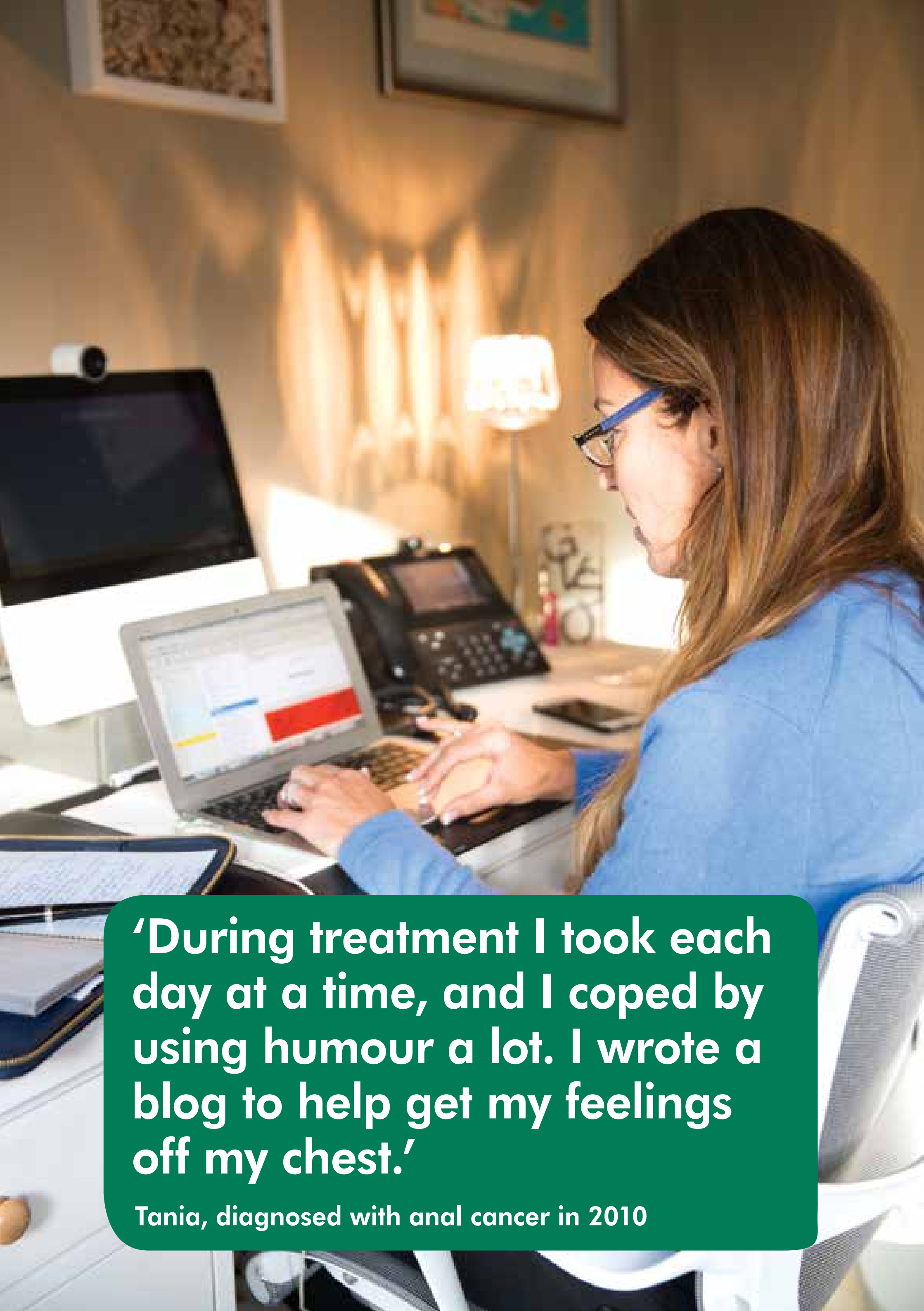
A practical guide to understanding cancer

UNDERSTANDING ANAL CANCER



‘During treatment I took each day at a time, and I coped by using humour a lot. I wrote a blog to help get my feelings off my chest.’

Tania, diagnosed with anal cancer in 2010

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.

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

In this booklet we've included quotes from people who have had anal cancer, which you might find helpful. They are from people who have chosen to share their stories with us, including Tania, who is on the cover of this booklet. Others are from members of our Online Community (**macmillan.org.uk/community**) or people who have chosen to share their story with us through **macmillan.org.uk/cancervoices**

At the end of this booklet are some useful addresses and websites (see pages 115 to 119). There's also space for you to fill in with any notes or questions for your doctor or nurse (see pages 120 to 121).

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

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

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

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health 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. You can find more information at **macmillan.org.uk/cancerregistry**

Contents

THE ANUS AND ANAL CANCER

What is cancer?

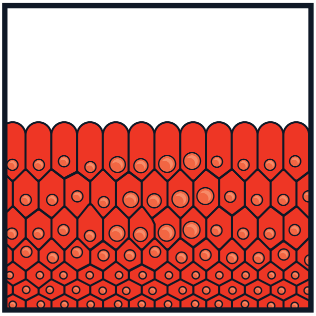
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues in our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair.

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

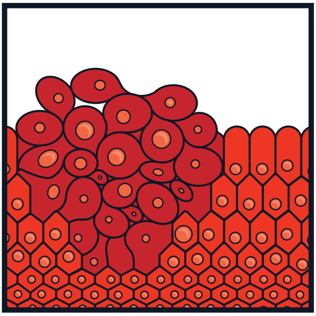
Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (tumour).

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

Normal cells



Cells forming a tumour



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

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

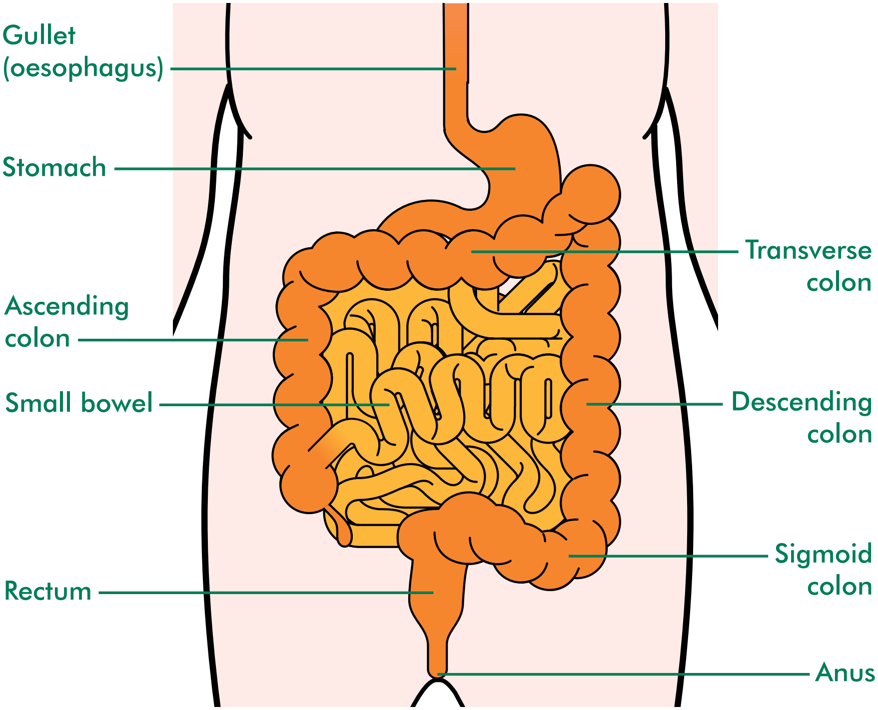
When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

