MACMILLAN
CANCER SUPPORT

UNDERSTANDING RECTAL CANCER

> ‘I find the support I’ve got from the Macmillan centre really wonderful. The ex-nurse who runs the centre has masses of helpful booklets and other information.’

Ann, diagnosed with rectal cancer

About this booklet

This booklet is about rectal cancer. The rectum is part of the bowel. We have separate information about small bowel cancer, colon cancer and anal cancer.

The booklet explains what rectal cancer is, and how it is diagnosed and treated. It also talks about your feelings when you are diagnosed with cancer and has practical advice on dealing with work and finances. When we mention bowel cancer in this booklet, this includes rectal cancer.

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

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

How to use this booklet

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

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

On pages 136 to 143, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see page 144).

Quotes

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

For more information

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

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

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

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

Contents

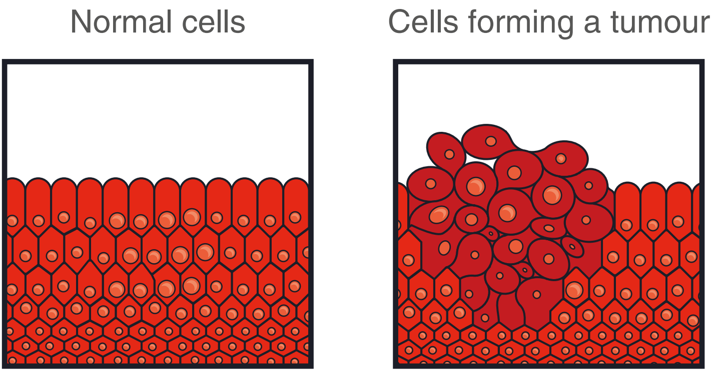
THE BOWEL AND RECTAL CANCER

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



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

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

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

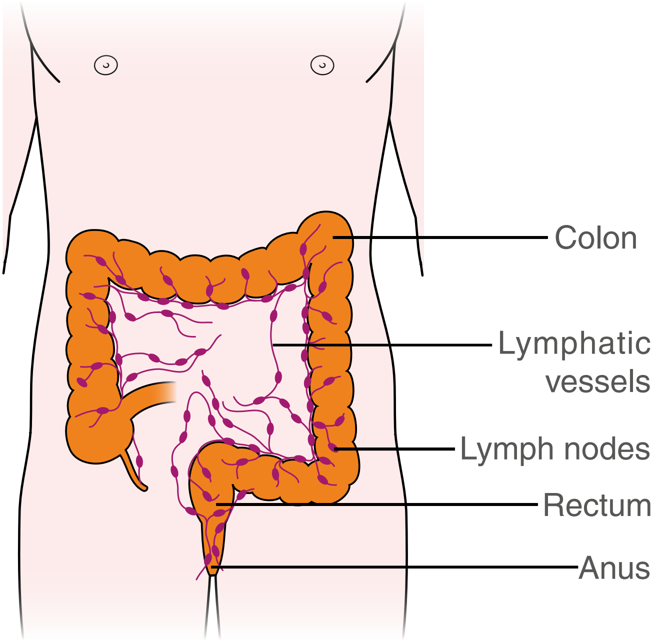
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 8). When these cancer cells reach another part of the body, they may grow and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

The lymphatic system

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

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection. If bowel cancer spreads, it is most likely to spread to nearby lymph nodes.

Lymph nodes close to the bowel



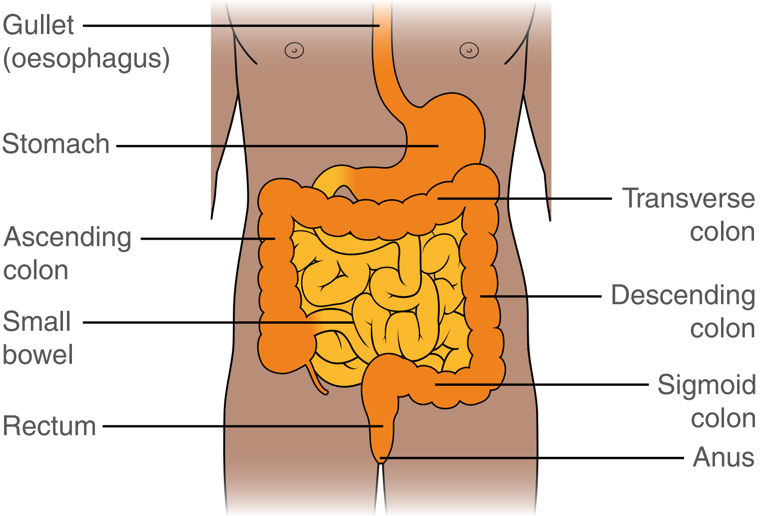
The bowel

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

- the small bowel
- the large bowel.

The large bowel is made up of the colon, rectum and anus.

The digestive system



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

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

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

The anus is the opening at the end of the large bowel. It contains a ring of muscle called the sphincter. This muscle helps to control when you empty your bowels.

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 three: the upper, middle and lower third.

The upper third is the section directly after the sigmoid colon (see page 9). The lower third is where the large bowel joins the anus. The middle third is in between.

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

Causes and risk factors

In the UK, about 41,000 people get cancer in the large bowel each year. The large bowel includes the colon and the rectum (see page 9).

The exact cause of bowel cancer is unknown. But, things called risk factors can increase the chance of a person developing it. Having one or more risk factors does not mean you will definitely get bowel cancer. And if you do not have any risk factors, it does not mean you will not get bowel cancer.

Age

Like most types of cancer, bowel cancer is more common in older people. In the UK, around 4 in 10 bowel cancer cases (44%) each year are diagnosed in people aged 75 and over.

Diet

Eating a lot of red and processed meat increases the risk of bowel cancer. Red meat includes beef, lamb, pork, veal, venison and goat.

Processed meat includes smoked meat, ham, bacon, sausages, pate and tinned meat. Eating fried or grilled meat may also increase the risk.

Current UK guidelines recommend that you eat no more than 70g of red meat per day. That is about 3 slices of ham or 1 lamb chop. No link has been found between bowel cancer and eating poultry such as chicken and turkey, or seafood. Not eating enough fruit and fresh vegetables may also increase the risk.

Physical activity

People who are not physically active are more likely to develop bowel cancer.

Body weight

Being overweight can increase the risk of developing bowel cancer, especially in men.

Smoking

Bowel cancer is more common in people who have smoked cigarettes for many years. If you are diagnosed with bowel cancer, it can help to stop smoking. Your doctor or nurse will talk to you about this.

Inflammatory bowel conditions

Having an inflammatory bowel condition, such as ulcerative colitis or Crohn's disease, can increase the risk of bowel cancer. People with these conditions may be offered regular bowel screening with a test called a colonoscopy (see page 20).

Irritable bowel syndrome is not an inflammatory bowel condition. It does not increase the risk of getting bowel cancer.

Type 2 diabetes

If you have type 2 diabetes, you are at a slightly higher risk of getting bowel cancer.

Family history

Most people who get bowel cancer do not have a family history of it. Having one family member who developed bowel cancer at an older age does not increase your risk.

If several close family members on the same side of your family have had bowel cancer, this may increase your risk. You may also have a higher risk if a close family member had bowel cancer before the age of 50. Close family members are parents, brothers and sisters.

People who have a history of bowel cancer in their family can be referred to a specialist clinic to have their risk assessed. People at higher risk of bowel cancer are offered bowel screening. This means having regular tests to look at the inside of the large bowel. For more information, contact your GP or call our cancer support specialists on **0808 808 00 00**.

Inherited (familial) conditions

About 5 in every 100 bowel cancers (5%) are caused by an inherited faulty gene.

There are two rare conditions that can run in families:

- familial adenomatous polyposis (FAP)
- Lynch syndrome (also called hereditary non-polyposis colorectal cancer or HNPCC).

People with either condition have a very high risk of developing bowel cancer.

Familial adenomatous polyposis (FAP)

FAP causes less than 1 in every 100 bowel cancers (less than 1%).

People with FAP have hundreds or thousands of benign tumours (polyps) in the lining of their colon. They may also have polyps in their rectum.

People with FAP have regular screening using colonoscopies to look for signs of cancer. It is usually recommended that people with FAP have an operation to remove their colon and sometimes their rectum. Unless the colon is removed, nearly everyone with FAP will develop bowel cancer.

Lynch syndrome (HNPCC)

People with Lynch syndrome have an increased risk of developing bowel cancer at a young age. Lynch syndrome causes about 4 in every 100 bowel cancers (4%).

If you have Lynch syndrome, you will usually have regular screening using colonoscopies. Screening normally starts from the age of 25. Or it may start 5 years before the age at which your youngest relative developed bowel cancer. The colonoscopy is usually repeated every 18 months to 2 years.

If you are concerned about your family history of bowel cancer, we have more information in our leaflet **Are you worried about bowel cancer?** (see page 132). We also have information about cancer and genetics in our booklet **Cancer and genetics – how cancer sometimes runs in families** (see page 132).

We have more information about FAP and Lynch syndrome on our website **macmillan.org.uk**

Bowel cancer is not infectious and cannot be passed on to other people.

Symptoms

The symptoms of rectal cancer may include:

- blood in or on your poo (stools), or bleeding from the back passage (rectum) – the blood may be bright red or dark
- a change in your normal bowel habit that happens for no obvious reason and lasts longer than 3 weeks – for example, diarrhoea or constipation
- unexplained weight loss
- pain in your tummy (abdomen) or back passage
- feeling that you have not emptied your bowel properly after you poo
- unexplained tiredness, dizziness or breathlessness
- a lower than normal level of red blood cells (anaemia).

Sometimes the cancer can cause a blockage (obstruction) in the bowel. You may feel constipated and bloated, have tummy pain or be sick (vomit).

These symptoms can be caused by conditions other than rectal cancer, but you should always have them checked by your doctor.

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

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

They can do tests to find out what might be causing the symptoms.

DIAGNOSING RECTAL CANCER

How rectal cancer is diagnosed

If you have symptoms, you will usually begin by seeing your GP, who will examine you. If they think that your symptoms could be caused by cancer, they will refer you to a specialist doctor.

Some people are diagnosed after taking a test as part of the NHS Bowel Screening Programme. Bowel screening is a way of finding bowel cancer at an early stage before it causes symptoms.

