Understanding Bowel Cancer
A guide for people with cancer, their families and friends

For information & support, call 13 11 20
This booklet has been prepared to help you understand more about bowel cancer (also known as colorectal cancer).

Many people feel understandably shocked and upset when told they have bowel cancer. We hope this booklet will help you, your family and friends understand how bowel cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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. 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 the Victorian Government’s optimal care pathways.¹
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What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. 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.

Sometimes cells don’t grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts

![Diagram of normal cells, abnormal cells, abnormal cells multiply, and malignant or invasive cancer](image-url)
The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process known as angiogenesis.

If cancerous 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 person may be experiencing symptoms caused by problems in the liver.

### How cancer spreads

- **Primary cancer**
- **Local invasion**
- **Angiogenesis** – tumours grow their own blood vessels
- **Lymph vessel**
- **Metastasis** – cells invade other parts of the body via blood vessels and lymph vessels

What is cancer?
The bowel is part of the digestive system, which is also called the gastrointestinal (GI) or digestive tract. 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. This solid waste matter is called faeces (also known as stools when it leaves the body through the anus). The bowel is made up of the small bowel and the large bowel.

### Small bowel
A long tube (4–6 m) that absorbs nutrients from food. Also called the small intestine, it is longer but narrower than the large bowel.

<table>
<thead>
<tr>
<th>Part</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duodenum</td>
<td>The first section of the small bowel; receives food from the stomach.</td>
</tr>
<tr>
<td>Jejunum</td>
<td>The middle section of the small bowel.</td>
</tr>
<tr>
<td>Ileum</td>
<td>The final and longest section of the small bowel; transfers waste to the large bowel.</td>
</tr>
</tbody>
</table>

### Large bowel
A tube that absorbs water and salts, and turns what is left over into waste (faeces). Also called the large intestine, the large bowel is about 1.5 m long.

<table>
<thead>
<tr>
<th>Part</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caecum</td>
<td>A pouch that receives waste from the small bowel. The appendix is a small tube hanging off the end of the caecum.</td>
</tr>
<tr>
<td>Colon</td>
<td>The main working area of the large bowel. Takes up most of the large bowel’s length and has four parts: ascending colon, transverse colon, descending colon and sigmoid colon.</td>
</tr>
<tr>
<td>Rectum</td>
<td>The last 15–20 cm of the large bowel.</td>
</tr>
<tr>
<td>Anus</td>
<td>The opening at the end of the digestive tract. During a bowel motion, the muscles of the anus relax to release faeces from the rectum.</td>
</tr>
</tbody>
</table>
The digestive system

- Small bowel
- Large bowel

Anus

The bowel
Key questions

Q: What is bowel cancer?
A: Bowel cancer is cancer in any part of the large bowel (colon or rectum). It is sometimes known as colorectal cancer and might also be called colon cancer or rectal cancer, depending on where it starts. Cancer of the small bowel is very rare and is usually called ‘small bowel cancer’ or ‘small intestine cancer’.

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

If untreated, bowel cancer can grow into the deeper layers of the bowel wall. It can spread from there to the lymph nodes. These small, bean-shaped masses are part of the body’s lymphatic system. If the cancer advances further, it can spread (metastasise) to other organs, such as the liver or lungs.

In most cases, the cancer is confined to the bowel for months or years before spreading.

Q: How common is bowel cancer?
A: Bowel cancer is the second most common cancer affecting people in Australia. It is estimated that about 15,000 people are diagnosed with bowel cancer every year. About one in 21 men and one in 30 women will develop bowel cancer before the age of 75. It is most common in people over 50, but it can occur at any age.²
Q: What are the symptoms?
A: In its early stages, bowel cancer may have no symptoms. However, many people with bowel cancer experience symptoms. These can include:
- blood in the stools or on the toilet paper
- a change in bowel habit, such as diarrhoea, constipation or smaller, more frequent bowel movements
- a change in appearance or consistency of bowel movements (e.g. narrower stools or mucus in stools)
- a feeling of fullness or bloating in the abdomen or a strange sensation in the rectum, often during a bowel movement
- feeling that the bowel hasn’t emptied completely after a bowel movement
- unexplained weight loss
- weakness or fatigue
- rectal or anal pain
- a lump in the rectum or anus
- abdominal pain or swelling
- a low red blood cell count (anaemia), which can cause tiredness and weakness.

