

**A practical guide to  
understanding cancer**

# **UNDERSTANDING ANAL CANCER**

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

# Contents

About this booklet	2
The anus and anal cancer	5
Diagnosing anal cancer	15
Treating anal cancer	29
After your treatment	65
Your feelings and relationships	85
Work and financial support	95
Further information	101

# About this booklet

**This booklet is about cancer of the anus.  
The anus is the name for the muscular  
opening at the end of the large bowel.**

The large bowel is made up of the colon, rectum and anus. We have separate booklets about colon or rectal cancer that we can send you.

We hope this information answers some of your questions and helps you deal with some of the feelings you may have. We also have a video on our website about anal cancer. You can watch it at [macmillan.org.uk/analcancer](https://www.macmillan.org.uk/analcancer)

In this booklet, we've included some comments from people who have had anal cancer, which you might find helpful. Some are members of our online community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)) and others have chosen to share their story with us through [macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices)

At the end of this booklet are some useful addresses and websites (pages 107–111). There's also space for you to fill in with any notes or questions for your doctor or nurse (see pages 112–113).

We can't advise you about the best treatment for yourself, because this information can only come from your own doctor or specialist nurse who is familiar with your medical history.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **[macmillan.org.uk](https://www.macmillan.org.uk)**

If you have found this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.



# THE ANUS AND ANAL CANCER

---

What is cancer?	6
The anus	8
The lymphatic system	10
Causes and risk factors	11
Symptoms	13

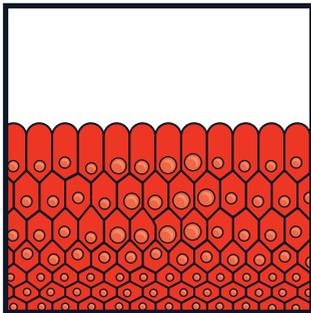
# What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues in our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair.

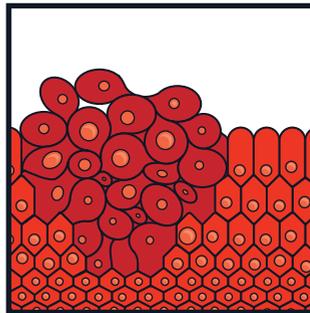
Cells receive signals from the body telling them when to divide and grow, and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and dies.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a **lump (tumour)**.

Not all lumps are cancer. Doctors can tell if a lump is cancer by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.



Normal cells



Cells forming a tumour

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

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or **lymphatic system** (see page 10).

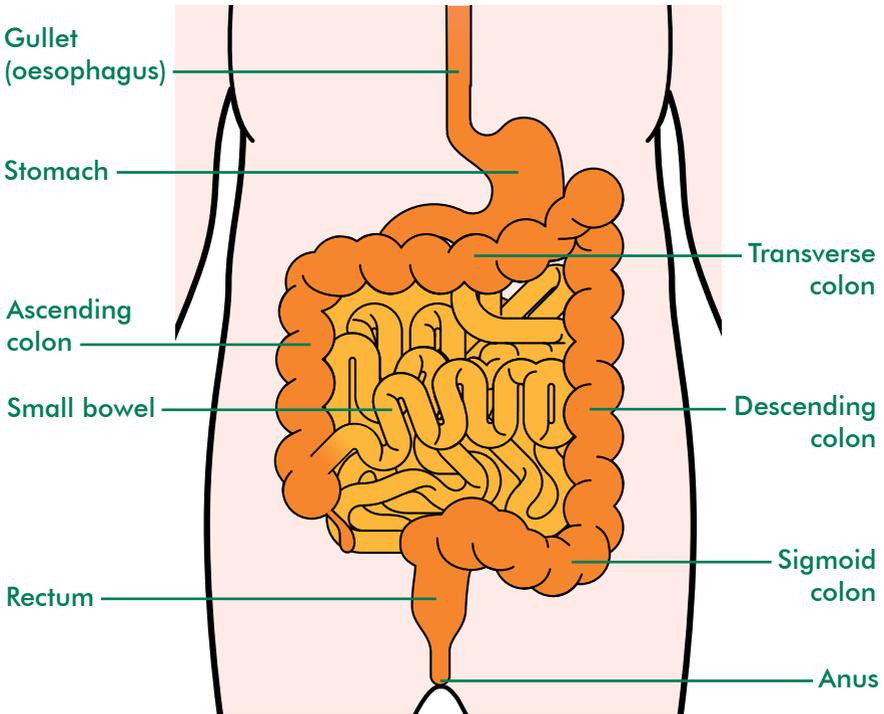
When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.



We have a video on our website that explains how cancer develops. You can watch it at [macmillan.org.uk/aboutcancer](https://www.macmillan.org.uk/aboutcancer)

# The anus

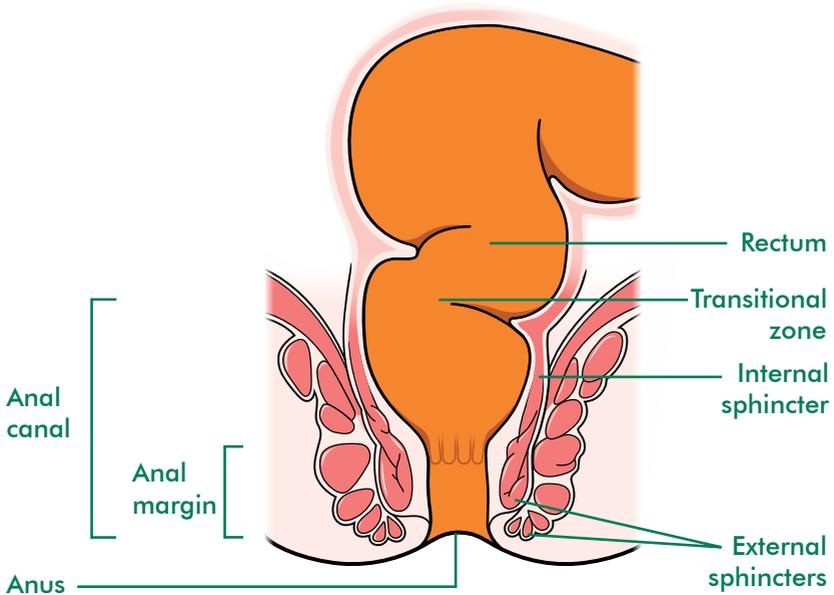
The anus is the name for the muscular opening at the very end of the large bowel, which is part of our digestive system.



The digestive system

When food has been swallowed, it passes down the gullet (oesophagus) to the stomach, where digestion begins. From here, it enters the small bowel, where essential nutrients are taken into the body. The digested food then moves into the colon, where water is absorbed. The remaining waste matter (stool or faeces), is held in the rectum (back passage) until it's ready to be passed from the body through the anus as a bowel motion (stool).

The area that connects the anus to the rectum is called the anal canal and is around 3–4cm (1–1½in) long. The lower end of the anal canal, where the anus opens, is called the anal margin. The anus is opened and closed by a ring of muscle known as the external sphincter.



A cross-section of the anal canal

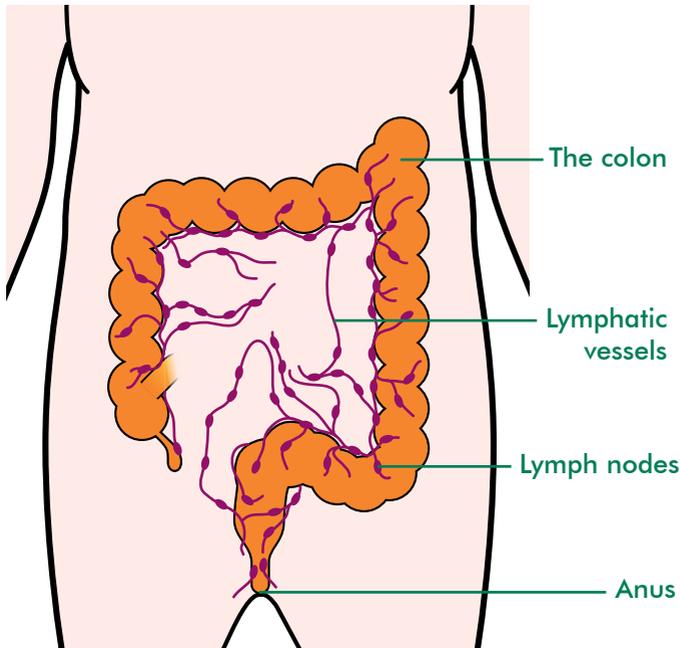
The walls of the anal canal are lined with cells called squamous cells. Nearly all anal cancers develop in these cells (see page 22).

Where the anal canal meets the rectum (transitional zone), the walls are lined with a mix of squamous cells and glandular cells. Glandular cells produce mucus that helps the bowel motions to pass through the anus.

# The lymphatic system

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

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection. Sometimes cancer can spread through the lymphatic system to nearby lymph nodes. You may have tests on the lymph nodes to look for cancer cells (see page 20).



There are many lymph nodes close to the bowel

# Causes and risk factors

In the UK, about 1,100 people develop anal cancer each year. It is slightly more common in women than men. The exact cause in most people is still unknown. However, we know that certain things called risk factors can increase a person's chances of developing it. Having one or more risk factors doesn't mean you will definitely get anal cancer. Equally, if you don't have any risk factors, it doesn't mean you won't get anal cancer.