We have a video on our website that explains how cancer develops. You can watch it at **macmillan.org.uk/aboutcancer**

The anus

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

The digestive system



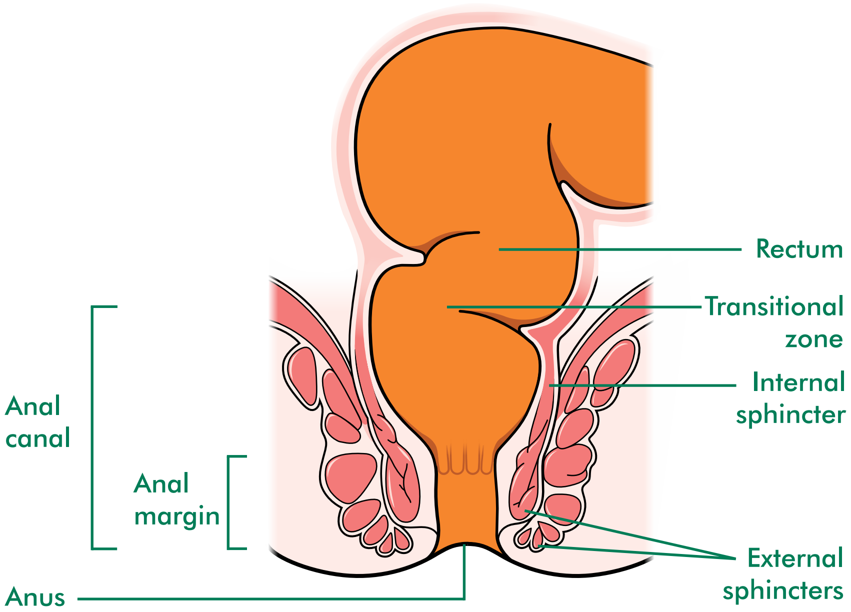
Food passes down the gullet (oesophagus) into the stomach to be digested. It then moves into the small bowel, where important nutrients are removed from it and absorbed into the body.

Digested food moves into the large bowel, where water is absorbed. The waste product (stools) remains in the back passage (rectum) until it can be passed out of the body through the anus.

The anal canal is about 3 to 4cm (1 to 1½in) 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 also has a ring of muscle called the external sphincter. This muscle helps to control when you pass bowel motions.

A cross-section of the anal canal



The walls of the anal canal are lined with cells called squamous cells. Nearly all anal cancers develop in these cells (see pages 26 to 27).

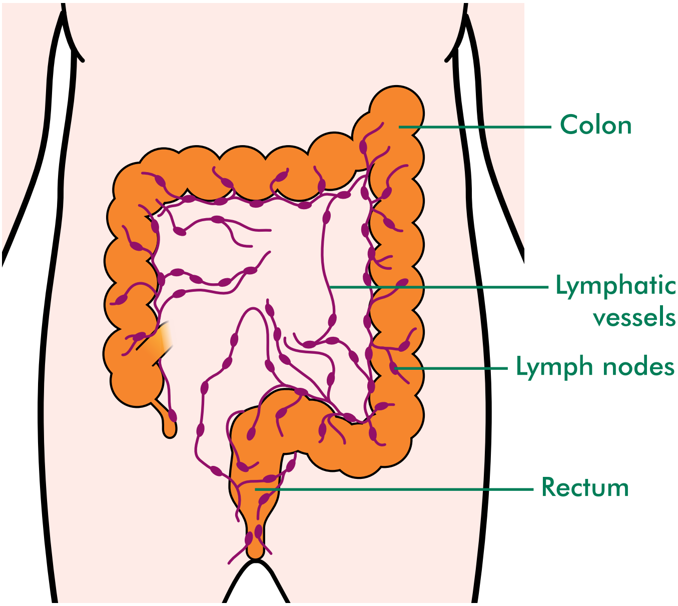
Where the anal canal meets the rectum (transitional zone), the walls are lined with squamous cells and glandular cells. Glandular cells make mucus that helps the bowel motions to pass through the anus.

The lymphatic system

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

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection. Sometimes cancer can spread through the lymphatic system to nearby lymph nodes. You may have tests on the lymph nodes to look for cancer cells (see page 24).

The lymph nodes close to the bowel



If anal cancer spreads to the lymph nodes, it is most likely to go to the nodes close to the rectum and in the groin.

Causes and risk factors

In the UK, about 1,200 people develop anal cancer each year. It is slightly more common in women than men.

Anal cancer has different risk factors. Having one or more of these risk factors does not mean you will definitely get anal cancer.

Most anal cancers are caused by the human papilloma virus (HPV). 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's passed on through sexual contact. Most people have HPV at some point and never know they've 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 developing a cancer.

We can send you more information about HPV and cancer.

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 (see page 11). 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 sexual contact. So 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 (see page 87).

We can send you more information about stopping smoking.

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. Women have a higher risk of anal cancer if they have had:

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


Cancer Centre

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.

The symptoms above can be caused by conditions other than anal cancer. But it's 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.

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

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 doesn’t take long. It will be less uncomfortable if you are able to relax. Let your GP know if you find the examination painful, because it’s 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) or to 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 in the same way your GP did. Then they will talk to you about the tests you need to have. We describe these tests over the next few pages.

Examination and biopsy

The specialist will examine the area for any signs of cancer. In women, this usually includes 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. Occasionally it may be done in the hospital outpatients department using a local anaesthetic.

Doctors use a thin tube called an anoscope to examine the anal canal. If they want to examine the rectum as well, 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, which has a light and a magnifier on the end, into your back passage to find 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, so they can be examined under a microscope.

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

Sometimes doctors can take a biopsy of the anal margin (see the illustration on page 9) without using an anoscope or proctoscope. If you have this biopsy taken, you will have a local anaesthetic to numb the area first.

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 (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. There is a photo of a CT scanner on the opposite page.

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

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

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

You might have a CT scan for the following reasons:

- It can be used to guide a biopsy. This is when a doctor takes a small amount of tissue, which will be examined under a microscope (see page 19). A biopsy involves an overnight stay in hospital, but you'll be told if this is planned.
- It may be used to identify the exact site of the tumour, or to check for any spread of the cancer.

A CT scanner

MRI (magnetic resonance imaging) scan

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

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Anal ultrasound scan

This test uses sound-waves to form a picture. It isn't used very often in diagnosing anal cancer.

A doctor passes a small probe that makes sound-waves into your back passage (rectum). It takes about 15 to 30 minutes. This can be uncomfortable, so let your doctor know if you have any pain.


NHS
SCOTLAND
RADIOGRAPHER

Fine needle aspiration (FNA) of the lymph nodes

You may have this test if the lymph nodes in your groin are larger than normal (see page 10). 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's very quick. You might have an ultrasound scan at the same time to help guide the needle.

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

PET-CT scan

This is a combination of a CT scan (see pages 20 to 21) and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have this scan. You can't eat for six hours before the scan, although you may be able to drink.

A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. Then you wait for at least an hour before having the scan. The scan usually takes 30 to 90 minutes. You should be able to go home afterwards.

