# Understanding stomach cancer



### About this booklet

This booklet is about stomach cancer. It is for anyone who is having tests for stomach cancer or has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains what stomach 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 122 to 132, there are details of other organisations that can help.

### Quotes

In this booklet, we have included quotes from people who have been diagnosed with cancer during their pregnancy, 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. 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.

### **Contents**

About stomach cancer	
Diagnosing stomach cancer	
Treating stomach cancer	
Coping with stomach cancer	

Further information

Financial support and work

19

33

95

109

117



## ABOUT STOMACH CANCER

The stomach	6
What is cancer?	9
The lymphatic system	- 11
Types of stomach cancer	12
Risk factors and causes	13
Symptoms	17

### The stomach

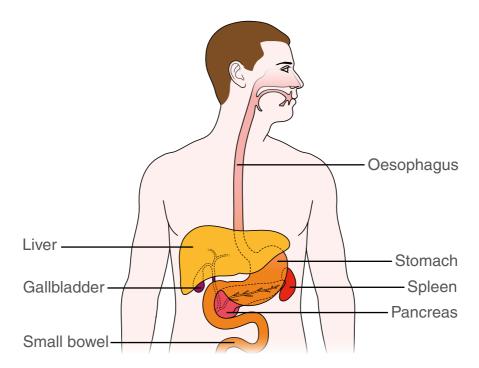
The stomach is a stretchy, muscular bag, which stores food and helps to break it down (digestion). It is in the upper left-hand side of the tummy area (abdomen). An adult's stomach is about 25cm long, but can expand to hold about 1 litre of food.

The upper part of the stomach joins to the oesophagus. The oesophagus is a muscular tube that connects the mouth to the stomach. The lower part of the stomach joins to the first part of the small (the duodenum). The pancreas, gall bladder and liver are close to the stomach. They produce juices and enzymes (chemicals) that help digest food.

After you have chewed and swallowed your food, it passes down the oesophagus to the stomach. The stomach churns up food and mixes it with acid and enzymes. This breaks the food down into much smaller pieces. This is how our bodies get the nutrients needed to give us energy and keep us healthy.

The stomach muscles squeeze together (contract) so that semi-solid food passes from the stomach into the small bowel. Digestive juices from the stomach and pancreas help the small bowel take in important substances from food. These include vitamin B12, iron and calcium.

### The position of the stomach

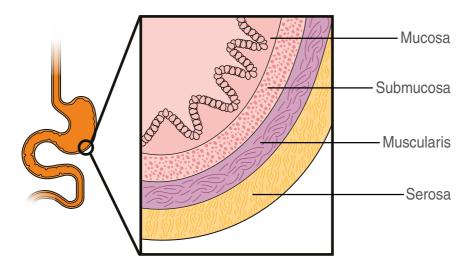


### The stomach wall

The wall of the stomach has four layers:

- The mucosa is the inner layer (stomach lining). It contains glands that produce enzymes and acid, which help digest food.
- The submucosa attaches the mucosa to the muscularis.
- The muscularis is a layer of muscle. It squeezes the stomach walls together to help move partly digested food into the small bowel.
- The serosa is a strong outer membrane which covers the stomach.

#### The stomach wall



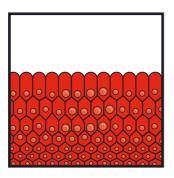
### What is cancer?

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.

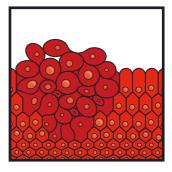
Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

### 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 page opposite). 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

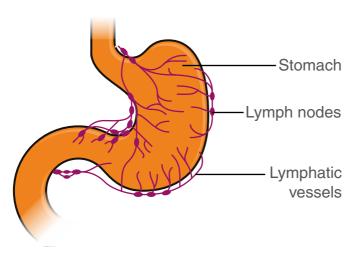
The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

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 stomach cancer

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

### The stomach and surrounding lymph nodes



## Types of stomach cancer

Knowing the type of stomach cancer you have helps your cancer doctor plan your treatment.

This information is about adenocarcinoma, which is the most common type of stomach cancer. More than 9 in 10 stomach cancers (95%) are adenocarcinoma, chemotherapy starts in the glandular cells of the stomach lining.