Not everyone with these symptoms has bowel cancer. Other conditions, such as haemorrhoids, diverticulitis (inflammation of pouches in the bowel wall) or cracks in the anal canal, can also cause these changes.

Changes in bowel function are common and often do not indicate a serious problem. However, any amount of bleeding is not normal and you should see your doctor for a check-up.
Q: What are the risk factors?

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

Risk factors include:

• **older age** – most people with bowel cancer are over 50, and the risk increases with age
• **polyps** – having a large number of polyps in the bowel
• **bowel diseases** – people who have an inflammatory bowel disease, such as Crohn’s disease or ulcerative colitis, have a significantly increased risk, particularly if they have had it for more than eight years
• **lifestyle factors** – being overweight, having a diet high in red meat (particularly processed meats such as salami or ham), drinking alcohol and smoking
• **strong family history** – a small number of bowel cancers run in families, see opposite
• **other diseases** – people who have had bowel cancer once are more likely to develop a second bowel cancer; some people who have had ovarian or endometrial 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.

Some factors reduce your risk of developing bowel cancer. These include being physically active, maintaining a healthy weight, cutting out processed meat, cutting down on red meat, reducing alcohol consumption and eating a high-fibre diet.
Q: Can bowel cancer run in families?

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

A family history of other cancers, such as endometrial cancer, may also increase your risk of developing bowel cancer.

There are also two rare genetic conditions that occur in some families. These cause a small number (5–6%) of bowel cancers.

- **Familial adenomatous polyposis (FAP)** – This condition causes hundreds of polyps to form in the bowel. If polyps caused by FAP are not removed, they may become cancerous.

- **Lynch syndrome** – Previously known as hereditary non-polyposis colorectal cancer (HNPCC), this syndrome is characterised by a fault in the gene that helps the cell’s DNA repair itself. Having Lynch syndrome increases the risk of developing bowel cancer and other cancers.

If you are concerned about your family risk factors, 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.
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). You will usually be referred to a specialist, such as a colorectal surgeon or a gastroenterologist. The specialist will arrange further tests.

<table>
<thead>
<tr>
<th>MDT health professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GP</strong></td>
</tr>
<tr>
<td>explains information provided by specialists; assists with treatment decisions; helps you obtain practical and emotional support; and works together with your specialists to provide your ongoing care</td>
</tr>
<tr>
<td><strong>colorectal surgeon</strong>*</td>
</tr>
<tr>
<td>diagnoses bowel cancer and operates on the bowel</td>
</tr>
<tr>
<td><strong>gastroenterologist</strong>*</td>
</tr>
<tr>
<td>diagnoses bowel cancer and specialises in diseases of the digestive system</td>
</tr>
<tr>
<td><strong>medical oncologist</strong>*</td>
</tr>
<tr>
<td>prescribes and coordinates the course of chemotherapy</td>
</tr>
<tr>
<td><strong>radiation oncologist</strong>*</td>
</tr>
<tr>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td><strong>cancer care coordinator or clinical nurse consultant (CNC)</strong></td>
</tr>
<tr>
<td>supports you and your family throughout treatment and liaises with other members of your health care team</td>
</tr>
<tr>
<td><strong>operating room staff</strong></td>
</tr>
<tr>
<td>include anaesthetists, technicians and nurses who prepare you for surgery and care for you during the operation and recovery</td>
</tr>
</tbody>
</table>

*Specialist doctor
Once your treatment for bowel cancer begins, you will be cared for by a range of health professionals who specialise in different areas of your treatment. This is called a multidisciplinary team (MDT) and it may include some or all of the health professionals listed in the table below.

