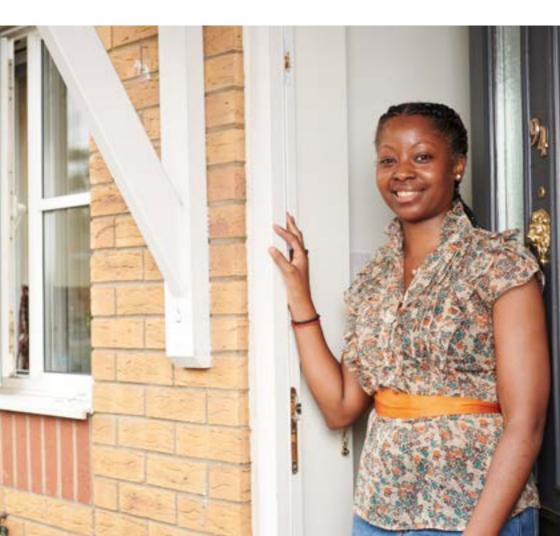


Understanding colon cancer



About this booklet

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

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

The booklet explains what colon cancer is and how it is treated. It also talks about your feelings when you are diagnosed with cancer and has practical advice on dealing with work and finances. We have more information about symptoms, tests and diagnosing colon cancer on our website. Visit <u>macmillan.org.uk/colon-cancer</u>

When we mention bowel cancer in this booklet, this includes colon cancer. We hope this booklet helps you deal with some of the questions or feelings you may have.

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

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the <u>contents list</u> to help you.

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

At the end of the booklet, there are <u>details of other organisations</u> <u>that can help</u>.

Quotes

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

For more information

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

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

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

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

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The colon and cancer

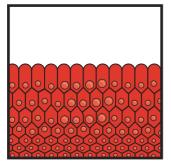
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What is cancer?

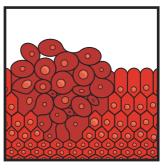
Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets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

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

Cells forming a tumour



Normal cells



Cells forming a tumour

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

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

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

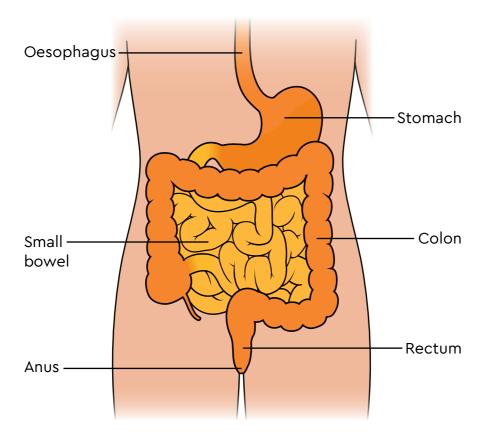
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another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

The bowel

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

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

Parts of the bowel



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

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

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

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

The colon

The colon is divided into 4 parts. Sometimes the name of the operation to remove the cancer includes the name of the part of bowel removed.

Ascending colon

The first part of the colon joins the small bowel. It goes up (ascends) the right side of your tummy (abdomen). It is called the ascending colon.

Transverse colon

The second part goes across the abdomen from your right to left side. It is called the transverse colon.

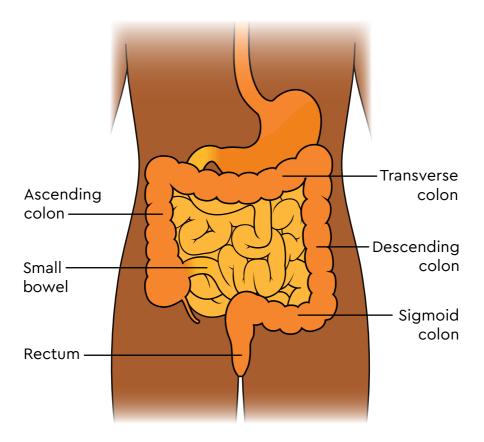
Descending colon

The third part goes down (descends) the left side of your abdomen. It is called the descending colon.

Sigmoid colon

The final part of the colon is an S-shaped bend that joins the rectum. It is called the sigmoid colon.

Parts of the colon



The lining of the colon

The lining of the colon is made up of different layers of tissue:

- The inner layer is made up of 2 layers called the mucosa (inner lining) and <u>the submucosa</u>. The mucosa is made up of cells called epithelial cells. The submucosa contains glands, blood vessels, lymph vessels and nerves.
- The middle is a thick layer of muscle.
- The outer layer is called the serosa.

Most colon cancers develop from small growths called polyps. These start in the mucosa.

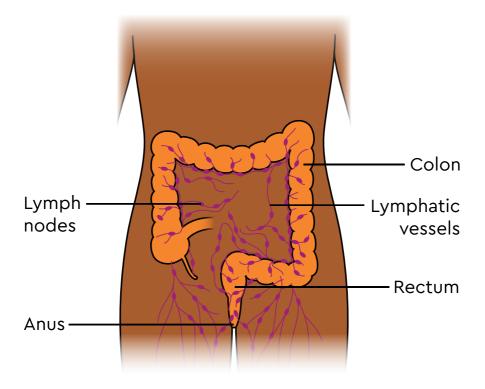
The lymphatic system

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

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

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

Lymph nodes close to the bowel



Your data and the cancer registry

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

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

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

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 131).