In England, Wales and Northern Ireland, people are invited to do a test at ages 60 to 74. In Scotland, people aged 50 to 74 are invited. In Scotland, England and Wales, the test is a FIT (faecal immunochemical test). Northern Ireland has also begun to use the FIT but some people may still have a FOB test (faecal occult blood test).

Testing is done every two years. You are sent a home test kit, which is used to collect a poo (stool) sample. If you have a family history of bowel cancer, you may need to have bowel screening at an earlier age.

Sometimes people are diagnosed with colon cancer after going to hospital with a problem, such as a bowel obstruction. This is when part of the bowel becomes blocked. It may cause symptoms such as:

- tummy pain
- nausea and vomiting
- constipation.

At the hospital

The doctor will ask you about your general health and any previous medical problems you have had. They will also ask whether you have a family history of bowel cancer.

The doctor will examine you and will do a rectal examination. This is when the doctor places a gloved finger into your back passage to feel for any lumps or swelling. It may feel uncomfortable, but is not usually painful.

You will usually have a blood test to check your level of red blood cells. If you have a low number of red blood cells, this is called anaemia. You will also have blood tests to check whether your liver and kidneys are working normally.

Your doctor will decide what other tests you need based on your symptoms, the examination and the results of your blood tests.

The main test used to look for bowel cancer is a colonoscopy. Other tests that are sometimes used to diagnose bowel cancer include:

- virtual colonoscopy
- sigmoidoscopy.

Colonoscopy

A colonoscopy looks at the inside of the whole length of the large bowel. You can usually have this test as an outpatient. It takes about an hour.

Your bowel must be completely empty for a colonoscopy. You will be told what you can eat and drink the day before the test. You will also take a medicine (laxative) to empty your bowel.

Just before the test, you may have an injection of a sedative into a vein (intravenously). This will make you feel drowsy and more relaxed while you have the colonoscopy.

Once you are lying on your side, the doctor or nurse will gently pass a flexible tube into your back passage. This tube is called a colonoscope. There is a tiny light and camera on the end of it. During the test, the doctor or nurse will use this to photograph any areas of the bowel that look abnormal. They may also take samples (biopsies) from these areas. The biopsies will be sent to the laboratory. In the laboratory they will be checked for cancer cells by a doctor who studies cells (pathologist).

Most people are ready to go home a few hours after having a colonoscopy. You will need someone to collect you from the hospital, as you should not drive for 24 hours after a sedative.

Virtual colonoscopy (CT colonography)

In a virtual colonoscopy, a computerised tomography (CT) scanner takes a series of x-rays. This builds up a three-dimensional picture of your bowel. It is done in the hospital CT department and you can usually have it as an outpatient.

This test may be done instead of a colonoscopy. Or it may be done if the colonoscopy did not give a clear enough picture.

Your bowel must be completely empty for a virtual colonoscopy. You will need to follow a special diet for a few days and take a laxative before the test. Your hospital will tell you what to do.

Your doctor may give you an injection to help the muscles in your bowel relax. You may also have an injection of a dye called a contrast medium at the same time. Your doctor will tell you if you are going to have this.

Just before the scan, your doctor passes a tube into your back passage (rectum) and pumps in some air and gas (carbon dioxide). This expands the bowel and helps to give a clearer picture. You will have two CT scans – one lying on your back and one lying on your front.

Sigmoidoscopy

This test looks at the inside of the rectum and the part of the colon closest to the rectum (the sigmoid colon). You can usually have it as an outpatient.

A sigmoidoscope is a tube with a light and camera on the end. You lie curled on your left side and a doctor or nurse passes the tube into your back passage. A small amount of air is pumped into the bowel to make it easier to see inside it. This will make you feel like you need the toilet, but the feeling will gradually go away once the test is over.

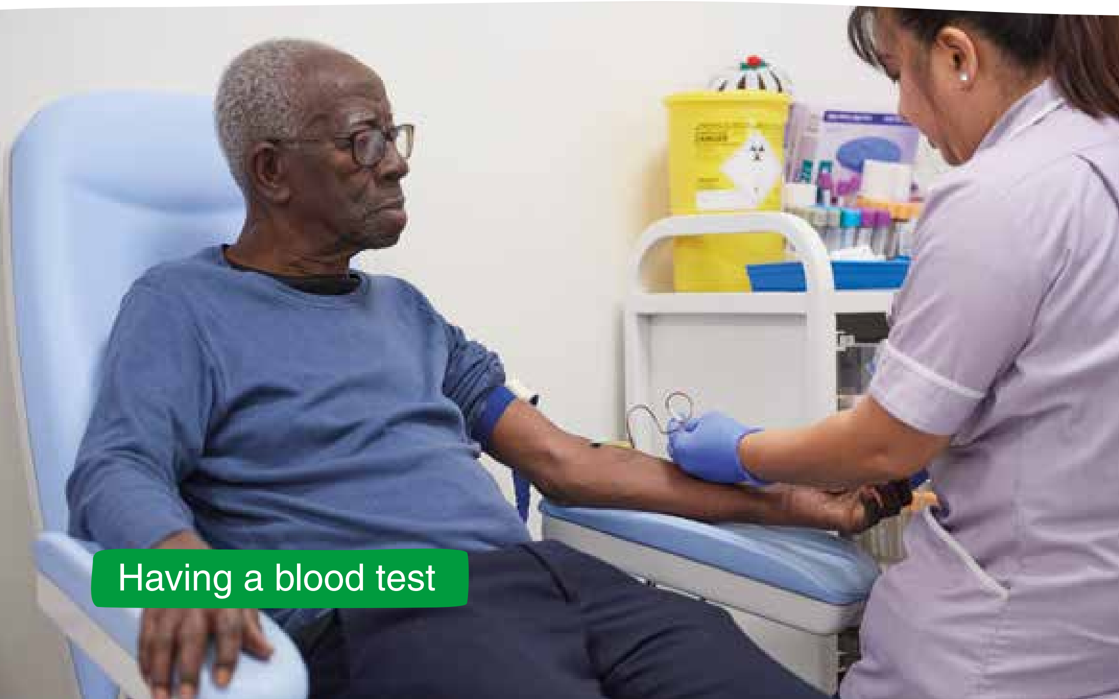
During the test, the doctor or nurse will take samples of tissue (biopsies) from any areas of the colon that look abnormal. This is painless. You should be able to go home as soon as the test is over.

Further tests

If any of your biopsies show that there is cancer in the rectum (to change), you will have more tests. These are to find out the size and position of the cancer and whether it has spread. This is called staging. The results will help you and your doctor decide on the best treatment for you. Some tests may be repeated during and after treatment. You may have any of the following tests.

Blood tests

You will have blood tests to assess your general health, such as how well your liver and kidneys are working. Your blood may be tested for a protein called carcinoembryonic antigen (CEA). Some people with bowel cancer have higher levels of this protein.



Having a blood test

MRI scan

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

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

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

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

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

Having a CT scan

CT scan

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

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

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

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

PET or PET-CT scan

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

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

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

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

Endorectal ultrasound scan (ERUS)

This test may be used to help plan your operation. Ultrasound scans use sound waves to build up a picture of body tissues. An endorectal ultrasound scan can show the size and where the cancer is in the rectum.

For the test, you lie on your left side with your knees bent up. A nurse or doctor gently passes a small, lubricated probe into the back passage. This produces an image of the rectum on a screen.

The scan takes about 10 minutes and you can usually go home as soon as it is over.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist or one of the organisations listed on pages 136 to 143 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Your data and the cancer registry

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

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

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 bowel, 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

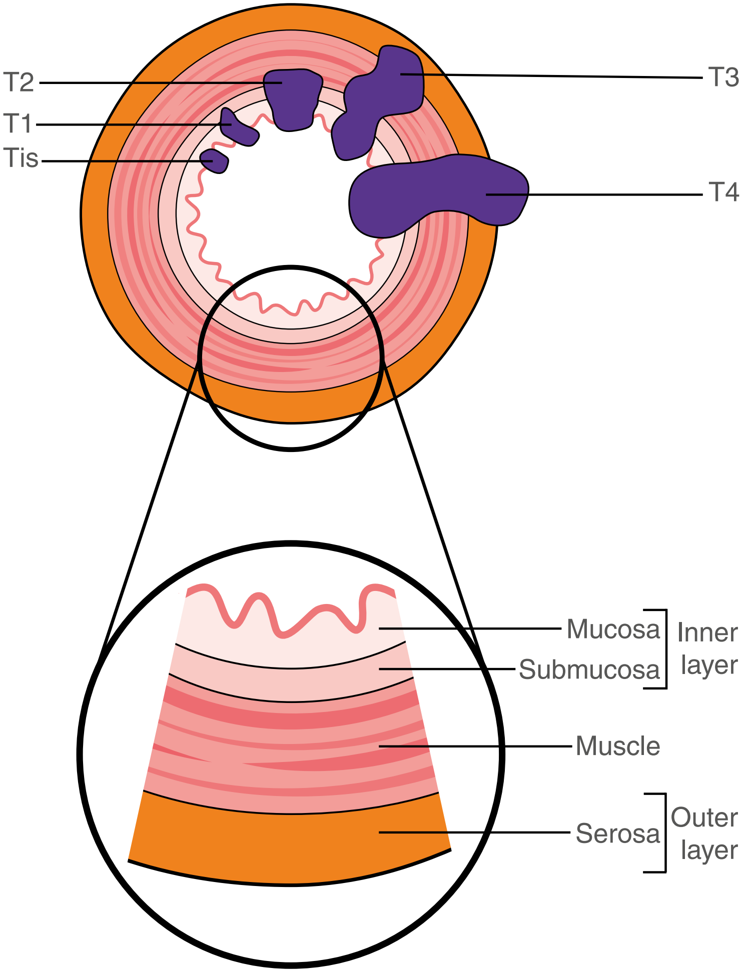
The bowel wall is made up of layers of different tissues.

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 bowel (submucosa).

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

Cross-section showing the different layers of the bowel and the different T stages of cancer (in purple)



T3 means the tumour has grown through the muscle layer of the bowel and into the tissues that surround the bowel, but not through the membrane covering the outside of the bowel (peritoneum).

T4 means the tumour has grown through the outer layer of the bowel wall (serosa) and through the peritoneum. A tumour at this stage can be described as T4a or T4b:

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

N – Nodes

N0 means no lymph nodes contain cancer cells.

