MACMILLAN
CANCER SUPPORT

UNDERSTANDING ANAL CANCER

> ‘I decided to write a blog all the way through which was humorous but brutally honest and I ended up with quite a few followers. Writing it really helped me to get it off my chest.’

Tania, diagnosed with anal cancer

About this booklet

This booklet is about anal cancer. The anus is part of the large bowel, which includes the colon and rectum. We have separate booklets about colon cancer and rectal cancer.

The booklet explains what anal cancer is, and how it is diagnosed and treated. It also talks about your feelings when you are diagnosed with cancer and has practical advice on dealing with work and finances.

We hope it helps you deal some of the questions and feelings you may have. We also have a video on our website about anal cancer. You can watch it at **macmillan.org.uk/analcancer**

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

On pages 116 to 123, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see page 124).

Quotes

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

For more information

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

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

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

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

Contents

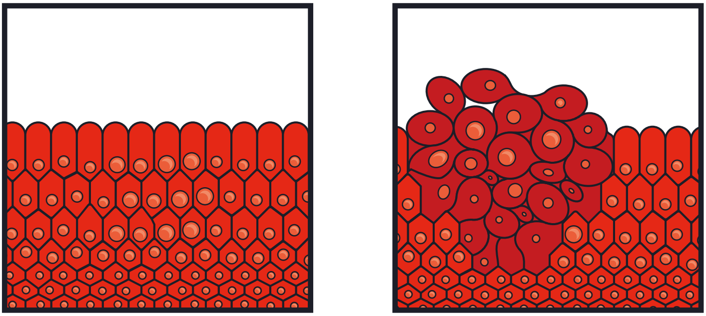
THE ANUS AND ANAL CANCER

What is cancer?

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

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

Cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

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

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

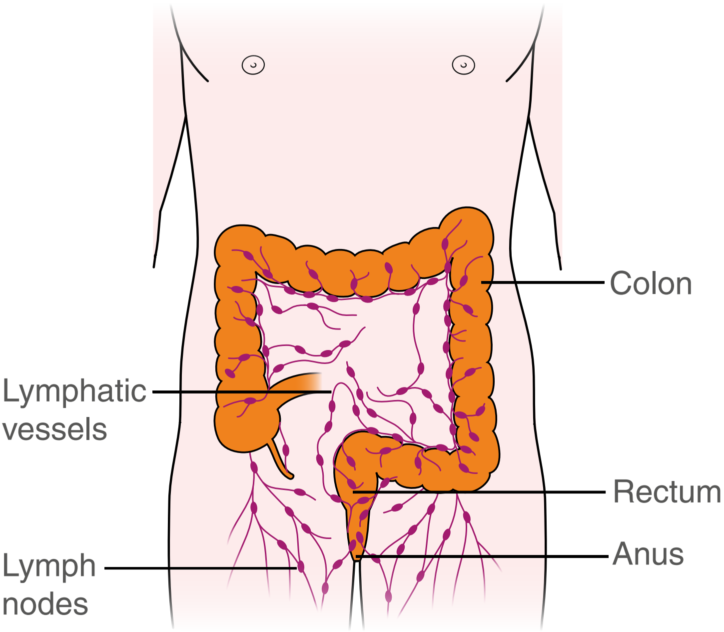
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 8). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The lymphatic system

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

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

Lymph nodes close to the bowel

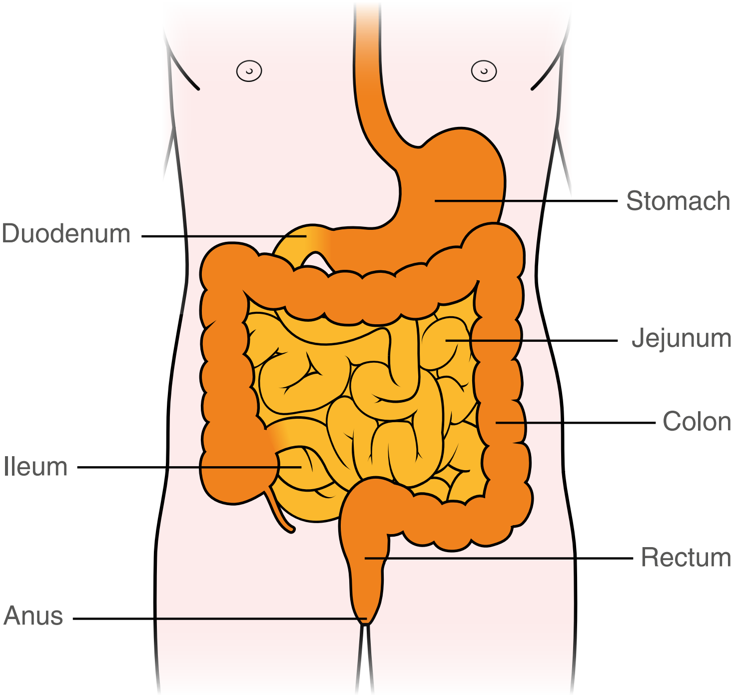


Sometimes anal cancer can spread to the lymph nodes close to the rectum and in the groin.

The anus

The anus is the opening at the end of the large bowel where we pass poo (stools) out of the body. The bowel (colon and rectum) and anus are part of the digestive system.

The digestive system



When you swallow food, it passes down the food pipe (oesophagus) to the stomach. This is where digestion begins.

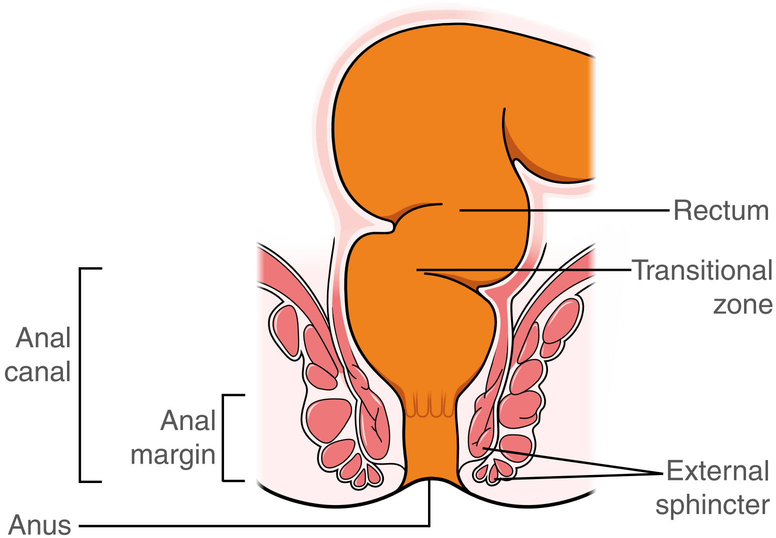
The food then enters the small bowel, where nutrients and minerals from food are absorbed. The digested food then moves into the colon. This is where water is absorbed.

The remaining waste matter (poo) is held in the rectum (back passage). Nerves and muscles in the rectum help to hold on to the poo until you are ready to pass it through the anus.

The anal canal is about 3 to 4cm (1 to 1½ in) long. It connects the anus to the rectum. The area where the anus opens at the lower end is called the anal margin or anal verge.

The anus has a ring of muscle called the external sphincter. This muscle helps to control when you empty your bowels.