Planning your treatment

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Finding out you have bowel cancer

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

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

- possible causes and risk factors
- symptoms
- tests to diagnose colon cancer.

You can find this information at macmillan.org.uk/bowel-cancer

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

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

Staging 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.

 ${\bf N}$ – describes whether the cancer has spread to the lymph nodes.

 \mathbf{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).

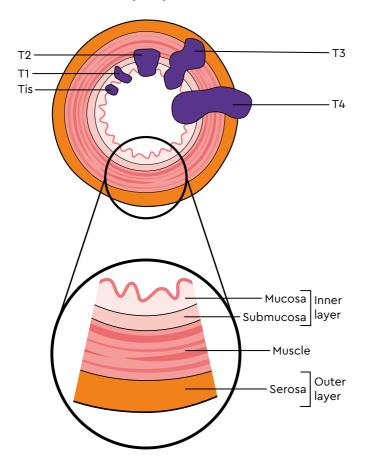
T2 means the tumour has grown into the muscle layer of the bowel wall but no further.

T3 means the tumour has grown through the muscle layer of the bowel and into the outer layer of the bowel wall (serosa).

T4 means the tumour has grown through the outer layer of the bowel wall (serosa) and into the tissue layer covering the outside of the bowel and other organs (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 nearby organs.

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



N – Nodes

NO means no lymph nodes contain cancer cells.

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

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

M – Metastases

MO means the cancer has not spread to distant organs.

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

Number staging system

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

Stage 0 – 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 1 and 2 bowel cancer are sometimes called early bowel cancer.

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 3 cancers are sometimes called locally advanced cancer.

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

Stage 4 cancer is sometimes called advanced or metastatic cancer.

Grading

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

Grade 1 (low-grade) – the cancer cells look similar to normal cells (called well differentiated). They grow slowly and are less likely to spread.

Grade 2 (moderate-grade) – the cancer cells look more abnormal. They are likely to grow faster than a low-grade cancer.

Grade 3 (high-grade) – the cancer cells look very abnormal (called poorly differentiated). They grow more quickly and are more likely to spread.



Tests on the bowel cancer cells

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

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

If you have advanced bowel cancer, you may have tests for other types of <u>gene changes in the cancer cells</u>.

Mismatch repair or microsatellite instability testing

DNA carries all your genetic information inside the cell. When a cell divides normally, the mismatch repair (MMR) system ensures new DNA is identical to the original. It does this by repairing any changes or mistakes in the DNA. If the MMR system is not working, cancers are described as MMR deficient. These cancers often show other DNA changes that can be found by testing for microsatellite instability (MSI).

Bowel cancer cells may be tested for either mismatch repair (MMR) or microsatellite instability (MSI).

This helps you and your doctor decide whether you need genetic testing. Genetic testing 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. We have more information about Lynch syndrome on our website. Visit <u>macmillan.org.uk/lynch-syndrome-ls</u>

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

RAS gene mutation

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

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

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

These are different types of RAS gene. Other RAS gene mutations that are tested for include the KRAS gene and NRAS gene. Testing for mutations can help doctors decide which treatment is more likely to work for you. These tests are usually used if you have <u>advanced</u> <u>bowel cancer</u>.

BRAF V600E gene mutation

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

Knowing whether you have the BRAF V600E gene mutation tells doctors more about how you might respond to certain treatments for advanced bowel cancer.

Checking the blood vessels and nerves

Cancer and surrounding tissues removed during surgery are checked by a doctor who specialises in cells (pathologist). They will check whether the cancer cells have spread into blood vessels or nerves within the tissues. If there are cancer cells here, there is more risk of the cancer spreading to other parts of the body. This information helps you and your doctor decide about having further treatment that aims to cure the cancer.



Treating colon cancer

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Treatment overview

Treatment for colon cancer includes:

- surgery
- chemotherapy
- targeted therapy
- immunotherapy.

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

The treatment you have depends on:

- the stage of the cancer
- the position of the cancer in the colon
- your general health
- your preferences.

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

Surgery

<u>Surgery</u> is one of the main treatments for colon cancer. It usually involves removing the part of the colon where the cancer is, and nearby lymph nodes. If the cancer has grown into tissue or organs nearby, the surgeon may remove parts of these too.

Sometimes surgery is used to <u>treat advanced colon cancer</u>. It may be used to help with symptoms. For example, you may have surgery if the cancer is causing a blockage in the bowel. Some people have surgery to remove colon cancer that has spread to another part of the body, such as the liver or lungs.

Chemotherapy

You may have chemotherapy before surgery. This is called neoadjuvant chemotherapy. Or you may have chemotherapy after surgery, to reduce the risk of the cancer coming back. This is called adjuvant chemotherapy. We have <u>more information</u> <u>on chemotherapy</u>.

