a slightly higher risk of oesophageal cancer.

In some people, acid reflux causes damage to the cells in the lining of the oesophagus. Over time this causes abnormal cells to develop in the lower oesophagus. This is called Barrett's oesophagus (BO). It is not cancer, but a small number of people with Barrett's oesophagus develop cancer. It is a pre-cancerous condition.

Obesity

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

Gender

Oesophageal cancer is more common in men than in women.

Age

The risk of developing oesophageal cancer increases as you get older. Most oesophageal cancers are diagnosed in people over the age of 40.

Smoking

Smoking increases the risk of oesophageal cancer. The longer a person smokes for and the more they smoke, the greater the risk. All types of smoking are harmful. You also have an increased risk of oesophageal cancer if you use betel quid (paan or pan). Smoking shisha may also increase your risk.

Alcohol

Drinking a lot of alcohol over a long period of time increases your risk of developing oesophageal cancer.

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over 3 or more days
- try to have several alcohol-free days every week.

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

Your risk increases if you drink more than 14 units of alcohol a week. People who drink alcohol and also smoke may have a greater risk.

Diet

Eating a diet that is high in fat and cholesterol may increase your risk of developing oesophageal cancer. Eating lots of fresh fruit and vegetables may help to reduce the risk.

Previous cancer treatment

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

Other medical conditions

There are two rare conditions that can increase the risk of oesophageal cancer:

- Achalasia is when the muscle that controls the opening between the oesophagus and the stomach does not relax properly.
- Tylosis is an inherited skin condition.

Symptoms

Some symptoms of oesophageal cancer can be like the symptoms of other common conditions. Symptoms include:

- difficulty swallowing because of feeling that your food is sticking in your throat or chest – this is the most common symptom of oesophageal cancer
- food coming back up before reaching the stomach (regurgitation), feeling sick (nausea) or being sick (vomiting)
- weight loss
- pain in the chest or back, or pain in the throat or chest when swallowing
- indigestion or heartburn that does not go away
- a hoarse voice or a cough that does not go away.

These symptoms can be caused by other conditions. But it is important to get them checked by your GP. They can arrange tests or refer you to a specialist if needed.

DIAGNOSING OESOPHAGEAL CANCER

How oesophageal cancer is diagnosed

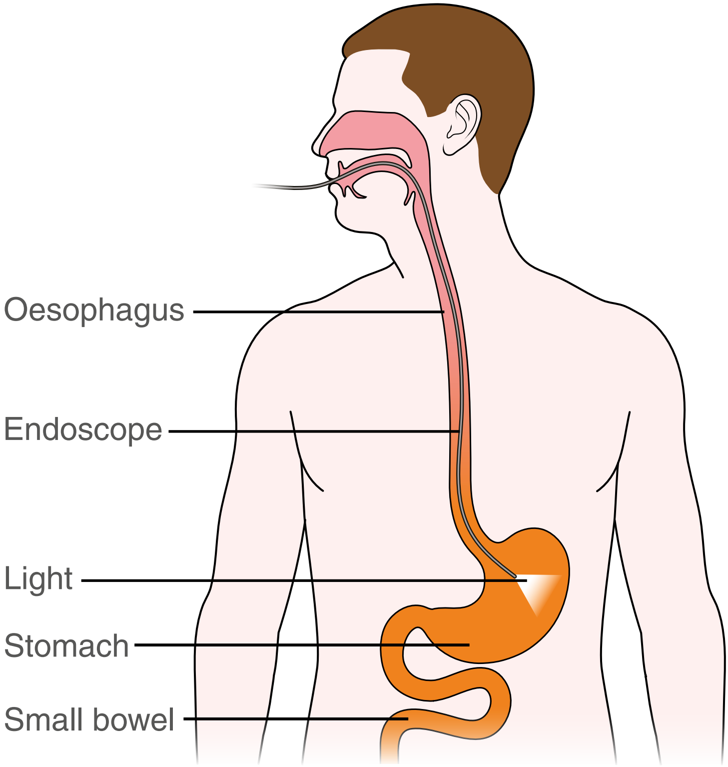
You usually start by seeing your GP. They will ask about your symptoms and examine you. You may have blood tests to check your general health. If your GP is not sure what the problem is, or thinks you may have cancer, they will refer you to hospital for a test called an endoscopy. If your GP thinks you may have cancer, you should be seen at the hospital within 2 weeks.

Endoscopy

An endoscopy is a test to look at the lining of the oesophagus, stomach and duodenum (the first part of the small bowel). Endoscopies can also be used to give treatment.

A doctor or specialist nurse uses a thin, flexible tube with a light and a camera at the end. This is called an endoscope. It helps them see any abnormal areas. They can look at the pictures from the camera on a screen. They may use the endoscope to pass some small tools into the oesophagus. This lets them remove small samples of tissue (biopsies).

Stomach endoscopy



You usually have an endoscopy as an outpatient, so you can go home the same day. Your doctor or nurse will ask you not to eat or drink anything for several hours before the test. They will also give you instructions about any medicines you are taking.

An endoscopy takes about 10 minutes, but you may be in the department for a few hours.

When you have the endoscopy, you lie on your side on a couch. The doctor or nurse may spray a local anaesthetic on to the back of your throat. This makes it numb, so you do not feel anything during the test. Or they may give you a sedative to make you feel drowsy. They inject the sedative into a vein in your arm. You may have both the injection and the spray.

The doctor or nurse then passes the endoscope down the oesophagus and into the stomach to have a look. During the endoscopy, they can remove small samples of tissue from any areas that look abnormal. The tissue is looked at under a microscope to look for any changes to cells.

After the test, the doctor or nurse gently removes the endoscope.

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

If you had a sedative, the effects should only last a few hours. You will need someone to drive you home or travel with you. If you had an anaesthetic spray, you need to wait until the numbness wears off before you eat or drink.