## Age

Like most types of cancer, the risk of developing anal cancer increases as you get older.

## Human papilloma virus (HPV)

Anal cancer is more likely to develop in people who've had a viral infection called the human papilloma virus (HPV). There are over 100 different types of HPV and only a few of them are linked to cancer.

HPV is a very common infection – about 80% of us will have an HPV infection at some point. The risk of having the virus increases with the number of sexual partners you have.



We can send you further information about HPV and cancer.

## Sexual activity

People who have anal sex are more likely to develop anal cancer. This may be because they are more likely to have anal HPV. However, anal cancer can also develop in people who haven't had anal sex or HPV.

## Lowered immunity

The immune system is part of the body's defence against infections and illnesses such as cancer. Anal cancer is more common in people who have a lowered immunity, such as people taking medicines to suppress their immune system after an organ transplant or people with conditions such as HIV.

## Smoking

Smoking tobacco increases the risk of developing anal cancer. Stopping smoking can help reduce the risk of developing cancer.



We have more information about stopping smoking that we can send you.

# Symptoms

The most common symptoms of anal cancer include:

- bleeding from the anus
- pain, discomfort and itching around the anus
- small lumps around the anus – which may be confused with piles (haemorrhoids)
- difficulty controlling your bowels (faecal incontinence)
- discharge of mucus from the anus
- ulcers around the anus that can spread to the skin of the buttocks.

About 1 in 5 (20%) people with anal cancer have no symptoms.

Although these symptoms can be caused by conditions other than anal cancer, it's important that you always have them checked by your GP. Many people are embarrassed or uncomfortable discussing this area of their body. But it's not unusual for doctors to examine the anus and back passage, and they will help put you at ease.



If you have symptoms that don't improve within a few weeks, or if your symptoms are getting worse, it's important that you're referred to a specialist. They can arrange tests to find out what the problem is.



# DIAGNOSING ANAL CANCER

---

How anal cancer is diagnosed	16
Types of anal cancer	22
Staging of anal cancer	24
Grading of anal cancer	27

# How anal cancer is diagnosed

You will usually start by seeing your GP, who will feel your tummy (abdomen) and may examine your back passage (a rectal examination). To do this, your GP places a gloved finger into your back passage to feel for any lumps or swellings. This may be uncomfortable, but it will be less uncomfortable if you are able to relax. Let your GP know if you find the rectal examination painful, as it's important that they tell the hospital specialist.

You may have a blood test to check for anaemia (a low number of red blood cells). You may also have blood tests to check whether your liver and kidneys are working normally.

If your GP is unsure what the problem is, or thinks that your symptoms could be caused by cancer, they will refer you to a hospital specialist. You will usually be referred to either a surgeon or a specialist in bowel conditions (a gastroenterologist).

If a cancer is suspected, you should be seen at the hospital within two weeks.

## At the hospital

At the hospital, the specialist will ask about your general health and any previous medical problems. They will examine you and repeat the rectal examination (as above). Women may also have an internal examination of their vagina, as the vaginal wall is very close to the anal canal.

The specialist will need to do some tests before they can diagnose anal cancer.

## Examination and biopsy

The doctor will put a thin tube into your back passage to examine the anal canal and rectum. This is called a **proctoscopy**. You'll have this test in the hospital outpatients department or on a ward.

You will be asked to lie curled on your left side while the doctor gently passes a tube (proctoscope) into your back passage. They doctors can see any abnormal areas by using a tiny light and camera on the end of the tube. If necessary, they can take a small sample of cells (**biopsy**). These cells will be examined under a microscope. You should be able to go home as soon as the proctoscopy is over.

A proctoscopy can be uncomfortable and may be painful. If it is too painful, the doctor may arrange to examine you under an anaesthetic. This is so that the specialist can examine the area more closely and take biopsies.

A biopsy of the anal margin (see the illustration on page 9) can sometimes be taken without using a proctoscope. A local anaesthetic will be used to numb the area before the biopsy is taken.

## Further tests

If the biopsy shows that you have anal cancer, you will need further tests to find out more about the position of the cancer and to see if it has begun to spread.

### **CT (computerised tomography) scan**

A CT scan takes a series of x-rays that build up a three-dimensional picture of the inside of the body. There is a photograph of someone having a CT scan on the opposite page.

The scan is painless and takes 10-30 minutes. It uses a small amount of radiation that is very unlikely to hurt you or anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

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

### **MRI (magnetic resonance imaging) scan**

This test is similar to a CT scan but uses magnetism, instead of x-rays, to build up a detailed picture of areas of your body.

The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used.



Before having the scan, you'll be asked to remove any metal belongings, including jewellery. Some people are given an injection of dye into a vein in the arm. This is called a contrast medium and can help make the picture clearer. During the test, you will be asked to lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It's also noisy, but you'll be given earplugs or headphones. You'll be able to hear, and speak to, the person operating the scanner.

### **Anal ultrasound scan**

This uses sound waves to form a picture. A small probe that produces sound waves is passed into the back passage (rectum). This scan can show the size and extent of the tumour and takes about 30 minutes. The test is usually painless, but let your doctor know if you have any pain.

### **Fine needle aspiration (FNA) of the lymph nodes**

You may have this test if the lymph glands in your groin are larger than normal. It is done to see if there are any cancer cells in the lymph glands.

The doctor passes a fine needle into the lymph node and withdraws (aspirates) some cells into a syringe. This might feel a little uncomfortable but it's very quick. You might have an ultrasound scan at the same time to help guide the needle.

After the test, a doctor will examine the sample under a microscope to check for cancer cells.

## PET-CT scan

This is a combination of a CT scan (see page 18) 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. They are not always necessary but you can discuss with your doctor whether one would be useful in your case. You may have to travel to a specialist centre to have one.

## Waiting for 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.

Remember that you don't have to keep your worries to yourself. Talking about how you feel and getting support from family, friends or your specialist nurse and doctor can make it a bit easier. You could also talk to a cancer support specialist on **0808 808 00 00**.

# Types of anal cancer

There are different types of anal cancer. Knowing the type you have allows your doctor to plan your individual treatment.

## Squamous cell carcinoma

Nearly all anal canal cancers (9 out of 10) develop in the squamous cells that line the anal canal and the anal margin (see the illustration on page 9). They are also known as keratinising squamous cell cancer.

## Basaloid carcinoma

These are cancers that develop in the squamous cells in the transitional zone (see the illustration on page 9). They are also known as non-keratinising squamous cell cancer.

## Adenocarcinoma

Some anal canal cancers develop in the glandular cells that produce mucus. They are rare – less than 5 in 100 (5%) anal cancers are this type. Anal adenocarcinomas behave very like rectal cancers and are treated in the same way.

## Basal cell carcinoma

This is a type of skin cancer that develops in the area around the anus. It is usually treated in the same way as other basal cell skin cancers.

## Melanoma

This is a type of skin cancer that develops from cells called melanocytes. These are cells that give our skin its colour. Anal melanoma is rare – less than 1 in 100 (1%) anal cancers are this type. They are usually treated in the same way as other skin melanomas.



The information in this booklet is about the treatment of squamous cell anal cancers, including basoloid cancers. We have separate information about the treatment of rectal cancer, skin cancer and anal melanoma that we can send you.

# Staging of anal cancer

The stage of a cancer describes its size and whether it has spread from where it started. Knowing the extent of the cancer helps the doctors to decide on the most appropriate treatment.

Generally, anal cancer is divided into four stages, ranging from small and localised, to cancer that has spread to other parts of the body. If the cancer has spread, this is known as **secondary** or **metastatic cancer**.

If the cancer comes back after initial treatment, it's known as **recurrent cancer**.

The most commonly used staging systems are number staging and the TNM staging system.

## Number staging

**Stage 1** – The cancer only affects the anus and is smaller than 2cm in size. It has not begun to spread into nearby lymph nodes or to the sphincter muscle.

**Stage 2** – The cancer is bigger than 2cm in size, but hasn't spread into nearby lymph nodes or to other parts of the body.

**Stage 3** – This is divided into two stages:

- **Stage 3A** – The cancer has spread to the lymph nodes near the rectum, or to nearby organs such as the bladder or vagina.
- **Stage 3B** – The cancer has spread to lymph nodes in the groin and pelvis, or to lymph nodes close to the anus, as well as nearby organs such as the bladder or vagina.

**Stage 4** – The cancer has spread to other parts of the body, such as the liver.

## TNM staging system

This system is more complex and can give more precise information about the tumour stage than the number staging system.

### T – Tumour

Doctors put a number next to the 'T' to describe the size and spread of the cancer.

**Tis** – This means the cancer is at its earliest stage (in situ). There are cancerous changes to some of the cells, but the abnormal cells are only found in the lining of the anus. If left untreated, these cells may develop into invasive cancer.

**T1** – The tumour is 2cm or smaller.

**T2** – The tumour is larger than 2cm, but not bigger than 5cm.

**T3** – The tumour is larger than 5cm.

**T4** – The tumour can be of any size but it has begun to grow into nearby structures, such as the vagina, bladder or urethra (the tube that carries urine from the bladder).

## **N – Nodes**

This describes whether there are any lymph nodes near the anus that have cancer in them. The 'N' may have an 'X' or a number written next to it:

**NX** – The lymph nodes were not examined.

**N0** – The lymph nodes were examined but no cancer was found.

**N1** – Cancer was found in the lymph nodes closest to the rectum (perirectal nodes).

**N2** – Cancer was found in the lymph nodes in the groin (inguinal nodes) or pelvis (pelvic nodes) on one side of the body.

