



# Understanding Bowel Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

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**13 11 20**



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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# About this booklet

This booklet has been prepared to help you understand more about bowel cancer (also known as colorectal cancer). Many people feel shocked and upset when told they have bowel cancer. We hope this booklet will help you, your family and friends understand how bowel cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about what to ask your treatment team (see page 71 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 72). You may also like to pass this booklet to your family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by bowel cancer. It is based on Australian clinical practice guidelines.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council**  
**13 11 20**

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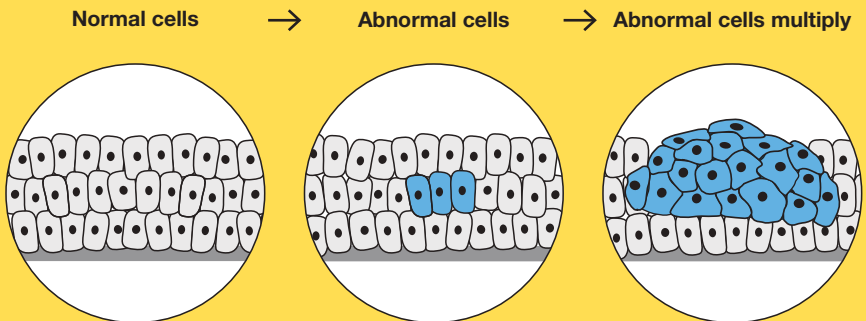
# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as bowel or breast cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

## How cancer starts

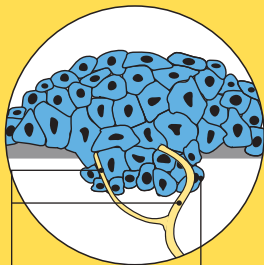


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, bowel cancer that has spread to the liver is called metastatic bowel cancer, even though the main symptoms may be coming from the liver.

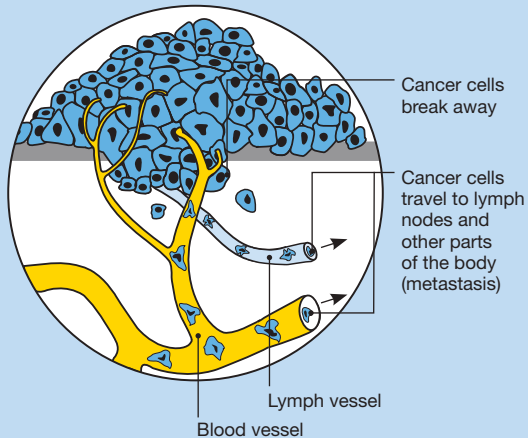
## How cancer spreads

### → Malignant cancer



Grows own  
blood vessels  
(angiogenesis)

Invades  
surrounding  
tissue



Cancer cells  
break away

Cancer cells  
travel to lymph  
nodes and  
other parts of  
the body  
(metastasis)

Lymph vessel

Blood vessel



# The bowel

The bowel is part of the lower gastrointestinal tract, which is part of the digestive system. The digestive system starts at the mouth and ends at the anus. It helps the body break down food and turn it into energy. It also gets rid of the parts of food the body does not use.

## The small bowel (small intestine)

This is a long tube (4–6 m) that absorbs nutrients from food. It is longer but narrower than the large bowel. It has three parts:

- **duodenum** – the first section of the small bowel; receives broken-down food from the stomach
- **jejunum** – the middle section of the small bowel
- **ileum** – the final and longest section of the small bowel; transfers waste matter to the large bowel.

## The large bowel (large intestine)

This tube is about 1.5 m long. It absorbs water and salts, and turns what is left over into solid waste matter (known as faeces, stools or poo when it leaves the body). The large bowel has three parts:

- **caecum** – a pouch that receives waste from the small bowel; the appendix is a small tube hanging off the end of the caecum
- **colon** – the main working area of the large bowel, the colon takes up most of the large bowel's length and has four parts: ascending colon, transverse colon, descending colon and sigmoid colon
- **rectum** – the last 15–20 cm of the large bowel.

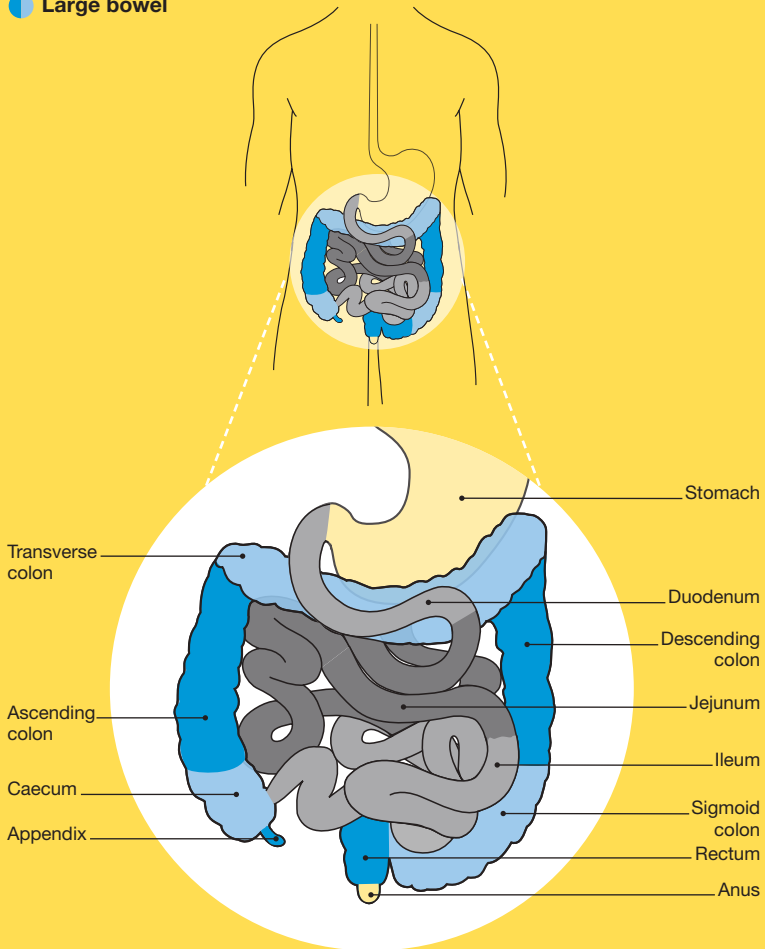
## The anus

This is the opening at the end of the bowel. During a bowel movement, the anal muscles relax to release faeces. Anal cancer is treated differently to bowel cancer: see our *Understanding Anal Cancer* fact sheet.



# The lower digestive system

- Small bowel
- Large bowel





## Key questions

### Q: What is bowel cancer?

**A:** Bowel cancer is cancer in any part of the large bowel (colon or rectum). It is sometimes known as colorectal cancer and might also be called colon cancer or rectal cancer, depending on where it starts. Cancer of the small bowel is very rare – it is called small bowel cancer or small intestine cancer. For information on its treatment and management, call 13 11 20.

Bowel cancer grows from the inner lining of the bowel (mucosa). It usually develops from small growths on the bowel wall called polyps. Most polyps are harmless (benign), but some become cancerous (malignant) over time.

If untreated, bowel cancer can grow into the deeper layers of the bowel wall. It can spread from there to the lymph nodes. If the cancer advances further, it can spread (metastasise) to other organs, such as the liver or lungs.

In most cases, the cancer is confined to the bowel for months or years before spreading. The National Bowel Cancer Screening Program aims to improve early detection (see page 16).

### Q: How common is bowel cancer?

**A:** Bowel cancer is the third most common cancer affecting people in Australia. It is estimated that about 15,250 people are diagnosed with bowel cancer every year. About one in 21 men and one in 31 women will develop bowel cancer before the age of 75. It is most common in people over 50, but it can occur at any age.<sup>2</sup>

## Q: What are the symptoms?

**A:** In its early stages, bowel cancer may have no symptoms. This is why screening is important to increase the chance of an early diagnosis (see page 16). However, many people with bowel cancer do experience symptoms. These can include:

- blood in the stools or on the toilet paper
- a change in bowel habit, such as diarrhoea, constipation or smaller, more frequent bowel movements
- a change in appearance or consistency of bowel movements (e.g. narrower stools or mucus in stools)
- a feeling of fullness or bloating in the abdomen or a strange sensation in the rectum, often during a bowel movement
- feeling that the bowel hasn't emptied completely
- unexplained weight loss
- weakness or fatigue
- rectal or anal pain
- a lump in the rectum or anus
- abdominal pain or swelling
- a low red blood cell count (anaemia), which can cause tiredness and weakness
- rarely, a blockage in the bowel (see pages 34–35).

Not everyone with these symptoms has bowel cancer. Other conditions, such as haemorrhoids, diverticulitis (inflammation of pouches in the bowel wall) or an anal fissure (cracks in the skin lining the anus), can also cause these changes. Changes in bowel function are common and often do not indicate a serious problem. However, any amount of bleeding is not normal and you should see your doctor for a check-up.

## Q: What are the risk factors?

- A:** The exact cause of bowel cancer is not known. However, research shows that people with certain risk factors are more likely to develop bowel cancer. Risk factors include:
- **older age** – most people with bowel cancer are over 50, and the risk increases with age
  - **polyps** – having a large number of polyps in the bowel
  - **bowel diseases** – people who have an inflammatory bowel disease, such as Crohn's disease or ulcerative colitis, have a significantly increased risk, particularly if they have had it for more than eight years
  - **lifestyle factors** – being overweight, having a diet high in red meat or processed meats such as salami or ham, drinking alcohol and smoking
  - **strong family history** – a small number of bowel cancers run in families (see opposite page)
  - **other diseases** – people who have had bowel cancer once are more likely to develop a second bowel cancer; some people who have had ovarian or endometrial (uterine) cancer may have an increased risk of bowel cancer
  - **rare genetic disorders** – a small number of bowel cancers are associated with an inherited gene (see opposite page).