Less common cancers that can start in the stomach include:

- soft tissue sarcomas, including gastrointestinal stromal tumours (GISTs)
- lymphomas, such as mucosa associated lymphoid tissue (MALT) lymphomas
- carcinoid tumours.

The tests and treatments for these types of stomach 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

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

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

### Gender

Stomach cancer is more common in men than in women. Men are twice as likely than women to get stomach cancer.

### Age

The risk of developing stomach cancer increases as you get older. Over half of people (51%) diagnosed with stomach cancer are aged 75 or older.

### Helicobacter pylori (H. pylori) infection

This is a stomach infection that causes inflammation of the stomach lining. Over a long time, it can increase the risk of cancer developing.

### **Smoking**

Smoking increases the risk of stomach cancer. The longer a person smokes for and the more they smoke, the greater the risk. The risk reduces when you stop smoking.

### Diet

Diet can affect the risk of stomach cancer. The following things can increase your risk:

- not eating enough fresh fruit and vegetables
- having too much salt in your diet
- eating a lot of processed meats
- eating foods that are smoked or pickled.

The number of people in the UK who develop stomach cancer is decreasing. This is probably because our diet is improving and we are eating more fresh foods.

### Being overweight

People who are very overweight have an increased risk of cancer in the area where the stomach joins the oesophagus. This area is called the gastro-oesophageal junction (GOJ).

### Stomach conditions

Some stomach conditions can increase the risk of developing stomach cancer.

### Changes to the stomach lining

Some medical conditions can cause changes to the stomach lining. This can increase your risk of stomach cancer. These conditions include the following:

- Pernicious angemia cells that line the stomach make something called intrinsic factor (IF). This helps us to absorb vitamin B12 and make red blood cells. Pernicious angemia causes the immune system to attack the cells that make IF. If you are not making enough IF, you do not absorb enough vitamin B12. This means you have too few red blood cells (anaemia).
- Atrophic gastritis this is a chronic inflammation of the stomach lining.

### Stomach surgery for another condition (such as an ulcer)

Removing part of the stomach reduces the amount of acid your stomach makes. This means you have less protection from bacteria, which can increase the risk of stomach cancer.

### Family history and risk of cancer

Most stomach cancers are not caused by inherited cancer genes. And most people who develop stomach cancer do not have a strong family history of it. But sometimes stomach cancer runs in families. This may be because close family members share some risk factors for stomach cancer. For example, they may eat a similar diet or have H. pylori infection. Rarely, it is caused by an inherited gene.

In general, the chance of there being a family link is greater when:

- a number of family members have been diagnosed with stomach cancer
- the family members who have been diagnosed with stomach cancer are closely related
- the family members were diagnosed with stomach cancer at a younger age.

### **Symptoms**

The early symptoms of stomach cancer can be like the symptoms of some common stomach conditions. Common symptoms of stomach cancer include:

- heartburn or indigestion that does not go away
- burping a lot
- loss of appetite
- · feeling full after eating only a small amount
- · weight loss.

Other possible symptoms are:

- pain or swelling in the upper tummy (abdomen) area
- being sick
- difficulty swallowing
- black poo (stools)
- feeling tired or breathless
- having hiccups a lot.

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 STOMACH CANCER

How stomach cancer is diagnosed Further tests	20	
	24	
Staging	27	
Grading	30	
Your data and the cancer registry	31	

## How stomach cancer is diagnosed

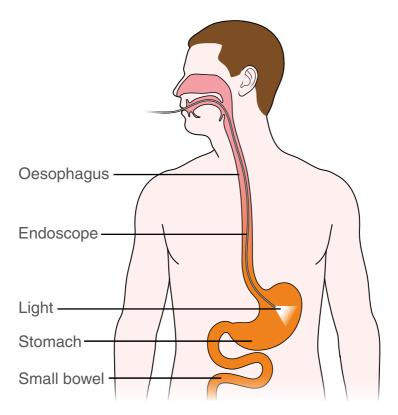
You usually start by seeing your GP. They will ask about your symptoms and examine you. You may have blood tests to check your general health. If your GP is not sure what the problem is, or thinks you may have cancer, they will refer you to hospital for a test called an endoscopy (see below). If your 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 gastrointestinal cancers. Or you may see a gastroenterologist who specialises in treating 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 specialist doctor or nurse will talk to you about your endoscopy results and arrange further tests (see pages 24 to 26).

