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CANCER SUPPORT

A practical guide to understanding cancer

# UNDERSTANDING COLON CANCER





**'When you get symptoms, you automatically assume that it's not going to be something bad. But if it is, the sooner you sort it out, the better.'**

Thom, diagnosed with colon cancer in 2010

# About this booklet

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

When we mention bowel cancer in this booklet, this includes colon cancer.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

We have videos on our website that feature people affected by bowel cancer talking about their experiences, and health professionals explaining treatments. Visit **macmillan.org.uk/cancerinformationvideos** to watch them.

This booklet includes quotes from people who have had bowel cancer. Some are from Thom, who is on the cover of this booklet. The rest are from **healthtalk.org**, our videos and people who have shared their experiences with us. To share your experience, visit **macmillan.org.uk/shareyourstory** Some names have been changed.

On pages 115–120, we have listed some useful contact details and other organisations that can help. On page 121, there is space to write down any notes or questions you have.

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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

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

## How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

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

If you find this booklet helpful, you could give it to your family and friends. They may also want information to help them support you.

# Contents

The bowel and colon cancer	<b>5</b>
Diagnosing colon cancer	<b>17</b>
Treating colon cancer	<b>33</b>
After treatment	<b>85</b>
Your feelings and relationships	<b>91</b>
Financial and work support	<b>103</b>
Further information	<b>109</b>



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

**Ann, diagnosed with bowel cancer in 2010**



# THE BOWEL AND COLON CANCER

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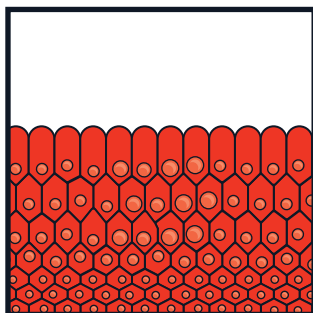
What is cancer?	6
The lymphatic system	8
The bowel	9
Risk factors and causes	11
Symptoms	15

# What is cancer?

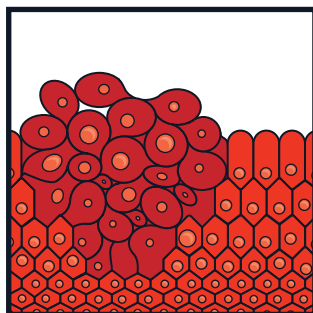
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (**tumour**). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a **biopsy**. The doctors examine the sample under a microscope to look for cancer cells.

## Normal cells



## Cells forming a tumour





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

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see next page). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a **secondary cancer** or a **metastasis**.

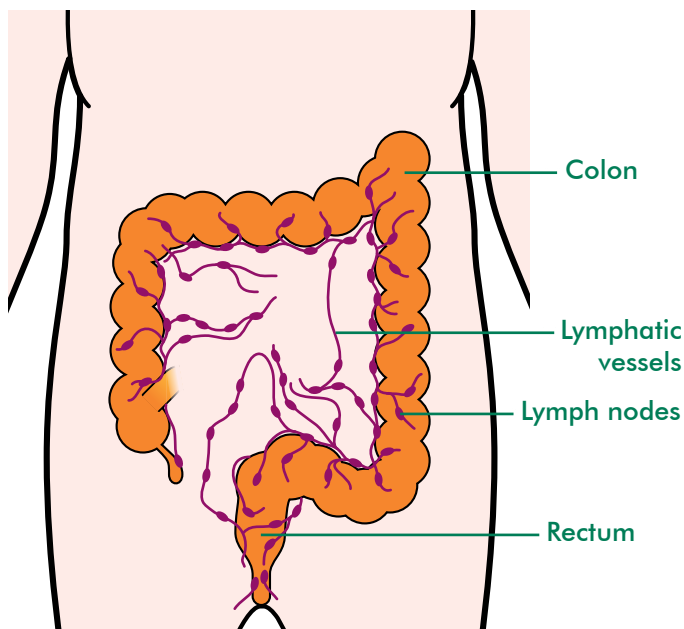
# The lymphatic system

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

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

If bowel cancer spreads, it's most likely to spread to nearby lymph nodes.

## Lymph nodes close to the bowel



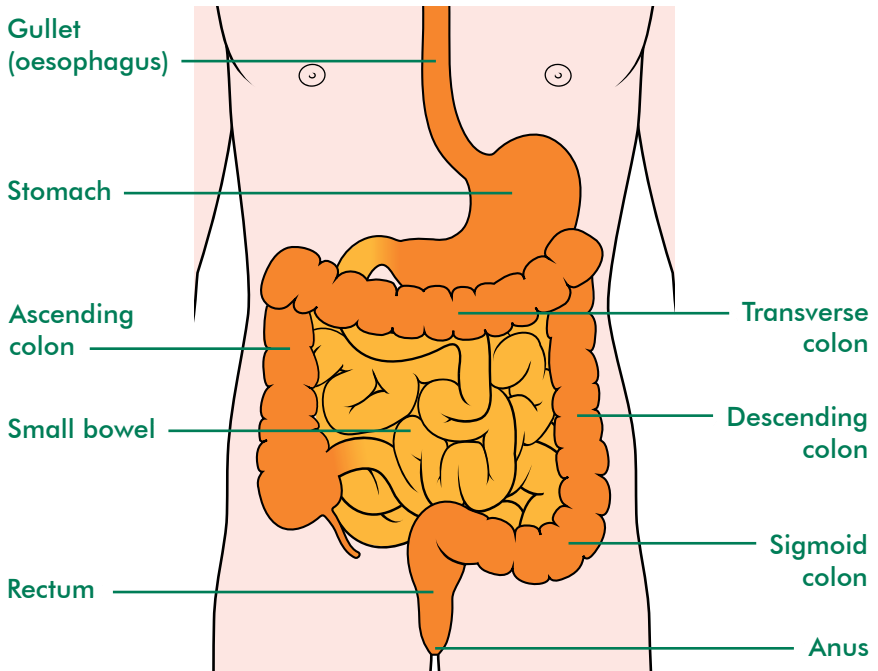
# The bowel

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

- the small bowel
- the large bowel.

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

## The bowel



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

It then enters the small bowel, where nutrients and minerals from food are absorbed. The digested food then moves into the colon, where water is absorbed. The remaining waste matter (stool or poo) is held in the rectum (back passage). It stays here until it is ready to be passed out of the body through the anus.

## The colon

The colon is divided into four sections. These are labelled on the diagram on the previous page.

### Ascending colon

The first part of the colon is joined to the small bowel and goes up the right side of the abdomen.

### Transverse colon

The second section goes across the abdomen from your right to your left side.

### Descending colon

The third section goes down the left-hand side of your abdomen.

### Sigmoid colon

The final part of the colon is an 'S' shape bend that joins on to the rectum.

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

# Risk factors and causes

In the UK, about 31,000 people develop colon cancer each year.

The exact cause of colon cancer is unknown. However, things called risk factors can increase the chance of a person developing it. Having one or more risk factors does not mean you will definitely develop colon cancer. Equally, if you do not have any risk factors, it doesn't mean you won't get colon cancer.

## Age

Like most types of cancer, colon cancer is more common in older people. In the UK, almost 6 in 10 bowel cancer cases (58%) each year are diagnosed in people aged 70 and over.

## Diet

Eating a lot of red and processed meat increases the risk of colon cancer. Red meat includes beef, lamb and pork. Processed meat includes smoked meat, ham, bacon, sausages, pâté and tinned meat. Eating fried or grilled meat may also increase the risk.

Eating two or more portions of red or processed meat a day seems to increase the risk the most. People who eat less than two portions a week have the lowest risk. No link has been found between colon cancer and eating poultry, such as chicken and turkey.

Not eating enough fruit and fresh vegetables may also increase the risk.

## Physical activity

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

## Body weight

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

## Smoking

Colon cancer is more common in people who have smoked cigarettes for many years.

## Inflammatory bowel conditions

Having an inflammatory bowel condition, such as ulcerative colitis or Crohn's disease, can increase the risk of colon cancer. People with these conditions may be offered regular bowel screening with a test called a colonoscopy (see pages 19–20).

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



## Family history

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

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

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

## Inherited (familial) conditions

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

There are two rare conditions that can run in families:

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

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

## Familial adenomatous polyposis (FAP)

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

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

People with FAP have regular screening using colonoscopies (see pages 19–20) to look for signs of cancer. It is usually recommended that people with FAP have an operation to remove their colon and sometimes their rectum. Unless the colon is removed, nearly everyone with FAP will develop bowel cancer.

## Lynch syndrome (HNPCC)

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

If you have Lynch syndrome, you will usually have regular screening using colonoscopies (see pages 19–20). Screening normally starts from the age of 25, or five years before the age at which your youngest relative developed bowel cancer. The colonoscopy is usually repeated every 18 months to two years.

If you are concerned about your family history of bowel cancer, we can send you our leaflet **Are you worried about bowel cancer?** We also have a more detailed booklet about cancer genetics, and a booklet about bowel screening. Call **0808 808 00 00** or visit **[be.macmillan.org.uk](https://be.macmillan.org.uk)** to order any of these.

**Colon cancer is not infectious and can't be passed on to other people.**

# Symptoms

The symptoms of colon cancer may include:

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

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

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

If you have symptoms that don't improve within a few weeks, or if your symptoms get worse, it is important that you are referred to a specialist. They can do tests to find out what the problem is.