Some things reduce your risk of developing bowel cancer, including being physically active, maintaining a healthy weight, cutting out processed meat, cutting down on red meat, drinking less alcohol, not smoking, and eating wholegrains, dietary fibre and dairy foods. Talk to your doctor about whether you should take aspirin, which has been shown to reduce the risk of developing bowel cancer.

## Q: Can bowel cancer run in families?

**A:** Sometimes bowel cancer runs in families. If one or more of your close family members (such as a parent or sibling) have had bowel cancer, it may increase your risk. This is especially the case if they were diagnosed before the age of 55, or if there are two or more close relatives on the same side of your family with bowel cancer. A family history of other cancers, such as endometrial (uterine) cancer, may also increase your risk of developing bowel cancer.

Some people have an inherited faulty gene that increases their risk of developing bowel cancer. These faulty genes cause a small number (about 5–6%) of bowel cancers. There are two main genetic conditions that occur in some families:

- **Familial adenomatous polyposis (FAP)** – This condition causes hundreds of polyps to form in the bowel. If these polyps are not removed, they may become cancerous.
- **Lynch syndrome** – This syndrome is characterised by a fault in the gene that helps the cell's DNA repair itself.

If you are concerned about your family history, talk to your doctor about having regular check-ups or ask for a referral to a family cancer clinic. To find out more, call Cancer Council 13 11 20.



For an overview of what to expect during your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/bowel-cancer](https://cancerpathways.org.au/optimal-care-pathways/bowel-cancer). This is a short guide to what is recommended from diagnosis to treatment and beyond.

## Q: Which health professionals will I see?

**A:** Your general practitioner (GP) will arrange the first tests to assess your symptoms, or further tests if you have had a positive screening test (see page 16). If these tests do not rule out cancer, you will usually be referred to a specialist, such as a colorectal surgeon or a gastroenterologist. The specialist

### Health professionals you may see

<b>GP</b>	assists with treatment decisions; provides ongoing care in partnership with specialists
<b>colorectal surgeon*</b>	diagnoses bowel cancer and performs bowel surgery
<b>gastroenterologist*</b>	diagnoses and treats disorders of the digestive system, including bowel cancer; may perform endoscopy
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>cancer care coordinator</b>	coordinates your care, liaises with MDT members, and supports you and your family throughout treatment; may be a clinical nurse consultant (CNC) or colorectal cancer nurse
<b>operating room staff</b>	include anaesthetists, technicians and nurses who prepare you for surgery and care for you during the operation and recovery

will arrange further tests. If bowel cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you may see a range of health professionals who specialise in different aspects of your care.

<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>stomal therapy nurse</b>	provides information about surgery and can support you to adjust to life with a temporary or permanent stoma
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>genetic counsellor</b>	provides advice for people with a strong family history of bowel cancer or with a genetic condition linked to bowel cancer
<b>social worker</b>	links you to support services and helps you with emotional, practical or financial issues
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility after treatment, and recommending aids and equipment
<b>counsellor, psychologist</b>	help you manage your emotional response to diagnosis and treatment

*\* Specialist doctor*



# Diagnosis

Some people have tests for bowel cancer because they have symptoms. Others may not have any symptoms, but have a strong family history of bowel cancer (see page 11) or have received a positive result from a screening test (see page 16).

The tests you have to diagnose bowel cancer depend on your specific situation. They may include general tests to check your overall health and body function, tests to find cancer, and tests to see if the cancer has spread (metastasised).

Some tests may be repeated during or after treatment to check how well the treatment is working. It may take up to a week to receive your test results. If you feel anxious while waiting for test results, it may help to talk to a friend or family member, or call Cancer Council 13 11 20 for support.

## Early and advanced bowel cancer

Some bowel cancers are diagnosed when they have already spread beyond the bowel (advanced bowel cancer). This may be because the primary cancer never caused obvious symptoms. The tests discussed in this chapter are used for diagnosing both early and advanced bowel cancer. The treatments are covered in separate chapters.

early bowel cancer



see pages 28–44

advanced bowel cancer



see pages 45–49



## General tests

### Physical examination

Your doctor will examine your body, feeling your abdomen for any swelling. To check for problems in the rectum and anus, your doctor will insert a gloved, lubricated finger into your anus and feel for any lumps or swelling. This is called a digital rectal examination (DRE).

The DRE may be uncomfortable, but it shouldn't be painful. Because the anus is a muscle, it can help to try to relax during the examination. The pressure on the rectum might make you feel like you are going to have a bowel movement, but it is very unlikely that this will happen.

### Blood test

You may have a blood test to assess your general health and to look for signs that suggest you are losing blood in your stools.

The blood test may measure chemicals that are found or made in your liver, and check your red blood cell count. Low red blood cell levels (anaemia) are common in people with bowel cancer, but may also be caused by other conditions.

### Immunochemical faecal occult blood test (iFOBT)

Depending on your symptoms, you may have an iFOBT. This test is generally not recommended for people who are bleeding from the rectum, but may be used for people with unexplained weight loss, abdominal pain, changes to their bowel habits or anaemia.

The iFOBT involves taking a sample of your stools at home. The stool sample is examined for microscopic traces of blood, which may be a sign of polyps, cancer or another bowel condition. An iFOBT does not diagnose cancer, but if it finds blood, your doctor will recommend you have a colonoscopy (see opposite page) as soon as possible, but no later than 120 days after getting the result.

## Screening test for bowel cancer

Screening is the process of looking for polyps or cancer in people who don't have any symptoms.

Screening is particularly important for bowel cancer, which often has no symptoms in its early stages.

It is generally recommended that people aged 50–74 have an iFOBT every two years. Finding bowel cancer early can significantly improve the chance of surviving the disease.

Through the National Bowel Cancer Screening Program, people aged 50 to 74 are automatically sent a free iFOBT kit. A kit can also be purchased from some pharmacies.

You complete the test at home. For more information, phone **1800 118 868** or visit [cancerscreening.gov.au](http://cancerscreening.gov.au).

The National Bowel Cancer Screening Program is aimed at low-risk people without symptoms of bowel cancer. If you have:

- symptoms of bowel cancer (see page 9), talk to your doctor about having a colonoscopy or other tests
- another bowel condition, such as chronic inflammatory bowel disease, talk to your doctor about appropriate surveillance
- a strong family history or a genetic condition linked to bowel cancer (see page 11), talk to your doctor about when you need to start iFOBTs or screening colonoscopies.

## Tests to find cancer in the bowel

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

### Colonoscopy and biopsy

A colonoscopy examines the whole length of the large bowel. It is still possible, however, that small polyps may be missed, especially if they are behind one of the many folds in the bowel or the bowel is not completely empty.

Before a colonoscopy, you will have a bowel preparation to clean your bowel (see page 19). On the day of the procedure, you will usually be given a sedative or light anaesthetic so you don't feel any discomfort or pain. This will also make you drowsy and may put you to sleep.

During the procedure, the doctor will insert a colonoscope (a flexible tube with a camera on the end) into your anus and up into your rectum and colon. Carbon dioxide or air will be passed into the colon.

If the doctor sees any suspicious-looking areas (such as polyps), they will remove the tissue for examination. This is known as a biopsy. During the colonoscopy, most polyps can be completely removed (a polypectomy). A pathologist will examine the tissue under a microscope to check for signs of disease and may look for specific genetic changes (see *Molecular testing* on page 24).

A colonoscopy usually lasts about 20–30 minutes. You will need to have someone take you home afterwards, as you may feel drowsy

or weak. An occasional side effect of a colonoscopy is temporary flatulence and wind pain, especially if air rather than carbon dioxide is passed into the bowel during the test. More serious but rare complications include damage to the bowel or bleeding. Your doctor will talk to you about the risks.

### **Less commonly used tests**

**CT colonography** – This uses a CT scanner (see pages 20–21) to create images of the colon and rectum and display them on a screen. It is also called virtual colonoscopy. It may be used if the colonoscopy was unable to show all of the colon or when a colonoscopy is not safe.

A CT colonography is not often used because it is not as accurate as a colonoscopy and exposes you to radiation. Your doctor also may not be able to see small abnormalities and cannot take tissue samples. This test is covered by Medicare only in some limited circumstances.

**Flexible sigmoidoscopy** – This test allows the doctor to see the rectum and lower part of the colon (sigmoid colon) only. To have a flexible sigmoidoscopy, you will need to have a light bowel clean-out, usually with an enema. Before the test, you may be given a light anaesthetic.

You will lie on your side while a thin, flexible tube called a sigmoidoscope is inserted gently into your anus and guided up through the bowel. The sigmoidoscope blows carbon dioxide or air into the bowel to inflate it slightly and allow the doctor to see the bowel wall more clearly. A light and camera at the end of the sigmoidoscope show up any unusual areas, and your doctor can take tissue samples (biopsy).

## Bowel preparation

Before some diagnostic tests, you will have to clean out your bowel completely. This is called bowel preparation and it helps the doctor see inside the bowel clearly. The process can vary, so ask if there are specific instructions for you. It's important to follow the instructions so you don't have to repeat the test. Talk to your doctor if you have any questions about the bowel preparation process or side effects.



### Change diet

For a few days before the diagnostic test, you may be told to avoid high-fibre foods, such as vegetables, fruit, wholegrain pasta, brown rice, bran, cereals, nuts and seeds. Instead, choose low-fibre options, such as white bread, white rice, meat, fish, chicken, cheese, yoghurt, pumpkin and potato.

### Drink clear fluids

Your doctor might advise you to consume nothing but clear fluids (e.g. broth, water, black tea and coffee, clear fruit juice without pulp) for 12–24 hours before the test. This will help to prevent dehydration.



