Cancer Council

CANCER TYPE

Understanding
Bowel Cancer

A guide for people with cancer, their families and friends

For information & support, call **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 8 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 or call your local Cancer Council.

Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.

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About this booklet

This booklet has been prepared to help you understand more about bowel cancer. Bowel cancer is also known as colorectal cancer or sometimes simply as colon cancer or rectal 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, this information may 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.[1]

☎ If you or your family have any questions or concerns, 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).

Contents

Key to icons

Icons are used throughout this booklet to indicate:

🔍 More information

❗ Alert

💡 Tips

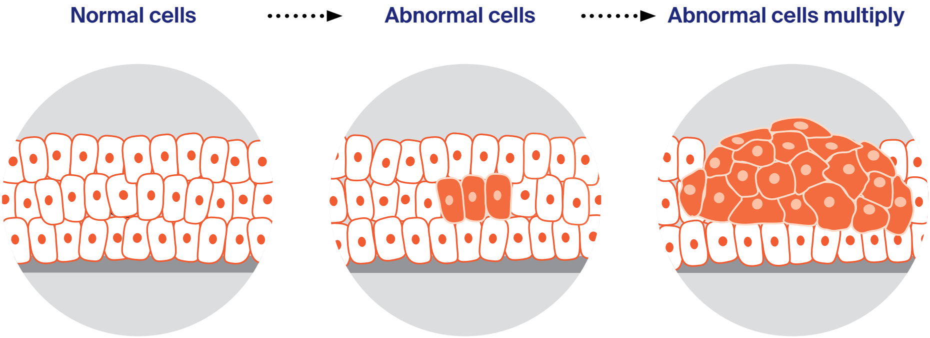
What is cancer?

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. These abnormal cells may turn into cancer.

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.

How cancer starts

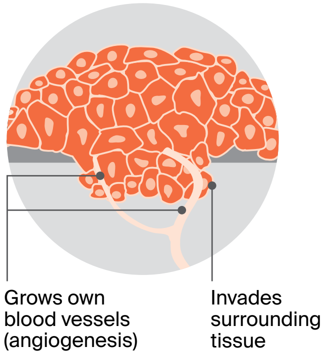


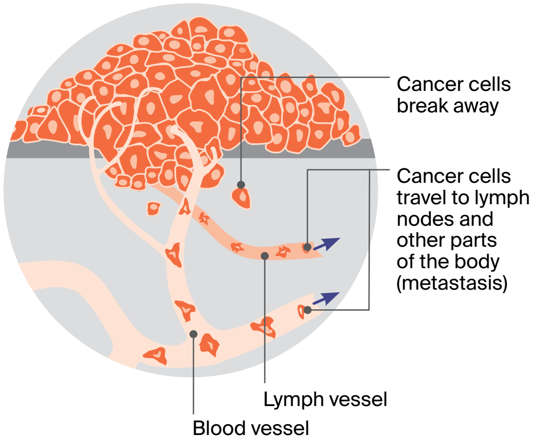
Not all tumours are cancer. Benign tumours tend to grow slowly and usually don’t move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ 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





The bowel

The bowel is part of the lower gastrointestinal (GI) 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 (also called small intestine)

This is a long tube (4–6 m) that absorbs nutrients from food. The small bowel is longer and narrower than the large bowel. It has 3 parts:

- **duodenum –** the top section; receives broken-down food from the stomach
- **jejunum –** the middle section
- **ileum –** the lower and longest section; moves waste into the large bowel.

The large bowel (also called large intestine)

This tube is about 1.5 m long. It absorbs water and salts, and turns what is left into solid waste (known as faeces, stools or poo when it leaves the body). The large bowel has 3 parts:

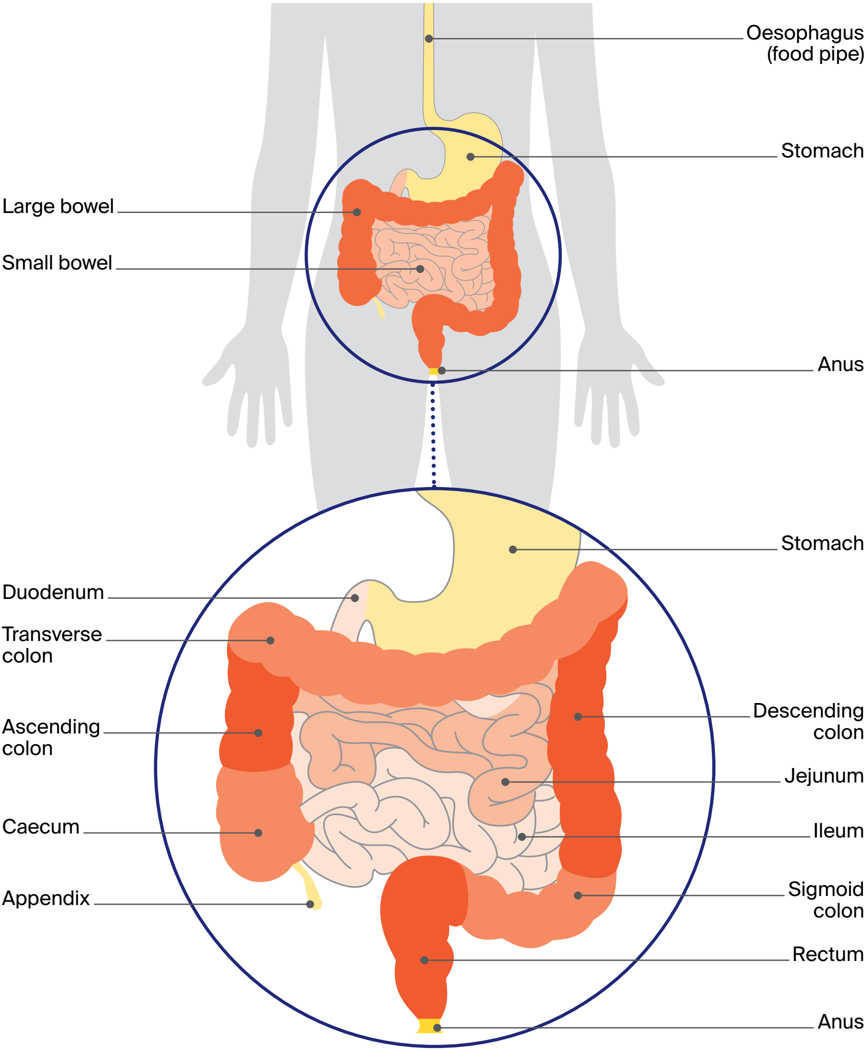
- **caecum –** looks like a pouch; it receives waste from the small bowel
- **colon –** the main working area of the large bowel, the colon makes up most of the large bowel's length and has 4 parts (ascending colon, transverse colon, descending colon and sigmoid colon); the term colon is often used to refer to all 4 parts of the colon and the caecum
- **rectum –** the last 15–20 cm of the large bowel.

The anus

This is the opening at the end of the large bowel. During a bowel movement, the anal muscles relax to release faeces.

▸ See our *Understanding Anal Cancer* fact sheet.

The lower digestive system



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 in the bowel it is found.

The cancer starts in the inner lining of the bowel wall. It usually develops from small growths called polyps. Most polyps are harmless (benign), but some may turn into cancer. To prevent this, polyps can be removed during a colonoscopy (see page 17).

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

Less common types of bowel cancer

Most bowel cancers are adenocarcinomas, which start in the 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 more information.

Cancer can also start in the small bowel (called small bowel cancer or small intestine cancer), or the appendix, but this is rare.

▶ See our fact sheets on small bowel cancer and appendix cancer.

Q: How common is bowel cancer?

A: Bowel cancer is a very common cancer in Australia. Each year, about 15,700 Australians are diagnosed with bowel cancer. It is most common in people over 50, but it can occur at any age.[2]

Q: What are the symptoms?

A: Some people have no symptoms and the cancer is found through screening (see page 16). However, many people with bowel cancer do experience symptoms. These can include:

- blood in faeces (poo) or on the toilet paper
- a change in bowel habits, such as diarrhoea, constipation or smaller, more frequent bowel movements
- a change in the look of faeces (e.g. narrower or with mucus)
- a feeling of fullness or bloating in the abdomen (belly) or a strange sensation in the rectum, often during a bowel movement
- feeling that the bowel hasn't emptied completely
- losing weight for no obvious reason
- 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 or iron deficiency), which can cause tiredness and weakness
- a blockage in the bowel (see pages 34–35).