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 a partner, your family or a close friend. Your specialist nurse or one of the organisations on pages 115 to 118 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

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

Nearly all anal canal cancers (9 out of 10 or 90%) develop in the squamous cells lining the anal canal and anal margin (see the illustration on page 9).

There are two main types of squamous cell carcinoma:

- Keratinising tumours.
- Non-keratinising tumours, which develop in the transitional zone (see page 9). They are sometimes called basaloid carcinomas.

Adenocarcinoma

Some anal canal cancers develop in the glandular cells that make mucus (see page 9). These are called adenocarcinomas. They are rare – less than 5 in 100 (5%) of all anal cancers are adenocarcinomas. They behave like rectal cancers, and they are treated in the same way as them.

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, including basaloid cancers. We have separate information about rectal cancer, skin cancer and anal melanoma that we can send you.

Staging of anal cancer

The stage of a cancer describes its size and 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. This ranges from cancers that are small and only in the anus (localised) to cancers that have spread to other parts of the body. If the cancer has spread, it 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
- the number staging system.

TNM staging system

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 contained (in situ) to only the lining of the anus. 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 2 to 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 was no cancer in the lymph nodes.
- **N1** – There was cancer in the lymph nodes closest to the rectum (perirectal nodes).
- **N2** – The lymph nodes in the groin (inguinal nodes) or pelvis (pelvic nodes) on one side of the body contained cancer.
- **N3** – This could be either one of the following:
  - There is cancer in the lymph nodes in the rectum and either in the groin or in the pelvis.
  - There is cancer in the lymph nodes in the groin or pelvis, on both sides of the body.

M – Metastasis

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

- **M0** – The cancer has not spread to other parts of the body.
- **M1** – The cancer has spread to other parts of the body, such as the liver or the lymph nodes in the tummy (abdomen).

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

Number staging

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

Stage 2 – The cancer is 2 to 5cm.

Stage 3 is divided into two stages:

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

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

Grading of anal cancer

The grade of a cancer gives doctors an idea of how quickly it may develop. Doctors look at a sample of the cancer cells under a microscope to find the grade.

Grade 1 (low-grade)

The cancer cells look quite similar to normal cells. They usually grow slowly. Doctors sometimes describe them as being well differentiated.

Grade 2 (moderate-grade)

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

Grade 3 (high-grade)

The cancer cells look very abnormal and usually grow more quickly. Doctors sometimes describe them as poorly differentiated.

TREATING ANAL CANCER

Treatment overview

Your treatment will depend on the stage of the cancer (see pages 28 to 30). The results of your tests (see pages 18 to 24) help your doctor plan your treatment.

It's important to fully talk over your treatment options with your doctor. This helps you understand why they're advising a certain treatment. You and your doctor can decide on the best treatment for your situation.

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

Surgery may be used in the following situations:

- If chemoradiation doesn't completely get rid of the cancer, surgery may be used afterwards.
- If you have an early-stage anal cancer that's under 2cm, it can sometimes be removed with surgery alone.
- Some people may have surgery to relieve symptoms before they start chemoradiation.
- Surgery may be used if the cancer comes back after treatment.

Radiotherapy is occasionally used on its own if you aren't well enough to have chemoradiation.

Chemotherapy may be used on its own if the cancer has spread to other parts of the body.

There is more information about these treatment types on pages 40 to 74.

How treatment is planned

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

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

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

> 'When I started treatment, the advice I took with me from Macmillan's Online Community was: "Listen to your body, and if you feel tired, relax. Let others help. You don't get a medal for being brave."'
>
> **Linda**

Second opinion

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

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

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

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

The advantages and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can happen. But these can usually be controlled with medicines. Cancer treatment can be given for different reasons, and the potential benefits will be different, depending on your individual situation.

If you have been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. But if a cure is not possible and the purpose of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to have it.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it, improving symptoms and quality of life. But for some people in this situation, the treatment will have no effect on the cancer and they will get the side effects without any of the benefit.

Making decisions about treatment in these circumstances is always difficult. You may need to discuss in detail with your doctor whether you want to have treatment. If you choose not to have it, they can still give you supportive (palliative) care, with medicines to control any symptoms.

Giving your consent

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

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

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

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

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment. You can use the space on pages 120 to 121 to do this.

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

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

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

Chemoradiation

Chemoradiation is often the main treatment for anal cancer. This is a combination of radiotherapy and chemotherapy. Below and on the opposite page is general information about chemoradiation. The sections on radiotherapy (pages 42 to 51) and chemotherapy (pages 52 to 60) have detailed information about the individual treatments and their side effects.

Why chemoradiation is given

Chemotherapy drugs can make cancer cells more sensitive to radiotherapy. Combining both treatments is often more effective than having either treatment on its own.

Chemoradiation is more effective at curing anal cancer than surgery. It also means you avoid having a stoma (see pages 62 to 65).

How chemoradiation is given

You usually have chemoradiation as an outpatient.

A common treatment plan involves 4 to 6 weeks of radiotherapy (see pages 42 to 52) and two cycles of chemotherapy (see pages 53 to 60). 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. Four weeks after you started treatment, you have a second cycle of chemotherapy.

You usually have the chemotherapy into a vein (intravenously). Some people have the fluorouracil through a portable chemotherapy pump (see page 54), which they take home. Sometimes people have a drug called capecitabine, which is taken as a tablet, instead of fluorouracil.

Side effects

There is information about the side effects of radiotherapy on pages 46 to 49 and the side effects of chemotherapy on pages 57 to 60.

Giving chemotherapy and radiotherapy together can make the side effects of treatment worse. Your doctor or specialist nurse will give you more information about chemoradiation and the possible side effects. The following side effects of chemoradiation may be worse than for either radiotherapy or chemotherapy alone:

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

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

> **‘I remember being rather scared when I needed to go to the bathroom, and I wore a lot of long dresses!’**
>
> **Tania**

A radiotherapy machine

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. The most common treatment for anal cancer is having radiotherapy in combination with chemotherapy (chemoradiation – see pages 40 to 41). You can also have radiotherapy on its own if your doctors think you aren't well enough to have chemoradiation.

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

Our booklet **Understanding radiotherapy** has more information about the treatment and how to cope with side effects.

How radiotherapy is given

You usually have it as an outpatient in the radiotherapy department. The radiotherapy is given using equipment similar to a large x-ray machine (see the photo opposite). This is called a linear accelerator (often called a linac).

The radiotherapy is usually given as a series of short, daily treatments. You have the treatments from Monday to Friday, with a rest at the weekend. The course of treatment lasts 4 to 6 weeks. The radiotherapy doesn't make you radioactive. It is perfectly safe for you to be with other people, including children, throughout your treatment.

Intensity-modulated radiotherapy (IMRT)

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

IMRT shapes the radiotherapy beams. This allows different doses of radiotherapy to be given to different areas. It means that lower doses can be given to healthy tissue – especially tissue that's more easily damaged by radiotherapy. This lowers the chance of immediate and long-term side effects. For example, it can reduce the risk of long-term bowel problems.

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

We have more information about IMRT, which we can send you.

Conformal radiotherapy

Conformal radiotherapy is another way of giving radiotherapy. A special attachment to the radiotherapy machine carefully arranges the radiation beams to match the shape of the cancer. Shaping the radiotherapy beams reduces damage to the surrounding healthy cells. This can reduce the side effects of the radiotherapy.