You may have a sore throat after the endoscopy. This is normal and should get better after a few days.

Seeing a specialist

If the endoscopy shows that you might have cancer, you will see a specialist doctor. This is usually a surgeon who specialises in oesophageal and gastro-intestinal cancers. Or you may see a gastroenterologist who specialises in treating oesophageal, stomach and digestive problems. You may also see a specialist nurse.

The specialist doctor will ask you about your general health and any previous medical problems. They will also examine you. You may have blood tests and a chest x-ray to check your general health. The doctor or nurse will talk to you about your endoscopy results and arrange further tests (see pages 26 to 30).

Some people may have a test called a barium swallow. For this test you drink a liquid called barium, which helps to show the oesophagus more clearly on an x-ray. You usually only have this test if you have not had an endoscopy.

Further tests

If the biopsy results from your endoscopy show there are cancer cells, your specialist doctor will arrange more tests. The tests may include the ones we describe in this section. These are to find out:

- which layers of the oesophageal wall the cancer is in (see pages 6 to 7)
- if it has spread outside the oesophagus.

CT (computerised tomography) scan

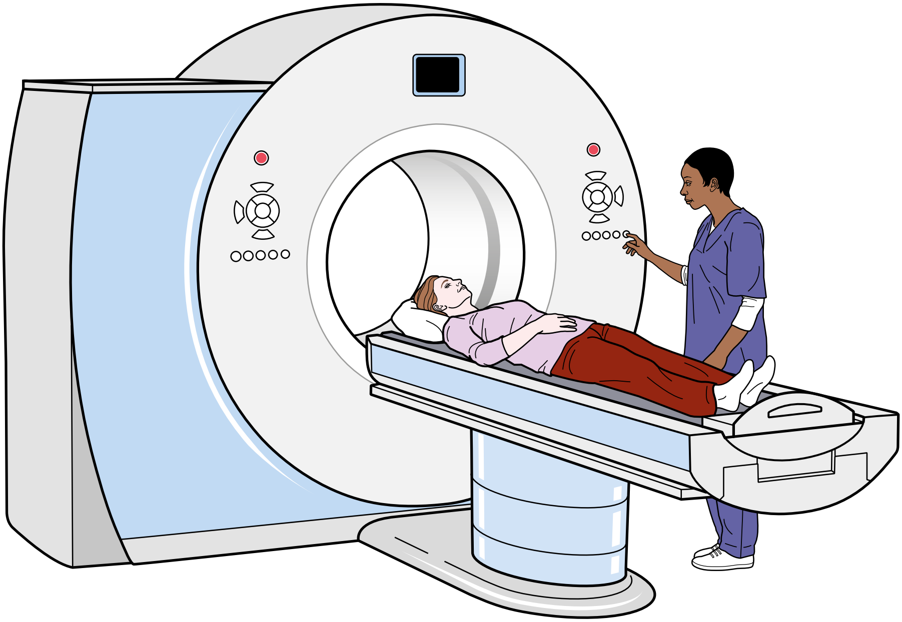
A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

CT scan



PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

Endoscopic ultrasound (EUS)

This is like an endoscopy, but the end of the endoscope has an ultrasound probe on it. The probe uses sound waves to produce an image of the wall of the oesophagus and surrounding area on a screen. This scan helps show:

- which layers of the oesophageal wall the cancer is in
- if it has spread to the lymph nodes or nearby tissue.

The ultrasound also helps guide the specialist doctor to the area of the oesophagus they want to take biopsies from.

You may have a slightly stronger sedative than for an endoscopy. This is because an EUS may take longer and you need to lie very still during this test. If you have a stronger sedative, the effects will last a little longer.

Laparoscopy

This is a small operation, which is done under a general anaesthetic.

The surgeon makes 3 or 4 small cuts (about 2cm long) in the skin and muscle of the tummy (abdomen). They then put a thin tube with a camera on the end into the tummy. This is called a laparoscope. The surgeon uses the laparoscope to look at the outside of the stomach, and the organs nearby. They may also take biopsies to check for cancer cells.

During the operation, the surgeon puts gas into the tummy to make it easier for them to see. This can cause uncomfortable wind or shoulder pain afterwards. It goes away in 1 to 2 days. Walking around and taking sips of peppermint water can help relieve the wind.

You should be able to get up as soon as the effects of the anaesthetic have worn off. You might need to stay in hospital overnight. You will have 1 or 2 stitches in the tummy where the cuts were made.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the support organisation listed on pages 138 to 148 can also provide support. You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Staging

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

- the stage of the cancer, which describes the cancer and whether it has spread
- the grade of the cancer, 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 surgery, or if you cannot have surgery. 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 you have using the:

- TNM staging system
- number staging system.

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

TNM staging system

T is for tumour, N is for nodes, and M is for metastasis. It can help to look at the information about the oesophagus (see pages 6 to 7) 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 has grown into the inner wall (mucosa or submucosa) of the oesophagus:
    - T1a – the tumour has grown into 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 lining (adventitia) of the oesophagus.
- T4 means the tumour has grown through the outer lining 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. 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 if the cancer is staged before or after surgery.

Grading

Grading is about how the cancer cells look under the microscope compared with normal cells:

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

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research. Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

TREATING OESOPHAGEAL CANCER

Treatment overview

Oesophageal cancer can be treated with surgery (see pages 48 to 67), chemotherapy (see pages 69 to 80) or radiotherapy (see pages 81 to 92). The treatments can be used alone or in combination with each other.

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 (see pages 6 to 7)
- the stage of the cancer (see pages 31 to 33)
- your general health
- 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.

Preparing for treatment

After you have been diagnosed with oesophageal cancer, you will be referred to a hospital dietitian. You might have difficulty eating and may have lost weight. A dietitian can give you advice on eating well and help you stop losing weight. This helps you prepare for treatment.