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

'I had a little indigestion, bloating and heartburn especially after indulging a bit too much. It was all quite vaque. I only mentioned it by chance to my GP and he offered an endoscopy.'

Louise

### **Further tests**

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

- which layers of the stomach wall the cancer is in (see page 8)
- if it has spread outside the stomach.

### CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

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

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

### **PET-CT** scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for 6 hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home 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 stomach and surrounding area on a screen. This scan helps to show:

- which layers of the stomach 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 stomach 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, family or a close friend. Your specialist nurse or one of the organisations listed on our database, can also provide support. You can also talk things over with one of our cancer support specialists on 0808 808 00 00.

## 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 stomach 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 stomach wall when you read this to understand the staging (see page 8).

- T describes how far the tumour has grown into the stomach 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 stomach:
  - 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 stomach.
- T3 means the tumour has grown into the outer lining of the stomach.
- T4 means the tumour has grown through the outer lining (serosa) of the stomach, or into nearby structures:
  - T4a the tumour has grown through the outer lining (serosa) of the stomach.
  - T4b the tumour has grown into nearby structures, such as the liver or pancreas.

### **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:
  - N3a means there are cancer cells in 7 to 15 nearby lymph nodes.
  - N3b means there are cancer cells in 16 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 (moderate or intermediate grade) means the cancer cells look more abnormal and grow slightly faster.
- Grade 3 (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 (see page 132).



## TREATING STOMACH CANCER

Treatment overview	34
Surgery	42
Chemotherapy	63
Radiotherapy	75
Targeted therapy and immunotherapy	82
Clinical trials	83
After treatment	87

### **Treatment overview**

The main treatments for stomach cancer are surgery (see pages 42 to 61) and chemotherapy (see pages 63 to 74). Sometimes, radiotherapy (see pages 75 to 81) or targeted therapy treatments are used (see page 82). The treatments can be used alone or in combination with each other.

Your treatment for stomach cancer depends on:

- the stage of the cancer (see pages 27 to 29)
- your general health
- your personal choices.

### **Preparing for treatment**

After you have been diagnosed with stomach 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.

If you smoke, you should try to stop or cut down before your operation. This will help reduce the risk of problems, such as getting a serious chest infection. It will also improve wound healing after the operation. Your GP can give you advice on giving up smoking.

### Treatment for early-stage stomach cancer

If you have a very early-stage stomach cancer, you may be offered a treatment to remove the cancer using an endoscope. This is called an endoscopic mucosal resection (EMR), or an endoscopic sub-mucosal dissection (ESD). Your surgeon may offer you this treatment if the tumour is very small and is only affecting the inner lining of the stomach.

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

If you have stomach cancer that has not spread, you may be offered surgery to remove the cancer. This is a major operation to remove part, or all, of the stomach and nearby lymph nodes. You need to be well enough to have this operation.

Chemotherapy is also used to treat stomach cancer. You may have chemotherapy before and after surgery to reduce the risk of the cancer coming back. It may be given with radiotherapy (chemoradiation).

### Treatment for stomach cancer that has spread

Sometimes, surgery is used to relieve the symptoms of stomach cancer that has spread. For example, it may be used if the cancer is causing a blockage (obstruction).

Chemotherapy may be used to treat stomach cancer that has spread. It may be given on its own when an operation is not possible. You may also have radiotherapy to relieve symptoms if the cancer is advanced.

Sometimes, a targeted therapy drug called trastuzumab is given with chemotherapy to treat stomach cancer that has spread. Trastuzumab is not suitable for everyone (see page 82). Your cancer doctor or specialist nurse can explain whether trastuzumab may help you.

If the cancer has spread and you decide not to have chemotherapy, you might have treatment to control your symptoms. You will usually see doctors or nurses who specialise in symptom control (palliative or supportive care).

If you are having problems with symptoms, you can see a member of the palliative care team at any time during treatment.

### 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 stomach and gastrointestinal 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 if you have problems with eating, drinking or weight loss.

It may also include other healthcare professionals, including:

- a palliative care doctor or nurse, who specialises in symptom control
- a physiotherapist, who helps the person if they 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 and 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.

