MACMILLAN
CANCER SUPPORT

Understanding rectal cancer

About this booklet

This booklet is about rectal cancer (cancer of the rectum). The rectum is part of the large bowel, which includes the colon and anus. We have separate information about colon cancer and anal cancer (page 136).

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

The booklet explains what rectal cancer is and how it is treated. It also talks about your feelings when you are diagnosed with cancer and has practical advice on dealing with work and finances. We have more information about testing for and diagnosing rectal cancer, as well as information about the risk factors and symptoms of rectal cancer on our website. Visit **macmillan.org.uk/rectal-cancer**

When we mention bowel cancer in this booklet, this includes rectal cancer. We hope this booklet 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 142 to 151, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse on page 152.

Quotes

In this booklet, we have included quotes from people who have had rectal cancer or similar experiences, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

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

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

If you are deaf or hard of hearing, call us using 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 PDFs and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

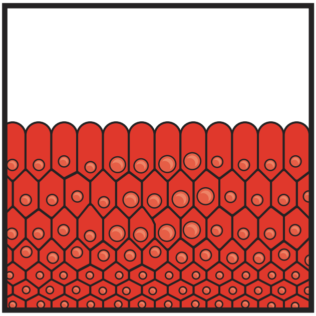
The rectum and cancer

What is cancer?

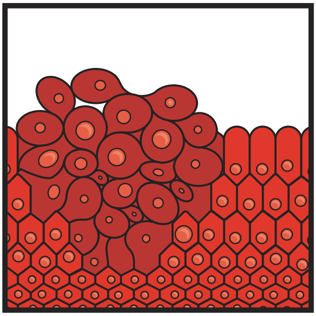
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets 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 (pages 10 to 11).

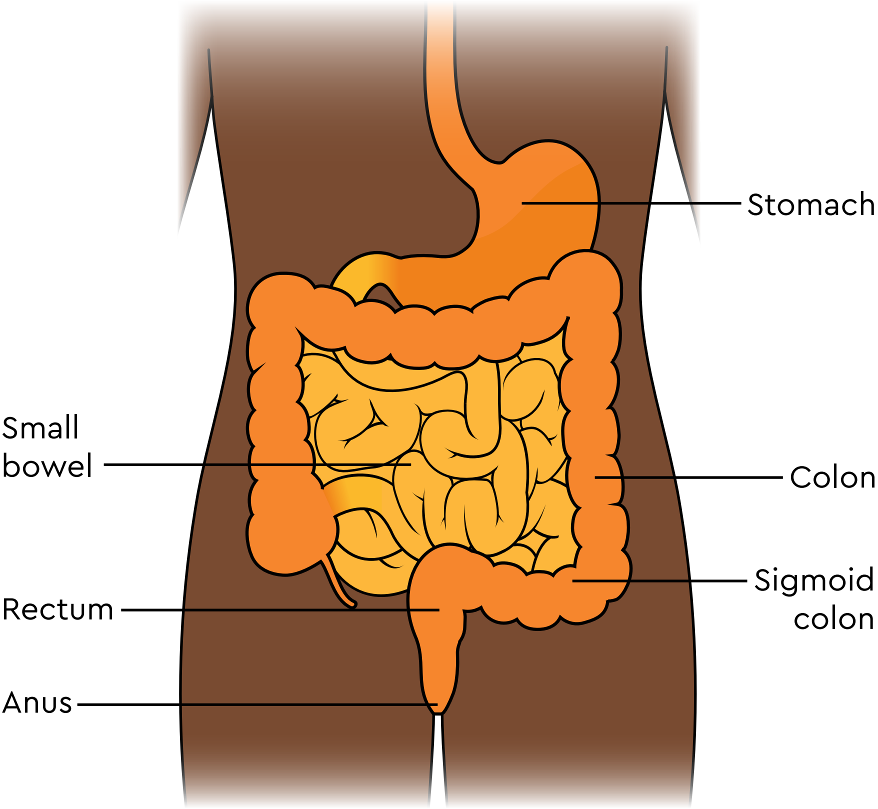
When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The bowel and rectum

The bowel is part of the digestive system. It is divided into 2 parts:

- the small bowel
- the large bowel, which is made up of the colon, rectum and anus.

Parts of the bowel



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

Food leaving the stomach then enters the small bowel. The small bowel absorbs nutrients and minerals from food.

The food then moves into the colon. The colon absorbs water. It also contains bacteria, which breaks down the food into waste matter (poo). The colon moves the waste into the back passage (rectum).

The nerves and muscles in the rectum help to hold on to the waste matter. They do this until you are ready to pass the waste matter through the opening at the end of the large bowel. The opening is called the anus. The anus contains a ring of muscle called the sphincter. This helps to control when you empty your bowels (poo).

The rectum

The rectum links the colon to the anus. It is about 15cm (6 inches) long.

To help describe where a cancer is, doctors divide the rectum into 3 parts:

- the upper third
- the middle third
- the lower third.

The upper third is the part directly after the sigmoid colon.
The lower third is where the large bowel joins the anus.
The middle third is in between the upper third and lower third.

The lining of the rectum is made up of layers of tissue. Most rectal cancers start in the inner lining and develop from small growths called polyps.

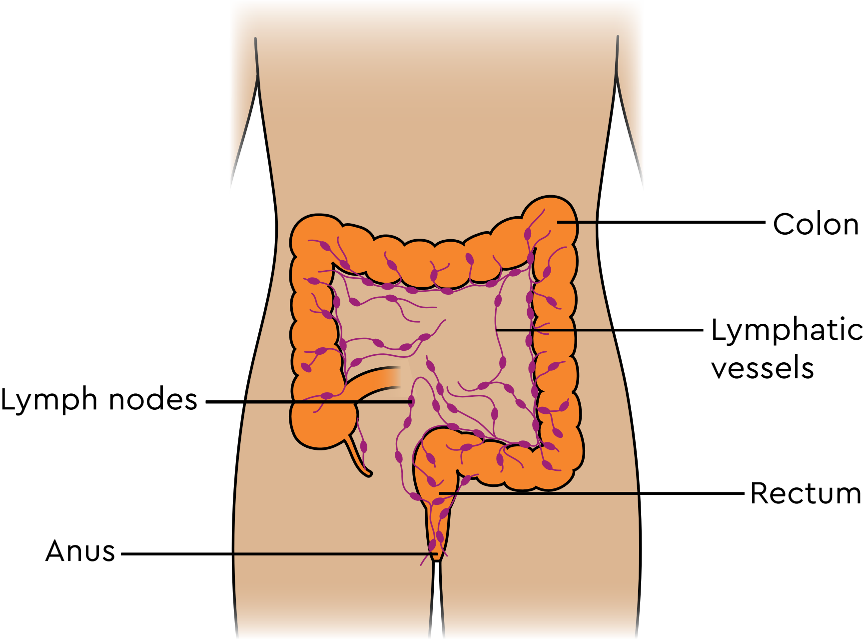
The lymphatic system

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

Lymph nodes close to the bowel



Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected by 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 (page 151).

Planning your treatment

Finding out you have rectal 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. For example, you may have been diagnosed through screening. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with rectal cancer. We have more information about:

- causes and risk factors
- symptoms
- tests to diagnose rectal cancer.

You can find this information at **macmillan.org.uk/rectal-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 meet with 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 and grading

Staging

The stage of a cancer describes its size and whether it has spread. Knowing the stage of the cancer helps doctors decide on the best treatment for you. The most commonly used staging system is the TNM system.

TNM staging system

T describes how far the tumour has grown into the wall of the rectum, 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 or lungs (secondary or metastatic cancer).

T – Tumour

The rectal wall is made up of layers of different tissues.

Tis means the cancer is at its earliest stage (in situ). It is growing into the mucosa but no further.

T1 means the tumour is only in the inner layer of the rectum. This is called the submucosa.