Planning your radiotherapy treatment

Radiotherapy has to be carefully planned to make sure it is as effective as possible. It's planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you'll be asked to have a CT scan (see pages 20 to 21) or to lie under a machine called a simulator. A simulator takes x-rays of the area to be treated.

You may need to have some small marks made on your skin. This is to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, so permanent marks (like tiny tattoos) are usually used. They are extremely small, and this will only be done with your permission. It may be a little uncomfortable while they are done.

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

At the beginning of each radiotherapy session, the radiographer will position you carefully on the couch and make sure you are comfortable.

During your treatment you'll be alone in the room, but you can talk to the radiographer who will watch you from the next room.

Radiotherapy is not painful, but you have to lie still for a few minutes during treatment.

Side effects of radiotherapy

You may develop side effects during your treatment. Side effects build up slowly when you start treatment. They usually disappear gradually over a few weeks or months after treatment finishes. Your doctor, nurse or radiographer will discuss this with you so you know what to expect. Let them know about any side effects you have during or after treatment. 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.

We can send you more information about giving up smoking. NHS Smokefree can also offer advice and support – find out more by visiting **nhs.co.uk/smokefree**

Tiredness

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

Diarrhoea and passing wind

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 or radiographer may give you advice about avoiding certain foods. Or a dietitian at the hospital can give you advice about this. Our booklet **Eating problems and cancer** has tips on coping with problems such as diarrhoea and wind.

Pain

You may experience a stinging sensation when you open your bowels. Your doctor can prescribe local anaesthetic creams to help with this. Tell your doctor or nurse if you have any pain.

Skin reaction

It's 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 also have soreness in the scrotum. Women may also 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's 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 painful, your doctor may suggest you have a fine tube (catheter) put into your bladder to drain the urine. They will remove this once your skin has healed.

> 'The hospital will give you drugs for the nausea and diarrhoea. They will also probably give you some aqueous cream for the inevitable sore bum. However, a good many of us also used aloe vera cream and found it very good.'
>
> **Graham**

> ‘I ate ginger biscuits to try and cope with nausea, and just whatever else I felt like.’
>
> **Tania**

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 sensation when you pass urine.

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

Feeling sick

Some people may feel sick (nauseous) during treatment. This is usually mild, and anti-sickness drugs (anti-emetics) can usually control it.

If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and your doctor can also prescribe them. It's important to try to drink plenty of fluids.

Hair loss

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

You may find it helpful to read our booklets on how to manage side effects during pelvic radiotherapy. We have one for men and one for women. To order one, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Possible late effects of radiotherapy

Some people may still have side effects months after treatment ends. Or they 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 (chemoradiation – see pages 40 to 41). Your doctor or nurse will talk to you about this.

Our booklets about pelvic radiotherapy have more information about reducing the risk of some possible late effects. To order them, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Bowel changes

You may have loose stools, or more frequent bowel movements than before. Or you may feel the need to rush to the toilet to urgently move your bowels. Some people may find the anus leaks a little (incontinence), for example when they pass wind.

For most people, the change is not severe. It can usually be easily managed with changes to your diet. Always tell your doctor if you have any of these problems. Some people may need to take medication. There is more advice about diet after surgery on page 81.

Fertility

Radiotherapy to the pelvic area usually causes infertility (the loss of the ability to have children) in both men and women.

If you are concerned about the risk of becoming infertile, it is important to discuss this with your specialist before starting treatment. You can read more about this on page 84.

Vaginal dryness and narrowing

Women may develop dryness and narrowing of the vagina.

Your specialist nurse may advise you to use a vaginal dilator. Dilators are tampon-shaped plastic tubes of different sizes, which you use with a lubricant. This helps keep the vaginal walls open and supple.

There are different creams, gels and lubricants that can help improve vaginal dryness. Your doctor or specialist nurse can give you more information about this.

Menopause

For women who have not been through the menopause, pelvic radiotherapy usually causes an early menopause.

This can cause hot flushes and sweats, vaginal dryness and other symptoms of menopause. Your doctor or nurse can give you advice on managing menopausal symptoms. You can ask them about taking HRT (hormone replacement therapy).

Erection difficulties

Men may become unable to have an erection (erectile dysfunction – ED) after treatment. If this is a problem, talk to your doctor or specialist nurse. Treatment with drugs such as sildenafil (Viagra®) can help some men get and maintain an erection. If you can't take these drugs, other methods may help (see pages 82 to 83).

We have more information in our booklet **Sexuality and cancer – information for men**.

Having chemotherapy

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. These drugs disrupt the growth of cancer cells, 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 40 to 41). 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).

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

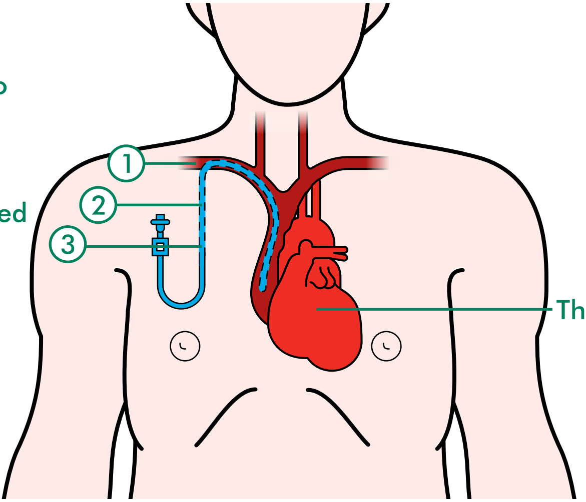
- **A central line** – This is a long, thin, flexible tube inserted into a vein in your chest. It stays in until you have finished your course of chemotherapy.
- **A PICC line** – This is a long, thin, flexible tube inserted into a vein in the crook of your arm. It stays in until you have finished your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

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.

There is lots more information on our website. Visit **macmillan.org.uk/chemotherapy** to:

- read more about central lines and PICC lines
- watch animations showing how central lines and PICC lines are put in the body
- watch videos that show a chemotherapy treatment centre, health professionals and people having treatment.

A central line



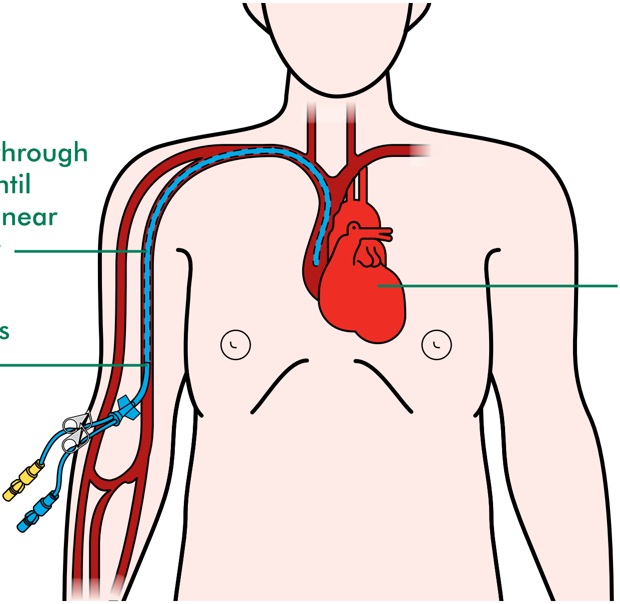
① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here

The heart

A PICC line



The line is threaded through the vein until the end is near your heart

Line comes out here

The heart

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 the side effects of the treatment.