A cross section of the anal canal



The walls of the anal canal are lined with cells called squamous cells (see page 27). Nearly all anal cancers develop in these cells.

Where the anal canal meets the rectum (transitional zone), the walls are lined with squamous cells and glandular cells. Glandular cells make mucus. This helps poo pass through the anus.

Causes and risk factors

In the UK, about 1,484 people develop anal cancer each year. It is more common in women than men.

Risk factors can increase the chance of a person developing a certain type of cancer. Having one or more risk factors does not mean you will definitely get anal cancer. If you do not have any risk factors, it does not mean you will not get anal cancer.

Most anal cancers are caused by the human papilloma virus (HPV) – see below. Almost everyone will have HPV at some point. But not everyone will develop anal cancer.

Human papilloma virus (HPV)

HPV is a virus that is linked to different cancers, including anal cancer. It is a common infection that is passed on through sexual contact. Most people have HPV at some point and never know they have had it.

There are over 100 types of HPV. Some types are more likely to cause cancer than others. Some types may cause genital warts. Using a condom can help reduce the risk of getting HPV.

Usually our immune system gets rid of the HPV infection without it causing any problems. But a small number of HPV infections may lead to cancer developing.

We have more information about HPV and cancer at **macmillan.org.uk.**

Lowered immunity

The immune system is part of the body’s defence against infections. Anal cancer is more common in people who have a lower immunity. This includes:

- people with HIV
- people taking medicines to suppress their immune system after an organ transplant.

Sexual activity

Having lots of sexual partners increases the chance of getting HPV. But even a person with only one partner can have this virus.

Having anal sex increases the risk of anal cancer. But HPV is passed on easily through any sexual contact. People may develop anal cancer even if they have never had anal sex.

Smoking

Smoking tobacco increases the risk of developing anal cancer. If you are diagnosed with anal cancer, stopping smoking has lots of benefits. Your doctor or nurse will talk to you about this.

Age

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

Anal intraepithelial neoplasia (AIN)

This is when abnormal cells develop in the skin just inside or outside the anus. This is usually caused by HPV.

Most people who have AIN have no symptoms. But symptoms can include:

- skin changes around the anus
- itching
- pain
- bleeding (but this is rare).

If AIN is left untreated, it can develop into anal cancer over many years.

Other cancers linked with HPV

HPV infection can also cause changes in the cells of the cervix or vulva. You may have a higher risk of anal cancer if you have had:

- abnormal cells in the cervix or vulva
- cancer of the cervix or vulva.

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 – these may be confused with piles (haemorrhoids)
- discharge of mucus from the anus
- ulcers around the anus
- difficulty controlling your bowels (leakage).

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

These symptoms can be caused by conditions other than anal cancer. But it is very important to get them checked by your GP. Many people are embarrassed or uncomfortable discussing this part of their body. But doctors are used to talking about and examining private areas of the body. They will help put you at ease.

It is important that your GP refers you to a specialist if:

- your symptoms do not improve within a few weeks
- your symptoms get worse.

Your specialist doctor can do tests to find out what might be causing the symptoms.

> ‘I had been to the doctor with bleeding and I was losing weight, despite having not done anything. I had a colonoscopy and it showed I had cancer.’

Kathy, diagnosed with anal cancer

DIAGNOSING ANAL CANCER

How anal cancer is diagnosed

You usually start by seeing your GP. They will feel your tummy (abdomen) and examine your back passage (rectal examination). Your GP will gently place a gloved finger into your back passage to feel for any lumps or swellings. This may be uncomfortable, but it does not take long. Let your GP know if you find the examination painful, because it is important for them to tell the hospital specialist.

You may have blood tests. This is to check for anaemia (a low number of red blood cells). The tests also check how well your liver and kidneys are working.

Your GP will refer you to a hospital specialist. This is usually either a surgeon or a specialist in bowel conditions (gastroenterologist). If your GP thinks you might have cancer, 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 feel your tummy and examine your back passage and talk to you about the tests you need to have.

Examination and biopsy

The specialist will examine the area for any signs of cancer. Women will probably have an internal examination of the vagina, as it very close to the anal canal.

Having an examination of the anus may be painful, so it is usually done under a general anaesthetic. This means you will be asleep so will not feel any pain. Some people may have this in the hospital outpatient department using a local anaesthetic. In this case, you will have an injection to numb the area, so you will not feel any pain.

Doctors use a thin tube called an anoscope to examine the anal canal. If they also examine the rectum, they use a slightly longer tube called a proctoscope.

You lie on your left side with your knees drawn up towards your chest. The doctor gently passes the tube into your back passage. The tube has a light and a magnifier on the end. The doctor uses it to look for any abnormal areas. They may apply a liquid to these areas to help them show up more clearly. The doctor removes a small sample of cells (biopsy) from any abnormal areas. The sample is sent to a laboratory. A doctor who specialises in studying cells (pathologist) checks it for cancer cells.

You should be able to go home as soon as the test is over or when you have recovered from the general anaesthetic.

Sometimes doctors can take a biopsy of the anal margin (see pages 10 to 11) without using an anoscope or proctoscope. If you have this, you will have a local anaesthetic to numb the area first.

Lymph nodes

The doctor will examine the lymph nodes in your groin as these are closest to the anus. If they are swollen, then you may have further tests to see if there is cancer in the lymph nodes.

Further tests

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

CT scan

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

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

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

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

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

Fine needle aspiration (FNA) of the lymph nodes

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

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 is very quick. You might have an ultrasound scan at the same time to help guide the needle.

After the test, a pathologist examines the sample under a microscope to check for cancer cells.

PET or PET-CT scan

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

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

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

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

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support (pages 116 to 123). You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

> **‘When I was diagnosed it was a shock, but the cancer team were great. They explained what treatment I was going to have and gave me a lot of information.’**
>
> **Denise, diagnosed with anal cancer**

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Types of anal cancer

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

Squamous cell carcinoma

9 out of 10 anal cancers (90%) develop in the squamous cells. The squamous cells make up the lining in the anal canal.

There are a few different types of squamous cell carcinoma, but they are all treated in the same way.

Adenocarcinoma

Some anal cancers develop in the glandular cells that make mucus. These are called adenocarcinomas. They are rare – less than 5 in 100 (5%) of all anal cancers are adenocarcinomas. Adenocarcinoma in the anus are very similar to 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 skin cancer that develops from cells called melanocytes, which give our skin its colour. Anal melanoma is rare – less than 1 in 100 anal cancers (1%) are this type. They are usually treated in the same way as other skin melanomas.

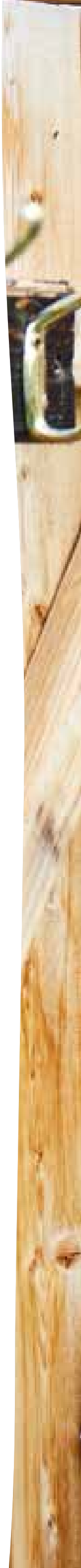
Small cell cancer

This type of cancer usually affects the lung, but it can be found in other parts of the body. Rarely, it can develop in the anus. It is treated in the same way as other small cell cancers.

This booklet is about squamous cell anal cancers. We have separate information about rectal cancer, skin cancer and anal melanoma in our booklets:

- Understanding rectal cancer
- Understanding skin cancer
- Understanding melanoma

For more information about these booklets, see page 112.