These symptoms can also be caused by other conditions, such as haemorrhoids, irritable bowel syndrome, diverticulitis (inflammation of pouches in the bowel), inflammatory bowel disease, or an anal fissure (cracks in the skin lining the anus). See your doctor if you are worried, the symptoms are ongoing or there is any bleeding.

Q: What are the risk factors?

A: The exact cause of bowel cancer is not known. Research shows that people with certain risk factors are more likely to develop bowel cancer. Risk factors include:

- **older age –** bowel cancer is most commonly diagnosed in people over 50, and the risk increases with age
- **polyps –** having a large number of polyps in the bowel
- **other 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 the disease for more than 10 years
- **lifestyle factors –** carrying extra weight, not being physically active, having a diet high in red meat or processed meats such as salami or ham, drinking alcohol, or smoking
- **strong family history –** a small number of bowel cancers run in families (see opposite page)
- **other cancers –** people who have had bowel cancer once are more likely to develop a second bowel cancer; some people who have had ovarian cancer or cancer of the uterus (endometrial 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 lifestyle habits 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 or no alcohol; not smoking; and eating wholegrains, dietary fibre and dairy foods.

Ask your doctor whether taking aspirin regularly might benefit you. Aspirin may reduce the risk of bowel cancer for some people.

Q: Can bowel cancer run in families?

A: Sometimes bowel cancer runs in families. The risk of developing bowel cancer may be higher if one or more of your close family members (such as a parent, brother or sister) has had bowel cancer. The risk is higher if they were diagnosed before the age of 55, or if 2 or more close relatives on the same side of your family have had bowel cancer. A family history of some other cancers, such as cancer of the uterus (endometrial cancer), may also increase the risk.

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 2 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 causes a fault in the gene that helps the cell's DNA repair itself. People with Lynch syndrome have an increased risk of developing bowel cancer, cancer of the uterus, and other cancers such as kidney, bladder and ovarian.

If you are worried 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 at every stage of your cancer care, visit cancer.org.au/cancercareguides/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.

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
colorectal surgeon	diagnoses bowel cancer; performs bowel surgery
gastroenterologist	diagnoses and treats disorders of the digestive system, including bowel cancer; may perform colonoscopy
radiation oncologist	treats cancer by prescribing and overseeing a course of radiation therapy
radiation therapist	plans and delivers radiation therapy
medical oncologist	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
cancer care coordinator	coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or colorectal cancer nurse
nurse	administers drugs and provides care, information and support throughout treatment

The specialist 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.

stomal therapy nurse	provides information about surgery and can help you adjust to life with a temporary or permanent stoma
dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
genetic counsellor	provides advice for people with a strong family history of bowel cancer or with a genetic condition linked to bowel cancer
social worker	links you to support services and helps you with emotional, practical and financial issues
physiotherapist, exercise physiologist	help restore movement and mobility, and improve fitness and wellbeing
occupational therapist	assists in adapting your living and working environment to help you resume usual activities after treatment
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
palliative care specialist and nurses	work closely with the GP and cancer team to help control symptoms and maintain quality of life

Diagnosis

Some people have tests for bowel cancer because they have symptoms; others have no symptoms but a strong family history of bowel cancer (see page 11) or have received a positive result through the National Bowel Cancer Screening Program (see page 16).

If your doctor suspects you have bowel cancer, you may have some of the tests described in this chapter, but you are unlikely to need them all. Some tests may be repeated during or after treatment to check how well treatment is working. It may take up to a week to get your test results. If waiting for test results makes you feel anxious, it may help to talk to a friend or family member, or call Cancer Council 13 11 20 for support.

General tests

Physical examination

Your doctor will ask to feel your abdomen for any swelling. To check for problems in the rectum and anus, they may also do an internal examination. This involves the doctor putting a gloved, lubricated finger into the anus to feel for any lumps or swelling. This is called a digital rectal examination (DRE). If you feel embarrassed or scared about having this examination, let your doctor know. A nurse may be present, but you can also ask for a family member or friend to be in the room with you for support.

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 check your general health and to look for signs that you are losing blood in your faeces (stools or poo).

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

Checking your faeces (poo) for signs of blood

A test called the immunochemical faecal occult blood test (iFOBT) looks for tiny amounts of blood in your faeces. It is commonly used as a screening test for bowel cancer (see next page).

An iFOBT is generally not recommended for people who are bleeding from the rectum or have bowel symptoms (change in bowel habit, anaemia, unexplained weight loss, abdominal pain). People with these symptoms are usually referred for a colonoscopy straightaway.

For an iFOBT, you usually collect a sample of your faeces at home. The sample is sent to a laboratory and examined for traces of blood, which may be a sign of polyps, cancer or another gastrointestinal condition.

If the test finds blood in your faeces, your doctor will recommend you have a colonoscopy (see page 17).

> *“I had very light blood streaks on toilet paper when wiping my bottom. After 2 weeks of this, I went to my doctor thinking it was haemorrhoids but he sent me for a colonoscopy.”* RICHARD

Screening test for bowel cancer

Screening is the process of looking for cancer or abnormalities that could lead to cancer in people who do not have any symptoms. Screening is particularly important for bowel cancer, which often has no symptoms in its early stages.

Screening program

Through the National Bowel Cancer Screening Program, people aged 50–74 are automatically sent a free iFOBT kit every 2 years. You do the test at home and send it back. You don't need to change what you eat or stop taking your medicines. A test kit can also be purchased from some pharmacies or online.

If the screening test is negative, it means it found no traces of blood in your sample and you'll receive another test in 2 years. If you develop symptoms between screening tests, let your doctor know. If the screening test is positive, it means there were traces of blood in your sample and you need more tests (see opposite page).

It is important that people do the screening test as it can find early cancers and some precancerous polyps in the bowel. Removing polyps reduces the risk of developing bowel cancer. Finding bowel cancer early improves the chance of surviving the disease.

If you have questions about how to do the test, need to update your contact details, or haven't received your test kit, call 1800 627 701 or visit cancerscreening.gov.au/bowel. If you are an Indigenous Australian, visit indigenousbowelscreen.com.au.

People with a higher risk

The National Bowel Cancer Screening Program is for 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 how they will monitor your risk of developing bowel cancer
- 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.

Colonoscopy and biopsy

Colonoscopy – The main test used to look for bowel cancer is a colonoscopy. This test lets your doctor look at the lining of the entire large bowel. Before the procedure, you will have a bowel preparation to clean your bowel (see page 19). It is very important to follow the instructions – the cleaner the bowel is, the more likely it is that the doctor will see any polyps or other areas of concern.

Most colonoscopies are done as day surgery at a hospital. 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. A colonoscopy usually takes about 20–30 minutes.

During the procedure, the doctor will put a colonoscope (a flexible tube with a camera on the end) through your anus and up into the rectum and colon. Carbon dioxide or air will be passed through the colonoscope to inflate the colon and make it easier for the doctor to see the bowel.

Biopsy – If the doctor sees any abnormal or unusual-looking areas, they will remove a sample of the tissue. This is known as a biopsy. They will also remove any polyps (polypectomy). A pathologist will examine the tissue or polyps under a microscope to check for signs of cancer and may look for specific gene changes (see *Molecular testing* on page 22).

Side effects – You will need to have someone take you home afterwards, as you may feel drowsy or weak, and you shouldn't drive for at least 24 hours after the procedure. The gas used to inflate the bowel during the test can sometimes cause bloating and wind pain. Rare complications include damage to the bowel (perforation), damage to the spleen or bleeding. Your doctor will talk to you about the risks.

Less commonly used tests

CT colonography – Also called virtual colonoscopy, this uses a CT scanner (see page 20) to create images of the colon and rectum. Bowel preparation is usually needed before the test (see opposite page). A CT colonography is done by a radiologist, a specialist who analyses x-rays and scans.

You may have a CT colonography if a colonoscopy didn't show all of the colon or when a colonoscopy is not safe. However, a CT colonography is not often used because it exposes you to radiation and is not as accurate as a colonoscopy. It can see only bigger polyps, not small ones.

If any abnormality is detected, you will need to have a colonoscopy so the doctor can take tissue samples. A CT colonography is covered by Medicare only in limited circumstances.

Flexible sigmoidoscopy – This test is similar to a colonoscopy but only lets the doctor see the rectum and lower part of the colon (sigmoid and descending colon). Before a flexible sigmoidoscopy, you will need to have a light bowel clean-out, usually with an enema (see opposite page). Just before the procedure, you may be given a light anaesthetic.

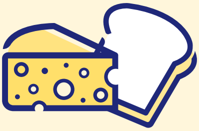
You will then lie on your left side while a colonoscope (or, sometimes, a shorter but similar tube called a sigmoidoscope) is put into your anus and guided up through the bowel. The colonoscope or sigmoidoscope blows carbon dioxide or air into the bowel to inflate it slightly so the doctor can see the bowel wall more clearly.