### Take prescribed laxatives

You will be prescribed a strong laxative to take 12–18 hours before the test. This is taken by mouth in tablet or liquid form over several hours, and will cause you to have several episodes of watery diarrhoea.

### Have an enema, if required

One common way to clear the bowel is using an enema. This involves inserting liquid directly into the rectum. The enema solution washes out the lower part of the bowel, and is passed into the toilet along with any faeces. You may be given an enema before a colonoscopy if the laxative hasn't completely cleaned out the bowel or on its own before a sigmoidoscopy.



Barium enema has been largely replaced by colonoscopy. Barium is a white contrast liquid that is inserted into the rectum and shows up any lumps or swellings during an x-ray.

## Further tests

If any of the tests on pages 15–18 show you have bowel cancer, you will have additional tests to see if the cancer has spread to other parts of your body.

### CEA blood test

Your blood may be tested for a protein called carcinoembryonic antigen (CEA). This protein is produced by some cancer cells. If the results of the blood test show that you have a high CEA level, your doctor may organise more tests. This is because other factors, such as smoking or pregnancy, may also increase the level of CEA. Your CEA level may be retested after treatment to see if the cancer has come back.

### CT scan

A CT (computerised tomography) scan uses x-ray beams to create detailed, cross-sectional pictures of the inside of your body. A scan is usually done as an outpatient. Most people are able to go home as soon as the test is over.


Before the scan, dye is injected into a vein to make the pictures clearer. This dye may make you feel hot all over and leave a strange taste in your mouth for a few minutes. You might also feel that you need to urinate, but this sensation won't last long.

During the scan, you will lie on a table that moves in and out of the CT scanner, which is large and round like a doughnut. Your chest, abdomen and pelvis will be scanned to check if the cancer has spread to these areas. The scan takes 5–10 minutes and is painless.

## MRI scan

An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed, cross-sectional pictures of the inside of your body. An MRI is recommended to more accurately determine the position and extent of rectal cancer. An MRI may also be used to scan the liver if your doctor suspects the cancer has spread to the liver. Usually only people with cancer in the rectum have an MRI; it is not commonly used for cancers higher in the bowel.

A dye might be injected into a vein before the scan to help make the pictures clearer. During the scan, you will lie on a treatment table that slides into a large metal tube that is open at both ends. The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you could become distressed, mention it beforehand to your medical team. You may be given a medicine to help you relax and you will usually be offered headphones or earplugs. The MRI scan may take between 30 and 90 minutes, depending on the size of the area being scanned and how many images are taken.



Before having scans, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you are diabetic, have kidney disease or are pregnant.

## PET-CT scan

A positron emission tomography (PET) scan combined with a CT scan is a specialised imaging test. The two scans provide more detailed and accurate information about the cancer. A PET-CT scan is most commonly used after surgery to help find out where the cancer has spread to in the body or if the cancer has come back after treatment.

Before the scan, you will be injected with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than the normal cells do. You will be asked to sit quietly for 30–90 minutes as the glucose spreads through your body, then you will be scanned. The scan itself will take around 30 minutes. Let your doctor know if you are claustrophobic as the scanner is a confined space.

Medicare only covers the cost of PET-CT scans for bowel cancer in limited circumstances. If this test is recommended, check with your doctor what you will have to pay.

### Less common types of cancer

About 9 out of 10 bowel cancers are adenocarcinomas, which start in the glandular tissue lining the bowel. Rarely, other less common types of cancer can also affect the bowel. These include lymphomas, squamous cell carcinomas, neuroendocrine tumours and gastrointestinal stromal tumours. These types of cancer aren't discussed in this booklet and treatment may be different. Call Cancer Council **13 11 20** for information about these cancer types, or speak to someone in your medical team.



## Staging bowel cancer

The tests described on pages 15–22 help show whether you have bowel cancer and whether it has spread from the original site to other parts of the body. Working out how far the cancer has spread is called staging and it helps your health care team decide the best treatment for you.

In Australia, there are two main systems used for staging bowel cancer:

- the Australian Clinico-Pathological Staging (ACPS) system
- the TNM staging system – TNM stands for tumour–nodes–metastasis. Each letter is assigned a number to show how advanced the cancer is.

Your doctor will combine the results of your early tests, as well as the tests on the cancer tissue and lymph nodes removed during surgery (see pages 29–33), to work out the overall stage of the cancer:

- **stage I (ACPS A)** – tumours are found only in the lining of the bowel (early or limited disease)
- **stage II (ACPS B)** – tumours have spread deeper into the layers of the bowel walls (locally advanced disease)
- **stage III (ACPS C)** – cancer has spread to nearby lymph nodes (locally advanced disease)
- **stage IV (ACPS D)** – tumours have spread beyond the bowel to other parts of the body, such as the liver or lungs, or to distant lymph nodes (advanced or metastatic disease).

In general, earlier stages have better outcomes. Almost 50% of bowel cancers in Australia are diagnosed at stages I and II. If you are finding it hard to understand staging, ask someone in your medical team to explain it in a way that makes sense to you.

## Molecular testing

If you are diagnosed with advanced bowel cancer, your doctor may order extra tests on the biopsy sample to look for particular features that can cause the cancer cells to behave differently. These tests may look for mutations in the RAS and BRAF genes or features in the cancer cells suggesting that further genetic testing is required. Knowing whether the tumour has one of these features may help your treatment team determine suitable treatment options. See *Systemic treatment* on pages 45–46 for more details.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of cancer.

Generally, the earlier that bowel cancer is diagnosed, the better the chances of successful treatment. If cancer is found after it has spread beyond the bowel to other parts of the body, it may still respond well to treatment and can often be kept under control.

Test results, the type of cancer, the rate and depth of tumour growth, the likelihood of response to treatment, and factors such as your age, level of fitness and medical history are important in assessing your prognosis. These details will also help your doctor advise you on the best treatment options.



## Key points about diagnosing bowel cancer

### General tests

General tests to investigate abnormal symptoms include a digital rectal examination (DRE), blood tests, and an immunochemical faecal occult blood test (iFOBT) to look for traces of blood in the stools.

### Main test

- A colonoscopy looks for polyps and cancer in the entire large bowel.
- Before a colonoscopy you will have a bowel preparation to clean out the bowel so the doctor can see inside more clearly.
- If the doctor sees a suspicious-looking area, they will take a tissue sample (biopsy).

### Other tests

Other tests can give more information about the cancer to help guide treatment. These tests may include:

- a blood test to check for a protein called carcinoembryonic antigen (CEA), which is produced by some cancer cells
- imaging scans (CT, MRI or PET-CT) to show the location of the cancer and whether it has spread
- molecular testing for gene mutations in the cancer cells.

### Staging and prognosis

The stage shows how far the cancer has spread through the body. Early bowel cancer is stage I. Locally advanced bowel cancer is stages II and III. Advanced bowel cancer is stage IV. In general, earlier stages have better outcomes.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 13) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 71 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

### Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

► See our *Understanding Clinical Trials and Research* booklet.



# Treatment for early bowel cancer

Treatment for early and locally advanced bowel cancer will depend on the type of bowel cancer you have. This is because colon cancer and rectal cancer are treated differently.

Your medical team will recommend treatment based on what will give you the best outcome, where the cancer is in the bowel, whether and how the cancer has spread, your general health, and your preferences.

The treatment options you are offered will depend on the guidelines for best practice in treating bowel cancer.<sup>1</sup> For some people, the best option may be to join a clinical trial (see previous page).

## Treatment options by type of bowel cancer

### Colon cancer

- Surgery is the main treatment for early and locally advanced colon cancer.
- If the cancer has spread to the lymph nodes, you may have chemotherapy after surgery. This is called adjuvant chemotherapy.
- Radiation therapy is not used for early colon cancer.

### Rectal cancer

- Surgery is the main treatment for early rectal cancer.
- If the cancer has spread beyond the rectal wall and/or into nearby lymph nodes (locally advanced cancer), before the surgery you will have either radiation therapy or chemotherapy combined with radiation therapy (chemoradiation). After the surgery you may have chemotherapy.

## Preparing for treatment

**Managing anaemia** – Many people with bowel cancer have anaemia or low iron levels. You may be given iron as tablets or intravenously to improve your iron levels and blood count before treatment begins.

**Improve diet and nutrition** – People with bowel cancer often lose a lot of weight and may become malnourished. A dietitian can provide advice on ways to reduce the weight loss through changes to your diet or liquid nutritional supplements. This will help improve your strength and lead to better treatment outcomes.

## Surgery

The type of surgery you have will depend on the location of the cancer in the bowel and your preferences. The aim of surgery is to remove as much of the cancer as possible and nearby lymph nodes.

### How the surgery is done

There are two ways to perform surgery for bowel cancer. Each method has advantages in particular situations – your doctor will advise which method is most suitable for you.

**Keyhole surgery** – Also called minimally invasive or laparoscopic surgery, this method involves several small cuts (incisions) in the abdomen. A thin tube (laparoscope) is passed through one of the cuts. The laparoscope has a light and camera. Long, thin instruments are inserted through other small cuts to remove the section of bowel with the cancer. Keyhole surgery usually means less pain and scarring, a shorter hospital stay and faster recovery.

**Open surgery** – This involves one long cut (incision) down the middle of your abdomen. Open surgery usually means a larger wound and slower recovery, and it requires a longer hospital stay. Open surgery is a well-established technique and widely available.

## **Surgery for cancer in the colon**

The most common type of surgery for colon cancer is a colectomy. It may be done as open surgery or keyhole surgery (see pages 29–30). There are different types of colectomies depending on which part of the colon is removed (see opposite page). Lymph nodes near the colon and some normal bowel around the cancer will also be removed.

The surgeon usually cuts the bowel on either side of the cancer (with a small border of healthy tissue called the margin) and then joins the two ends of the bowel back together. This join is called an anastomosis.