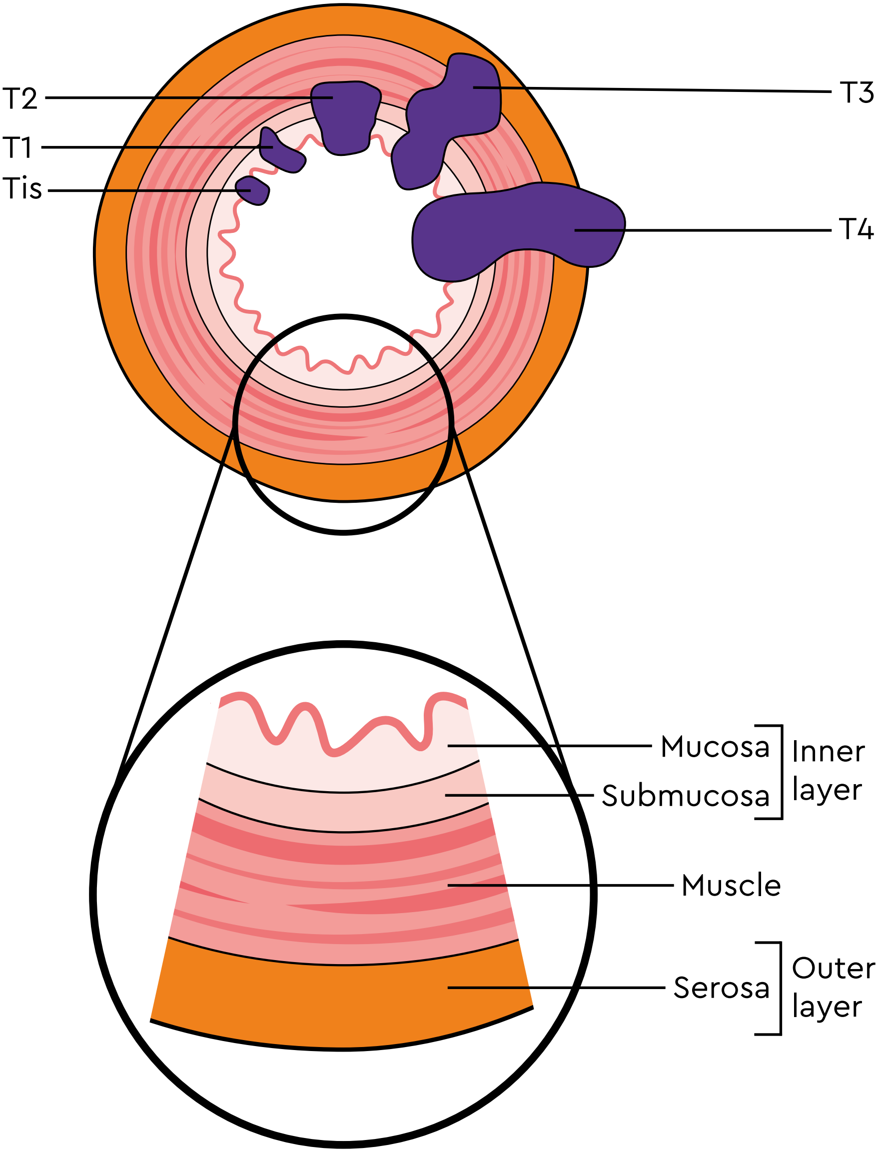
T2 means the tumour has grown into the muscle layer of the rectal wall but no further.

T3 means the tumour has grown through the muscle layer of the rectum and into the outer layer of the rectal wall. This is called the serosa.

T4 means the tumour has grown through the outer layer of the rectal wall (serosa) and into the tissue layer covering the outside of the rectum and other organs. This is called the peritoneum. A tumour at this stage can be described as **T4a** or **T4b**:

- **T4a** means the tumour has caused a hole in the rectal wall (perforation) and cancer cells have spread outside the rectum.
- **T4b** means it has grown into other nearby structures, such as other parts of the rectum or nearby organs.

Layers of the rectal wall and T stages of cancer



N – Nodes

N0 means no lymph nodes contain cancer cells.

N1 means there are cancer cells in up to 3 nearby lymph nodes or there are cancer cells in the tissues around the rectum.

N2 means there are cancer cells in at least 4 or more nearby lymph nodes.

M – Metastases

M0 means the cancer has not spread to distant organs.

M1 means the cancer has spread to distant organs, such as the liver or lungs. Or it has spread to distant parts of the tissue that covers the outside of the rectum and other organs (peritoneum).

Number staging system

Information from the TNM system can be used to give a number stage from 0 to 4.

Stage 0 means the cancer is at its earliest stage and is only in the mucosa (Tis N0 M0).

Stage 1 means the cancer has grown into the submucosa or muscle, but has not spread to the lymph nodes or elsewhere (T1 N0 M0 or T2 N0 M0).

Stage 2 means the cancer has grown through the muscle wall or through the outer layer of the rectum and may be growing into tissues nearby. The cancer has not spread to the lymph nodes or elsewhere (T3 N0 M0 or T4 N0 M0).

Stage 1 and 2 rectal cancer are sometimes called early rectal cancer.

Stage 3 means the tumour is any size and has spread to lymph nodes nearby, but it has not spread anywhere else in the body (Any T N1 M0 or Any T N2 M0).

Stage 3 cancer is sometimes called locally advanced cancer.

Stage 4 means the tumour is any size. It may have spread to nearby lymph nodes. The cancer may have spread to distant parts of the tissue that covers the outside of the rectum and other organs (peritoneum). Or it has spread to other parts of the body, such as the liver or lungs (Any T Any N M1).

Stage 4 cancer is sometimes called advanced or metastatic cancer.

Grading

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

Grade 1 (low-grade)

The cancer cells look similar to normal cells (well differentiated). They grow slowly and are less likely to spread.

Grade 2 (moderate-grade)

The cancer cells look more abnormal. They are likely to grow faster than a low-grade cancer.

Grade 3 (high-grade)

The cancer cells look very abnormal (poorly differentiated). They grow more quickly and are more likely to spread.

Tests on the cancer cells

Doctors may do further tests on the cancer cells taken during a biopsy or surgery.

If the cancer has spread to another part of the body, they may need to take a second sample of cancer cells. Your doctor will explain which tests are needed in your situation.

Mismatch repair or microsatellite instability testing

DNA carries all your genetic information inside the cell. When a cell divides normally, the mismatch repair (MMR) system ensures new DNA is identical to the original. It does this by repairing any changes or mistakes in the DNA.

If the MMR system is not working, cancers are described as MMR deficient. These cancers often show other DNA changes that can be found by testing for microsatellite instability (MSI).

Rectal cancer cells may be tested for either mismatch repair (MMR) or microsatellite instability (MSI). This helps you and your doctor decide whether you need further genetic testing.

Genetic testing may tell you whether you have rectal cancer caused by an inherited condition called Lynch syndrome. People with Lynch syndrome have an increased risk of developing rectal cancer at a young age.

The results of these tests can also be used to help make treatment choices.

We have more information on Lynch syndrome on our website. Visit **macmillan.org.uk/lynch-syndrome-ls**

RAS gene mutation

Doctors may test the rectal cancer cells for the RAS gene mutation.

RAS genes help control cell growth. Changes to RAS genes can affect the type of treatment you have. For example, some targeted therapy drugs do not work on rectal cancer cells that have the RAS gene mutation. These drugs include cetuximab or panitumumab. Other treatments are used instead.

A normal RAS gene is sometimes called RAS wild type. If you have this, targeted therapy may be suitable for you.

These are different types of RAS gene. Other RAS gene mutations that are tested for include the KRAS gene and NRAS gene. Testing for mutations can help doctors decide which treatment is more likely to work for you. These tests are usually used if you have advanced rectal cancer (pages 112 to 113).

BRAF V600E gene mutation

Doctors may also test rectal cancer cells for a change in the BRAF gene.

The BRAF gene makes a protein involved in cell growth. A specific change to this gene (V600E) means that the protein becomes overactive. This makes rectal cancer cells grow and divide more quickly.

Knowing whether you have the BRAF V600E gene mutation tells doctors more about how you might respond to certain treatments for advanced rectal cancer (pages 112 to 113).

Checking the blood vessels and nerves

Cancer and surrounding tissues removed during surgery are checked by a doctor who specialises in cells (pathologist). They will check whether the cancer cells have spread into blood vessels or nerves within the tissues.

If there are cancer cells here, there is more risk of the cancer spreading to other parts of the body. This information helps you and your doctor decide about having further treatment that aims to cure the cancer.

Treating rectal cancer

Treatment overview

Treatment for rectal cancer includes:

- surgery
- radiotherapy
- chemotherapy
- targeted therapy
- immunotherapy.

You may have a combination of treatments. The results of your tests help your cancer doctor plan your treatment.

The treatment you have depends on:

- the stage of the cancer (pages 17 to 21)
- the position of the cancer in the rectum
- your general health
- your preferences.

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

Surgery

Surgery is one of the main treatments for rectal cancer (pages 42 to 53). The operation usually involves removing part or all of the rectum, and nearby lymph nodes. If the cancer has grown into tissue or organs nearby, the surgeon may remove parts of these too.

Sometimes surgery is used to treat advanced rectal cancer (pages 54 to 55). It may be used to help with symptoms. For example, you may have surgery if the cancer is causing a blockage in the bowel.

Some people have surgery to remove a cancer that has spread to another part of the body, such as the liver or lungs.

Radiotherapy

You may have radiotherapy (pages 94 to 109) or chemoradiation (pages 110 to 111) before rectal surgery.

Chemoradiation is when you have chemotherapy and radiotherapy together. Radiotherapy or chemoradiation before surgery can shrink the cancer. This may mean it can be completely removed with surgery. These treatments also help reduce the risk of the cancer coming back in the rectum, or in the tissues close to it.

Radiotherapy is also sometimes used to relieve symptoms, such as pain or bleeding. This is called palliative radiotherapy.

Chemotherapy

You may have chemotherapy (pages 82 to 93) after surgery, to reduce the risk of the cancer coming back. This is called adjuvant chemotherapy.

Some people have chemotherapy as well as chemoradiation before surgery. Chemotherapy may be given before or after chemoradiation (pages 110 to 111).

Having chemotherapy and chemoradiation before surgery is called total neoadjuvant therapy (TNT) – page 98. Some people who have this treatment may not need to have surgery. They will be regularly monitored and will have surgery if the cancer starts to grow again.

Rectal cancer sometimes spreads to other parts of the body, such as the liver or lungs. This is called secondary or advanced cancer. In this situation, you may have chemotherapy to shrink the cancer and control it for as long as possible. Some people with advanced cancer have chemotherapy to shrink the cancer before having an operation to remove it.

Targeted therapy

You may have targeted therapy to control advanced rectal cancer (pages 112 to 113). You may have it on its own or in combination with chemotherapy.

Immunotherapy

Some immunotherapy drugs can also be used to treat rectal cancer that has spread to other parts of the body.

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 at **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 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.

If the cancer has spread to your liver or lungs, you may also be referred to an MDT that specialises in surgery for advanced cancer. The 2 teams will work together to plan your treatment.

