Understanding anal cancer

> “It was hard telling my friends about my diagnosis as they didn't know what to say. There was little information available on anal cancer. I didn't know anyone in my family that I could talk to about it.”

Tania, diagnosed with anal cancer

About this booklet

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

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

The booklet explains what the anus is and how anal cancer is treated. It also has information about feelings and practical and financial issues. We have more information about testing for and diagnosing anal cancer on our website. Visit macmillan.org.uk/anal-cancer

We hope it helps you deal with some of the questions or feelings you may have.

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

How to use this booklet

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

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

On pages 104 to 114, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had anal cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Tania, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

Contents

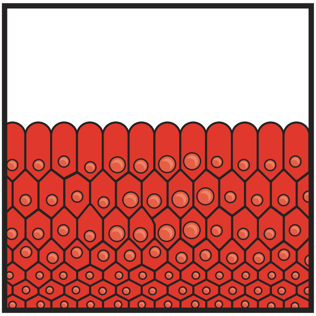
The anus and cancer

What is cancer?

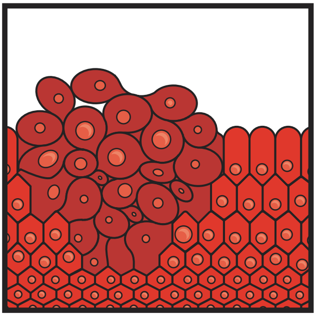
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets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

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

Cells forming a tumour



Normal cells



Cells forming a tumour

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

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

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

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system.

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

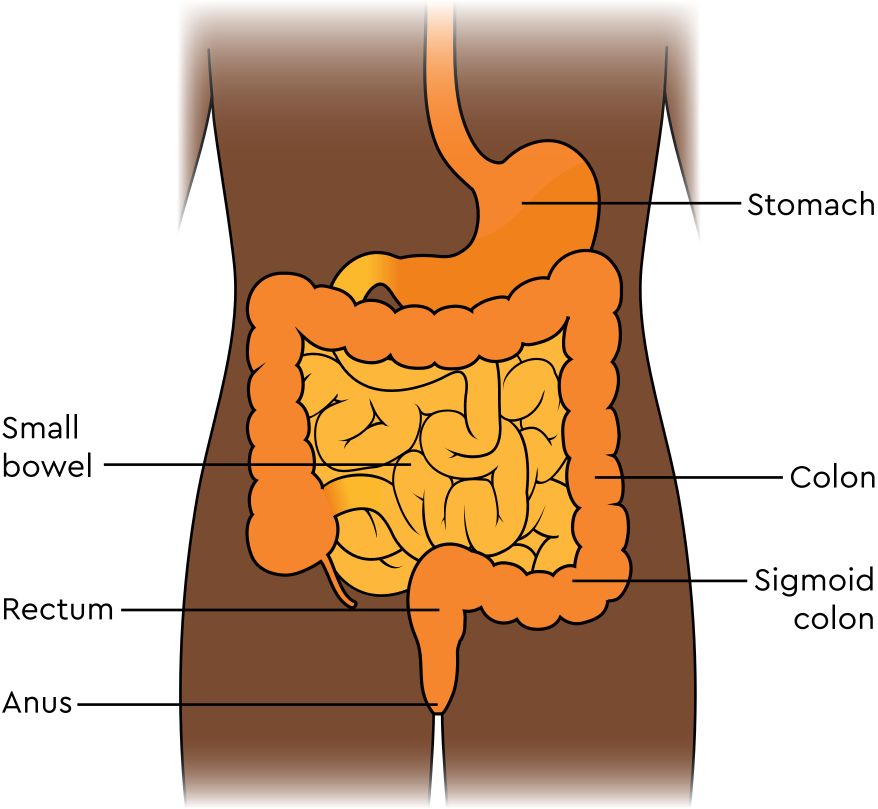
The anus

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

Food passes down the gullet (oesophagus) to the stomach, where digestion begins. It then enters the small bowel, which absorbs nutrients and minerals. The digested food then moves into the colon, which absorbs water. The colon also contains bacteria which breaks down the food into waste matter (poo). The colon moves the waste into the rectum.

Nerves and muscles in the rectum help to hold on to the poo until you are ready to pass it through the anus.

Bowel anatomy



The anal canal

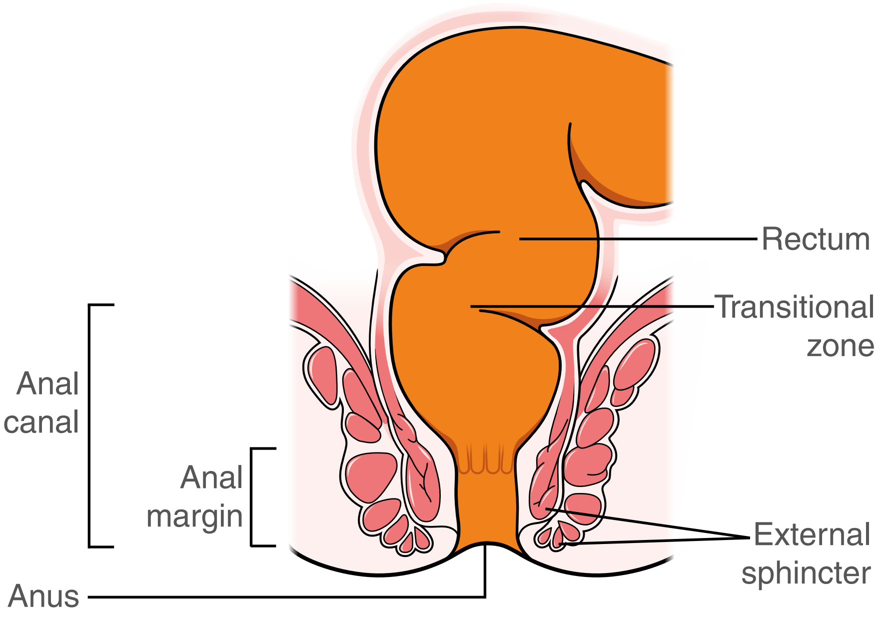
The anal canal connects the rectum to the anus. The anal canal is about 3 to 4cm (1 to 1½ inches) long. The area where the anus opens at the lower end is called the anal margin or anal verge.