Staging of anal cancer

The stage of a cancer describes its size and if it has spread from where it started. Knowing the stage helps the doctors decide on the best treatment for you.

Generally, anal cancer is divided into four stages. Cancers that are small and only in the anus are called localised cancer. Cancer that has spread to other parts of the body is called secondary or metastatic cancer.

If a cancer comes back after it is first treated, it is called a recurrent cancer.

The staging systems most commonly used for anal cancer are:

- TNM staging
- number staging.

TNM staging system

T – describes the size of the tumour and whether it has grown into nearby tissues or organs.

N – describes whether the cancer has spread to the lymph nodes.

M – describes whether the cancer has spread to another part of the body, such as the liver.

This system is more complicated. It gives precise information about the tumour stage.

T – Tumour

Doctors put a number next to the T to describe the size and spread of the cancer.

- **Tis** – The cancer is at its earliest stage. There are cancerous changes to some of the cells, but they are only in the lining of the anus (in situ). If left untreated, these cells may spread into the tissues outside the lining and become an invasive cancer.
- **T1** – The tumour is 2cm or smaller.
- **T2** – The tumour is bigger than 2cm and less than 5cm.
- **T3** – The tumour is bigger than 5cm.
- **T4** – The tumour can be any size, but it has started to grow into nearby structures, such as the vagina, bladder or urethra (tube that carries urine from the bladder).

N – Nodes

This describes whether any lymph nodes near the anus contain cancer cells.

- **NX** – The lymph nodes were not examined.
- **N0** – There is no cancer in the lymph nodes.
- **N1** – There is cancer in the lymph nodes closest to the anus. The lymph nodes closest to the anus are in the rectum.

Stage N1 can be broken down into 3 further stages called N1a, b or c. These stages depend on which lymph nodes in the groin and pelvis have cancer cells in them.

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 or the lymph nodes in the tummy (abdomen).

Number staging system

Stage 1 – The cancer only affects the anus. It is smaller than 2cm.

Stage 2a – The cancer is 2 to 5cm and has not spread to any lymph nodes.

Stage 2b – The cancer is 5cm or more and has not spread to any lymph nodes.

Stage 3a – The cancer is 2cm or smaller and has spread to the lymph nodes near the rectum and in the groin or pelvis.

Or

The cancer is 2 to 5cm and has spread to the lymph nodes near the rectum and in the groin or pelvis.

Stage 3b – The cancer is any size and has spread to nearby organs such as the bladder, urethra or vagina.

Stage 3c – The cancer is any size and has spread to lymph nodes in the groin and pelvis.

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

Grading

The grade describes how cancer cells look and behave compared to normal cells. Doctors will look at a sample of the cancer cells under a microscope to find the grade of your cancer.

Grade 1 (low-grade) – The cancer cells tend to grow slowly and look similar to normal cells (they are well differentiated). These cancers are less likely to spread than higher-grade cancers.

Grade 2 (moderate-grade) – The cancer cells look more abnormal.

Grade 3 (high-grade) – The cancer cells tend to grow more quickly and look very abnormal (they are poorly differentiated). These cancers are more likely to spread than low-grade cancers.

Our cancer support specialists can tell you more about staging and grading. You can call them on **0808 808 00 00**. It is also important to talk to your doctor for detailed information about your situation.

TREATING ANAL CANCER

Treatment overview

The treatment you have depends on the stage of the cancer (see pages 30 to 33) and your general health. Your test results will help your doctor plan your treatment.

It is important to talk about your treatment options with your doctor. They can explain why they are suggesting a certain treatment plan and how the treatment may affect you.

Chemoradiation

The main treatment for anal cancer is a combination of radiotherapy and chemotherapy. This is called chemoradiation (see pages 42 to 43). Chemoradiation is usually successful and most people do not need surgery.

Radiotherapy

You may have radiotherapy (see pages 45 to 51) on its own if you are not well enough to have chemoradiation. Radiotherapy can also be used to help with symptoms if the cancer has spread.

Chemotherapy

You may have chemotherapy on its own if the cancer has spread to other parts of the body (see pages 52 to 59). It may help to control the cancer and improve symptoms.

Surgery

You may have surgery (see pages 60 to 72):

- after chemoradiation, if the chemoradiation does not get rid of all the cancer
- if the cancer comes back after chemoradiation
- to remove an early-stage anal cancer – but this will depend on the size of the tumour and where it is in the anus
- if you cannot have radiotherapy – this may be because you have had radiotherapy to the pelvis before
- before starting chemoradiation to help with any symptoms.

How treatment is planned

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

This MDT may include:

- a surgeon, who specialises in anal and bowel cancers
- an oncologist (cancer doctor), who specialises in chemotherapy and radiotherapy
- a nurse specialist, who gives information and support
- a radiologist, who helps to interpret x-rays and scans
- a pathologist, who gives information about the type and size of the cancer
- a stoma care nurse, who gives information and support about stoma care.

Other healthcare professionals may include:

- a gastroenterologist, who specialises in bowel problems
- a dietitian
- a physiotherapist
- an occupational therapist
- a psychologist or counsellor.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

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

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

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

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

We have more information in our booklet **Making treatment decisions** (see page 112).

> **'I have realised that we are all different – not everyone wants to talk about cancer. But we pretty much all want information.'**
>
> **Tania, diagnosed with anal cancer**

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (see pages 38 to 39).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

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

Second opinion

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

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

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion at **macmillan.org.uk**

Chemoradiation

Chemoradiation is when chemotherapy and radiotherapy are given at the same time. It is sometimes called chemoradiotherapy. It is often the main treatment for anal cancer. We have separate information on radiotherapy (see pages 45 to 51) and chemotherapy (see pages 52 to 59), which includes detailed information about the individual treatments and their side effects.

Why chemoradiation is given

Chemotherapy drugs can make cancer cells more sensitive to radiotherapy. This can help the radiotherapy to work better. Having both treatments often works better than having either treatment on its own.

Chemoradiation has a better chance of curing anal cancer than surgery. It also means you may avoid having a stoma (see pages 64 to 65).

How chemoradiation is given

You usually have chemoradiation as an outpatient.

A common treatment plan involves having 4 to 6 weeks of radiotherapy and 2 cycles of chemotherapy. The chemotherapy drugs usually given are fluorouracil (5FU) and mitomycin.

In the first week of treatment, you start chemotherapy and have your first radiotherapy treatment. You have radiotherapy Monday to Friday, for 4 to 6 weeks. 4 weeks after you started treatment, you have a second cycle of chemotherapy.

You usually have the chemotherapy into a vein (intravenously). You may have fluorouracil through a portable chemotherapy pump, which you take home. Or you may have a drug called capecitabine instead of fluorouracil, which you take as a tablet.

Side effects

Having chemotherapy and radiotherapy together can make the side effects of treatment worse. Your cancer doctor or specialist nurse will give you more information about chemoradiation and the possible side effects. You may have the following side effects:

- tiredness (fatigue)
- diarrhoea
- sore skin in the area being treated.

Tell your cancer doctor, specialist nurse or radiographer about your side effects. They can help you find ways to cope with them.

> ‘Radiotherapy “down there” was the most physically challenging and I would say chemotherapy was the most mentally challenging. That was an interesting thing in itself.’