Talking about your treatment plan

After the MDT meeting, you will usually meet with 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 or control the cancer
- 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 your 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 whether your treatment is likely to cause any late effects and how these can be managed.

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, this may be 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 about making treatment decisions in our booklet **Making treatment decisions** (page 136) and on our website. Visit **macmillan.org.uk/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 (pages 34 to 35).

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 meet with 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 on our website. Visit **macmillan.org.uk/second-opinion**

Preparing for treatment (prehabilitation)

Your specialist doctor and nurse might talk to you about preparing for your treatment. This is sometimes called prehabilitation.

Prehabilitation helps you to improve your fitness, health and well-being before treatment. This can help you to recover more quickly. It might also help your treatment to work better.

Prehabilitation is often suggested if you are having surgery. It is also useful if you are starting radiotherapy or chemotherapy, especially chemoradiation (pages 110 to 111).

Even if your treatment is starting a few weeks after your diagnosis, improving your general health can make a difference. It can help you to feel you are doing something by being involved in your cancer treatment.

Some hospitals have specific programmes for prehabilitation to support you. You might see different health professionals, such as a clinical nurse specialist, a dietitian, a physiotherapist or counsellor, or a psychologist (pages 32 to 33).

Enhanced recovery programmes are similar to prehabilitation. They also aim to reduce the time you spend in hospital after surgery and speed up your recovery. As part of an enhanced recovery programme, you will be given information about diet and exercise before surgery. You may also be given nutritional drinks to take before surgery.

What preparing for treatment might involve

Your emotional well-being

A diagnosis of cancer is often overwhelming. Talking about how you feel to family and friends, or to your cancer team, can make a difference. Some people find joining a cancer support group helpful. Your hospital may have a Macmillan Information and Support Centre or similar service (page 139).

Changes to your diet

Eating a healthy and varied diet before treatment can improve your well-being. It can help you to have more energy. A dietitian may give you specific advice to follow. We have more information on diet and cancer you might find helpful in our booklet **Healthy eating and cancer**.

Exercises to improve fitness

You may be asked to do exercises to improve your heart health and make your muscles stronger. Being fitter may help you to cope with treatment side effects and reduce the risk of complications after surgery. We have more information about this in our booklet **Heart health and cancer treatment**.

You can even improve your fitness in a few weeks by doing regular exercise, such as walking. We have more information about this in our booklet **Physical activity and cancer**.

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

Stopping smoking

Try to stop smoking as soon as you can before treatment. Even stopping 2 to 3 weeks before surgery, and not smoking afterwards, reduces your risk of complications. Your wounds are more likely to heal more quickly and your stay in hospital may be shorter.

Stopping smoking increases the chances of radiotherapy (pages 94 to 109) and chemoradiation (pages 110 to 111) working better. It also means side effects are likely to be less severe.

It can be very difficult to stop smoking, especially when you are stressed.

The NHS has a lot of information and support to help you stop smoking. Visit the NHS website for the country where you live (page 146).

We also have information about stopping smoking on our website. Visit **macmillan.org.uk/stop-smoking**

Alcohol

If you drink alcohol, it might help to drink less or stop before your treatment. Try to make sure you are staying within the recommended guidelines. We also have information about reducing the amount of alcohol you drink (page 119).

Surgery for rectal cancer

Surgery is the most common treatment for rectal cancer.

You may have radiotherapy (pages 94 to 109), chemotherapy (pages 82 to 93) or chemoradiation (pages 110 to 111) before surgery. This can make it easier to remove the cancer. It also lowers the risk of the cancer coming back in the rectum or in the tissues close to it.

Surgery to remove rectal cancer

There are different types of surgery for rectal cancer. The type of surgery you have will depend on:

- the stage of the cancer (pages 17 to 21)
- where it is in the rectum
- your general health.

Surgery to remove part or all of the rectum is called a resection.

The tissue the surgeon removes is sent to a pathologist. They check it carefully to see whether there are cancer cells close to the edge. The edge is called the margin.

If the pathologist finds cancer cells in the margin, there might be a higher risk of the cancer coming back. This is not common. But if it happens, you may be offered a second operation or radiotherapy.

Surgery for early-stage rectal cancer

If you have a very small, stage 1 rectal cancer (page 20), you may have an operation called a local excision. This is a small operation to remove the cancer and some of the healthy tissue surrounding it. The cancer can usually be removed through the anus. This means the surgeon does not have to make a cut in your tummy.

There are 2 ways your surgeon can do this.

Transanal endoscopic microsurgery (TEM)

The surgeon passes a long, flexible tube into the anus and the rectum. The tube is called an endoscope. It has a light and camera on the end. This allows the surgeon to find the tumour and remove it precisely.

Transanal minimally invasive surgery (TAMIS)

The surgeon places a small port into the anus. A port is a circular device that holds the anus open. This allows the surgeon to see the rectum clearly.

The surgeon then passes a laparoscope and other instruments through the port into the rectum to remove the cancer. A laparasope is a thin tube with a small camera on the end.

Surgery for locally advanced rectal cancer

If you have locally advanced rectal cancer, the type of surgery you have depends on:

- where the cancer is in the rectum
- the size of the tumour
- how far it is from the anus.

Open or laparoscopic surgery

Your operation may be done as open surgery or keyhole surgery. This is called laparoscopic surgery.

Open surgery means the surgeon makes 1 large cut, usually near the belly button. The length of the cut depends on the size of the cancer and where it is.

Laparoscopic surgery means the surgeon makes 4 or 5 small cuts in the tummy. They pass a thin tube through 1 of the cuts. The tube is called a laparoscope. It has a small camera on the end. The surgeon then passes specially designed surgical tools through the other cuts. The surgeon uses these tools to remove the cancer.

Laparoscopic surgery is also sometimes called minimally invasive surgery. You usually recover more quickly from it than from open surgery.

Robotic surgery

Robotic surgery is when laparoscopic surgery is helped by a machine. The laparoscope and the surgical equipment are attached to robotic arms. The surgeon controls the robotic arms, which can move very precisely. This is very specialised surgery and only available in some hospitals in the UK.

Your surgeon will talk to you about which type of surgery is likely to be best in your situation.

Stomas (colostomy or ileostomy)

Sometimes during surgery, the surgeon needs to create a stoma. This is an opening the surgeon makes through the tummy (abdominal) wall. It connects the bowel to the surface of the tummy. The stoma is round or oval-shaped, and it looks pink and moist. It has no nerve supply, so it does not hurt.

Having a stoma means stools (poo) and wind will not pass out of the rectum and anus in the usual way. Instead, they will pass out of the stoma, into a disposable bag you wear over the stoma.

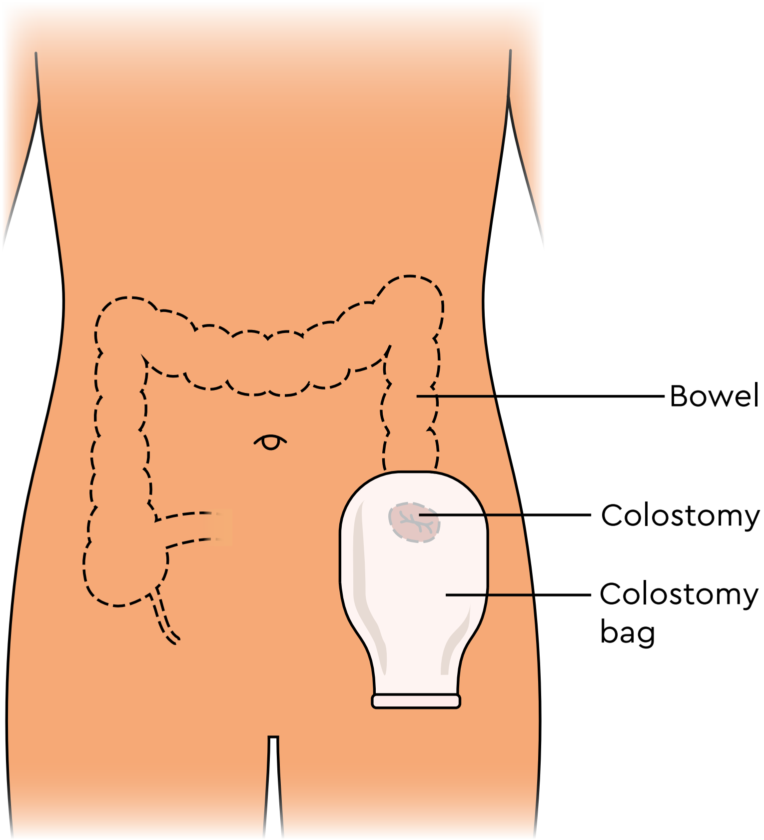
If the stoma is made from an opening in the colon, it is called a colostomy (page 46). If it is made from an opening in the small bowel (ileum), it is called an ileostomy (page 47).

Stomas may be temporary or permanent. The surgeon may make a temporary stoma to allow the bowel to heal after surgery. If you have a temporary stoma, you will usually have an operation to close the stoma and rejoin the bowel after you have finished your treatment. This operation is called a stoma reversal.