**N3** – Cancer was found in either the rectal nodes and the nodes in the groin or pelvis OR in the nodes in the groin or pelvis on both sides of the body.

## **M – Metastasis**

Metastasis means that the cancer has spread to other parts of the body.

**M0** – The cancer has not spread to other parts of the body.

**M1** – The cancer has spread to other parts of the body, such as the liver.

Our cancer support specialists on **0808 808 00 00** can tell you more about TNM staging. It's also important to talk to your doctor for detailed information about your situation.

# Grading of anal cancer

The grade of a cancer gives doctors an idea of how quickly it may develop. Doctors will look at a sample of the cancer cells under a microscope to find the grade of your cancer. There are three grades: grade 1 (low-grade), grade 2 (moderate- or intermediate-grade) and grade 3 (high-grade).

## Grade 1 (low-grade)

The cancer cells tend to grow slowly and look quite similar to normal cells. They are sometimes described as being well differentiated. These cancers are less likely to spread than higher grade cancers.

## Grade 2 (moderate-grade)

The cancer cells look more abnormal. They are sometimes described as being moderately differentiated.

## Grade 3 (high-grade)

The cancer cells tend to grow more quickly and look very abnormal. They are sometimes described as poorly differentiated. These cancers are more likely to spread than low-grade cancers.



# TREATING ANAL CANCER

---

Treatment overview	30
Radiotherapy	35
Chemotherapy	43
Chemoradiotherapy	52
Surgery	54
Research – clinical trials	62

# Treatment overview

Treatment depends on the stage of the cancer and where it is in the anus. Your doctors will have carried out various tests (see pages 16–21) to help them plan your treatment.

It's important that you have the chance to discuss treatments with your doctor. This will help you understand why a particular treatment has been suggested, and how the treatment may affect you.

The main treatment for anal cancer is a combination of radiotherapy and chemotherapy. This is called **chemoradiotherapy**. The treatments are usually given at the same time (concurrently). Combined treatment is usually very successful and most people don't need any surgery.

**Surgery** may sometimes be used to relieve symptoms before chemoradiotherapy. If chemoradiotherapy doesn't get rid of all the cancer or if there are signs that it has come back (recurred), surgery may sometimes be used. Small, early stage anal cancers are sometimes removed with surgery alone.

**Radiotherapy** is occasionally used on its own if you aren't fit or well enough to have combined chemotherapy and radiotherapy.

**Chemotherapy** may be used on its own to treat an advanced anal cancer.



There is more information about these treatment types on pages 35–61.

## How treatment is planned (MDT)

A team of specialists will meet to discuss and decide on the best treatment for you. This multidisciplinary team (MDT) will include:

- a surgeon who specialises in bowel cancers
- an oncologist (cancer specialist), who specialises in chemotherapy and radiotherapy
- a nurse specialist, who gives information and support
- a radiologist, who analyses x-rays and scans
- a pathologist, who advises on the type and extent of the cancer
- a stoma care nurse, who gives information and support about stoma care.

It may also include other healthcare professionals, such as a gastroenterologist (doctor who specialises in bowel problems), dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

## Second opinion

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

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready. This will help you make sure your concerns are covered during the discussion.

## The advantages and disadvantages of treatment

You may be frightened of having cancer treatments because of the side effects that can happen. However, these can usually be controlled with medicines.

Before you start your treatment, it's important that you're fully aware of the advantages and possible disadvantages and side effects. Your doctor or specialist nurse will explain these to you. If you choose not to have treatment, you will be given supportive (palliative) care to control your symptoms.

Making decisions about treatment is always difficult. You can think about whether the side effects of treatment outweigh the possible benefits. You can discuss this in detail with your doctor.



There is more information in our booklet, *Making treatment decisions*. We can send you a free copy.

## Giving your consent

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

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

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

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment. You can use the space on pages 113–114 to do this.

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

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

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



# Radiotherapy

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

Radiotherapy, usually in combination with chemotherapy (chemoradiotherapy – see pages 52–53), is the most common treatment for anal cancer. The chemotherapy makes the cancer cells more sensitive to radiotherapy.

You may have radiotherapy on its own if your doctors feel that you aren't fit enough to have chemoradiotherapy. It's sometimes used on its own to relieve symptoms of advanced anal cancer.



You might find it helpful to read our booklet *Understanding radiotherapy*, which has more information about the treatment and how to cope with side effects.

## How radiotherapy is given

Radiotherapy can be given in two ways:

- From outside the body as **external beam radiotherapy**. This is the most common way of giving radiotherapy for anal cancer.
- By putting radioactive material into or close to the tumour. This is known as **internal radiotherapy** or **brachytherapy**. It isn't used to treat anal cancer very often. Your doctor or specialist nurse can give you more information.

## External radiotherapy

Radiotherapy for anal cancer is usually given to you as an outpatient in the radiotherapy department, as a series of short daily treatments. The radiotherapy is given using equipment similar to a large x-ray machine called a linear accelerator (often called a Linac). The treatments are usually given for a few minutes Monday–Friday, with a rest at the weekend. The course of treatment lasts 5–6 weeks. External radiotherapy doesn't make you radioactive and it's perfectly safe for you to be with other people, including children, throughout your treatment.

**Conformal radiotherapy** is a common way of giving external radiotherapy. A special attachment to the radiotherapy machine carefully arranges the radiation beams to match the shape of the cancer. Shaping the radiotherapy beams reduces the damage to the surrounding healthy cells. This can reduce the side effects of the radiotherapy treatment and may allow higher doses to be given, which could be more effective.

Another type of radiotherapy, known as **intensity-modulated radiotherapy (IMRT)** which is similar to conformal radiotherapy, may be used in some hospitals. We have more information about IMRT, which we can send you.

## Planning your radiotherapy treatment

To make sure radiotherapy is as effective as possible, it has to be carefully planned by a clinical oncologist (a doctor who specialises in radiotherapy treatment for cancer).

Your treatment will be planned on your first visit to the radiotherapy department.

Usually, you'll have a CT scan of the area to be treated. The doctor may place a small metal marker on the skin around your anal margin (see the illustration on page 9). The marker shows up on the scan so that the doctor can see the exact area to be treated. The radiographer may draw tiny marks on your skin. These marks must stay visible throughout your treatment, and permanent marks (like tiny tattoos) may be used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

## Treatment

Before each session of radiotherapy, you'll be carefully positioned on the couch. The radiographer will make sure that you are comfortable.

During your treatment, which only takes a few minutes, you'll be left alone in a room. You can talk to the radiographer who will be watching you from another room. Radiotherapy isn't painful, but you do have to be still for a few minutes during treatment.

## Possible side effects of radiotherapy

You may develop side effects over the course of your treatment. These usually disappear gradually over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you so you know what to expect. Let them know about any side effects you have during or after treatment, as there are often things that can be done to help. If you smoke, it can help to reduce the side effects if you give up (see page 77).

### **Extreme tiredness (fatigue)**

Radiotherapy can make you feel very tired. Try to get as much rest as you can, especially if you have to travel a long way for treatment. Balance this with some physical activity, such as short walks, which will give your more energy. You may find our booklet *Coping with fatigue* helpful.

### **Diarrhoea and passing wind**

The radiotherapy is likely to cause irritation and inflammation of the rectum and anus. This can cause problems with your bowels, such as diarrhoea or passing more wind. These can sometimes be reduced by avoiding particular foods. Your doctor or a dietitian at the hospital can give you advice about this. Our booklet *Eating problems and cancer* has tips on coping with problems such as diarrhoea and wind.

### **Skin reaction**

It's likely that your skin will be sore in the area being treated. This includes soreness around the anus and in the groin, as well as the scrotal area for men and the vulval area for women. This usually starts about 2–3 weeks after treatment starts. The skin may become blistered and sore, and the area may be quite painful. You can be prescribed painkillers to help with this. The skin reaction will last for 3–4 weeks after the radiotherapy has finished, and should eventually heal completely.

The hospital staff will check the area and will advise you how to look after your skin. It's important that you only use products they recommend. If it becomes very painful to pass urine, the staff may suggest that you have a fine tube (catheter) put into your bladder to drain the urine. This is removed once your skin has healed.

'The hospital will give you drugs for the nausea, diarrhoea, and cream for (possibly) itchy hands. Whilst practice varies, they will also probably give you some aqueous cream for the inevitable sore bum. However a good many of us also used aloe vera creams and found it very good.'

**Graham**

### **Inflammation of the bladder (cystitis)**

Radiotherapy to the anal area may cause inflammation of the lining of the bladder. This can make you feel as though you want to pass urine often. You may also feel a burning sensation when you pass urine. It helps to drink plenty of water and other fluids to make your urine less concentrated. Your doctor can prescribe medicine to make passing urine more comfortable.

### **Feeling sick**

Some people may feel sick (nauseated), but this is usually mild and anti-sickness drugs (anti-emetics) can usually control this well. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can also be prescribed by your doctor. It's important to drink plenty of fluids if you can.



We can send you information about controlling sickness and nausea.

## Hair loss

It's common to lose your pubic hair. It should grow back after your treatment finishes, although the hair loss may be permanent.

These side effects usually decrease gradually once the treatment has ended, but it may take some months for skin changes to go back to normal. It's important to discuss any problems with your doctor or specialist nurse, as there are often ways to reduce them.