Colon cancer sometimes spreads to other parts of the body such as the liver or lungs. This is called <u>secondary or advanced cancer</u>. If the cancer has spread, you may have chemotherapy to shrink the cancer and control it for as long as possible.

Some people with advanced cancer have chemotherapy to shrink the cancer before having an operation to remove it.

You may have chemotherapy to relieve symptoms if the cancer has come back after treatment.

Targeted therapy

You may have targeted therapy to control advanced bowel cancer. You may have it on its own or in combination with chemotherapy.

Immunotherapy

Some immunotherapy drugs can be used to treat advanced bowel cancer.

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

Clinical trials

Your cancer doctor may invite you to take part in a clinical trial. We have more information on clinical trials at <u>macmillan.org.uk/</u> <u>clinical-trials</u>

How your treatment is planned

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

Multidisciplinary team (MDT) meeting

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

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

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

Other healthcare professionals may include:

- a gastroenterologist a doctor who treats problems with the digestive system
- a dietitian someone who gives information and advice about food and food supplements
- a physiotherapist someone who gives advice about exercise and mobility
- an occupational therapist (OT) someone who gives information, support and aids to help people with tasks such as washing and dressing
- a psychologist someone who gives advice about managing feelings and behaviours
- a counsellor someone who is trained to listen to people's problems and help them find ways to cope.

If the cancer has spread to your liver or lungs, you may also be referred to an MDT that specialises in surgery for advanced cancer. The 2 teams will work together to plan your treatment. "When I was diagnosed it was a shock, but the cancer team were great. They explained what treatment I was going to have and gave me a lot of information about side effects. "

Denise, diagnosed with anal cancer

Talking about your treatment plan

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

Your cancer doctor should explain:

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

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

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

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

Making treatment decisions

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

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

We have more information about making treatment decisions. Visit <u>macmillan.org.uk/making-treatment-decisions</u>

Giving your permission (consent)

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

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

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

Second opinion

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

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

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

We have more information about getting a second opinion on our website. <u>Visit macmillan.org.uk/second-opinion</u>



Preparing for treatment (prehabilitation)

Your doctor and nurse might talk to you about preparing for your treatment. This is sometimes called prehabilitation. It helps you to improve your fitness, health and well-being before treatment. This can help you to recover more quickly. It might also help your treatment to work better.

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

Some hospitals have specific programmes for prehabilitation to support you. You might see <u>different health professionals</u>, such as a clinical nurse specialist, a dietitian, a physiotherapist, counsellor or psychologist.

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

What preparing for treatment might involve

Your emotional well-being

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

Changes to your diet

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

Exercises to improve fitness

You may be asked to do exercises to improve your heart health and make your muscles stronger. Being fitter may help you to cope with treatment side effects and reduce the risk of complications after surgery. You can even improve your fitness in a few weeks by doing regular exercise, such as walking. We have more information you may find useful in our booklet <u>Physical activity and cancer</u>.

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



Stopping smoking

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

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

The NHS has a lot of information and support to help you give up smoking. Look on the <u>NHS website</u> for the country where you live.

We also have information about stopping smoking. Visit <u>macmillan.org.uk/stop-smoking</u>

Alcohol

If you drink alcohol, it might help to cut down or stop before your treatment. Try to make sure you are staying within <u>the recommended</u> <u>guidelines</u>. We also have information about reducing the amount of alcohol you drink. Visit <u>macmillan.org.uk/lifestyle</u>



Surgery for colon cancer

Surgery is the most common treatment for colon cancer. The type of surgery you have will depend on:

- the size of the cancer
- where it is in the bowel
- whether it has spread.

Your doctor will discuss this with you.

Removing very small, early-stage colon cancers

Some very small, early-stage colon cancers can be removed from the bowel lining using a colonoscope. This means the surgeon does not have to make a cut in your tummy (abdomen). The operation is sometimes called a local resection.

For a local resection, you may have a general anaesthetic. Or you will be given drugs called sedatives to make you sleepy. The surgeon passes a colonoscope into your back passage (rectum) and along the bowel until they reach the cancer. They use small cutting tools to remove the cancer and some healthy tissue (margins) from the affected area.

A doctor called a pathologist examines the cancer that has been removed to find out its grade.

Your surgeon may recommend a second operation to remove more of the colon if:

- the cancer cells look very abnormal (high-grade)
- the cancer has not been completely removed.

Removing part or all of the colon

Surgery to remove part or all of the colon is called a resection or colectomy. How much of the colon is removed depends on the <u>size of the cancer and where the cancer is</u>.

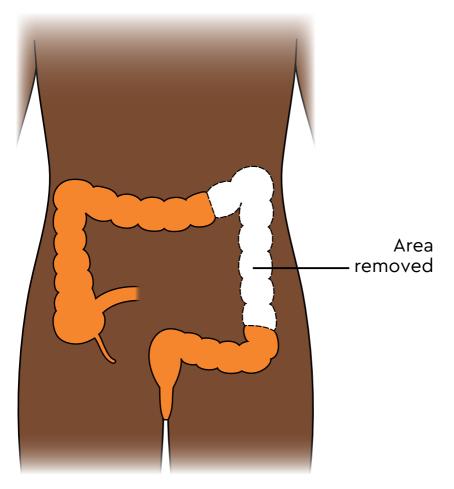
After the surgeon has removed the affected part of the colon, they join the 2 open ends of the bowel together. Sometimes they may need to <u>create a stoma</u>. The surgeon will usually remove the lymph nodes close to the colon. These are tested for cancer cells in a laboratory.