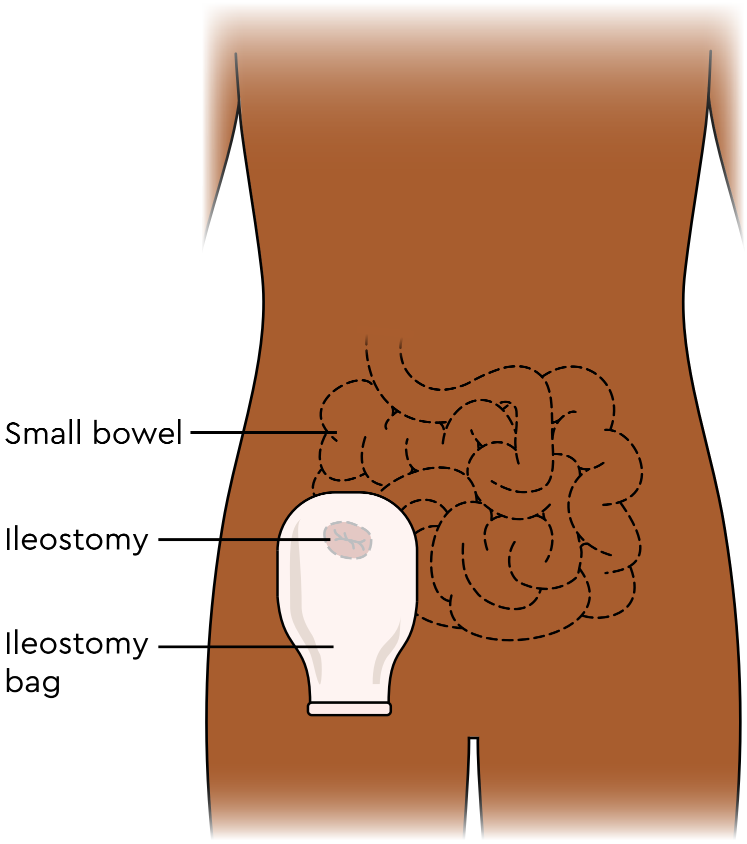
If the cancer is very low in the rectum and close to the anus, you are more likely to need a permanent stoma.

Your surgeon will tell you whether you are likely to have a stoma, and whether it will be temporary or permanent. If you need to have a stoma, you will be referred to a nurse who specialises in stoma care. They can talk to you about what to expect.

A colostomy and colostomy bag



An ileostomy and ileostomy bag



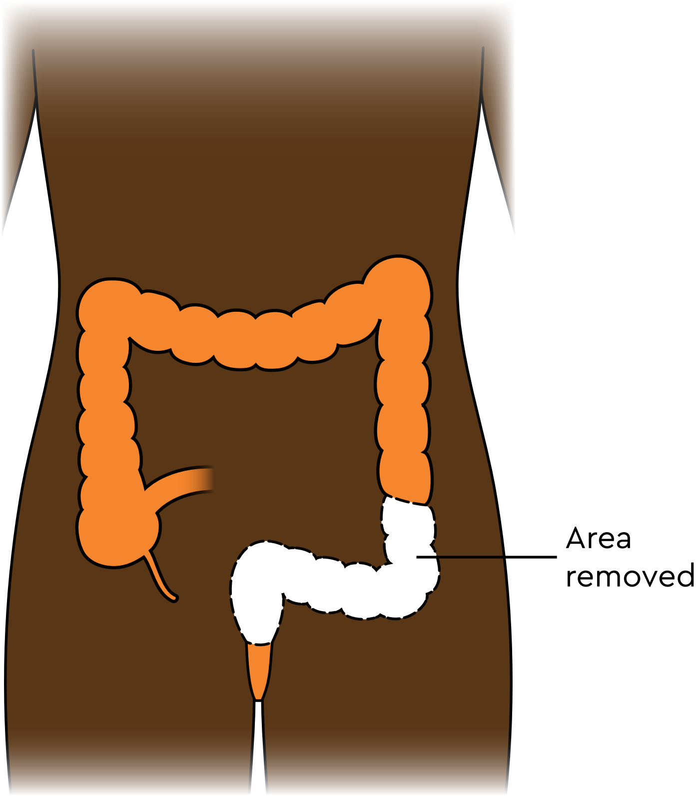
Anterior resection

If you have cancer in the upper or middle part of the rectum, you may have an operation called an anterior resection or low anterior resection (LAR).

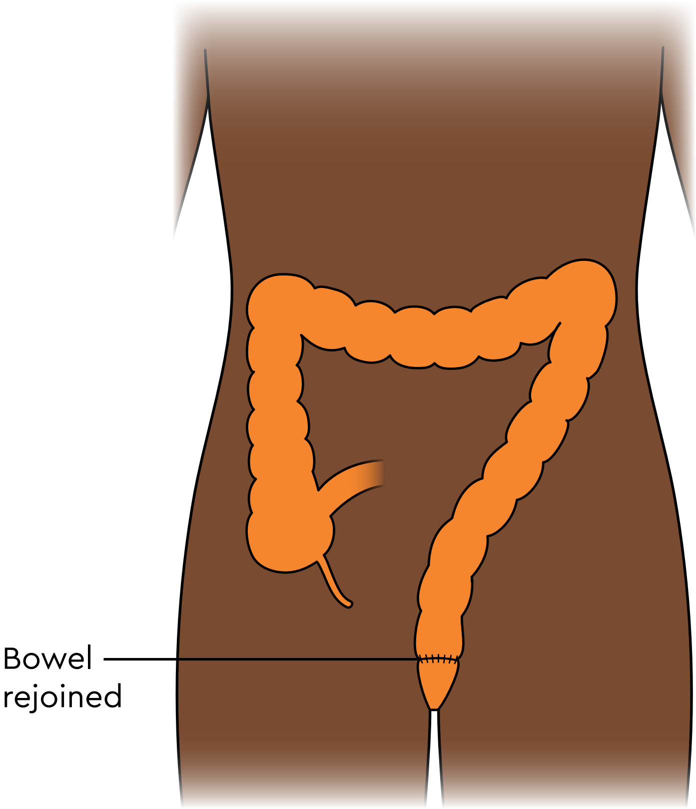
The surgeon removes the part of bowel that contains the cancer. They then rejoin the 2 open ends of bowel. The diagrams show the part of the bowel that is removed (page 50), and how the 2 ends are rejoined (page 51).

You may have a temporary stoma after this operation (pages 76 to 81). This is usually an ileostomy. You can usually have a stoma reversal a few months later.

Anterior resection



Anterior resection rejoined

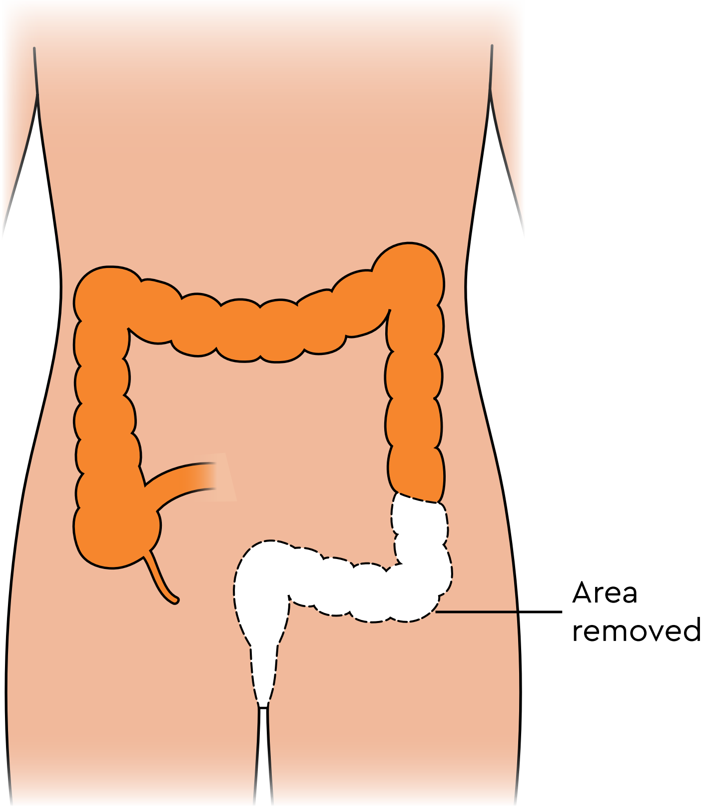


Abdominal perineal resection (APR)

If the cancer is very close to the anus, you may need an operation called an abdominal perineal resection (APR). This is when the surgeon needs to remove the rectum and anus, to remove all the cancer. You will have a permanent stoma after this operation. This is usually a colostomy (pages 45 to 46).

As well as the wound 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. This operation can be done as either keyhole (laparoscopic) surgery or open surgery (page 44). It depends on the size of the tumour.

Abdominal perineal resection



Total mesorectal excision (TME)

As well as removing the cancer using one of the operations mentioned, many surgeons also remove some of the fatty tissue around the rectum. This contains lymph nodes and blood vessels. The fatty tissue is called the mesorectum. The operation to remove it is called a total mesorectal excision (TME).

Surgery for advanced rectal cancer

There are different types of surgery for advanced rectal cancer.

If the cancer has spread to other parts of the body, such as the liver or lungs, you may be able to have surgery to remove it.

Surgery is only suitable for some people with secondary liver cancer or secondary lung cancer. You can talk to your cancer doctor about whether this surgery may be helpful for you.

We have more information about treatment for advanced rectal cancer that has spread to other parts of the body (pages 112 to 113).

If the cancer has grown into other organs nearby, you may need to have some of the organs in your pelvis removed. This operation is called a pelvic exenteration. Your doctor will explain more about this operation and whether it is suitable for you.