## Possible long-term side effects of radiotherapy

Newer ways of giving radiotherapy aim to reduce the risk of permanent side effects. This has meant that the number of people who develop long-term problems is reducing. However, when radiotherapy is given with chemotherapy, the long-term effects of radiotherapy may be increased.



We can send you a booklet about the possible long-term effects of pelvic radiotherapy.

## Vaginal dryness

Women may develop dryness and narrowing of the vagina. Because of this, you may need to use a lubricating jelly during sex. You may also be advised to use a vaginal dilator with lubricating jelly to help keep the vaginal walls open and supple. Your doctor or specialist nurse can give you more information about this.

## **Bowel changes**

A few people find that the way their bowel works is permanently altered. However, for most people, the change is not usually severe. It can usually be easily managed, although you may need to take medication.

## **Fertility**

Radiotherapy to the pelvic area is very likely to cause infertility (the loss of the ability to have children) in both men and women. If you are concerned about the risk of becoming infertile, it's important to discuss this with your specialist before starting treatment. We have information about cancer treatments and fertility in men and women.

## **Menopause**

Women who have not been through the menopause may find that treatment brings on an early menopause. This can cause hot flushes and sweats. Your doctor or nurse can give you advice on managing menopausal symptoms.

## **Erectile dysfunction**

Men may become unable to have an erection (erectile dysfunction – ED) after treatment. Talk to your doctor or specialist nurse if this is a problem for you. We have information in our booklets about sexuality and cancer.

These effects can be distressing. Discuss them with your doctor or specialist nurse, who can help you to find ways of dealing with them. See pages 82–83 for more information.



# Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs work by disrupting the growth of cancer cells, but they also affect normal cells. The chemotherapy drugs are usually given by injection into a vein (intravenously).

Chemotherapy is usually given in combination with radiotherapy (chemoradiotherapy – see pages 52–53).

Chemotherapy may be used on its own to treat advanced anal cancer to help shrink the size of the tumour and improve symptoms.

The most commonly used chemotherapy drugs are:

- mitomycin
- fluorouracil (5FU)
- capecitabine (Xeloda<sup>®</sup>), which is taken as a tablet and sometimes used instead of fluorouracil.

Other drugs that may be used are:

- cisplatin
- carboplatin
- paclitaxel.

We can send you information about individual chemotherapy drugs and combinations.

## How chemotherapy is given

Most chemotherapy drugs for anal cancer are given by injection into a vein (intravenously).



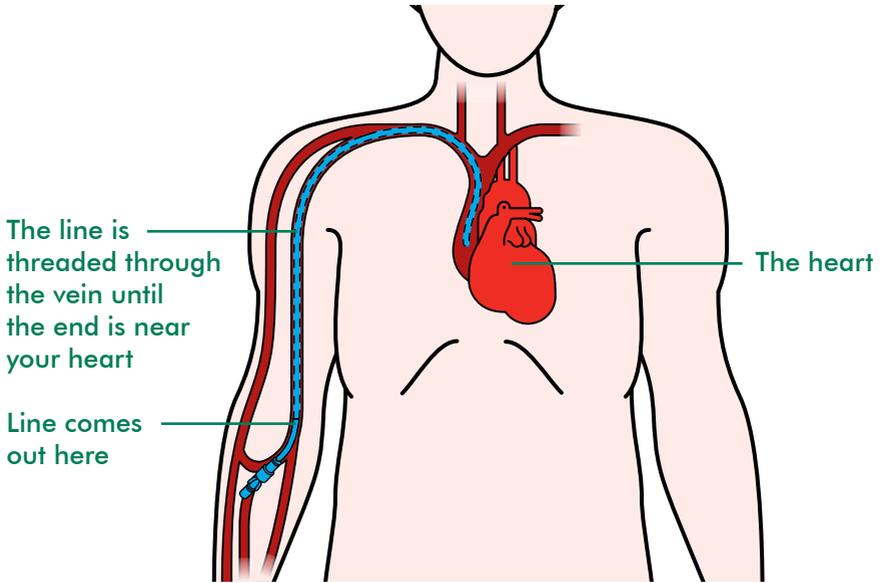
There are three videos about chemotherapy on our website. They show inside a treatment centre and feature health professionals and people having treatment. Visit [macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)

You may be given drugs into your vein through one of the following:

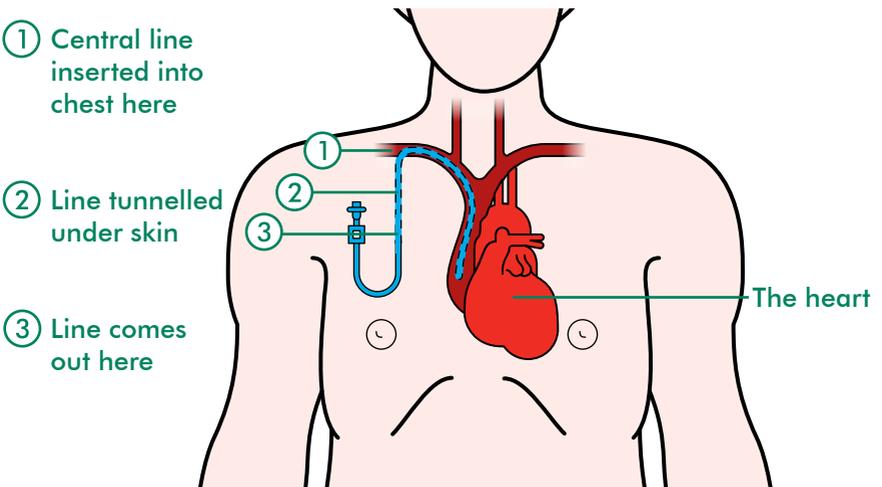
- A PICC line – a long, thin, flexible tube inserted into a vein in the crook of your arm. It stays in until your whole course of chemotherapy is completed.
- A central line – a long, thin, flexible tube inserted into a vein in your chest. It stays in until your whole course of chemotherapy is completed.
- A cannula – a short, plastic tube put into a vein in the back of your hand or arm. It's taken out before you go home.

You can read more about PICC and central lines in our general booklet about chemotherapy.

Sometimes chemotherapy can be given continuously through a small portable pump, which is attached to your PICC or central line. A controlled amount of the drug is given into the bloodstream over a set period of time. This means that you can go home with the pump, and spend less time in hospital.



A PICC line



A central line



On our website there are two animations that show how PICC lines and central lines are put in the body. Visit [macmillan.org.uk/havingaPICCline](https://www.macmillan.org.uk/havingaPICCline) and [macmillan.org.uk/havingacentralline](https://www.macmillan.org.uk/havingacentralline)

You can have intravenous chemotherapy as an outpatient or inpatient, depending on the treatment. If the treatment lasts for only a few hours, it's usually given as an outpatient.

If your treatment lasts a few days you will usually have it as an inpatient. It may be possible for you to have it as an outpatient. Your specialist will discuss this with you.

After the treatment, you'll usually have a rest period of a few weeks. This allows your body to recover from the side effects of the treatment. The treatment and rest period make up a cycle of treatment. Your doctor or specialist nurse will explain how many cycles of treatment you need.

## Possible side effects of chemotherapy

Chemotherapy can sometimes cause side effects, but if your cancer is causing symptoms it can also make you feel better by relieving them. Most people have some side effects from chemotherapy. Your doctor or nurse will tell you more about what to expect. Tell them about any side effects you have as they can usually be well controlled with medicines.



Common side effects are described here. Although they can be hard to deal with, they usually disappear gradually when your treatment finishes.

## Risk of infection

Chemotherapy can reduce the number of white blood cells, which help fight infection. If the number of your white blood cells is low, you'll be more prone to infections. A low white blood cell count is called neutropenia.

Always contact the hospital immediately on the 24-hour contact number you've been given and speak to a nurse or doctor if:

- you develop a high temperature, which may be over 37.5°C (99.5°F) or over 38°C (100.4°F) depending on the hospital's policy – follow the advice that you have been given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection) or diarrhoea.

If necessary, you'll be given antibiotics to treat any infection.

You'll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally, your treatment may need to be delayed if the number of your white blood cells is still low.

## Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

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

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. You'll feel more energetic and any breathlessness will be eased.

### **Tiredness (fatigue)**

You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing. Balance rest with some physical activity – even going for short walks will help increase your energy levels. Our booklet *Coping with fatigue* has more helpful tips.

'I kept a daily journal. I wrote various things, such as the time I took painkillers, important because you may suffer with "chemo brain" ie being forgetful. Also when I had bowel movements as the nurses all ask the question, 'Have you been?'. Also how much pain I had, how many times, how I felt, was I happy or sad, who visited me.'

**Valerie**

## **Nausea and vomiting**

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent, or greatly reduce, this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

## **Diarrhoea**

Some chemotherapy drugs used to treat anal cancer can cause diarrhoea. This often starts several days after the treatment. If you're taking chemotherapy tablets or capsules at home, it's important to let your doctor or nurse know if you have diarrhoea. Your treatment may need to be stopped until the diarrhoea is better. It's important to drink plenty of fluids if you have diarrhoea. You may also be able to help control it by eating a low-fibre diet.