The treatment and rest period make up a **cycle** of treatment. Your doctor or specialist nurse will explain how many cycles of treatment you need.

Having chemotherapy

Possible side effects of chemotherapy

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

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

Risk of infection

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

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

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

If necessary, you'll be given anti-biotics to treat any infection.

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

Bruising and bleeding

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

Anaemia (low number of red blood cells)

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

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

Tiredness (fatigue)

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

Nausea and vomiting

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

Diarrhoea

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

Sore mouth

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicine to prevent or clear mouth infections.

Sore hands and feet

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

> 'I kept a daily journal. I wrote various things, such as the time I took painkillers, which was important because you may suffer with "chemo brain" – being forgetful. Also I wrote when I had bowel movements, as the nurses all asked. And I wrote how much pain I had, how I felt, was I happy or sad, and who visited me.'
>
> Valerie

Fertility

Chemotherapy may affect your fertility (being able to get pregnant or father a child). It's important to talk to your doctor or nurse about this before treatment starts. There is more information about this on page 84.

Contraception during and after chemotherapy

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

Sex during chemotherapy

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

There's more information about sex and fertility on pages 82 to 84.

Surgery

Surgery is not a common treatment for anal cancer, because chemoradiation (see pages 40 to 41) is often the only treatment needed.

Surgery may be your main treatment if you have a very small tumour outside the anus (anal margin). This is only if the surgeon can remove it without affecting how you have a bowel motion.

Surgery may also be used:

- if chemoradiation doesn't completely get rid of the cancer
- if there are signs the cancer has come back
- if you can't have radiotherapy, for example because you've had radiotherapy to the pelvis before
- to relieve a blockage in the bowel before you have treatment with chemoradiation
- if you are a woman and want to have children in the future.

If you need surgery, your doctor will talk it over with you. They will advise you about the type of operation and how it will help.

If you smoke, try to stop 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 heal after the operation. Your hospital team or GP can give you advice and support to help you give up smoking.

Types of surgery

Local excision

This operation 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 the illustration on page 9).

Because the anal sphincter isn't usually affected, you won't have permanent problems with bowel control after surgery.

Your doctors may recommend you have radiotherapy or chemoradiation after surgery. This is usually when there are some cancer cells in the tissue close to where they removed the cancer.

Abdominal-perineal resection (APR)

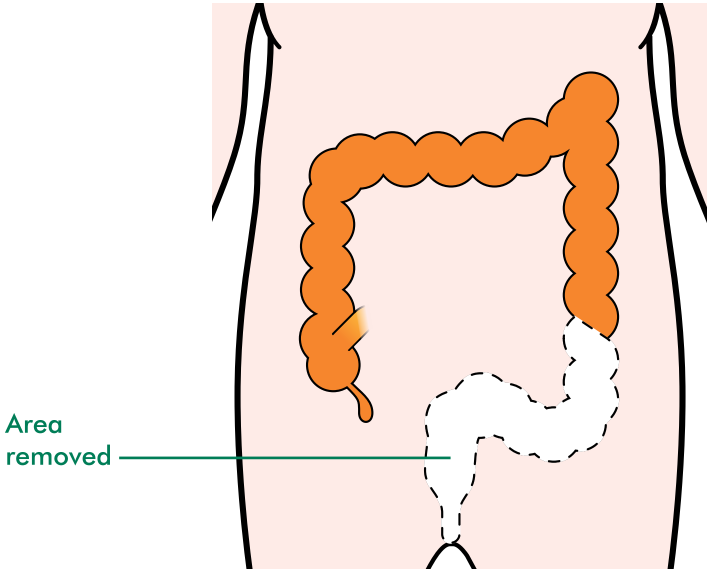
This is a major operation to remove the anus, rectum and part of the large bowel (colon) – see the illustration opposite. Doctors usually only advise having an APR if:

- the cancer hasn't gone completely after chemoradiation
- the cancer comes back after treatment.

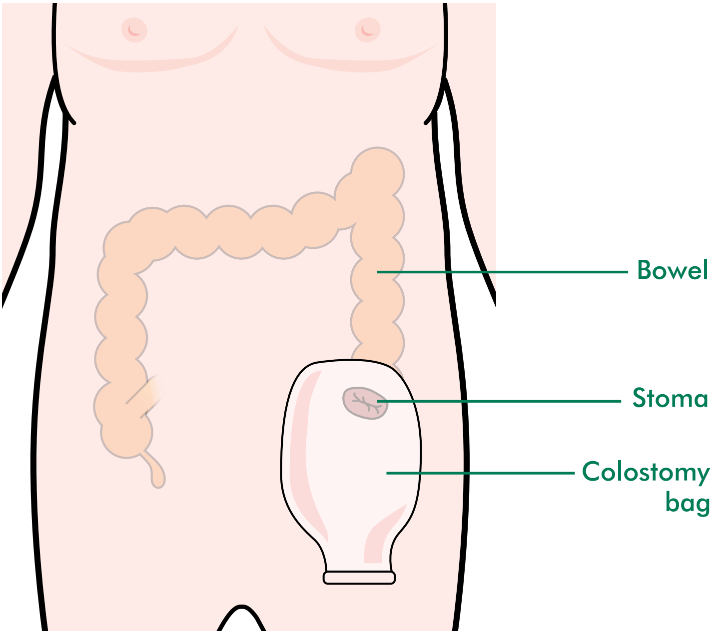
Because an APR involves removing the anus and rectum, it means having a permanent colostomy. The surgeon moves the open end of the bowel to the surface of the tummy (abdomen). The opening is called a stoma. Your bowel motions (stools) then pass out of the body into a colostomy bag – see the illustration opposite.

This can be upsetting and take time to adjust to. Your surgeon and a stoma nurse will talk it over carefully with you before the operation. Your nurse will give you a lot of support, and there are organisations that also help. See pages 72 to 73 for more information about having a stoma.

Abdominal-perineal resection



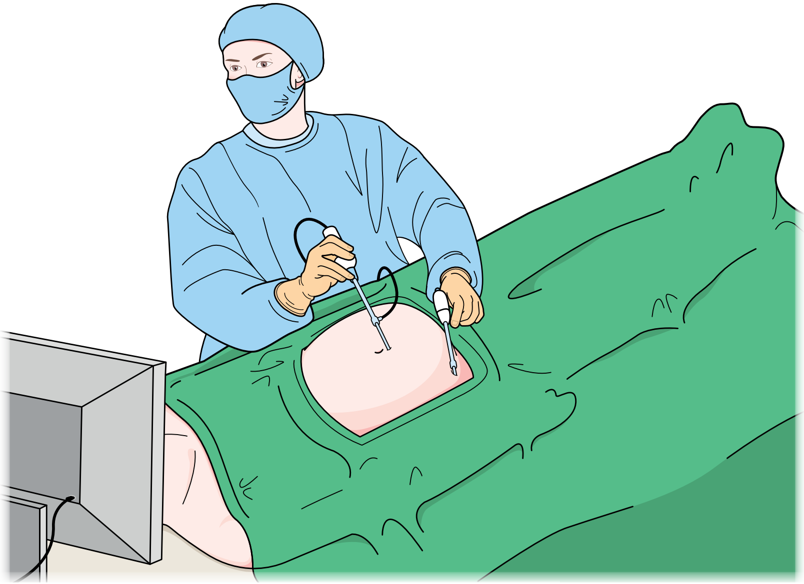
A colostomy bag



After the APR operation, you usually have two wounds. You have a tummy wound and a wound 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.