For more information about pelvic exenteration:

- for women and other people assigned female at birth, visit **macmillan.org.uk/pelvic-exenteration-women**
- for men and other people assigned male at birth, visit **macmillan.org.uk/pelvic-exenteration-men**

Treating a blocked bowel (bowel obstruction)

Sometimes rectal cancer can cause the bowel to narrow. This stops stools (poo) from passing through. This is called a blocked bowel or bowel obstruction.

It can cause symptoms such as:

- bloating
- pain in the lower part of your tummy (abdomen), usually with cramps
- vomiting (being sick).

A bowel obstruction usually needs to be treated urgently. It can be treated in different ways.

Stenting

The doctor uses a colonoscope to insert an expandable metal tube called a stent into the blockage. They may use an x-ray to see where to insert the tube. The tube expands to hold the bowel open, so stools can pass through it again. You are usually given sedation to have this done.

You may have a stent for a short time before having an operation to remove the cancer. Some people will have a permanent stent. Your doctors will explain what the aim of the stent is in your situation.

Surgery

A surgeon removes the blocked section of bowel. If the bit of blocked bowel cannot be removed, the blocked bowel can be relieved by creating a stoma (pages 45 to 47). This means you pass stools out of the stoma.

The surgeon may remove the cancer at the same time, or in another operation later on.

We have more information about having a blocked bowel on our website. Visit **macmillan.org.uk/blocked-bowel**

Before your operation

Your doctor and nurse might talk to you about improving your fitness and well-being before surgery. They may give you advice about stopping smoking, physical activity and your diet. The aim is to help you to recover more quickly. This is sometimes called prehabilitation. Or you may be asked to follow an enhanced recovery programme to reduce the time you spend in hospital.

We have more information about preparing for treatment on pages 39 to 41.

Preparing for your operation

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
- a recording of your heart (ECG).

For some types of surgery, your bowel needs to be empty. A nurse may advise you about preparing for your operation. You may need to follow a special diet. You may need to take a laxative for a few days before the operation. You will also be asked not to eat or drink for a few hours before the operation.

Before the operation, you will usually be given antibiotics. These are to prevent infection. You may have them as an injection or tablets.

You will meet a member of the surgical team to discuss the operation. If you are going to have a stoma (pages 45 to 47), you will also meet a stoma care nurse, who will explain what is involved.

During your clinic appointment, you can ask questions or share any concerns you have about the operation. 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.

You will usually go into hospital on the morning of the operation. You will be given elastic stockings (TED stockings) to wear during the operation and for some time afterwards. This is to prevent blood clots in your legs.

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 these.

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

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

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

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 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.

Wound care

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

You may be given antibiotics to help prevent wound infection. Tell your nurse or doctor straight away if your wound:

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

These can be signs that the wound is infected.

Possible complications

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

Depending on the type of operation you have had, you will probably be ready to go home 2 to 7 days after surgery.

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

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 (pages 76 to 81).

Colostomy UK and Ileostomy and Internal Pouch Support Association (page 143) 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.

Bowel function after surgery

Most people have changes in how their bowel works after rectal surgery.

If you have had a transanal local excision (page 43) and you do not have a stoma, your bowel will usually recover quite quickly.

After an anterior resection (pages 49 to 51), you may have a temporary stoma. After the stoma has been reversed, it can take several months for your bowel function to settle into a more regular pattern. For some people, bowel function may never become regular.

If you had radiotherapy (pages 94 to 109) or chemoradiation (pages 110 to 111) before or after rectal surgery, this will also affect your bowel. This could mean it takes longer to get back to having regular bowel movements.

You may notice 1 or more of the following changes:

- You need to pass stools (poo) more often. This might be several times a day.
- You feel that you cannot wait when you need to pass stools (urgency).
- You have diarrhoea.
- You have constipation.
- You are losing control over when you empty your bowels (incontinence).
- You have difficulty telling the difference between wind and stools.
- You feel bloated or are passing a lot of wind.
- You have a sore bottom.
- Some food and drinks affect your bowel movements.

Any changes usually improve over time.

After rectal surgery, some people develop a condition called low anterior resection syndrome (LARS). LARS is a group of symptoms that can have an impact on a person's quality of life. Symptoms include:

- needing to pass stools more often
- feeling an urgency to pass stools.

Tell your surgeon or specialist nurse if you have these problems or any other symptoms that affect your quality of life.

Diet after surgery

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

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

Eating at regular times encourages your bowel to work more regularly. You may find it easier to eat several small meals a day, rather than 1 or 2 large meals. Having plenty of high-protein foods in your diet will help your body to heal after surgery. These include:

- fish
- meat and poultry – for example, chicken, duck or turkey
- tofu
- eggs
- dairy and dairy alternative products.

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

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

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

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

Always check with your dietitian, doctor or specialist nurse if you are not sure what to do. We have more information in our booklet **Healthy eating and cancer** (page 136).

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

Coping with bowel changes

There are things you can do that can help you cope with bowel changes. These can help you feel more confident and in control. If your symptoms continue, always ask for help from your cancer doctor or specialist nurse.

Diarrhoea

Diarrhoea is a common side effect after surgery and during cancer treatment.

Some types of medication can also cause diarrhoea, such as antibiotics or laxatives.

Your cancer doctor or specialist nurse may recommend that you take anti-diarrhoea drugs. The most commonly used drug is loperamide. It slows down your bowel movements, making stools more solid and less frequent. It is available on prescription, or you can buy it from a pharmacy. Some people find that taking loperamide regularly, 30 minutes before meals, works well for them.

It may take time to find the dose that works best for you. Your doctor or specialist nurse may recommend you start with a low dose and increase this until it works.

It is safe to take loperamide for as long as you need it. But you should discuss this with your doctor or specialist nurse.

Diarrhoea is not usually caused by the food that you eat. But making small changes to your diet might help.

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

- wholemeal breads
- oats
- peeled or tinned fruit and well-cooked root vegetables.

It is important to drink plenty of fluids if you have loose stools or diarrhoea or constipation. Try to drink at least 2 litres (3½ pints) of fluid a day.

Fluids can include:

- water
- milk
- juice
- hot drinks, such as tea, coffee or hot chocolate
- isotonic sports drinks.

If you have a lot of diarrhoea or stoma activity, tell your dietitian or stoma care nurse. They can explain changes you could make to your diet to help manage diarrhoea.

Wind

You may feel windy or bloated after surgery. The following tips may help:

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

Constipation

Constipation can sometimes be a problem after surgery. If you have constipation, contact the hospital for advice. Your doctor can give you drugs called laxatives to help.

Here are some tips that may help:

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

A dietitian can talk to you about changes you can make to your diet to help with constipation. If you have a stoma, your stoma care nurse will give you advice about your diet (page 79). It may help to keep a daily food diary of what you eat and how different foods affect you.

We have information about cancer and common eating problems and what can help in our booklet **Eating problems and cancer** (page 136).

Protecting your skin

Emptying your bowels frequently or having loose stools can make the skin around your bottom sore. These tips may help:

- Keep the skin around your bottom clean and dry. Whenever possible, wash the area after a bowel movement.
- Use unperfumed wet wipes or damp cotton wool instead of toilet paper. These are softer on your skin. Pat the area gently when drying.
- Use absorbent pads and barrier wipes or sprays to help protect your skin. A colorectal or continence nurse can advise you about pads and creams to use.
- Wear cotton underwear. This allows your skin to breathe. Avoid tight jeans or other clothes that may rub the area.

Managing stress

Your emotions can affect your bowel. Anxiety and stress can make your stools looser and bowel movements more frequent. If you do not feel in control of your bowel, this can also be stressful.

Learning how to relax may help your bowel settle. Relaxing is also good for your general health. Your cancer doctor or specialist nurse can tell you about any relaxation classes in your area or online. Some support groups also offer relaxation classes.

Pelvic floor exercises

There are exercises you can do to strengthen the muscles used for bowel control. There are 2 main groups of muscles that are important for bowel control:

- the sphincter muscles in the back passage (anus)
- the pelvic floor muscles.

Pelvic floor muscles are also important for bladder control and sexual function.

Pelvic floor exercises may help if you have problems with leakage of wind or stools from your back passage. A colorectal or continence specialist can tell you whether these exercises are likely to help you. They can also teach you how to do them.

It can take at least 12 weeks of doing pelvic floor exercises 3 times a day to rebuild strength in these muscles. As your muscles improve, try doing the exercises while doing everyday jobs.

Going out

If your bowel movements are not predictable, you may feel worried about going out, especially to somewhere new. Planning ahead so that you are prepared can help you feel more confident.

The Bladder and Bowel Community offers a Just Can't Wait card (page 142). This may help you to get access to a toilet more quickly when you are out. It states that the card holder has a medical condition that requires urgent access to a toilet. You can either order a plastic card by post or download your card onto your smartphone.

You may find it easier to use a disabled toilet. These usually offer more privacy. They have a wash basin and more space if you need to change.

The National Key Scheme offers Disabled people access to about 10,000 locked public toilets across the UK. You can buy a key from Disability Rights UK (page 149). It can also send you details of where the toilets are.

Macmillan also has a toilet card for people who have problems with bowel or bladder control. It should help you get urgent access to a toilet when out in public. You can get a toilet card by contacting the Macmillan Support Line or ordering one at **orders.macmillan.org.uk**

Call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm. ☎

> **"There is a light at the end of the tunnel. You can still do all the things you want to do, but it's about the approach now. You have to plan things. Like going on a night out – I need to plan where the toilets are and the timings after a meal. It affects your daily life and your hobbies, but you can still achieve things. „**

Mark, diagnosed with bowel cancer

Carrying a bag with supplies

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

You may want to include:

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

If you have a stoma

Having a stoma (pages 45 to 47) is a big change to your body, whether it is temporary or permanent. It can take time to get used to having a stoma and managing it.