<table>
<thead>
<tr>
<th>Health Professional</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>nurses</td>
<td>care for you during and after surgery; administer drugs; and provide care, information and support throughout your treatment</td>
</tr>
<tr>
<td>stomal therapy nurse</td>
<td>provides information about surgery and adjusting to life with a temporary or permanent stoma</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends an eating plan to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td>genetic counsellor</td>
<td>provides advice for people with a strong family history of bowel cancer or with a genetic condition linked to bowel cancer</td>
</tr>
<tr>
<td>social worker</td>
<td>links you to support services and helps you with emotional or practical issues</td>
</tr>
<tr>
<td>counsellor, psychologist</td>
<td>provide emotional support and help manage any feelings of depression and anxiety</td>
</tr>
<tr>
<td>physiotherapist, occupational therapist</td>
<td>assist with physical and practical problems, including restoring range of movement after surgery</td>
</tr>
</tbody>
</table>

* *Specialist doctor*
Diagnosis

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

To diagnose bowel cancer, your GP will examine you. This will include a digital rectal examination (see below). They will refer you to a specialist for further tests. The tests you have depend on your specific situation and may include:

- general tests to check your overall health and body function
- tests to find cancer
- tests to see if the cancer has spread (metastasised).

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

General tests

Physical examination

Your doctor will examine your body, feeling your abdomen for any swelling.

To check for problems in the lowest part of the bowel (anus and rectum), your doctor will insert a gloved finger into your anus and feel for any lumps or swelling. This is called a digital rectal examination (DRE).
The DRE may be uncomfortable, but it shouldn’t be painful. Because the rectum is a muscle, it can help to try to relax during the examination. The pressure on the rectum might make you feel like you are going to have a bowel movement, but it is very unlikely that this will happen.

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

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

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

Screening is the process of looking for polyps or cancer in people who don’t have any symptoms. It is particularly important for bowel cancer, which often has no symptoms in its early stages.

The faecal occult blood test (FOBT) looks for microscopic traces of blood in your stools, which may be a sign of polyps, cancer or another bowel condition. An FOBT does not diagnose cancer, but if it finds blood, your doctor will recommend you have a colonoscopy (see opposite) within 30 days.

Everyone over 50 should have an FOBT every two years. Finding bowel cancer early can significantly improve the chance of surviving the disease. Through the National Bowel Cancer Screening Program, people aged 50 to 74 are automatically sent a free FOBT kit. A kit can also be purchased from some pharmacies.

You complete the test at home. For more information, phone 1800 118 868 or see cancerscreening.gov.au.

The FOBT is only for low-risk people without symptoms of bowel cancer. Anyone with symptoms of bowel cancer (see page 9) must talk to their doctor about having a colonoscopy or other tests.

If you have a strong family history or a genetic condition linked to bowel cancer (see page 11), the FOBT is not the right test for you. You and other family members may need screening colonoscopies.

A screening colonoscopy is recommended for high-risk people at 50 years of age, or 10 years before the earliest age a family member was diagnosed with bowel cancer, whichever comes first. Your doctor will let you know how often the test should be repeated.
Tests to find cancer in the bowel

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

Colonoscopy

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

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

- During the procedure, the doctor will insert a flexible tube with a camera on the end, called a colonoscope, into your anus and up into your rectum and colon. Carbon dioxide or air will be passed into the colon. Your doctor will look for abnormal tissue (such as polyps), and take a sample (biopsy) for further examination.

A colonoscopy usually takes about 20–30 minutes. You will need to have someone take you home afterwards, as you may feel drowsy or weak. An occasional side effect of a colonoscopy is temporary flatulence and wind pain, especially if air rather than carbon dioxide is passed into the bowel during the test. More serious but rare complications include damage to the bowel or bleeding. Your doctor will talk to you about the risks.
Less commonly used tests

Virtual colonoscopy – This uses a CT or MRI scanner (see pages 20–21) to create images of the colon and rectum and display them on a screen. It is also known as CT colonography.

A virtual colonoscopy is not often used because it is not as accurate as a colonoscopy and involves exposure to radiation. Your doctor may not be able to see small abnormalities and cannot take tissue samples. Virtual colonoscopy is covered by Medicare only in some circumstances when a colonoscopy isn’t feasible.