There are 3 types of colectomy:

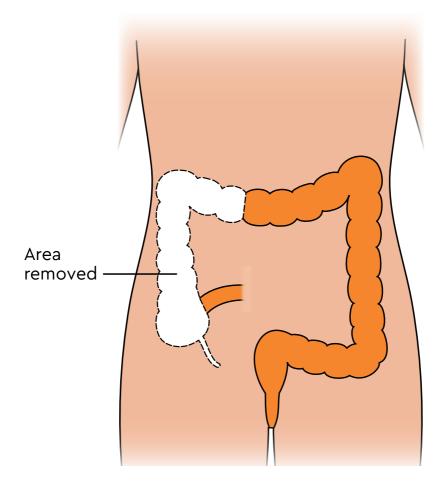
- **Total colectomy** the surgeon removes the whole colon. They bring the end of the small bowel (ileum) to the surface of the tummy to make a stoma. This is called an ileostomy. Sometimes the surgeon is able to join the small bowel to the rectum, so an ileostomy is not needed.
- Left hemi-colectomy the surgeon removes the left half of the transverse colon and the descending colon.
- **Right hemi-colectomy** the surgeon removes the right half of the transverse colon and the ascending colon.

These diagrams show the parts of the colon removed during these operations.

A left hemi-colectomy



A right hemi-colectomy



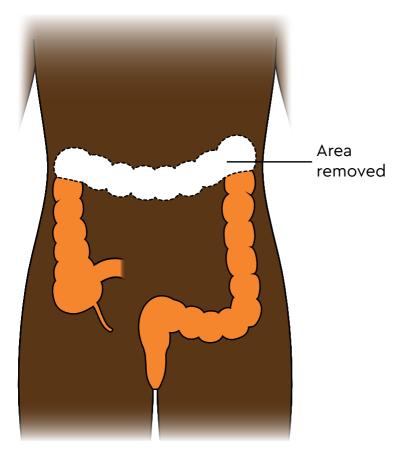
Some people have an operation to remove the sigmoid colon (the S-shaped bend that joins the colon to the rectum). This is called a sigmoid colectomy or high anterior resection. The surgeon may join the 2 open ends of bowel together. Or they may need to create a type of stoma called a colostomy.

Area removed

A sigmoid colectomy

Some people have an operation to remove the transverse colon (the top part of the colon). This is called a transverse colectomy.

A transverse colectomy





My surgeon explained in more detail about the procedure and recovery. He mentioned that keyhole surgery would be performed which would mean my recovery would be quicker than with open surgery.

Bei

Open or laparoscopic surgery

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

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

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

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

Robotic surgery

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

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

Stomas (colostomy or ileostomy)

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

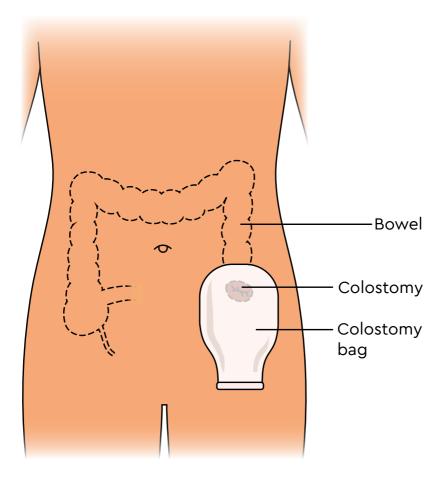
Having a stoma means stools (poo) and wind will not pass out of the rectum and anus in the usual way. Instead, they will pass out of the stoma, into a disposable bag you wear over the stoma. If the stoma is made from an opening in the colon, it is called a colostomy. If it is made from an opening in the small bowel (ileum), it is called an ileostomy.

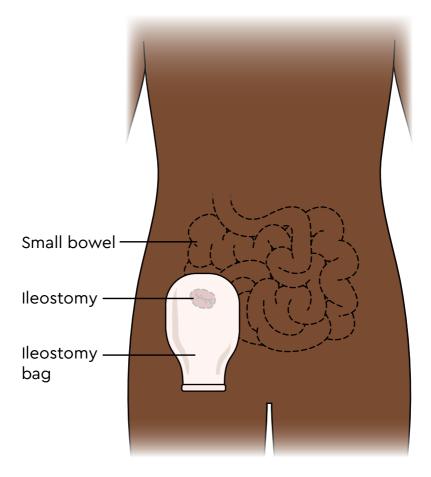
Stomas may be temporary or permanent. Only a small number of people with colon cancer need a permanent stoma.