Tania, diagnosed with anal cancer

Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where treatment is given, while doing as little harm as possible to normal cells. Anal cancer is usually treated with radiotherapy, in combination with chemotherapy (chemoradiation). You can also have radiotherapy on its own if your doctors think you are not well enough to have chemoradiation.

Radiotherapy may also be used to relieve symptoms if the cancer has spread to other parts of the body.

External beam radiotherapy

External beam radiotherapy is given from a radiotherapy machine outside the body.

This treatment is normally given as a number of short, daily treatments in a radiotherapy department. These are called treatment sessions or fractions. It is given using a machine that looks like a large x-ray machine or CT scanner. Each treatment takes 10 to 15 minutes. The treatments are usually given Monday to Friday, with a rest at the weekend. Your doctor will talk with youabout the treatment and possible side effects.

Intensity-modulated radiotherapy (IMRT)

A type of radiotherapy called IMRT is usually used for anal cancer.

IMRT shapes the radiotherapy beams and allows different doses of radiotherapy to be given to different parts of the treatment area. This means lower doses of radiotherapy are given to the healthy tissue surrounding the tumour. This can help reduce the risk of side effects and late effects. It may also allow higher doses of radiotherapy to be given to the tumour.

Your doctor can tell you more about IMRT and whether it is a suitable treatment for you.

Conformal radiotherapy

Conformal radiotherapy is another way of giving radiotherapy. The radiotherapy beams are specially shaped to fit the treatment area. This can reduce the side effects of the radiotherapy.

Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment. You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

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

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

These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

The doctor may place a small metal marker on the skin around your anus. The marker shows up on the scan so the doctor can see the exact area to be treated.

Treatment sessions

The radiographer will explain what will happen. At the start of each treatment session (called a fraction), they make sure you are in the correct position on the couch and that you are comfortable.

When everything is ready, they leave the room so you can have the radiotherapy. The treatment only takes a few minutes. You can talk to the radiographers through an intercom or signal to them during the treatment. They can see and hear you from the next room.

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

Side effects of radiotherapy

You may have side effects during your treatment. Side effects build up slowly when you start treatment. They usually get better slowly 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. Tell them about any side effects you have during or after treatment. There are often things they can do to help.

Side effects caused by smoking

The side effects of radiotherapy are made worse by smoking. Smoking will also make your treatment less effective. Your cancer doctor or nurse will advise you to try to stop smoking. They can give you support and advice.

NHS Smokefree can offer advice and support – find out more by visiting **nhs.co.uk/smokefree**

Tiredness

Tiredness (fatigue) can continue for weeks or a few months after your treatment has finished. You might be more tired if you have to travel to hospital each day. If you are also having other treatment such as chemotherapy, this can make you even more 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.

Diarrhoea and passing wind

Radiotherapy is likely to cause changes in how your bowel works. This can cause problems such as diarrhoea or passing more wind than usual. Your doctor can prescribe medicines to help.

Your nurse, radiographer or a hospital dietitian may give you advice about avoiding certain foods. We have more information about coping with problems such as diarrhoea and wind.

Pain

You may have some stinging or pain when you pass stools (poo). Your doctor can prescribe local anaesthetic creams to help with this. Tell your doctor or nurse if you have any pain.

Skin reactions

It is likely that your skin will be sore in the area being treated.

This usually happens 2 to 3 weeks after treatment starts. You may have soreness around the anus and in the groin. Men may have soreness in the scrotum. Women may have soreness in the vulva. If you have IMRT, your doctor may be able to avoid these areas. This means that skin reactions are usually milder. The radiographer or nurse will check the area and tell you how to look after your skin. It is important to follow the advice they give you and only use products they recommend.

Sometimes the skin may become blistered and sore, which can be painful. Your doctor can prescribe painkillers, creams and dressings to help with this. The skin reaction may get worse towards the end of treatment and for up to 6 weeks afterwards. It usually heals quickly after that.

If your skin reaction makes passing urine (pee) painful, your doctor may suggest you have a fine tube (catheter) put into your bladder to drain the urine. They will remove this when your skin has healed.

Inflammation of the bladder (cystitis)

Radiotherapy to the anal area may cause inflammation of the lining of the bladder. This can make you feel you want to pass urine more often. It also gives you a burning feeling when you pass urine.

It helps to drink plenty of water and other fluids. Your doctor can prescribe medicine to make passing urine more comfortable.

Feeling sick

Radiotherapy may make you feel sick (nausea) or be sick (vomit). Sickness can usually be well controlled and stops when treatment finishes. Your healthcare team may give you anti-sickness (anti-emetic) drugs to prevent nausea or vomiting.

Hair loss

Most people lose their pubic hair. It should grow back after your treatment finishes, although the hair loss is sometimes permanent.

We have more information about managing side effects during pelvic radiotherapy at **macmillan.org.uk**

Possible late effects of radiotherapy

You may still have side effects months after treatment finishes. Or you may develop new side effects months or years later. These are called long-term side effects or late effects. Newer ways of giving radiotherapy aim to reduce the risk of getting late effects. There is slightly more risk of developing late effects when you have radiotherapy and chemotherapy together. Your doctor or nurse will talk to you about this.

We have more information in our booklets **Managing the late effects of pelvic radiotherapy in men** and **Managing the late effects of pelvic radiotherapy in women** (see page 112).

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. These drugs disrupt the way cancer cells grow and divide, but they also affect normal cells. The chemotherapy drugs are usually given by injection into a vein (intravenously) or as tablets.

For people with anal cancer, chemotherapy is usually given in combination with radiotherapy (chemoradiation) – see pages 42 to 43. Chemotherapy can also be used on its own if the cancer has spread to other parts of the body. It may help control the cancer and improve symptoms.

The most commonly used chemotherapy drugs for anal cancer are:

- mitomycin
- fluorouracil (5FU)
- capecitabine (Xeloda®), 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). The chemotherapy goes directly into your blood and is carried to all areas of your body.

It can be given through one of the following:

- A central line – This is a long, thin tube inserted into a vein in your chest. It stays in until you have finished your course of chemotherapy.
- A PICC line (peripherally inserted central venous catheter) – This is a long, thin, flexible tube inserted into a vein in the arm. It stays in until you have finished your course of chemotherapy.
- A cannula – This is a short, thin tube put into a vein in the back of your hand or arm. It is taken out before you go home.

We have more information about central lines, PICC lines and implantable ports at **macmillan.org.uk**

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

We have more information in our booklet **Understanding chemotherapy** (see page 112). This includes the following videos at **macmillan.org.uk/chemotherapy**:

- Animations showing how central lines and PICC lines are put in the body.
- Videos showing a chemotherapy treatment centre, health professionals and people having treatment.

You usually have chemotherapy as an outpatient. After the treatment, you usually have a rest period of a few weeks. This lets your body recover from any treatment side effects.

The treatment and rest period make up a cycle of treatment. Your cancer 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 the cancer is causing symptoms, chemotherapy can also make you feel better by relieving them. Most people have some side effects from chemotherapy. Your cancer 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.

We describe the common side effects here. Although they can be hard to cope with, they usually slowly disappear when your treatment finishes.

Risk of infection

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

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

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

Symptoms of an infection include:

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

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

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

Bruising and bleeding

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

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

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

Anaemia (low number of red blood cells)

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

Feeling tired

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

Feeling sick

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

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

Diarrhoea

Some chemotherapy drugs can cause diarrhoea. This can happen in the first few days of treatment. But it usually happens between treatment cycles. If you have this side effect, tell your nurse or doctor as they can give you medicine to help. If you still have diarrhoea after 24 hours, it is important to contact the hospital on the telephone numbers you have been given and speak to a doctor or nurse. If you have a stoma, your stoma care nurse can also give you advice and support.