While you are waiting for treatment, it is important to eat as well as possible. Your GP can give you food supplements to help increase the amount of calories you have. This may help slow down weight loss. This is important to help you to cope better with the treatment and keep your physical fitness and strength.

It may help to try eating softer foods. Foods like soup, ice cream, jelly and custard may be easier to swallow. You may also find it easier to manage small, soft meals 4 or 5 times a day, rather than 2 or 3 bigger meals. You can also use a food mixer to blend foods you like, to help you eat more. If you cannot swallow anything, tell the hospital straight away.

If you feel well enough, it can help to try to get more physically active before your operation. Keeping active, such as going for regular, short walks, can improve your energy levels. It may also help speed up your recovery after an operation. We have more information on keeping active in our booklet **Physical activity and cancer** (see page 134). We have more information about maintaining your weight on our website **macmillan.org.uk**

If you smoke, you should try to stop before your operation. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

Treating early-stage oesophageal cancer

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

If you have a very early-stage oesophageal cancer, you may be offered a treatment to remove the cancer using an endoscope. This is called an endoscopic mucosal resection (EMR) (see pages 48 to 49), or an endoscopic sub-mucosal dissection (ESD).

Your cancer doctor may offer you this treatment if the tumour is very small and is only affecting the inner lining of the oesophagus. An EMR may also be offered if there are very abnormal cell changes to the lining of oesophagus (pre-cancerous changes).

Your cancer doctor will talk to you about the treatment options that might be best in your situation.

If you have an early-stage oesophageal cancer that has not spread, you may be offered surgery to remove the cancer. This is a major operation and you need to be well enough to have it. You may have chemotherapy and a course of radiotherapy before the operation. This is called chemoradiation. You may have this treatment if the cancer has spread nearby (locally advanced), or is too large to be removed with an operation. Chemoradiation can help shrink the tumour, so it can be removed with an operation.

You may not be able to have surgery because of other health problems. Or you might choose not to have it. If you do not have surgery, you may be offered chemoradiation instead. If you are not well enough to have chemotherapy, you might be offered radiotherapy on its own.

Treating advanced-stage oesophageal cancer

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 oesophageal cancer, you may be offered chemotherapy. This can help control the cancer and improve symptoms. You might be given radiotherapy to help relieve symptoms such as pain.

You might be offered treatment as part of a research trial (clinical trial) – see pages 94 to 95. Your cancer doctor can tell you if there are any suitable trials for you to take part in.

If you have difficulty swallowing:

- Your cancer doctor may suggest putting a tube into the oesophagus. This can help keep it open, so food can pass through more easily. This is called a stent.
- 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 in the section of our website (**macmillan.org.uk**) about eating problems.

How treatment is planned

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

The multidisciplinary team may include:

- a surgeon, who specialises in oesophageal and stomach cancers
- an oncologist, who is a doctor specialising in radiotherapy and chemotherapy
- a gastroenterologist, who is a doctor specialising in diagnosing and treating problems with the digestive system
- a specialist nurse, who can give you information and support
- a dietitian, who can give you advice you if you have problems with eating, drinking or weight loss.

It may also include other healthcare professionals, including:

- a speech and language therapist (SLT), who can help with swallowing difficulties
- a palliative care doctor or nurse, who specialises in symptom control
- a physiotherapist, who helps if you have problems moving around
- an occupational therapist, who makes sure you are safe and comfortable at home – they can suggest and arrange minor changes to your home
- a psychologist or counsellor, who can talk with you to help you sort out your feelings and find ways of coping with them.

After the MDT meeting, your cancer doctor or specialist nurse will talk to you about your treatment options. You can decide together on the best treatment plan for you.

Decisions about treatment

Your cancer doctor may offer you a choice of treatments. This may happen if more than one treatment could work equally well for the type and stage of cancer you have. You might find it hard to make a decision.

If you are asked to make a decision, make sure you have enough information about the different options. It will help to meet with both a surgeon and an oncologist, who can explain the more about the treatments. Ask about what is involved in each treatment and about possible side effects, to help you decide what is right for you.

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

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

The benefits and disadvantages of treatment

Many people worry about having cancer treatments, because of side effects. But these can usually be controlled with medicines. You might have treatment for different reasons. The possible benefits will depend on your individual situation.

If you have early-stage oesophageal cancer, you might have surgery with the aim of curing the cancer. If the cancer has spread outside the oesophagus, you might have treatments to help shrink the cancer. This can improve your symptoms and help control the cancer.

If the cancer has spread to other parts of the body, you might have treatment to help control it and improve symptoms and your quality of life. But sometimes the treatment has no effect on the cancer, and you still have the side effects to cope with.

When the aim of treatment is to try to cure the cancer, deciding whether to have it may be easy. But if a cure is not possible and the aim is to control the cancer for a time, making a decision about treatment might be harder. You may want to talk about it with your cancer doctor, specialist nurse and people close to you.

Our booklet **Making treatment decisions** has more information to help you make difficult decisions (see page 134).

If you decide not to have treatment, you will have medicines to control any symptoms. This is sometimes called supportive or palliative care.

Second opinion

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

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

Giving consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment.

No medical treatment can be given without your consent.

Before you are asked to sign the form you should be given full information about:

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

If you do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations.

It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment.

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

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

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

Surgery

If the cancer is at an early stage, you may have surgery with the aim of curing the cancer. The main operation used to treat oesophageal cancer is called an oesophagectomy. In this operation, the part of the oesophagus containing the cancer is removed.

Endoscopic mucosal resection (EMR)

An EMR can be used to treat very early-stage oesophageal cancers that are just in the inner lining of the oesophagus (the mucosa).

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 wire loop called a snare.

The most common side effects of an EMR 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. This is to reduce the risk of the cancer coming back. For example, they may suggest you have a treatment called radiofrequency ablation (RFA).