**'My symptoms worsened and a visit to the doctor resulted in tests for Crohn's disease amongst other things. The possibility of cancer never crossed my mind.'**

**Thom**



# DIAGNOSING COLON CANCER

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How colon cancer is diagnosed	18
Staging and grading	27

# How colon cancer is diagnosed

If you have symptoms, you will usually begin by seeing your GP, who will examine you. If they think that your symptoms could be caused by cancer, they will refer you to a specialist doctor. You should be seen at the hospital within 14 days.

Some people are diagnosed after taking a test as part of the NHS Bowel Screening Programme. Bowel screening is a way of finding bowel cancer at an early stage before it causes symptoms. In England, Wales and Northern Ireland, men and women aged 60 to 74 are invited to do a faecal occult blood test (FOB test) every two years. In Scotland, the ages range from 50 to 74. They are sent a home test kit, which is used to collect a poo (stool) sample.

If you have a family history of bowel cancer, you may need to have bowel screening at an earlier age (see page 13).

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



## At the hospital

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

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

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

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

- virtual colonoscopy (see page 20)
- sigmoidoscopy (see page 21).

### Colonoscopy

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

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

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

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

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

### **Virtual colonoscopy (CT colonography, CT enema, CT pneumocolon)**

In a virtual colonoscopy, a computerised tomography (CT) scanner (see page 22) takes a series of x-rays, which builds up a three-dimensional picture of your bowel. It is done in the hospital CT department and you can usually have it as an outpatient.

This test may be done instead of a colonoscopy, or it may be done if the colonoscopy didn't give a clear enough picture.

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

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

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

## Sigmoidoscopy

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

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

During the test, the doctor or nurse will take samples of tissue (biopsies) from any areas of the colon that look abnormal. This is painless.

You should be able to go home as soon as the test is over.

## Further tests

If any of your biopsies show that there is cancer in the colon, you will have more tests. These are to find out the size and position of the cancer and whether it has spread. This is called staging (see pages 27–31). The results will help you and your doctor decide on the best treatment for you.

Some tests may be repeated during and after treatment to check your progress. Your doctor or specialist nurse will explain this to you.

You will usually have blood tests and a CT scan. Some people also have a magnetic resonance imaging (MRI) or a PET-CT scan.

## Blood tests

You will have blood tests to assess your general health.

Your blood may be tested for a protein called carcinoembryonic antigen (CEA). Some people with bowel cancer have higher levels of this protein. If your level of CEA is high, your doctors may check it regularly to see how well your treatment is working.

## CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

You will be asked not to eat or drink for at least four hours before the scan.

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

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

Someone having a CT scan



## **MRI (magnetic resonance imaging) scan**

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

Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.



## PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture (see page 22), and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned.

You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30–90 minutes. You should be able to go home after the scan.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 115–120 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

## Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **[macmillan.org.uk/cancerregistry](https://macmillan.org.uk/cancerregistry)**. To find details about the cancer registry in your area, see page 117.

# Staging and grading

## Staging

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

### TNM staging system

**T** – describes how far the tumour has grown into the wall of the bowel, and whether it has grown into nearby tissues or organs.

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

**M** – describes whether the cancer has spread to another part of the body such as the liver or lungs (secondary or metastatic cancer).

## **T – Tumour**

The bowel wall is made up of layers of different tissues (see diagram opposite).

**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).

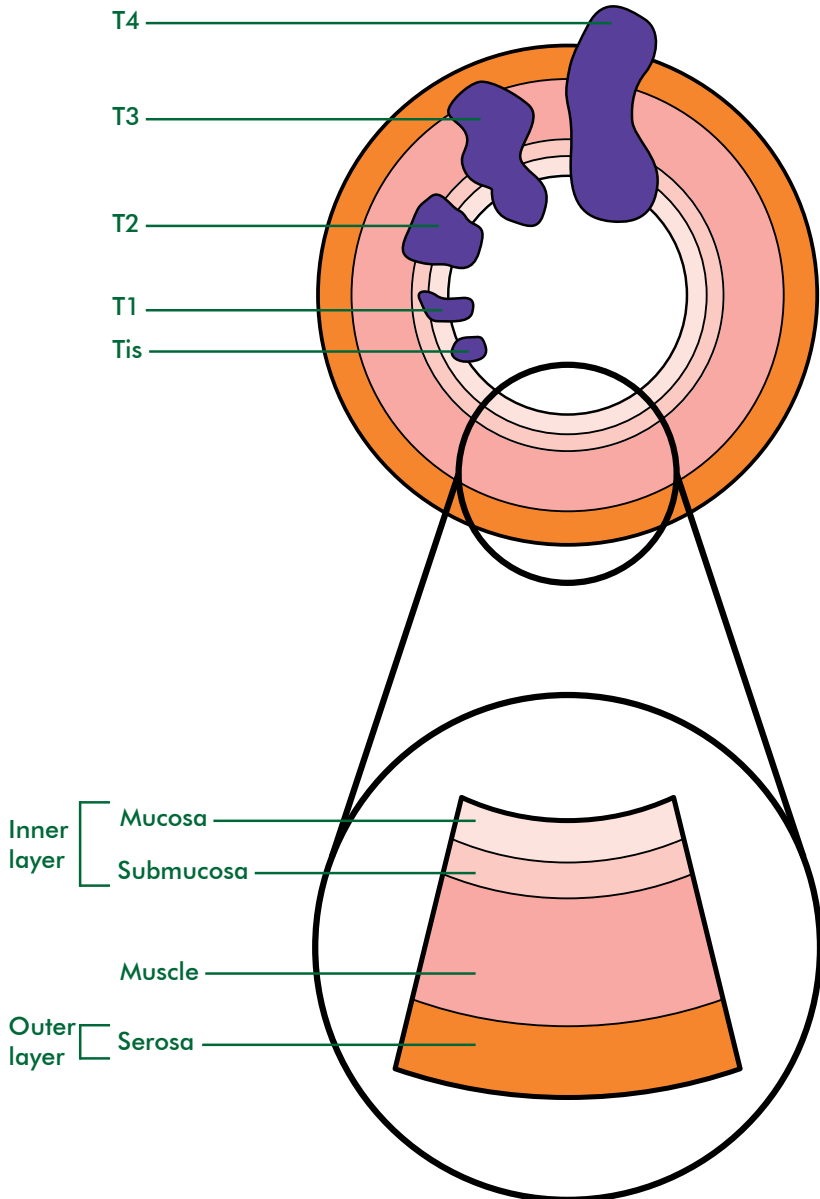
**T2** means the tumour has grown into the muscle layer of the bowel wall but no further.

**T3** means the tumour has grown into the outer lining of the bowel wall (serosa) but no further.

**T4** means the tumour has grown through the outer layer of the bowel wall (serosa) and through the membrane covering the outside of the bowel wall (peritoneum).

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

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



## N – Nodes

**N0** means no lymph nodes contain cancer cells.

**N1** means there are cancer cells in up to three nearby lymph nodes.

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

## M – Metastases

**M0** means the cancer hasn't spread to distant organs.

**M1** means the cancer has spread to distant organs such as the liver or lungs.

## Number staging system

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

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

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

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

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

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


## Grading

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

**Grade 1 (low-grade)** – The cancer cells tend to grow slowly and look similar to normal cells (they are well differentiated). These cancers are less likely to spread than higher grade cancers.

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

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

A woman with short, layered grey hair is shown from the chest up, looking off to the right with a slight smile. She is wearing a white top with a blue floral pattern. The background is a soft-focus green field with trees in the distance.

**'I eat what I feel like, even if it might be a bit inconvenient the next day, but I avoid fruit juice and real coffee.'**

**Ann**



# TREATING COLON CANCER

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Treatment overview	34
Surgery	40
Bowel function after surgery	56
If you have a stoma	61
Chemotherapy	65
Targeted therapies	76
Treating cancer that has spread to the liver	78
Research – clinical trials	82

# Treatment overview

Treatments used for colon cancer include surgery, chemotherapy and targeted therapy. Often, a combination of treatments is used.

What treatment you have depends on the stage of the cancer and where it is in the colon. It also depends on your general health and preferences.

It is important that you have the chance to discuss treatments with your doctor. This will help you understand why a particular plan of treatment has been suggested, and how the treatment may affect you.

**Surgery** to remove the cancer is one of the main treatments for colon cancer. The operation usually involves removing the affected part of the colon, as well as nearby lymph nodes (see pages 40–46). If the cancer has grown into tissue or organs nearby, the surgeon may remove parts of these too.

Sometimes, surgery is used to help with symptoms rather than cure the cancer. This may be if the cancer is causing a blockage in the bowel (see pages 48–49). Occasionally, surgery may be used to remove cancer that has spread to a distant part of the body, such as the liver or lungs. This is called secondary or advanced cancer (see pages 47–48).

**Chemotherapy** (see pages 65–75) may be given before surgery (neoadjuvant chemotherapy) or after surgery (adjuvant chemotherapy) to reduce the risk of the cancer coming back.

If cancer has spread to the liver or lungs (secondary cancer), chemotherapy may be the main treatment. It is given to shrink the cancer and to control it for as long as possible.

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

Chemotherapy may be used to shrink cancer and relieve symptoms if the cancer has come back after treatment.

**Targeted therapies** (see pages 76–77) are sometimes used on their own or in combination with chemotherapy to control secondary cancer.

Your cancer specialist may invite you to take part in a **clinical trial**. You can read more about this on pages 82–83.

## How treatment is planned

In most hospitals, a team of specialists called a multidisciplinary team (MDT) will talk to you about the treatment they feel is best for your situation.