A light and camera at the end of the colonoscope or sigmoidoscope show up any unusual areas, and your doctor can take tissue samples (biopsies).

Bowel preparation

Before some tests, you will have to empty your bowel completely to make sure the doctor can see the bowel clearly. This is called bowel preparation (or washout). The bowel preparation process can vary, so ask your doctor what you need to do. It's important to follow the instructions you are given so you don't have to repeat the test.

Change diet



A few days before the test, start eating low-fibre foods, such as white bread, white rice, meat, fish, chicken, cheese, yoghurt, pumpkin and potato. Don't eat high-fibre foods, such as most vegetables, fruit, wholegrain pasta, brown rice, cereals, nuts and seeds.

Take prescribed laxatives

You will be prescribed a strong laxative as a powder you need to mix with water, or as a tablet. You will take the laxative over several hours, starting 12–18 hours before the test. The laxative will cause you to have several episodes of watery diarrhoea and you will need to stay home to be near a toilet.

Drink clear fluids

Your doctor might advise you to have 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.

Have an enema, if required

One common way to clear the lower part of the bowel is using an enema. You may be given an enema by a nurse at the hospital before a colonoscopy if the laxative hasn't completely cleaned out the bowel, or if you are only having a flexible sigmoidoscopy. An enema involves putting liquid directly into the rectum. The liquid washes out the lower part of the bowel, along with any faeces.

Further tests

If any of the tests on pages 15–18 show you have bowel cancer, you will have more tests to see if the cancer has spread to other parts of your body. Before any test, ask how much you will have to pay.

CEA blood test

Your blood may be tested for a protein produced by some cancer cells. This is called a tumour marker. The most common tumour marker for bowel cancer is called carcinoembryonic antigen (CEA). 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. If your CEA level is high, it will be retested after treatment to see if it has returned to normal. Not all bowel cancers have a raised CEA.

CT scan

A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of the inside of the body. CT scans are usually done at a hospital or radiology clinic. When you make the appointment for the scan, you will be given instructions to follow about what you can eat and drink before the scan.

As part of the procedure, a 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 (wee or pee), but this sensation won't last long.

During the scan, you will need to lie still on a table that moves in and out of the CT scanner. Your chest, abdomen and the area between your hip bones (pelvis) will be scanned to see if the cancer has spread to these areas. The scan itself 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 pictures of the inside of your body.

Usually only people with cancer in the rectum have an MRI; it is not commonly used for cancers higher in the bowel. An MRI may also be used to scan the liver if an abnormality seen on a CT scan needs further investigating.

Before the scan, let your medical team know if you have a pacemaker or any other metallic object in your body. If you do, you may not be able to have an MRI scan as the magnet can interfere with some metallic objects. Newer devices are often safe to go into the scanner.

Before the MRI, you may be injected with a dye to help make the pictures clearer. During the scan, you will lie on an examination 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 scan may take 30–90 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 have diabetes or kidney disease, are pregnant or breastfeeding, or are claustrophobic (afraid of confined spaces).

Molecular testing

If you are diagnosed with bowel cancer, the biopsy sample or the tissue removed during surgery (see pages 30–34) will usually have more tests. Called molecular tests, they look for gene changes (mutations) and other features in the cancer cells that may be causing them to multiply and grow.

Your treatment team uses the results of molecular testing to tell them what treatment may work for you and which treatment may not work.

For example, some targeted therapy drugs do not work for people with a RAS gene mutation. Immunotherapy drugs also only work for people with a fault in the gene that helps the cell's DNA repair itself (called mismatch repair or MMR genes). See *Drug therapies* on pages 45–47 for more details.

PET–CT scan

A positron emission tomography (PET) scan combined with a CT scan is a specialised imaging test. The 2 scans provide more detailed and accurate information about the cancer. A PET–CT scan is most commonly used before surgery to help find out where the cancer has spread to in the body. It can also be used after surgery to check if the cancer has come back after treatment.

When you make the appointment for the scan, you will be given instructions to follow about how to prepare for the scan, including what you can eat and drink.

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

Staging bowel cancer

The tests described in this chapter help show whether you have bowel cancer and whether it has spread from the original site to other parts of the body. This is known as staging and it helps your health care team advise you on the best treatment options.

The most common staging system for bowel cancer is the TNM system, which stands for tumour–node–metastasis. The Australian Clinico-Pathological Staging (ACPS) system may also be used in some hospitals. The TNM system gives numbers to:

- the size of the tumour (T1–4)
- whether or not lymph nodes are affected (N1–2)
- whether the cancer has spread or metastasised outside the bowel (M0–M1).

Based on the TNM numbers, the doctor then works out the cancer's overall stage (see the box on the next page for more detail). Around half of all bowel cancers in Australia are diagnosed at stage 1 or 2.

The stage can be predicted before surgery based on the results of your early tests, but may be revised after surgery, following tests on the cancer tissue and lymph nodes removed during surgery (see pages 30–34).

Stages of bowel cancer

stage 1	tumour is found only in the inner layers of the bowel wall
stage 2	tumour has spread deeper into the layers of the bowel wall
stage 3	tumour is in any layer of the bowel wall and has spread into nearby lymph nodes
stage 4	tumour has spread beyond the bowel to other parts of the body, such as the liver or lungs, or to distant lymph nodes

If you are finding it hard to understand staging, ask someone in your health care team to explain it in a way that makes sense to you.

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 anyone to predict the exact course of the disease.

Your doctor can give you an idea about the common issues that affect people with bowel cancer. Generally, the earlier that bowel cancer is diagnosed, the better the chances of successful treatment, but people with more advanced bowel cancer may still respond well to treatment.

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.

Key points about diagnosing bowel cancer

General tests	General tests to check for abnormal symptoms include a digital rectal examination (DRE), blood tests, and the immunochemical faecal occult blood test (iFOBT). The iFOBT looks for tiny amounts of blood in your faeces (stools or poo).
Main test	• A colonoscopy looks for polyps and cancer in the entire large bowel. • Before a colonoscopy, you will have a bowel preparation to empty 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).
Further tests	Other tests can give more information about the bowel 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 describes how far the cancer has spread. • Stage 1 bowel cancer is found only in the inner layers of the bowel; stage 2 has spread deeper into the bowel wall; stage 3 is in any layer and has spread to nearby lymph nodes; stage 4 has spread to other parts of the body. • In general, bowel cancers found at earlier stages have a better chance of successful treatment.

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, as it may not 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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.
▸ See our *Understanding Clinical Trials and Research* booklet.

Treatment for early bowel cancer

This chapter covers treatment for stages 1–3 bowel cancer (see page 24). Your health care 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.

Colon cancer and rectal cancer are treated differently. The treatments you are offered will depend on the guidelines for best practice in treating bowel cancer.[1] You may have more than one treatment and treatments may be given in different orders and combinations.

Treatment options by type of bowel cancer

Colon cancer	Rectal cancer
• Surgery is the main treatment for 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 rarely used for colon 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, it is common to have chemotherapy combined with radiation therapy (chemoradiation). Most often this takes place before surgery. This is called neoadjuvant treatment. • Some people may have radiation therapy or chemotherapy on their own before surgery. • After surgery you may have further chemotherapy.

Preparing for treatment (prehabilitation)

Talk with your doctors about whether you need to do anything to prepare for treatment. This is known as prehabilitation, and it may improve your strength, help you cope with treatment side effects and improve the results of treatment.

Manage anaemia – Many people with bowel cancer have anaemia or low iron levels. You may be given iron as tablets or injections to increase your iron levels and red blood cell count (haemoglobin level) before starting treatment.

Give up smoking – If you are a smoker, you will be encouraged to stop smoking before surgery. Continuing to smoke can increase the risk of complications, delay wound healing and delay your recovery after surgery. Smoking may make any side effects you have after other treatments worse. For support, call the Quitline on 13 7848.

Improve diet and nutrition – People with bowel cancer often lose weight and may become malnourished. If you are finding it hard to eat enough, a dietitian can suggest ways to change your diet to limit weight loss, reduce blockages and make having bowel movements easier. This will help improve your strength and lead to better treatment outcomes.

Avoid alcohol – Talk to your doctor about how much alcohol you drink. Alcohol can affect how the body works and increase the risk of complications after surgery, including bleeding and infections.

Begin or continue an exercise program – Exercise will help build up your strength for recovery. Talk to your doctor or physiotherapist about any precautions you should take, and the amount and type of exercise that is right for you.