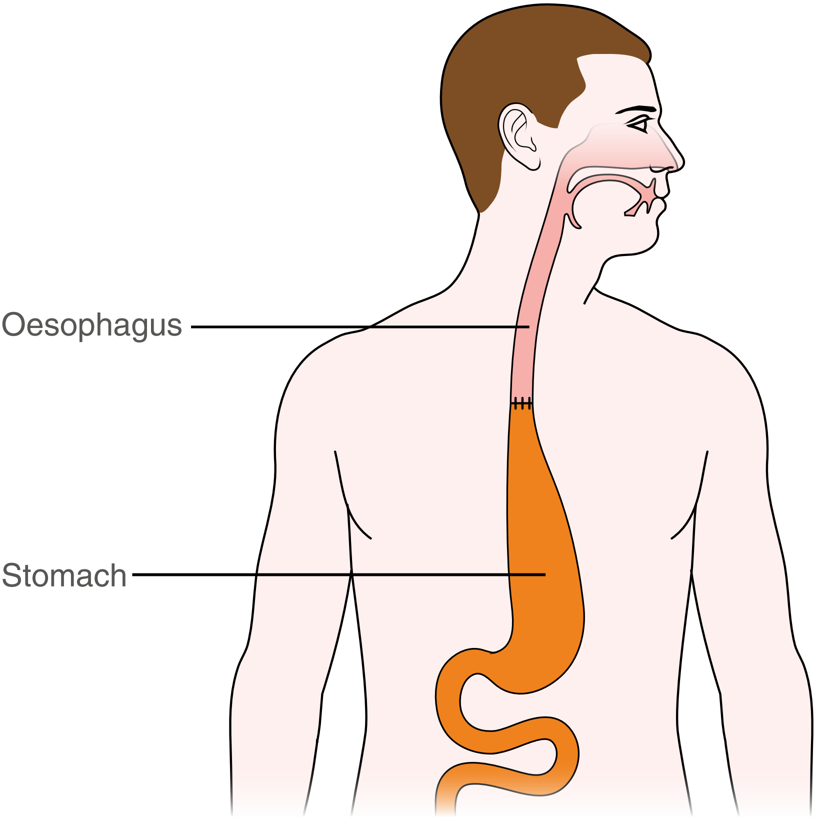
Your doctor or nurse will talk to you about the preparation and recovery for this type of surgery.

Oesophagectomy

The part that is removed depends on the size and position of the cancer inside the oesophagus:

- If the cancer is in the lower part of the oesophagus or has grown into the stomach – the surgeon removes the top of the stomach and the affected part of the oesophagus. They then join together the remaining parts of the oesophagus and stomach.
- 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.

Oesophagectomy



You may need to stay in hospital for a few weeks after surgery to the oesophagus.

Your cancer doctor will talk with you about the operation you are going to have. 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.

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 doctor who specialises in studying cells (pathologist) then looks at the lymph nodes under a microscope. This is to see 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 two main ways the surgeon can do your operation:

- 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 two-stage oesophagectomy. Sometimes they also make a cut in the neck, which is called a three-stage oesophagectomy.
- Trans-hiatal oesophagectomy – 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 eating and drinking.

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.

Minimally invasive surgery (keyhole surgery)

The surgeon does this operation through a few small cuts in the tummy (abdomen), rather than one large opening. It is sometimes called keyhole 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. If the surgeon does this surgery inside the chest to reach the oesophagus, this is called a thoracoscopy. If they do the surgery inside the tummy, it is called a laparoscopy.

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.

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 might need to stay in the intensive care unit for a while after surgery. Other possible risks include:

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

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

You will be in hospital for a few weeks with this type of operation. 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-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 see the doctor who gives you the anaesthetic (anaesthetist) when you are at a clinic, or 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 it is fine to ask lots of 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 are given information about exercises you can do to help you get fitter before surgery, as well as 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 longer 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 two 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 (CVC or central line) – this 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 using a needle.
- A naso-gastric 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 fluid that may have collected around the lungs. The fluid drains into a bottle. Tell your cancer doctor or a nurse if it is uncomfortable.
- A feeding tube (jejunostomy) – this 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.
- Abdominal drain – this is a tube that is put into the abdomen to help drain fluid and prevent swelling.
- 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 encourage you to get out of bed and move around as soon as possible. This helps reduce the risk of complications after surgery, such as blood clots and infections. 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.

> ‘The day after my operation, a physiotherapist and two of her colleagues sat me up in my bed and got me coughing. They then got me out of bed, gave me a Zimmer frame, picked up all my monitors and walked with me up and down the high-dependency unit I was in. This happened for the next 7 or 8 days, and I actually looked forward to the physio as it made me feel better.’
>
> **Clint**

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, so they will give you some painkillers to take home with you.

> ‘They were really good about pain management and had dedicated nurses that would check on your pain levels. I wasn’t pain free, but they absolutely did their best to help manage it.’
>
> **Chris**

Your wound

You will probably have a dressing covering your wound, which might not be removed for 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 gives the new joins made during surgery some time to heal.

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 a carer, they can learn how to use it too. You will see 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.


home enteral syringe

Starting to recover from surgery

You will still be recovering for some time after you go home. Try building up the amount you do slowly. 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 about going home from hospital in our booklet **Going home from hospital**, which explains how to get support after you get home (see page 134).

Outpatient appointment

Before you leave hospital, you will be given an appointment for your check-up at an outpatient clinic. 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 it is common to 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. Talk to your cancer doctor or dietitian if you continue to have problems with food.

> ‘My husband had surgery and is now at home. He is recovering well and remarkably eating anything he wants – just smaller portions and more often.’
>
> **Sue**

Indigestion

Indigestion or reflux (a backward flow of digestive juices into the oesophagus) can happen after stomach 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 or taking charcoal tablets. You can buy these from a pharmacy.