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

N2 means there are cancer cells in four 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.

Number staging system

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

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

Stage 1 – 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 – The cancer has grown through the muscle wall or through the outer layer of the bowel 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 3 – The tumour is any size and has spread to lymph nodes nearby, but has not spread anywhere else in the body (Any T N1 M0 or Any T N2 M0).

Stage 4 – The tumour is any size. It may have spread to nearby lymph nodes. The cancer has spread to other parts of the body such as the liver or lungs (Any T Any N M1).

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

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

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

Tests on the bowel cancer cells

Doctors may do further tests on the bowel cancer cells from a biopsy taken when you were first diagnosed. Or they may test bowel cancer cells that were removed during surgery. Sometimes they may need to take a second sample of bowel cancer cells if the cancer has spread to another part of your body.

Not everyone will need all the following tests. Your doctor will explain which tests are needed in your situation.

Micro-satellite instability

Bowel cancer cells may be tested for micro-satellite instability (MSI). DNA carries all your genetic information inside the cell. When a cell divides normally, a repair system ensures that the new DNA is identical to the original DNA by repairing any changes to the DNA. With MSI, this repair system is faulty. This test can detect if this is the case.

MSI testing can help you and your doctor decide whether you may need further genetic tests. Genetic tests may tell you whether you have bowel cancer caused by an inherited condition called Lynch syndrome. People with Lynch syndrome have an increased risk of developing bowel cancer at a young age. Visit **macmillan.org.uk** for more about Lynch syndrome.

Checking the blood vessels and nerves

Cancer and surrounding tissues removed during surgery are checked to see if the cancer has spread into blood vessels or nerves within the tissues. If cancer has spread into the blood vessels or nerves, it can increase the risk of the cancer spreading to other parts of the body. Knowing more about this can help you and your doctor decide whether you may need further treatment after your surgery.

RAS gene mutation

Doctors may test the cancer cells for certain gene changes (mutation). In bowel cancer doctors check for a change called the RAS gene mutation. RAS genes help control cell growth. Changes to RAS genes can affect what type of treatment you might have. For example, some targeted therapies do not work on bowel cancer that has the RAS gene mutation.

BRAF gene mutation

Doctors may also test the bowel cancer cells for a change in the BRAF gene. The BRAF gene makes a protein that is involved in cell growth. A change to this gene means that the protein becomes overactive which can make cancer cells grow and divide more quickly.

Knowing whether you have the BRAF gene mutation can tell doctors more about how you might respond to certain treatments.

TREATING RECTAL CANCER

Treatment overview

Treatments used for rectal cancer include surgery, radiotherapy, chemotherapy and sometimes targeted therapy. Often, a combination of treatments is used. The results of your tests help your doctor plan your treatment (see pages 40 to 41).

The treatment you have depends on:

- the stage of the cancer
- the position of the cancer in the rectum
- your general health and 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 to remove the cancer is one of the main treatments for rectal cancer (see pages 44 to 62). The operation usually involves removing part, or all, of the rectum, as well as nearby lymph nodes (see page 8). If the cancer has grown into tissue or organs nearby, the surgeon may remove parts of these too.

Sometimes, surgery is used to help with symptoms. This may be if the cancer is causing a blockage in the bowel (see pages 55 to 56). Sometimes surgery is used to remove cancer that has spread to a distant part of the body, such as the liver or lungs.

Radiotherapy

You may have radiotherapy or chemoradiation before rectal surgery (see pages 76 to 97). Chemoradiation is when chemotherapy and radiotherapy are used together (see page 97). Having the treatment before surgery can shrink the cancer, which 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.

> **My surgeon explained how I had a stage 3 rectal adenocarcinoma and that I would need to have chemotherapy and radiotherapy to try and shrink the tumour as much as possible before surgery, where I would need either a temporary or permanent colostomy and stoma formed.**
>
> **Joanna, diagnosed with rectal cancer**

Chemotherapy

Sometimes chemotherapy is given after surgery to reduce the risk of the cancer coming back (see pages 88 to 96). This is called adjuvant chemotherapy.

Rectal cancer can sometimes spread to other parts of the body, such as the liver or lungs. This is called secondary or advanced cancer. If you have secondary cancer, chemotherapy may be the main treatment. It is given to shrink the cancer and to control it for as long as possible. Some people with secondary cancer have chemotherapy to shrink the cancer before having an operation to remove it.

Other treatments

Targeted therapies may also be used to control secondary cancer (see pages 100 to 103). They are sometimes used on their own, but are usually given in combination with chemotherapy.

Other treatments may also be used to treat bowel cancer that has spread to other parts of the body (see pages 98 to 103).

Your cancer doctor may invite you to take part in a clinical trial (see pages 104 to 105).

‘My cancer was discovered during a colonoscopy for something else. I had a week’s intensive radiotherapy to reduce the tumour and the week after that I went in for the operation, on the understanding that it would be keyhole surgery.’

Ann, diagnosed with rectal cancer

How treatment is planned

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

This MDT includes:

- a surgeon, who specialises in bowel cancers
- an oncologist (cancer doctor), who specialises in radiotherapy, chemotherapy and targeted therapies
- a nurse specialist, who gives information and support
- a radiologist, who helps to interpret x-rays and scans
- a pathologist, who gives information about the type and size of the cancer
- a stoma care nurse, who helps to care for a stoma if you have had a colostomy or ileostomy operation (see pages 47 to 48).

Other healthcare professionals may include:

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

If the cancer has spread to your liver or lungs, you may also be referred to an MDT that specialises in surgery for secondary cancer in the liver or lungs. In this situation, the two MDTs will work together to plan your treatment.

Our booklet **Making treatment decisions** has more information that you might find helpful (see page 132).

Talking about your treatment plan

After the MDT meeting, your cancer specialist or nurse will talk to you about your treatment options.

They will explain the main aims of treatment.
These may be to try to:

- cure the cancer
- help you live longer
- relieve symptoms.

They will also tell you the possible short-term and long-term side effects of the treatments. Deciding which treatments are right for you is usually a joint decision between you and your cancer team.

If there is one treatment that has been shown to work best, most people are usually happy to be guided by their cancer doctor. But there can be times when the choice of treatment will depend on your preferences. For example, this might be if there are two or more treatments that may work equally well, but cause different side effects. Or it may be if having an additional treatment may only slightly increase the chance of a cure but may cause side effects.

If a cure is not possible and the aim of the treatment is to control the cancer, it may be more difficult to decide what to do. You may need to discuss this in more detail with your cancer doctor. If you choose not to have the treatment, you can still have supportive (palliative) care to control any symptoms.

When making treatment decisions, it is important to talk about things properly with your cancer team. It can help to make a list of the questions you want to ask the at your next appointment. It is also helpful to have a family member or close friend with you at appointments. You could also write notes about what is said.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (see page 41).

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

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

Second opinion

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

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

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

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

Surgery for rectal cancer

Surgery is the most common treatment for rectal cancer.

You may have radiotherapy or chemoradiation before surgery (see pages 76 to 97). 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 or surgery you have will depend on:

- the stage of the cancer (see pages 28 to 33)
- where it is in the rectum
- your general health.

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

After the operation, all the tissue that the surgeon has removed is sent to a pathologist. They check the tissue carefully for any cancer cells close to the edge. The edge is called the margin. If they find cancer cells in the margin, there might be a higher risk of 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 you may have an operation called a local resection. This is a small operation to remove the cancer and some 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 (abdomen).

The surgeon passes a long, flexible tube with a tiny camera at the end (an endoscope) into the anus and the rectum. This allows the surgeon to find and remove the tumour precisely. This surgery is called transanal endoscopic microsurgery (TEM) or transanal minimally invasive surgery (TAMIS), depending on the surgical instrument used.

If the cancer is very low in the rectum and close to the anus, the surgeon may be able to remove the cancer through the anus without using an endoscope. This is called a transanal rectal resection.

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 as laparoscopic (keyhole) surgery.

Open surgery means the surgeon makes one large cut (incision), usually near the tummy button. The length of the cut depends on the size of the cancer and where it is.

Laparoscopic surgery means the surgeon makes four or five small cuts in the tummy rather than one large cut. They pass a thin tube with a small camera (a laparoscope) into the tummy through one of the cuts. They then pass specially designed surgical tools through the other cuts to remove the cancer. Laparoscopic surgery is sometimes called keyhole surgery or minimally invasive surgery. You usually recover more quickly from this type of surgery than from open surgery.

Laparoscopic surgery may also be done using a technique called robotic-assisted surgery. This is when the surgeon uses surgical tools attached to the end of robotic arms to remove the cancer. Robotic surgery is still a new technique and is not available in all 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)

During the operation to remove the cancer, sometimes the surgeon needs to create a stoma. This is an opening that is made 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 does not hurt.

Having a stoma means stools (poo) will not pass out of the rectum and anus in the usual way. Instead, it will pass out of the stoma, into a disposable bag that is worn over the stoma.

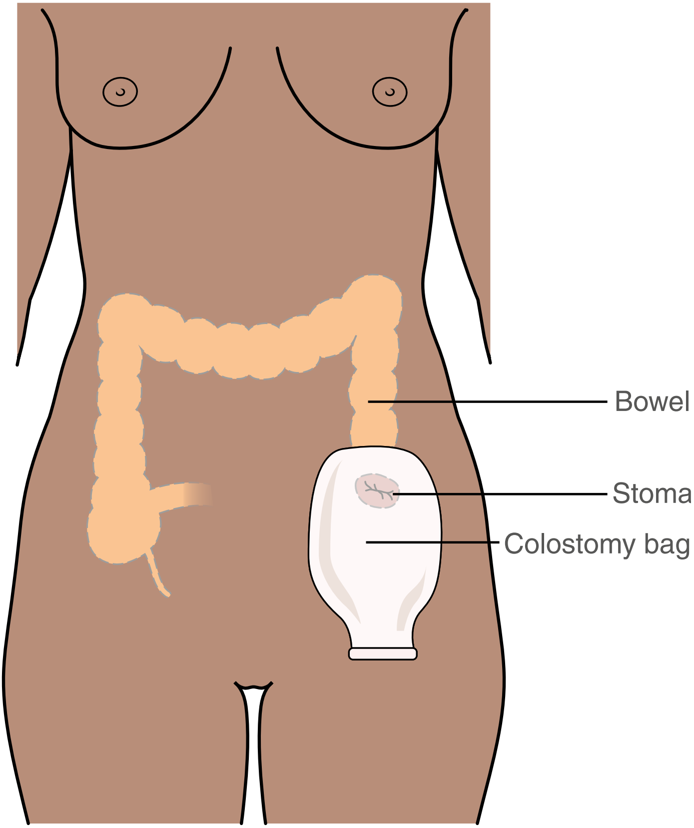
If the stoma is made from an opening in the colon, it is called a colostomy. If it is made from an opening in the small bowel (ileum), it is called an ileostomy.