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

The walls of the anal canal are lined with cells called squamous cells. Nearly all anal cancers develop in these cells.

The anal canal meets the rectum in an area called the transitional zone. The walls in the transitional zone are lined with squamous cells and glandular cells. Glandular cells make mucus. This helps poo pass through the anus.

Anal canal


Rectum
Transitional zone
Anal canal
Anal margin
External sphincter
Anus

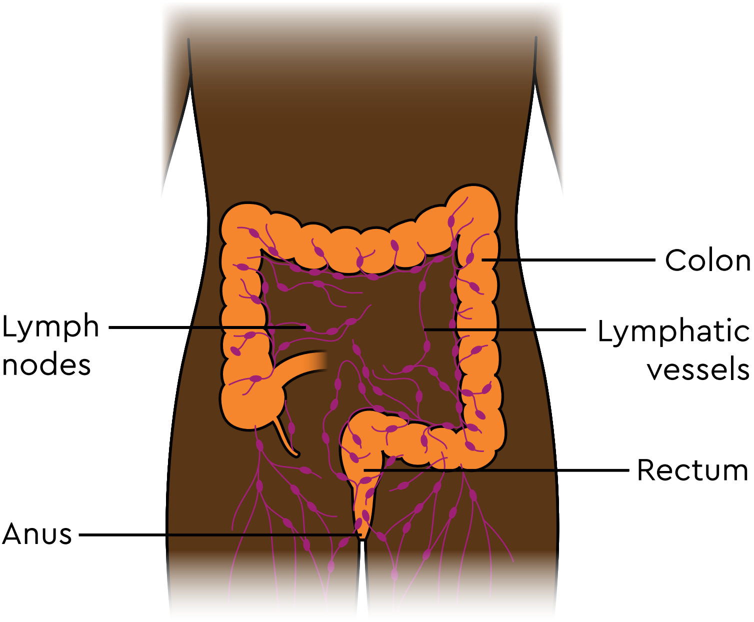
The lymphatic system

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

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

If bowel cancer spreads, it is most likely to spread to the lymph nodes close to the bowel.

Lymph nodes close to the bowel



Types of anal cancer

There are different types of anal cancer. The most common type of anal cancer is squamous cell carcinoma.

Squamous cell carcinoma

Most anal cancers develop in the squamous cells. The squamous cells make up the lining of the anal canal.

There are different subtypes of squamous cell carcinoma. But they are all treated in the same way.

This information is about squamous cell cancer of the anus.

Other types of anal cancer

There are some rare types of anal cancer. These are treated differently.

Adenocarcinoma

Sometimes cancer develops in the glandular cells in the anal canal. These cells make mucus. This type of cancer is called adenocarcinoma. It is not common. It is similar to rectal cancer and treated in the same way. We have more information in our booklet Understanding rectal cancer.

Mucosal melanoma

This is a type of skin cancer that develops from cells called melanocytes. These give skin its colour. Mucosal melanoma of the anus is rare. We have separate information about mucosal melanoma. Visit macmillan.org.uk/anorectal-melanoma

Other cancers

Rarely, other types of cancer can start in the anus. These include:

- gastrointestinal stromal tumours (GISTs)
- neuroendocrine tumours (NETs)
- lymphoma.

We have more information about these types of cancers on our website. Visit www.macmillan.org.uk/cancer-types

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

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

Planning your treatment


EASY

Finding out you have anal cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with anal cancer. We have more information on our website about:

- testing
- diagnosing
- possible causes
- risk factors
- symptoms

Visit macmillan.org.uk/anal-cancer

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment you will have. You might choose to spend some time reading about the cancer. Or you may prefer to wait until you see your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on **0808 808 00 00**. They will be able to talk to you about what has happened and any worries you have.

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.

The staging systems most commonly used for anal cancer are:

- TNM staging
- number staging.

TNM staging system

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

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

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

T – Tumour

Tis – the cancer is at its earliest stage. There are cancerous changes to some of the cells, but they are only in the lining of the anus. This is sometimes called in situ.

T1 – the tumour is 2cm or smaller.

T2 – the tumour is bigger than 2cm but not over 5cm.

T3 – the tumour is bigger than 5cm.

T4 – the tumour can be any size, and has started to grow into nearby structures, such as the vagina, bladder or the tube that carries urine from the bladder (urethra).

N – Nodes

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

NX – the lymph nodes were not examined.