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

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

A colostomy and colostomy bag





An ileostomy and ileostomy bag

Surgery for advanced colon cancer

If the cancer has spread to other parts of the body, you may be able to have surgery to remove it. It can sometimes lead to a cure.

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

We have more information about treatment for <u>colon cancer</u> <u>that has spread to other parts of the body</u>.

Treating a blocked bowel (bowel obstruction)

Sometimes colon cancer can cause the bowel to narrow. This stops stools from passing through. This is called a blocked bowel or bowel obstruction. It can cause symptoms such as:

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

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

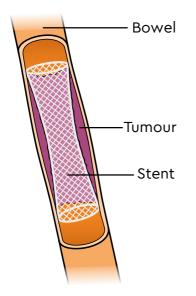
We have more information about bowel obstruction on our website. Visit <u>macmillan.org.uk/blocked-bowel</u>

Stenting

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

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

A part of the bowel with a stent inside



Surgery

Some people will have surgery to treat a bowel obstruction. A surgeon will remove the blocked section of bowel.

If the bit of blocked bowel cannot be removed, the blocked bowel can be relieved by <u>creating a stoma</u>. This means you pass stools out of the stoma.

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

Before your operation

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

We have more information about preparing for treatment on pages 38 to 40.

Preparing for your operation

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

For some types of bowel surgery, your bowel needs to be empty. A nurse may advise you about preparing for your operation. You may need to follow a special diet. You may need to take a laxative for a few days before the operation. You will also be asked not to eat or drink for a few hours before the operation. Before the operation, you will usually be given antibiotics. These are to prevent infection. You may have them as an injection or tablets.

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

During your clinic appointment, you can ask questions or share any concerns you have about the operation. If you live alone, or care for someone else, you may need help when you go home after surgery. Tell a nurse as soon as possible. They can help to make arrangements for you.

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

After your operation

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

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

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



A physiotherapist came to see me the morning after keyhole surgery, to get me up out of bed and walking. I was encouraged to walk around the ward to build my strength every day.

Bei

Pain

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

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

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

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

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

Feeling sick or being sick

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

Drips and drains

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

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

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

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

Eating and drinking

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

Wound care

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

You may be given antibiotics to help prevent wound infection. It is important to tell your nurse or doctor straight away if your wound:

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

These can be signs that the wound is infected.

Possible complications

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

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

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

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

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

Going home

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

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

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

The Ileostomy and Internal Pouch Support Association,

and <u>Colostomy UK</u>, have details of companies that provide stoma supplies. You will need a prescription from your GP to get these. In England, prescriptions are free for people with cancer. But if you are aged between 16 and 60, you will need to make sure your doctor or GP signs an FP92A form saying that you are entitled to free prescriptions.

Prescriptions are free for people living in Scotland, Wales or Northern Ireland.

Bowel function after surgery

After surgery, it may take several weeks or months before your bowel function settles into a more regular pattern. To begin with, you may notice 1 or more of the following changes:

- Some food and drinks affect your bowel movements.
- You need to pass stools (poo) more often. This might be several times a day.
- You feel that you cannot wait when you need to pass stools (urgency).
- You have <u>diarrhoea</u>.
- You feel bloated or pass a lot of wind.
- You have <u>constipation</u>.
- You have <u>a sore bottom</u>.

Tell your surgeon or specialist nurse if you are having problems, or if your bowel movements are not settling into a more 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 will probably advise you to follow a specific diet while your bowel recovers from surgery. They may give you different advice depending on:

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

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

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

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

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

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

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

Always check with your dietitian, doctor or specialist nurse if you are not sure what to do. We have more information in our booklet <u>Healthy eating and cancer</u>.

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

Coping with bowel changes

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

Diarrhoea

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

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

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

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

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

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

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

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

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

Fluids can include:

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

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

Wind

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

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

Constipation

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

Here are some tips that may help:

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

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

We have information about cancer and common eating problems in our booklet <u>Eating problems and cancer</u>.

Protecting your skin

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

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

Managing stress

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

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

Pelvic floor exercises

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

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

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

Pelvic floor exercises may help if you have problems with leakage of wind or stools from your back passage. A colorectal or continence specialist can tell you 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, 3 times a day, to rebuild strength in these muscles. As your muscles improve, try doing the exercises while doing everyday jobs.

Going out

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

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

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

The National Key Scheme offers people with a disability access to about 10,000 locked public toilets across the UK. You can buy a key from <u>Disability Rights UK</u>. It can also send you details of where the toilets are.

Macmillan also has a toilet card for people who have problems with bowel or bladder control. It should help you get urgent access to a toilet when out in public. You can get a toilet card by contacting our support line on <u>0808 808 00 00</u> or ordering one at <u>orders.macmillan.org.uk</u>

Carrying a bag with supplies

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

You may want to include:

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

There is light at the end of the tunnel. You can still do all the things you want to, you just have to plan things. If I go on a night out - I need to plan where the toilets are and the timings after the meal. It affects your daily life but you can still achieve things.

Mark, diagnosed with bowel cancer

If you have a stoma

<u>Having a stoma</u> is a big change to your body, whether it is temporary or permanent. It can take time to get used to having a stoma and managing it.