Stomas may be temporary or permanent. A surgeon may make a temporary stoma to allow the bowel to heal after surgery. If you have a temporary stoma, you will usually have a second smaller operation a few months later to close the stoma and re-join the bowel. This operation is called a stoma reversal.

If the cancer is very low in your 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 after your operation, and whether it will be temporary or permanent. If you need to have a stoma, you will be referred to a stoma nurse who specialises in stoma care. They can talk to you about what to expect.

Colostomy bag

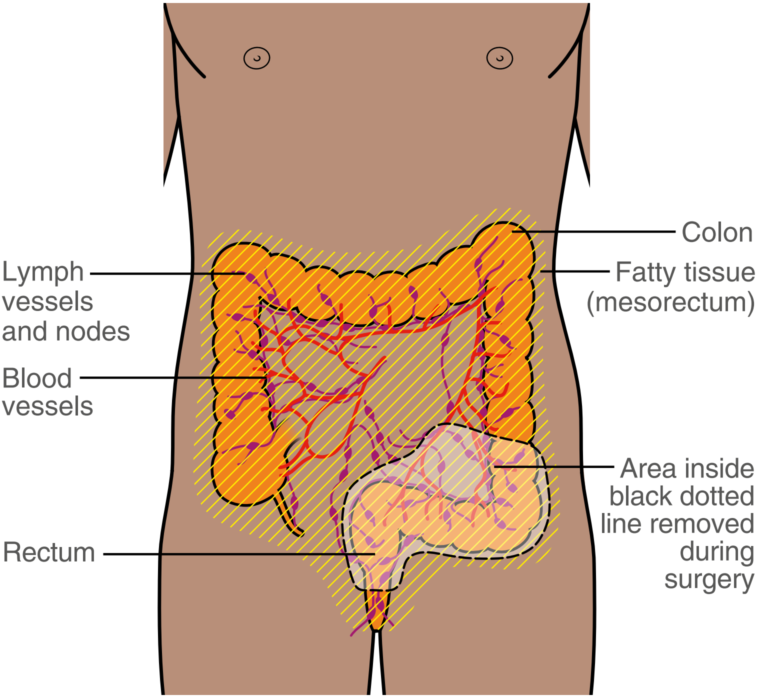


> **As the time went on I got more and more used to living with my colostomy bag. It didn’t take as long as I expected, after around 5 or 6 weeks I was proficient with my stoma care.**
>
> **Joanna, diagnosed with rectal cancer**

Total mesorectal excision (TME)

If you have a larger rectal cancer, you will usually need to have most of the rectum removed. This is usually done using an operation called total mesorectal excision (TME). A TME is when the surgeon removes some of the fatty tissue around the rectum (mesorectum). The fatty tissue contains lymph nodes and blood vessels. This means all the lymph nodes near to the tumour are removed, which reduces the risk of the cancer coming back. If possible, the surgeon joins the colon to the top of the anus.

Large bowel and mesorectum

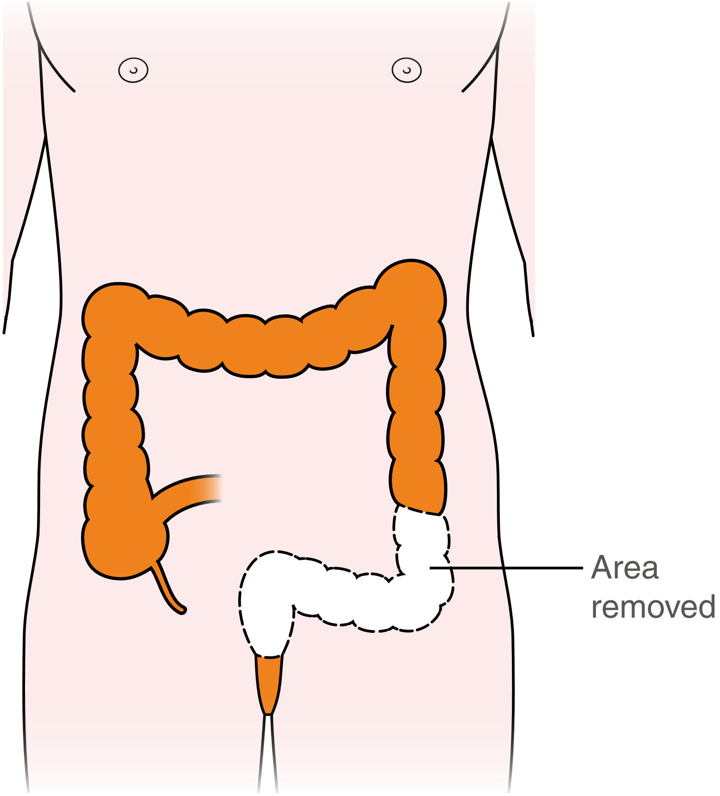


Most people with rectal cancer have a TME as part of their surgery. In the illustration, the black dotted line shows an example of the tissue that may be removed during a TME operation.

Anterior resection

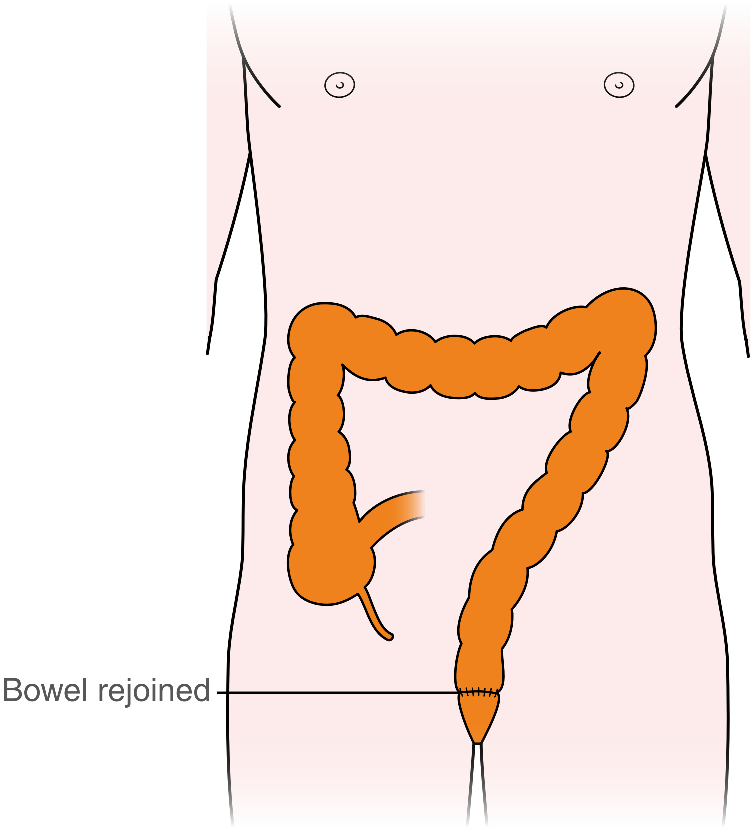
Rectal cancers in the upper and middle part of the rectum can be removed by an operation called an anterior resection. The surgeon removes the part of bowel that contains the cancer, then re-joins the two open ends of bowel. The illustration below shows the part of the bowel that is removed.

Anterior resection



The illustration below shows how the two ends are joined together. This operation is also called a low anterior resection (LAR). You may have a temporary stoma (usually an ileostomy) after this operation. You can usually have a stoma reversal a few months later.

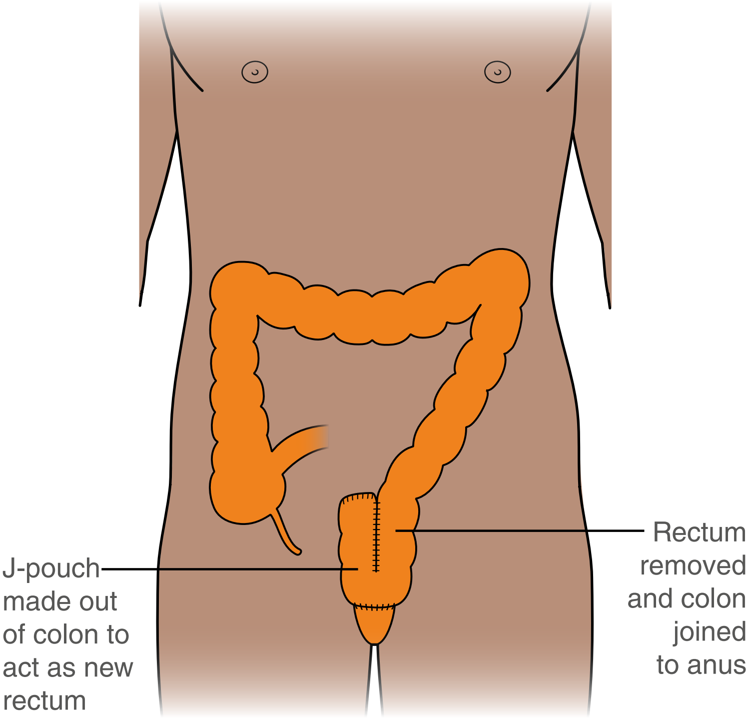
Anterior resection re-joined



Colo-anal and J-pouch surgery

If the cancer is low in the rectum, the surgeon may use an operation called a colonic J-pouch. This is used to join the bowel to the anus. It is a type of reconstructive surgery. The surgeon makes a pouch, called a J-pouch, from part of the colon, before joining it to the anus. The pouch acts like a new rectum and stores stools (poo) until it is convenient to pass them. The illustration below shows a J-pouch. You may have a temporary stoma (usually an ileostomy) after this operation. This allows the bowel to heal. You can usually have a stoma reversal a few months later.