You will usually meet a stoma care nurse before your operation. They will talk to you about what is involved and can answer any questions you may have. You may also find it helpful to talk to someone who has experience living with a stoma. Your specialist nurse, doctor or stoma nurse may be able to arrange this for you. You can also contact Colostomy UK or Ileostomy and Internal Pouch Association (page 143).

A stoma nurse will usually meet with you the day after your operation. For the first few days, they will show you how to look after the stoma and change the bags. The stoma will be swollen at first. It can take several weeks before it settles down. The stoma nurse will help you cope with any problems and make sure you feel able to look after your stoma before you go home. It is a good idea to have a family member or friend with you when you are shown how to look after your stoma. They can then support and help you at home, if needed.

Nobody expects you to be able to cope straight away. Looking after a stoma will get easier with time and practice. The stoma care nurse will continue to support you after you go home.

If you have an ileostomy (pages 45 to 47), you will wear a bag that opens at the bottom, so you can empty it. An ileostomy produces semi-liquid waste all the time. You will need to empty the bag several times a day. If you need to empty the bag very often, your doctor can prescribe anti-diarrhoea medicines to help.

A colostomy (pages 45 to 46) may be active 2 or 3 times a day, but this will vary from person to person. What you eat will also affect how active the colostomy is. It may settle into a pattern after a few weeks. You may be able to predict when it is likely to be active. You will usually need to change your stoma bag 1 to 3 times a day.

You may be taught how to flush out (irrigate) your colostomy once a day. This helps to control when it is active. If you want to try this, talk to your stoma care nurse. You can find more information about irrigation from Colostomy UK (page 143) – visit **colostomyuk.org**

Whenever you change or empty your bag, make sure that you have everything you need before you start. It is a good idea to keep all your stoma equipment together, such as bags and cleaning wipes. Give yourself plenty of time, so you can work at your own pace without any interruptions.

> **"As time went on, I got more and more adjusted to living with my colostomy bag. It didn't take as long as I expected. After around 5 or 6 weeks, I was proficient with my stoma care."**
>
> Joanna, diagnosed with rectal cancer

Stoma supplies

There are different types of ileostomy and colostomy bags and supplies. Your stoma care nurse will give you some supplies to take home with you. They will also provide prescription information so your GP can prescribe stoma supplies when you are at home. You can get stoma supplies from a pharmacy or a specialist stoma supply company. Your stoma nurse will advise you about this.

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 signs an FP92A form saying that you are entitled to free prescriptions. Prescriptions are free for people living in Scotland, Wales or Northern Ireland.

When you are at home, you can contact the stoma nurse if you have any problems. Or your local district nurses may visit you to make sure you are coping with your stoma.

Having a stoma is a big change in your life. It may affect your relationships, as you may feel uncomfortable about your body. For example, you may be worried about a partner seeing your stoma. These feelings are a natural part of coping with a stoma.

Your stoma nurse will be able to tell you about any stoma management programmes that may help. Macmillan has information about coping with changes to your body in our booklet **Body image and cancer** (page 136).

Diet with a stoma

If you have a stoma, your nurse or dietitian will usually advise you to follow a low-fibre diet for a few weeks. When your stoma becomes less active, you can start to introduce more foods into your diet.

Some people find that certain foods make their stoma more active, so they need to avoid them. Examples are:

- pips and skins of fruit
- beans
- nuts and seeds
- dried fruit
- bran
- raw vegetables.

It is important to drink plenty of fluids. But if your stoma is very active, your stoma care nurse or dietitian may advice you to reduce the amount of fluid you drink in a day. Limiting caffeine and alcohol can help. Your stoma nurse or dietitian can give you more advice.

Support videos

There are helpful videos to support you if you have a stoma:

- Visit **youtube.com/@macmillancancer/videos** and search for 'stoma' to watch our video **All About Stoma Care**. In this video, a stoma nurse talks about looking after a stoma and shows the supplies you might use. You can also watch Pat's story of living with a stoma.
- **Healthtalk.org** has video and audio clips of people with stomas talking about their experiences.

Macmillan Online Community

Our ileostomy, colostomy and stoma support group provides peer support for people:

- having an ileostomy or colostomy
- living with a stoma
- after a stoma.

People can support each other and discuss things like bag recommendations, managing a stoma and foods to avoid. For more information, visit **macmillan.org.uk/community**

Support from other organisations

Colostomy UK has a 24-hour free helpline (page 143). It also has Live Chat available on its website Monday to Friday, 9am to 5pm.

Ileostomy and Internal Pouch Association offers one-to-one support as well as an online forum where you can chat to other people who may be in a situation similar to you (page 143).

Stoma reversal

A stoma reversal operation is when the piece of bowel that formed your stoma is rejoined with either the colon or small bowel. The stoma opening is closed. This means you will pass stools (poo) from your bottom again.

If you have a temporary stoma, you can usually have a stoma reversal sometime after your treatment finishes.

When you have a stoma reversal operation is different for each person. Your surgeon and specialist nurse can tell you more about having a stoma reversal and when it might be best to have it done.

They can advise you about:

- what to expect
- how long it may take to recover
- what your bowel function may be like.

After a stoma reversal, it can take some time for your bowel function to get back to normal. Your specialist nurse will be able to give you advice and support during this time.

You can also learn more about stoma reversal from Colostomy UK (page 143).

> **"The colostomy bag doesn't affect my body confidence any more. It did at first, as it was a very new and alien thing. But once I'd grieved for the parts of my body I'd lost and accepted my new self, I felt just as confident as before."**
>
> Joanna, diagnosed with rectal cancer

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. This is sometimes called systemic anti-cancer therapy (SACT). Chemotherapy drugs disrupt the way cancer cells grow and divide. But they also affect normal cells.

Chemotherapy is often given in combination with radiotherapy. This is called chemoradiation (pages 110 to 111).

Your doctors may offer you chemotherapy:

- before surgery, to shrink the cancer and reduce the risk of it coming back
- before or after chemoradiation, and before surgery – this is called total neoadjuvant therapy (TNT) – page 98
- after surgery, to reduce the risk of the cancer coming back
- as the main treatment, if the cancer has spread to parts of the body, such as the liver or lungs.

The drugs most often used to treat rectal cancer are:

- fluorouracil (5FU), usually given with folinic acid (leucovorin)
- capecitabine (Xeloda®)
- oxaliplatin (Eloxatin®)
- irinotecan (Campto®)
- trifluridine and tipiracil (Lonsurf®)
- raltitrexed (Tomudex®).

Often, 2 or more chemotherapy drugs are given in combination. The most often used combinations are:

- FOLFOX – folinic acid, fluorouracil and oxaliplatin
- CAPOX (XELOX) – capecitabine and oxaliplatin
- FOLFIRI – folinic acid, fluorouracil and irinotecan
- FOLFOXIRI – folinic acid, fluorouracil, oxaliplatin and irinotecan.

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

How chemotherapy is given

You may have chemotherapy into a vein (intravenously) or as a tablet. If you have chemotherapy into a vein, it goes directly into your blood. The blood carries it to all areas of your body. If you have chemotherapy as a tablet, it 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 rectal cancer:

- fluorouracil (5FU)
- capecitabine (Xeloda®).

> "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 AirPods in, watch a film and chill for 3 hours. "

Luke, diagnosed with bowel cancer

If you are having chemotherapy into a vein, you have it 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.

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

You usually have chemotherapy as a session of treatment over several hours or days. This is followed by a rest period. This is to let your body recover from any side effects of treatment. The treatment and rest period make up a cycle of treatment. Your cancer doctor or specialist nurse will explain how many cycles of treatment you need.

Side effects of chemotherapy

Chemotherapy drugs can cause different side effects. Many of these can be managed with different medicines and most of them will get better after treatment ends. Chemotherapy affects everyone differently. Some people may have only a few side effects whereas others may have more.

Your cancer doctor or nurse will tell you more about what to expect. Tell them about any side effects you have, as they can usually be well controlled with medicines.

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

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

- chemotherapy – **macmillan.org.uk/chemotherapy**
- chemotherapy drugs – **macmillan.org.uk/treatment-and-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.

Diarrhoea

Some chemotherapy drugs can cause diarrhoea. Diarrhoea means passing more stools than is usual for you, or having watery or loose stools. If you have a stoma (pages 45 to 47), it will be more active than usual.

Sometimes diarrhoea can be severe. Your hospital team may give you anti-diarrhoea drugs to take at home. It is important to follow any advice from them about taking anti-diarrhoea drugs.

Contact the hospital on the 24-hour number straight away if:

- you have diarrhoea at night
- you have uncomfortable stomach cramps
- you have diarrhoea 4 or more times in a day
- you have a moderate increase in stoma activity
- the anti-diarrhoea drugs do not work within 24 hours.

If you are taking capecitabine tablets, the hospital may ask you to stop taking them. They will tell you when you can start taking them again.

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.

Throat spasm

Rarely, oxaliplatin can cause a spasm in the throat area around the voicebox (larynx). This can cause difficulties with swallowing and breathing. This might happen during treatment, or in the first few days after treatment.

This side effect can be frightening, but it should only be temporary. If you have breathing difficulties, take long, deep breaths through your nose. This will have a calming effect and help your breathing return to normal.