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

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

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

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

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

You may be taught how to flush out (irrigate) your colostomy once a day. This helps to control when it is active. If you want to try this, talk to your stoma care nurse. You can find more information about irrigation on the <u>Colostomy UK website</u>.

Whenever you change or empty your bag, make sure that you have everything you need before you start. It is a good idea to keep all your stoma equipment, such as bags and cleaning wipes, together. Give yourself plenty of time, so you can work at your own pace without any interruptions. "As the time went on I got more and more adjusted to living with my colostomy bag. It didn't take as long as I expected. After around 5 or 6 weeks I was good at my stoma care. "

Joanna, diagnosed with bowel cancer

Stoma supplies

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

In England, prescriptions are free for people with cancer. But if you are aged between 16 and 60, you will need to make sure your doctor signs an FP92A form saying that you are entitled to free prescriptions. Prescriptions are free for people living in Scotland, Wales or Northern Ireland.

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

Having a stoma is a big change in your life. It may affect your relationships, as you may feel uncomfortable about your body. For example, you may be worried about a partner seeing your stoma. These feelings are a natural part of coping with a stoma. Your stoma nurse will be able to tell you about any stoma management programmes that may help. We have more information about coping with changes in your body in our booklet <u>Body image and cancer</u>.

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



Diet with a stoma

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

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

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

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

Support videos

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

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

Macmillan Online Community

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

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

People can support each other and discuss things like bag recommendations, managing a stoma and foods to avoid.

Support from other organisations

<u>Colostomy UK</u> has a 24-hour free helpline. It also has Live Chat available on its website Monday to Friday, 9am to 5pm.

<u>The Ileostomy and Internal Pouch Association</u> offers one-to-one support as well as an online forum where you can chat to other people who may be in a situation similar to you.

Stoma reversal

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

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

When you have a stoma reversal operation is different for each person. Your surgeon and specialist nurse can tell you more about having a stoma reversal and when it might be best to have it done. They can advise you about what to expect, how long it may take to recover and what your bowel function may be like.

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

You can also learn more about stoma reversal from Colostomy UK.

The colostomy bag doesn't affect my confidence any more. It did at first as it was very new. But once I'd grieved for the parts of my body I'd lost and accepted my new self, I felt just as confident as before.

Joanna, diagnosed with bowel cancer

Chemotherapy

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

Your doctors may offer you chemotherapy in the following situations:

- After surgery, to reduce the risk of cancer coming back. This is called <u>adjuvant therapy</u>. It is usually given to people with stage 3 colon cancer. Some people with stage 2 colon cancer may also be offered chemotherapy.
- Before surgery for some stage 2 and some stage 3 colon cancers, to shrink the cancer and reduce the risk of it coming back.
- Before surgery, if you are having cancer removed from the liver or lungs.
- As the main treatment, if the cancer has spread to other parts of the body, such as the liver or lungs. This aims to control it for as long as possible.

The drugs most often used to treat colon cancer are:

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

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

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

We have more information about many chemotherapy drugs and combinations on our website. Visit <u>macmillan.org.uk/</u> <u>treatments-and-drugs</u>

How chemotherapy is given

You may have chemotherapy into a vein (intravenously) or as a tablet. If you have chemotherapy into a vein, it goes directly into your blood. The blood carries it to all areas of your body. If you have chemotherapy as a tablet, it is absorbed into the blood and also reaches all areas of your body.

Before you start treatment, you may have a blood test to check whether you have low levels of an enzyme called DPD. People who have low DPD levels can have more serious side effects with 2 of the chemotherapy drugs used to treat bowel cancer. These are fluorouracil (5FU) and capecitabine. If you are having chemotherapy into a vein, you have it through 1 of the following:

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

We have more information on our website about: cannulas, central lines, PICC lines and implantable ports on our website:

- cannulas <u>macmillan.org.uk/cannulas</u>
- central lines macmillan.org.uk/central-lines
- PICC lines macmillan.org.uk/picc-lines
- implantable ports macmillan.org.uk/implantable-ports

When your cannula, line or port is in place, a chemotherapy nurse will give you the drugs through it. This may be as an injection, as a drip (infusion) or through a pump. You usually have chemotherapy as an outpatient. Some people need to be in hospital for a few days to have their treatment.

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

Side effects of chemotherapy

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

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

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

We describe some of the common side effects here. We have more information about chemotherapy side effects on our webpages about chemotherapy and chemotherapy drugs. Visit <u>macmillan.org.uk/treatments-and-drugs</u>

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



Risk of infection

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

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

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

Symptoms of an infection include:

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

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

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

Bruising and bleeding

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

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

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

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

Anaemia (low number of red blood cells)

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

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

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

Diarrhoea

Some chemotherapy drugs can cause diarrhoea. Diarrhoea means passing more stools than is usual for you, or having watery or loose stools. If you <u>have a stoma</u>, it will be more active than usual.