This MDT will include a:

- **surgeon** who specialises in bowel cancers
- **medical oncologist** who specialises in chemotherapy and targeted therapies
- **clinical oncologist** who specialises in radiotherapy, chemotherapy and targeted therapies
- **radiologist** who helps to interpret x-rays and scans
- **pathologist** who advises on the type and size of the cancer
- **colorectal cancer** nurse specialist who specialises in cancers of the colon and rectum, and offers support and information
- **stoma care nurse** who helps to care for a stoma when someone has had a colostomy or ileostomy operation (see pages 45–46).

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

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

Your specialist team will consider a number of factors when advising you on your treatment options. These include your general health, the stage of the cancer and if it has spread to other parts of the body.

## Talking about your treatment plan

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

They will explain the main aims of treatment. These may be to try to cure the cancer, to help you live longer or to relieve symptoms. They will also tell you the possible short-term and long-term side effects of the treatments.

**'I've had so much help from doctors, community nurses, nurses, social workers, the surgeon, everybody. And the surgeon went into every detail with me, which I think helped.'**

**Erika**

Deciding which treatments are right for you is usually a joint decision between you and your cancer team. Cancer specialists have expert knowledge of the treatments, but you know your situation, beliefs and preferences.

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

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

When making treatment decisions, it is important to talk things over carefully with your cancer team. It can help to make a list of the questions you want to ask them. You can take this to your next appointment. It is also helpful to have a relative or close friend with you at appointments. You may choose to keep notes about what has been said. You can use page 121 to write down any questions or notes.

You can order our free booklet **Making treatment decisions** from **be.macmillan.org.uk** or by calling us on **0808 808 00 00**. It explains how you can find out about treatment options and what things may help you make your decision.

## Giving your consent

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

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

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

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

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

You are free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes.

You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

'I always go to appointments armed with my list of queries, as it is easy to forget them if new information is being given. I took someone with me to my initial surgical meeting and the first post-operative meeting, so that I had a note-taker and I could concentrate on asking my prepared list of questions. I did the same when I started chemotherapy.'

**Muriel**

# Surgery

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 and whether it has spread. Your doctor will discuss this with you.

## Surgery to remove colon cancer

### Local resection

Very early-stage colon cancers can sometimes be removed using an operation called a local resection. During this operation, the surgeon uses a colonoscope (see pages 19–20) to remove the cancer from the lining of the bowel. A pathologist will examine the cancer that has been removed. If it is a high-grade (see page 31), your surgeon may recommend that you have a second operation to remove more of the colon. This is to make sure that no cancer cells are left behind.

### Removing part or all of the colon

Removing the whole colon is called a **total colectomy**.

Removing half of the colon is called a **hemi-colectomy**.

Depending on where the cancer is, either the left side or the right side may be removed.

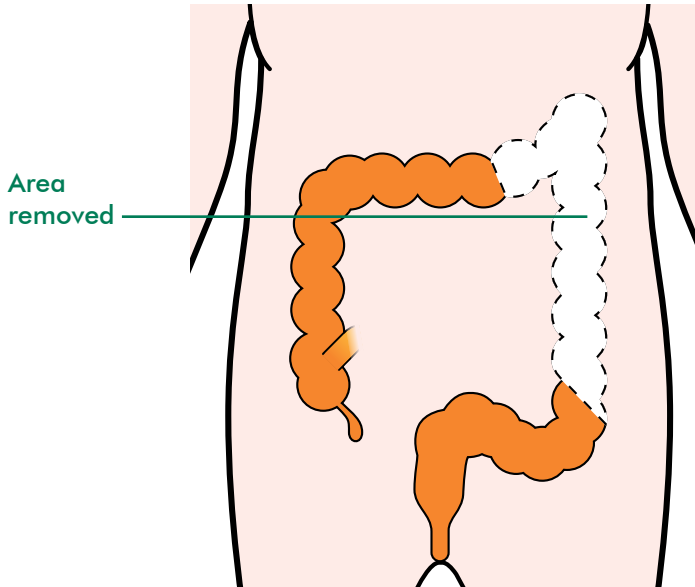
In a **left hemi-colectomy**, the left half of the transverse colon and the descending colon is removed.

In a **right hemi-colectomy**, the right half of the transverse colon and the ascending colon is removed.

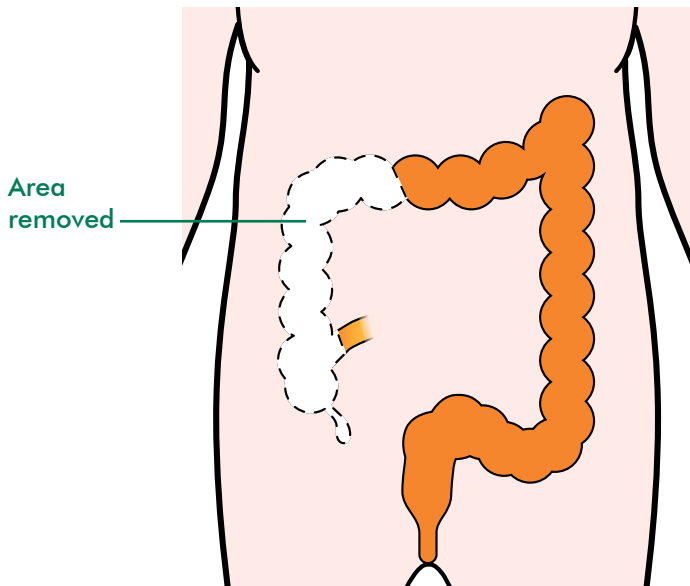
The diagrams opposite show the parts of the colon that are removed during these operations.



## A left hemi-colectomy

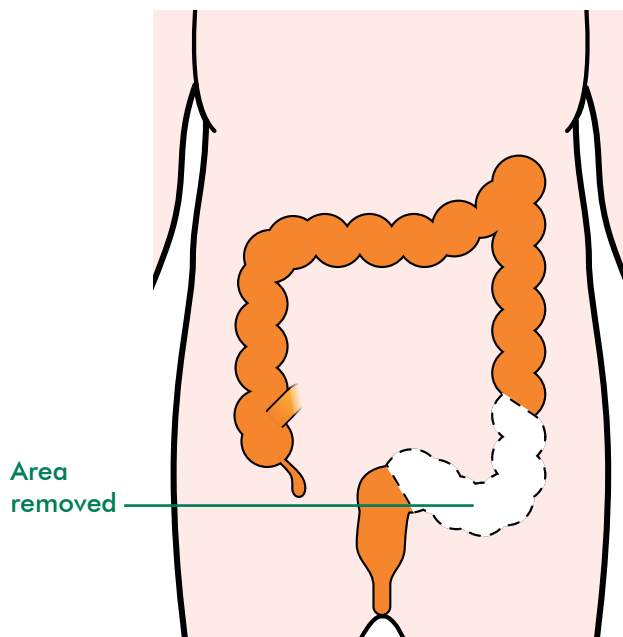


## A right hemi-colectomy



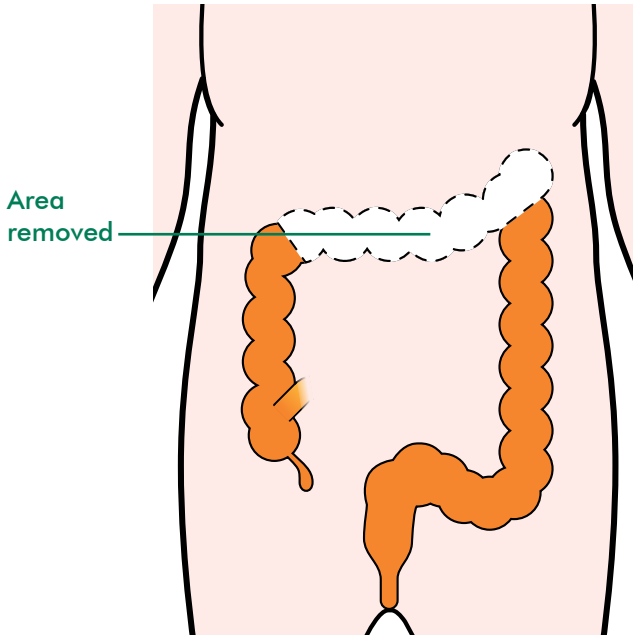
Some people have an operation to remove the sigmoid colon. This is called a **sigmoid colectomy**.

## A sigmoid colectomy



Some people have their transverse colon removed, which is called a **transverse colectomy**.

## A transverse colectomy



During surgery, the piece of bowel that contains the cancer is removed. The two open ends are then joined together. The join is known as an anastomosis. The lymph nodes near the colon are also removed, because this is usually the first place the cancer spreads to.

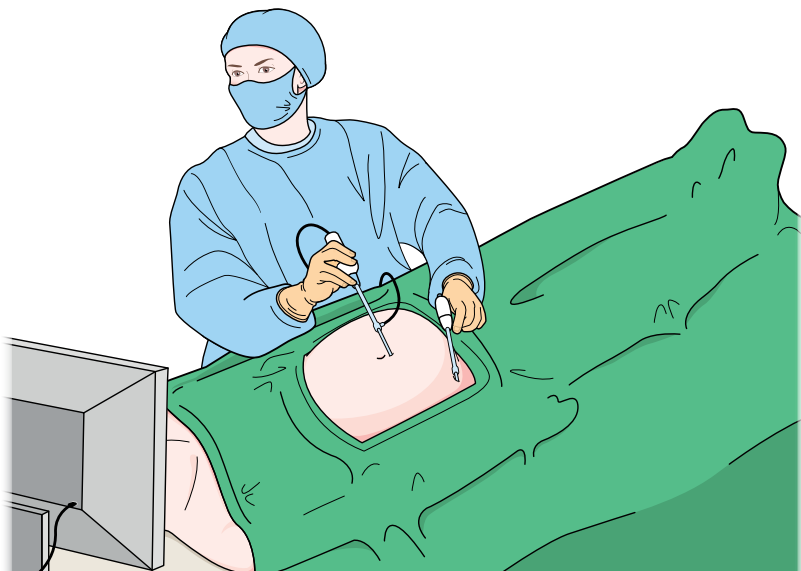
## Open or laparoscopic surgery

Your operation may be carried out as open surgery or as laparoscopic (keyhole) surgery.