Sometimes an APR may be done using **keyhole surgery** (laparoscopic surgery). The surgeon does the operation using only four or five small cuts (about 1cm each) in your abdomen. They use specially designed instruments that can be put through these small cuts. There will still be a wound where the anus has been closed.

Keyhole surgery



Having a temporary stoma

This is occasionally done before chemoradiation. It involves having surgery to make a temporary stoma (see pages 62 to 63).

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 leakage of your bowel motions (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.

Having a blood test

Planning your operation

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 usually have a hospital appointment before your operation to have some tests and make sure you're fit enough for the operation. This is called a pre-assessment clinic.

Pre-assessment clinic

You will usually see a nurse, and you may also see an anaesthetist. The nurse will ask about your medical history and do simple checks, such as your blood pressure, temperature and weight.

You may have some of the following tests:

- blood tests
- a chest x-ray to check your lungs
- an electrocardiogram (ECG), to check the rhythm and rate of the heart.

Some people may have other tests as well.

It's important you understand everything about the operation you are having. You should be given an opportunity to discuss the operation with your surgeon. This might happen at the pre-assessment clinic. You will need to sign a consent form to say that you agree to the operation. No operation will be done without your consent.

Enhanced recovery programme (ERP)

Some hospitals follow an enhanced recovery programme. This helps speed up recovery and it involves you more in your care. It involves careful planning before your operation so you are properly prepared. Any arrangements needed for you to go home will also be organised for you.

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

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

After your operation

When you wake up after surgery

You will probably feel quite drowsy. You may not remember much about the first couple of hours after you wake up. A nurse will take your blood pressure regularly. 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 have some of the following, but not everyone will need all of these:

- A drip (intravenous infusion) to give you fluids until you are eating and drinking normally.
- A tube (drain) in your wound to drain extra fluid into a small bottle. This is usually removed after a few days.
- A small tube (catheter) in your bladder that drains urine into a collection bag. It is usually removed when you start walking around.
- A tube going up the nose and into the stomach (naso-gastric tube) to remove fluid from the stomach until the bowel starts working again.

Pain

You may have some pain after surgery, but this will be controlled with painkillers. You may have painkillers:

- as tablets
- as injections
- through a tube into a vein in your hand or arm (cannula), which is connected to a pump
- as a continuous dose into the spinal fluid through a fine tube and a pump (epidural).

The pain control you need will depend on the type of operation you've had. Always let the nurse know if you are still in pain.

Painkillers occasionally make it difficult to have a bowel motion (constipation). If your bowels aren't moving, let your nurses know. They can give you medicines to help them move more regularly.

After an APR (see pages 62 to 64), it may be uncomfortable to sit down. This will improve as the wound heals.

Moving around

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

To reduce the risk of blood clots, you will wear special stockings. You may also be given injections under the skin of a drug (heparin) that prevents blood clots.

Feeling sick or being sick

The nurse will give you anti-sickness (anti-emetic) injections or drugs to control any sickness. If you still feel sick, tell the nurse looking after you.

Wound care

Your wounds may be closed with stitches, clips or staples. They are usually removed after you go home by a practice nurse at your GP surgery. Some surgeons use dissolving stitches that don’t 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 your doctors used a flap of tissue to close your wound, you will need to lie on your side for 3 to 4 days after your operation. This reduces pressure on your wound and helps it heal.

You will be able to sit on your bottom for five minutes at first. As things improve, you slowly increase this amount of time. Your doctor 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.

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. Let them know straight away if you:

- have any bleeding
- feel unwell
- have symptoms of an infection, such as a cough or discharge from your wound
- 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, let a doctor know straight away.

If you have a stoma

This can be difficult at first. Learning to look after a stoma takes time and patience. No one expects you to be able to cope straight away. Like anything new, it will get easier with time and practice.

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

You may find it helpful to talk to someone who is living with a stoma. Your nurse or doctor can often arrange for a volunteer to visit you. This can be very helpful, especially in the first few months after your operation.

> 'Yes, there is this big thing of, "Oh no, not a stoma," but the darn things can help. And with the aid of good stoma nurses, they are manageable.'
>
> **Glyn**

Before surgery, your stoma nurse or doctor carefully plans the position of the stoma. This means the colostomy bag will stay in place, whatever you are doing.

At first, the stoma will be slightly swollen. It can take several weeks before it settles down. For the first few days, your nurse will show you how to look after it. They will also empty and change the bag.

As soon as you're feeling well enough, your nurse will show you how to clean the stoma and change the bags. It may help for a partner or close relative to be there too. It means they can help if you have any difficulties when you go home. There are different types of colostomy bags and supplies. The nurse will help you choose what's suitable for you.

They will give you stoma supplies to go home with. After this, you will need to order them from your chemist or a specialist supply company. The supplies are free, but you need a prescription from your GP. If you're aged 16 to 60, make sure your doctor signs the form saying you're entitled to free prescriptions.

Once you're at home, you can phone the stoma nurse if you have any problems. Or a district nurse can visit to make sure you're coping with your stoma.

Having a stoma is a big change in your life. It can also affect relationships, as some people are uncomfortable about their bodies or about a partner seeing their stoma. These feelings are a natural part of coming to terms with having a stoma, and usually slowly get better over time.

There are different organisations that can support you:

- You can contact the Colostomy Association (see page 116) to talk about any concerns you have.
- Healthtalkonline has video and audio clips of people with stomas talking about their experiences. Visit **healthtalkonline.org**
- Call us on **0808 808 00 00** to talk to our cancer support specialists. We also have two videos about stomas on our website. Visit **macmillan.org.uk/havingastoma** to watch a stoma nurse talking about looking after a stoma and showing the supplies you might use. Visit **macmillan.org.uk/livingwithastoma** to watch Pat's story of living with a stoma. And visit **macmillan.org.uk/bodyimage** to read more about body image and cancer.
- There are other helpful organisations listed on pages 115 to 118.

Going home

This will depend on the type of operation you had. If it's a small operation, you will be ready to go home after a couple of days. After a bigger operation, it may take up to two weeks.

You'll be given an appointment to attend an outpatient clinic for your post-operative check-up. If you have stitches, clips or staples in your wound, these are usually taken out 7 to 10 days after surgery. Your practice nurse or a district nurse can do this.

Some people take longer than others to recover from their operation. We have more information about getting ready to go home from hospital. To order it, call us on **0808 808 00 00**.

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

Research – clinical trials

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

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

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

Taking part in a trial

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

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

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

There is a trial called PLATO (personalising radiotherapy dose in anal cancer). It aims to find the best way of giving radiotherapy for different stages of anal cancer.

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

Blood and tumour samples

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

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

AFTER YOUR TREATMENT

Follow-up

After treatment has finished, you'll have regular check-ups with your doctor. They will examine you, ask how you are feeling and ask if you have any new symptoms.

You may also have other tests and scans to help your doctors check how well treatment has worked. Your doctor and 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, let your doctor know straight away. Your doctor will check what may be causing your symptoms and if they are linked to your treatment (late effects).