Preventing weight loss

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

You will usually see 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 protein food supplements – these are available on prescription as liquids or powders.

We have more information on building up your weight on our website (**macmillan.org.uk**) that you can read or print. Or you can call us – see page 134.

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 two types of dumping syndrome. These are early dumping syndrome and late dumping syndrome. Late dumping syndrome is more common after an oesophagectomy.

> ‘It takes time, but the body gets used to the new digestive arrangement and dumping gets easier. Plus, you get to know how to avoid it.’
>
> **Brent**

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.

> ‘It was very difficult trying to find out what food I could eat normally, because I had early dumping syndrome. It made me feel light-headed, nauseous and gave me diarrhoea. This made me very weak and I started losing weight.’
>
> **Clint**

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. If you feel the symptoms starting, you could try taking glucose tablets or eating a sugary snack.

Controlling early or late dumping syndrome

For most people, the symptoms of dumping syndrome slowly reduce over time. Tell your cancer doctor or dietitian if the symptoms do not stop. 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 (see pages 98 to 102).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It may be used on its own, or with surgery (see pages 48 to 67), radiotherapy (see pages 81 to 92) or a targeted therapy (see page 93) drug.

Chemotherapy for adenocarcinoma (see page 13) may be given:

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

Chemotherapy for squamous cell carcinoma (see page 13) may be given:

- with radiotherapy (chemoradiation)
- on its own (palliative treatment)
- with targeted therapy (palliative treatment).

> ‘My first session of chemotherapy was painless (apart from the injections prior to my PICC line being put into my arm). I sat in a chair for 6 hours, attached to a drip. Chemotherapy hits you later, and it was a few days after my first treatment that I felt worse – lethargic, tired and thirsty.’
>
> **Clint**

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 (see pages 81 to 92).

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. This is called definitive chemoradiation

Chemotherapy makes the cancer cells more sensitive to radiotherapy. This can help make the radiotherapy work better. Your cancer doctor or specialist nurse will explain what your course of chemoradiation involves.

If you have chemoradiation, your side effects may be worse than they would be if you had just one treatment type. Your cancer doctor, specialist nurse or radiographer will tell you how to manage and treat any side effects.

Palliative treatment

Chemotherapy can be used as the main treatment if the cancer:

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

You may have more than one course of chemotherapy. It can help control the cancer and reduce symptoms. Some people with adenocarcinoma have a targeted therapy (see page 93) drug called trastuzumab as well as chemotherapy. You will have tests first to see if trastuzumab is a suitable treatment for you.

Chemotherapy drugs used to treat oesophageal cancer

The chemotherapy drugs most commonly used are:

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

Other chemotherapy drugs may also be used.

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

Common combinations for both types are:

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

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

- ECF, which uses epirubicin, cisplatin and 5FU
- EOX, which uses epirubicin, oxaliplatin and capecitabine
- FLOT, which uses 5FU, leucovorin, oxaliplatin and docetaxol.

How chemotherapy is given

You usually have chemotherapy treatment in a chemotherapy day unit. This means you can go home on the same day. If you have it as an inpatient, you only need a short stay in hospital.

Chemotherapy is usually given as a session of treatment. 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
- 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.

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 about chemotherapy on our website and in our booklet **Understanding chemotherapy** (see page 134).

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.

Risk of infection

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

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

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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

The number of white blood cells 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.

Anaemia (low number of red blood cells)

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

Bruising and bleeding

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

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

Some people may need a drip to give them extra platelets. This is called a platelet transfusion. We have more information about platelet transfusions (see page 134).

Feeling tired

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

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. 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.

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. Tell your doctor or nurse if your anti-sickness drugs are not helping, as there are several different types you can take.

We have more information about feeling sick (see page 134).

Loss of appetite

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

Sore mouth

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

If your mouth is sore:

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

Changes to your taste

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

Diarrhoea

Some chemotherapy drugs can cause diarrhoea. Your doctor can prescribe drugs to control this. Try to drink at least 2 litres (3½ pints) of fluids every day if you have diarrhoea.

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

Sometimes, your treatment may need to be stopped for a time.

Numbness or tingling in hands or feet

Some chemotherapy drugs can affect the nerves in your hands or feet. This can cause tingling or numbness, a sensation of pins and needles or muscle weakness (peripheral neuropathy).

It is important to tell your doctor if this happens. They may need to change the chemotherapy drug if it gets worse. Usually, peripheral neuropathy slowly gets better when chemotherapy finishes, but sometimes it is permanent.

Sore hands and feet

Sore hands and feet is sometimes called palmar-plantar or hand-foot syndrome. It does not usually last long and improves when treatment finishes. Your doctor may prescribe creams or a vitamin called pyridoxine (vitamin B6), which some people find helpful. It can also help to:

- keep your hands and feet cool
- avoid tight-fitting clothing, such as socks, shoes and gloves.

Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

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

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

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

Effects on the heart

Chemotherapy can affect the way the heart works. You may have tests to see how well your heart is working. These may be done before, during, and sometimes after treatment. If the treatment is causing heart problems, your doctor can change the type of chemotherapy you are having.

Contact a doctor straight away if you:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor.

We have more information on effects on the heart (see page 134).

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant.

If you are a woman, your periods may become irregular or stop. This may be temporary, but for some women it is permanent. Your menopause may start sooner than it would have done.

There may be ways to preserve fertility for men and women. If you are worried about fertility, it is important to talk with your doctor before you start treatment.

We have more information on fertility (see page 134).

Radiotherapy

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

Some normal cells in the area can also be damaged by radiotherapy. This can cause side effects (see pages 86 to 89). As the normal cells recover, the side effects usually get better.