This symptom may be worse in cold temperatures. It may help to avoid cold drinks during treatment, and for a few days afterwards. It may also help to wrap up warm and cover your nose and mouth in cold weather.

It is important to tell your doctor if you have this side effect. They may give the next doses of oxaliplatin over 4 to 6 hours to reduce the chance of throat spasms.

Numb or tingling hands or feet

Some chemotherapy drugs can affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. You might find it hard to do fiddly tasks such as fastening buttons or tying shoe laces. If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug.

Hair loss

Many of the chemotherapy drugs for colon and rectal cancer do not cause hair loss, but you may still get some hair thinning. The chemotherapy drug irinotecan can cause hair loss. Your hair may get thinner or you may lose all the hair from your head.

Your nurse can talk to you about ways to cope with hair loss. Hair loss is almost always temporary. Your hair will usually grow back after treatment ends. We have more information about this:

- in our booklet **Coping with hair loss** (page 136)
- on our website at **macmillan.org.uk/hair-loss**

Sore and red hands and feet

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 capecitabine or fluorouracil. It usually gets better after treatment ends.

Effects on the heart

Fluorouracil and capecitabine can affect how the heart works. You may have tests to see how well your heart is working. These may be done before, during and after treatment.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- breathlessness
- dizziness
- changes to your heartbeat
- swollen feet and ankles.

Always call **999** if you have:

- chest pain, pressure, heaviness, tightness or squeezing across the chest
- difficulty breathing.

We have more information about heart health in our booklet **Heart health and cancer treatment** (page 136).

Effects on sex life

Having chemotherapy can sometimes affect your sex life. Side effects like tiredness and feeling sick can reduce your sex drive and make having sex difficult.

If you have a partner, try to tell them how you feel. It can also help to talk with your doctor or specialist nurse about your concerns. They can reassure you and support you with any problems. We have more information in our booklet **Cancer and your sex life** (page 136).

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, talk with your doctor before you start treatment. We have more information about fertility in our booklet **Cancer and fertility** (page 136).

Radiotherapy for rectal 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 (pages 103 to 109). 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 rectal cancer, you usually have radiotherapy in combination with chemotherapy. This is called chemoradiation (pages 110 to 111). Chemotherapy can make cancer cells more sensitive to radiotherapy.

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

How radiotherapy is given

You can have radiotherapy externally from a machine. Or you can have it internally from radioactive substance placed inside the body.

You usually have external radiotherapy for rectal cancer (pages 95 to 97). But it can also be given internally. Internal radiotherapy is also called brachytherapy (pages 98 to 101).

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 external beam radiotherapy as short, daily treatments in a hospital radiotherapy department. These are called treatment sessions or fractions.

Each treatment session takes 10 to 15 minutes. But the treatment itself only takes a few minutes. You usually have treatment sessions Monday to Friday, with a break at the weekend. Your doctor will talk to you about the treatment and possible side effects.

Intensity-modulated radiotherapy (IMRT)

A type of radiotherapy called IMRT is usually used for rectal 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 suitable 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.

Conformal radiotherapy

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

When external radiotherapy is given

You usually have radiotherapy for rectal cancer before surgery. It is rarely given after surgery. If you are unable to have surgery, radiotherapy may be your main treatment. Some people have internal radiotherapy on its own.

Radiotherapy before surgery (neoadjuvant radiotherapy)

Radiotherapy before surgery is called neoadjuvant radiotherapy. It aims to:

- shrink the cancer to make surgery easier
- reduce the risk of cancer coming back.

You have radiotherapy as either:

- a short course Monday to Friday, for 1 week
- a long course for up to 6 weeks, usually with chemotherapy – this is called chemoradiation (pages 110 to 111).

After a short course or long course of radiotherapy, you usually wait for at least 6 weeks before having surgery. During this time, the radiotherapy or chemoradiation continues to work.

Depending on how well the treatment has worked, you might be offered the option of surveillance or monitoring rather than surgery. This involves having regular monitoring with physical examinations and tests. If there are any signs of the cancer coming back, you can then have surgery.

Radiotherapy after surgery (adjuvant radiotherapy)

If you did not have radiotherapy before surgery, you may have it afterwards. It is usually given if cancer cells are found on the edge of the healthy tissue (margin) removed during surgery. You have radiotherapy to reduce the risk of the cancer coming back. This is called adjuvant radiotherapy.

You usually have adjuvant radiotherapy Monday to Friday, for 4 to 5 weeks. You may have radiotherapy with chemotherapy. This is called chemoradiation (pages 110 to 111).

Total neoadjuvant therapy (TNT)

This means having a course of radiotherapy with chemotherapy. You can have the chemotherapy either before radiotherapy or after. You might have this treatment if the cancer is locally advanced (pages 17 to 21). Depending on how well the treatment works, it might mean you no longer need surgery.

After treatment, you will be monitored closely with regular physical examinations and tests including a rectal MRI and sigmoidoscopy. If there are any signs of the cancer coming back, you can then have surgery. We have more information about having a sigmoidoscopy on our website at **macmillan.org.uk/sigmoidoscopy**

Internal radiotherapy (brachytherapy)

Internal radiotherapy gives you radiotherapy from inside the body. It gives a high dose of radiotherapy to the tumour, but the areas nearby get a much lower dose.

There are 2 types of internal radiotherapy for rectal cancer:

- high-dose-rate (HDR) brachytherapy
- low-energy contact x-ray brachytherapy (Papillon treatment).

Some people have brachytherapy after a course of external radiotherapy (pages 95 to 97). Papillon treatment may be used on its own (pages 100 to 101). This is usually if you have early rectal cancer and cannot have surgery or choose not to have it.

High-dose-rate (HDR) brachytherapy

HDR brachytherapy uses radioactive material delivered through a fine tube (applicator) placed close to or inside the tumour. The applicator connects to a machine outside the body. This machine controls the amount of radiation you receive. It switches off automatically when your prescribed dose has been given.

Before you decide to have this treatment, your doctor will explain what it involves.

You will be given information on how to prepare for treatment. You can have HDR brachytherapy as a day patient. You will usually be given a sedative before treatment. This is to help you relax and feel sleepy. You might need up to 3 treatment sessions.

Before treatment, your nurse will give you a liquid into your back passage. This is called an enema. It helps you to empty your bowels.

During treatment, you usually lie on your back with your legs raised on leg rests. The doctor or nurse puts the applicator tube into the rectum. You have an x-ray to check it is in the correct position.

The treatment is not painful and usually takes 15 to 30 minutes. When your treatment is finished, the radiographers remove the applicator.

Low-energy contact x-ray brachytherapy (Papillon treatment)

You may have this type of brachytherapy for early rectal cancer. Your doctor will explain what it involves. This treatment is not available in all cancer centres.

You may have it on its own, with external radiotherapy or with chemoradiation. This depends on the stage of the cancer (pages 17 to 21). Some people decide to have this treatment because they do not want surgery. If it does not work well, your doctor will usually advise you to have surgery.

You have Papillon treatment every 2 weeks. You might have 2 to 4 treatment sessions. You can have treatment as an outpatient. You do not need a general anaesthetic.

Before treatment, you might be asked to follow a low-fibre diet for a few days (page 40). You may also have an enema. This is when a nurse gives a liquid into your back passage, to help empty your bowels.

The radiographer will show you the right position for treatment. You might need to lie on your back or kneel over. The radiographer puts some gel around the anus to numb it. They then apply some cream to help relax the muscles.

The doctor examines the area using a sigmoidoscope and then inserts a fine tube (applicator) to deliver the radiation. The actual treatment only takes a few minutes.

This treatment is only available in a few hospitals, so you may need to travel to have it. Ask your cancer doctor whether this is an option for you.

You can learn more about Papillon treatment from the Clatterbridge Cancer Centre (page 145). Visit **clatterbridgecc.nhs.uk** and search for 'Papillon treatment'. Or visit **papillonpatientsupport.com** for more information and support (page 143).

Radiotherapy for advanced cancer

You may have external radiotherapy to treat rectal cancer that has spread or has come back after treatment. It is most likely to be used to treat cancer in the pelvis. This is the area between the hip bones. The aim is to shrink the cancer and help with symptoms such as bleeding or pain. It may also be used to treat symptoms if the cancer has spread to other organs in the body.

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 area to be treated
- the dose of radiotherapy.

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

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

Preparing for external 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 person who operates the machine is called a radiographer. They give you information and support during your treatment.

The radiographer will explain what will happen. At the start of each treatment session (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 radiographer 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

Side effects depend on:

- the dose of radiotherapy
- whether it is external or internal (pages 94 to 101)
- whether you also have chemotherapy – this is called chemoradiation (pages 110 to 111).

Side effects usually begin 1 to 2 weeks after starting treatment. They may continue to get worse for a few weeks after treatment, before starting to get better. Side effects usually improve slowly over the next few weeks or more.

Smoking can make side effects worse. If you smoke, try to stop or smoke less. The NHS has a lot of information and support to help you stop smoking. Visit the NHS website for the country where you live (page 146).

It is important to tell your radiographer, cancer doctor or specialist nurse if you have side effects. They will give you advice on how to manage them and prescribe treatments that can help.

We have more information about the immediate side effects of pelvic radiotherapy on our website. Visit **macmillan.org.uk/pelvic-radiotherapy-side-effects**

Sometimes side effects do not go away completely. Side effects can develop months or years after treatment. These are called long-term or late effects. Tell your specialist nurse or cancer doctor if side effects do not get better, or you notice new side effects. There are different things that may be able to help.