# 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 stomach cancer, you might have surgery with the aim of curing the cancer. If the cancer has spread outside the stomach, 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, but 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. 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 not 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

Surgery for early-stage stomach cancer should only be done by specialist surgeons. It is not available in all hospitals, so you may need to travel to a hospital further away to have the operation.

Even when the cancer has spread outside the stomach to the surrounding area, it may still be possible to remove it.

This is major surgery, and you may not be well enough to have it. Talk to your surgeon about the benefits and risks of this operation before making a decision.

Most people need treatment with chemotherapy as well as surgery (see pages 63 to 74). Sometimes, surgery is the only treatment that is needed. This is usually when stomach cancer is diagnosed at the earliest possible stage. Or it may be because you are not well enough to have both chemotherapy and surgery.

The operation you have depends on where the cancer is in the stomach and its size. You may have all or part of the stomach removed. The surgeon also takes away an area of healthy tissue around the cancer. This is to try to make sure all the cancer cells are gone. The area of healthy tissue is called a margin.

They also remove nearby lymph nodes (see page 11) and the omentum. The omentum is the fatty tissue that covers the stomach and the front of the bowel.

The surgeon may remove parts of some nearby organs. This depends on the position of the cancer and how far it has spread. This may include:

- the lower part of the oesophagus (the tube that connects the mouth to the stomach)
- the upper part of the small bowel (duodenum)
- the spleen or part of the pancreas.

# Partial gastrectomy

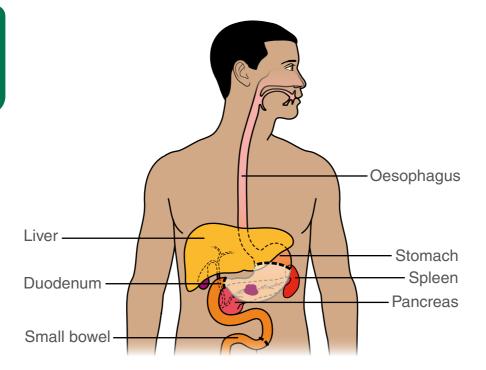
Depending on the position and size of the cancer, it may be possible to keep part of the stomach. This is called a partial gastrectomy. Having this operation makes eating easier after surgery.

#### If the cancer is in the lower stomach near the small bowel

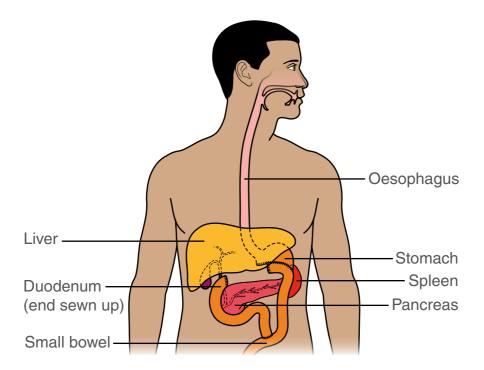
The surgeon removes the lower part of the stomach. They then reconnect the remaining part of the stomach to the small bowel.

The stomach is usually connected lower down the small bowel than it was before. This is to stop bile (a digestive fluid) and pancreatic juice from going back up the oesophagus. The juices drain from the gallbladder further down into the small bowel. The surgeon sews up the part of the small bowel (duodenum) that used to attach to the lower stomach.

# Cancer in the lower part of the stomach



### The lower stomach is removed

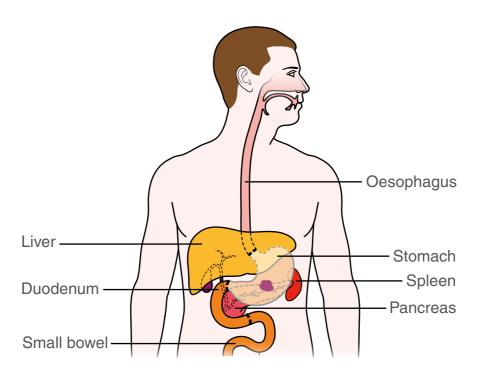


# Total gastrectomy

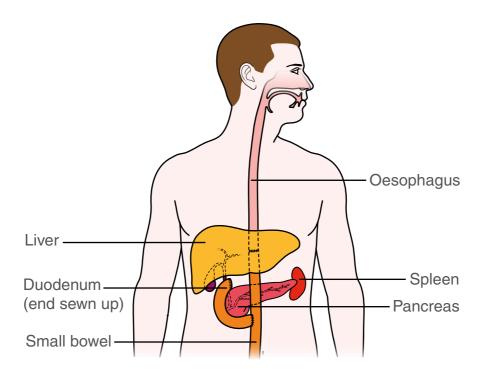
The surgeon removes the whole stomach. They usually do this operation if the cancer is in the upper or middle part of the stomach.