Sometimes one end of the bowel is brought through an opening made in your abdomen and stitched onto the skin. This procedure is called a colostomy (if made from the large bowel) or ileostomy (if made from the small bowel). The opening – called a stoma – allows faeces to be removed from the body and collected in a bag.

The stoma is usually temporary, and the operation is reversed later. In some cases, the stoma is permanent. Advances in surgical techniques have led to fewer people needing a permanent stoma. For further information about stomas, see pages 50–55.

After surgery, you will have a scar. Most people who have open surgery have a scar from above their navel to their pubic area.



## Types of colectomies

 Area removed

## Right hemicolectomy



The right side of the colon is removed.\*

## Left hemicolectomy



The left side of the colon is removed.\*

## Transverse colectomy



The middle part of the colon is removed.

## Sigmoid colectomy



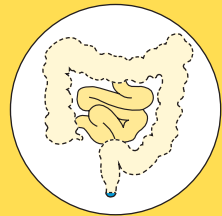
The sigmoid colon is removed.

## Subtotal or total colectomy



Most or all of the bowel is removed.

## Proctocolectomy



All of the colon and rectum are removed.

\* If the transverse colon is also removed, it is called an extended right or left hemicolectomy.

## **Surgery for cancer in the rectum**

There are different types of operations for cancer in the rectum (see opposite page). The type of operation you have depends on where the cancer is located, whether the bowel can be rejoined, and where in the rectum the join can be made.

The surgery may be performed using an open or keyhole approach (see pages 29–30). You may have an anterior resection or abdominoperineal resection (also known as an abdominoperineal excision).

**Anterior resection** – This is the most common operation. It may include creating a temporary stoma, which will be reversed later. For further information about stomas, see pages 50–55.

**Abdominoperineal resection** – This procedure may be recommended if the cancer is near the anal sphincter muscles or if it is too low to be removed without causing incontinence (accidental loss of faeces). After an abdominoperineal resection you will need a permanent stoma (colostomy). Speak to your surgeon about any concerns you may have.

## **Other types of surgery**

**Local excision** – People who have very early stage rectal cancer or are not fit for a major operation may have a local excision. The surgeon inserts an instrument into the anus to remove the cancer from the lining of the rectum, along with a margin of healthy tissue, without cutting into the abdomen. Methods include transanal excision (TAE), transanal endoscopic microsurgery (TEMS) and transanal minimally invasive surgery (TAMIS).

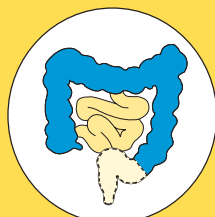
## Types of resections

 Area removed



### High anterior resection

The surgeon removes the lower left part of the colon and the upper part of the rectum. Nearby lymph nodes and surrounding fatty tissue are also removed. The lower end of your bowel is rejoined to the top of the rectum.



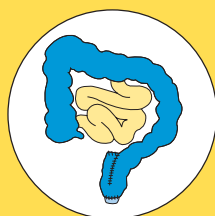
### Abdominoperineal resection or excision (APR or APE)

The sigmoid colon, the entire rectum and the anus are removed. Your surgeon uses the descending colon to create a permanent stoma (known as a colostomy) for faeces to leave the body. The anal area will be stitched up and permanently closed.



### Ultra-low anterior resection

The lower left part of the colon and the entire rectum are removed, along with nearby lymph nodes and fatty tissue. The end of the bowel is joined to the lowest part of the rectum, just above the anus. In some cases, the surgeon creates another way for waste to leave the body (see below).



### Colonic J-pouch

An internal pouch is made from the lining of the large bowel. This J-pouch will be connected to the anus and work as a rectum. You may have a temporary ileostomy (a stoma from the small bowel, see page 51), which will be reversed once the J-pouch heals.

**If there are two cancers** – In a small number of people, two separate cancers may be found in the large bowel at the same time. The cancers may be discovered through diagnostic tests or during surgery. In this case, there are several options for surgery:

- remove two sections of the bowel
- remove one larger section of the bowel, which includes both areas with cancer
- remove the entire colon and rectum (proctocolectomy) to prevent any chance of another cancer forming.

The type of surgery your doctor recommends depends on several factors including your age, the location of the tumours in the bowel, genetic and other risk factors, and your preferences.

### **Surgery for a blocked bowel (bowel obstruction)**

Sometimes as the bowel cancer grows it completely blocks the bowel. This is called bowel obstruction. Waste matter cannot pass through the blocked bowel easily, and may cause:

- bloating and abdominal pain
- constipation
- nausea and vomiting.

Sometimes the obstruction is found and cleared during the surgery to remove the cancer. In other cases, the bowel obstruction will mean you have to have emergency surgery to clear the blockage.

It may be possible to rejoin the bowel during the surgery, but some people may need a stoma (see pages 50–55). Sometimes a stoma is made “upstream” from the obstruction to relieve the blockage and

to allow time for staging scans of the cancer or chemoradiation before surgery, to make sure the cancer is removed completely.

Not everyone with a blockage will want to have surgery or be fit enough to have it. To help keep the bowel open so that stools can pass through again, your surgeon may be able to insert a small hollow tube (stent) inside the colon. A stent may also help manage the blockage until you are well enough to have an operation. Your surgeon will use a colonoscope (see page 17) to find the blockage and place the stent.

If you are unable to have surgery or a stent, you may be given medicine to help control the symptoms of a bowel obstruction.

## Risks of bowel surgery

Your surgeon will talk to you about the risks and complications of bowel surgery. As with any major operation, bowel surgery has risks. Complications may include infection, bleeding, blood clots, damage to nearby organs, or leaking from the joins between the removed parts of the bowel. You will be carefully monitored for any side effects afterwards.



Most hospitals in Australia have programs to reduce the stress of surgery and improve your recovery. These are called enhanced recovery after surgery (ERAS) or fast track surgical (FTS) programs, and they encourage you to play an active part in your care through pre-admission counselling, and education about pain control, diet and exercise so you know what to expect each day after the surgery.

## What to expect after surgery

This is a general overview of what to expect. The process varies from hospital to hospital, and everyone will respond to surgery differently.

### Recovery time

- Your recovery time after the operation will depend on your age, the type of surgery you had and your general health.
- You will probably be in hospital for 4–7 days, but it can take 2–3 months to fully recover.
- You will have to wear compression stockings while you are in hospital to help the blood in your legs to circulate.
- You will also be given a daily injection of a blood thinner to reduce the risk of developing blood clots.
- Some people also wear a special cuff that applies intermittent pressure to the legs.
- Some people may have to wear the stockings and have the injections for a couple of weeks after the surgery.

### Pain relief

- You will have some pain and discomfort for several days after surgery, but you will be given pain-relieving medicines to manage this.
- Pain relief may be given in various ways:
  - by an injection near your spinal column (epidural or spinal anaesthetic)
  - through a drip which you can control with a button (PCA – patient controlled analgesia)
  - as pills or tablets
  - through little tubes giving local anaesthetic near your wound (TAP block catheters).
- Let your doctor or nurse know if you are in pain so they can adjust the medicines to make you as comfortable as possible. Do not wait until the pain is severe.

## Drips and tubes

- You will be given fluids through a drip (also called an intravenous or IV infusion) until you can start eating and drinking again. You may need a drip for a few days.
- You may also have other tubes – from your bladder to drain urine (catheter) or from your abdomen to drain fluid from around the surgical area.
- In most centres, you will be given water to drink a few hours after the surgery and you will usually start on solid foods the day after the surgery (or even on the day of the surgery if you feel well). You may also be given nutritional supplements to drink.
- In some centres, you will not have anything to eat or drink for several days after the surgery.

## Activity/exercise

- Your health care team will encourage you to walk the day after the surgery.
- You will need to avoid heavy lifting (more than 3–4 kg) for about 4–6 weeks.
- A physiotherapist will teach you breathing or coughing exercises to help keep your lungs clear. This will reduce the risk of getting a chest infection.
- Gentle exercise has been shown to help people manage some of the common side effects of treatment and speed up a return to usual activities.

## Side effects of bowel surgery

**Changes in bowel and sexual function** – Many people find that their bowel and bladder functions change. These usually improve within a few months but, for some people, it can take longer. See pages 56–58 for more details. Erection problems can also be an issue for some men after rectal cancer surgery (see page 41).

➤ See our *Sexuality, Intimacy and Cancer* booklet.

**Changes to your diet** – See pages 59–61 for information.

**Fatigue** – It is normal to feel tired after surgery. Although it's a good idea to stay active and do gentle exercise as recommended by your doctor, you may find that you tire easily and need to rest during the day. Take breaks if you feel tired, and follow your doctor's advice about restrictions, such as avoiding heavy lifting. You might have to remind your family and friends that it may take several months to recover from surgery.

**Temporary or permanent stoma** – See pages 50–55 for details.

## Radiation therapy

Also known as radiotherapy, this treatment uses a controlled dose of radiation, such as focused x-ray beams, to kill or damage cancer cells. The radiation is targeted to the specific area of the cancer, and treatment is carefully planned to do as little harm as possible to your normal body tissue near the cancer. Radiation therapy is often combined with chemotherapy (chemoradiation). This is because chemotherapy makes cancer cells more sensitive to radiation.



Radiation therapy is not generally used to treat locally advanced colon cancer. Commonly, a short course of radiation therapy or a longer course of chemoradiation is used to shrink the tumour before surgery for locally advanced rectal cancer. The aim of this treatment is to make the cancer as small as possible before it is removed. This means it will be easier for the surgeon to completely remove the tumour and reduces the risk of the cancer coming back.

Occasionally, if the rectal cancer is found to be more advanced than originally thought, radiation therapy may be used after surgery to destroy any remaining cancer cells.

External beam radiation therapy is the most common type of radiation therapy for rectal cancer. Newer techniques deliver the dose to the affected area without damaging surrounding tissue. These improvements have reduced the side effects from radiation therapy.