Sometimes diarrhoea can be severe. Your hospital team may give you anti-diarrhoea drugs to take at home. It is important to follow any advice from them about taking anti-diarrhoea drugs. Contact the hospital on the 24-hour number straight away if:

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

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

Feeling sick

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

Sore mouth

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

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

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it ends. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or use machinery. We have more information in our booklet <u>Coping with fatigue (tiredness)</u>.

Throat spasm

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

This side effect can be frightening, but it should only be temporary. If you have breathing difficulties, take long, deep breaths through your nose. This will have a calming effect and help your breathing return to normal. This symptom may be worse in cold temperatures. It may help to avoid cold drinks during treatment, and for a few days afterwards. It may also help to wrap up warm and cover your nose and mouth in cold weather.

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

Numb or tingling hands or feet

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

Hair loss

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

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

We have more information in our booklet Coping with hair loss.

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

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Sore and red hands and feet

This treatment can affect the palms of your hands and the soles of your feet. This is called palmar-plantar or hand-foot syndrome.

If you have white skin, these areas may become red. If you have black or brown skin, these areas might get darker. The skin on the palms of your hands and the soles of your feet may:

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

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

Effects on the heart

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

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

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

Always call 999 if you have:

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

We have more information about heart health in our booklet <u>Heart health</u> and cancer treatment.

Effects on sex life

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

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

Contraception

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

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

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your doctor before you start treatment. We have more information about fertility in our booklet <u>Cancer and fertility</u>.

Treatment for advanced bowel cancer

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

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

- where the cancer is
- the treatment you have already had
- your general health
- the results of tests on the bowel cancer cells
- your preferences.

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

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

If the cancer affects more than 1 area of the body, you may have treatment with anti-cancer drugs. These treat cancer wherever it is in the body. Sometimes a combination of treatments is used. Different drug treatments can be used to treat advanced bowel cancer. The main treatment is <u>chemotherapy</u>. Other drug treatments for advanced bowel cancer include targeted therapy and immunotherapy. Your doctors may give you targeted therapy with chemotherapy.

The type of targeted therapy or immunotherapy drugs you may have depends on the results of <u>tests on the cancer cells</u>. For example, it may depend on whether:

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

A type of radiotherapy called stereotactic radiotherapy can sometimes be used to treat small secondary tumours. We have more information about this at <u>macmillan.org.uk/sabr</u>

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

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

You doctor may talk to you about taking part in a cancer clinical trial. We have more information about clinical trials at <u>macmillan.org.uk/</u> <u>clinical-trials</u>

We have more information about treatment for advanced bowel cancer on our website. Visit <u>macmillan.org.uk/advanced-bowel-cancer</u>



After treatment

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Follow-up

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

At your check-ups, a specialist doctor will:

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

You may have regular blood tests to check for a protein called carcinoembryonic antigen (CEA). You may also have CT scans and colonoscopies as part of your follow-up.

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

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

"At times it almost feels like it didn't actually happen to me. It seems like such a strange time when I think back to it. I am happy to have it behind me. I don't like to be a victim and I certainly don't want to be defined by my cancer. "

Jaswinder, diagnosed with colon cancer

Well-being and recovery

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

Be physically active

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

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

Stop smoking

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

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

We have more information about giving up smoking on our website. Visit <u>macmillan.org.uk/stop-smoking</u>



Drink less alcohol

NHS guidelines suggest that both men and women should:

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

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

Try to reduce stress in your life

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

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

Sex and fertility

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

If you 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 sex life. Talking about your feelings may help reduce your anxiety. If you have a partner, you may both find it takes time to adjust to any changes.

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

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

Chemotherapy might cause the menopause, which can lower your sex drive. Your doctor or nurse may prescribe hormone replacement therapy (HRT) to help with menopausal symptoms. Many people find it difficult to talk about sexual difficulties because they feel embarrassed. Your doctor or nurse will be used to talking about these issues. Let them know if you are having problems with your sex life. They may be able to give you advice or refer you to a sex therapist or counsellor. We have more information in our booklets <u>Body image and cancer</u> and <u>Sex and cancer</u>.

LGBTQ+

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

There are organisations that can give you support. It may also help to share your experience with other people through <u>Macmillan's</u> <u>Online Community</u>. Or we have more information in our booklet <u>LGBTQ+</u> <u>people and cancer</u>.

Fertility

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

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



Your feelings and relationships

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Your feelings

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

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

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

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

Talking to family, friends or other people affected by cancer may help.

For more information or for help finding local support groups, visit <u>macmillan.org.uk/supportgroups</u> Or talk to other people on our Online Community at <u>macmillan.org.uk/community</u>

We have more information about other ways we can help you.



Relationships

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

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

If you are a family member or friend

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

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

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

Talking to children and teenagers

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

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

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

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

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Work and financial support

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Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers in our booklet <u>Working while caring for someone with cancer</u>.

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

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

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

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

Our booklet <u>Help with the cost of cancer</u> has lots more information.