Surgery

The type of surgery you have will depend on the position of the cancer in the bowel and your preferences. The aim of surgery is to remove the area of the bowel with the cancer and the nearby lymph nodes.

How the surgery is done

You will be given a general anaesthetic and will have either open or keyhole surgery. Each method has advantages in particular situations – your doctor will discuss which method is most suitable for you.

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

Keyhole (minimally invasive, laparoscopic or robotic) surgery – The surgeon makes several small cuts in the abdomen and passes a thin tube with a light and camera (laparoscope) into one of the openings. They then insert tools into the other cuts to remove the section of the bowel with cancer, using images from the camera as a guide. Keyhole surgery is sometimes done using a robotic system. Keyhole surgery usually means less pain and scarring, a shorter hospital stay and faster recovery.

Surgery for cancer in the colon

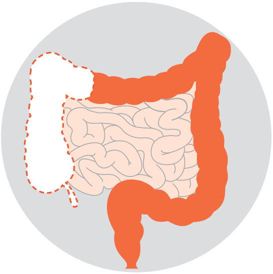
The most common type of surgery for colon cancer is a colectomy (removal of a part of the colon, see opposite page). Lymph nodes near the cancer and some normal bowel around the cancer are also removed.

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 2 ends of the bowel back together. This join is called an anastomosis.

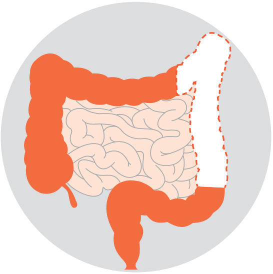
Types of colectomies

◌ **Area removed**

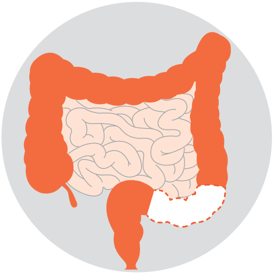
There are different types of colectomies depending on which part of the colon is removed. The surgery may be done as open or keyhole surgery.



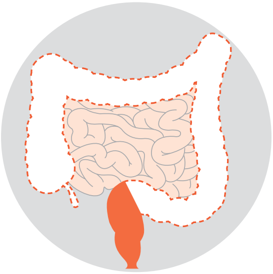
Right hemicolectomy
The right side of the colon is removed.



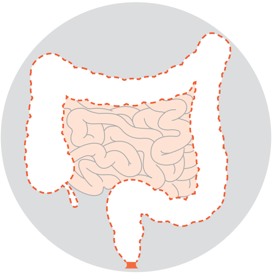
Left hemicolectomy
The left side of the colon is removed.



Sigmoid colectomy
The sigmoid colon is removed.



Subtotal or total colectomy
Most or all of the colon is removed.



Proctocolectomy
All of the colon and the rectum are removed.

Having a stoma – Sometimes one end of the bowel is brought through an opening made in your abdomen and stitched onto the skin. The opening – called a stoma – allows faeces to be collected in a bag. The stoma is usually temporary, and the operation is reversed later. In some cases, the stoma is permanent. Improved surgical techniques mean fewer people need a permanent stoma. For more information about stomas, see pages 50–54.

Surgery for cancer in the rectum

The type of operation you have depends on where in the rectum the cancer is, whether the bowel can be rejoined, and where in the rectum the join can be made. There are 2 main types of operation – an anterior resection or an abdominoperineal resection (also known as an abdominoperineal excision).

Anterior resection – This is the most common operation. You may have a high anterior resection or an ultra-low anterior resection (see opposite page). As part of the procedure, the surgeon may create a temporary stoma, which will usually be reversed later. For further information about stomas, see pages 50–54.

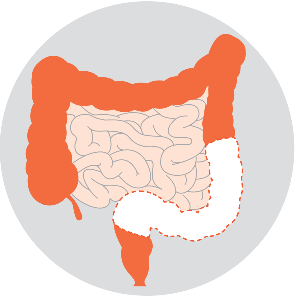
Abdominoperineal resection – This procedure may be recommended if the cancer is near the anal sphincter muscles or it is too low to be removed without causing incontinence (loss of control over bowel movements). After an abdominoperineal resection, you will need a permanent stoma (colostomy). See pages 50–54 for more details and speak to your surgeon about any concerns you may have.

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

Types of resections

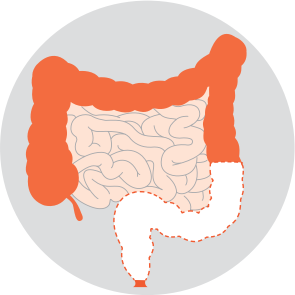
◌ **Area removed**

There are different types of operations for cancer in the rectum. The surgery may be done as open or keyhole surgery (see page 30).



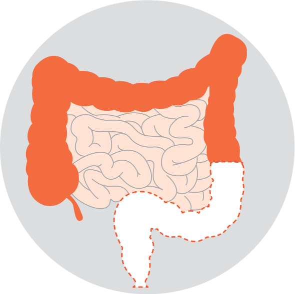
High anterior resection

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 remaining rectum.



Ultra-low anterior resection

The lower left part of the colon and all or part of the rectum are removed, along with nearby lymph nodes and surrounding fatty tissue. The end of the remaining bowel is joined to the lowest part of the rectum, just above the anus. In some cases, the surgeon may make a pouch using the remaining colon and join this pouch to the anus to improve ongoing bowel function. This is known as a colonic J-pouch.



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, see page 51) for faeces to leave the body. The anal area will be stitched up and permanently closed.

Other types of surgery for colon or rectal cancer

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 puts 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).

If there are 2 cancers – In a small number of people, 2 separate cancers may be found in the large bowel at the same time. The cancers may be discovered through tests or during surgery. In this case, there are several options for surgery, including to remove:

- 2 sections of the bowel
- one larger section of the bowel that includes both areas with cancer
- all of the colon and rectum (proctocolectomy, see page 31) to prevent any chance of another cancer forming.

The type of surgery your doctor recommends depends on several factors, including your age, where the tumours are 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 a bowel obstruction. Waste matter cannot pass through the blocked bowel easily, and may cause bloating and abdominal pain; constipation; and nausea and vomiting.

Sometimes the obstruction is found and cleared during the surgery to remove the cancer. In other cases, you will need emergency surgery to clear the blockage. If a section of the bowel needs to be removed, it may be possible to rejoin the bowel during the surgery, but some people may need a stoma (see pages 50–54). 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 (see page 39) before surgery.

Having a stent – If only one area of the bowel is blocked or you are not fit enough for major bowel surgery, you may have a small hollow tube (stent) put in to help keep the bowel open and relieve symptoms. A stent may be permanent or it can be used to help manage the blockage until you are fit enough to have a colectomy or resection. The stent is inserted through the rectum using a colonoscope (see page 17).

Preventing bowel blockages – A dietitian can suggest ways to avoid bowel blockages: for some people this may mean adding more fibre to the diet to help food or waste pass through the blockage or stent more easily. Other people may be advised to eat low-fibre foods. Talk to a dietitian about suitable foods for your situation.

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

Risks of bowel surgery

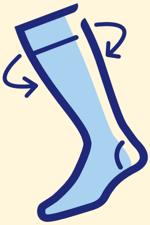
Your surgeon will talk to you about the risks and complications of bowel surgery. As with any major operation, surgery for bowel cancer has risks. These may include infection, bleeding, blood clots, damage to nearby organs, or leaking from the joins between the remaining parts of the bowel. After the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

For information on what to expect after surgery, see the next 2 pages. You may also experience some of the side effects discussed on page 38.

What to expect after surgery

This is a general overview of what to expect. Your recovery time after the operation will depend on your age, whether you had open or keyhole surgery,

Recovery time



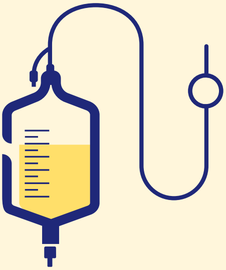
- In hospital you will have to wear compression stockings to keep the blood flowing in your legs.
- You will also be given a daily injection of a blood thinner to reduce the risk of developing blood clots.
- Some people also wear special cuffs around the legs to keep the calf muscles moving.
- Some people may have to wear the compression stockings and have the injections for a couple of weeks after the surgery.
- You will need to avoid driving after the surgery until you can move freely without pain. Discuss this issue with your doctor. Check with your car insurer for any exclusions about major surgery and driving.