During treatment, you will lie on a treatment table under a machine called a linear accelerator. Each treatment takes only a few minutes, but a session may last 10–20 minutes because of the time it takes to set up the machine.

There will be a break between radiation therapy and surgery to allow the treatment to have its full effect. If radiation therapy is given with chemotherapy, you will have it once a day for 5–6 weeks, then there will be a gap of 6–12 weeks before surgery. If radiation therapy is given by itself, you will have a shorter course, usually for five days, then a shorter gap before surgery.

➤ See our *Understanding Radiation Therapy* booklet.

## Side effects of radiation therapy

The side effects of radiation therapy vary. Most are temporary and disappear a few weeks or months after treatment. Radiation therapy for rectal cancer is usually given over the pelvic area, which can irritate the bowel and bladder (see pages 56–58).

Common side effects include feeling tired, needing to pass urine more often and burning when you pass urine (cystitis), redness and soreness in the treatment area, diarrhoea, constipation or faecal urgency and incontinence (see page 56). Radiation therapy can cause the skin or internal tissue to become less stretchy and harden (fibrosis). It can also affect fertility and sexual function (see opposite page).

People react to radiation therapy differently, so some people may have few side effects, while others have more. Your treatment team will give you advice about possible side effects and how to manage them.

### Radiation proctitis

Radiation to the pelvic area can damage the lining of the rectum, causing inflammation and swelling (known as radiation proctitis). This can cause a range of symptoms including diarrhoea, the need to empty the bowels urgently and loss of control over the bowels (faecal incontinence). When treating rectal cancer, these side effects may appear shortly after radiation therapy, but are generally not a problem long term because the rectum is removed during surgery. Your treatment team will talk to you about your risk of developing radiation proctitis. See also pages 56–62 for some ways to cope with bowel changes.

## Effects on fertility and sexual function

Radiation therapy to the pelvis and rectum can affect your ability to have children (fertility) and sexual function.

### For men

- Radiation therapy can damage sperm or reduce sperm production. This may be temporary or permanent.
- Most doctors suggest that men use contraception and don't have unprotected sex during and for one month after radiation therapy.
- You will be able to store sperm at a hospital or fertility clinic before treatment starts. Talk to your doctor about this.
- Because radiation therapy can damage blood vessels and nerves that produce erections, some men may have erection problems. Your doctor may prescribe medicine or refer you to a specialist clinic to manage this problem.

### For women

- Radiation therapy can lead to the vagina becoming shorter and narrower, making sexual intercourse painful. Your doctor may suggest you use a vaginal dilator after radiation therapy is finished to help gradually widen the entrance and prevent the side walls sticking together. Using dilators can be challenging. Your doctor or a physiotherapist can provide practical advice on using a dilator.
- Talk to your doctor about creams and moisturisers to help with vaginal discomfort and dryness.
- In some cases, radiation therapy can stop the ovaries producing female hormones. This can cause menopause and infertility.
- Menopause can be managed by hormone replacement therapy, which can be taken if you've had rectal cancer. After menopause you will not be able to conceive a child.
- Share your feelings about any fertility issues with your partner, a counsellor or a fertility specialist.

See our *Fertility and Cancer* and *Sexuality, Intimacy and Cancer* booklets.

## Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells while doing the least possible damage to healthy cells. If the cancer has spread outside the bowel to lymph nodes or to other organs, chemotherapy may be recommended:

**Before surgery (neoadjuvant)** – Some people with locally advanced rectal cancer have chemotherapy before surgery to shrink the tumour and make it easier to remove. You are likely to have chemotherapy together with radiation therapy (chemoradiation).

**After surgery (adjuvant)** – Chemotherapy may be used after surgery for either colon or rectal cancer to get rid of any remaining cancer cells and reduce the chance of the cancer coming back. If your doctor recommends chemotherapy, you will probably start as soon as your wounds have healed and you've recovered your strength, usually within eight weeks.

**On its own** – If the cancer has spread to other organs, such as the liver or lungs, chemotherapy may be used either to shrink the tumours or to reduce symptoms and make you more comfortable (see page 48).

You may have chemotherapy through a liquid drip into a vein (intravenously) or as tablets. It may also be given through a thin plastic tube called a central venous access device. Some people have chemotherapy at home through a portable bottle called an infusor pump. You will probably have chemotherapy as a course of several sessions (cycles) over 4–6 months. Your medical oncologist will explain your treatment schedule.

## Side effects of chemotherapy

People react to chemotherapy differently – some people have few side effects, while others have many. The side effects depend on the drugs used and the dose. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be prevented or controlled with medicine. It is uncommon to need a break or change in your treatment.

Common side effects include tiredness; feeling sick (nausea and vomiting); diarrhoea; mouth sores and ulcers; changes in appetite, taste and smell; sore hands and feet; and hair loss or thinning. You may also be more likely to catch infections.

Pins and needles, numbness, redness or swelling in the fingers and toes are more common if using the chemotherapy drug called oxaliplatin. Skin peeling and increased sensitivity to sunlight are more common if using the chemotherapy drug called fluorouracil (or 5-FU).

Keep a record of the doses and names of your chemotherapy drugs handy. This will save time if you become ill and need to visit the emergency department.

➤ See our *Understanding Chemotherapy* booklet.



During chemotherapy, you will have a higher risk of getting an infection or bleeding. If you have a temperature over 38°C, contact your doctor or go to the emergency department. Tell your doctor if you feel more tired than usual, or if you bruise or bleed easily.



## Key points about treating early bowel cancer

### Treatments for early colon cancer

- The main treatment is surgery to remove part or all of the colon (colectomy).
- There are different types of colectomies depending on where the cancer is located.
- If cancer has spread from the colon to nearby lymph nodes, you may have chemotherapy after surgery.

### Treatments for early rectal cancer

- The main treatment is surgery to remove all or part of the rectum (resection).
- There are different types of resections depending on where the cancer is located.
- If cancer has spread from the rectum into nearby tissue or lymph nodes, you will usually have radiation therapy or chemoradiation before the surgery.
- A local excision to remove the cancer may occasionally be used for very early stage rectal cancer.

### How surgery is done

- Surgery for bowel cancer may be done as keyhole surgery (several smaller cuts) using a tiny surgical instrument with a camera and light, or open surgery (one large cut).
- During bowel surgery, the surgeon cuts the bowel on either side of the cancer and joins the two ends back together.
- If it is not possible to join the bowel back together or if the bowel needs time to heal, a diversion is created for faeces to come through a hole (stoma) in the abdominal wall.



# Treatment for advanced bowel cancer

When bowel cancer has spread to the liver, lung or lining of the abdomen and pelvis (omentum and peritoneum), this is known as advanced or metastatic (stage 4) bowel cancer. To control the cancer, slow its growth and manage symptoms such as pain, you may have a combination of chemotherapy, targeted therapy, radiation therapy and surgery.

## Systemic treatment

Advanced bowel cancer is commonly treated with drugs that reach cancer cells throughout the body. This is called systemic treatment, and includes chemotherapy (see pages 42–43) and targeted therapy.

Targeted therapy drugs work differently from chemotherapy drugs. While chemotherapy drugs affect all rapidly dividing cells and kill cancerous cells, targeted therapy drugs affect specific molecules within cells to block cell growth.

Monoclonal antibodies are the main type of targeted therapy drug used in Australia for advanced bowel cancer. They include:

**Bevacizumab** – This drug stops the cancer developing new blood cells and growing. It is given as a drip into a vein (intravenous infusion) every two to three weeks, with chemotherapy.

**Cetuximab and panitumumab** – These drugs target specific features of cancer cells known as epidermal growth factor receptors (EGFR). They only work for people who have a normal RAS gene (known as RAS wild-type). The tumour will be tested

for changes (mutations) in these genes before you are offered these drugs (see page 24). These drugs are usually given as a drip into a vein (intravenous infusion). They may be given with chemotherapy or on their own after other chemotherapy drugs have stopped working.

Other types of targeted therapy drugs may be available on a clinical trial (see page 27). Talk with your doctor about the latest developments and whether you are a suitable candidate.

Scans and blood tests will be used to monitor your response to systemic treatments. If results show that the cancer is shrinking or is under control, chemotherapy and/or targeted therapy will continue. If the cancer is growing, that treatment will stop and alternative treatments will be discussed.

### Side effects of targeted therapy

The side effects of targeted therapy vary depending on the drugs used. Common side effects of bevacizumab include high blood pressure, tiredness, bleeding and headaches. The most common side effects of cetuximab and panitumumab are skin problems (redness, swelling, an acne-like rash or dry, flaky skin), tiredness and diarrhoea.

➤ See our *Understanding Targeted Therapy* fact sheet.

### Radiation therapy

Radiation therapy can also be used as a palliative treatment for both advanced colon and advanced rectal cancer. It can be used to stop bleeding and, if the cancer has spread to the bone or formed a mass in the pelvis, it can reduce pain. For further details, see pages 38–41.



## Surgery

If the cancer has spread to other parts of the body, you may still be offered surgery. This can help remove some secondary cancers (e.g. in the liver or lungs) or relieve a bowel obstruction (see pages 34–35).

You may have surgery to remove parts of the bowel along with all or part of other affected organs. This may be called an en-bloc resection or, if the cancer is in your pelvis, an exenteration.

If the cancer has spread to the lining of the abdomen (peritoneum), you may have surgery to remove as many tumours as possible. This is known as a peritonectomy or cytoreductive surgery. Sometimes, a heated chemotherapy solution is inserted into the abdomen during a peritonectomy. This is called hyperthermic intraperitoneal chemotherapy (HIPEC). Recent studies suggest that surgery alone may be as effective as surgery followed by HIPEC, and ongoing research continues to test the best approach to treatment.

The type of operation used for advanced bowel cancer will depend on your situation, so talk to your surgeon about what to expect. Your medical team will advise what kind of follow-up and treatment is recommended after surgery. Regular check-ups have been found to improve survival for people after surgery for bowel cancer, so you should have check-ups for several years (see page 66).