J-pouch

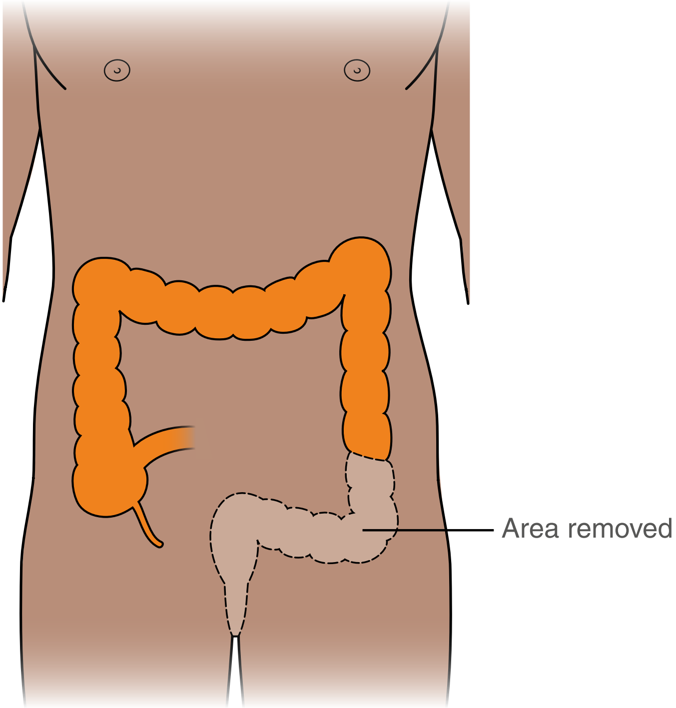


Abdomino-perineal resection (APR)

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

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, depending on the size of the tumour.

Abdominal perineal resection



Surgery for advanced rectal cancer

There are different types of surgery for advanced rectal cancer.

Pelvic exenteration

If the cancer has grown into other organs nearby, you may need a bigger operation to try to remove it. This is called a pelvic exenteration. Your doctor will explain more about this operation and if it is suitable for you.

Liver resection

If the cancer has spread to the liver (secondary liver cancer), the most common treatment is chemotherapy (see pages 88 to 96). The aim is to shrink the cancer and control it for as long as possible.

You may be able to have surgery to remove the part of the liver that is affected by cancer. This operation is called a liver resection. It can sometimes lead to a cure.

A liver resection is a major operation. It is done by a surgeon who is experienced in liver surgery (hepatobiliary surgeon) in a specialist hospital. This treatment is only suitable for a few people with secondary liver cancer.

Sometimes the liver resection is done at the same time as an operation to remove the cancer in the rectum.

If you have secondary liver cancer, you can talk to your cancer doctor about whether this surgery may be helpful for you. You may have a course of chemotherapy before a liver resection.

We have more information about secondary cancer in the liver and how it is treated in our booklet **Understanding secondary cancer in the liver** (see page 132).

Lung resection

The main treatment for cancer that has spread to the lungs is chemotherapy. But you may be offered surgery to remove the affected part of the lung.

Radiofrequency ablation or microwave ablation are sometimes used to treat bowel cancer that has spread to the liver or lungs. These treatments destroy cancer cells using heat (see page 102).

Treating a blocked bowel (bowel obstruction)

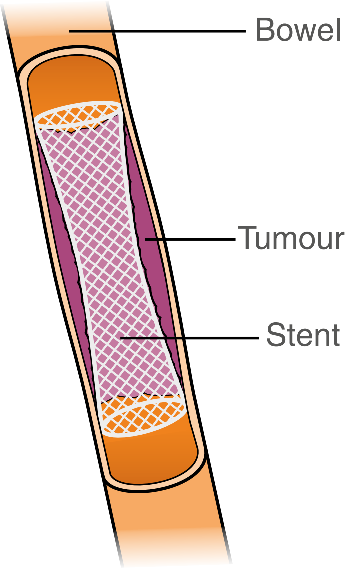
Sometimes, rectal cancer can narrow the bowel, which stops stools (poo) from passing through. This can cause symptoms such as tummy pain and vomiting. It usually needs to be treated urgently. A blocked bowel can be relieved in different ways.

Stenting

The doctor may use a colonoscope (see page 20) to insert an expandable metal tube (a stent) into the blockage. They may use an x-ray to see where to insert the tube. The tube then expands to hold the bowel open, so the 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. Or sometimes a stent stays in permanently to treat the blockage. Your doctors will explain what the aim of the stent is in your situation.

A part of the bowel with a stent inside



Surgery

Sometimes a bowel obstruction is treated with an operation to remove the blocked section of bowel. Most people have a temporary or permanent stoma after this operation (see pages 47 to 48). The surgeon may remove the cancer at the same time, or later in another operation.

If it is not possible to remove the cancer, the blocked bowel can be relieved by creating a stoma. This means stools (poo) pass out of the stoma.

Before your operation

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

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

For some types of bowel surgery, you may need to follow a special diet or take some medicine, called a laxative. This is to empty your bowels before your surgery. For example, you may need to take a laxative for a few days before the operation. You will also be asked to not eat or drink for a few hours before the operation. Your doctor or nurse will advise you about this.

Before the operation, you will usually be given antibiotics 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 after the operation, you will also meet a stoma care nurse who will explain what is involved.

This is a good time to share any questions or concerns you have about the operation If you live alone, or care for someone else, you may need help when you go home after surgery. Tell a nurse as soon as possible so they can help to make arrangements for you.

Some hospitals follow an enhanced recovery programme, which aims to reduce the time you spend in hospital and speed up your recovery. You will also be more involved in your own care. For example, you will be given information about diet and exercise before surgery. You may also be given nutritional supplement drinks.

Your hospital team will make any arrangements needed for you to go home. Your doctor will tell you if an enhanced recovery programme is suitable for you, and if it is available.

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

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 and discomfort after your operation. Painkillers can help control this. If you feel sick or are in pain, tell the nurses. They can give you medicines to help with sickness. They might also need to change the dose or type of painkiller you are taking.

You may be given a spinal block during the operation. This is an injection of a long-lasting painkiller into the fluid around the spinal cord. It gives pain relief for up to 24 hours. Or you may have a continuous dose of painkiller into the spinal fluid through a fine tube and a pump. This is called an epidural.

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

Painkillers sometimes slow down your bowel function (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 get a prescription for painkillers you can take at home as needed.

Feeling sick or being sick

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

Drips and drains

At first, you are given fluids into a vein in your hand or arm. This is called a drip or intravenous infusion. When you are eating and drinking normally again, the drip is removed.

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

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

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

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.

Wound care

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

You may be given antibiotics to help prevent any wound infection.

While you are in hospital and after you go home, tell your nurse or doctor straight away if your wound:

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

These can be signs that the wound is infected.

Possible complications

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

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

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

Going home

Depending on the type of operation you have had, you will probably be ready to go home 3 to 7 days after surgery.

Before leaving hospital, you will be given an appointment to go to an outpatient clinic for your post-operative check-up. At the appointment, your doctor will talk to you about whether you need any further treatment, for example chemotherapy (see pages 88 to 96).

If you have stitches, clips or staples in your wound, these are usually taken out 7 to 10 days after the operation. A nurse at your GP surgery can do this. If you cannot leave home, a district nurse can visit you.

If you have a stoma, the hospital will give you stoma supplies to take home. When you have used these, you will need to order supplies from your pharmacy or direct from a specialist supply company. Your stoma care nurse can tell you about these. The Ileostomy and Internal Pouch Support Association and Colostomy UK also have details of companies that provide stoma supplies (see pages 136 to 137). You will need a prescription from your cancer doctor or GP to get stoma supplies. In England, prescriptions are free for people with cancer. However, if you are aged between 16 and 60, you will need to make sure your doctor signs the form saying that you are entitled to free prescriptions. Prescriptions are free for people living in Scotland, Wales and Northern Ireland.

> You have routine of going for treatment and having to take medication and have scans. After that's all gone, you do feel a bit adrift – because you're so used to having that routine. It's a strange feeling.

Cath, diagnosed with rectal cancer

Bowel function after surgery

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

If you had a local resection, your bowel will usually recover quite quickly (see pages 46 to 48).

After TME surgery, it could take several months for your bowel function to get into a more regular pattern (see pages 49 to 53). It may never be the same as it was before the cancer. In time, it should settle into more of a routine that will become normal for you. If you had radiotherapy or chemoradiation before or after rectal surgery, this will also affect your bowel (see pages 76 to 97). This could mean it takes longer to get back to having regular bowel movements.

After rectal surgery, you may have one or more of the following changes:

- needing to pass stools (poo) more frequently – this might be several times a day
- feeling that you cannot wait when you need to pass stools (urgency)
- diarrhoea
- constipation
- losing control over when you empty your bowels (incontinence)
- difficulty telling the difference between wind or stools
- feeling bloated or passing a lot of wind
- having a sore bottom
- not being able to have certain food and drinks without them affecting your bowel movements.

Any changes usually improve over time. Tell your surgeon or specialist nurse if you are having problems, or if your bowel movements are not settling into a regular pattern. They can give you advice, prescribe medicines or refer you to a continence specialist nurse or dietitian.

Diet after surgery

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

- the type of surgery you had
- how much of your bowel has been removed
- whether you have a stoma (see pages 47 to 48).

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

Eating at regular times encourages your bowel to work more regularly. If you have lost your appetite, it may be easier to eat several small meals a day, rather than one or two large meals. Having plenty of high-protein foods in your diet will help your body to heal after surgery, for example:

- fish
- meat
- eggs
- dairy products.

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

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

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

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

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

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

Our booklets **Healthy eating and cancer** and **The building-up diet** have more information that you might find useful (see page 132).

Coping with bowel changes

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

Diarrhoea

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

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

It is important to drink at least 1 to 2 litres of fluid a day (1¾ to 3½ pints), especially if you have loose stools or diarrhoea or constipation. Fluids can include:

- water
- milk
- juice
- hot drinks.

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

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

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

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

Wind

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

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

Constipation

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

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

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

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

We have information in our booklet **Eating problems and cancer**. It explains common eating difficulties and offers practical tips for managing them (see page 132).

Protect 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 back passage clean and dry. Whenever possible, wash the area after a bowel movement.
- Use unperfumed wet wipes, as they are softer on your skin than toilet paper. Pat the area gently when drying.
- You may find wiping with damp cotton wool softer on your skin.
- Use absorbent pads and barrier creams (such as Cavilon®, Sudocrem® or Bepanthen) to help protect your skin. A colorectal or continence nurse can tell you the best pads and cream to use.
- Wear cotton underwear, which 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 and is also good for your general health. Your cancer doctor or specialist nurse can tell you about any relaxation classes in your area. 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 two 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 if 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, three 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.