Pain relief

- You will have some pain and discomfort for several days after surgery, but this can be controlled with pain medicines.
- Pain medicines may be given:
  - by an injection near your spinal column (epidural or spinal anaesthetic)
  - through a drip you can control with a button (patient-controlled analgesia or PCA)
  - as pills or tablets
  - through little tubes giving local anaesthetic near the wound (transversus abdominis plane or 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.

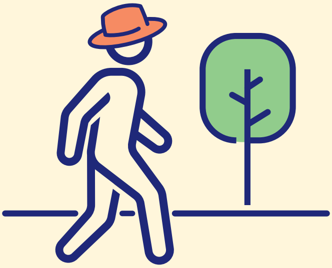
whether you have a stoma, and your general health. You will probably be in hospital for 2–7 days, but it can take 2–3 months to fully recover.

Drips and tubes



- You will be given fluids through a drip (also called an intravenous or IV infusion) until you can start drinking and eating. 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.

Exercise



- Your treatment team will encourage you to walk the day after the surgery.
- 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 help them return to their usual activities faster.
- See an exercise physiologist or physiotherapist for advice. Visit essa.org.au/find-aep to find an exercise physiologist, and visit choose.physio/find-a-physio to find a physiotherapist.
- Your doctor may advise you to avoid sexual intercourse for a few weeks after surgery. Ask them when you can have penetrative sex again, and explore other ways you and your partner can be intimate, such as massage.

Side effects of bowel surgery

Temporary or permanent stoma – Some people go home with a stoma. A stomal therapy nurse will see you after the operation to teach you how to look after the stoma and attach the bags. See pages 50–54 for details. You will stay in hospital until you feel confident managing the stoma.

Changes in bowel and bladder function – You may notice changes to how your bowel and bladder work. These changes usually improve within a few months but, for some people, it can take longer. See pages 55–59 for more details. Internal scar tissue (adhesions) from bowel surgery can increase the risk of developing a bowel obstruction (see pages 34–35). This may occur even many years after the surgery.

Changes in sexual function – In males, removing the rectum may affect the nerves controlling erections or ejaculation. You may have trouble getting or keeping an erection firm enough for intercourse or other sexual activity. In females, 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.
▸ See our *Sexuality, Intimacy and Cancer* booklet.

Changes to what you can eat – See pages 60–61 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.
▸ See our *Understanding Fatigue and Cancer* fact sheet.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage cancer cells so they cannot grow, multiply or spread. Radiation therapy may be given on its own or in combination with chemotherapy (chemoradiation). The chemotherapy makes cancer cells more sensitive to radiation.

When is radiation therapy given

Radiation therapy may be recommended for rectal cancer but is rarely used to treat colon cancer. You may have radiation therapy:

Before surgery (neoadjuvant) – Radiation therapy is used before surgery to shrink the tumour. This makes it easier for the surgeon to completely remove the cancer and also reduces the risk of the cancer coming back.

After surgery (adjuvant) – 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. This only happens if radiation therapy was not given before surgery.

Having radiation therapy

External beam radiation therapy is the most common type of radiation therapy for rectal cancer. Newer technology means that treatment machines can accurately deliver a high dose to the affected area, with much lower doses going to the surrounding tissue. This helps to reduce the side effects from radiation therapy.

You will have more imaging scans to help your radiation oncologist design a treatment plan for your situation. This will include the number of sessions you'll have and whether you will also have chemotherapy.

Before treatment, some small marks like a freckle may be tattooed on your skin to help pinpoint the exact area to receive the radiation. Treatment is given daily on weekdays. 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. The treatment is painless and can't be seen or felt.

After finishing your neoadjuvant treatment, there will be a break before surgery. This gives time for the radiation therapy to have its full effect.

Side effects of radiation therapy

Most side effects are temporary and disappear a few weeks or months after treatment. Feeling tired is a common side effect. Radiation therapy for rectal cancer is usually given over the pelvic area, which can affect your sexual function and ability to have children (fertility, see opposite page).

Radiation therapy can also irritate the bowel and bladder. This may mean needing to pass urine (wee or pee) more often and burning when you pass urine (cystitis); redness and soreness in the treatment area; faecal urgency and incontinence (see pages 55–56); diarrhoea (see pages 57–58); constipation; and mucus discharge or small amounts of bleeding from the anus. Radiation therapy can cause the skin or internal tissue to become less stretchy and harden (fibrosis). It can also inflame the lining of the rectum (radiation proctitis, see page 57).

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

▶ See our *Understanding Radiation Therapy* booklet.

Sexual function and fertility after radiation therapy

You may find it helpful to share your feelings about any sexual or fertility issues with your partner, a counsellor, a sexual therapist or a fertility specialist.

For males

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

For females

- Radiation therapy can cause the vagina to become shorter and narrower, making intercourse painful.
- Your doctor may suggest using a vaginal dilator after treatment ends and the area has healed. A vaginal dilator can help gradually widen the entrance and prevent the side walls sticking together. Your doctor or a physiotherapist can provide practical advice on how to use a dilator.
- Talk to your doctor about creams and moisturisers to help with vaginal discomfort and dryness.
- Extra lubrication may make sexual intercourse more comfortable. Choose a water-based or silicone-based gel without perfumes or colouring.
- In some cases, radiation therapy can stop the ovaries producing oestrogen and progesterone. This can cause menopause – after menopause you will not be able to conceive a child.
- Menopause can be managed with menopause hormone therapy (MHT).

► See our *Sexuality, Intimacy and Cancer, Fertility and Cancer*, and *LGBTQI+ People and Cancer* booklets, and listen to our “Sex and Cancer” podcast episode.

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 to lymph nodes or to other organs, you may have chemotherapy:

Before surgery (neoadjuvant) – Some people with rectal cancer have chemotherapy before surgery to shrink the tumour and make it easier to remove. You may have chemotherapy on its own or combined with radiation therapy (chemoradiation).

After surgery (adjuvant) – Chemotherapy may be used after surgery for either colon or rectal cancer to destroy any remaining cancer cells and reduce the chance of the cancer coming back. If your doctor recommends chemotherapy, you will probably start treatment as soon as your wounds have healed and you've recovered your strength, usually within 6–8 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).

Having chemotherapy

Generally, chemotherapy is given through a drip inserted into a vein (intravenously). To reduce the need for repeated needles, you may receive chemotherapy through a device inserted beneath your skin. Examples include a port-a-cath or a peripherally inserted central catheter (PICC). Sometimes chemotherapy is taken as tablets you swallow.

Chemotherapy is commonly given as a period of treatment followed by a break. This is called a cycle. You will probably have several cycles over 4–6 months. The length of the cycle depends on the drugs used. Your medical oncologist will explain your treatment schedule. Usually, you have chemotherapy during day visits to a hospital or treatment centre. Some people have chemotherapy at home through a portable pump.

Side effects of chemotherapy

The side effects of chemotherapy vary, depending on the drugs used and the dose. Your medical oncologist or nurse will talk to you about the likely side effects, including how they can be prevented or controlled. If side effects are hard to manage, the chemotherapy treatment can be adjusted to reduce the side effects while still giving you a good result.

Side effects may include tiredness; feeling sick (nausea and vomiting); diarrhoea; lip and mouth sores; changes in appetite, taste and smell; sore hands and feet (peripheral neuropathy); and hair loss or thinning.

The chemotherapy drug oxiplatin may make your hands, feet, mouth and throat sensitive to cold items (e.g. cold food and drinks, air conditioning), causing pins and needles and numbness. Skin rash and increased sensitivity to sunburn 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 get an infection and need to visit the emergency department (see below).

▸ 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 or the "shivers and shakes", contact your doctor or go to the emergency department immediately. 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 in the colon the cancer is. • If cancer has spread to nearby lymph nodes, you may have chemotherapy after surgery (adjuvant chemotherapy).
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 in the rectum the cancer is. • A local excision to remove the cancer may occasionally be used for very early-stage rectal cancer. • If the cancer has spread to nearby tissue or lymph nodes, before the surgery you will usually have chemoradiation. • Some people have radiation therapy or chemotherapy on their own before surgery.
How surgery is done	• Surgery for bowel cancer may be done as open surgery (one large cut), or keyhole surgery (several smaller cuts). • During bowel surgery, the surgeon cuts the bowel on either side of the cancer and joins the 2 ends back together (anastomosis). • If it is not possible to join the bowel back together or if the bowel needs time to heal, the surgeon will create a way for faeces (stools or poo) to come through an opening (stoma) in the abdominal wall.

Treatment for advanced bowel cancer

When bowel cancer has spread outside the bowel to other parts of the body such as 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, a combination of different treatments may be recommended. These may include chemotherapy, targeted therapy, immunotherapy, radiation therapy and surgery. For some people, the best option may be to join a clinical trial (see page 27).