Many people find they get anxious before their follow-up appointments. This is natural. It may help to get support from family, friends or one of the organisations listed on pages 115 to 118 during this time.

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

Diet after surgery

After surgery, you may notice certain foods upset your bowel. High-fibre foods, such as fruit and vegetables, may make your stools loose and make you go to the toilet more often. Tell your doctor or nurse if this happens, as they can give you medicine to help. It's important to drink plenty of fluids if you have diarrhoea.

There are no rules about which foods to avoid. Foods that cause problems for one person may be fine for another person. After a while, you may find that things settle down.

After surgery, it sometimes takes months for bowel movements to get back to normal. Some people may find their bowel is permanently more active than it was before. They may have to eat carefully to control their bowel movements. Your stoma nurse will give you advice about this.

You may also find your bowel produces more wind than it did before. This can be uncomfortable. Drinking peppermint water or taking charcoal tablets can help reduce this. Your doctor can prescribe these for you, or you can get them from your chemist.

If you continue to have problems with bowel movements or wind, talk to a dietitian at the hospital. They can give you specialist advice for your individual situation.

You may find our information on eating problems and cancer helpful. To order it, call us on **0808 808 00 00**.

Sex and fertility

Sex

Your diagnosis, treatment and side effects may affect your sex life and how you feel about yourself as a man or a woman. Difficulties often improve slowly after treatment, although for some people it may take longer.

If you have a partner, you may both find it takes time to adjust to any changes. Most people can go back to their usual sex life. But some people find their surgery or the side effects of treatment prevents that.

You may feel insecure and worry about whether your present or future partner will find you sexually attractive, especially if you have a stoma. It is normal to feel like this when you're adjusting to body changes.

Men may find that treatment has damaged the nerves that go to the sexual organs. If this happens, a man may not be able to have or maintain an erection. They may also have problems with orgasm and ejaculation. There are treatments available that can help men have erections, such as:

- tablets like sildenafil (Viagra®)
- vacuum pumps
- pellets inserted into the penis
- implants.

It's important to discuss this with your doctor as soon as you notice a problem. Treatment can often be more effective when it's started sooner.

Women may also find that treatment has damaged the nerves that are important for sexual function. Sometimes this causes problems with arousal and orgasm. This may improve over time, but sometimes it is permanent.

If you have any of these problems, talk it over with your doctor or specialist nurse. They can offer the best advice and may refer you for a specialist assessment. Taking HRT can help if you have problems caused by menopausal symptoms.

Surgery to remove the anus means anal sex and anal play are no longer possible. If the anus hasn't been removed but you have had radiotherapy, you may need to be cautious with anal sex. The tissues in the area may be fragile and less able to heal. It may make anal sex uncomfortable or impossible. Your doctor can tell you more about this.

Cuddles, kisses and massage can show how much you care for someone, even if you don't feel like having sex. You can wait until you and your partner feel ready – there's no right or wrong time. If you feel things are awkward between you, it can help to talk about it. Many people find they feel reassured after talking to their partner.

You can also talk to your doctor or nurse about your concerns, and the organisations listed on pages 115 to 118 can give you support. It may also help to share your experience with other people through Macmillan's Online Community – visit **community.macmillan.org.uk**

There's more information in our booklets about sexuality and cancer. We have one booklet for men and one for women. To order a free copy, call us on **0808 808 00 00**.

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

Fertility

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

It's important to talk to your cancer specialist about any fertility concerns before treatment starts. There may be things they can do:

- For men, it may be possible to store sperm.
- For women who have a partner, it may be possible to remove eggs, fertilise them with their partner's sperm and store them.
- For women who don't have a partner, it may be possible to remove eggs and freeze them so they may be fertilised later.

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

We have more information in our booklets about cancer treatments and fertility. There's one booklet for men and one for women. To order a free copy, visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Well-being and recovery

Many people with anal cancer are cured. But recovery takes time. Some people have side effects that slowly improve, while others may have ongoing problems.

Taking good care of yourself may help you recover more quickly. You can read more about this over the next few pages.

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

Positive lifestyle changes

Some people may decide to focus more on making positive changes to their lifestyle after cancer. A healthy lifestyle can include having a well-balanced diet, getting some exercise, reducing stress and being involved in your healthcare.

Some changes help reduce the risk of developing another cancer or other illnesses, such as heart disease and strokes. Stopping smoking is very important, as it also reduces the risk of the cancer coming back.

If you’re thinking about making any major changes to your lifestyle, it’s a good idea to talk it over with your doctor or specialist nurse first.

Stop smoking

Anal cancer is more likely to come back in people who smoke. So stopping smoking is important. It will also reduce the risk of getting other smoking-related cancers and diseases, such as heart disease and stroke.

Our leaflet **Giving up smoking** has information and tips to help you quit.

Eat well

A well-balanced diet should include:

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

But if treatment has affected your bowel, foods high in fibre may cause diarrhoea. If this happens, ask your nurse or a dietitian at the hospital. They can advise you on what the best diet is for you.

Try to reduce your intake of:

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

Don’t drink too much alcohol

Stick to the NHS recommendations that men and women should:

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

Get physically active

You can start gently and build up the amount of physical activity you do. There are different types of exercise you can try, such as walking, hiking, cycling or swimming. We have more information in our booklet **Physical activity and cancer**.

Our **Move more** guide to becoming more active may help you get started. Call us on **0808 808 00 00** and we'll send you a copy.

Reduce stress

There are different ways to reduce stress. Different people find different things helpful, but you could try the following:

- Be more physically active.
- Make time to do things you enjoy or things that make you laugh.
- Try complementary therapies, such as meditation or yoga.
- Talk to someone about your feelings or have counselling (see pages 90 to 91).
- Try painting or drawing.
- Write a journal or online blog.

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

Get involved in your healthcare

Being involved in your healthcare means:

- taking any medicines as directed
- going to your follow-up appointments
- being aware of the symptoms of the cancer coming back, and looking out for them
- letting your doctor or specialist nurse know what is important to you.

We can send you information about self-management and cancer.

Getting help and support

Different people can help you during and after treatment.

Practical help

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

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

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

Emotional help

It's common to have different, and sometimes difficult, feelings after cancer treatment (see pages 94 to 97). But as you recover and get back to your everyday life, these usually get easier to deal with. Talking to family and friends often helps.

If you think you may be depressed or feel helpless or anxious a lot of the time, talk to your cancer specialist or nurse. They can refer you to a psychologist or counsellor who specialises in the emotional problems people with cancer often have. Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call us on **0808 808 00 00**.

Complementary therapies

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

Support groups

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

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

Online support

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

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

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

Guilt

Some people feel guilty or blame themselves or others for the cancer. Or you may try to find reasons for why it has happened to you.

Because of the part of the body affected and the risk factors involved, some people may feel ashamed or embarrassed. Remember that most people have HPV at some point without even knowing it. Try not to feel you're to blame in any way. Focus on looking after yourself and getting the help and support you need.