Many treatments for advanced bowel cancer are best performed in a specialised centre. Call **13 11 20** for more information or to ask about assistance that may be available if you have to travel a long way.



## Other treatments

If the cancer cannot be removed with surgery, but has only spread to a small number of places in a single area, your doctor may recommend another type of treatment to destroy or control the cancer. These treatments, including thermal ablation, selective internal radiation therapy (SIRT) and stereotactic body radiation therapy (SBRT), are only suitable for some people. They are best performed in a specialised centre or may be offered as part of a clinical trial (see page 27).

## Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care.

Many people think that palliative treatment is for people at the end of their life, but it may help at any stage of advanced bowel cancer. It is about living for as long as possible in the most satisfying way you can.

Sometimes treatments such as surgery, chemotherapy, radiation therapy or targeted therapy are given palliatively. The aim is to help relieve symptoms such as pain or bleeding by shrinking or slowing the growth of the cancer.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical, social and spiritual needs.

- See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.



## Key points about advanced bowel cancer

<b>What it is</b>	Advanced bowel cancer is cancer that has spread from the bowel to another part of the body or come back after the initial treatment.
<b>Treatment goal</b>	Treatment aims to control the cancer, slow down its spread and manage any symptoms.
<b>The main treatment</b>	Systemic treatments, including chemotherapy and targeted therapy, are used to control the cancer's growth and stop it spreading.
<b>Targeted therapy</b>	Monoclonal antibodies are the main type of targeted therapy drug used for advanced bowel cancer. They include bevacizumab, cetuximab and panitumumab. The tumour may need to be tested to see if these drugs will be effective.
<b>Other treatment options</b>	Other options might include chemotherapy, radiation therapy, surgery, and palliative treatments. For some people, the best option may be to join a clinical trial.
<b>Treatment side effects</b>	All treatments can cause side effects, such as pain, tiredness, skin problems or diarrhoea. Talk to your doctor about how to manage any side effects.



# Having a stoma

A stoma is a surgically created opening in the abdomen that allows faeces to leave the body. The end of the bowel is brought out through the opening and stitched onto the skin. Some people need a stoma after bowel surgery.

## Types of stoma

The two types of stoma are a colostomy (made from the colon in the large bowel) and an ileostomy (made from the ileum in the small bowel). A stoma may be temporary or permanent.

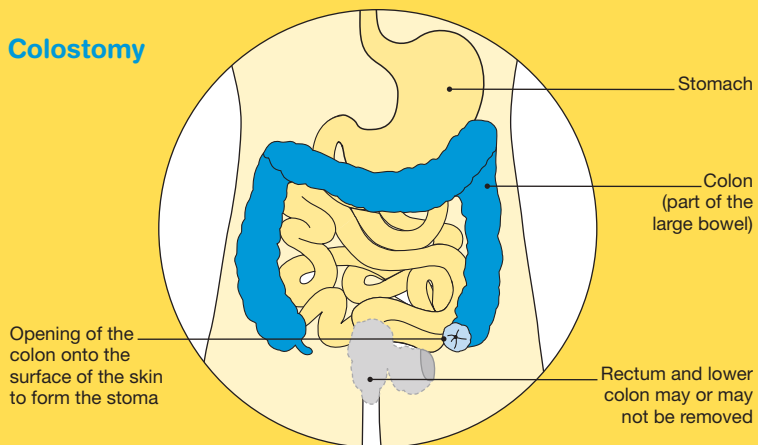
A temporary stoma is needed only until the newly joined bowel has healed. In this situation, a loop stoma is often used. A loop of the bowel is brought out, and then opened and stitched to the skin. This creates two openings. If you have a temporary stoma, you will have another operation, usually after 3–12 months, to close the stoma and rejoin the bowel. This is called a stoma reversal. The process for reversing the stoma will depend on the type of stoma you have. Less than 10% of people with bowel cancer need a permanent stoma.

Like the inside of the mouth, a stoma is soft, moist, and red or pink in colour. It may be level with the surrounding skin or slightly raised. The stoma itself doesn't have any feeling, but the skin around it does.

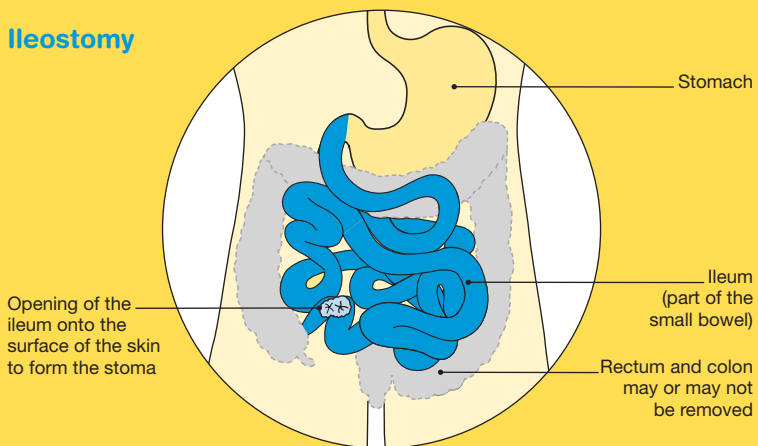
Stomas vary in size and can change shape during the weeks after surgery. A stomal therapy nurse (see page 54) will usually see you before any surgery which may result in a stoma. They will also see you after your operation to teach you how to look after the stoma and give you advice about any changes to your stoma or the skin around it.

## Bowel stomas

### Colostomy



### Ileostomy



 Area that may be removed

## How the stoma works

When the bowel moves, wind and waste matter (faeces, stools or poo) come out through the stoma. You cannot control when this happens, but a small disposable bag is worn on the outside of the body to collect the waste. This is called a stoma bag or an appliance. Stoma bags have adhesive on the back so they stick firmly to the skin and provide a leak-proof, odour-proof system. A filter lets out any wind (but not the odour), which should stop the wind inflating the bag. The bag usually can't be seen under clothing.

**Attaching the bag** – A stomal therapy nurse (see page 54) will help you choose an appliance that suits your body shape and the stoma, and will explain how to attach it securely.

**Emptying the bag** – Stoma bags can be drainable (able to be emptied) or closed (discarded after each bowel movement). With an ileostomy, you wear a drainable bag because the waste matter tends to be watery or soft. With a colostomy, the bag may be drainable or closed, depending on the consistency of your waste matter. A drainable bag has to be emptied down the toilet when it is about one-third full. A closed bag should be put in a rubbish bin after each bowel movement (not flushed down the toilet).



Some people don't like to wear stoma bags. If you have a colostomy in your descending colon, you may be able to learn how to give yourself a type of enema (colostomy irrigation) to remove the waste every day or two. Talk to your doctor and stomal therapy nurse about this option.

## Living with a stoma

Having a stoma, even temporarily, is a big change in a person's life and takes some getting used to. However, thousands of Australians have a stoma and most lead a relatively normal life.

The stoma may sometimes affect your travel plans, social life and sexual relationships, but these issues can be managed, especially with some planning. Unless your job or hobbies are particularly strenuous, you should still be able to participate in your usual activities.

You may worry about how you will look. Although the stoma bag may seem obvious to you, most people won't notice anything is different unless you tell them. The stoma's location may make some clothes less comfortable (e.g. tight waistbands or belts), but you will generally be able to continue wearing your normal clothes. You might consider buying underwear designed for people with a stoma.

Many people with a stoma worry that the stoma will affect their ability to give or receive sexual pleasure. In women, if the rectum is removed, there may be a different feeling in the vagina during intercourse. It may be uncomfortable, as the rectum no longer cushions the vagina. In men, creating a stoma usually involves removing part or all of at least one organ in the pelvic area. This may affect the nerves controlling erections.

For people with a stoma, some foods can cause blockages. This means solids, fluids and gas can't move through as they normally would. To help the stoma settle and to avoid blockages, you may need to make some dietary changes (see pages 59–61). Over time, most people find they can eat a normal healthy diet.

A stoma blockage can be uncomfortable and cause a bloated feeling or nausea. If you experience symptoms of a blockage for more than two hours or you start vomiting, contact your nurse or hospital. For tips on avoiding blockages, see page 61.

## **Support for people with a stoma**

**See a stomal therapy nurse** – If there is a chance you could need a stoma, the surgeon will probably refer you to a stomal therapy nurse before surgery. Stomal therapy nurses are registered nurses with special training in stoma care. They can talk to you about the best place for the stoma to be located, answer questions about your surgery and recovery, and give you information about adjusting to life with a stoma. For more details, visit the Australian Association of Stomal Therapy Nurses at [stomalthrapy.com](http://stomalthrapy.com) or call Cancer Council 13 11 20.

**Join a stoma association** – With your consent, the stomal therapy nurse will sign you up to a stoma (or ostomy) association. For a small annual membership fee, you will be able to obtain free stoma appliances and products. Stoma associations also provide assistance and information to members and coordinate support groups for people of all ages. The Australian Council of Stoma Associations represents stoma associations across Australia. Go to [australianstoma.com.au](http://australianstoma.com.au).

**Register for the Stoma Appliance Scheme** – The Australian Government’s Stoma Appliance Scheme (SAS) provides free stoma supplies to people with a temporary or permanent stoma. To apply for the SAS, you must hold a Medicare card and belong to a stoma association. Visit [health.gov.au](http://health.gov.au) and type “Stoma Appliance Scheme” into the search box for more details.





## Paul's story

The first sign of the bowel cancer was that I had a little bit of bleeding when I went to the toilet. I thought it might be polyps, but when it became more frequent and heavy, I decided to go to the GP.

My GP put me onto a specialist who used a little camera to have a look inside when I went to have a colonoscopy a week later. Right away, my doctor showed me a picture of a large tumour in my lower bowel.