Drug therapies

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), targeted therapy and immunotherapy.

The drugs used for bowel cancer are rapidly changing as clinical trials find newer drugs (see page 27). Your medical oncologist will discuss which combination of drugs is best for your situation. You may also be able to get other drugs through a clinical trial.

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, you'll continue to have chemotherapy or targeted therapy or both. If the cancer is growing, that treatment will stop and your doctor will discuss other treatments.

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. 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 vessels and growing. It is given as a drip into a vein (intravenous infusion) every 2–3 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 22). 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.

Encorafenib – This drug is used to treat a type of colorectal cancer with a mutation in the BRAF gene. It is given as tablets you swallow daily and used in combination with cetuximab.

Side effects – The side effects of targeted therapy vary depending on the drugs used. For a detailed list of side effects, visit eviq.org.au. Common side effects include:

- bevacizumab – high blood pressure, tiredness, bleeding and headaches
- cetuximab and panitumumab – skin problems (redness, swelling, an acne-like rash or dry, flaky skin), tiredness and diarrhoea
- encorafenib – fever, tiredness, joint pain, skin problems, sore eyes.

▶ See our *Understanding Targeted Therapy* fact sheet.

Immunotherapy

Immunotherapy uses the body's own immune system to fight cancer. Checkpoint inhibitors are the main type of immunotherapy drug used for the small number of advanced bowel cancers that have a fault in the mismatch repair (MMR) gene. The drug pembrolizumab is given directly into a vein through a drip (infusion) and the treatment is repeated every 3 or 6 weeks. How many infusions you receive will depend on how you respond to the drug.

Side effects – Like all treatments, checkpoint inhibitors can have side effects. Because these drugs act on the immune system, they can sometimes cause the immune system to attack healthy cells in any part of the body. This can lead to a variety of side effects such as rash, itchy skin, diarrhoea, breathing problems, inflammation of the liver, hormone changes and temporary arthritis. Your doctor will discuss possible side effects with you.

▸ See our *Understanding Immunotherapy* fact sheet.

Radiation therapy

Radiation therapy can be used as a palliative treatment for both advanced colon and advanced rectal cancer. It can be used to control the growth of the tumour and relieve symptoms such as bleeding. If the cancer has spread to the bone or formed a mass in the pelvis, radiation therapy can reduce pain. For further details, see pages 39–41.

If the tumour has spread to the liver, you may be offered a specialised type of radiation therapy. Options may include selective internal radiation therapy (SIRT, also called radioembolisation) or stereotactic body radiation therapy (SBRT).

▸ See our *Understanding Secondary Liver Cancer* fact sheet.

Surgery

Some people are able to have surgery to remove bowel cancer that has spread. Generally, surgery is not recommended if you are unwell or the cancer has spread to many places in the body.

- If the cancer has spread to the liver or lungs, surgery may remove parts of the bowel along with all or part of other affected organs. This may be called an en-bloc resection.
- If the cancer has spread to the lining of the abdomen (peritoneum), some people have surgery to remove as many tumours as possible. This is known as a peritonectomy or cytoreductive surgery. Sometimes, a heated chemotherapy solution is put into the abdomen for 60–90 minutes during a peritonectomy. This is called hyperthermic intraperitoneal chemotherapy (HIPEC).

Thermal ablation

If the cancer cannot be removed with surgery, but has spread to only a small number of places in a single area, your doctor may recommend thermal ablation. This uses heat to destroy the tumour. The heat may come from radio waves (radio frequency ablation) or microwaves (microwave ablation). It is best performed in a specialised centre.

Palliative treatment

This is treatment that aims to slow the spread of cancer and relieve symptoms without trying to cure the disease. Treatments given palliatively for advanced bowel cancer may include surgery, chemotherapy, radiation therapy or targeted therapy.

▸ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets, and listen to our advanced cancer podcast.

Key points about treating advanced bowel cancer

What it is	Advanced bowel cancer is cancer that has spread from the bowel to another part of the body or come back after the initial treatment.
Treatment goal	Treatment aims to control the cancer, slow down its spread and manage any symptoms.
Main treatment	Drug therapies, including chemotherapy, targeted therapy and immunotherapy, are used to control the cancer's growth and stop it spreading.
Targeted therapy	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 help.
Immunotherapy	A small number of people with advanced bowel cancer may be given a checkpoint inhibitor called pembrolizumab.
Other treatment options	Other options might include radiation therapy, surgery and supportive treatments like pain relief. For some people, the best option may be to join a clinical trial.
Treatment side effects	All treatments can cause side effects, such as tiredness, skin problems or bowel issues. 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 (stools or poo) to leave the body. Some of the bowel is then brought out through the opening and stitched onto the skin. There are 2 types of stoma (colostomy and ileostomy, see opposite page).

Understanding stomas

A stoma may be temporary (usually formed from a loop of the bowel) or permanent (formed from the end of the bowel). If surgery may result in a stoma, you will usually see a stomal therapy nurse (see page 54) beforehand. They will mark on your abdomen where the stoma will be placed, taking into account your skin folds and your clothing style.

Temporary stoma – This is needed only until the newly joined bowel has healed. A loop of the bowel is brought out through the opening in the abdomen, and then cut and stitched to the skin. This creates 2 openings. You will have another operation, usually after 3–12 months, to close the stoma and rejoin the bowel. This is called a stoma reversal.

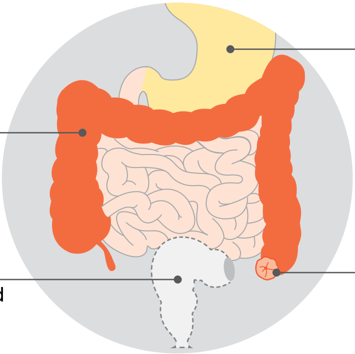
Permanent stoma – About 1 in 10 people with rectal cancer need a permanent stoma when the tumour involves the anal sphincter muscles or the sphincter is not strong enough to control the bowel (incontinence, see pages 55–56). Permanent stomas are not often used for colon cancer.

Appearance – 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 doesn't have any feeling, but the skin around it does. Stomas vary in size and can change shape after surgery.

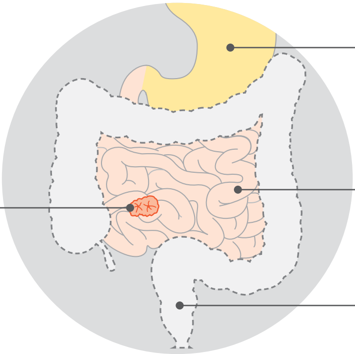
Bowel stomas

○ **Area that may be removed**

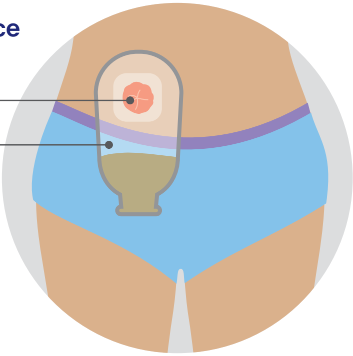
Colostomy
(made from the colon)



Ileostomy
(made from the ileum)



Stoma bag or appliance



How the stoma works

When the bowel moves, wind and waste matter come out through the stoma. You cannot control when this happens, so a small bag is worn on the outside of the body to collect the waste matter. This is called a stoma bag or an appliance. Stoma bags have adhesive on the back so they stick securely 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. If your bag keeps filling up with air, ask your stomal therapy nurse if there are things you can do to prevent this.

Attaching the bag – A stomal therapy nurse (see page 54) will help you choose a bag 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 (thrown out after each bowel movement). After a colostomy, you may be able to wear a drainable or closed bag, depending on the consistency of your waste matter. After an ileostomy, you wear a drainable bag. How often you need to empty or change a stoma bag is affected by what you eat and drink.

- Closed bags may need changing 1–3 times a day. They should be put in a rubbish bin, not flushed down the toilet.
- Drainable bags have to be emptied in the toilet when about one-third full, and replaced every couple of days. A colostomy bag may need emptying 1–3 times a day. An ileostomy bag may need emptying 4–6 times a day because the waste is more watery.

If you have a colostomy in your descending colon, you may be able to wash out the colon with water (colostomy irrigation) to remove the faeces, then wear a small cover rather than a stoma bag. Talk to your doctor or stomal therapy nurse about this option.

Living with a stoma

Having a stoma, even temporarily, is a big change and takes some getting used to. Thousands of Australians have a stoma and most lead a relatively normal life. The stoma may sometimes affect your lifestyle, but most issues can be managed, especially with some planning.