N0 – there is no cancer in the lymph nodes.

N1 – there is cancer in the lymph nodes close to or further from the anus.

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

M – Metastasis

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

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

M1 – the cancer has spread to other parts of the body, such as the liver or the lymph nodes in the tummy (abdomen).

Number staging system

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

Stage 2 is divided into:

Stage 2a – the cancer is bigger than 2cm but not over 5cm and has not spread.

Stage 2b – the cancer is bigger than 5cm and has not spread to any lymph nodes.

Stage 1 and 2 are sometimes called early anal cancer.

Stage 3 is divided into:

Stage 3a – the cancer is 5cm or smaller and has spread to the lymph nodes near the rectum and in the groin or pelvis.

Stage 3b – the cancer is any size and has spread to nearby organs such as the bladder, urethra or vagina but has not spread to any lymph nodes.

Stage 3c – the cancer is bigger than 5cm. Or it can be any size but has grown into areas nearby such as the vagina, bladder or urethra. The cancer has spread to lymph nodes in the groin and pelvis.

Stage 3 is sometimes called locally advanced cancer.

Stage 4 – the cancer has spread to other parts of the body, such as the liver or lungs. It is sometimes called advanced or metastatic cancer.

Treating anal cancer

Treatment overview

The treatment you have depends on the stage of the cancer and your general health. Your test results will help your cancer doctor plan your treatment.

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

Chemoradiation

The main treatment for anal cancer is chemoradiation. This is when you have radiotherapy and chemotherapy together. Chemoradiation is usually successful. Most people do not need surgery after it.

Radiotherapy

If you are not well enough to have chemoradiation, you may have radiotherapy on its own. Radiotherapy can also be used to help with symptoms if the cancer has spread.

Chemotherapy

If the cancer has spread to other parts of the body, you may have chemotherapy on its own. It may help to control the cancer and improve symptoms.

Surgery

You may have surgery:

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

Other treatments

Targeted therapy or immunotherapy may be used to treat anal cancer that has come back or spread to other tissues.

Your cancer doctor can tell you if targeted therapy or immunotherapy may be suitable for you.

Clinical trials

Your cancer doctor may invite you to take part in a clinical trial. We have more information about clinical trials on our website. Visit macmillan.org.uk/clinical-trials

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT looks at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Surgeon – a doctor who does operations (surgery).
- Clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Stoma care nurse – a nurse who gives information and support to people who have a stoma.

Other healthcare professionals may include:

- a gastroenterologist – a doctor who treats problems with the digestive system
- a dietitian – someone who gives information and advice about food and food supplements
- a physiotherapist – someone who gives advice about exercise and mobility

- an occupational therapist (OT) – someone who gives information, support and aids to help people with tasks such as washing and dressing
- a psychologist – someone who gives advice about managing feelings and behaviours
- a counsellor – someone who is trained to listen to people's problems and help them find ways to cope.

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

Talking about your treatment plan

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

Your cancer doctor should explain:

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

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

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed (page 50).

You may need more than 1 meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

We have more information in our booklet Making treatment decisions.

Giving your permission (consent)

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

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

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

Second opinion

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

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

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

We have more information about getting a second opinion.
Visit macmillan.org.uk/second-opinion

Chemoradiation for anal cancer

Chemoradiation is when you have chemotherapy and radiotherapy at the same time. It is sometimes called chemoradiotherapy. It is often the main treatment for anal cancer.

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

Chemoradiation has a better chance of curing anal cancer than surgery. It also means you may avoid having a stoma.

How chemoradiation is given

You usually have chemoradiation as an outpatient. Most people have radiotherapy Monday to Friday for just over 5 weeks. Chemotherapy and radiotherapy start on the same day.

You usually have the chemotherapy drug mitomycin into a vein on the first day of your radiotherapy only. You then take capecitabine tablets 2 times a day on the days you have radiotherapy.

Some people have a drug called fluorouracil into a vein instead of capecitabine. You have it through a portable chemotherapy pump, which you take home. It is usually given continuously for a few days on week 1 and 5 of your radiotherapy.

Your doctor or nurse will tell you about the drugs you will have and how often you have them. We have more information about these drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

DPD

Before starting this chemoradiation, you should have a blood test to check whether you have low levels of an enzyme called DPD. This is called DPD deficiency. People who have low DPD levels can develop serious or life-threatening side effects if they have certain chemotherapy drugs. This includes 5FU and capecitabine. If you have DPD deficiency, this can affect the treatments that are available for you.

Side effects of chemoradiation

Having chemotherapy and radiotherapy together can make the side effects of treatment worse. Your cancer doctor or specialist nurse will give you more information about chemoradiation and the possible side effects. During chemoradiation you will usually have weekly blood tests to monitor the levels of your different blood cells.

> "Radiotherapy 'down there' was the most physically challenging and I would say chemotherapy was the most mentally challenging. That was an interesting thing in itself. „
>
> Tania

Radiotherapy for anal cancer

Radiotherapy uses high-energy rays to destroy cancer cells. It destroys cancer cells in the area of the body you have it, while doing as little harm as possible to normal cells.

Some normal cells in the area being treated can also be damaged by radiotherapy. This can cause side effects.
As the normal cells recover, the side effects usually get better.