**Open surgery** means the surgeon makes one large cut (incision). Afterwards, you have a wound that goes down in a line from just below your breastbone (sternum) to just below the level of your tummy button (navel). Some people have a wound that goes across their tummy instead.

In **laparoscopic (keyhole) surgery**, the surgeon makes four or five small cuts in the tummy rather than one big cut. They pass a laparoscope into the tummy through one of the cuts. A laparoscope is a thin tube containing a light and camera. They then pass specially designed surgical tools through the other cuts to remove the cancer.

## A surgeon performing laparoscopic surgery



Laparoscopic surgery is sometimes used when the cancer is small. It uses a specialised technique and is not available in all hospitals. If this surgery is the best type for you to have, you may be referred to another hospital to have it done. Recovery from laparoscopic surgery is usually quicker than recovery from open surgery. Your surgeon will talk to you about which type of surgery is likely to be best in your situation.

## Stomas (colostomy or ileostomy)

During the operation to remove the cancer, an opening is sometimes made through the tummy (abdominal) wall. This lets the bowel connect onto the surface of the tummy. It is called a stoma. It is round or oval, and it looks pink and moist. The stoma has no nerve supply, so it doesn't hurt. Poo (stools) will no longer pass out of the rectum and anus in the usual way. Instead it will pass out of the stoma, into a disposable bag that is worn over the stoma.

The stoma is made from an opening in part of the bowel. 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 can be temporary or permanent. Only a small number of people with colon cancer need a permanent stoma. A surgeon may make a temporary stoma to allow the bowel to heal after surgery.

There are two kinds of stoma:

- a **loop stoma**
- an **end stoma**.

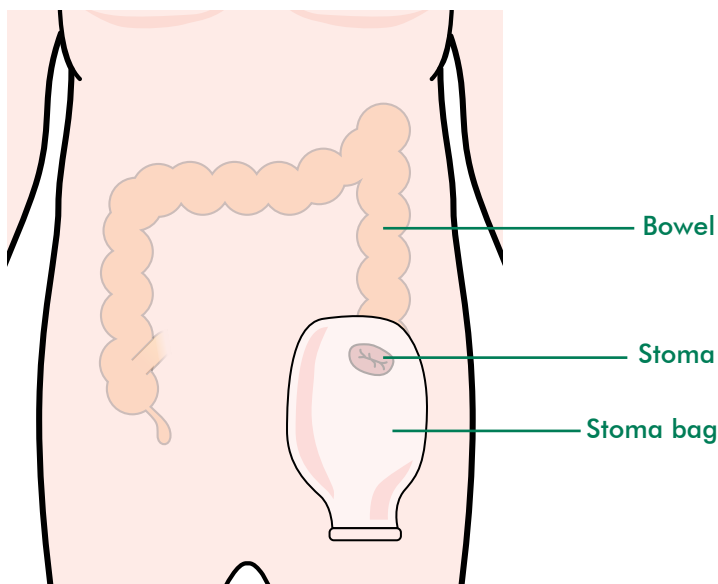
To make a loop stoma, the surgeon pulls a small loop of bowel out through a cut in the tummy. They then make an opening in the loop of bowel and stitch the loop to the skin. This forms the stoma.

To make an end stoma, the surgeon removes the section of bowel that contains cancer. This leaves two open ends of bowel. The surgeon brings the active end out to the surface of the tummy and stitches it into place. This forms a stoma. The inactive end of bowel, which leads to the rectum (back passage), is stitched closed and left inside the tummy.

If you have a temporary stoma, you will usually have a second smaller operation a few months later to close the stoma and rejoin the bowel. This operation is called a stoma reversal (see page 63).

If you need to have a stoma, you will be referred to a stoma nurse who specialises in stoma care.

## A stoma and stoma bag



## Surgery for advanced colon cancer

The most common areas of the body that colon cancer might spread to are the liver and the lungs.

### Liver resection

If colon cancer has spread to the liver, the most common treatment is chemotherapy (see pages 65–75). The aim is to shrink the cancer and control it for as long as possible.

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

Liver resection is a major operation that takes three to seven hours. It is done by surgeons experienced in liver surgery (hepatobiliary surgeons) in specialist hospitals. This treatment is only suitable for a few people with secondary liver cancer.

Sometimes the liver resection is done at the same time as an operation to remove the cancer in the colon. But it is usually done as a separate operation.

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

Pages 78–79 have information about other treatments for secondary cancer in the liver.

Our booklet **Understanding secondary cancer in the liver** has information about treatments you may have. Order it from **be.macmillan.org.uk** or call us on **0808 808 00 00**.

## **Lung resection**

The main treatment for cancer that has spread to the lungs is chemotherapy. But occasionally, people may be offered surgery to remove the affected part of the lung. This is usually only possible if the cancer is in just one lung, although some surgeons will operate on both lungs in certain circumstances.

Radiofrequency ablation may sometimes be used (see pages 78–&9).

## **Treating a blocked bowel (bowel obstruction)**

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

### **Stenting to relieve a blocked bowel**

The surgeon uses a colonoscope (see pages 19–20) to insert an expandable metal tube (stent) into the blockage. The tube then expands to hold the bowel open (see opposite page).

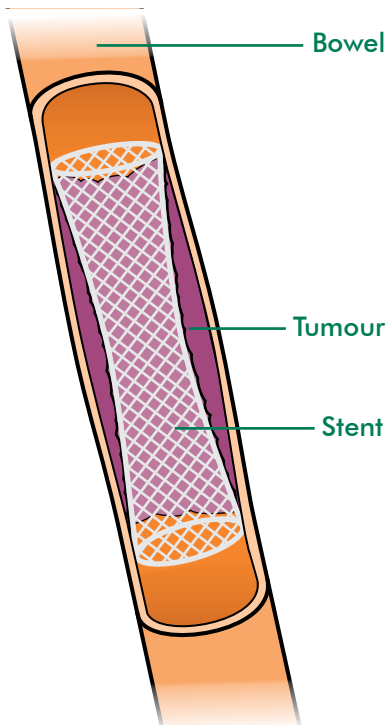
The cancer causing the blockage can usually be removed with an operation at a later date.

### **Surgery to relieve a blocked bowel**

Sometimes, a bowel obstruction is treated with an operation to remove the blocked section of bowel. The surgeon may remove the cancer at the same time or do this later in another operation at a later stage. Most people will have a temporary or permanent stoma after this operation (see pages 45–46).



## A part of the bowel with a stent inside



## Before your operation

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

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

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

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

You will meet a member of the surgical team to discuss the operation. If you are going to have a stoma after the operation, you will also meet a stoma care nurse who will explain what is involved. This is a good time to share any questions or concerns you have about the operation. If you think you may need help when you go home after surgery, for example because you live alone or care for someone else, tell your nurse as soon as possible. It will help them to make arrangements in plenty of time.

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

Any arrangements needed for you to go home will also be organised for you. Your doctor will tell you if an enhanced recovery programme is suitable for you and if it is available.

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



## After your operation

You will be encouraged to start moving around as soon as possible. This helps prevent complications, such as chest infections and blood clots. The nurses will encourage you to do regular leg movements and deep breathing exercises. A physiotherapist or nurse can explain these to you.

On the evening of the operation or on the following day, you will usually be helped to get out of bed or to sit up for a short time. After this, you will be encouraged to be up for longer periods and to begin walking around the ward.

### Pain

It is normal to have some pain and discomfort after your operation. This can be controlled with painkillers. If you feel sick or are in pain, tell the nurses. They can give you medicines to relieve sickness. You may need to have your dose or type of painkiller changed.

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

Painkillers can also be given through a tube into a vein in your hand or arm (a cannula). The tube is connected to a pump. This is called a PCA (patient-controlled analgesia). You can give yourself an extra dose of painkiller when you need it by pressing a button. The machine is set so you get a safe dose and can't have too much.

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

## **Drips and drains**

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

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

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

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

## **Eating and drinking**

You will usually be able to eat and drink again soon after surgery. You may be given supplement drinks for a few days, to help your recovery.

## Going home

Depending on the type of operation you have had, you'll probably be ready to go home three to seven days after surgery.

You will be given an appointment to attend an outpatient clinic for your post-operative check-up. At the appointment, your doctor will talk to you about whether you need to have any further treatment, such as radiotherapy or chemotherapy.

If you have stitches, clips or staples in your wound, these are usually taken out 7 to 10 days after the operation. Your practice nurse can do this. If you can't leave home, a district nurse can visit you.

If you have a stoma, the hospital will give you stoma supplies to go home with. After this, you will need to order supplies from your chemist or direct from a specialist supply company. Your stoma care nurse can tell you about these. **The Ileostomy and Internal Pouch Support Group** and the **Colostomy Association** also have details of companies (see pages 115–116). You will need a prescription from your GP to get stoma supplies. If you are aged between 16 and 60, make sure your doctor signs the form saying that you're entitled to free prescriptions.