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

How a stoma might affect your sex life – You may worry that the stoma will affect your ability to give or receive sexual pleasure. Getting used to looking after the stoma will help you feel more confident. Sexual activity for people with a stoma may need a little more planning, but can still be satisfying and fulfilling.
▸ See our *Sexuality, Intimacy and Cancer* booklet.

How a stoma might affect what you can eat – Sometimes foods can build up and 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 change what you eat (see page 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 2 hours or you start vomiting, contact your nurse or hospital.

Stoma prolapse – This is when some of the bowel comes out through the stoma opening. Sometimes the prolapse will slide back in by itself, but it may pop in and out. Your stomal therapy nurse or surgeon can tell you how to look after the prolapsed stoma and adapt the stoma bag.

Support for people with a stoma

See a stomal therapy nurse – If there is a chance you could need a stoma, the surgeon will usually refer you to a stomal therapy nurse before surgery. Stomal therapy nurses are registered nurses with special training in stoma care. They are available at most major hospitals, district nursing agencies and in private practice. A stomal therapy nurse can talk to you about the best position for the stoma, answer questions about your surgery and recovery, and give you information about adjusting to life with a stoma. To find a nurse, visit the Australian Association of Stomal Therapy Nurses at stomaltherapy.au.

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 and coordinate support groups. Visit the Australian Council of Stoma Associations at australianstoma.com.au for more information.

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 and type "stoma appliance scheme" into the search box for more details.

Find a support group – There are many support groups or forums on social media you can follow or join.

Managing bowel and dietary changes

Treatment for bowel cancer can affect how your bowel and digestion work. These changes can be difficult to adjust to. They usually improve over time, but issues may be ongoing and require specialised help. If you experience problems, talk to your GP, specialist doctor, specialist nurse or dietitian. To find an accredited practising dietitian, visit dietitiansaustralia.org.au and use the "find a dietitian" search tool.

> Surgery for rectal cancer can lead to symptoms such as faecal incontinence, constipation or frequent bowel movements. This is known as low anterior resection syndrome (LARS), and it can last for months or years. If you have ongoing bowel effects after rectal surgery, talk to your surgeon. Ways to improve bowel function may include changing what you eat, taking medicines and having physiotherapy.

Incontinence

Incontinence is when a person is not able to control their bowel or bladder. It may be caused by different treatments for bowel cancer.

Faecal incontinence – After surgery or radiation therapy, the movement of waste through the large bowel can become faster. You may feel that you can't wait when you need to go to the toilet (urgency), you need to go more often, or you have less 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 bowel movements (diarrhoea).

Urinary incontinence – This is when urine (wee or pee) leaks from your bladder without you being able to control it.

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.

While you may feel embarrassed if you have bowel or bladder changes, there are ways to manage the symptoms. Incontinence usually improves in a few months, but sometimes take years. Talk to your treatment team about whether any bowel or bladder changes are likely to be permanent.

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 your 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 continence.org.au.
- Find out the location of toilets near where you are. Visit toiletmap.gov.au or download the National Public Toilet Map app to your smartphone.
- The Australian Government's *Improving Bowel Function After Bowel Surgery* booklet provides helpful tips about managing bowel problems. To get a copy, call 1800 33 00 66 or visit continence.org.au/get-help/resources.

Radiation proctitis

Radiation to the pelvic area can affect the lining of the rectum, causing inflammation and swelling (known as radiation proctitis). This can lead to a range of side effects including diarrhoea and bleeding from the rectum, the need to empty the bowels urgently, and loss of control over the bowels (faecal incontinence, see page 55).

These side effects may appear shortly after radiation therapy for rectal cancer, but are generally not an ongoing problem because the rectum is removed during surgery.

Your treatment team will talk to you about the risk of developing radiation proctitis and ways to cope with bowel changes.

Diarrhoea

Diarrhoea is the frequent passing of loose, watery faeces (stools or poo). It can also cause abdominal cramping, wind and pain. Different types of treatment can cause diarrhoea:

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 faeces. With a shorter bowel, the faeces don’t form as solidly as before. This may be ongoing, but there are many ways of managing diarrhoea.

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.

Drug therapies – Chemotherapy, immunotherapy and targeted therapy drugs can cause diarrhoea and nausea. These side effects will go away after treatment and you can gradually return to a normal diet.

How to manage diarrhoea

- Eat small frequent meals instead of 3 big ones. Try eating every 2 hours.
- Low-fibre foods may be easier to digest, e.g. bananas, white rice, white pasta, white bread, potatoes, white fish and steamed chicken without the skin.
- Limit foods that increase bowel activity, e.g. caffeine; alcohol; spicy, fatty or oily foods; high-sugar fluids such as juice and soft drink; artificial sweeteners.
- Raw fruits and vegetables, wholegrain breads and cereals, or legumes (e.g. lentils, chickpeas), may make diarrhoea worse. If they do, you may want to cut back on these foods for a few days.
- Lactose in dairy foods may make diarrhoea worse. Try low-lactose or soy-based products instead.
- Watch for warning signs of dehydration. These include a dry mouth, dark yellow urine, dizziness and confusion. If dehydration is left untreated, it can be dangerous.
- Drink plenty of water to avoid becoming dehydrated. Consider having an oral rehydration solution, such as Hydralyte or Gastrolyte.
- If your anus becomes sore, clean the area with warm water and a soft cloth. Ask your treatment team to recommend a cream.
- Having diarrhoea can make you feel tired. Try to rest as much as possible and ask family or friends to help.
- Talk to your treatment team about ways to control diarrhoea, such as using over-the-counter medicines and changing what you eat.
- Ask for a referral to a dietitian or physiotherapist who looks after bowel issues. If diarrhoea continues for a few days, see a doctor.

Wind (flatulence)

Many people who have treatment for bowel cancer, especially surgery, find that it gives them wind, commonly referred to as gas or farting. This is usually temporary and improves with time.

See the tips below on what foods to eat and what to avoid. This is a guide only as foods can affect people differently.

How to manage wind

- Try chewing charcoal tablets, eating natural yoghurt and drinking peppermint tea.
- Cut your food into small, bite-sized pieces.
- Chew your food slowly and thoroughly.
- When you have a drink, take small sips and don't use a straw.
- Talk to your doctor about what types of light exercise you can do to relieve bloating and wind.
- Foods such as eggs, legumes (e.g. lentils and chickpeas), fizzy drinks, and sugar-free foods may increase gas. If they do, you may find it helpful to limit these foods.
- Try keeping a food and symptom diary (see next page) to help identify foods that cause wind.

> *"Three months after the ileostomy, I went in for the reversal surgery. You have to stay in hospital until you pass wind, which took 6 days. Passing wind will never lose its amusement."* RICHARD

Eating after treatment

Immediately after treatment – particularly surgery – you may be on a modified diet. What you are able to eat might depend on the type of surgery you've had, how much of your bowel was removed and whether you have a stoma.

During and after treatment, you may find that certain foods upset your bowel and cause diarrhoea or wind (see pages 57–59). Your health care team may suggest foods to avoid, but as foods can affect people differently, you will need to experiment to work out which foods cause problems for you. It is better to limit – not exclude – these foods in your diet, as you may find that what you can handle improves over time.

Keeping a diary of what you eat can help. Make a note of the foods that cause constipation, diarrhoea or wind. Your ability to handle different foods usually gets better with time but can take many months. When returning to your usual diet, introduce one food at a time. If something causes a problem, try it again in a few weeks to see if your response has improved. Share this information with the health care team as it can help them figure out how to manage any issues.

▸ See our *Nutrition for People Living with Cancer* booklet.

> *"When I first got put back together after the ileostomy, processed food really messed with me. The more processed it is, the slower my body deals with it. Some of the things I loved – pizza, processed meat, bread, red meat and potato – play with me. The greener the better – salads, fruit, fish, chicken really make me feel sensational."* RICHARD

Eating with a stoma

If you have a stoma, you may need to change what you eat in the first few weeks to help the stoma settle. The amount of stoma output will vary depending on how much you eat and when you eat.

Nuts, seeds and very fibrous foods can block the stoma. By trial and error, you might work out which particular foods irritate the stoma, but these vary considerably between people.

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

Ways to manage stoma blockages

- Eat regular meals.
- Avoid eating a large amount of food at one time.
- Try to maintain a balanced diet so your body gets the nutrients it needs.
- Aim to drink 8–10 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 certain foods, talk to a dietitian about alternatives.
- You may find cooked foods easier to digest.
- Limit foods that are more likely to cause blockages. These include high-fibre foods, raw vegetables, fruit and vegetable skins, nuts, seeds, kernels (e.g. corn, popcorn) and sausage skins.
- Have small amounts of a new food. If it doesn't irritate the stoma, try a larger amount next time.
- Massage your belly and the area around the stoma. Lie on your back, pull your knees up to your chest and roll from side to side. This may help move the blockage through the stoma.