These are the most common side effects of radiotherapy. You may not get all of these.

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 or surgery, this can make you 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. This will give you more energy.

Skin reactions

Sometimes the skin in the treated area and around it might:

- feel sore or itchy
- redden if you have white skin
- darken if you have black or brown skin
- become moist and sometimes blister or peel, usually towards the end of treatment.

Not everyone will get these side effects. 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 if needed, such as creams or dressings.

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 to relieve any discomfort around the back passage and perineum.

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

Pain

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

Bowel changes

You may experience problems with your bowel, such as:

- loose stools (poo) or diarrhoea
- passing a lot of wind
- needing to pass stools urgently and more frequently
- cramping pains in your tummy or back passage
- constipation
- tenesmus – 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.

Tell your doctor or nurse if you have any of these symptoms.

If you have diarrhoea, your doctor will prescribe anti-diarrhoea tablets to help. You might also be advised to make changes to your diet during radiotherapy.

Tell your specialist nurse or radiographer if you have any leakage. This is called incontinence. They will give you advice and explain how to look after the skin in that area.

Inflammation of the bladder (cystitis)

Radiotherapy to the rectal area may cause inflammation of the lining of the bladder. This can make you feel you want to pass urine (pee) 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.

Hair loss

Most people lose their pubic hair after radiotherapy to the pelvic area. It should grow back after your treatment finishes, although sometimes pubic hair loss might be permanent.

Changes to the vagina

Sometimes radiotherapy might make the lining of the vagina sore and inflamed. If this happens, you may be advised not to have sex during treatment and for a few weeks afterwards.

Radiotherapy can make the vagina narrower, less stretchy and drier than before. This can make having sex painful. It can also make having internal examinations difficult in the future.

During and after treatment, your nurse may recommend you use vaginal dilators to try to prevent the vagina from narrowing. Dilators are plastic tubes shaped like a tampon. They are available in different sizes that you use with a lubricant. We have more information about this in our booklet **Cancer and your sex life** (page 136).

Vaginal dryness can be relieved with lubricants or creams. Hormone creams can also help with dryness and vaginal narrowing. These are available on prescription from your GP.

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 the menopause.

We have more information on our website at **macmillan.org.uk/menopausal-symptoms**

Effects on the ovaries and womb

Radiotherapy for rectal cancer can affect the ovaries and the lining of the womb. This often means you will not be able to get pregnant or be able to carry a pregnancy after treatment.

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.

We also have information about fertility and cancer treatment in our booklet **Cancer and fertility** (page 136).

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 (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 at all. We have more information in our booklet **Cancer and your sex life** (page 136).

Effects on sperm

Radiotherapy to the pelvis might make you infertile. This means being unable to make someone pregnant. 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 in our booklet **Cancer and fertility** (page 136).

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 (chemoradiation). 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. This includes advice on how they can be managed or treated. Visit **macmillan.org.uk/pelvic-radiotherapy-late-effects**

Chemoradiation for rectal cancer

Chemoradiation is when you have chemotherapy and radiotherapy at the same time. It is sometimes called chemoradiotherapy.

Chemotherapy drugs 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.

You may have chemoradiation:

- before surgery, to help shrink the cancer and reduce the risk of cancer coming back in or around the rectum
- after surgery, to reduce the risk of cancer coming back in or around the rectum.

The chemotherapy drug most commonly used for rectal cancer is capecitabine (Xeloda®). You take capecitabine as tablets. You start the tablets on the first morning of your radiotherapy. You take them throughout your radiotherapy.

There are different schedules for taking capecitabine tablets. Your doctor or nurse will tell you when and how often you should take them.

DPD

Before starting this treatment, 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 worse. Your cancer doctor or specialist nurse can give you more information about chemoradiation and its possible side effects. During chemoradiation, you will usually have weekly blood tests to monitor the levels of your different blood cells.

Treatment for advanced rectal cancer

Rectal cancer can spread to other parts of the body – for example, the liver or lungs. This is called secondary or advanced rectal cancer.

Different treatments can be used to treat advanced rectal cancer. Your treatment will depend on:

- where the cancer is
- the treatment you have already had
- your general health
- the results of tests on the rectal cancer cells (pages 22 to 25)
- your preferences.

It is sometimes possible to control advanced rectal cancer for a long time. In some people, it might be possible to cure the cancer. Your doctors can talk to you about the aim of your treatment.

If the cancer is only in 1 area of the body, your doctors may suggest treatment with surgery, radiotherapy or ablation. Ablation uses extreme temperatures to destroy cancer cells.

If the cancer affects more than 1 area of the body, you may have treatment with anti-cancer drugs. These treat cancer wherever it is in the body. Sometimes a combination of treatments is used.

Different drug treatments can be used to treat advanced rectal cancer. The main treatment is chemotherapy (pages 82 to 93). Other drug treatments for advanced rectal cancer include targeted therapy and immunotherapy. Your doctors may give you targeted therapy with chemotherapy.

The type of targeted therapy or immunotherapy drugs you may have depends on the results of tests on the rectal cancer cells (pages 22 to 25). For example, it may depend on whether:

- there are certain types of gene changes in the cancer cells
- the cancer cells show high microsatellite instability.

A type of radiotherapy called stereotactic ablative radiotherapy (SABR) can sometimes be used to treat small secondary tumours. We have more information on our website at **macmillan.org.uk/sabr**

Embolisation may also be used to treat advanced rectal cancer. Embolisation is a way of cutting off the blood supply to the tumour. There are different types of embolisation. This treatment may relieve symptoms and help to control the cancer for some time.

Your doctor will talk to you about which treatments may be the most helpful. You can then decide together the best treatment for you.

You doctor may talk to you about taking part in a cancer clinical trial. We have more information about clinical trials on our website at **macmillan.org.uk/clinical-trials**

After treatment

Follow-up

After your treatment has finished, you will have regular check-ups. 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 have regular blood tests to check for a protein called carcinoembryonic antigen (CEA). You may also have:

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

If you notice any new symptoms between check-ups, tell your GP, cancer doctor or nurse as soon as possible. Your doctor will check what may be causing your symptoms and whether they are caused by your treatment.

You may feel anxious before check-ups. This is natural. It may help to get support from family or friends. You might also find it helpful to contact a support organisation (pages 142 to 151).

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 rectal 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 about physical activity and cancer in our booklet **Physical activity and cancer** (page 136).

Stop smoking

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

Stopping smoking reduces your risk of heart or lung disease, bone thinning (osteoporosis) and smoking-related cancers. Stopping smoking can be difficult, but lots of support is available.

We have more information about stopping smoking on our website. Visit **macmillan.org.uk/stop-smoking**

Drink less alcohol

NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in 1 week
- spread the alcohol units you 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. Drinkaware has more information about alcohol and drinking guidelines (page 145). Visit **drinkaware.co.uk**

Try to reduce stress in your life

Being diagnosed with rectal 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 (page 136):

- **Body image and cancer**
- **Cancer and your sex life**.

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** (page 136).

There are organisations that can give you support (page 150). It may also help to share your experience with other people through Macmillan's Online Community at **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** (page 136).

Your feelings and relationships

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 138 to 141 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**
- **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**.

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

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 (page 145).

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 136).

Work and financial support

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 (page 136).

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 (pages 147 to 148)
- Advice NI if you live in Northern Ireland (page 147).

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**

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

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.

Our booklets have more information that may be helpful:

- **Work and cancer**
- **Working while caring for someone with cancer**
- **Self-employment and cancer**.

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**.


Help and support for people affected by cancer in
East Sussex

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 **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

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 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.

Bowel cancer support organisations

Bladder and Bowel Community

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

Bowel Cancer UK

Tel **0207 940 1760**
www.bowelcanceruk.org.uk
Email 'Ask the Nurse' **nurse@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**
www.colostomyuk.org
Supports people who have had, or are about to have, a colostomy. Provides information and advice on bladder and bowel symptoms.

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.

Papillon Patient Support

www.papillonpatientsupport.com
Patient-led website for Papillon radiotherapy for rectal cancer. The website is run by people who have had Papillon treatment for rectal cancer themselves. Provides information and support and has questions and answers.

General cancer support organisations

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.

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.

The Clatterbridge Cancer Centre

Tel **0800 169 5555**
www.clatterbridgecc.nhs.uk
Provides non-surgical specialist cancer care and support to people affected by cancer.

General health information

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Offers information on 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.

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 'Therapist directory' page.

Emotional and mental health support

Samaritans

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

Financial support or legal advice and information

Advice NI

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

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 1111**
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 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

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.

With thanks to: Lindsey Allan, Macmillan Oncology Dietitian; The Association of Stoma Care Nurses UK; Dr Michael Braun, Consultant Medical Oncologist; Dr Rachel Cooper, Consultant Clinical Oncologist; Mr James Crosbie, Consultant Colorectal Surgeon; Prof Chris Cunningham, Associate Professor of Colorectal Surgery; Dr Lesley Dawson, Consultant Medical Oncologist and Honorary Senior Lecturer in Medical Oncology; Mr Mark George, Consultant Colorectal and General Surgeon; Amanda Gunning, Clinical Lead for Stoma Care; Manju Khanna, Senior Macmillan Colorectal CNS; Dr Asad Qureshi, Consultant Clinical Oncologist; and Dr Amen Sibtain, Consultant Clinical Oncologist.

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

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

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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

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

The booklet explains what rectal 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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