Carrying a Just Can’t Wait card 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 get a card from the Bladder and Bowel Community (see page 136).

You can use disabled toilets too. These often offer more privacy, have a wash basin and more space if you need to change.

The National Key Scheme offers people with a disability access to about 9,000 locked public toilets across the UK. You can buy a key from Disability Rights UK. They 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 one by phoning our support line on **0808 808 00 00** or ordering one at **be.macmillan.org.uk**

Carry a bag with supplies

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

You may want to include:

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

If you have a stoma

Having a stoma is a big change to your body, whether it is temporary or permanent. It can take time to get used to the change.

In most hospitals, there are stoma care nurses who you will usually meet before your operation. You may also find it helpful to talk to someone who is used to 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 the Ileostomy and Internal Pouch Association (see pages 136 to 137).

You will usually see a stoma care nurse on the first 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 and it can take several weeks before it settles down. The stoma care nurse will help you cope with any problems. You may want to have a family member or friend with you when you are shown how to care for your stoma. This means they will know how to help you at home, if needed.

Learning to look after a stoma takes time and patience. No one expects you to be able to cope straight away. It 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, you will wear a stoma bag that opens at the bottom, so you can empty it. An ileostomy produces semi-liquid waste continuously, so you will need to empty the bag several times a day. If the bag needs emptying very often, your doctor can prescribe you anti-diarrhoea medicines to help.

A colostomy may be active 2 or 3 times a day, but this will vary from person to person. It will also be affected by what you eat. It will usually settle into a pattern after a few weeks, so you can predict when it is likely to be active. You will usually need to change your stoma bag 1 to 3 times a day.

Some people with a colostomy are taught how to flush out (irrigate) their colostomy once a day. This helps them to control when it is active. If you want to try this, talk to your stoma care nurse.

Before you change or empty your bag, make sure that you have plenty of bags and cleaning materials with you. It is a good idea to keep everything you need in one place, so that you do not have to search for things at the last minute. Give yourself plenty of time, so you can work at your own pace without any interruptions.

Stoma supplies

There are different types of ileostomy and colostomy bags and supplies. Your stoma care nurse will give you supplies to take home with you. When you have used these, you will need to order supplies from your pharmacy or a specialist supply company. Your stoma care nurse will help you choose what is suitable for you.

You will need a prescription from your GP to get stoma supplies. In England, prescriptions are free for people with cancer. However, 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 and Northern Ireland.

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

Having a stoma is a big change in your life. It can also affect relationships, as you may feel uncomfortable about your bodies or about a partner seeing your stoma. These feelings are a natural part of coping with having a stoma, and usually gradually get better over time.

Our booklet **Body image and cancer** has more information that you might find helpful (see page 132).

Support videos

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

- Visit **macmillan.org.uk/videos** to watch a stoma nurse talking about looking after a stoma and showing 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.

Stoma reversal

If you have a temporary stoma, you can usually have an operation to reverse the stoma when your treatment finishes. This is when the piece of bowel from your stoma is re-joined with either your colon or small bowel, and the stoma opening is closed. This means you will pass stools (poo) from your bottom again.

How the stoma reversal is done depends on the type of stoma you have. When you have a stoma reversal operation is different for each person. It can be from a few months after the stoma was made, to 1 or 2 years later. Your surgeon and stoma nurse can tell you more about having a stoma reversal and when it might be best to have it done.

After a stoma reversal, it may take some time for your bowel function to get back to normal. We have information about coping with bowel changes in our **Managing the late effects of bowel cancer treatment** booklet (see page 132). You can also learn more about stoma reversal from Colostomy UK (see page 136).

> **The colostomy bag doesn’t affect my body confidence anymore, it did at first as obviously, it’s a very new and alien thing. But once I’d accepted my new self I felt just as confident as before.**
>
> **Joanna, diagnosed with rectal cancer**

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. It destroys cancer cells in the area where treatment is given, while doing as little harm as possible to normal cells. It is often given in combination with chemotherapy. This is called chemoradiation (see page 97). 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, including children, throughout your treatment.

Our booklet **Understanding radiotherapy** has more information that you might find helpful (see page 132).

How radiotherapy is given

Radiotherapy can be given externally or internally.

External beam radiotherapy

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

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

Internal radiotherapy

Internal radiotherapy uses a radioactive material that is put inside the body to treat cancer.

High-dose-rate (HDR) brachytherapy is a newer treatment. We do not know all the possible risks and benefits yet. Before you decide to have this treatment, your doctor will explain what it involves. They will talk with you about possible benefits and risks. They may also give you written information to help you make your decision.

HDR brachytherapy uses radioactive material (the source) that is placed close to or inside the tumour. The source is left in place to give the correct dose of treatment. As with external radiotherapy, the source uses high-energy rays to treat the cancer.

Before the treatment, the rectum needs to be emptied. Your nurse will give you a liquid into your back passage. This is called an enema. This liquid helps you to empty your bowel. Brachytherapy is usually given under a general anaesthetic and the treatment takes about an hour.

Some people with early-stage rectal cancers may be treated with a type of brachytherapy called Papillon treatment. This can be given as an outpatient and you do not need a general anaesthetic. It may be given on its own or with external radiotherapy. It is only available in a few hospitals, so you may need to travel to have it. If you want to find out if this is an option for you, ask your cancer doctor. You can read more about it at **contactpapillon.com**

We have more information about internal radiotherapy on our website. Visit **macmillan.org.uk**

When radiotherapy is given

Radiotherapy may be used instead of surgery if you are unable to have surgery. Your doctor will talk to you about the benefits and risks of surgery and radiotherapy.

Radiotherapy before surgery

Radiotherapy is sometimes given before surgery. This aims to:

- shrink the cancer, so that it is easier to remove with surgery (see pages 44 to 75)
- reduce the risk of the cancer coming back.

You may have a short course of radiotherapy. It is given once a day, Monday to Friday, the week before surgery.

Or you might have a long course of radiotherapy that lasts up to 6 weeks. To help make the radiotherapy more effective, it is usually given with chemotherapy (chemoradiation) – see page 97.

After a long course of radiotherapy, you wait for at least 6 weeks before having surgery. During this time, the radiotherapy or chemoradiation will continue to work, shrinking the cancer.

Radiotherapy after surgery

If radiotherapy was not given before surgery, you may have it afterwards. This is if cancer cells are found on the edge of healthy tissue (margin). You may have radiotherapy with chemotherapy (chemoradiation) – see page 97.

External radiotherapy is usually given Monday to Friday, for 4 to 5 weeks.

Radiotherapy for advanced cancer

External radiotherapy may be used to treat rectal cancer that has spread or come back after treatment. It is most likely to be used to treat cancer in the pelvis (the area between the hip bones). The aim is to shrink the cancer and help with symptoms such as bleeding or pain.

You can usually only have radiotherapy for advanced cancer if you have not had it to treat cancer in the same area before.

Planning your radiotherapy treatment

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

Your radiotherapy team use information from this scan to plan:

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

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They help the radiographer make sure you are in the correct position for each session of radiotherapy. These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you will be alone in the room, but you can talk to the radiographer who will watch you from the next room. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

Side effects of radiotherapy

Side effects depend on:

- the dose of radiotherapy
- whether it is external or internal
- whether you have chemotherapy as well (chemoradiation).

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 give up or cut down. Drink at least 2 to 3 litres of fluid a day. Try to avoid drinks with caffeine and alcohol as these can make bowel and bladder symptoms worse.

It is important to tell your radiographer, cancer doctor or specialist nurse if you have side effects. They can give you advice on how to manage them and prescribe treatments that can help. It may take some time to recover, particularly after longer courses of radiotherapy or chemoradiation. Look after yourself by getting enough rest and slowly increasing how much physical activity you do. This will help with your recovery.

Sometimes side effects do not completely go away. 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 many things that can be done to help.

We have more information about side effects during pelvic radiotherapy treatment in our booklets **Pelvic radiotherapy in women – managing side effects during treatment**, and **Pelvic radiotherapy in men – managing side effects during treatment** (see page 132).

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 even more tired.

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

Skin reactions

The skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice about looking after your skin. If your skin becomes sore or itchy or changes colour, tell them straight away. They can give you advice and treatments if needed. Skin reactions should get better within 4 weeks of treatment finishing.

During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with mild, unperfumed soap and water and gently pat it dry
- avoid rubbing your skin
- avoid wet shaving
- avoid hair-removing creams or products, including wax
- follow your radiotherapy team's advice about using moisturisers
- protect the treated area from the sun.

Bowel changes

You may experience problems with your bowel such as:

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

If you have diarrhoea, your doctor will prescribe anti-diarrhoea tablets to help (see pages 67 to 68).

If you have tummy cramps or constipation, tell your cancer doctor or specialist nurse. They can prescribe things to help.

Tell your specialist nurse or radiographer if you have any incontinence. They will give you advice on coping with this. They will also explain how to look after the skin in that area.

You may be advised to make changes to your diet during radiotherapy. Bowel side effects usually start to improve about 2 weeks after radiotherapy finishes. Sometimes they take a few months to get better.

Bladder changes

Radiotherapy can irritate the bladder. You may feel like you need to pass urine (pee) more often. You may also have a burning feeling when you pass urine.

Always tell your radiotherapy team if you have any side effects during, or after your course of treatment. There are drugs that can improve bladder side effects and help you feel more comfortable.

Try drinking at least 2 to 3 litres (3½ to 5½ pints) of fluids a day. Try to drink more water and less drinks that may irritate the bladder. These include drinks containing caffeine, such as tea, coffee, drinking chocolate and cola. You should also try to drink less alcohol, fizzy drinks, acidic drinks (orange and grapefruit juice) and drinks with artificial sweeteners (diet or light drinks).

Hair loss

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

Additional side effects in women

Changes to the vagina

Radiotherapy can make the lining of the vagina sore and inflamed. You may be advised not to have sex during treatment and for a few weeks after. This is to allow any inflammation or side effects to settle. Ask your doctor or nurse for advice.

It is important that you do not get pregnant during your treatment. This is because radiotherapy can harm the developing baby. You should use contraception to prevent a pregnancy during your treatment and for a time after.