Key points about bowel and dietary changes

Having a stoma	After bowel surgery, some people will need to have a stoma, which is a surgically created opening in the abdomen. Waste passes out of the body through this opening and is collected in a bag. A stoma may be temporary or permanent.
Common bowel and bladder changes	After treatment for bowel cancer, most people find the way their bowel works changes. You may have trouble controlling your bowel (faecal incontinence) or bladder (urinary incontinence), have diarrhoea, or suffer from wind.
Managing dietary and bowel changes	• Stomal therapy nurses and stoma associations can provide support and information to help you get used to life with a stoma. • There are many ways to manage incontinence, and changes to how your bowel and bladder work. For support and information, talk to your health care team. • Drinking plenty of fluid throughout the day will help avoid dehydration and reduce constipation and blockages. • You may need to change what you eat, especially if the diarrhoea or wind is ongoing, or if you have a blockage in the stoma. • 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. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.
▸ See our *Nutrition for People Living with 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.
▶ See our *Cancer and Your Finances* and *Cancer, Work and 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. The experience of cancer 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 bowel 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, because counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. 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. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Follow-up appointments

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

How often you need to see your doctor will depend on the level of monitoring needed for the type and stage of the cancer. Talk to your doctor about how often you need to have check-ups or colonoscopies. 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. Don't wait for your next appointment.

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 recurrence is confined to the bowel and nearby lymph nodes, you may be able to have surgery to remove 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, immunotherapy or radiation therapy (see pages 45–48). These treatments may remove the cancer, help control its growth and relieve symptoms. If your bowel becomes blocked, you will need urgent 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 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.

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 Australia – Carers Australia provides information and advocacy for carers. Visit 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, nurse or stomal therapy 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 by location.

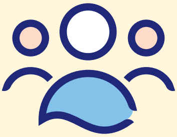
Cancer Council 13 11 20

Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

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.

Information resources

Cancer Council produces booklets and fact sheets on more than 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.

Practical help

Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

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	**cancer.org.au**
Cancer Council Online Community	**cancercouncil.com.au/OC**
Cancer Council podcasts	**cancercouncil.com.au/podcasts**
Guides to Best Cancer Care	**cancer.org.au/cancercareguides**
Australian Association of Stomal Therapy Nurses	**stomaltherapy.au**
Australian Council of Stoma Associations (ACSA)	**australianstoma.com.au**
Cancer Australia	**canceraustralia.gov.au**
Cancer Screening	**cancerscreening.gov.au**
Colorectal Surgical Society of Australia and New Zealand	**cssanz.org**
Continence Foundation of Australia	**continence.org.au**
Dietitians Australia	**dietitiansaustralia.org.au**
eviQ Cancer Treatments Online	**eviq.org.au**
Healthdirect Australia	**healthdirect.gov.au**
Services Australia (including Centrelink and Medicare)	**servicesaustralia.gov.au**
International	
American Society of Colon and Rectal Surgeons	**fascrs.org**
The Association of Coloproctology of Great Britain and Ireland	**acpgbi.org.uk**
Bowel Cancer UK	**bowelcanceruk.org.uk**

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 regular 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. Also known as the belly.

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

advanced cancer
Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

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

anastomosis
The joining back together of 2 tubes, such as 2 cut ends of the bowel.

anterior resection
An operation 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/appliance.

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
The term bowel often refers to the large bowel. See also large bowel; small bowel.

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 type of thin plastic tube inserted into a vein. It gives access to a vein so chemotherapy or fluid can be given, and blood can be taken.

chemoradiation (chemoradiotherapy)
Treatment that combines chemotherapy with radiation therapy.

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 include right and left hemicolectomies, sigmoid, subtotal and total colectomies, and proctocolectomy.

colon
The main working area of the large bowel, where water is removed from solid waste

matter. Its 4 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 to increase the capacity of the "new" rectum.

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 (computerised tomography) scan
This scan uses x-rays to create cross-sectional pictures 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 of the anus, rectum or prostate.

enema
A liquid solution put into the rectum to wash out the lower bowel.

faeces
Waste matter that normally leaves the body through the anus. Also known as stools or poo.

familial adenomatous polyposis (FAP)
A condition that causes hundreds of polyps to form in the large bowel.

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

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.

hyperthermic intraperitoneal chemotherapy (HIPEC)
Chemotherapy in which the drugs are heated and inserted directly into the abdomen for 60–90 minutes during a peritonectomy.

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
A test that checks faeces for tiny amounts of blood. Also called iFOBT.

immunotherapy
Drugs that use the body's own immune system to fight cancer.

incontinence
The accidental or involuntary loss of urine (wee or pee) or faeces (poo).

inflammatory bowel disease
A benign condition that causes inflammation of the bowel.

keyhole surgery
Surgery done through several small cuts in the body using a viewing instrument with a

light and camera. Also called laparoscopic, minimally invasive or robotic surgery.

large bowel
Part of the lower digestive system. The large bowel stores waste until it leaves the body as faeces. Its main sections are the colon and rectum. 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
Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

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

metastasis (plural: metastases)
A cancer that has spread from a primary cancer in another part of the body. Also known as secondary or advanced cancer.

MRI scan
Magnetic resonance imaging scan. The scan uses magnetic fields and radio waves to take detailed cross-sectional pictures of the body.

open surgery
A surgical method that uses one large cut in the body to view and access the organs.

pelvic exenteration
Surgical removal of all organs from the pelvis.

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

peritonectomy
An operation to remove part of the lining of the abdomen (peritoneum).

PET–CT scan
Positron emission tomography scan combined with CT scan. In a PET scan, a person is injected with a small amount of radioactive 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
An operation to remove the entire colon and rectum.

radiation therapy
The use of targeted radiation to kill or damage 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.

selective internal radiation therapy (SIRT)
A type of internal radiation therapy used to treat liver cancers.

sigmoid colon
The part of the colon below the descending colon and above the rectum and anus.

small bowel
The middle part of the gastrointestinal tract, which takes food from the stomach and absorbs nutrients. It has 3 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 intestinal cancer.

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

stereotactic body radiation therapy (SBRT)
A type of radiation therapy that delivers high doses of precise radiation.

stoma
A surgically created opening to allow urine or faeces to leave the body. Also called ostomy.

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

surgery
A procedure performed by a surgeon to remove or repair a part of the body. Also known as an operation or surgical resection.

systemic treatment
Cancer drugs that spread throughout the whole body. Includes chemotherapy, targeted therapy and immunotherapy.

targeted therapy
Drugs that target specific features of cancer cells to stop them growing and spreading.

thermal ablation
Treatment that uses extreme temperatures (thermal) to destroy cancer cells without actually removing them from the body.

transanal endoscopic microsurgery (TEMS)
Removing rectal cancer using specially designed equipment inserted through the anus.

transanal excision (TAE)
Removing rectal cancer through the anus using surgical equipment.

transanal minimally invasive surgery (TAMIS)
A surgical platform that lets the surgeon remove a rectal cancer through the anus using laparoscopic equipment.

transverse colon
The part of the colon between the ascending and descending colon.

tumour marker
Chemical produced by cancer cells and released into the blood. It may suggest the presence of a tumour.

virtual colonoscopy
A medical imaging procedure that uses a CT scanner to create and display images of the colon and rectum.

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
- cancervic.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, viewed 26 September 2022, available from wiki.cancer.org.au/australia/Guidelines:Colorectal_cancer.
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2022*, viewed 29 September 2022, available from aihw.gov.au/reports/cancer/cancer-data-in-Australia.

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 experienced health professionals 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.

TIS TRANSLATING AND INTERPRETING SERVICE

If you need information in a language other than English, an interpreting service is available. Call 131 450.

National Relay Service

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

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Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

For information & support
on cancer-related issues,
call Cancer Council 13 11 20

Visit your local Cancer Council website

Cancer Council ACT	actcancer.org
Cancer Council NSW	cancercouncil.com.au
Cancer Council NT	cancer.org.au/nt
Cancer Council Queensland	cancerqld.org.au
Cancer Council SA	cancersa.org.au
Cancer Council Tasmania	cancer.org.au/tas
Cancer Council Victoria	cancervic.org.au
Cancer Council WA	cancerwa.asn.au
Cancer Council Australia	cancer.org.au

*This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.*

Cancer Council

UNDERSTANDING BOWEL CANCER

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