'After surgery, it was a couple of weeks before my first outing. It was quite strange being out and especially among so many people, but it made me realise that I had more stamina than I thought and gave me the courage to go out for a walk on my own.'

**Muriel**

# Bowel function after surgery

Your bowel function will usually settle into a regular pattern after a few weeks or months. But to begin with, you may have one or more of the following changes:

- needing to poo several times a day (more frequently)
- feeling that you can't wait when you need to poo (urgency)
- diarrhoea
- constipation
- feeling bloated or passing a lot of wind
- having a sore bottom.

These effects usually improve over time. Tell your surgeon or specialist nurse if you are having problems, or if your bowel is not settling into a routine. They can give you advice, prescribe medicines or refer you to a continence specialist nurse or dietitian.

'In the early days, it took quite a time for the bowels to settle down. I did have some nausea, but had pills from the doctor that I could take as and when required.'

**Linda**

## Diet after bowel surgery

Eating at regular times helps to encourage a regular pattern for your bowel function. If you have a poor appetite, it may be easier to eat several small meals a day, rather than one or two large meals. Drink at least one to two litres of fluid a day, especially if you have loose stools or diarrhoea.

Including high-protein foods such as fish, meat and eggs in your diet will help your body to heal after surgery.

It is important to eat a wide range of different food types for a healthy, well-balanced diet. But some foods may cause problems. Keeping a daily diary of what you eat and how this affects you can help.

If you have diarrhoea, choose low-fibre foods such as white bread and pasta instead of wholemeal. Eat fewer leafy green vegetables, cook vegetables well and peel fruit.

As your bowel settles, try to gradually reintroduce foods that caused you problems. You may find they no longer affect your bowel. If you continue to be limited in what you can eat, you may want to get advice from a dietitian.

Treatment such as anti-diarrhoeal medicine may help you to manage your bowel symptoms better, which may allow you to eat a wider range of foods. See page 61 for more information about these medicines.



## Wind

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

- Eat slowly and chew food well.
- Be aware that beans, beer, chewing gum, fizzy drinks and onions can cause wind.
- Peppermint capsules or oil, and fennel or mint tea may help.

Our booklet **Eating problems and cancer** has information about common eating difficulties after cancer. It explains why they happen and offers some practical tips for managing them.

## Anti-diarrhoea medicines

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

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

It is safe to take loperamide for as long as you need it, but you should discuss this with your doctor.

## Coping with bowel changes

It may take time for your bowel function to settle. In the meantime, there are things that can help you feel more confident and in control.

### Protect your skin

If you poo frequently or it is loose after surgery, the skin around your bottom may become sore. These tips may help:

- Keep the skin around your back passage clean and dry.
- Use unperfumed wet wipes, as they are softer on your skin than toilet paper.
- Use absorbent pads and barrier creams (such as Cavilon® or Sudocrem®) to help protect your skin.
- Wear cotton underwear, which allows your skin to breathe.

### Managing stress

Your emotions can affect your bowel. Anxiety and stressful situations can make poo looser and more frequent. If you don't feel in control of your bowel, this in itself can be stressful.

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

## Going out

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

Carrying a **Just Can't Wait** card may help you to get access to a toilet more quickly when you are out. It states that the card holder has a medical condition that requires urgent access to a toilet. You can get a card from the Bladder and Bowel Community (see pages 115).

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

**The National Key Scheme** offers people with a disability access to about 9,000 locked public toilets across the UK. You can buy a key from Disability Rights UK (see page 118). They can also send you details of where the toilets are.

Macmillan also has a toilet card for people who have problems with bowel or bladder control. It gives you urgent access to a toilet when out in public. You can get one by phoning our support line on **0808 808 00 00** or you can order one at **[be.macmillan.org.uk](https://be.macmillan.org.uk)**

## Carry a bag with supplies

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

You may want to include:

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

# If you have a stoma

Having a stoma is a big change to your body, whether it is temporary or permanent. It can take time to adjust to. You may find it helpful to talk to someone who is used to living with a stoma. Your stoma nurse may be able to arrange this for you. You can also contact the Colostomy Association or the Ileostomy and Internal Pouch Support Group (see pages 115–116).

If you want to talk about any concerns you have, you can also contact our cancer support specialists on **0808 808 00 00**. There are details of other helpful organisations on pages 115–120.

You will usually see a stoma care nurse on the first day after your operation. They will begin to teach you how to look after the stoma.

The stoma will be swollen at first, but will shrink to its final size within a few weeks. If you have a loop stoma (see pages 45–46) there may be a rod underneath the loop to support it. A nurse will usually take the rod out after a few days.

Learning to look after a stoma takes time and patience, and no one expects you to be able to cope perfectly straight away. Like anything new, it will get easier with time and practice. You will continue to have support from a stoma care nurse after you go home. They can help you cope with any problems.

You may want to have a family member or friend with you while you are taught how to care for your stoma. This means they will know how to help you at home, if needed.

If you have an ileostomy, you will wear a stoma bag that opens at the bottom so you can empty it. An ileostomy produces semi-liquid waste continuously, so you will need to empty the bag several times a day.

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

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

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

We have a video of a stoma nurse talking about looking after a stoma and showing the supplies you might use. Visit **[macmillan.org.uk/livingwithastoma](https://www.macmillan.org.uk/livingwithastoma)**

## Stoma reversal

If you have a temporary stoma, you can usually have an operation to reverse the stoma when your treatment is over. This means you will pass poo (stools) from your bottom again.

The timing of a stoma reversal operation varies from person to person. It can range from a few months after the stoma was made, to one or two years later.

How stoma reversal is done depends on whether you have a loop stoma or an end stoma (see pages 45–46).

To reverse a loop stoma, the surgeon closes the opening in the loop of bowel that was used. They then remove the stitches holding the loop of bowel in place on the skin. The bowel goes back inside the tummy (abdomen).

To reverse an end stoma, the surgeon removes the stitches that are holding the piece of bowel up to the skin. The piece of bowel is rejoined to the rest of the bowel inside the tummy.

After a stoma reversal, it may take some time for your bowel habit to get back to normal. You may find the advice on pages 56–61 helpful.

Someone having chemotherapy





# Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

Chemotherapy may be given:

- after surgery, to reduce the risk of cancer coming back.
- before surgery (if you are having cancer removed from the liver or lungs), to shrink the cancer and reduce the risk of it coming back.
- as the main treatment (if it has spread to parts of the body such as the liver or lungs) to try to control it for as long as possible.

The drugs most commonly used to treat bowel cancer are:

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

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

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

## How chemotherapy is given

You usually have chemotherapy as an outpatient. Most drugs are given into a vein (intravenously). Some drugs, such as capecitabine and trifluridine or tipiracil, are taken as capsules or tablets.

There are three videos about chemotherapy on our website. They show inside a treatment centre and feature people having treatment and health professionals. Visit **[macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)**

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

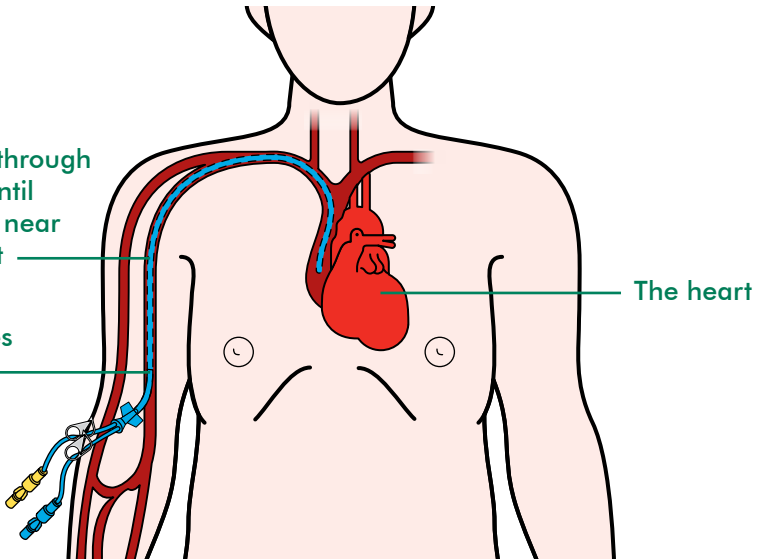
- A cannula – a short, plastic tube put into a vein in the back of your hand or arm. It's taken out before you go home.
- A PICC line – a long, thin, flexible tube inserted into a vein in the crease of your arm. It stays in until your whole course of chemotherapy is completed.
- A central line – a long, thin, flexible tube inserted into a vein in your chest. It stays in until your whole course of chemotherapy is completed.
- An implantable port (sometimes called a portacath) – a thin, soft, plastic tube, put into a vein in your chest or arm. It has an opening (port) just under the skin.