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

For anal cancer, you usually have radiotherapy in combination with chemotherapy. This is called chemoradiation. If your doctors think you are not well enough to have chemoradiation, you may have radiotherapy on its own

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

Radiotherapy does not make you radioactive. It is safe for you to be with other people throughout your treatment, including children.

External beam radiotherapy

External beam radiotherapy is given from a radiotherapy machine. The machine looks like a large x-ray machine or CT scanner.

You usually have a number of short, daily treatments in a radiotherapy department. These are called treatment sessions or fractions.

Each treatment takes 10 to 15 minutes. The treatments are usually given Monday to Friday, with a break at the weekend. Your doctor will talk with you about the treatment and possible side effects.

Intensity-modulated radiotherapy (IMRT)

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

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

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

Volumetric-modulated arc radiotherapy (VMAT)

VMAT is a newer way of giving IMRT. It is sometimes called RapidArc®. The radiotherapy machine moves around you and reshapes the beam during treatment. This makes it more accurate and shortens the treatment time.

Planning your radiotherapy treatment

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

Your radiotherapy team uses information from this scan to plan:

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

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

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

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

Preparing for your radiotherapy

You will be sent information about having a full bladder for your treatment sessions as guidance to when you should start drinking fluids. This will also be discussed during your first treatment session. The advice may change during your course of treatment, as your ability to hold urine will change.

Treatment sessions

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

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

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

Side effects of radiotherapy

You may have side effects during your treatment. Side effects build up slowly when you start treatment. They usually get better slowly over a few weeks or months after treatment finishes. Your cancer doctor, nurse or radiographer will discuss this with you so you know what to expect. Tell them about any side effects you have during or after treatment. There are often things they can do to help.

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.

Tiredness

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

Try to get as much rest as you can, especially if you have to travel a long way for treatment. Balance this with some physical activity, such as short walks, which will give your more energy.

Skin reactions

This is a common side effect. The skin in the area that is treated, such as around the anus, the groin, vagina or scrotum (where the testicles are) may:

- feel sore or itchy
- redden if you have white skin
- darken if you have black or brown skin
- become moist and blister or peel – which can be painful towards the end of treatment.

Your radiographer or specialist nurse will give you advice about looking after your skin. Tell them straight away about any skin changes. They can give you advice or treatments such as creams or dressings. They can also prescribe painkillers for you.

During treatment, you are usually advised to:

- wash your skin gently with mild, unperfumed soap and water
- gently pat dry and avoid rubbing your skin
- wear loose-fitting clothes made from natural fibres, such as cotton
- follow your radiotherapy team's advice about moisturising the treated area
- spend some time sitting or lying on your side to help relieve any discomfort around the back passage and perineum.

Skin reactions should start getting better within 4 weeks of treatment finishing.

Pain

Skin reactions can be painful especially when you pass stools (poo). Your doctor can prescribe local anaesthetic creams to help with this. But you might need stronger painkillers to take regularly until the pain improves. Your doctor will prescribe these for you. Always tell your doctor, nurse or radiographer if you have any pain.

Bowel changes

You may experience problems with your bowel such as:

- loose stools (poo)
- passing a lot of wind
- needing to pass stools urgently and more frequently
- cramping pains in your tummy or back passage
- constipation
- tenesmus – this is the feeling that you need to go to the toilet even if your bowel is empty
- having some bleeding or mucus coming from the back passage.

If you have diarrhoea, your doctor will prescribe anti-diarrhoea tablets to help. Tell your specialist nurse or radiographer if you have any leakage (incontinence). They will give you advice and explain how to look after the skin in that area.

You might be advised to make changes to your diet during radiotherapy.

Inflammation of the bladder (cystitis)

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

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

Feeling sick

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

Hair loss

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

Changes to the vagina

Radiotherapy can make the lining of the vagina sore and inflamed. You may be advised not to have sex during treatment and for a few weeks after.

After radiotherapy, the vagina may be narrower, less stretchy and drier than before. This may make having sex painful or make it difficult if you need to have internal examinations. Your nurse may recommend you use vaginal dilators to try to prevent the vagina from narrowing. Dilators are plastic tubes shaped like tampons. They are available in different sizes that you use with a lubricant.

Vaginal dryness can be relieved with vaginal lubricants or creams. Hormone creams can also help with dryness and vaginal narrowing. Your doctor can prescribe these.

We have more information in our booklet Cancer and your sex life.

Early menopause

If you are still having periods, radiotherapy to the pelvic area may cause menopause. This means you will not be able to get pregnant. Your doctor can prescribe hormone replacement therapy (HRT) to improve symptoms of menopause. We have more information on our website. Visit macmillan.org.uk/menopausal-symptoms

Effects on the ovaries and womb

Radiotherapy for anal cancer can affect the ovaries and the lining of the womb. This often means you will not be able to get pregnant (infertility) or carry a pregnancy after treatment. Your team will give you information about this.

If you would like to have children in the future, talk to your doctor or specialist nurse before you start treatment. There may be options for preserving your fertility.

Contraception

It is important that you do not get pregnant or make someone pregnant during radiotherapy, and for a few months after it has finished. Your doctors usually recommend that you use contraception during this time.

Problems getting an erection

Radiotherapy for rectal cancer can cause problems getting or keeping an erection. This is called erectile dysfunction or ED. Your radiotherapy team can explain what is likely to happen. There are different treatments that can help with ED.