After radiotherapy, the vagina may be narrower, less stretchy and drier than before. These changes can be uncomfortable, and may make having sex painful. They may also make it difficult if you need to have internal examinations in the future. Your nurse may recommend you use vaginal dilators to try to prevent the vagina from narrowing. Dilators are tampon-shaped, plastic tubes of different sizes that you use with a lubricant.

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

Early menopause

If you are still having periods, radiotherapy to the pelvic area may cause the menopause. The menopause means your ovaries no longer produce eggs. This means you will not be able to get pregnant. Your team will give you more information about this.

Hormone replacement therapy (HRT) replaces the hormones your ovaries can no longer produce. This can improve symptoms of the menopause.

Effects on fertility

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 carry a pregnancy after treatment. Your team will give you information about this.

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

Additional side effects in men

Sex

It is important that you do not make someone pregnant during radiotherapy, and for a few months after it has finished. Sperm produced during treatment and for some time after may be damaged. This can affect the developing baby if a pregnancy is started at this time. To prevent a pregnancy, your doctors may recommend that you use contraception during treatment and for a time after.

Radiotherapy for rectal cancer can cause problems getting or keeping an erection. This is called erectile dysfunction or ED. You may find your erections are not as strong as they were before the treatment. You may get an erection, but then lose it. Or you may be unable to get an erection at all. Your radiotherapy team can explain what is likely to happen.

You may have a sharp pain when you ejaculate. This is because radiotherapy can irritate the tube that runs through the penis from the bladder (the urethra). The pain should get better a few weeks after treatment finishes.

Effects on fertility

Radiotherapy may make you unable to make someone pregnant (infertile). Your doctor or nurse can talk to you about this.

For some men, it may be possible to have sperm stored before the treatment starts. This is called sperm banking. The sperm can then be used in the future. It is important to talk to your cancer doctor or specialist nurse before your treatment starts.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. These drugs disrupt the way cancer cells grow and divide, but they also affect normal cells. It is often given in combination with radiotherapy. This is called chemoradiation (see page 97).

Chemotherapy may be given:

- after surgery, to reduce the risk of cancer coming back
- before surgery, to shrink the cancer and reduce the risk of it 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 commonly used to treat bowel cancer are:

- fluorouracil (5FU) often given with folinic acid (leucovorin)
- capecitabine (Xeloda®)
- oxaliplatin (Eloxatin®)
- Irinotecan (Campto®)
- trifluridine and tipiracil (Lonsurf®).

Often, two or more chemotherapy drugs are given in combination. The three most commonly used combinations are:

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

How chemotherapy is given

You usually have chemotherapy as an outpatient. It can be given into a vein or taken by mouth as a tablet. Chemotherapy given into a vein (intravenous) goes directly into your blood and is carried to all areas of your body.

It can be given through:

- a cannula – a short, thin tube put into a vein in your arm or the back of your hand
- a central line – a long, thin tube inserted into a vein in your chest
- a PICC (peripherally inserted central venous catheter) put into a vein in the arm and threaded through to a vein in the chest
- an implantable port (portacath) put into a vein, with an opening (port) under the skin on your chest or arm.

When your cannula, line or port is in place, the chemotherapy drugs can be given into it. This is normally done by injection, as a drip or through a pump.

Intravenous chemotherapy is usually given as a session of treatment over several hours or days. This is followed by a rest period of a few weeks. This lets your body to 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

Chemotherapy drugs may cause side effects, but these can usually be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that is planned for you. The main side effects are described here as well as some ways to reduce or control them.

Risk of infection

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

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

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

Symptoms of an infection include:

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

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

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

Bruising and bleeding

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

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

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

Anaemia (reduced number of red blood cells)

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

Diarrhoea

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

If you have a stoma, your stoma care nurse can also give you advice and support.

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

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

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

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

Feeling sick

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

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

Sore mouth

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

If your mouth is sore:

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

Feeling tired

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

Laryngeal spasm

Rarely, oxaliplatin can affect the area around the voicebox (larynx). This can make you feel as though it is difficult to swallow and breathe. This might happen during treatment, or in the first few days after treatment. This side effect can be very frightening, but it should only last for a short time. If you have breathing difficulties take long, deep breaths through your nose. This will help you to keep calm and help your breathing return to normal.

This symptom may be worse in cold temperatures. Try to avoid cold drinks and ice cubes during treatment and for a few days afterwards. It might also help to wear warm clothing 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 you your infusion over a longer period of time (for example over 4 to 6 hours) in future cycles. This will reduce the chance of a laryngeal spasm happening again.

Numb or tingling hands or feet

Oxaliplatin can cause numb or tingling hands or feet. This side effect is called peripheral neuropathy. You may notice that you have difficulty doing up buttons or similar fiddly tasks. This is because the drug can affect nerve endings.

This symptom may be worse in cold temperatures. If you notice that it is caused by the cold, avoid cold drinks and wear warm clothing in cold weather. You could wear gloves, socks, and a scarf to cover your nose and mouth. Use gloves when you are taking things out of the freezer or refrigerator.

It is important to tell your doctor about any tingling or numbness. They may lower the dose of the drug to help. Sometimes this side effect may not happen with the first treatment, but after several treatments. This is called a cumulative effect. It may continue for several months, but should improve slowly after the treatment finishes. Sometimes it is permanent.

Hair loss

Many of the chemotherapy drugs for colon and rectal cancer do not cause hair loss. But if you have the chemotherapy drug irinotecan (Campto®), you may have the following side effects:

- your hair may get thinner
- you may lose all the hair from your head.
- you may lose your eyelashes, eyebrows or other body hair.

Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and your hair will usually grow back after treatment ends. We have more information in our booklet **Coping with hair loss** (see page 132).

Sore hands and feet

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

Effects on memory and concentration

Sometimes chemotherapy can affect your memory, concentration and ability to think clearly. Your doctor may call these problems cancer-related cognitive changes (CRCC), or chemo brain. Chemo brain does not affect everyone and is usually mild. If you are worried about this, talk to your doctor or nurse.

Effects on the heart

Fluorouracil (5FU) and capecitabine (Xeloda®) can affect the way the heart works. If you are having one of these drugs, you may have tests to see how well your heart is working. You may have these before, during and sometimes after treatment.

Tell your doctor straight away if you:

- have pain or tightness in your chest
- feel breathless
- notice changes to your heartbeat at any time.

These symptoms can be caused by other conditions, but it is important to get them checked.

Effects on sex life

Having chemotherapy can sometimes affect your sex life (see pages 110 to 111). Side effects like tiredness, feeling sick or weak can reduce your sex drive and make having sex difficult.

If you have a partner, it is important to try to tell them how you feel. It can also help to talk with your doctor or specialist nurse about any concerns about your sex life. They can often reassure you and support you with any problems. We have more information on effects on your sex life for men and women in our **Cancer and your sex life** booklet (see page 132).

Contraception

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

Fertility

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

Chemoradiation

Chemoradiation is when chemotherapy and radiotherapy are given at the same time. It is sometimes called chemoradiotherapy.

Chemoradiation may be given:

- 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.

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.

The chemotherapy drug most commonly used to treat rectal cancer is capecitabine. You take capecitabine as tablets. You start the tablets on the first morning of your radiotherapy. You take them every day throughout the course of your radiotherapy. Your nurse will tell you when and how you should take these.

Having both treatments 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.

> **The start of treatment was chemo and radio combined. Things were not too bad actually. The only thing I struggled with was the intense tiredness, and I had a couple of times where I felt sick, but nothing particularly extreme.**
>
> **John, diagnosed with rectal cancer**

Bowel cancer that has spread to other parts of the body

Bowel cancer can spread to other parts of the body such as the liver or lungs. This is called secondary bowel cancer. If the cancer cannot be removed with surgery, the main treatment is usually chemotherapy (see pages 88 to 96). This may be given with a targeted therapy (see below).

Other treatments, such as radiofrequency ablation and radiotherapy, may also be used to treat secondary bowel cancer. They may relieve symptoms and help to control the cancer for some time. If you have secondary bowel cancer, your doctor will talk to you about what treatments may be the most helpful.

Targeted therapies

Targeted therapy drugs target something in or around a cancer cell that is helping it grow and survive. Targeted therapies are sometimes used to treat bowel cancers (colon or rectal) that have spread to other parts of the body. They may be given on their own or with chemotherapy.

Your doctor will tell you if they think a targeted therapy will be helpful in your situation. These drugs are not always available through the NHS. If a drug is not available on the NHS, there may be different ways you can still have it. Your doctor can give you advice. They may be able to apply for funding to get the treatment on the NHS. We have more information about targeted therapy drugs, the Cancer Drugs Fund and what you can do if a treatment is not available. Visit **england.nhs.uk/cancer/cdf**

Cetuximab and panitumumab

Cetuximab and panitumumab are both a type of targeted therapy drug called monoclonal antibodies. They are also called cancer growth inhibitors.

Some cancers have receptors on their surface called epidermal growth factor receptors (EGFRs). A protein called epidermal growth factor activates the receptors, causing the cancer cells to grow. Cetuximab and panitumumab lock onto the EGFRs and block signals that tell the cancer cells to grow and divide.

Before cetuximab or panitumumab are used, doctors test the cancer cells for cell changes (mutations) in the RAS and BRAF gene. This helps your doctor decide if cetuximab or panitumumab is appropriate for you.

Not all bowel cancers respond to cetuximab and panitumumab. They only work on bowel cancers that have a normal RAS gene and no changes to the BRAF gene (see page 33).

Cetuximab and panitumumab are given into a vein as an infusion (intravenously). You often have them with chemotherapy.

Other targeted therapy drugs

Other targeted therapy drugs that may be used include:

- bevacizumab (Avastin®)
- aflibercept (Zaltrap®)
- ramucirumab (Cyramza®)
- regorafenib (Stivarga®).

These are all a type of targeted therapy called angiogenesis inhibitors.

These block the chemical signals that cells use to make blood vessels grow. This makes it difficult for a tumour to develop the network of blood vessels it needs to get a blood supply. Without a good blood supply, the tumour does not get the oxygen and nutrients it needs. This may slow the tumour's growth, or sometimes cause it to shrink.

Bevacizumab, aflibercept and ramucirumab are given into a vein as an infusion (intravenously). Regorafenib is taken as tablets.

Side effects

Some targeted therapies can cause an allergic reaction. This may happen when the drug is being given or shortly after. Signs of an allergic reaction can include:

- flu symptoms
- a sudden drop in blood pressure
- feeling sick.