On our website there are two animations that show how PICC lines and central lines are put in the body. Visit **[macmillan.org.uk/havingapiccline](https://www.macmillan.org.uk/havingapiccline)** and **[macmillan.org.uk/havingacentralline](https://www.macmillan.org.uk/havingacentralline)**

## A PICC line

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

Line comes out here

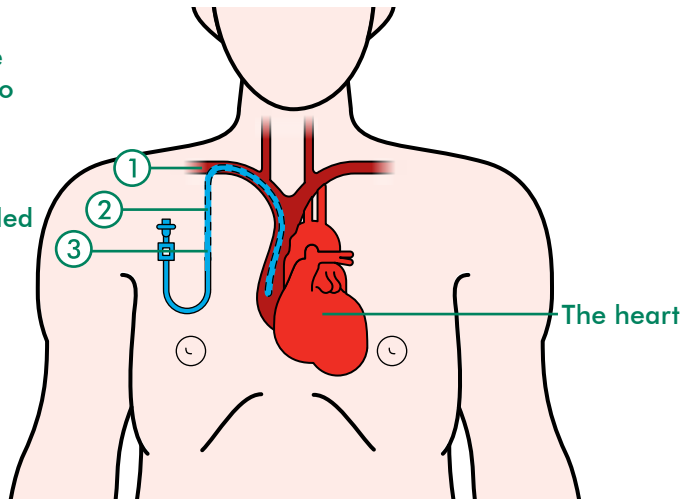


## A central line

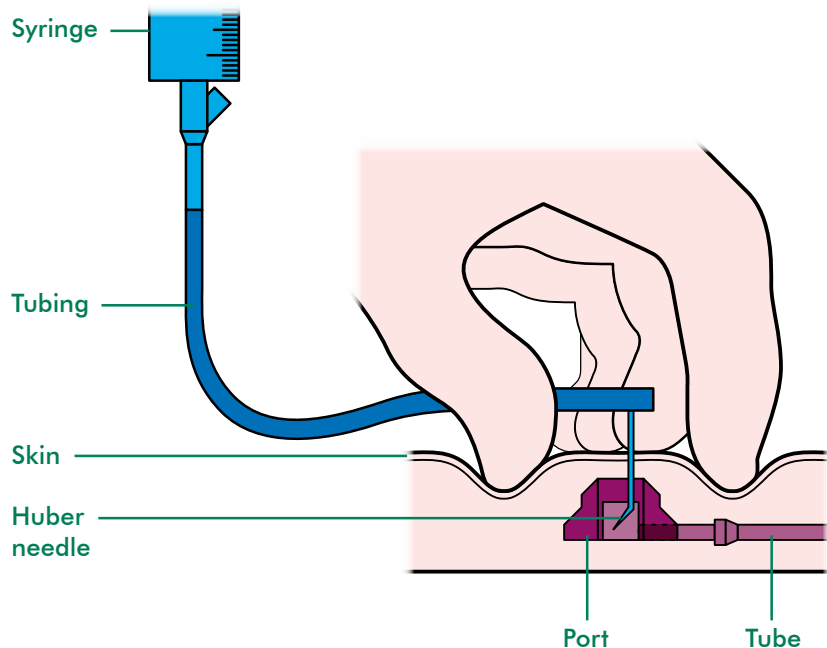
① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here



## An implantable port



Chemotherapy is sometimes given through a small, portable pump attached to your PICC or central line. You are given a controlled amount of the drug continuously into the bloodstream over a set period of time.

Intravenous chemotherapy is given as a session of treatment over several hours or days. This is followed by a rest period of a few weeks, which allows your body to recover from any side effects. The treatment and rest period make up a cycle of treatment. Your cancer specialist will tell you how many cycles of treatment you will have.

Our booklet **Understanding chemotherapy** explains this treatment in more detail. We can also send you information about all of the drugs and side effects mentioned here – call us on **0808 808 00 00**.

## Side effects

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

### Risk of infection

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

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

- your temperature goes over 37.5°C (99.5F) or over 38°C (100.4F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection, such as:
  - feeling shivery
  - a sore throat
  - a cough
  - diarrhoea
  - needing to pass urine often.

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

## **Bruising and bleeding**

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

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

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

## **Anaemia (low number of red blood cells)**

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

## **Diarrhoea**

Some chemotherapy drugs can cause diarrhoea. This usually happens in the first few days of treatment. If you have this side effect, let your nurse or doctor know as they can give you medicine to help. If you still have diarrhoea after 24 hours, it is important to contact the hospital on the telephone numbers you have been given and speak to a doctor or nurse. If you have a stoma, your stoma care nurse can also give you advice and support.

Make sure you drink up to two litres of fluid a day to replace the fluid you are losing. Eat less fibre, such as cereals, raw fruits and vegetables, until the diarrhoea improves.

Sometimes diarrhoea is more severe. If you have more than four to six episodes of diarrhoea a day, contact the hospital and speak to a doctor or nurse.

If you are taking capecitabine and your diarrhoea doesn't settle, tell your doctor or nurse. Sometimes you may have to stop taking capecitabine until the diarrhoea gets better.

Some people need to go to hospital to have fluids through a drip (infusion) or they may need antibiotics.

## Feeling sick

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

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

## Sore mouth

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

If your mouth is sore:

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

## Feeling tired

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

## Breathing and swallowing

Rarely, oxaliplatin can temporarily affect the area around the voicebox (larynx). This can cause it to spasm and make you feel as if it is difficult to breathe and swallow. It can be frightening, but only lasts for a short time. If this happens, try to take long, deep breaths through your nose. This will calm you and help your breathing return to normal.

This side effect may happen during treatment or in the first few days after treatment. It may be worse in cold temperatures. Avoid cold drinks and ice cubes during treatment and for a few days after. It might also help to wrap up warm and cover your nose and mouth in cold weather.



If you have this side effect, it is important to let your doctor know. They may give your oxaliplatin infusion over a longer time (four to six hours) in future cycles, which reduces the chance of it happening again.

## **Your hair**

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or other body hair. Hair loss usually starts after your first or second treatment.

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

Hair loss is almost always temporary and your hair will usually grow back after treatment ends.

## **Sore hands and feet**

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

## **Numb or tingling hands or feet**

Oxaliplatin can cause this side effect, which is called peripheral neuropathy. You may notice that you have difficulty doing up buttons or similar fiddly tasks, due to effects of the drug on nerve endings.

Cold temperatures may trigger this side effect. If you notice that it is related to the cold, avoid cold drinks and wrap up warmly in the cold weather. You could wear gloves, socks, and a scarf to cover your nose and mouth. Use gloves when you are taking things out of the freezer or refrigerator.

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

## **Effects on memory and concentration**

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

## **Changes in the way the heart works**

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

If you have pain or tightness in your chest, feel breathless, or notice changes to your heartbeat at any time, tell your doctor straight away. These symptoms can be caused by other conditions, but it is important to get them checked.

## Your sex life

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

### Protecting your partner

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

‘The main thing is to follow the advice of the chemo nurses. They have lots of good practical advice because they deal with this on a daily basis and have heard it all before.’

**Emmanuel**

# Targeted therapies

Targeted therapies interfere with the way cancer cells grow. They are sometimes called biological therapies.

Targeted therapies are sometimes used to treat bowel cancers that have spread to other parts of the body. They may be given on their own or with chemotherapy.

Targeted therapies that may be used include:

- cetuximab (Erbix<sup>®</sup>)
- panitumumab (Vectibix<sup>®</sup>)
- bevacizumab (Avastin<sup>®</sup>)
- aflibercept (Zaltrap<sup>®</sup>)
- ramucirumab (Cyramza<sup>®</sup>)
- regorafenib (Stivarga<sup>®</sup>).

All of these drugs are given into a vein as an infusion (intravenously) except for regorafenib, which is taken as tablets.

Cetuximab (Erbix<sup>®</sup>) and panitumumab (Vectibix<sup>®</sup>) are both a type of targeted therapy called EGFR inhibitors. They stop cancer cells from getting messages that tell them to grow.

Not all bowel cancers respond to cetuximab or panitumumab. Your doctors will test the cancer cells for a cell change called a RAS gene mutation, which is called being tested to find out your **RAS status**. Knowing if these genes are normal or changed (mutated) can help the doctors decide whether cetuximab or panitumumab will be appropriate for you.

Cetuximab and panitumumab are often given with chemotherapy.

Bevacizumab (Avastin®), aflibercept (Zaltrap®), ramucirumab (Cyramza®) and regorafenib (Stivarga®) work by preventing the cancer from developing a blood supply. This deprives it of oxygen and nutrients. Drugs that interfere with blood vessel growth are called angiogenesis inhibitors or anti-angiogenics.

If your cancer specialist thinks that a targeted therapy may be helpful, they will discuss this with you. However these drugs are not widely available through the NHS. If a drug isn't available on the NHS, there may be different ways you are still able to have it. Your doctor can give you advice. They may be able to apply for funding to get it. We can send you information about targeted therapy drugs, the Cancer Drugs Fund and what you can do if a treatment is not available. Call us on **0808 808 00 00**.

## Side effects

Some targeted therapies can cause an allergic reaction. This may happen when the drug is being given or shortly after. Signs of an allergic reaction can include flu symptoms, a drop in blood pressure or feeling sick. An allergic reaction is most common with the first dose of the drug. To reduce this risk, the first dose is given slowly over a few hours. You may also be given drugs to make an allergic reaction less likely.

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

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

# Treating cancer that has spread to the liver

If cancer has spread to the liver (secondary liver cancer) and can't be removed with surgery, the main treatment is usually chemotherapy (see pages 65–75). This may be given with a targeted therapy (see pages 76–77).

Other treatments, such as radiofrequency ablation, cryotherapy and radiotherapy, may also be used to treat secondary liver cancer. They may relieve symptoms and help to control the cancer for some time.

If you have secondary liver cancer, your doctor will talk to you about what treatments may be the most helpful.

## Radiofrequency ablation (RFA)

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

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

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

Sometimes, a similar treatment called microwave ablation (MWA) is used.