The cancer was aggressive, so my medical team wanted to start treating it right away. They recommended a short course of radiation therapy followed by an operation.

I had a week of intense radiation therapy. I experienced some nausea, so I'd have to take some medicine for that about an hour afterwards. The treatment also caused some stomach upset.

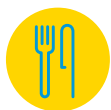
Before the operation, I saw a stoma nurse who talked to me about what to expect.

The surgeon planned to make a temporary stoma, but halfway through the operation, he saw that the tumour was all the way down the bowel and he had to make a permanent one.

I'm used to the colostomy now, but I have my up and down days. I feel self-conscious sometimes because I think the bag is noticeable under most fitted men's clothing. Other people say it's not noticeable, but I don't wear the same things I used to.

I have learnt to live with the stoma. It took some time, but I worked out which foods went through easily.

Having a colostomy hasn't stopped me travelling – I've been able to holiday in Bali a couple of times.



# Managing bowel and dietary changes

After treatment for bowel cancer, many people find that they need to adjust to changes to their digestion or bowel function. Changes to how your bowel or bladder works can be very distressing and difficult to adjust to. These changes may be temporary or ongoing, and may require specialised help. If you experience any of these problems, talk to your GP, specialist doctor, specialist nurse or dietitian.

## Incontinence

Incontinence is when a person is not able to control their bowel or bladder. It may be caused by different types of treatment.

**Faecal incontinence** – The movement of waste through the large bowel can become faster after surgery or radiation therapy. This can mean you need to go to the toilet more urgently and more often. It may also result in a loss of control over bowel movements. Bowel surgery or radiation therapy may weaken the anus, making it difficult to hold on when you feel the need to empty your bowels, particularly if you have loose stools (diarrhoea).

**Urinary incontinence** – This is when urine leaks from your bladder without your control. Bladder control may change after surgery or radiation therapy. For example, radiation therapy can irritate the lining of your bladder, because the bladder is located near the large bowel. Some people find they need to urinate more often, need to go in a hurry or don't fully empty the bladder.

If you have bowel or bladder changes, you may feel embarrassed, but there are ways to manage the symptoms. Incontinence issues usually

improve in a few months, but sometimes take years. Talk to your health care team about whether any bowel or bladder changes are likely to be permanent.

For ways to manage incontinence:

- Talk to your surgeon or GP about available treatments. They may refer you to the hospital continence nurse or physiotherapist, who can suggest exercises to strengthen the pelvic floor muscles.
- Call the National Continence Helpline on 1800 33 00 66 to talk to a continence nurse about continence aids, if needed, or visit [bladderbowel.gov.au](http://bladderbowel.gov.au).
- Visit [toiletmap.gov.au](http://toiletmap.gov.au) to locate public toilets near you. You can also download the National Public Toilet Map App from the App Store (Apple phones) or Google Play (Android phones).



The Australian Government's *Improving Bowel Function After Bowel Surgery* booklet provides helpful tips about managing bowel problems. Visit [continence.org.au/resources](http://continence.org.au/resources) to get a copy, or call **1800 33 00 66**.

## Diarrhoea

Diarrhoea, the frequent passing of loose, watery stools, may be caused by different types of treatment:

**Surgery** – If you have had part of your bowel removed, your bowel movements may be looser than you were used to. This is because the bowel absorbs water to form your stools. With a shorter bowel, the stools don't form as solidly as before. This may be ongoing.

**Radiation therapy** – Diarrhoea is a common side effect of radiation therapy. It can take some weeks to settle down after treatment has finished. For a small number of people, diarrhoea is ongoing.

**Chemotherapy** – This can cause diarrhoea and nausea. These side effects will go away after treatment and you can gradually resume a normal diet.

The fast movement of food through your bowel before your body can absorb the water and nutrients can make you dehydrated. Signs of dehydration include a dry mouth, dark urine, dizziness and confusion. If left untreated, this can be dangerous. To manage dehydration, drink plenty of water and consider using a rehydration drink. If your anus becomes sore, a pharmacist can recommend a cream.

Having diarrhoea can also make you feel tired. Try to rest as much as possible and ask family or friends to help out with chores. Talk to your doctor and nurses about ways to control diarrhoea, such as using medicines, changing your diet (see page 60) and replacing fluids. You may also be referred to a dietitian or to a physiotherapist who specialises in bowel function.

## Wind (flatulence)

Many people who have treatment for bowel cancer, especially surgery, find that it gives them wind. Reducing the foods that produce wind may be helpful. These might include fruit and vegetables with a high amount of carbohydrates that cannot be digested and absorbed in the intestine (see table on pages 60–61).

## Diet after treatment

Immediately after treatment – particularly surgery – you may be on a modified diet. During and after recovery from treatment, you may find that some foods cause discomfort, wind or diarrhoea (see pages 60–61).

Your treatment team may tell you about some foods to avoid, but different foods can affect people differently, so you will need to experiment to work out which foods cause problems for you. It is best to limit – not eliminate – these foods from your diet, as you may find that what you can handle improves over time.

Keeping a food and symptom diary can help. Your ability to handle different foods usually improves with time but can take many months. If you find that dietary fibre makes any bowel problems worse, you may need to eat low-fibre foods.

If you have a stoma, you may need to make some dietary changes in the first few weeks to help the stoma settle. Nuts, seeds and very fibrous foods can lead to a blockage in the stoma. The level of stoma output will vary depending on how much you eat and when you eat. By trial and error, you might identify particular foods that irritate the stoma, but these vary considerably between people.

Most people with a stoma return to their normal diet. If you have concerns, your doctor or stomal therapy nurse may refer you to a dietitian.

- See our *Nutrition and Cancer* booklet for information about eating well during and after cancer treatment.

## Coping with dietary issues

### General

- Everyone responds to food differently.
- Try different foods more than once to see how you react. If a food doesn't cause you any problems, you don't need to avoid it.
- If you have ongoing problems with food and eating, talk to your treatment team.
- You may be able to see a dietitian at your cancer treatment centre – check with your cancer care coordinator.
- You can also ask your GP for a referral to a dietitian who specialises in cancer. To find an Accredited Practising Dietitian in your area, call **1800 812 942** or visit **daa.asn.au**.

### Diarrhoea

- Eat low-fibre foods, such as white rice, white pasta, white bread, rice-based cereal, potatoes, fish and lean meat.
- Well-cooked vegetables without seeds, husks or skin, such as carrots, potato and pumpkin, are good choices.
- Eat three small meals a day and snack often.
- If you suspect that a food causes diarrhoea, avoid it for 2–3 weeks. Reintroduce one food at a time. If the diarrhoea flares up again, you may want to avoid that food.
- Avoid foods that increase bowel activity, e.g. caffeine; alcohol; spicy, fatty or oily foods; or artificial sweeteners.
- Don't eat too many raw fruits and vegetables, wholegrain breads and cereals, or legumes (e.g. lentils, chickpeas), as they may make diarrhoea worse.
- Avoid dairy foods if they cause problems, or try low lactose or soy-based dairy products.

## Wind

- Try chewing charcoal tablets, eating natural yoghurt and/or drinking peppermint tea.
- Cut food into small, bite-sized pieces.
- Chew your food slowly and thoroughly.
- When you have a drink, take small sips.
- Talk to your doctor about doing light exercise to relieve bloating and gas.
- Avoid foods that increase gas, e.g. eggs, legumes such as lentils and chickpeas, large serves of dairy products, and fizzy drinks.
- Don't eat too many raw fruits and vegetables.

## Stoma blockages

- Eat regular meals.
- Try to maintain a balanced diet so your body is well nourished.
- Drink up to eight glasses of fluid a day so you stay well hydrated.
- Cut food into small, bite-sized pieces, and chew slowly and thoroughly.
- If you have trouble eating a certain food, talk to a dietitian about alternatives.
- You may find cooked food easier to digest.
- Some foods are more likely to cause blockages in some people. These include high-fibre foods, raw vegetables, fruit and vegetable skins, nuts, seeds, kernels (e.g. corn, popcorn), and sausage skins.
- Try small amounts of a new food. If it's okay, try more next time.



## Key points about changes to bowel function

### Having a stoma

Some people will need to have a stoma, which is a surgically created opening in the abdomen. Waste (faeces or stools) passes out of the body through this opening and is collected in a bag. A stoma may be temporary or permanent.

### Common changes

After treatment for bowel cancer, most people find their bowel function changes. You may have trouble controlling your bowel or bladder, have diarrhoea, or suffer from wind.

### Managing changes

- Stomal therapy nurses and stoma associations can provide support and information to help you adjust to life with a stoma.
- There are many ways to manage incontinence, and changes to bowel and bladder function. For support and information, talk to your treating doctors.
- Drinking plenty of fluid throughout the day will help avoid dehydration and reduce constipation and blockages.
- You may need to change your diet, especially if the diarrhoea or wind is ongoing, or if you have a stoma blockage.
- A dietitian can give you advice on removing certain foods from your diet, and tell you if and when to reintroduce them.





# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. See pages 59–61 for information about coping with dietary issues after treatment and choosing the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

**Sexuality** – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



# Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline **13 11 14** or visit [lifeline.org.au](http://lifeline.org.au).

## Follow-up appointments

After treatment ends, you will have regular check-ups to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. You will usually have a physical examination and you may have blood tests (including checking of CEA levels, see page 20), scans or regular colonoscopies.

How often you will need to see your doctor will depend on the level of monitoring needed for the type and stage of the cancer. Your doctor may want to see you two to four times a year for the first year, twice a year for the next few years, and then yearly for a few years. Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

## What if bowel cancer returns?

For some people, bowel cancer does come back after treatment, which is known as a recurrence. It is important to have regular check-ups so that if cancer does come back, it can be found early.

If the cancer is confined to the bowel and nearby lymph nodes, it may be possible to surgically remove it. Removing the tumour can help relieve symptoms and, in some cases, may stop the cancer.