> 'I thought my friends were going to be looking on the internet and looking up my cancer, because they'd want to help and they'd want to understand and they'd probably never heard of it. And they would think, "Maybe there is something she did that she didn't tell us about". It was a bit embarrassing.'
>
> **Tania**

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

Shock and disbelief

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

Fear and anxiety

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

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

Avoidance

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

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

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

Anger

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

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

Feeling alone

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

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

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

If you need more help

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

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

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

If you are a relative or friend

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

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

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

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

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

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

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

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

Teenagers

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

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

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


One Bite at a Time

WORK AND FINANCIAL SUPPORT

Work

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

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

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

Employment rights

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

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

Financial help and benefits

Cancer can mean extra expenses, such as the cost of travelling to hospital, car parking charges and higher heating or food bills. If you can no longer work, your income may also be affected. This can cause more worries at a difficult time.

If your income is low or you are struggling to cope with the financial effects of cancer, you may be entitled to financial help. Call our cancer support specialists on **0808 808 00 00**. They can give you information to help you access benefits and financial support. Some other organisations can also offer help with financial issues (see page 119).

If you can't work because you're ill, you may be able to get Statutory Sick Pay (SSP). Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you don't qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who can't work because they're ill or disabled.

There are two different types of ESA:

- **Contribution-based** – you can get this if you have paid enough National Insurance.
- **Income-based** – you can get this if your salary and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit (see opposite) is replacing income-related ESA. This is for people who are looking for work or on a low income.

Universal Credit

This is a new benefit that has started replacing income-based ESA, tax credits and other means-tested benefits in England, Scotland and Wales. It is for people of working age who are not working or don't earn much money.

Universal Credit is gradually being introduced to different areas. The benefit you should apply for will depend on where you live and your situation. There are plans to introduce Universal Credit in Northern Ireland in the near future.

In some areas, you may be able to claim tax credits instead of Universal Credit. This may be a better option for you. Call our welfare rights advisers on **0808 808 00 00**. They can help you find out which benefits you may be able to claim.

Personal Independence Payment (PIP)

This is a new benefit for people aged 16 to 64 in England, Scotland and Wales. It is for people who find it difficult to walk or look after themselves.

Disability Living Allowance (DLA)

This benefit is mainly for people living in Northern Ireland who are under the age of 65. It is for people who find it difficult to walk or look after themselves. At some point, it is expected that PIP will replace DLA in Northern Ireland. In England, Scotland and Wales, you can only make a new DLA claim for a child aged under 16.

Attendance Allowance (AA)

This is for people anywhere in the UK who are aged 65 or over and find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself.

Our welfare rights advisers can help you find out which benefits you may be able to claim. Call them on **0808 808 00 00**.

If you have an urgent claim

If you are terminally ill and are expected to live for less than six months, you can apply for some benefits under special rules. Applying under special rules means your claim will be dealt with quickly and you will get the benefit you apply for at the highest rate. If you get benefits under special rules and then live for longer than six months, the benefits won't be affected.

This can be difficult to think and talk about. Usually a member of your healthcare team, such as a specialist nurse, will be able to help you fill in any forms.

Help for carers

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

More information

The benefits system can be hard to understand, so it is a good idea to talk to an experienced welfare rights adviser. You can call the Macmillan Support Line on **0808 808 00 00** to speak to a financial guide. Although we have listed some benefits here, there may be others you can get.

You can find out about state benefits and apply for them online at:

- **gov.uk** if you live in England, Scotland or Wales
- **nidirect.gov.uk** if you live in Northern Ireland.

These websites have information about financial support, your rights, employment and independent living. You can also get information from the relevant Department for Work and Pensions helplines or Citizens Advice. In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland. See page 119 for details of these three organisations.

Our booklet **Help with the cost of cancer** has more detailed information about benefits. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a free copy. We also have a useful video at **macmillan.org.uk/gettingfinancialhelp**

Insurance

People with cancer may find it hard to get certain types of insurance, including life insurance and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 119.

Our booklet **Insurance** may also be helpful. Order a copy by calling **0808 808 00 00** or visiting **be.macmillan.org.uk**


Macmillan Support & Information Centre
WELCOM
Welcome
SUPPORT AND INFORMATION

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

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

Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

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

Anal and bowel cancer support organisations

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.

Beating Bowel Cancer

Tel 08450 719301
(Mon–Thu, 9am–5.30pm)
Email nurse@beatingbowelcancer.org
www.bowelcancer.org

Gives information and support to people affected by bowel cancer.

Bladder and Bowel Community

Tel 01926 357220
Email help@bladderandbowelfoundation.org
www.bladderandbowelfoundation.org

Provides information and advice on bladder and bowel symptoms.

Bowel Cancer UK

Tel (England & Wales)
020 7940 1760
Email (England & Wales)
admin@bowelcanceruk.org.uk
Tel (Scotland) 0131 225 5333
Email (Scotland) scotadmin@bowelcanceruk.org.uk
Tel (Northern Ireland)
07798 523 668
Email (Northern Ireland)
bernadette.mcgarry@bowelcanceruk.org.uk
www.bowelcanceruk.org.uk

Gives information and support to people affected by bowel cancer.

Colostomy Association

Tel 0800 328 4257
Email cass@colostomyassociation.org.uk
www.colostomyassociation.org.uk
Assists and supports people who have or are about to have a colostomy.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339 (Mon–Fri, 9am–1pm)
Email helpline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK

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

Cancer Support Scotland

Tel 0800 652 4531 (Mon–Fri, 9am–5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various 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
(Daily, 8am–8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

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 Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk

Scottish Cancer Registry

Tel 0131 275 7777
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 02920 373500
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

Counselling and emotional support

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**

UK Council for Psychotherapy (UKCP)

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

Support for carers

Carers Trust

Email support@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777
(Mon–Fri, 10am–4pm)
Helpline (Northern Ireland)
028 9043 9843
Email
advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Financial information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674
(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)
www.nidirect.gov.uk/money-tax-and-bfits
Has information about disability benefits and carers' benefits.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office or on one of these websites:

England
www.citizensadvice.org.uk

Wales
www.citizensadvice.org.uk/wales

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon–Fri, 8am–6pm)
Carer's Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon–Thu, 8.30am–5pm,
Fri, 8.30am–4.30pm)
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

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

You can search for more organisations on our website at **macmillan.org.uk/organisations** or call us on **0808 808 00 00**.

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.

Thanks

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

With thanks to: Dr Rachel Cooper, Consultant in Oncology; Dr Andrew Gaya, Consultant Clinical Oncologist; Claire McGilly, Colorectal CNS; Dr Catriona McLean, Consultant Clinical Oncologist; Jacqueline Peck, Colorectal and Anal Cancer CNS; Val Weston, Colorectal CNS; and Mr Sanjaya Wijeyekoon, Consultant Colorectal Surgeon. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

Sources

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

Czito B, et al. Cancer of the anal region. *Devita, Hellman and Rosenberg's cancer: principles and practice of oncology.* 10th edition. Lippincott Williams & Wilkins. 2015.
Edge, et al. *AJCC cancer staging handbook (7th edition)*. Chicago Springer. 2011.
Glynne R, et al. Anal cancer: ESMO-ESSO-ESTRO clinical practice guidelines for diagnosis, treatment and follow-up. *Annals of oncology.* 2014.

Can you do something to help?

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

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

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

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

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

27530

This booklet is about 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, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am 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.

© Macmillan Cancer Support, February 2017. 2^{nd} edition. MAC14811. Next planned review 2019. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Printed using sustainable material. Please recycle.

Health & care information you can trust

The Information Standard Certified Member

What's this logo? Visit **macmillan.org.uk/ourinformation**

WE ARE MACMILLAN. CANCER SUPPORT