You may also have a sharp pain when you ejaculate. The pain should get better a few weeks after treatment finishes. You might also find that you ejaculate less fluid or none.

Effects on sperm

Radiotherapy to the pelvis might make you unable to make someone pregnant (infertile). It may be possible to have sperm stored before treatment starts. This is called sperm banking. It is important to talk to your cancer doctor or specialist nurse about this before your treatment starts.

We have more information about fertility on pages 82 to 83.

Possible late effects of radiotherapy

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

Some late effects include:

- bladder changes, such as needing to pass urine more often or urgently
- bowel changes, such as diarrhoea or bleeding from the back passage
- effects on your sex life.

We have more information about these and other late effects of pelvic radiotherapy Including advice on how they can be managed or treated in our booklets:

- Managing the bladder late effects of pelvic radiotherapy
- Managing the bowel late effects of pelvic radiotherapy.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call us on **0808 808 00 00**.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is sometimes called systemic anti-cancer therapy (SACT). Chemotherapy drugs disrupt the way cancer cells grow and divide. But they also affect normal cells. It is usually given in combination with radiotherapy. This is called chemoradiation.

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®).

Mitomycin is usually given with fluorouracil. Sometimes capecitabine is used instead of fluorouracil.

Other drugs that may be used are:

- cisplatin
- carboplatin
- paclitaxel.

We have more information about chemotherapy drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

How chemotherapy is given

Chemotherapy drugs for anal cancer are usually given by injection into a vein (intravenously). Some people have chemotherapy as a tablet. Chemotherapy given into a vein goes directly into your blood which carries it to all areas of your body. Chemotherapy given as a tablet is absorbed into the blood and also reaches all areas of your body.

Before you start treatment, you may have a blood test to check whether you have low levels of an enzyme called DPD. People who have low DPD levels can have more serious side effects with 2 of the chemotherapy drugs used to treat anal cancer. These are fluorouracil (5FU) and capecitabine.

You might have chemotherapy through 1 of the following:

- a cannula – a short, thin tube the nurse puts into a vein in the arm or hand
- a central line – a fine tube that goes under the skin of the chest and into a vein close by
- a PICC line – a fine tube that is put into a vein in the arm and goes up into a vein in the chest
- an implantable port (portacath) – a disc that is put under the skin on the chest or arm and goes into a vein in the chest.

We have more information about:

- cannulas at macmillan.org.uk/cannulas
- central lines at macmillan.org.uk/central-lines
- PICC lines at macmillan.org.uk/picc-lines
- implantable ports at macmillan.org.uk/implantable-ports

When your cannula, line or port is in place, a chemotherapy nurse will give you the drugs through it. This may be as an injection, as a drip (infusion) or through a pump.

Sometimes you have chemotherapy through a small, portable pump attached to your central line, PICC line or port. The pump controls the amount of chemotherapy going into your bloodstream over a set period of time. You can go home with the pump so you spend less time in hospital.

You usually have chemotherapy as an outpatient. Some people may need to be in hospital for a few days to have their treatment.

> **"Probably the hardest place is when you're sitting in that chemo chair and people are trying to talk to you as well. When I was in my chemo chair, I just wanted to put my headphones on, watch a film and chill for 3 hours. „**

Luke, diagnosed with anal cancer

Side effects of chemotherapy

Chemotherapy drugs can cause side effects. But chemotherapy can also help relieve symptoms of anal cancer. So you may feel better with chemotherapy, even if you have some side effects.

Your cancer doctor or nurse will tell you more about what to expect. Tell them about any side effects you have. Side effects can usually be well controlled with medicines. Visit macmillan.org.uk/chemotherapy

We describe some of the common side effects here. We have more information about chemotherapy side effects on our web pages about chemotherapy and chemotherapy drugs.

Although they can be hard to cope with, side effects usually get better after your treatment finishes.

Risk of infection

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

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number you have been given:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

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

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

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red, brown or purple spots on the skin that may look like a rash.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and lightheaded.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

Sore mouth

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals. Contact the hospital straight away on the 24-hour number if:

- your mouth or throat is sore, or affecting how much fluid you can drink or food you can eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

Feeling tired

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

Palmar-plantar or hand-foot syndrome

This treatment can affect the palms of your hands and the soles of your feet. This is called palmar-plantar or hand-foot syndrome. If you have white skin, these areas may become red. If you have black or brown skin, these areas might get darker. The skin on the palms of your hands and the soles of your feet may:

- be sore
- be painful, tingle, or swell
- peel, crack or blister.

If you have any of these symptoms, contact the hospital straight away on the 24-hour number. They can give you advice. This is especially important if you have any broken skin or if walking is difficult. The symptoms can be caused by the drugs capecitabine or fluorouracil. They usually get better after treatment ends.

Contraception

Your doctor, nurse or pharmacist will advise you not to get pregnant or make someone pregnant while having this treatment and for some time afterwards. The drugs may harm a developing baby. It is important to use contraception to prevent pregnancy. Follow their advice about:

- what types of contraception to use
- how long after treatment you should continue to use contraception.

Fertility

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

Surgery for anal cancer

Most people with anal cancer are treated with chemoradiation. This may be the only treatment they need.