## **Sore mouth**

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Some people find that sucking on ice may be soothing. Drink plenty of fluids and clean your teeth regularly and gently with a soft toothbrush, to help reduce the risk of infections in your mouth. Tell your nurse or doctor if your mouth is sore. They can prescribe mouthwashes and medicine to prevent or clear mouth infections.

## **Sore hands and feet**

This is called palmar-plantar, or hand-foot, syndrome. It gets better when treatment ends. Your doctor or nurse can give you advice and prescribe creams to improve the symptoms. It can help to keep your hands and feet cool and to avoid tight-fitting socks, shoes and gloves.

## **Fertility**

Chemotherapy may affect your fertility (being able to get pregnant or father a child). If you are worried about this, you can talk to your doctor or nurse before treatment starts.

## **Contraception**

Your doctor will advise you not to become pregnant or to father a child while having chemotherapy. This is because the drugs may harm a developing baby. It's important to use effective contraception during, and for a few months after, chemotherapy. You can talk to your doctor or nurse about this.

## **Sex**

If you have sex within the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

There's more information about sex and fertility on pages 82–83.



# Chemoradiotherapy

Chemoradiotherapy is a combination of chemotherapy and radiotherapy. It's sometimes known as chemoradiation and is the main treatment for anal cancer.

The chemotherapy drugs can make the cancer cells more sensitive to radiotherapy, so a combination of treatment is usually more effective than having radiotherapy or chemotherapy alone.

## How chemoradiotherapy is given

Your doctor will explain the treatment plan that is best for you. A commonly used treatment plan involves 5–6 weeks of radiotherapy (see pages 35–41) and two cycles of chemotherapy (see pages 43–50).

The most commonly used chemotherapy drugs used are fluorouracil (5FU) and mitomycin. Sometimes a drug called capecitabine, which is taken as a tablet, is used instead of fluorouracil.



We can send you information about individual chemotherapy drugs and combinations.

On the first day of treatment, you will start the chemotherapy. You will also have your first radiotherapy treatment. You will have radiotherapy Monday–Friday, for 5–6 weeks. Four weeks after you started treatment, you will have a second cycle of chemotherapy.

If you are well enough, the radiotherapy is usually given to you as an outpatient. You may have to stay in hospital if you are having the chemotherapy as an infusion. But it's usually possible for you to go home each day with a portable chemotherapy pump (see page 44). If you are having chemotherapy tablets, you can go home each day after the radiotherapy.

## **Side effects of chemoradiotherapy**

Giving chemotherapy and radiotherapy together can make the side effects of treatment worse. Your doctor or specialist nurse will give you more information about chemoradiotherapy and the possible side effects. You may get more tired and have more problems with diarrhoea and sore skin. Tell your doctor, specialist nurse or radiographer about your side effects so that they can help you find ways to cope with them.

# Surgery

Surgery used to be the main treatment for anal cancer. For most people with anal cancer, a combination of chemotherapy and radiotherapy (**chemoradiotherapy** – see pages 52–53) is now more likely to be recommended. Chemoradiotherapy is more effective at curing the cancer than surgery and usually means that you don't need to have a permanent colostomy (see below).

Surgery may sometimes be used if your chemoradiotherapy treatment doesn't completely get rid of the cancer, or if there are signs that the cancer has returned (recurred). Sometimes it's used if radiotherapy isn't appropriate, for example if you've had radiotherapy to the area before. Occasionally, it's used to relieve symptoms before treatment with chemoradiation.

Surgery may also be used to remove small tumours.

Your doctor will discuss with you whether surgery is needed and if so, the most appropriate type of surgery for your situation.

## Types of surgery

### Local excision

This may sometimes be used to treat small, early stage cancers in the anal margin (see the illustration on page 9).

The operation only removes the area of the anus containing the cancer cells. The anal sphincter isn't usually affected, so you should still be able to control your bowel in the normal way.

Your doctors may sometimes recommend that you have radiotherapy or chemoradiotherapy after you've had surgery.

## Abdomino-perineal excision

If the cancer hasn't gone completely after chemoradiotherapy, or if it comes back after treatment, you may be advised to have an abdomino-perineal (AP) excision. This involves removing the anus, the rectum and part of the large bowel (colon).

After an AP excision, you will usually have two wounds – an abdominal wound where the surgeon has removed the anus and rectum, and a wound where the anus has been surgically closed.

Sometimes the surgeon can do the operation using only four or five small cuts (about 1cm each) in your abdomen. They use specially designed instruments that can be put through these small cuts. This type of surgery is known as **laparoscopic** or **keyhole surgery**. There will still be a wound where the anus has been surgically closed.

Because the rectum and anus are removed, you will need a permanent colostomy. This involves diverting the open end of the bowel to the surface of the abdomen (tummy area), to allow bowel motions (stools) to be passed out of the body into a colostomy bag. The opening on the abdominal wall is called a stoma. See pages 70–74 for more information about having a colostomy.

## **Surgery to relieve symptoms**

Occasionally, you may need surgery to make a temporary colostomy (see page 55) before chemoradiotherapy starts. A temporary colostomy may be used to help relieve symptoms if:

- you are having a lot of difficulty opening your bowels
- the cancer is causing incontinence, a blockage in the bowel or significant pain
- there is an opening between the bowel and the skin or another organ, such as the bladder or vagina (a fistula).

Sometimes surgery may be done if there is a risk of a fistula forming.

After the treatment is finished, you will be assessed to see if the stoma can be closed to allow you to pass your stools through the back passage again.

## **Before your operation**

Before your surgery, the doctor and specialist nurses will explain the operation to you. They will tell you what to expect immediately after the surgery and in the few days after it. This is a good opportunity to ask any questions about the operation. If you need to have a colostomy, you will also meet a stoma care nurse.

Each hospital does things slightly differently, but you will probably be admitted to the ward on the day before your operation. This is so your doctors and nurses can do any further tests. You may be asked to follow a strict diet and take a medicine (laxative) to empty your bowels the day before surgery. Your nurse or doctor will explain this to you.

You will be given antibiotics as an injection into a vein (intravenously) just before and after surgery to prevent infections.

## After your operation

How quickly you recover from your operation will depend on your general health and the type of surgery you've had. Your doctor and specialist nurse can speak to you about what to expect.

### Getting moving

After your operation, you'll be encouraged to start moving around as soon as possible. This is an essential part of your recovery. Even if you have to stay in bed, it's important to do regular leg movements and deep breathing exercises. A physiotherapist or nurse will explain these exercises to you.

As you won't be moving around as much as usual, you may be at risk of blood clots. To prevent this, you'll be asked to wear special stockings, and may also be given injections of a drug (heparin) to prevent blood clots. These are given under the skin (subcutaneously).

### Drips and diet

When you go back to the ward, you'll have a drip (infusion) that gives you fluids through a thin tube (cannula) inserted into a vein in your hand or arm. This will be taken out once you're able to eat and drink normally again.

You may also have a thin tube that passes down your nose into your stomach, which is known as a nasogastric or NG tube. It allows any fluids to be removed from your stomach so that you don't feel sick. It's normally taken out after a few days.

You'll probably be ready to start taking sips of water on the evening or day after your surgery. This will be increased gradually and you will start a light diet as soon as possible.

### **Drains**

Often a small tube (catheter) is put into your bladder. This drains urine into a collecting bag. This is usually taken out after a couple of days. You may also have a drainage tube in your wound, to drain any extra fluid and make sure the wound heals properly. A drain isn't always needed.

### **Pain**

After your operation, you'll probably have some pain or discomfort for a few days. There are several different types of painkillers that can be given to you either at regular intervals or when you need them. You may be given painkillers into a vein in your arm through a pump.

The pump can be set to give you a controlled amount of painkiller, or you may be able to control this yourself by pressing a button. This is called patient-controlled analgesia (PCA). You can give yourself an extra dose of painkiller when you need it by pressing a button. The machine is set so you get a safe dose and can't have too much.

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

Always let your doctor or nurse know if you have any pain or discomfort. The painkillers or the dose can be changed to suit your needs. After an abdomino-perineal resection, it may be uncomfortable to sit down, but this should gradually get better as the wound begins to heal.



## Going home

Depending on the type of operation you've had, you'll probably be ready to go home 2–14 days after surgery. If you think that you might have problems when you go home (for example, if you live alone or have several flights of stairs to climb), let your nurse or the social worker know when you're admitted to the ward. They can then arrange help before you leave hospital.

You'll be given an appointment to attend an outpatient clinic for your post-operative check-up.

If you have stitches, clips or staples in your wound, these are usually taken out 7–10 days after the operation. Your practice nurse can do this. If you can't leave home, a district nurse can visit you.

If you have a stoma, the hospital will give you stoma supplies to go home with. After this, you will need to order supplies from your chemist or direct from a specialist supply company. Your stoma care nurse can tell you about these.

Some people take longer than others to recover from their operation. We have more information about getting ready to go home from hospital.

### **Enhanced Recovery Programme (ERP)**

Some hospitals follow an Enhanced Recovery Programme that can help to reduce complications following surgery, and speed up recovery. It also involves you more in your own care. The programme involves careful planning before your operation so that you're properly prepared. Any arrangements needed for you to go home will also be organised for you.

You'll be encouraged to take high-protein and high-calorie supplements before and after your surgery, and to start moving around as soon as possible, sometimes on the day of the operation. After you've gone home, you'll be regularly reviewed to make sure that you are recovering well.

Your doctor will tell you if an enhanced recovery programme is suitable for you and if it's available at your hospital.