An allergic reaction is most common with the first two of doses of the drug, but can happen later. To reduce this risk, you will have the first dose over a few hours. Your nurse will closely monitor you during the infusion.

Your doctor or nurse should tell you about possible side effects before you start treatment. They will also tell you who you should contact if you develop any.

The most common side effect of cetuximab and panitumumab is a skin rash. Other possible effects include diarrhoea, hair changes and sore eyes.

The most common side effect of bevacizumab, aflibercept, ramucirumab and regorafenib is high blood pressure. There is also a small risk they may cause a hole (perforation) in the bowel. If you have any side effects during treatment, you should always tell your cancer doctor or specialist nurse.

Immunotherapy

Immunotherapy drugs encourage the immune system to recognise and help destroy cancer cells. Immunotherapy drugs for bowel cancer are not regularly used by, or available on, the NHS. They are only available as part of a clinical trial. Talk to your cancer doctor or specialist nurse for more information about immunotherapy.

Your cancer doctor may consider immunotherapy if both of these things apply:

- the cancer has spread to other parts of the body
- the cancer shows changes (mutations) to DNA called microsatellite instability (MSI) – see page 32.

Your cancer doctor will talk with you if immunotherapy may be an option for you.

Radiofrequency ablation (RFA)

RFA uses heat to destroy cancer cells. An electrode (like a needle) sends an electric current (radiofrequency) to the tumour. The electric current heats the cancer cells to high temperatures and destroys (ablates) them. As the cancer cells die, the area that has been treated gradually shrinks and becomes scar tissue.

RFA does not always destroy all the cancer cells. Some people may need to be treated more than once. RFA can be repeated if the tumour starts to grow again.

The most common way to give RFA involves a doctor placing one or more electrodes through the skin into the tumour. A CT scanner shows the position of the liver and tumours on a screen. This guides the doctor as they put each electrode into place.

Stereotactic radiotherapy

Stereotactic radiotherapy uses many small beams of radiation to target the tumour. This makes it very precise. It means high doses of radiotherapy can be given to very small areas of the body. It is also called stereotactic ablative radiotherapy (SABR).

Stereotactic radiotherapy is given using a specially adapted radiotherapy machine. The machine delivers beams of radiotherapy from many different angles, which meet at the tumour. This means the tumour gets a very high dose of radiotherapy, but surrounding healthy tissues get a very low dose. This treatment is only available in some hospitals in the UK. Your doctor can give you more information.

Selective internal radiotherapy (SIRT)

SIRT is used to treat cancer in the liver. A doctor injects tiny radioactive beads into the bloodstream. They stick permanently in small blood vessels in and around the liver tumour. The beads give off radiation, which damages the cancer cells. They also block the blood vessels to the tumour. This stops the blood supply to the tumour so it does not get the oxygen and nutrients it needs.

The radioactivity of each bead can only affect tissue that is very close by, so other parts of the liver are not affected. SIRT does not make you radioactive.

SIRT is only suitable for some secondary liver cancers. Your doctor or specialist nurse can talk to you about whether it is suitable for you. Our booklet **Understanding secondary cancer in the liver** has more information you might find useful (see page 132). We also have more information about radiofrequency ablation, SABR and SIRT at **macmillan.org.uk**

Clinical trials

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

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

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

Taking part in a trial

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

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

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

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

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

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** – see page 132.

Giving blood and tumour samples

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

Your samples can only be stored for research if you give your consent (see pages 42 to 46). Your cancer doctor can answer any questions you have.

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

The samples may be used to:

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

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

AFTER TREATMENT

Follow-up

After your treatment has finished, you will have regular check-ups, which usually continue for several years. You may also have scans or x-rays, and sometimes colonoscopies. If you have any problems or notice any new symptoms between check-ups, tell your GP, cancer doctor or nurse as soon as possible.

Many people feel anxious before their appointments. This is natural. It may help to get support from family, friends or organisations which offer support (see pages 136 to 142).

Well-being and recovery

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

Be physically active

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

We have more information about being physically active in our **Physical activity and cancer** booklet (see page 132). You can also watch videos about the benefits of physical activity, including stories from people with cancer. Visit **macmillan.org.uk**

Try to reduce stress in your life

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

- going for a walk
- spending time with family or friends
- listening to music or watching a film
- trying activities such as yoga, or using relaxation techniques to control breathing
- being more physically active and looking after your well-being
- talking to someone about how you feel (see pages 114 to 118).

Sex life after rectal cancer

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 (see page 86). Medicines such as sildenafil (Viagra®) can help you get an erection. If you are having erection difficulties, talk to your doctor as soon as possible. The sooner you start treatment, the more effective it is.

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

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

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

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

There are organisations that can give you support (see page 142). It may also help to share your experience with other people through Macmillan's Online Community (see page 134). We also have information in our booklet **Cancer and your sex life** (see page 132).

Fertility

Treatments for rectal cancer can affect your ability to start a pregnancy (fertility) – see page 111. This can be difficult to cope with, even if you have a family or did not plan to have children. It is important to tell your healthcare team any concerns you have about your fertility before treatment starts. They can tell you what options might be available if you would like to have a child in the future.

We have more information about cancer treatment and fertility for men and women in our booklets **Cancer and fertility – information for men** and **Cancer and fertility – information for women** (see page 132).

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

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

Shock and denial

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

Fear and anxiety

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

It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

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

Avoidance

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

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

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

Anger

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

Guilt and blame

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

Feeling alone

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

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

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

If you need more help

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

Talk to your doctor or nurse if:

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

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

We have more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 132).

> **‘I had always been the sporty guy in my group of friends, then suddenly I was the sick one. I hated the change in my identity.’**
>
> **Michael, diagnosed with rectal cancer**

Relationships

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

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

If you have a partner

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

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

Family and friends

You may feel that your family and friends are not always understanding if you do not feel positive. You may feel they do not realise how much treatment affects your life. Talking openly about how you feel will help them to understand and give you the support you need.

Our booklet, **Talking about cancer**, has more information that you might find helpful (see page 132).

If you are a family member or friend

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

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

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

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

We have more information in our booklet **Talking with someone who has cancer** (see page 132).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 132).

Talking to children about cancer

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

Talking to children about the cancer can:

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

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

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

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

Teenagers

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

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

Our booklet **Talking to children and teenagers when an adult has cancer** has more information (see page 132).

FINANCIAL SUPPORT AND WORK

Financial help and benefits

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

Statutory Sick Pay

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

Benefits

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

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

Employment and Support Allowance (ESA)

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

Universal Credit

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

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

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

Personal Independence Payment

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

Attendance Allowance

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

Special rules

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

Help for carers

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

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

Macmillan Grants

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

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

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

Insurance

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

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

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 132). Our Online Community forum on travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on 0**808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 140).

Our booklet **Help with the cost of cancer** has lots more information (see page 132).

Work

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

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 132). There is also lots more information at **macmillan.org.uk/work**

Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 132).

> **‘I felt it was important for me to keep myself busy and continue as normally as possible for as long as I could. My employers were flexible with allowing me to work from home which was really helpful.’**
>
> **Gentian, diagnosed with rectal cancer**

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

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

Work support

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

Other useful organisations

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

Bowel cancer support organisations

Bladder and Bowel Community

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

Bowel Cancer UK

www.bowelcanceruk.org.uk
Gives information and support to people affected by bowel cancer.

England and Wales

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

Scotland

Tel **0131 285 3846**
Email **scotadmin@bowelcanceruk.org.uk**

Northern Ireland

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

Colostomy UK

Helpline **0800 328 4257**
Email **info@colostomyuk.org**
www.colostomyuk.org

Supports people who have had, or are about to have, a colostomy. Provides information and advice on bladder and bowel symptoms.

IA – The Ileostomy and Internal Pouch Association

Tel **0800 018 4724**
Email **info@iasupport.org**
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 radiotherapy

www.contactpapillon.com
A website dedicated to Papillon radiotherapy. It is run by people with cancer and carers. It gives information about what Papillon radiotherapy is and has a forum where you can share your feelings, questions or tips with others.

General cancer support organisations

Cancer Black Care

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

Maggie’s Centres

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

Riprap

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

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (Mon to Fri, 8am to 10pm,
and Sat and Sun, 9am to 5pm)
www.nhsinform.scot
NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **01455 883 300**
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at itsgoodtotalk.org.uk

Emotional and mental health support

Samaritans

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

Financial support or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

British Red Cross

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

Citizens Advice

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

England

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

Wales

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

Scotland

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

Disability and Carers Service

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

GOV.UK

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

Jobs and Benefits Office Enquiry Line Northern Ireland

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

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
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** (Mon to Fri, 10am to 10pm,
and Sat, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers UK

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

Cancer registries

The cancer registry

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

National Cancer Registration and Analysis Service

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

Scottish Cancer Registry

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

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland Cancer Registry

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

Your notes and questions

Disclaimer

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

Thanks

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

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

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

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

Sources

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

R Glynne-Jones, PJ Nilson, C Aschele et al. ESMO-ESSO-ESTRO Clinical practice guidelines for diagnosis, treatment and follow up for anal cancer. July 2014. European Society of Medical Oncology. Available from www.esmo.org/Guidelines/Gastrointestinal-Cancers/Anal-Cancer (accessed October 2019).

National Institute for Health and Excellence (NICE). Colorectal cancer: diagnosis and management clinical guidelines. Updated December 2014. Available from www.nice.org.uk/guidance/cg131 (accessed October 2019).

Association of Coloproctology of Great Britain & Ireland (ACPGBI). Volume 19. Issue S1. Guidelines for the management of cancer of the colon, rectum and anus. 2017. Available from www.onlinelibrary.wiley.com/toc/14631318/19/S1 (accessed October 2019).

National Institute for Health and Care Excellence. Preoperative high dose rate brachytherapy for rectal cancer. 2015. Available from www.nice.org.uk/guidance/ipg531 (accessed October 2019).

BMJ. Best practice colorectal cancer. Updated 2018. Available from www.bestpractice.bmj.com/topics/en-gb/258 (accessed October 2019).

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

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

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

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

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

MACMILLAN
CANCER SUPPORT

© Macmillan Cancer Support, April 2020. 5th edition.
MAC12475_E05. Next planned review April 2023.
Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.

Trusted
Information
Creator

Patient Information Forum