Make sure you drink at least 2 litres (3½ pints) of fluid each day to replace the fluid you are losing. Eat less fibre, such as cereals, raw fruits and vegetables, until the diarrhoea improves.

Sometimes diarrhoea is more severe. If you have diarrhoea more than 4 times in a day or at night, it is important to contact the hospital straight away and speak to a doctor or nurse.

If you are taking capecitabine and your diarrhoea does not get better, tell your doctor or nurse. Sometimes you may have to stop taking capecitabine until the diarrhoea gets better.

You may need to go to hospital to have fluids through a drip (infusion), or you may need antibiotics.

Sore hands and feet

This is sometimes called palmar-plantar or hand-foot syndrome. It can be caused by capecitabine (Xeloda®) or 5FU. It gets better when treatment ends. Your doctor or nurse may prescribe creams or tablets to improve the symptoms. Using non-perfumed moisturising creams can help relieve symptoms. It can help to keep your hands and feet cool and to avoid tight-fitting socks, shoes and gloves.

Sore mouth

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

If your mouth is sore:

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

Fertility

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

Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Sex

If you have sex during a course of chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluids.

Surgery for anal cancer

Surgery is not often needed to treat anal cancer. This is because chemoradiation is often the only treatment needed.

You may have surgery if you have a very small tumour in the anal margin (see page 11). This is only if the surgeon can remove it without affecting how you pass stools (poo).

You may also have surgery:

- after chemoradiation, if the chemoradiation does not get rid of all the cancer
- if the cancer comes back after having chemoradiation
- if you cannot have radiotherapy, for example because you have had radiotherapy to the pelvis before
- to relieve a blockage in the bowel before you have chemoradiation.

If your doctor thinks you need surgery, they will explain the type of surgery you need and how it will help.

Types of surgery

Local excision

This surgery only removes the area of the anus containing the cancer cells. It is sometimes used to treat small, early-stage cancers in the anal margin (see page 11).

You will not have long-term problems with bowel control after this surgery. This is because the anal sphincter (see page 11) is not usually affected.

Your doctors may recommend you have radiotherapy (see pages 45 to 51) or chemoradiation (see pages 42 to 43) after surgery. This is usually if there are some cancer cells in the tissue close to where the cancer was removed.

Abdominal-perineal resection (APR)

This surgery removes the anus, rectum and part of the colon (see page 63). Doctors usually only advise having an APR if:

- chemoradiation has not got rid of all the cancer
- the cancer comes back after treatment.

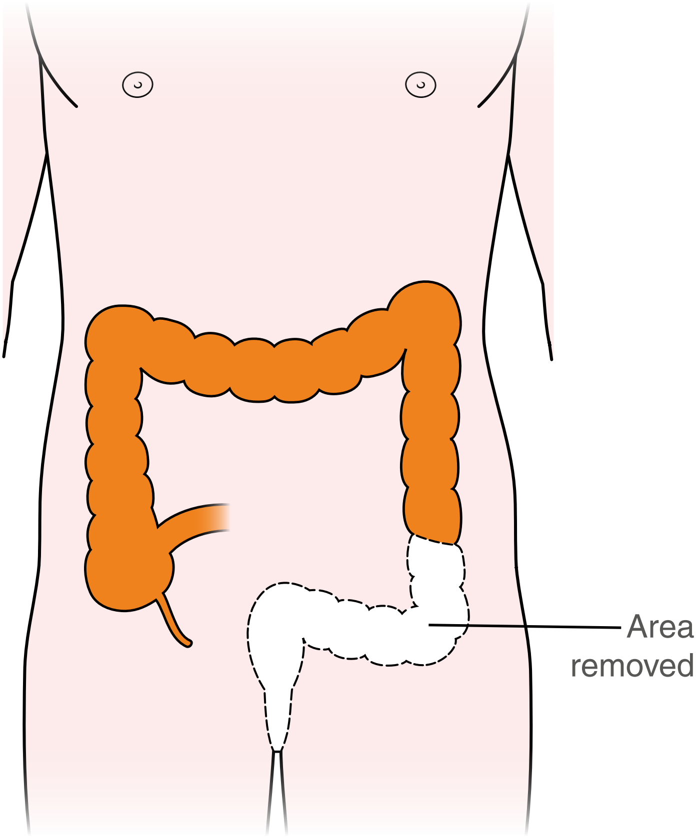
You can have an APR as open surgery. This is when the surgeon makes one large cut in your tummy. Or you can have it as keyhole (laparoscopic) surgery. This is when the surgeon makes 3 or 4 small cuts in your tummy. They use special instruments that can fit through these cuts to remove the cancer.

As well as the wound or wounds on your tummy, you will have a wound on your bottom where the anus has been closed. The anus may be closed using muscle, fat and skin from another part of the body. This is called a flap.

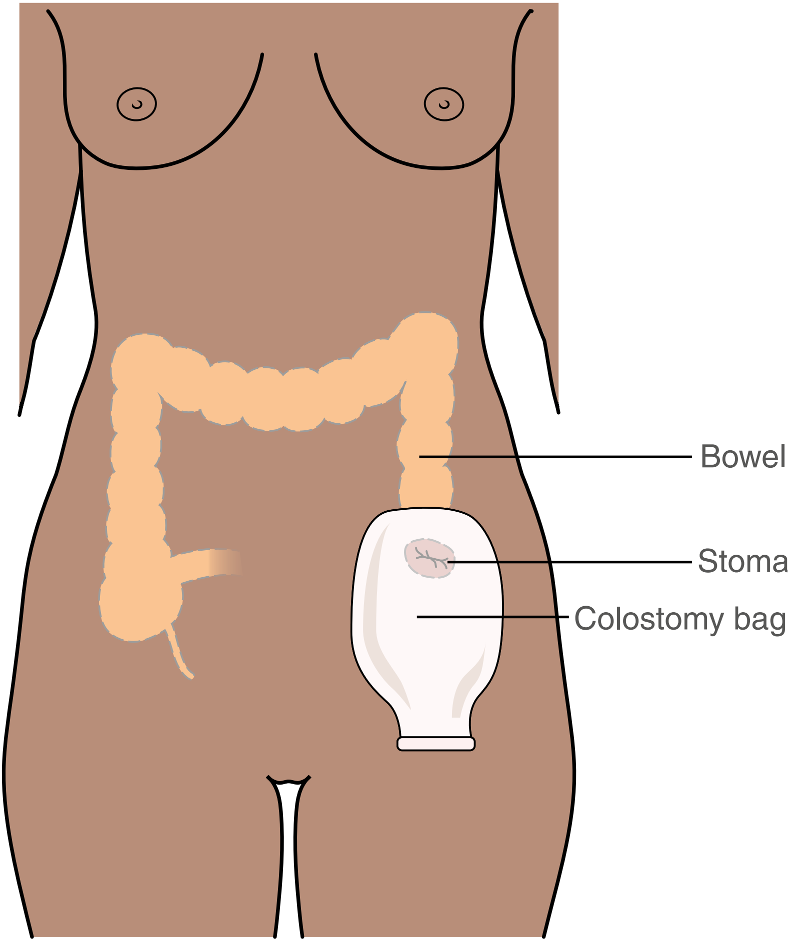
An APR removes the anus and rectum. This means you will have a permanent stoma (colostomy) – see page 65. A stoma is an opening that is made through the tummy (abdominal) wall. It connects the bowel to the surface of the tummy. This means stools will not pass out of the rectum and anus in the usual way. Instead, it will pass out of the stoma into a disposable bag that is worn over the stoma.