Radiotherapy can be given in two ways:

- External-beam radiotherapy – a radiotherapy 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 (brachytherapy – see pages 90 to 91) – a radioactive material is put inside the body to treat the cancer. The radioactive material is put near or inside the tumour. Internal radiotherapy is not often 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 (see page 134).

External-beam radiotherapy for oesophageal cancer

External beam radiotherapy is usually given in combination with chemotherapy to treat oesophageal cancer. This is called chemoradiation (see page 92). Chemoradiation is sometimes given:

- instead of surgery, with the aim of curing the cancer
- before surgery, to shrink the tumour.

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

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. During the scan, you need to lie in the position you will be in for your radiotherapy treatment.

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 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, talk to your radiographer.

Feeding tube

Radiotherapy to the oesophagus can cause a sore throat and difficulty swallowing, which can make it hard to eat. 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 tube – the tube is put into the nose and passed down the oesophagus into the stomach.
- Gastrostomy feeding tube – the tube is 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. They can give you information about the type of tube to be used. You will also have support from a dietitian. A speech and language therapist (SLT) can help you with any swallowing problems you may have.

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

Having radiotherapy treatment

Radiotherapy is normally given as a number of short, daily treatments in a hospital radiotherapy department. You usually have it every day from Monday to Friday, with a rest at the weekend. Each treatment takes 10 to 15 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 start of each session, the radiographers will make sure you are in the correct position on the treatment couch. They will also make sure you are comfortable. You may have a CT scan when you are in position. A radiographer checks the images to get more information about the position of the tumour.

The radiographers 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 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.

Being positioned for radiotherapy

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 sick (nausea) and tired. It may also make the inside of the oesophagus inflamed, making swallowing painful. These side effects usually get better when treatment finishes. Side effects will depend on the radiotherapy dose and the length of your treatment.

Your cancer doctor, specialist nurse or radiographer can advise you about 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 being treated sometimes gets dry and irritated. During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as a cotton
- wash your skin gently with mild, unperfumed soap and water and gently pat it dry.

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

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 can give you medicines to help.

If swallowing is painful, it may mean you do not eat enough. If this happens, you may need to see 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.

We have more information about how to cope with a dry mouth (see page 134).

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 about eating (see page 134).

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.

We have more information about feeling sick (see page 134).

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.

Our booklet **Coping with hair loss** has more information (see page 134).

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.

Our booklet **Coping with fatigue (tiredness)** has more information (see page 134).

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 it easier to swallow.

Effects on the lungs

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

We have more information about cancer and breathlessness (see page 134).

Internal radiotherapy (brachytherapy) for oesophageal cancer

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. Brachytherapy is given to help control the cancer and improve symptoms.

There are two ways of giving internal radiotherapy:

- It can be given through an endoscope – a thin, flexible tube (endoscope) is placed through the mouth and down the throat until the tip is in the stomach. A machine then sends radioactive pellets into the tube.
- 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.

We have more information about radiotherapy and its side effects on our website (**macmillan.org.uk**). You might also find it helpful to watch our video about radiotherapy.

Chemoradiation for oesophageal cancer

Chemotherapy and radiotherapy can be given at the same time. This is called chemoradiation. Certain chemotherapy drugs make the cancer more sensitive to radiotherapy. These include:

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

Chemoradiation is used to treat squamous cell carcinoma and adenocarcinoma. These are the two main types of oesophageal cancer.

Chemoradiation can be used:

- instead of surgery, if you are not well enough to have surgery
- before surgery, to shrink the tumour
- as part of a clinical trial (see pages 94 to 96).

Having chemotherapy and radiotherapy together can make the side effects of treatment worse. It may not be suitable for people who have other health problems. Your cancer doctor or specialist nurse can give you more information about chemoradiation and its possible side effects.

Targeted therapy and immunotherapy

Sometimes a targeted therapy drug called trastuzumab is given with chemotherapy to treat advanced oesophageal cancer. Targeted therapy drugs target something in or around the cancer cell that is helping it grow and survive.

Trastuzumab only works for people with an oesophageal cancer that has high levels of a protein called HER2. Only people with an adenocarcinoma (see page 13) can have this. Tests can be done on 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.

You may be offered immunotherapy drugs such as nivolumab, or pembrolizumab. These are not widely available through the NHS. When a drug is not available through the NHS it may still be possible to have it in some situations. Your cancer doctor can tell you more about this.

Immunotherapy treatment has been shown to be helpful for treating a few different cancers. Currently immunotherapy is not commonly used to treat oesophageal cancer. But you may be offered it as part of a clinical trial (see pages 94 to 96). Doctors are also testing other targeted therapy drugs in clinical trials.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a 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.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** (see page 134).

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

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 eating well
- 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 (HNA) to plan your care. These assessments give you the chance to think about physical, emotional, practical, financial and spiritual concerns. 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. There is more information in our leaflet **Holistic Needs Assessment: Planning your care and support** (see page 134).

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. You can also talk to one of our cancer support specialists.

We have more information about getting support after treatment (see page 134).

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 usually have a soft diet while you are still in hospital. You are normally advised to keep to this diet for a few weeks. This helps keep the oesophagus open as it heals. It also helps to eat small amounts more often.

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 a more normal 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.

Indigestion

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

- Try to eat slowly.
- Try not to lie down for about 30 to 60 minutes after eating.
- 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 you do not feel full with fluids.

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
- milk products
- high-fat foods
- high-fibre foods.

If the diarrhoea is severe or does not go away, talk to your cancer doctor, specialist nurse or dietitian.

We have more information about diarrhoea (see page 134).

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 softer 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. This includes raw fruit and vegetables, tough meat and crusty bread.
- If you use any 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.

We have more information about maintaining a healthy lifestyle (see page 134).

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases the risk of smoking-related cancers and heart disease.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

Eat healthily and stick to sensible drinking guidelines

Eating healthily will give you more energy and help your recovery. A well-balanced diet should include 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.