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

Your doctors may also offer you surgery:

- after chemoradiation, if the chemoradiation does not remove all the cancer
- if the cancer comes back after chemoradiation
- if you cannot have radiotherapy – for example, because you have had radiotherapy to the pelvis before
- to relieve a blockage in the bowel (bowel obstruction) before you have chemoradiation.

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

Types of surgery

Local excision

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

This operation will not usually affect the anal sphincter. This means you will not have long-term problems with bowel control afterwards.

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

Abdominal perineal resection (APR)

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

- chemoradiation has not removed all the cancer
- the cancer has returned after treatment.

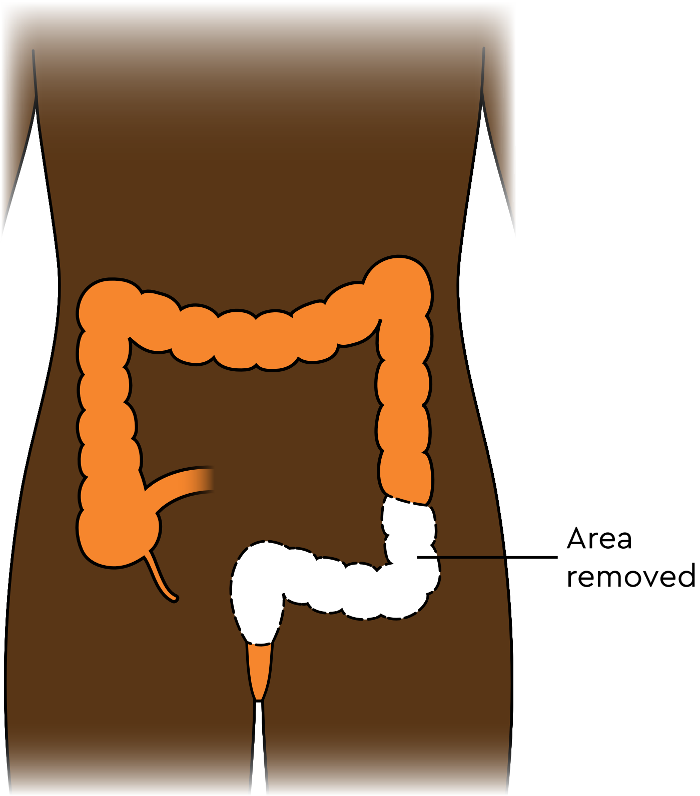
This operation can be done as either keyhole (laparoscopic) surgery or open surgery. This depends on the size of the tumour.

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

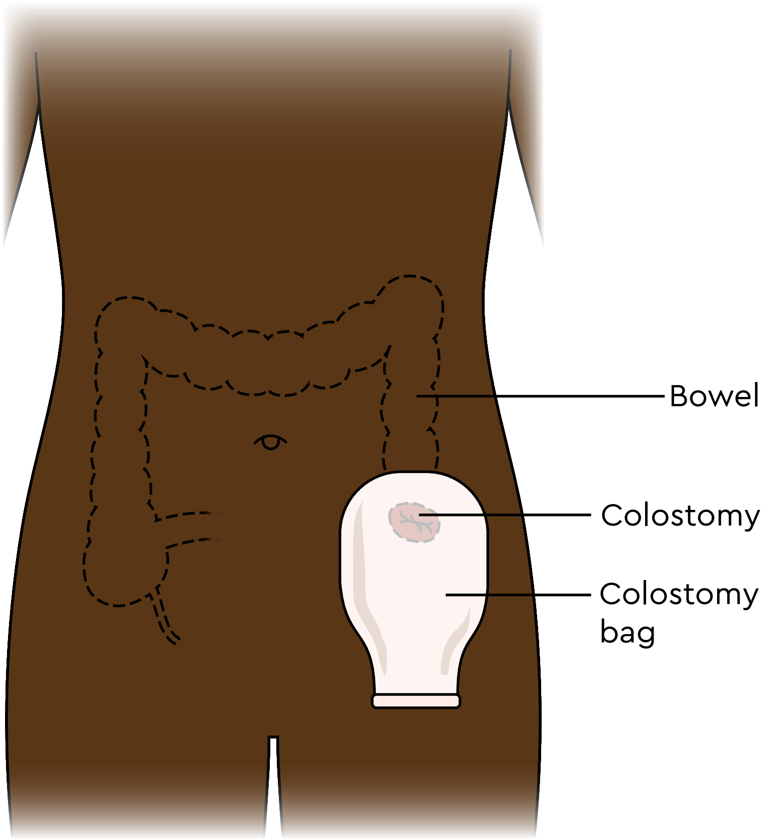
You will have a permanent stoma (colostomy) after this operation. This can be upsetting and it may take time to adjust to. Your surgeon and a stoma nurse specialist will talk to you before the operation to help you prepare. You can ask them any questions. Your nurse will give you lots of support, and there are organisations that can help.

We have more information about having a stoma on our website.
Visit macmillan.org.uk/what-is-a-stoma

Abdominal perineal resection



Stoma and stoma bag (colostomy) resection



Having a stoma before chemoradiation

Before chemoradiation, some people may need to have an operation to create a stoma.

You may have a stoma to relieve symptoms in the following situations:

- The cancer is causing you to have problems controlling your bowel. This is called incontinence.
- There is an abnormal opening between the bowel and skin. An abnormal opening between 2 areas of the body is called a fistula.
- There is a fistula between the bowel and another organ, such as the bladder or vagina.
- There is a risk of a fistula forming.
- The cancer is causing a blockage in the bowel (bowel obstruction).