When the surgeon removes the stomach, they connect a part of the small bowel to the oesophagus. They connect it slightly lower down than where the stomach used to join. This is to stop bile (a digestive fluid) and pancreatic juice from going back up the oesophagus. The juices drain from the gallbladder further down into the small bowel. The surgeon sews up the part of the small bowel (duodenum) that used to attach to the lower stomach.

### Tumour in upper middle part of stomach



#### Stomach is removed



# Laparascopic 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 a long, fine tube with a camera and a light on the end through the cuts to see and work inside the body.

For a total gastrectomy, the surgeon makes a few small cuts and one larger cut. They remove the stomach through the larger cut.

# Surgery to relieve a blockage in the stomach

Sometimes the cancer causes a blockage that stops food from passing through the stomach. Your cancer doctor may suggest putting a tube into the stomach. This can help keep the stomach open, so food can pass through it more easily. The tube is called a stent. It can be placed:

- in the opening at the top of the stomach
- at the lower end of the stomach, where it opens into the small bowel.

You will have a local anaesthetic, which is given as a spray to the throat. Or you may have some medicine to make you sleepy (sedation). Sometimes a general anaesthetic may be used. The doctor puts an endoscope down the oesophagus and into the stomach. They can then pass a stent into the area where the blockage is, to allow food to pass through.

Sometimes the surgeon does an operation to bypass the blockage. They do this by making a new connection between the stomach and small bowel. This allows food to pass through a different way.

Surgery or stents can be used to relieve a blockage and symptoms, but will not cure the cancer.

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

# 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 will 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 a high-dependency unit for a few days after your operation. 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.
- A feeding tube (jejunostomy) this is a 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.

#### **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.

#### 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 fluids.

### **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.

# Starting to recover

You will still be recovering for some time after you go home and will need to take things easy for a few weeks.

Try building up the amount you do slowly. Gentle exercise, such as regular walks, builds up your energy. 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 loads 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, which explains how to get support after you get home in our booklet Going home from hospital (see page 118).

'Some days I can't quite believe what my body has been through. Life is fairly normal, some days I get tired but it's all manageable. I've even just started exercising and I am focused on rebuilding muscle.'

Louise

### **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.

### **Eatina**

If you have had part of your stomach removed, the remaining stomach will not be able to hold as much food as before. 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.

If you had all of the stomach removed, the food you eat will go straight from the oesophagus into the small bowel. This does not affect being able to digest food, but the small bowel cannot hold as much food as the stomach could. Your body will slowly adjust, so you can eat more at one time.

### Diarrhoea and vomiting

You may have diarrhoea for a few days or weeks after surgery. Your cancer doctor or specialist nurse will give you medicines to help with this.

Some people have tummy pain and feel full when they wake up in the morning. This may get better after vomiting clear fluid, which has some dark brown fluid (bile) in it. This can be upsetting, but it may only last for a short time. Your cancer doctor or specialist nurse might give you medicines to help with this.

If some foods regularly make your diarrhoea and vomiting worse, it may help to avoid them. Tell your cancer doctor or specialist nurse if:

- the symptoms do not improve
- you are struggling to eat.

### **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 do 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.

'I eat the proteins first and leave the vegetables for last in case I can't eat everything. Over time the portion sizes have got slightly bigger and my taste buds have started to improve. It took a few months but I enjoy my food more.

Karen

### **Dumping syndrome**

The stomach normally stores food and releases it into the bowel in a controlled way. After an operation to remove the stomach, 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.

#### 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 guickly. This draws fluid into the bowel from the surrounding organs and tissues, which causes your blood pressure to drop.

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

#### Late dumping syndrome

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

### Getting the vitamins and minerals you need

After surgery, your body may not be able to absorb certain vitamins and minerals from your food as well as it could before. You need these to keep healthy, so you may need to have them as an injection or as tablets.