## Sex life after bowel surgery

Once you've recovered from the operation you should be able to go back to your usual sex life. This may depend on the type of surgery you've had. Your doctor or specialist nurse can discuss this with you.

You may find you feel self-conscious about the change in your body's appearance, especially if you now have a colostomy.

Sometimes the operation can cause damage to the nerves that go to the sexual organs. If this occurs, a man may not be able to have or maintain an erection, and may have problems with orgasm and ejaculation. Women may also find that their sexual function or response is affected. This may improve over time – however sometimes it is permanent. If you notice these problems, discuss them with your doctor or specialist nurse, they can offer the best advice and may refer you for a specialist assessment.

There's more information about sexuality on pages 82–83.

# Research – clinical trials

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

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

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

## Taking part in a trial

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

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

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



Our booklet *Understanding cancer research trials (clinical trials)* describes clinical trials in more detail. Call us on 0808 808 00 00 and we'll send you a copy.

## Blood and tumour samples

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

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



# AFTER YOUR TREATMENT

---

Follow-up	66
Diet after surgery for anal cancer	68
If you need a colostomy	70
Well-being and recovery	75
Sex and fertility	82

# Follow-up

After your treatment has finished, you'll have regular check-ups with your doctor. They will examine you and ask you how you are feeling and if you have any new symptoms. You may also have other tests and scans, such as a CT scan, MRI scan or ultrasound. The follow-up appointments will continue for several years, but will become less frequent as time goes on.

If you have any problems or notice any new symptoms between your appointments, let your doctor know as soon as possible. Late side effects that you should tell your doctor about include:

- bleeding from the back passage (rectum), vagina or bladder – these are often a late side effect of radiotherapy
- difficulty passing bowel motions or wind (flatus)
- sexual problems
- irritated skin around the anus, groin, scrotum or vulva
- pain in the pelvis.

Your doctor may be able to help you with these problems. We can send you information about the possible late effects of radiotherapy to the pelvic area.

Many people find that they get anxious before their follow-up appointments. This is natural and it may help to get support from family, friends or one of the organisations listed on pages 107–111 during this time.



For people whose treatment is over apart from regular check-ups, our booklet *Life after cancer treatment* gives useful advice on how to keep healthy and adjust to life after cancer.

# Diet after surgery for anal cancer

After surgery, you may notice that certain foods upset the normal working of your bowel, or colostomy if you have one. High-fibre foods, such as fruit and vegetables, may make your stools loose and make you pass them more often than normal.

Depending on the type of surgery you've had, you may have diarrhoea. Tell your doctor or nurse if this happens, as they can give you medicine to help. It's important to drink plenty of fluids if you have diarrhoea.

This is often only a temporary reaction, and after a while you may find that the same foods don't have any effect. There are no set rules about the types of food to avoid and each person needs to experiment for themselves. Foods that disagree with one person may be fine for another.

You may also find that your bowel produces more wind than before, and this can sometimes build up in the abdomen and cause pain. Drinking peppermint water or taking charcoal tablets can help to reduce this. Your doctor can prescribe these for you, or you can get them from your chemist.

It can sometimes take months for your bowel movements to get back to normal after surgery, and you'll probably need to find out which foods are right for you through trial and error. Some people may find that their bowel is always more active than before their surgery, and that they have to eat carefully to control their bowel movements.

If you continue to have problems, it's important to talk to a dietitian at the hospital. They can give you specialist advice for your individual situation.



You may find our information on eating problems and cancer helpful.



## If you need a colostomy

Some people with anal cancer will need to have a colostomy. This can be daunting at first. Learning to look after a stoma takes time and patience, and no one expects you to be able to cope straight away. Like anything new, it will get easier with time and practice.

In most hospitals, there are specially-trained nurses called stoma care nurses who you'll usually meet before your operation. They will show you how to look after your stoma and help you cope with any problems.

'Yes there is this big thing of 'oh no, not a stoma', but the darn things can help and with the aid of good stoma nurses they are manageable.'

**Glyn**

You may also find it helpful to talk to someone who is used to living with a stoma. Your nurse or doctor can often arrange for a volunteer to visit you and talk to you about the more practical and personal aspects of living with a stoma. This advice can be invaluable, particularly in the first few months after your operation. You can contact the Colostomy Association (see page 108) or our cancer support specialists on **0808 808 00 00** to talk about any concerns you have.

The Healthtalkonline website has information about colostomies. It also has video and audio clips of people who have stomas talking about their experiences (visit [healthtalkonline.org](http://healthtalkonline.org)).



We have two videos about stomas on our website. Visit [macmillan.org.uk/havingastoma](http://macmillan.org.uk/havingastoma) to watch a stoma nurse talking about looking after a stoma and showing the supplies you might use. Visit [macmillan.org.uk/livingwithastoma](http://macmillan.org.uk/livingwithastoma) to watch Pat's story of living with a stoma after surgery for rectal cancer.

Before your operation, the nurse or doctor will carefully plan the position of your stoma so that your bag stays in place, whether you are sitting, standing or moving around.

For the first few days after your operation, your nurse will show you how to look after your colostomy and make sure that the bag is emptied and changed as often as necessary. At first, your stoma will be slightly swollen and it can take several weeks before it settles down to its normal size.

As soon as you're feeling well enough, the nurse will show you how to clean your stoma and change the bags yourself. There are several different types of bag or appliance available, and the nurse will help you choose a suitable one.



## Looking after a stoma

When the nurse is showing you how to look after your stoma, it may help for a partner or close relative to be with you. They can help you if you have any difficulties when you get home.

Before you leave hospital, your nurse will make sure that you have a good supply of stoma bags. Before you start to change or empty your bag, make sure that you have plenty of bags and cleaning materials with you. It's a good idea to keep everything you need in one place, so that you don't have to search for things at the last minute. Give yourself plenty of time and privacy, so that you can work at your own pace without any interruptions.

Some people with a colostomy avoid wearing a bag by flushing out (irrigating) their colostomy about once a day, although this method doesn't suit everyone. Your stoma nurse will be able to discuss this with you in more detail.

'It does take a little bit of time to get used to it, and it takes confidence to get out there in the real world. Nobody's going to know. You don't have to go into places where there's going to be a lot of people straight away. Just do things in little bite-size chunks and see how it goes.'

**Pat**

## Stoma supplies

There are different ways of getting stoma supplies when you're at home. You can get all your supplies from your chemist. Sometimes it's better to get your supplies direct from a specialised supply company. These may also offer a cut-to-fit and home delivery service. The Colostomy Association has details of companies (see page 108).

The supplies are free, but you'll need a prescription from your GP. If you're aged 16–60, make sure that your doctor signs the form saying that you're entitled to free prescriptions.

## Home support

Once you're at home, you can phone the stoma nurse if you have any problems. Your GP may also arrange for a district nurse to visit you for a few days when you first leave hospital. They can make sure you're coping at home, and sort out any problems that you may have with your stoma.

Having a colostomy is a big change in your life. Many people find that they are embarrassed by the stoma, and that it affects the way they feel about their bodies. This can also affect relationships, and some people are uncomfortable about their partner seeing their stoma.

These feelings are a natural part of coming to terms with the changes that a stoma causes, and usually decrease gradually over time.

You can contact our cancer support specialists on **0808 808 00 00** if you want to chat about any concerns you have. Details of helpful organisations are on pages 107–109.

# Well-being and recovery

Many people survive anal cancer. However, the treatment can be very hard on the body and it may be some time before you are feeling fit and well again. Some people experience treatment side effects that gradually improve over time, while others may have ongoing effects.

You may have a range of other effects such as trouble sleeping, or feeling weaker and more tired than usual, rather than more specific side effects. You may also have gained weight or have stiff muscles or joints.

'There's no getting away from the fact that cancer is life-altering and for a while, it does dictate how you live your life. This can be difficult to accept, but try and look on it as a temporary setback and go with the flow. Time will pass, you will come out the other side.'

**Angela**

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

## Positive lifestyle changes

Some people want to make changes to their lifestyle after cancer. You might choose to make just a few changes or completely change the way you live. Adopting a healthy lifestyle doesn't have to be very difficult or expensive.

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

Your healthy lifestyle will be individual to you, and what is right for you may not be right for someone else. A healthy lifestyle can include having a well-balanced diet, getting some exercise, reducing stress and being involved in your healthcare. You'll need to think about any side effects of treatment when planning changes to your diet and exercise. Don't try to do too much too soon.

If you're considering making some major changes to your lifestyle, it can be a good idea to discuss your plans with your doctor or specialist nurse.

### **Eat well**

A well-balanced diet should include:

- plenty of fresh fruit and vegetables (at least five portions a day)
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic fluids.

Try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Before making major changes to your diet, it's a good idea to discuss your plans with your specialist or with a dietitian at the hospital.

### **Stop smoking**

Anal cancer is more likely to come back in people who smoke. If you smoke, giving up is one of the healthiest decisions you can make. Stopping smoking has many other health benefits and reduces your risk of other diseases such as heart disease and stroke. Our booklet *Giving up smoking* has information and tips to help you quit.

### **Get physically active**

Exercise doesn't have to be particularly strenuous. You can start gently and build up the amount of physical activity you do. Whatever your age or physical health, there will be some kind of exercise you could try, such as walking, hiking, cycling or swimming. Activities like gardening, dancing and playing sport are also good to try.