## Cryotherapy

Doctors can also use very low temperatures to destroy cancer cells. This is called cryotherapy. Like with RFA, they put an instrument into the body towards the tumour.

## Radiotherapy

Radiotherapy uses high-energy rays to kill cancer cells. Doctors may use specialised radiotherapy techniques to treat secondary cancer in the liver.

### Selective internal radiotherapy (SIRT)

A doctor injects tiny radioactive beads into a blood vessel close to the tumours. The radiation destroys the blood vessels and stops blood flow to the tumours. Without a blood supply, the tumours shrink and may die. The radiation only travels a few millimetres so other parts of the liver are not affected and it doesn't make you radioactive.

## Stereotactic radiotherapy

Stereotactic radiotherapy is a precise treatment that can give high doses of radiotherapy to small areas of the body.

Stereotactic radiotherapy is given using a specially adapted radiotherapy machine. The machine delivers beams of radiotherapy from many different angles, which overlap at the tumour. This means the tumour gets a very high dose of radiotherapy, but surrounding tissues get a very low dose.

This treatment is only available in some hospitals in the UK. Your doctor can give you more information.

We have more information about secondary liver cancer and its treatments in our booklet **Understanding secondary cancer in the liver**. Call **0808 808 00 00** or visit **[be.macmillan.org.uk](https://be.macmillan.org.uk)**





## Research – clinical trials

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

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

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

### Taking part in a trial

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

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

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

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. We can send you a free copy.

## Blood and tumour samples

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

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



**‘The exercise helps me. Yes, I still sometimes find it difficult getting out of bed, but knowing how much better I feel afterwards is enough for me to get out there and do something about it.’**

**Jane, diagnosed with colon cancer in 2011**

# AFTER TREATMENT

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Well-being and recovery	86
Sex life after colon cancer	88



# Well-being and recovery

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

Many people feel anxious before their appointments. This is natural. It may help to get support from family, friends or one of the organisations listed on pages 115–120.

## Beginning to recover

After your treatment, it may be some time before you feel fit and well again. Living a healthy lifestyle can help your body recover more quickly and may help reduce the risk of cancer returning. A healthy lifestyle also reduces the risk of other illnesses, such as heart disease and stroke.

Adopting a healthy lifestyle is about making small, achievable changes to the way you live, which will improve your health and well-being. It includes having a well-balanced diet, keeping active, keeping to a healthy weight, reducing stress and not smoking.

If you smoke, giving up is the most important thing you can do for your health. Our booklet **Giving up smoking** can give you information and tips on how to do this.

## Keeping active

You can slowly increase the amount of physical activity you do. Whatever your age or physical health, there will be something you could try. This could be walking, hiking, cycling or swimming. Activities such as gardening, dancing and sport are also good to try.

'I was told that it was a good idea to exercise and that is something that I have kept up. It helped me get back into a routine.'

Ron

## Reducing stress

Having cancer can be a stressful experience. But there are things that can help. Make time to relax and do things you enjoy or that make you laugh. You may want to start a new hobby or evening class. Writing a journal or online blog may also help.

You may want to learn some new ways of relaxing, such as meditation or yoga. Some people find praying or thinking about spirituality helps.

You may find it helpful to read our booklet **Life after cancer treatment** may help. We also have booklets about diet, exercise and coping with emotions.

# Sex life after colon cancer

Treatments for colon cancer can affect your sex life and how you see yourself. You may feel too tired to have sex during treatment and for a while after. Most people find that this gradually improves, but occasionally it can last for months or even longer.

Sometimes, surgery can damage the nerves of sexual organs. If this happens, a man may not be able to have or maintain an erection. There can also be problems with orgasm and ejaculation. Women may also find that their sexual function or response is affected. Orgasm may be less intense than before and it may take longer to reach orgasm. This may be because of changes to blood flow and nerves in the pelvic and genital area. These changes may improve over time, but are sometimes permanent.

Sildenafil (Viagra®) may help a man to get erections. If you are having erection difficulties, talk to your doctor as soon as possible. Treatment is often more effective if started sooner.

After your operation, you may have a scar or stoma. If you feel self-conscious about changes to your body, it can affect your sexual desire. Talking about your feelings may help reduce your anxiety.

If you are having any sexual difficulties, talk to your doctor or nurse. There are often things that can be done to help. Some people find it difficult to talk about sexual issues because they feel embarrassed or self-conscious. Your doctor, stoma care nurse or specialist nurse will be used to talking about these issues. They can give you advice and refer you for specialist help and support if necessary.



Our booklets **Sexuality and cancer – information for men** and **Sexuality and cancer – information for women** explain the effects that cancer and its treatments can have on sexuality. It also offers ways of coping and solutions to sexual problems. To order a booklet, visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)** or call us on **0808 808 00 00**.

'My husband was very good about it. He didn't find it difficult to cuddle me and we did have intercourse during the time that I had the stoma. He saw it as something that was aiding me to get better, as opposed to it being an invasion on my body that he found unpleasant.'

**Anita**



**'Before my diagnosis I was young, strong-minded and independent. Accepting emotional support was a big step, and it's an even a bigger challenge to admit that you need it.'**

**Thom**

# YOUR FEELINGS AND RELATIONSHIPS

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Your feelings	92
Who can help?	96
Relationships	98
If you are a relative or friend	100
Talking to children	101

# Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

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

## Fear and anxiety

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

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

## Avoidance

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

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

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

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://macmillan.org.uk/supportgroups)**

You can also talk to other people going through the same thing on our Online Community at [macmillan.org.uk/community](https://macmillan.org.uk/community)

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

## If you need more help

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

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

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

# Who can help?

Many people are available to help you and your family.

**District nurses** work closely with GPs and make regular visits to patients and their families at home if needed.

The **hospital social worker** can give you information about social services, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as **Macmillan nurses**. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

**Marie Curie nurses** help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.





**'Alongside the support from my family in the first instance, the support from Macmillan was second to none. It is so necessary.'**

**Thom**

# Relationships

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

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

## If you have a partner

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

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

## Family and friends

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

Our booklet **Talking about cancer** has useful tips about talking with people close to you.



**'I did have some moments where I felt overwhelmed by it. But then I get up, see my son and think about how happy I am each day.'**

**Ron, who was supported by family and friends**

# If you are a relative or friend

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

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

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

Our booklet **Talking to someone who has cancer** has more suggestions if you have a friend or relative with cancer.

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

We have more information about supporting someone with cancer at **[macmillan.org.uk/carers](https://macmillan.org.uk/carers)**

# Talking to children

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

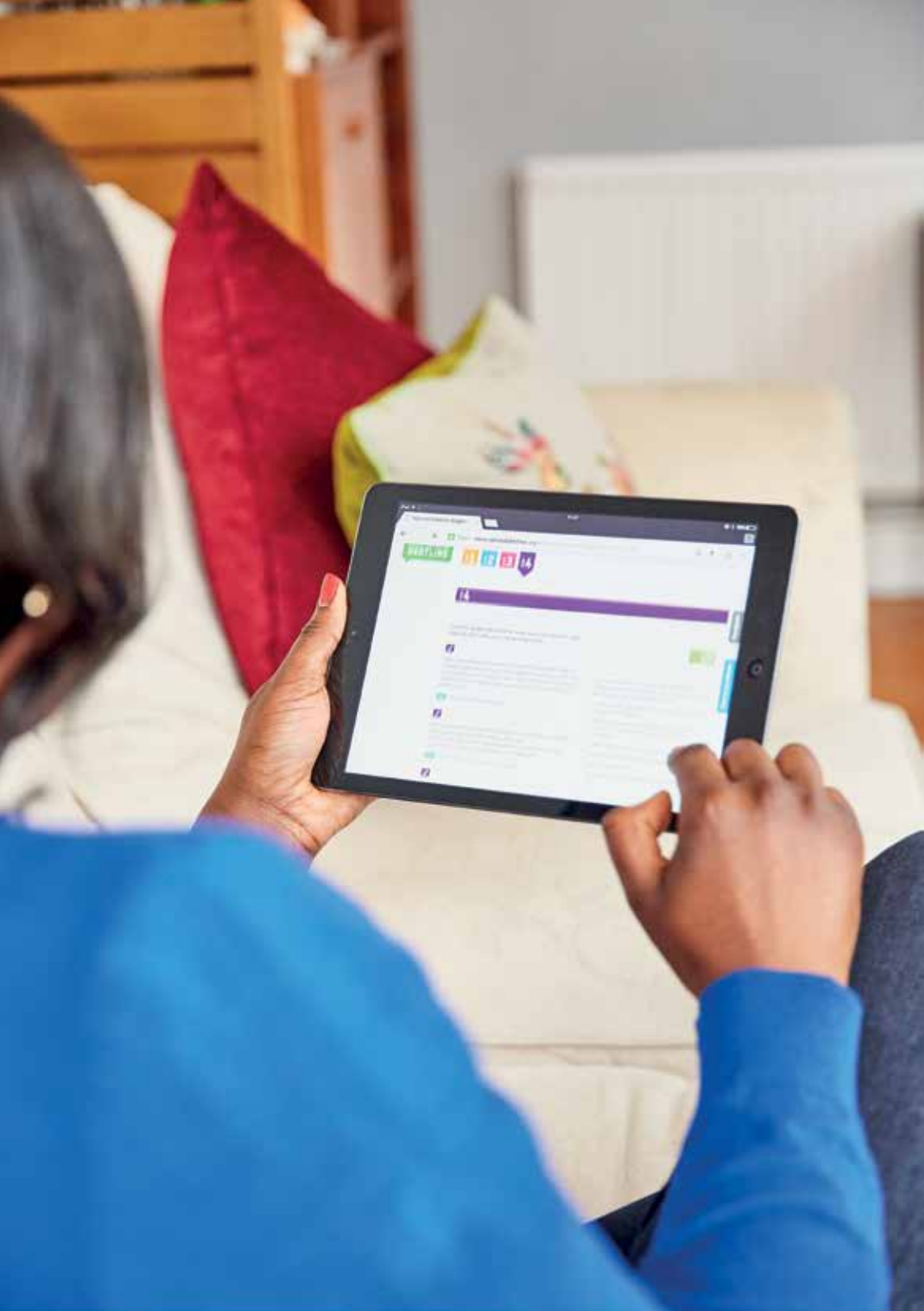
How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information and gradually tell them more to build up a picture of your illness.