Vitamin B12 is important for making healthy red blood cells. If all of the stomach was removed, the practice nurse at your GP surgery will give you B12 injections every few months. If only part of the stomach was removed, your GP will do a blood test to check your levels of B12 from time to time.

The stomach also helps absorb other nutrients. This includes folate (vitamin B9) and iron, which are important for making red blood cells. It also absorbs calcium, which we need for strong teeth and bones. Your GP will do regular blood tests to check you are getting enough of these nutrients from your diet.

Ask your dietitian for advice if you are worried about your diet or your weight. If you do not have a dietitian, your cancer doctor or specialist nurse can arrange for you to see one.

# **Problems swallowing**

When the whole stomach is removed, the lower end of the oesophagus is joined to the upper end of the small bowel. The join is called an anastomosis. Sometimes the join becomes narrow, which can make it difficult to swallow food. This is called a stricture.

If you are having problems swallowing, tell your specialist nurse or cancer doctor straight away. Your cancer doctor can do an endoscopy to look into the gullet to check for a stricture. They may be able to stretch it to make swallowing easier. Sometimes they insert a small tube into the stricture to keep it open. This is called a stent.

If you are having problems swallowing, you may find you start losing weight quite quickly. It can help to try eating soft or pureed foods and have nourishing drinks. Rarely, you may need to have food through a tube (enteral feeding) for a short time. Your cancer doctor, specialist nurse or dietitian can give you more information about this.



# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It may be used on its own, or with surgery (see pages 42 to 61), radiotherapy (see pages 75 to 81) or a targeted therapy drug (see page 82).

Chemotherapy for stomach cancer may be given:

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

# Perioperative chemotherapy

When chemotherapy is used both before and after surgery, it is called perioperative chemotherapy. This treatment shrinks the tumour to make surgery more effective. This 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.

# Adjuvant chemotherapy

When chemotherapy is used after surgery, it is called adjuvant chemotherapy. Adjuvant chemotherapy may be given to reduce the risk of the cancer coming back.

#### Chemoradiation

This is when you have chemotherapy at the same time as radiotherapy (see pages 75 to 81).

Chemoradiation may be given after surgery for people who have not already had chemotherapy. It helps reduce the risk of the cancer coming back.

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 have a targeted therapy drug called trastuzumab as well as chemotherapy (see page 82). You will have tests first to see if trastuzumab is a suitable treatment for you.

### Chemotherapy drugs used to treat stomach cancer

Usually, a combination of drugs is used to treat stomach cancer. The treatments are named after the initials of the drugs included. Possible treatments include:

- ECX, which uses epirubicin, cisplatin and a tablet called capecitabine (Xeloda®)
- EOX, which uses epirubicin, oxaliplatin and capecitabine (Xeloda®)
- ECF, which uses epirubicin, cisplatin and fluorouracil (5FU)
- FLOT, which uses fluorouracil (5FU), folinic acid (leucovorin), oxaliplatin and docetaxel (Taxotere®)
- FOLFOX, which uses folinic acid, fluorouracil (5FU) and oxaliplatin
- XELOX (CAPOX), which uses capecitabine (Xeloda®) and oxaliplatin.

You will have scans to show how well the cancer is responding to treatment. If the cancer has not responded well enough, your doctor may decide to change your treatment to different chemotherapy drugs. For example, they may give you irinotecan, docetaxel or paclitaxel.

You can find more information on chemotherapy drugs on our website macmillan.org.uk

# 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. Stomach 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 118).

#### 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.

### **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.

### 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.

### 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.

#### **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.

# 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. As the normal cells recover, the side effects usually get better.

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

#### Radiotherapy for stomach cancer

Radiotherapy for stomach cancer may be given:

- with chemotherapy after surgery to reduce the risk of cancer coming back – this is called chemoradiation (see page 64)
- to help symptoms, such as bleeding from the stomach - this is called palliative radiotherapy.

## 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.

## Having radiotherapy treatment

Radiotherapy is normally given as a number of short, daily treatments in a hospital radiotherapy department. A radiotherapy machine aims high-energy rays at the area of the body being treated. This type of radiotherapy is called external-beam radiotherapy.