This can be upsetting and takes time to adjust to. Your surgeon and a stoma nurse will talk to you before the operation. You can ask them any questions you have. Your nurse will give you lots of support, and there are organisations that can help (see pages 116 to 123). We have more information about having a stoma (see page 65).

Abdominal-perineal resection



A colostomy bag



Having a temporary stoma

This is sometimes done before chemoradiation. It involves having surgery to make a temporary stoma.

After chemoradiation is finished, your doctors assess you to see if the stoma can be closed. This will allow you to pass stools through the anus again.

A temporary stoma may be used to relieve symptoms if:

- the cancer is causing you to have problems controlling your bowel (incontinence)
- there is an opening between the bowel and skin (a fistula)
- there is an opening between the bowel and another organ, such as the bladder or vagina (a fistula)
- there is a risk of a fistula forming
- the cancer is causing a blockage in the bowel.

Before your operation

If you smoke, try to give up or cut down before your operation. This will help reduce your risk of chest problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice and support to help you give up smoking. We also have more information at **macmillan.org.uk**

Your operation will be carefully planned. For an APR, there may be different specialists involved. This could include a plastic surgeon and a gynaecologist if you are a woman.

You will go to a pre-assessment clinic for tests to check you are fit for the operation. These may include blood tests, a blood pressure check and a recording of your heart (ECG).

You will meet a member of the surgical team to talk about the operation. If you are going to have a stoma after the operation, you will also meet a stoma care nurse who will explain what is involved.

This is a good time to share any questions or concerns you have about the operation. If you think you may need help when you go home after surgery, for example because you live alone or care for someone else, tell your nurse as soon as possible. It will help them to plan your care in plenty of time.

Some hospitals follow an enhanced recovery programme, which aims to reduce the time you spend in hospital and speed up your recovery. You will also be more involved in your own care. For example, you will get information about diet and exercise before surgery. You may also be given nutritional supplement drinks to take. Your hospital team will make any arrangements needed for you to go home. Your doctor will tell you if an enhanced recovery programme is suitable for you and if it is available.

After your operation

You will be encouraged to start moving around as soon as possible. Even if you have to stay in bed, it is important to do regular leg movements and deep-breathing exercises. A physiotherapist or nurse will explain these exercises to you.

To reduce the risk of blood clots, you will wear TED stockings. Your nurse may also give you medication to prevent blood clots. This will be given as injections under the skin.

On the evening of the operation or on the next day, a nurse will help you get out of bed or sit up for a short time. Gradually, you will be able to sit or stand up for longer and to start walking around the ward.

Drips and drains

Depending on the type of operation, you may have some tubes attached to your body. If you had a small operation, you may not have any tubes at all. You may be given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. It is removed when you are eating and drinking normally again.

You may have a tube put in during the operation to drain urine (pee) from your bladder. This is called a catheter. It is taken out once you are eating and drinking normally and can walk to the toilet.

You may have a nasogastric tube. This is a tube that goes up the nose and down into the stomach. It removes fluid from the stomach until the bowel starts working again.

You may have a tube attached to a bottle close to the operation wound to drain fluid away. A nurse will remove it after a few days, when fluid stops draining.

Pain

It is normal to have some pain and discomfort after your operation. Painkillers can help control this. If you still have pain, tell your doctor or nurse. You may need to have your dose or type of painkiller changed. The pain control you need will depend on the type of operation you have had.

You may have a continuous dose of painkiller into the spinal fluid through a fine tube and a pump. This is called an epidural.

Painkillers can also be given through a tube into a vein in your hand or arm (a cannula). The tube is connected to a pump. This is called a PCA (patient-controlled analgesia). You can give yourself an extra dose of painkiller when you need it by pressing a button on the pump. The machine is set so you get a safe dose and are unable to have too much.

Painkillers sometimes slow down your bowel function (constipation). If your bowels are not moving, tell your nurses. They can give you medicines to help.

After an APR it may be uncomfortable to sit down. This will improve as the wound heals.

Before you can go home, your pain needs to be controlled by tablets. You will get a prescription for painkillers you can take at home as needed.

Feeling sick or being sick

The nurse will give you anti-sickness medication if you feel sick or are being sick. If this does not work, tell your nurse. They may give you a different type of anti-sickness medication.

Wound care

Your wounds may be closed with stitches, clips or staples. A nurse at your GP surgery usually removes these after you go home. Sometimes a district nurse can come to your home to remove them. Some surgeons use dissolving stitches that do not need to be removed.

Sometimes your surgeon may use a flap of tissue to close the wound, instead of stitches or clips. This is more likely if you have already had radiotherapy. If you have a flap, you will not be able to sit on your bottom for 2 to 4 days after your operation. This reduces pressure on your wound and helps it heal.

You will only be able to sit for short periods at first. As things improve, you can slowly increase this. You can lie on your side but will still need to change your position regularly. Your doctor or nurse will give you advice about how often to change position when sitting.

You may be given antibiotics to help prevent any wound infection. While you are in hospital and after you go home, tell your nurse or doctor straight away if your wound:

- becomes hot
- becomes painful
- bleeds
- leaks any fluids.

These can be signs that the wound is infected.

Possible complications

This will depend on the type of operation you had. The most common complications after surgery are:

- a wound infection
- bleeding in the operation area
- a chest infection
- a blood clot.

The nurses will monitor you for these complications. Tell them straight away if you:

- have any bleeding
- feel unwell
- have symptoms of an infection, such as a cough
- have signs of a wound infection (see opposite page)
- have swelling and redness in a limb.

Most people who have surgery go home without complications. But if you do have any problems when you get home, tell your doctor straight away.

Going home

When you can go home will depend on the type of operation you have had. If it is a small operation, you will be ready to go home after 2 days.

After a bigger operation, it may take up to 2 weeks.

Before leaving hospital, you will be given an appointment to go to at 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 to 10 days after surgery. A nurse at your GP surgery can do this. If you cannot leave home, a district nurse can visit you.

Recovering from an operation takes time. Some people take longer to recover than others.

Clinical trials

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

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

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

Taking part in a trial

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

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

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

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

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

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** – see page 112.

Giving blood and tumour samples

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

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

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

The samples may be used to:

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

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

AFTER YOUR TREATMENT

Follow-up

After treatment has finished, you will have regular check-ups with your cancer doctor. They will:

- examine you
- ask how you are feeling
- ask if you have any new symptoms.

You may also have other tests and scans so your doctors can check how well treatment has worked. Your cancer doctor and specialist nurse will explain more about this.

The follow-up appointments usually continue for up to five years. You have them less often as time goes on.

If you notice any new symptoms between your appointments, tell your cancer doctor straight away. Your doctor will check what may be causing your symptoms and if they are caused by your treatment (late effects).

You may feel anxious before your follow-up appointments. This is natural. It may help to get support from family members or friends. You might also find it helpful to get support from a support organisation (see pages 116 to 123).