After you finish chemoradiation, your doctors will assess you to decide whether you can have the stoma reversed. This will mean you can pass stools through the anus again. It is not always possible to reverse the stoma.

Before your operation

Your operation will be carefully planned. For an APR, there may be different specialists involved. This might include a plastic surgeon and a gynaecologist.

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

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

If you live alone, or care for someone else, you may need help when you go home after surgery. Tell a nurse as soon as possible. They can help to make arrangements for you.

After your operation

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

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

After your operation, a nurse will usually help you to get out of bed or to sit up for a short time. Gradually, you will be able to sit or stand up for longer, and to start walking around the ward.

Pain

It is normal to have some pain or discomfort for a few days after surgery. This can be controlled with painkillers. Immediately after your operation you may have painkillers in the following ways:

- By mouth (orally).
- As an injection.
- Through an epidural. This is a small, thin tube in your back that goes into the space around your spinal cord. It gives you continuous pain relief.
- Through a patient-controlled analgesia pump (PCA pump). The pump is attached to a fine tube (cannula) in a vein in your arm. You control the pump using a handset that you press when you need more of the painkiller.
- Through a thin tube called a rectus catheter that your surgeon places in your tummy. You may have this kind of catheter if you have the cut downwards from your belly button to your tummy.
- A combination of some of the above.

It is important to tell your doctor or nurse if the pain is not controlled. They can change your painkillers.

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

After an APR, it may be uncomfortable to sit down. This will improve as the wound heals. You may be given a special cushion to help make you more comfortable.

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

Wound care

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

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

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

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

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

These can be signs that the wound is infected.

Feeling sick or being sick

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

Drips and drains

You may be given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. Your nurse usually takes this out when you are able to eat and drink normally.

During bowel cancer surgery, you usually have a tube put in to drain urine (pee) from your bladder. This is called a catheter. A nurse will take this out when you are able to eat and drink normally and can walk to the toilet.

You may have a nasogastric tube. This is a tube that goes up the nose and down into the stomach. A nurse uses this to remove fluid from the stomach. Once the bowel starts working again, the nurse will take the tube out.

You may have a tube in your tummy, close to the wound. This drains fluid into a small drainage bag or bottle. A nurse will usually remove the drain after a few days.

Eating and drinking

You are usually able to eat and drink again soon after surgery. You may be given nutritional supplement drinks for a few days, to help your recovery. Your doctor, nurse or dietitian can advise what to eat and drink as you get better.

Possible complications

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

- a wound infection
- bleeding in the area operated on
- a chest infection
- a blood clot
- a leak from the join in your bowel.

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

- have any bleeding
- feel unwell
- have symptoms of an infection, such as a cough or feeling shivery
- have signs of a wound infection
- have swelling and redness in a limb.

If you have any problems when you get home, tell your doctor straight away.

Going home

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

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

Before leaving hospital, you will be given an outpatient appointment for your post-surgery check-up. At the appointment, your doctor will talk to you about whether you need any further treatment.

If you have a stoma, the hospital will give you some stoma supplies to take home. But you may also need to order stoma supplies from a pharmacy or specialist supplier. Your stoma care nurse can guide you through this process.

IA – The Ileostomy and Internal Pouch Support Association, and Colostomy UK have details of companies that provide stoma supplies. You will need a prescription from your GP to get these. In England, prescriptions are free for people with cancer. But if you are aged between 16 and 60, you will need to make sure your doctor or GP signs an FP92A form saying that you are entitled to free prescriptions. Prescriptions are free for people living in Scotland, Wales or Northern Ireland.

After treatment

> "When the treatment finished, it's a feeling of flatness and not quite knowing where to go. Everybody thinks that the difficult bit is going to be the treatment and the surgery not the recovery, but I found that reasonably easy to cope with, because it was structured I think."

Kathy, diagnosed with anal cancer

Follow-up

After treatment has finished, you will have regular check-ups every few months for the first 2 years. These usually continue for up to 5 years. You have them less often as time goes on.

At your check-ups, a specialist doctor will:

- examine you
- ask how you are feeling and whether you have any ongoing treatment side effects
- ask whether you have any new symptoms.

You may also have other tests to check how well treatment has worked. This includes:

- an MRI – macmillan.org.uk/mri-scan
- a CT scan – macmillan.org.uk/ct-scan

Your doctor and specialist nurse will explain more about this.

If you notice any new symptoms between check-ups, tell your GP, cancer doctor or nurse straight away. Your doctor will check what may be causing your symptoms and whether your symptoms are late effects of treatment.

You may feel anxious before check-ups. This is natural. It may help to get support from family members or friends. You might also find it helpful to contact a support organisation.

Well-being and recovery

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

Be physically active

Being physically active helps keep your weight healthy and can reduce stress and tiredness. It helps to keep your bones strong and your heart healthy. It also reduces the risk of heart disease, stroke and diabetes.

We have more information in our booklet Physical activity and cancer.

> "I did daily walks around the block, despite walking like John Wayne. These walks were advised, as it helps with healing. It certainly helped me with my frame of mind. My reward after that was to lounge in my new bed for a couple of hours with Netflix. „

Helen, diagnosed with anal cancer

Stop smoking

Stopping smoking is the healthiest decision you can make. Smoking is a risk factor for colon cancer.