Macmillan Grants

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

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

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

Insurance

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

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

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



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

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

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

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

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

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

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

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

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About our information

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

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

Order what you need

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

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

Online information

All our information is also available online at <u>macmillan.org.uk/</u> <u>information-and-support</u> 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

interactive PDFs

Draille

- large print
- British Sign Language
- translations.

easy read booklets

Find out more at macmillan.org.uk/otherformats

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

The language we use

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

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

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to <u>macmillan.org.uk/talktous</u> If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call <u>0808 808 00 00</u> and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit <u>macmillan.org.uk/financialsupport</u> to find out more about how we can help you with your finances.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/financialsupport to find out more about how we can help you with your finances.

Help with energy costs

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

Macmillan Grants

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

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

Help with work and cancer

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

Work support

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Bowel cancer support organisations

Bladder and Bowel Community

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

Bowel Cancer UK

Tel <u>0207 940 1760</u> <u>www.bowelcanceruk.org.uk</u> Gives information and support to people affected by bowel cancer.

England

Email admin@bowelcanceruk.org.uk

Scotland

Email scotadmin@bowelcanceruk.org.uk

Wales

Email walesadmin@bowelcanceruk.org.uk

Northern Ireland

Email <u>niadmin@bowelcanceruk.org.uk</u>

Colostomy UK

Helpline <u>0800 328 4257</u> Email <u>hello@colostomyuk.org</u> <u>www.colostomyuk.org</u> 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 <u>0800 018 4724</u> Email <u>info@iasupport.org</u> <u>www.iasupport.org</u> Offers support to help anyone who has had, or is about to have, their colon removed and has an ileostomy or internal pouch.

General cancer support organisations

Cancer Black Care

Tel <u>0734 047 1970</u>

www.cancerblackcare.org.uk

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline <u>0800</u> 783 3339 www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Maggie's

Tel 0300 123 1801

www.maggies.org

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

Penny Brohn UK

Helpline <u>0303 3000 118</u>

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

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

Tenovus

Helpline <u>0808 808 1010</u>

www.tenovuscancercare.org.uk

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

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net

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

NHS.UK

www.nhs.uk

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

NHS 111 Wales

<u>111.wales.nhs.uk</u>

NHS health information site for Wales.

NHS Inform

Helpline <u>0800 224 488</u> <u>www.nhsinform.scot</u> NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

Emotional and mental health support

Mind

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Citizens Advice

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

England

Helpline <u>0800 144 8848</u> www.citizensadvice.org.uk

Scotland

Helpline <u>0800 028 1456</u> www.cas.org.uk

Wales

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

Disability and Carers Service

Tel <u>0800 587 0912</u>

Textphone 0800 012 1574

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

GOV.UK

www.gov.uk

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

Jobs and Benefits Office Enquiry Line Northern Ireland

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

Equipment and advice on living with a disability

British Red Cross

Tel <u>0344 871 1111</u> www.redcross.org.uk

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel <u>0330 995 0400</u> (not an advice line) www.disabilityrightsuk.org

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

www.livingmadeeasy.org.uk

Provides free, impartial advice about all types of disability equipment and mobility products.

Support for older people

Age UK

Helpline <u>0800 678 1602</u>

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

Igbt.foundation

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

OUTpatients

www.outpatients.org.uk

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

Support for carers

Carers UK

Helpline <u>0808 808 7777</u>

www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

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

Wales - Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

Your notes and questions

Disclaimer

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

Thanks

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

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

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

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

Sources

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

Bednarski BK. Surgical resection of primary colon cancer. UpToDate 2023. Available from: <u>www.uptodate.com/contents/</u> <u>surgical-resection-of-primary-colon-cancer</u> [accessed January 2023].

Cervantes A, Adam R, Rosello S et al. Metastatic colorectal cancer: ESMO Clinical Practice Guideline for diagnosis, treatment and followup. Ann Oncol. 2023 Jan; 34(1):10–32. doi: 10.1016/j.annonc.2022.10.003. Epub 2022 Oct 25.

National Institute for Health and Care Excellence (NICE). Colorectal cancer: diagnosis and management clinical guidelines. Updated December 2021. Available from: <u>www.nice.org.uk/</u> <u>guidance/NG151</u> [accessed November 2023].

Poston GJ, Tait D et al. Diagnosis and management of colorectal cancer: summary of NICE guidance. BMJ. 2011; 343 :d6751. Available from: <u>www.bmj.com/content/343/bmj.d6751</u> [accessed January 2023].

Can you do something to help?

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

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

5 ways you can help someone with cancer

1. Share your cancer experience

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

2. Campaign for change

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

3. Help someone in your community

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

4. Raise money

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

5. Give money

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

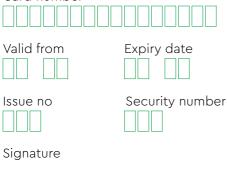
Email

Please accept my gift of £ (Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support OR debit my:

Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



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



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

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

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

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

For information, support or just someone to talk to, call <u>0808 808 00 00</u> or visit <u>macmillan.org.uk</u> Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on <u>18001</u> <u>0808 808 00 00</u>, or use the Relay UK app.

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



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I got through it by keeping things as normal as possible. Seeing friends and family, going for short walks before the tiredness hit me, cuddles in front of the TV with my husband.

Bei, diagnosed with colon cancer