You usually have radiotherapy as an outpatient from Monday to Friday. Usually, each appointment takes about 10 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 make sure you are in the correct position on the treatment couch. They will also make sure you are comfortable and 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.

## Side effects of radiotherapy

Radiotherapy can cause side effects in the area of your body that is being treated. You may also have some general side effects, such as feeling tired. After treatment finishes, it may be 1 to 2 or weeks before side effects start getting better. After this, most side effects usually slowly go away.

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

#### **Tiredness**

Radiotherapy often makes people feel tired. Tiredness may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks
- eat a healthy diet and drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information about coping with tiredness (fatigue) in our booklet Coping with fatigue (tiredness) – see page 118.



#### Skin reactions

The skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

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

Skin reactions should get better within 4 weeks of treatment finishing.

During your treatment, you are usually advised to:

- · wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with mild, unperfumed soap and water and gently pat it dry
- avoid rubbing the skin
- avoid wet shaving
- avoid hair-removing creams or products, including wax
- follow your radiotherapy team's advice about using moisturisers
- protect the treated area from the sun.

#### 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.

#### **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.

#### **Indigestion**

Radiotherapy to the stomach can cause indigestion. Let your radiographer or specialist nurse know if you have this. They may be able to give you medicines to help.

#### **Tummy pain**

This should get better after treatment. Your cancer doctor can give you painkillers to help.

# Targeted therapy and immunotherapy

Sometimes a targeted therapy drug called trastuzumab is given with chemotherapy to treat advanced stomach 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 a stomach cancer that has high levels of a protein called HER2. Between 10 and 15 out of every 100 people with stomach cancer (10 to 15%) have a HER2-positive cancer. 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 stomach cancer. But you may be offered it as part of a clinical trial (see pages 83 to 85). 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.

## 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. You will usually talk with someone from your healthcare team at the appointment. This may be your surgeon, cancer doctor, specialist nurse or another health professional.

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 cancer 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. We have more information in our booklet Holistic Needs Assessment: Planning your care and support (see page 118). 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 plans are not used everywhere, but more hospitals are starting to use them.

You might feel very anxious before your appointments. This is natural. It can help to get support from family members, friends your specialist nurse or a support organisation (see pages 122 to 132). You can also talk to one of our cancer support specialists free on 0808 808 00 00, or visit macmillan.org.uk

#### Eating after treatment for stomach cancer

It can take a few months to recover from treatment for stomach 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. 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 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 about eating after you have gone home, contact the dietitian or your specialist nurse for advice.

## Starting to recover after surgery

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

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

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

#### Stop smoking

If you smoke, 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.

'I find that although I can't feel hunger, I can feel my energy levels dipping. I always have snacks in my bag (my young grandchildren love this) because I can always give myself a boost with a snack."

Donna

#### 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.

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.

#### Share your experience

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

We can help you share your story. Visit macmillan.org.uk/ 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.

#### **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. 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 you may find useful (see page 118).

#### 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 pages 122 to 132), 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 community.macmillan.org.uk



# COPING WITH STOMACH CANCER

Your feelings	96
If you are a relative or friend	101
Your relationships  Talking to children about cancer	102 104

# 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.

> 'Friends kept me from ever feeling sorry for myself and relatives who I probably upset from time to time kept right behind me. Of course my closest family were my absolute rocks and got the balance between help and encouragement just right.

**David** 

#### **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 118).

'In reality, whilst I describe my journey through this course as a personal challenge, in reality it was anything but. The people around me were pillars of strength.'

David

# 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 118).

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 118).

# 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 118).

## 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 118).



# 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 118).

# 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.



# FINANCIAL SUPPORT AND WORK

Financial help	and benefits	i 110
Work		114

# 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.

#### **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 booklet **Travel and cancer** (see page 118). 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 126).

Our booklet **Help with the cost of cancer** has lots more information (see page 118).

## 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 118). 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 118).



# FURTHER INFORMATION

About our information	118
Other ways we can help you	119
Other useful organisations	122

# **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-andsupport 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).

# Other useful organisations

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

## Stomach cancer support organisations

**Guts UK Tel** 020 7486 0341 **Email** info@gutscharity.org.uk www.qutscharity.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.orq.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.cancersupport scotland.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

Tel 0300 123 1801 Email enquiries@maggies.org

www.maggies.org

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

**Penny Brohn UK Helpline** 0303 3000 118 (Mon to Fri, 10am to 2pm) 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.orq.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@tenovuscancer care.org.uk

## www.tenovuscancer care.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 **FNHS** health information site for Wales.