Stopping smoking reduces your risk of heart or lung disease, bone thinning (osteoporosis) and smoking-related cancers. Stopping smoking can be difficult, but there is lots of support available. We have more information on our website. Visit macmillan.org.uk/stop-smoking

Drink less alcohol

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in 1 week
- spread the alcohol units they drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, 1 small glass (125ml) of wine, or a single measure (25ml) of spirits. There is more information about alcohol and drinking guidelines at drinkaware.co.uk

Try to reduce stress in your life

Being diagnosed with bowel cancer can be very stressful. A way of coping with stress is to make time to relax. Some examples of ways to relax or reduce stress include:

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

Sex and fertility

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

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

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

Women, and other people assigned female at birth, may find orgasms are less intense than before. This is caused by changes to blood flow and nerves in the pelvic and genital areas. These changes may improve over time but are sometimes permanent.

Radiotherapy to the pelvic area can cause the menopause, which may lower your sex drive. Your doctor or nurse may prescribe hormone replacement therapy (HRT) to help with menopausal symptoms.

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

Many people find it difficult to talk about sexual difficulties because they feel embarrassed. Your doctor or nurse will be used to talking about these issues. Let them know if you are having problems with your sex life. They may be able to give you advice or refer you to a sex therapist or counsellor. We have more information in our booklets Your sex life and cancer and Body image and cancer.

LGBTQ+

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

There are organisations that can give you support. It may also help to share your experience with other people through Macmillan's Online Community. Visit macmillan.org.uk/community

Fertility

Treatments can affect your ability to get pregnant or make someone pregnant (your fertility).

This can be difficult to cope with, even if you have children already or did not plan to have children. Tell your healthcare team any concerns you have about your fertility before treatment starts. They can tell you what options might be available if you would like to try to preserve your fertility and have a child in the future. We have more information in our booklet Cancer and fertility.

Your feelings and relationships

> “I have realised that we are all different and that not everyone wants to talk about cancer but we pretty much all want information. I decided to write a blog all the way through which was humorous but brutally honest and I ended up with quite a few followers.”

Tania

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet How are you feeling? The emotional effects of cancer.

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information on pages 100 to 103 about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets Talking about cancer and Cancer and relationships: Support for partners, families and friends.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet Talking with someone who has cancer.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet Looking after someone with cancer.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website riprap.org.uk offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call us on
0808 808 00 00.

Work and finances

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (pages 98 to 102).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

Macmillan Grants

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

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit macmillan.org.uk/grants

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

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

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

Work

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

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call us on
0808 808 00 00.

Further information

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at macmillan.org.uk/otherformats

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 accessing benefits

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Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing, to changes needed to your home.

Call us on **0808 808 00 00** to find out more about Macmillan Grants.

Help with work and cancer

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

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser.

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

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

Anal and bowel cancer support organisations

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
Email **help@bladderandbowel.org**
www.bladderandbowel.org
Provides information and advice on bladder and bowel symptoms.

Bowel Cancer UK

Tel **020 7940 1760**
www.bowelcanceruk.org.uk
Gives information and support to people affected by bowel cancer.

England

Email **admin@bowelcanceruk.org.uk**

Scotland

Email **scotadmin@bowelcanceruk.org.uk**

Wales

Email **walesadmin@bowelcanceruk.org.uk**

Northern Ireland

Email **niadmin@bowelcanceruk.org.uk**

Colostomy UK

Helpline **0800 328 4257**
Email **hello@colostomyuk.org**
www.colostomyuk.org
Supports people who have had, or are about to have, a colostomy. Provides information and advice on bladder and bowel symptoms.

HPV and Anal Cancer Foundation

Tel **0203 488 6567**
Email **info@analcancerfoundation.org**
Provides information and support to people affected by anal cancer.

IA – The Ileostomy and Internal Pouch Association

Tel **0800 018 4724**
www.iasupport.org
Offers support to help anyone who has had, or is about to have, their colon removed and has an ileostomy or internal pouch.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
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**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

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

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

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

Disability and Carers Service

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

GOV.UK

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

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Equipment and advice on living with a disability

British Red Cross

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

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

Helpline **0300 123 3084**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage.
Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
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 **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is 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 a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Your notes and questions

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Paul Ross, Consultant Medical Oncologist.

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

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

Sources

Below is a sample of the sources used in our anal cancer information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Rao S, Guren MG, Khan K, Brown G et al. Anal cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology. 2021;32; 9:1087–1100. Available from https://doi.org/10.1016/j.annonc.2021.06.015 [accessed Jan 2023].

Palefsky JM, Lee JY, Jay N et al. Treatment of anal high-grade squamous intraepithelial lesions to prevent anal cancer. New England Journal of Medicine. 2022; 386:2273–82. Available from doi: 10.1056/NEJMoa2201048 [accessed Jan 2023].

Willett CG. Treatment of anal cancer. UpToDate. Available at https://www.uptodate.com/contents/treatment-of-anal-cancer [accessed Jan 2023].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

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 / /

Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

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 what anal cancer is and how it may be treated. It also has information about feelings, practical issues and money.

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

For information, support or just someone to talk to, call **0808 808 00 00** or visit macmillan.org.uk

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

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

Trusted Information Creator
Patient Information Forum

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