## Reduce stress

Having cancer can be a stressful experience. But there are lots of ways to reduce the stress in your life. Make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate or pray, or to start a new pastime or an evening class. You may find it helpful to write a journal or online blog.

'I decided to write a blog all the way through, which was humorous and brutally honest and I ended up with quite a few followers. Writing it helped me to get it off my chest and what my bloggers told me was it helped them to understand.'

**Tania**

## Get involved in your healthcare

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

## Getting help and support

Different people can help you during and after treatment.

### Practical help

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

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

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

### Emotional help

It's common to have different, and sometimes difficult, feelings after cancer treatment (see pages 86–89). But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family and friends often helps.

If you think you may be depressed or feel helpless or anxious a lot of the time, talk to your cancer specialist or nurse.

They can refer you to a psychologist or counsellor who specialises in the emotional problems of people with cancer. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and let you know about services in your area.

### Complementary therapies

Some people find that using some complementary therapies help them to relax or cope with treatment side effects. Some hospitals or support groups may offer therapies such as relaxation or aromatherapy. Our booklet *Cancer and complementary therapies* has information about the different types of therapy.



## Support groups

Self-help or support groups offer a chance to talk to other people who understand what you're going through. You can call us or visit our website for information about support groups in the UK.

'The best thing was the cancer support group. They tried to give us something practical to do. We started to cross stitch, which is something I really enjoy. There were people with cancer, survivors and close relatives.

**Caroline**

## Online support

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



Our online community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)) is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups.

# Sex and fertility

Anal cancer and its treatments can have an impact on your sex life and your ability to have children (fertility).

## Sex

Anal cancer, its treatment and side effects may affect your sex life and your feelings about yourself as a man or woman. Difficulties often gradually improve after treatment, although for some people it may take longer.

There may need to be a period of adjustment for you and your partner. You may feel insecure and worry whether or not your present or future partner will find you sexually attractive, especially if you have a colostomy. It can help to try to talk about it with them if you feel things are awkward between you.

Cuddles, kisses and massage can show how much you care for someone, even if you don't feel like having sex. You can wait until you and your partner feel ready – there's no right or wrong time.

## Getting some help

Talking about your feelings may help lessen your anxieties. Try not to feel embarrassed talking to your doctor or nurse about what is troubling you. They can refer you for counselling if you think that would be helpful.

There are treatments available, such as sildenafil (Viagra®) that can help men achieve erections. It's important to discuss this with your doctor as soon as you notice a problem, as treatment can often be more effective if started sooner.



We have booklets about sexuality and cancer for men and women, which you may find helpful. To order a free copy, visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us.

Let your doctor or specialist nurse know if any difficulties with your sex life don't improve. They may be able to reassure you and offer further help and support. If you feel uncomfortable talking to your doctor or nurse, you can call us on **0808 808 00 00**.

## Fertility

Some anal cancer treatments can affect your ability to have children (fertility). Chemotherapy can affect the quality of sperm in men and may cause an early menopause in some women. Radiotherapy to the pelvic area is very likely to cause infertility in both men and women.

It's important to talk to your cancer specialist about your fertility before treatment starts. Sometimes it may be possible to store sperm if you're a man. If you're a woman, it may be possible to remove eggs, fertilise them with your partner's sperm and store them.

Becoming infertile can be very hard to live with, whether or not you already have children. Some people find it helpful to talk through their feelings with a trained counsellor. If you need more specialist help, ask your doctor or nurse to arrange this for you.



There's more information in our booklets about cancer treatments and fertility. We have one booklet for men and one for women.



# YOUR FEELINGS AND RELATIONSHIPS

---

Your feelings	86
If you are a relative or friend	91
Talking to children	92

# Your feelings

## Guilt and embarrassment

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. You may feel ashamed because of the part of the body affected and its link with sexual activity and HPV. However, you shouldn't feel you're to blame in any way. Exactly how a person gets HPV is often uncertain and it's not always possible to find a sexual explanation. Remember most people have HPV at some point in their life without even knowing it. Try to focus on looking after yourself and getting the help and support you need.

'I thought my friends are going to be looking on the internet and looking up my cancer because they want to help and they'll want to understand and they've probably never heard of it. And they're going to think 'Maybe there is something she did that she didn't tell us about'. It was a bit embarrassing.'

**Tania**

Understandably, many people may find the treatments for anal cancer embarrassing. Don't be afraid to ask your doctor or nurse as many questions as you like, as this may help to put your mind at rest. If you feel that you need support, you can contact our cancer support specialists.

## Shock and disbelief

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

## Fear and anxiety

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

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

## Avoidance

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

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

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

## Anger

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

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

## Feeling alone

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

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

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

## If you need more help

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

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



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



# If you are a relative or friend

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

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

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

Our booklet *Lost for words – how to talk to someone with cancer* has more suggestions if you have a friend or relative with cancer.

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



We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

## Talking to children

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

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

'I have a 12 year old daughter and we did make the decision to tell her it was cancer. She is quite mature and we felt she would cope with it, which she has very well. We encourage her to talk about it to us and not to go away and worry, but to ask the questions she needs answers to. She also gets a lot of support at school.'

**Jacqueline**

## Teenagers

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

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



Our booklet *Talking to children and teenagers when an adult has cancer* has more information. There is also a video on our website that may help at [macmillan.org.uk/talkingtochildren](http://macmillan.org.uk/talkingtochildren)



# WORK AND FINANCIAL SUPPORT

---

Work 96

Financial help and benefits 97

# Work

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

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

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

## Employment rights

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



Our booklets *Work and cancer*, *Working while caring for someone with cancer* and *Self-employment and cancer* have more information. There's also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)

# Financial help and benefits

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

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

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

There are two different types of ESA:

- **contributory** – you can get this if you have made enough national insurance contributions
- **income-related** – you can get this if your income and savings are below a certain level.

From October 2013, a new benefit called **Universal Credit** is replacing income-related ESA. This is for people who are looking for work or on a low income.

**Personal Independence Payment (PIP)** is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance.

**Attendance Allowance (AA)** is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

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

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 111). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 111.



Our booklets *Insurance* and *Getting travel insurance* may also be helpful.

UNDERSTANDING  
**PRIMARY  
BONE CANCER**

IG  
L  
R

**COPING WITH  
SHORTNESS  
OF BREATH**

ING  
EFFECTS OF  
L  
R

UNDERSTANDING  
**BRAIN  
TUMORS**

UNDERSTANDING  
**INVASIVE AND  
ADVANCED  
BLADDER CANCER**

**CONTROLLING THE  
SYMPTOMS  
OF CANCER**

**CONTROLLING THE  
SYMPTOMS  
OF CANCER**

**BREAST  
RADIATION  
POSSIBLE SIDE  
EFFECTS**

**MEN AND  
WOMEN**

**RUNNING**



# FURTHER INFORMATION

---

About our information	102
Other ways we can help you	104
Other useful organisations	107
Your notes and questions	112

# About our information

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

## Order what you need

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

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

**There you'll also find videos**

featuring real-life stories from people affected by cancer, and information from health and social care professionals.

## Other formats

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

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

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

## Help us improve our information

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

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

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



# Other ways we can help you

**At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.**

## Talk to us

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

### Macmillan Support Line

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

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](https://www.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](https://www.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](https://www.macmillan.org.uk/selfhelpandsupport)

## Online community

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

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

## Help with work and cancer

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

Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

# Other useful organisations

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

## Bowel cancer support

### Beating Bowel Cancer

Harlequin House,  
7 High Street,  
Teddington TW11 8EE

**Tel** 08450 719301

(Mon–Thu, 9am–5.30pm)

**Email** nurse@beating

bowelcancer.org

**www.bowelcancer.org**

Gives information and support to people affected by bowel cancer.

### Bladder and Bowel Foundation

SATRA Innovation Park,  
Rockingham Road,  
Kettering NN16 9JH

**Tel** 0845 345 0165

**Email** info@bladderand

bowelfoundation.org

**www.bladderand  
bowelfoundation.org**

Provides information and advice on bladder and bowel symptoms.

### Bowel Cancer UK

**www.bowelcanceruk.org.uk**

Gives information and support to people affected by bowel cancer.

### Bowel Cancer UK in England and Wales

Willcox House,  
140–148 Borough High Street,  
London SE1 1LB

**Tel** 020 7940 1760

**Email** admin@bowel

canceruk.org.uk

### Bowel Cancer UK in Scotland

20 Queen Street,  
Edinburgh EH2 1JX

**Tel** 0131 225 5333

**Email** scotadmin@

bowelcanceruk.org.uk

### Bowel Cancer UK in Northern Ireland

Contact Karen Donaghey on **karen.donaghey@  
bowelcanceruk.org.uk**

### **Colostomy Association**

Enterprise House  
95 London Street  
Reading RG1 4QA  
**Tel** 0800 328 4257

**Email** [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

**[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)**

Assist and support people who have or are about to have a colostomy.

### **Cancer information and support**

#### **Cancer Black Care**

79 Acton Lane,  
London NW10 8UT  
**Tel** 020 8961 4151

#### **Email**

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

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

Offers information and support for people with cancer from ethnic communities, and their friends, carers and families.

### **Cancer Focus**

#### **Northern Ireland**

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Tel** 0800 783 3339

(Mon–Fri, 9am–1pm)

**Email** [hello@cancerfocusni.org](mailto:hello@cancerfocusni.org)

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

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

### **Cancer Research UK**

**[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)**

Has patient information on all types of cancer and has a clinical trials database.