If bowel cancer has spread beyond the bowel (advanced or metastatic bowel cancer), you may be offered treatment, such as surgery, chemotherapy, targeted therapy or radiation therapy, to remove the cancer or help control its growth (see pages 45–49). If your bowel becomes blocked, you will need prompt treatment (see pages 34–35).



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Associations** – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



## Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” Sam

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).



## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian	
Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
<i>The Thing About Cancer</i> podcast	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Australian Council of Stoma Associations (ACSA)	<a href="http://australianstoma.com.au">australianstoma.com.au</a>
Australian Association of Stomal Therapy Nurses	<a href="http://stomalthrapy.com">stomalthrapy.com</a>
Bladder and Bowel	<a href="http://bladderbowel.gov.au">bladderbowel.gov.au</a>
Cancer Screening	<a href="http://cancerscreening.gov.au">cancerscreening.gov.au</a>
Colorectal Surgical Society of Australia and New Zealand	<a href="http://cssanz.org">cssanz.org</a>
Continence Foundation of Australia	<a href="http://continence.org.au">continence.org.au</a>
Department of Human Services	<a href="http://humanservices.gov.au">humanservices.gov.au</a>
Dietitians Association of Australia	<a href="http://daa.asn.au">daa.asn.au</a>
eviQ	<a href="http://eviq.org.au">eviq.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
International	
American Society of Colon and Rectal Surgeons	<a href="http://fascrs.org">fascrs.org</a>
Association of Coloproctology of Great Britain and Ireland	<a href="http://acpgbi.org.uk">acpgbi.org.uk</a>





# Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

## Diagnosis

- What type of bowel cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- Will I need a stoma? If so, will it be temporary or permanent?
- Will you refer me to a stomal therapy nurse?
- If I don't have the treatment, what should I expect?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

## Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

## After treatment

- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



# Glossary

## **abdomen**

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

## **abdominoperineal resection (APR)**

An operation for rectal cancer. This involves removing the sigmoid colon, the rectum and anus, and creating a permanent colostomy.

## **anaemia**

A reduction in the number or quality of red blood cells in the body.

## **anastomosis**

The joining together of two tubes, such as two cut ends of the bowel.

## **anterior resection**

A surgical procedure to remove cancer in part of the rectum.

## **anus**

The opening at the end of the bowel where solid waste matter normally leaves the body.

## **appliance**

See stoma bag.

## **ascending colon**

The right side of the bowel.

## **biopsy**

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

## **bowel**

In this booklet, the term bowel refers to the large bowel, which includes the colon and the rectum.

## **bowel cancer**

Cancer of the large bowel; also known as colorectal, colon or rectal cancer.

## **bowel movement**

Defecation. To pass waste matter from the bowels.

## **bowel obstruction**

When the bowel is blocked and waste matter cannot pass through easily.

## **caecum**

The pouch at the start of the large bowel that receives waste from the small bowel.

## **carcinoembryonic antigen (CEA)**

A protein found in the blood of some people with bowel cancer.

## **catheter**

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

## **central venous access device (CVAD)**

A thin plastic tube inserted into a vein. The CVAD gives access to a vein so blood or chemotherapy can be given and blood can be taken. Types of CVADs include port-a-caths and PICC lines.

## **chemoradiation**

Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

## **colectomy**

An operation in which cancerous areas of the colon are cut out and the healthy parts are sewn back together. Colectomies are named for the part removed. They include: right and left hemicolectomies, and transverse, sigmoid, subtotal and total colectomies.

### **colon**

The main working area of the large bowel, where water is removed from solid waste matter. Its four parts are the ascending colon, transverse colon, descending colon and sigmoid colon.

### **colon cancer**

Cancer that develops in the main part of the large bowel, the colon.

### **colonic J-pouch**

An internal pouch surgically created using the lining of the large bowel.

### **colonoscopy**

An examination of the large bowel with a camera on a flexible tube (colonoscope), which is passed through the anus.

### **colorectal cancer**

See bowel cancer.

### **colostomy**

A surgically created opening (stoma) in the abdomen to the outside of the body. It is made from the colon (part of the large bowel). Also, the operation that creates this stoma.

### **CT scan**

Computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the body.

### **descending colon**

The left side of the colon.

### **digital rectal examination (DRE)**

An examination in which a doctor puts a gloved finger into the anus to feel for abnormalities in the rectum or anus.

### **endoscope**

A flexible tube with a light and camera on the end. It is used during diagnostic tests.

### **enema**

A liquid solution put into the bottom (rectum) to wash out the bowels.

### **faecal incontinence**

Inability to control bowel movements, resulting in accidental loss of faeces.

### **faeces**

Waste matter that normally leaves the body through the anus. See also stools.

### **familial adenomatous**

### **polyposis (FAP)**

An inherited condition that causes a very large number of polyps to form in the large bowel. The polyps will become cancerous if untreated.

### **gastrointestinal (GI) tract**

The passage from the mouth to the anus that allows a person to digest food and get rid of waste. The lower GI tract includes the colon, rectum and anus.

### **ileostomy**

A surgically created opening (stoma) in the abdomen to the outside of the body. It is made from the ileum (part of the small bowel). Also, the operation that creates this stoma.

### **ileum**

The lowest section of the small bowel; transfers waste to the large bowel.

### **immunochemical faecal occult blood test (iFOBT)**

A test that checks stools for microscopic traces of blood.

### **incontinence**

The accidental or involuntary loss of urine or faeces.

### **inflammatory bowel disease**

A benign condition that causes inflammation of the bowel.

### **keyhole surgery**

A surgical technique that involves several small cuts instead of one large cut on the abdomen. Also called laparoscopic or minimally invasive surgery.

### **large bowel**

Part of the lower GI tract. The large bowel stores waste until it leaves the body as faeces. Its four main sections are the caecum, colon, rectum and anus. Also called the large intestine.

### **local excision**

A type of surgery for selected small rectal cancers. The surgeon operates through the anus to remove the cancer without cutting into the abdomen.

### **lymph nodes**

Part of the lymphatic system, these small, bean-shaped structures collect and destroy bacteria and viruses.

### **malignant**

Cancerous. Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

### **MRI scan**

Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

### **pelvis**

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.

### **PET scan**

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

### **polyp**

A projecting growth from a surface in the body, such as the large bowel. Most polyps are benign, but they can become malignant.

### **proctocolectomy**

The surgical removal of the entire colon and rectum.

### **radiation therapy**

The use of targeted radiation to damage or kill cancer cells so they cannot multiply, grow or spread. Also called radiotherapy.

### **rectal cancer**

Cancer that develops in the rectum, the last part of the large bowel.

### **rectum**

The last 15–20 cm of the large bowel, just above the anus.

### **screening**

An organised program to identify disease in people before any symptoms appear.

### **sigmoid colon**

The section of the colon below the descending colon and above the rectum.

### **sigmoidoscopy**

A procedure in which a doctor inserts a sigmoidoscope into the anus to examine the rectum and lower colon.

### **small bowel**

The middle part of the gastrointestinal tract, which takes food from the stomach and absorbs nutrients. It has three sections: the duodenum, jejunum and ileum. Also known as the small intestine.

### **small bowel cancer**

A rare cancer that occurs in the small bowel. Also called small intestine cancer.

### **stent**

A metal or plastic tube placed into a blocked organ to create a passage for substances to pass through.

### **stoma**

A surgically created opening to the outside of the body.

### **stoma bag/appliance**

A bag or pouch used to cover a stoma and collect urine or faeces.

### **stomal therapy nurse**

A registered nurse who specialises in caring for people with stomas.

### **stools**

The bulky mass of waste matter that normally leaves the body through the anus. Also known as faeces or poo.

### **targeted therapy**

Drugs that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

### **transanal endoscopic microsurgery (TEMS)**

Removing part of the cancer using an endoscope inserted into the anus.

### **transanal excision (TAE)**

Removing part of the cancer using an instrument inserted into the anus.

### **transverse colon**

The section of the colon between the ascending and descending colon.

### **virtual colonoscopy**

A medical imaging procedure that uses a CT or MRI scanner to create and display images.

### **waste matter**

Material remaining after food has been digested that normally leaves the body through the anus. Known as faeces, stools or poo when it leaves the body.

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](https://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](https://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](https://cancersa.org.au/glossary)

## **References**

1. Cancer Council Australia Colorectal Cancer Guidelines Working Party, *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer*, Cancer Council Australia, Sydney, 2017. Available from: [https://wiki.cancer.org.au/australia/Guidelines:Colorectal\\_cancer](https://wiki.cancer.org.au/australia/Guidelines:Colorectal_cancer) (accessed 22 August 2018).
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: colorectal (bowel) cancer*, AIHW, Canberra, December 2017.



## How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

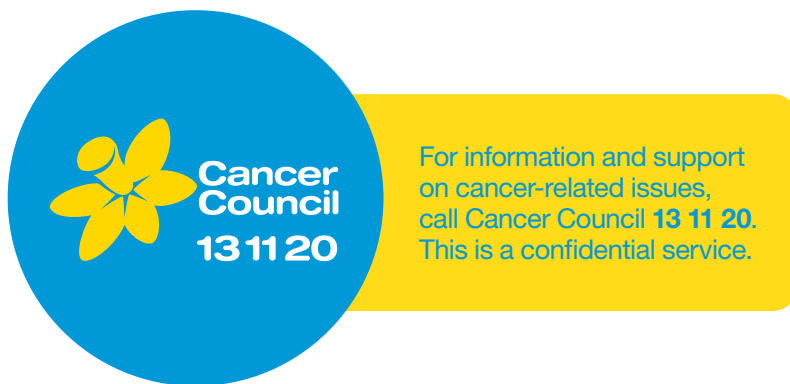
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
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To support Cancer Council, call your local Cancer Council or visit your local website.*