## Teenagers

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

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

Our booklet **Talking to children and teenagers when an adult has cancer** includes discussion about sensitive topics. There's also a video on our website that may help, at **[macmillan.org.uk/talkingtochildren](http://macmillan.org.uk/talkingtochildren)**





# FINANCIAL AND WORK SUPPORT

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Financial help and benefits 104

Work 107

# Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

**Personal Independence Payment (PIP)** is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance (DLA)** in England, Scotland and Wales.



**Attendance Allowance (AA)** is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

'On the financial side of things, I pretty quickly worked out that I had to find some option, otherwise I wouldn't be able to pay my rent and I wouldn't be able to pay all my bills. Denise, my benefits advisor, told me exactly what I was and wasn't entitled to.'

**Thom**

## Help for carers

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

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 119). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

## Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance.

A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 118–119.

Our booklets **Insurance** and **Getting travel insurance** may also be helpful.

# Work

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

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

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

## Employment rights

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. There's also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)



# FURTHER INFORMATION

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About our information	110
Other ways we can help you	112
Other useful organisations	115
Your notes and questions	121

# About our information

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

## Order what you need

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

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

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

## Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

## Help us improve our information

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

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

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



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres.

There, you can speak with someone face to face.

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

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.



## Talk to others

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

### Support groups

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

### The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

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

## Help with work and cancer

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



### Macmillan's My Organiser app

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

# Other useful organisations

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

## Bowel cancer support

### Beating Bowel Cancer

**Tel** 020 8973 0011

(Mon–Thu, 9am–5.30pm,  
Friday, 9am–4pm)

**Email** nurse@

beatingbowelcancer.org

**www.bowelcancer.org**

Gives information and support to people affected by bowel cancer.

### Bladder and Bowel Community

**Tel** 01926 357220

**Email** help@bladderandbowelcommunity.org

**www.bladderandbowelfoundation.org**

Provides information and advice on bladder and bowel symptoms.

### The Bobby Moore Fund

**Tel** 020 3469 8881

**Email** bmf@cancer.org.uk

**www.bobbymoorefund.org**

Raises money for research into bowel cancer.

## Bowel Cancer UK in England and Wales

**Tel** 020 7940 1760

**Email**

admin@bowelcanceruk.org.uk

**www.bowelcanceruk.org.uk**

Offers information and support to people affected by bowel cancer.

## Bowel Cancer UK in Scotland

**Email** scotadmin@

bowelcanceruk.org.uk

## Bowel Cancer UK in Northern Ireland

**Email** bernadette.mcgarra@

bowelcanceruk.org.uk

## Colostomy Association

**Tel** 0800 328 4257

**Email** cass@

colostomyassociation.org.uk

**www.**

**colostomyassociation.org.uk**

Provides practical help, support and reassurance to people who have or are about to have a colostomy, their carers, friends, and families.

### **IA – The Ileostomy and Internal Pouch Support Group**

**Tel** 0800 018 4724

**Email** [info@iasupport.org](mailto:info@iasupport.org)

**www.iasupport.org**

Offers support to help anyone who has had, or is about to have, their colon removed and has an ileostomy or internal pouch.

### **General cancer support organisations**

#### **Cancer Black Care**

**Tel** 020 8961 4151

**Email**

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**www.cancerblackcare.org.uk**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

#### **Cancer Focus**

##### **Northern Ireland**

**Helpline** 0800 783 3339

(Mon–Fri, 9am–1pm)

**Email**

[helpline@cancerfocusni.org](mailto:helpline@cancerfocusni.org)

**www.cancerfocusni.org**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

#### **Cancer Support Scotland**

**Tel** 0800 652 4531

(Mon–Fri, 9am–5pm)

**Email**

[info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**www.**

**cancersupportscotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

#### **Maggie's Centres**

**Tel** 0300 123 1801

**Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

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

**Tenovus****Helpline** 0808 808 1010

(Daily, 8am–8pm)

**Email**

info@tenovuscancercare.org.uk

**www.****tenovuscancercare.org.uk**

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

**Cancer registries****The cancer registry**

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

**National Cancer Registration Service****Tel** 020 7654 8000**Email** enquiries@phe.gov.uk**www.ncr.nhs.uk****Scottish Cancer Registry****Tel** 0131 275 7777**Email** nss.csd@nhs.net**www.isdscotland.org/health-topics/cancer/scottish-cancer-registry****Welsh Cancer Intelligence and Surveillance Unit (WCISU)****Tel** 02920 373500**Email**

general.enquiries@wales.nhs.uk

**www.wcisuwales.nhs.uk****Northern Ireland Cancer Registry****Tel** 028 9097 6028**Email** nicr@qub.ac.uk**www.qub.ac.uk/nicr**

## **Counselling and emotional support**

### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

**www.bacp.co.uk**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

### **UK Council for Psychotherapy (UKCP)**

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**www.psychotherapy.org.uk**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## **Equipment and advice on living with a disability**

### **Disability Rights UK**

**Tel** 0207 250 8181

(Mon–Fri, 10–12:30pm, and 1.30–4pm)

**Email**

[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**www.**

**[disabilityrightsuk.org](http://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.

## **Financial or legal advice and information**

### **Benefit Enquiry Line**

#### **Northern Ireland**

**Helpline** 0800 220 674

(Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm)

**Textphone**

028 9031 1092

**www.nidirect.gov.uk/  
money-tax-and-benefits**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

## Citizens Advice

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

### England

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### Wales

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

### Scotland

**[www.cas.org.uk](http://www.cas.org.uk)**

### Northern Ireland

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

## Department for Work and Pensions (DWP) Personal Independence Payment (PIP) Helpline

0345 850 3322

**Textphone** 0345 601 6677  
(Mon–Fri, 8am–6pm)

### Carer's Allowance Unit

**Tel** 0345 608 4321

**Textphone** 0345 604 5312  
(Mon–Thu, 8.30am–5pm,  
Fri, 8.30am to 4.30pm)

**[www.](http://www.gov.uk/browse/benefits)**

**[gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

## GOV.UK

**[www.gov.uk](http://www.gov.uk)**

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

## NiDirect

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland.

## Support for carers

### Carers Trust

**Email** [support@carers.org](mailto:support@carers.org)

**[www.carers.org](http://www.carers.org)**

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

## **Carers UK**

### **Helpline**

**(England, Scotland, Wales)**

0808 808 7777

(Mon–Fri, 10am–4pm)

**Helpline (Northern Ireland)**

028 9043 9843

### **Email**

[advice@carersuk.org](mailto:advice@carersuk.org)

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK.

Can put people in contact with support groups for carers in their area.

## **Support for older people**

## **Age UK**

### **Helpline**

**(England and Wales)**

0800 169 2081

**Helpline (Scotland)**

0800 470 8090

**Helpline (Northern Ireland)**

0808 808 7575

**[www.ageuk.org.uk](http://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.

## **Support for young people**

## **Teenage Cancer Trust**

**Tel** 020 7612 0370

(Mon–Fri, 9am–5.30pm)

### **Email**

[hello@teenagecancertrust.org](mailto:hello@teenagecancertrust.org)

**[www.teenagecancertrust.org](http://www.teenagecancertrust.org)**

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

## **Youth Access**

**Tel** 020 8772 9900

(Mon–Fri, 9.30am–1pm  
and 2–5.30pm)

### **Email**

[admin@youthaccess.org.uk](mailto:admin@youthaccess.org.uk)

**[www.youthaccess.org.uk](http://www.youthaccess.org.uk)**

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **[youthaccess.org.uk/find-your-local-service](http://youthaccess.org.uk/find-your-local-service)**



# YOUR NOTES AND QUESTIONS

A series of horizontal green lines for writing notes and questions. The lines are evenly spaced and extend across the width of the page, providing a structured area for student input.

## 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 Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Andrew Gaya, Consultant Clinical Oncologist; Mr Mark George, Consultant in Colorectal Surgery; Sue Hale, Colostomy Association; Dr Amen Sibtain, Consultant Clinical Oncologist; and Sarah Thompson, Clinical Nurse Specialist – Colorectal Cancer.

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

## Sources

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

Colorectal cancer: diagnosis and management. National Institute of Health and Care Excellence (NICE). 2011. Updated 2014.

Colorectal cancer overview: staging. NICE. 2016 [accessed July 2016].

Diagnosis and management of colorectal cancer: A national clinical guideline. SIGN. 2011. Updated 2016.

# Can you do something to help?

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

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



## **Share your cancer experience**

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

## **Campaign for change**

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

## **Help someone in your community**

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

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

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Signature

Date      /      /

## Don't let the taxman keep your money

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

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

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

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

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



Registered with  
**FUNDRAISING  
REGULATOR**

If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

27530

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

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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

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