If your treatment has finished apart from having regular check-ups, we have information in our booklet **Life after cancer treatment** (see page 112). This gives you advice on how to keep healthy and adjust to life after cancer.

Diet after surgery

Your doctor, dietitian or specialist nurse may advise you to follow a specific diet while your bowel recovers from surgery. They may give you different advice depending on:

- the type of surgery you had
- how much of your bowel has been removed
- whether you have a stoma.

It is important to remember that your symptoms are probably caused by your surgery and not the foods you eat.

Eating at regular times encourages your bowel to work more regularly. If you have lost your appetite, it may be easier to eat several small meals a day, rather than one or two large meals. We have more information in our booklet **The building-up diet** (see page 112). Having plenty of high-protein foods in your diet will help your body to heal after surgery. These include:

- fish
- meat
- eggs
- dairy products.

For the first few days after your surgery, you may be advised to follow a low fibre diet. This is to allow your bowel to recover. Low fibre foods include:

- white bread
- pasta
- plain crackers
- refined breakfast cereals
- peeled fruit and vegetables – if cooking them, make sure they are cooked well.

After your surgery, it is important to try and eat a healthy, well-balanced diet. But some healthy foods may cause problems. Depending on the type of surgery you had, you may be advised to avoid some types of high-fibre foods. These include:

- foods with pips
- skins of fruit
- undercooked and raw vegetables.

Always check with your dietitian, doctor or specialist nurse if you are not sure what to do.

As your bowel function settles, you can gradually try foods again that caused you problems. You may find they do not affect your bowel anymore. If you continue to have problems with eating, ask your cancer doctor or specialist nurse to refer you to a dietitian.

Coping with bowel changes

It may take time for your bowel function to settle. But there are things that can help you cope with bowel changes and feel more confident and in control. If your symptoms continue, always ask for help from your cancer doctor or specialist nurse.

Diarrhoea

If you have diarrhoea, you may be advised to add some fibre (roughage) to your diet. This can help to reduce diarrhoea, as it bulks up stools. Foods high in fibre include:

- wholemeal breads
- beans
- oats
- fruit and vegetables.

It is important to drink at least 2 litres (3½ pints) of fluid a day, especially if you have loose stools or diarrhoea or constipation. Fluids can include:

- water
- milk
- juice
- hot drinks.

You may have a lot of diarrhoea or pass a lot from your stoma. If this happens, have less fluid at mealtimes.

Your cancer doctor or specialist nurse may recommend you take anti-diarrhoea drugs. The most commonly used drug is loperamide (also called Imodium® or Diareze®). It slows down your bowel movements, making the stools more solid and less frequent.

Taking loperamide regularly, half an hour before meals, works well for some people. Loperamide is also available as a syrup, so you can change the dose as needed. It may take time to find the dose that works best for you. Your cancer doctor may recommend you start with a low dose and increase this until it works.

It is safe to take loperamide for as long as you need it, but you should discuss this with your cancer doctor. Your dietician can explain changes you could make to your diet to help manage diarrhoea.

Wind

You may have problems with excess wind or bloating after bowel surgery. Here are some tips:

- Try to avoid food and drink that can cause wind – this includes beans, garlic, onions, sugar-free chewing gum, fizzy drinks and some alcoholic drinks.
- Eat slowly and chew food well.
- Taking peppermint capsules or drinking peppermint water diluted with some warm water might help. You can get these from your local pharmacy.
- Drinking peppermint or fennel tea may also help.

Constipation

Constipation can sometimes be a problem after surgery to your bowel. Here are some tips that may help:

- Drink at least 2 litres (3½ pints) of fluids each day.
- Eat high-fibre foods, such as fruit, vegetables and wholemeal bread.
- Do regular, gentle exercise, like going for short walks.

If you have constipation, contact the hospital for advice. Your doctor can give you drugs called laxatives to help.

Ask your dietician about what changes you can make to your diet. If you have a stoma, your stoma nurse will give you advice about this. It can help to keep a daily food diary of what you eat and how different foods affect you.

We have information in our booklet **Eating problems and cancer** that explains common eating difficulties and offers practical tips for managing them (see page 112).

Carry a bag with supplies

Pack a bag with things you may need when you go out. This will make you feel more confident and help you to cope if an accident happens.

You may want to include:

- wet wipes
- barrier cream, such as Cavilon® or Sudocrem® or Bepanthen
- loperamide (anti-diarrhoea tablets), if you have problems controlling your bowel
- pads and spare underwear
- stoma supplies, if you have a stoma
- a change of clothing
- a sealable bag.

Sex life after anal cancer

Your diagnosis, treatments and side effects may affect your sex life and how you see yourself. You may feel too tired to have sex during treatment and for a time after. This often gradually improves after treatment, but for some people it may take longer.

If you have had an operation, you may have a scar or stoma. If you feel self-conscious about changes to your body, it can also affect your sexual desire. Talking about your feelings may help your anxiety. If you have a partner, you may both find it takes time to adjust to any changes.

Sometimes surgery (see pages 60 to 72) and radiotherapy (see pages 45 to 51) can cause problems with getting and keeping an erection. Medicines such as sildenafil (Viagra®) can help you get an erection. If you are having erection difficulties, talk to your doctor as soon as possible. The sooner you start treatment, the more effective it is.

Women may find that changes to blood flow and nerves in the pelvic and genital area make orgasm less intense than before. It may also take longer to reach orgasm. These changes may improve over time but are sometimes permanent. Radiotherapy to the pelvic area can cause the menopause, which may lower your sex drive. Your doctor or nurse may prescribe hormone replacement therapy (HRT) to help with menopausal symptoms.

If you have had radiotherapy, you may need to be cautious with anal sex and anal play. The tissues in the area may be fragile. This can make anal sex uncomfortable. Surgery to remove the anus means anal sex and anal play are no longer possible.

Many people find it difficult to talk about sexual difficulties because they feel embarrassed or self-conscious. Your doctor or nurse will be used to talking about these issues. So it can help to talk to them if you are having problems with your sex life. They may be able to offer help and support, or refer you to a sex therapist or counsellor.

If you identify as LGBT+, you may worry about being treated insensitively by your healthcare team. You may have some specific questions. Having your sexual or gender identity acknowledged can help you feel more supported. It also means your healthcare team can give you the right information and advice.

There are organisations that can give you support (see pages 116 to 123). It may also help to share your experience with other people through Macmillan's Online Community (see page 89).

Fertility

Treatments for anal cancer can affect your ability to start a pregnancy (fertility). This can be difficult to cope with, even if you have a family or did not plan to have children. It is important to tell your healthcare team any concerns you have about your fertility before treatment starts. They can tell you what options might be available if you would like to have a child in the future.

We have more information in our booklets **Cancer treatment and fertility – information for men** and **Cancer treatment and fertility – information for women** (see page 112).

Well-being and recovery

After cancer treatment, some people choose to make some positive lifestyle changes. You may have already followed a healthy lifestyle before bowel cancer. But you may be more focused on making the most of your health.

Be physically active

Being physically active helps keep your weight healthy and can reduce stress and tiredness. It helps to keep your bones strong and your heart healthy.

We have more information in our booklet **Physical activity and cancer** (see page 112). You can also watch videos about the benefits of physical activity, including stories from people with cancer.