We have more information about eating healthily (see page 134).

It is recommended that men and women drink no more than 14 units of alcohol a week, and have a few alcohol-free days a week. One 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.

We have more information about keeping active (see page 134).

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 **Cancer Voices** at **macmillan.org.uk/cancervoices** for more information. Or call our support line on **0808 808 00 00**.

Getting 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. You can also call our Financial guidance team on **0808 808 00 00.**

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

We have more information about practical help (see page 134).

Emotional help

It is common to have different, and sometimes difficult, feelings 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. See pages 135 to 137, or call us on **0808 808 00 00**.

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.

We have more information in our booklet **Cancer and complementary therapies** (see page 134).

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through.

Call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for information about support groups in the UK.

Online support

Many people get support on the internet. There are online support groups (see page 138 to 148), 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 our Online Community at **macmillan.org.uk/community**

COPING WITH OESOPHAGEAL CANCER

Advanced oesophageal cancer

Cancer that started in the oesophagus and has spread to other parts of the body is called advanced cancer. The cancer may be advanced when it is first diagnosed. Or it may have come back after treatment – this is called a recurrent cancer. We have more information about advanced and recurrent cancers (see page 134).

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

If you have advanced oesophageal cancer, you may be offered treatment such chemotherapy (see pages 69 to 80), radiotherapy (see pages 81 to 92) or targeted therapies (see page 93). 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 one or more of the treatments we list here. The treatments may need to be repeated.

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 about having an endoscopy on pages 22 to 24.

The stent helps keep the oesophagus open, so food can pass through more easily. This makes eating more comfortable, but you may have to avoid certain types of food to stop the stent from getting blocked.

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

> ‘A stent was fitted which although not a pleasant experience has made a tremendous difference and my husband is now eating well.’
>
> **Pauline**

Stretching (dilatation)

Your surgeon may offer this treatment if it is not possible to put a stent into the oesophagus. 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 (see pages 81 to 92) or surgery (see pages 48 to 67).

It is a simple and quick procedure. It may be done under a general anaesthetic or with medicine to make you feel sleepy (sedation). You may need to have the procedure more than once.

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.

Having laser treatment is similar to having an endoscopy. It takes about 15 minutes. You may need 2 or 3 sessions of treatment. We have more information about having an endoscopy on pages 22 to 24.

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

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

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

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

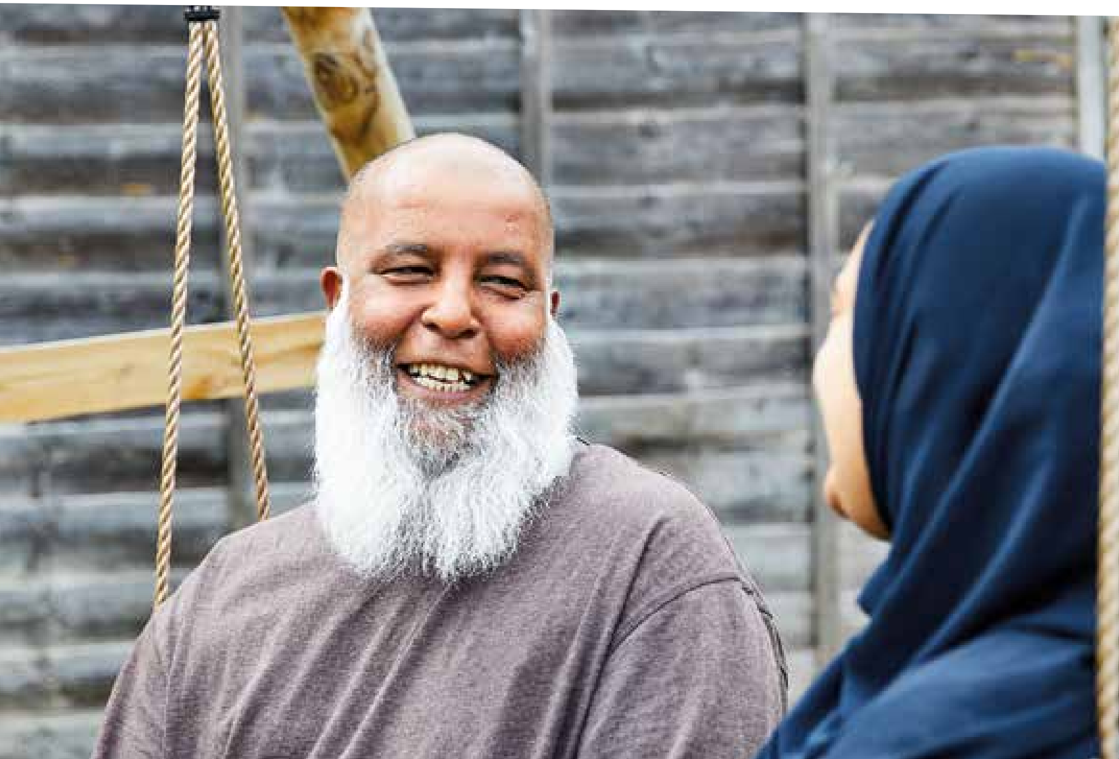
You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer booklet** (see page 134).



If you are a relative or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about talking to someone with cancer in our booklet **Talking with someone who has cancer** (see page 134).

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. You may find our booklet **Looking after someone with cancer** useful (see page 134).

Your relationships

Cancer and its treatment can cause changes in your relationships with people close to you. The experience might make relationships stronger, and the support of family and friends may help you cope. But cancer is stressful, and this can affect relationships. Any problems usually improve over time, especially if you can talk honestly about them.

Your partner

Some couples become closer through a cancer experience. But cancer can put a lot of strain on a relationship and problems sometimes develop. If a relationship was already difficult, the stress of a major illness may make things worse.