## NHS Inform Helpline 0800 22 44 88 (7 days a week, 8am to 8pm) 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 evidencebased information leaflets on a wide variety of medical and health topics. Also reviews and links to many healthand illness-related websites.

## Counselling

**British Association** for Counselling and Psychotherapy (BACP) **Tel** 01455 883 300 (Mon to Fri, 10am to 4pm) Email bacp@bacp.co.uk Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor 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) 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 nonjudgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

#### Financial support or legal advice and information

## Advice NI Helpline 0800 915 4604 Email advice@adviceni.net Provides advice on a variety of issues including financial, legal, housing and employment issues.

**Benefit Enquiry Line** Northern Ireland Helpline 0800 232 127 (Mon, Tue, Wed and Fri, 9am to 5pm, 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.

Carer's Allowance Unit Tel 0800 731 0297 **Textphone** 0800 731 0317 (Mon to Fri, 8am to 6pm) www.gov.uk/carersallowance

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 0800 144 8848 www.citizensadvice.org.uk

**Scotland** Helpline 0800 028 1456 www.cas.orq.uk

**Wales** Helpline 0800 702 2020 www.citizensadvice.org.uk/ wales

Macmillan Benefits Advice Service (Northern Ireland) **Tel** 0300 1233 233

Civil Legal Advice Helpline 0345 345 4345 (Mon to Fri, 9am to 8pm, Sat, 9am to 12.30pm) **Textphone** 0345 609 6677 www.gov.uk/civil-legaladvice

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** 028 9031 1092 nidirect.gov.uk/disabilityand-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, Thu, 10am to 5pm) **Textphone** 028 9031 1092 www.nidirect.gov.uk/moneytax-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 Housina 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-localcouncil

Scotland www.cosla.gov.uk/councils

Wales www.wlga.wales/welshlocal-authority-links

## **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 **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 (not an advice line) 0330 995 0400

**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.

**Living Made Easy** Helpline 0300 999 0004 (Mon to Fri, 10am to 4pm) Email info@dlf.org.uk www.livingmadeeasy.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, 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, UKwide 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, 9am to 9pm)

Email helpline@lgbt.foundation www.lqbt.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) Tel 0808 808 7777 (Mon and Tues, 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 **Email** info@hospiceuk.org

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, 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) 0214 318 014 www.ncri.ie (Ireland)

Northern Ireland **Cancer Registry** Tel 0289 097 6028 Email nicr@qub.ac.uk www.qub.ac.uk/nicr

**Scottish Cancer Registry** www.ndrs.nhs.uk/cancerregistration-your-rights-andprivacy.

Welsh Cancer Intelligence and Surveillance Unit (WCISU) Tel 0292 010 4278 phw.nhs.wales/servicesand-teams/welshcancer-intelligence-andsurveillance-unit-wcisu/

#### **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 thirdparty 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, Professor 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 booklet below. If you would like more information about the sources we use, please contact us at cancerinformationteam@macmillan.org.uk

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

Available from www.nice.org.uk/guidance/ng12

National Institute for Health and Care Excellence (NICE). Suspected cancer:

recognition and referral. NICE guideline [NG12]. 2015.

Smyth, Verheij, Allum et al. Gastric Cancer: ESMO Clinical Practice Guidelines.

Annals of Oncology. 2016;27:5

Available from: www.esmo.org/Guidelines/Gastrointestinal-Cancers/Gastric-Cancer

## Can you do something to help?

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

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



#### Share your cancer experience

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

#### Campaign for change

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

#### Help someone in your community

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

#### Raise money

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

#### Give money

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

Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

# Please fill in your personal details Mr/Mrs/Miss/Other Name Surname Address Postcode Phone Email Please accept my gift of £ (Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro Card number Valid from Expiry date

# Don't let the taxman keep your money

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

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

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

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

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

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

Security number

Issue no

Signature

Date

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

REGULATOR



## This booklet is about stomach cancer. It is for anyone who has been diagnosed with stomach cancer. There is also information for carers, family members and friends.

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

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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.



Patient Information Forum