> ‘There’s a light at the end of the tunnel. You have to plan things. If I go on a night out, I need to plan where the toilets are and the timings after a meal. It affects you daily life and your hobbies but you can still achieve things.’

Mark, diagnosed with bowel cancer

Try to reduce stress in your life

Being diagnosed with anal cancer can be a stressful time in your life. One way of coping with stress is to make time to relax. Some examples of ways to relax or reduce stress include:

- going for a walk
- spending time with family or friends
- listening to music or watching a film
- trying activities such as yoga, or using relaxation techniques to control breathing
- being more physically active and looking after your well-being
- talking to someone about how you feel.

We have more information in our booklet **Talking about cancer** (see page 112). We also have more information about relaxation techniques in our booklet **Cancer and complementary therapies** (see page 112).

Get 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, district nurses can visit you at home to help with this.

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. Call us or visit **macmillan.org.uk/supportgroups** for information about support groups in the UK.

Online support

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

Our Online Community is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups. Visit **macmillan.org.uk/community**


EASY

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

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

Shock and denial

You may find it hard to believe it when your doctor tells you that you have cancer. It is 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 cannot think or talk about anything but the cancer. This is because your mind is trying to process what you are going through.

Fear and anxiety

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

Sadness and depression

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

Avoidance

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

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

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

Anger

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

Guilt and blame

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

Feeling alone

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

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

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

If you need more help

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

Talk to your doctor or nurse if:

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

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

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 112).

> **‘It was hard telling my friends about my diagnosis as they didn’t know what to say. There was little info available on anal cancer. I didn’t know anyone in my family that I could talk to about it.’**
>
> **Tania, diagnosed with anal cancer**

Relationships

Your experience of cancer may strengthen your relationships with people close to you. You may feel that you would not have coped so well without support from family and friends.

However, cancer is stressful and this may affect your relationships. Any problems usually improve over time, especially if you talk openly with each other.

If you have a partner

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

Couples that are close may assume that they know what each other is thinking, but they may not always be right. Talking openly about your feelings and listening to each other can help you understand each other's point of view.

Family and friends

You may feel that your family and friends are not always understanding if you do not feel positive. You may feel they do not realise how much treatment affects your life. Talking openly about how you feel will help them to understand and give you the support you need. We have more information in our booklet **Talking about cancer** (page 112).

If you are a family member or friend

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

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

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

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

We have more information in our booklet **Talking to someone with cancer** (see page 112).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 112).

Talking to children about cancer

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

Talking to children about the cancer can:

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

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

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

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

Teenagers

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

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

We have more information in out booklet **Talking to children and teenagers when an adult has cancer** (see page 112). We also have a video on our website about talking to children.

FINANCIAL SUPPORT AND WORK

Financial help and benefits

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

Statutory Sick Pay

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

Benefits

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

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

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

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

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

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

Macmillan Grants

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

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

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

Insurance

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

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 112). Our Online Community forum on **Travel insurance** may also be helpful. For more information, visit **macmillan.org.uk/travelinsurancegroup**

More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 120).

Our booklet **Help with the cost of cancer** has lots more information (see page 112).

Work

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

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

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

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

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 112). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 112).

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

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

Work support

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

Other useful organisations

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

Anal and bowel cancer support organisations

Bowel Cancer UK

www.bowelcanceruk.org.uk

Gives information and support to people affected by bowel cancer.

England and Wales

Tel **020 7940 1760**
Email **admin@bowelcanceruk.org.uk**

Scotland

Tel **0131 281 7351**
Email **scotadmin@bowelcanceruk.org.uk**

Northern Ireland

Tel **07798 523 668**
Email **niadmin@bowelcanceruk.org.uk**
www.bowelcanceruk.org.uk

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
Email **help@bladderandbowel.org**

Provides information and advice on bladder and bowel symptoms.

Colostomy UK

Helpline **0800 328 4257**
Email **info@colostomyuk.org**
www.colostomyuk.org
Supports people who have had, or are about to have, a colostomy.

HPV and Anal Cancer Foundation

Tel **020 7272 3347**
Email **info@analcancerfoundation.org**
www.analcancerfoundation.org
Gives information and support to people affected by anal cancer.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Maggie's Centres

Tel **0300 123 1801**
Email **enquiries@maggiescentres.org**
www.maggiescentres.org

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

Riprap

www.riprap.org.uk

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

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk

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

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS.UK

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (Mon to Fri, 8am to 10pm, and Sat and Sun, 9am to 5pm)

www.nhsinform.scot

NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **01455 883 300**

Email **bacp@bacp.co.uk**

www.bacp.co.uk

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

Emotional and mental health support

Samaritans

Helpline **116 123**

Email **jo@samaritans.org**

www.samaritans.org

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

Financial support or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline **0800 022 4250** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline **03444 111 444**
www.citizensadvice.org.uk

Wales

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

Scotland

Helpline **0808 800 9060**
www.cas.org.uk

Disability and Carers Service

Tel **0800 587 0912** (Mon to Fri, 9am to 5pm)
Textphone **0800 012 1574**
www.nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

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

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250** (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
Textphone **020 7562 2050**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Support for older people

Age UK

Helpline **0800 055 6112** (Daily, 8am to 7pm)
www.ageuk.org.uk/services/age-uk-advice-line/
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 10am to 6pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777 (Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry

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

National Cancer Registration and Analysis Service

Tel **020 7654 8000**
Email **enquiries@phe.gov.uk**
www.ncras.nhs.uk
Tel (Ireland) **021 4318 014**
www.ncri.ie

Scottish Cancer Registry

Tel **0131 275 7050**
Email **nss.csd@nhs.net**
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **029 2037 3500**
Email **general.enquiries@wales.nhs.uk**
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel **028 9097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Disclaimer

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

Thanks

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With thanks to: Lindsay Allen, Macmillan Oncology Dietitian; Dr Erica Beaumont, Consultant Clinical Oncologist; Dr Michael Braun, Consultant Colorectal and General Surgeon; Dr Rachel Cooper, Consultant Clinical Oncologist; Mr James Crosbie, Consultant Colorectal Surgeon; Mr Mark George, Consultant Colorectal and General Surgeon; Adele Hug, Macmillan Oncology Dietician; Amanda Justice, Colorectal Clinical Nurse Specialist; Professor Rachel Kerr, Medical Oncologist; Mr James Kinross, Senior Lecturer and Consultant in Colorectal Surgery; Renitha Kwong, Oncology Dietitian; Dr Sin Lau, Consultant in Medical Oncology; Dr Catriona McLean, Consultant Clinical Oncologist; Jacquie Peck, Colorectal and Anal Cancer CNS; Alexandra Poole, Lead Colorectal Specialist Nurse; Vanessa Shearwood, Senior Colorectal Specialist Nurse; and Mr Sanjay Wijeyekoon, Specialist Laparoscopic Colorectal and General Surgeon.

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

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

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

Association of Coloproctology of Great Britain & Ireland (ACPGBI). Volume 19. Issue S1. Guidelines for the management of cancer of the colon, rectum and anus. 2017. Available from: **www.onlinelibrary.wiley.com/toc/14631318/19/S1** (accessed October 2019).
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R Muirhead, RA Adams, DC Gilbert et al. National guidance for IMRT in anal cancer. December 2016 (accessed October 2019).

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

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

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

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