Even couples that are close may not always know how their partner is feeling. Talking openly about your feelings and listening to each other can help you understand each other.

We have more information in our booklet **Cancer and relationships: support for partners, families and friends** that you may find useful (see page 134).

Family and friends

Your family and friends may not always understand if you are not feeling positive about things. They may not know how much the cancer and its treatment is affecting your life. Talking about how you feel will help them give you the support you need. We have more information in our booklet **Talking about cancer** (see page 134).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Talking to teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

More information

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (see page 134).

We also have a video on our website about talking to children that you may find useful. Visit **macmillan.org.uk/talkingtochildren**

Who can help?

There is lots of help available for you and your family.

District nurses work closely with GPs and can visit you regularly at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim.
These may include:

- meals on wheels
- a home helper
- money to help with hospital transport fares
- help with childcare for you during and after treatment.

In many areas of the UK, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes called Macmillan nurses. But many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You might meet them when you are at a clinic or in hospital.

Marie Curie nurses help care for people who are close to the end of their lives in their own homes. Your GP or specialist nurse can usually arrange a visit from a palliative care nurse or Marie Curie nurse.

There is also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your cancer doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families.

Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call them on **0808 808 00 00**.

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 134). Our Online Community forum Travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 142).

Our booklet **Help with the cost of cancer** has lots more information (see page 134).

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can 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, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide 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 (see page 134). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 134).

FURTHER INFORMATION

About our information

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

Order what you need

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

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** 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
- eBooks
- large print
- translations.

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

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

Oesophageal cancer support organisations

Barrett's Oesophagus Campaign

Tel 020 8346 0171
Email
info@barrettscampaign.uk
www.barrettscancer.org

An organisation set up to promote research into Barrett's oesophagus. Provides support to people with Barrett's oesophagus and their families.

Guts UK

Tel 020 7486 0341
Email info@gutscharity.org.uk
www.gutscharity.org.uk

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

The Oesophageal Patients Association

Helpline 0121 704 9860
(Mon to Fri, 9am to 5pm)
Email enquiries@opa.org.uk
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 their families.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
www.cancerblackcare.org.uk

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

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org

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

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org

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

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org

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

Macmillan Cancer Voices

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 Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.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
(Mon to Fri, 9.30am to 5pm)
Email helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

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

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
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

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

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.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor on the website.

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline 0300 123 3393
(Mon to Fri, 9am to 6pm)
Text 86463
Email info@mind.org.uk
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
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

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 2450
(Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Carer's Allowance Unit

Tel 0800 731 0297
(Mon to Fri, 8am to 6pm)
Textphone 0800 731 0317
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 their online webchat or find details for your local office in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Northern Ireland

Helpline 0800 028 1881
www.citizensadvice.co.uk

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Wales

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

Civil Legal Advice

Helpline 0345 345 4345
(Mon to Fri, 9am to 8pm,
and Sat, 9am to 12.30pm)
Textphone 0345 609 6677
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
(Mon to Fri, 9am to 5pm)
Textphone 0800 587 0937
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

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
(Mon, Tue, Wed and Fri,
9am to 5pm, and Thu,
10am to 5pm)
Textphone 0800 587 1297
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

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 in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.gov.uk/authorities

Macmillan Benefits Advice Service (Northern Ireland)

Tel 0300 1233 233

Money Advice Scotland

Tel 0141 572 0237
Email info@moneyadvicescotland.org.uk
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel 03448 920 902
(Daily, 8.30am to 5pm)
Textphone
18001 03448 920 900
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel 080 0138 1111
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline 0800 023 6868
Email contact@unbiased.co.uk
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
Textphone 020 7562 2050
Email contactus@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel 0330 995 0400
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

Helpline 0300 999 0004
(Mon to Fri, 10am to 4pm)
Email info@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Motability Scheme

Tel 0300 456 4566
(Mon to Fri, 8am to 7pm,
and Sat, 9am to 1pm)
Textphone 0300 037 0100
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
(Mon to Sat, 8am to 8pm
and Sun, 10am to 6pm)
Textphone Use Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**
Email helpline@scope.org.uk
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 older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk

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

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
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.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
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 020 7520 8200
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
(Mon to Fri, 8am to 6pm, Sat, and 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline 01962 712 690
Email
rosie@naturaldeath.org.uk
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Cancer registries

The cancer registry

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

National Cancer Registration and Analysis Service

Tel 0207 654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Northern Ireland Cancer Registry

Tel 0289 097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Scottish Cancer Registry

Tel 0131 275 7050
Email nss.csd@nhs.net
www.isdscotland.org/healthtopics/cancer/scottishcancer-registry

A UK-wide group of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 0292 037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

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 our Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Katherine Aitken, Consultant Clinical Oncologist; Maria Bliss, Clinical Nurse Specialist; Catherine Fleuret, Dietician; Mr Mike Hallissey, Consultant Surgeon; Pauline McCulloch, Clinical Nurse Specialist; Professor Muntzer Mughal, Consultant Surgeon; Dr Ganesh Radhakrishna, Consultant Clinical Oncologist; Mr Peter Safranek, Consultant Surgeon; Dr Hamid Sheikh, Consultant Clinical Oncologist; and Jane Wraight, Clinical Nurse Specialist.

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 **cancerinformationteam@macmillan.org.uk**

Sources

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

Lordick, Mariette, Haustermans, et al. Oesophageal Cancer: ESMO Clinical Practice Guidelines. Annals of Oncology. 2016;27. Available from www.esmo.org/guidelines/gastrointestinal-cancers/oesophageal-cancer

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

National Institute for Health and Care Excellence (NICE). Suspected cancer: recognition and referral. NICE guideline [NG12]. 2015. Available from www.nice.org.uk/guidance/ng12

Can you do something to help?

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

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

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

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

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

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

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

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

27530

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

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or **visit macmillan.org.uk**

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

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

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