### **Cancer Support Scotland**

Calman Cancer Support  
Centre, 75 Shelley Road,  
Glasgow G12 0ZE

**Tel** 0800 652 4531

**Email** [info@](mailto:info@cancersupportscotland.org)

[cancersupportscotland.org](http://cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

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

## **Macmillan Cancer Voices** **[www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices)**

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

## **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street,  
Glasgow G2 6AY

**Tel** 0300 123 1801

### **Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Provide information about cancer, benefits advice, and emotional or psychological support.

## **Tenovus**

Head Office,  
Gleider House, Ty Glas Road,  
Cardiff CF14 5BD

**Tel** 0808 808 1010

(Mon–Sun, 8am–8pm)

**[www.tenovus.org.uk](http://www.tenovus.org.uk)**

Aims to help everyone get equal access to cancer treatment and support.

## **Counselling, bereavement and emotional support**

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

BACP House,  
15 St John's Business Park,  
Lutterworth LE17 4HB

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

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

Promotes awareness and availability of counselling and signposts people to appropriate services.

You can search for a qualified counsellor on the website.

## **Support for carers**

### **Carers UK**

20 Great Dover Street,  
London SE1 4LX

**Tel** 0808 808 7777

(Mon–Fri, 10am–4pm)

**Email** [info@carersuk.org](mailto:info@carersuk.org)

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

Offers information and support to carers. Can put people in touch with local support groups. Has national offices for Scotland, Wales and Northern Ireland:

### **Carers Scotland**

The Cottage,  
21 Pearce Street,  
Glasgow G51 3UT  
**Tel** 0141 445 3070  
**Email** [info@carerscotland.org](mailto:info@carerscotland.org)  
**www.carersuk.org/scotland**

### **Carers Wales**

River House,  
Ynsbridge Court,  
Cardiff CF15 9SS  
**Tel** 029 2081 1370  
**Email** [info@carerswales.org](mailto:info@carerswales.org)  
**www.carersuk.org/wales**

### **Carers Northern Ireland**

58 Howard Street,  
Belfast BT1 6PJ  
**Tel** 028 9043 9843  
**Email** [info@carersni.org](mailto:info@carersni.org)  
**www.carersuk.org/northernireland**

### **Carers Trust**

32–36 Loman Street,  
London SE1 0EH  
**Tel** 0844 800 4361  
**Email** [info@carers.org](mailto:info@carers.org)  
**www.carers.org**  
A charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care. Works to improve support, services and recognition for anyone living with the challenges of caring. Has offices in Scotland and Wales:

#### **Glasgow office**

Skypark 3, Suite 1/2,  
14/18 Elliott Place,  
Glasgow G3 8EP  
**Tel** 0300 123 2008  
In Scotland, Carers Trust is known as The Princess Royal Trust for Carers.

#### **Cardiff office**

3<sup>rd</sup> Floor,  
33–35 Cathedral Road,  
Cardiff CF11 9HB  
**Tel** 0292 009 0087

## Financial or legal information

### Citizens Advice

Provides advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

#### England and Wales

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

#### Scotland

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

#### Northern Ireland

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

You can also find advice online in a range of languages at [adviceguide.org.uk](http://adviceguide.org.uk)

### Department for Work and Pensions (DWP) Disability Benefits Helpline

08457 123 456

**Textphone** 0845 722 4433

### Personal Independence Payment Helpline

0845 850 3322

**Textphone** 0845 601 6677

### Carer's Allowance Unit

0845 608 4321

**Textphone** 0845 604 5312

### [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

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

### GOV.UK

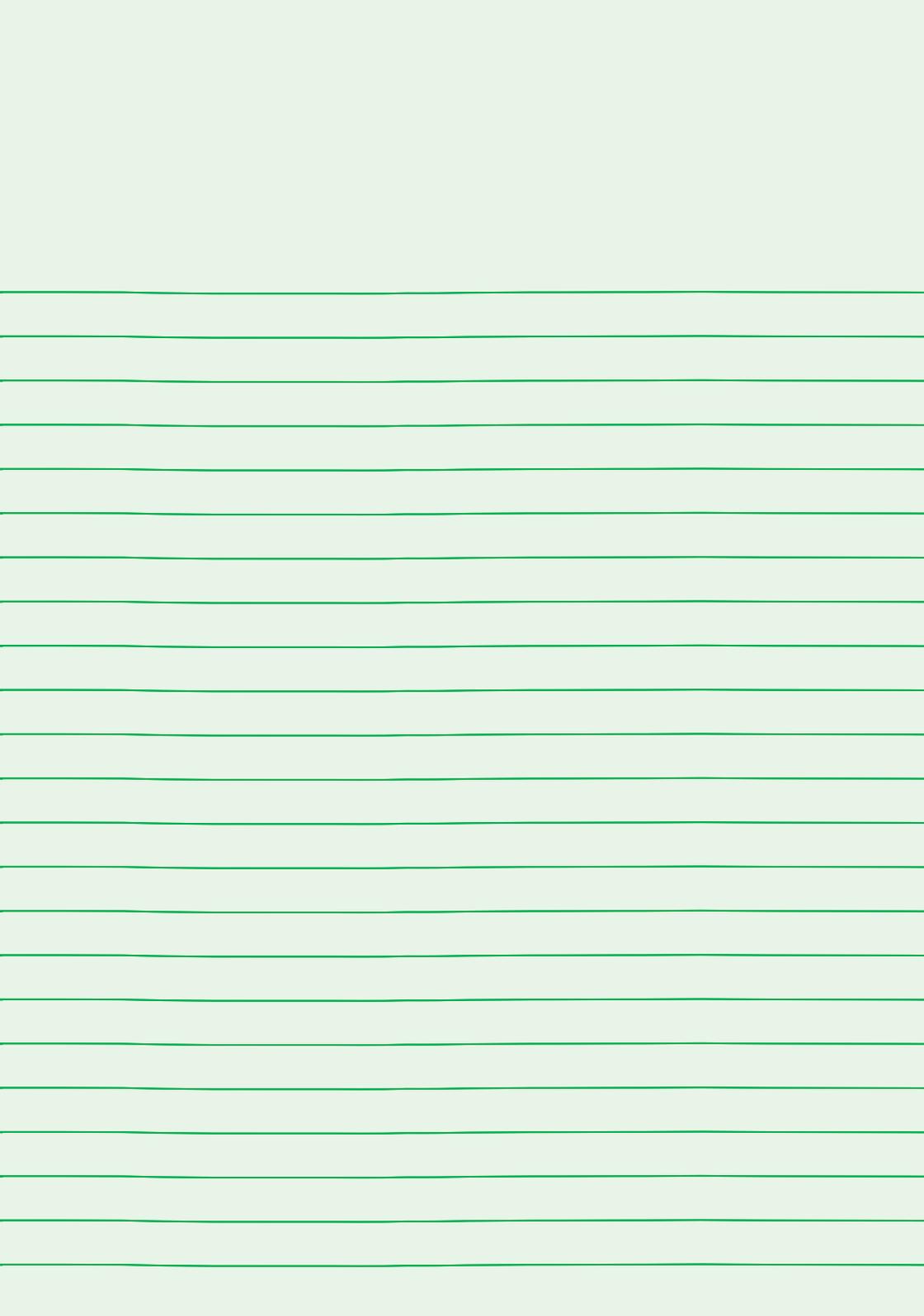
[www.gov.uk](http://www.gov.uk)

Has comprehensive information about social security benefits and public services.



You can search for more organisations on our website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations), or call us on 0808 808 00 00.





## Disclaimer

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

## Thanks

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

With thanks to: Dr Richard Adams, Clinical Oncologist; Fiona Butler, Macmillan Colorectal Cancer CNS; Dr Rachel Cooper, Consultant in Oncology; Mr Mark George, Consultant Colorectal Surgeon; Catriona Mclean, Consultant Clinical Oncologist; and the people affected by cancer who reviewed this edition.

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at [bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)

Cummings B & Brierley J. *Anal cancer*. Perez and Brady's Principles and Practice of Radiation Oncology (6<sup>th</sup> edition). Lippincott Williams & Wilkins. 2013.

Jiang Y, et al. *Cancer of the Anal Region*. Devita, Hellman and Rosenberg's Cancer: Principles and Practice of Oncology (9<sup>th</sup> edition). Lippincott Williams & Wilkins. 2011.

National Cancer Institute. *Staging information for anal cancer*. <http://www.cancer.gov/concertopics/pdq/treatment/anal/HealthProfessional/page3> (accessed April 2014).

Ryan D, et al. *Clinical features, staging, and treatment of anal cancer*. UpToDate online. [http://www.uptodate.com/contents/clinical-features-staging-and-treatment-of-anal-cancer?source=see\\_link](http://www.uptodate.com/contents/clinical-features-staging-and-treatment-of-anal-cancer?source=see_link) (accessed April 14). March 2014.

# 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](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

□□□□	□□□□	□□□□	□□□□
------	------	------	------

Valid from

□□	□□
----	----

Expiry date

□□	□□
----	----

Issue no

□□□
-----

Security number

□□□□
------

Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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](https://macmillan.org.uk/donate)

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.  
Non-English speaker? Interpreters available.  
Braille and large print versions on request.

© Macmillan Cancer Support, 2014. 1<sup>st</sup> edition. MAC14811.  
Next planned review 2017. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**