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

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

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

Before some diagnostic tests, you will have to clean out your bowel completely. This will help the doctor see inside the bowel clearly. Cleaning out the bowel is called bowel preparation. The process varies for different people and between hospitals, so ask if there are any specific instructions for you. It’s important to follow the instructions so you don’t have to repeat the test. Talk to your doctor if you have any concerns about the bowel preparation process, or if you experience any side effects.

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

Drink clear fluids
Your doctor might advise you to drink only fluids, such as broth, water, black tea and coffee, and clear fruit juice without pulp for 12–24 hours before the test. This will help to prevent dehydration.

Ask if you need an enema
One common way to clear the bowel is using an enema. This involves inserting liquid directly into the rectum. The enema solution washes out the lower part of the bowel, and is passed into the toilet along with any faeces.

Change diet
For a few days before the diagnostic test, you may be told to avoid high-fibre foods, such as vegetables, fruit, wholegrain pasta, brown rice, bran, cereals, nuts and seeds. Instead, choose low-fibre options, such as white bread, white rice, meat, fish, chicken, cheese, yoghurt, pumpkin and potato.
Further tests
If any of the tests on pages 14–18 show you have bowel cancer, you will have additional tests to see if the cancer has spread to other parts of your body.

Your blood may be tested for a protein called carcinoembryonic antigen (CEA). This protein is produced by some cancer cells. If blood test results 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 CEA levels. CEA levels may be retested after treatment to see if the cancer has come back.

CT scan
A CT (computerised tomography) scan uses x-rays to take many pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture. A scan is usually done as an outpatient. Most people are able to go home as soon as the test is over.

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

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

An MRI (magnetic resonance imaging) scan uses a powerful magnet to build up cross-sectional pictures of the inside of your body. Only people with cancer in the rectum have an MRI; it is not commonly used for cancers higher in the bowel. An MRI may be used before surgery to stage rectal cancer or before radiotherapy.

Before the scan, let your doctor know if you have a pacemaker or any other metallic object in your body. The magnet can interfere with some pacemakers, but some newer pacemakers are MRI-compatible. As with a CT scan, a dye might be injected into a vein before the scan 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 may become distressed, mention it beforehand to your medical team. You may be given a medicine to help you relax and you will usually be offered headphones or earplugs.

The MRI scan may take between 30 and 90 minutes, depending on the size of the area being scanned and how many images are taken.
**FDG-PET scan**

Medicare does not currently cover the cost of an FDG-PET (fluorodeoxyglucose-positron emission tomography) scan for bowel cancer, but this scan can find disease at sites that may not be picked up on a CT scan. If this test is recommended, check with your doctor what you will have to pay.

Before an FDG-PET scan, you will be injected with a special modified sugar molecule (fluorodeoxyglucose or FDG). You will be asked to sit quietly for 30–90 minutes while the solution moves through your body.

Your body is then scanned for areas with high levels of FDG. Cancer cells absorb more of the FDG, so they will be highlighted when your body is scanned.

It will take several hours to prepare for and have the scan.

**Staging bowel cancer**

The tests described on pages 14–22 help show whether you have bowel cancer and whether it has spread. Working out how far the cancer has spread is called staging and it helps the doctor decide on the best treatment for you.

There are different systems for staging bowel cancer. The Australian Clinico-Pathological Staging (ACPS) and Dukes staging system have been widely used in Australia, but TNM staging (see table opposite) is becoming more common.
When staging is done before surgery, it is known as the clinical stage – it represents your doctor’s estimate of the extent of the disease and is based on the tests used to diagnose the cancer. Staging done after treatment, such as surgery, is called the pathologic stage. This uses the findings of the early tests, as well as the tests on the cancer tissue and lymph nodes removed during surgery (see pages 30–37). These results are usually available about a week after the surgery. The pathologic stage is more precise in determining the extent of the cancer.

**TNM staging**

Used for many types of cancer, the TNM system gives information about the tumour, nodes and metastasis. Each letter is assigned a number that shows how advanced the cancer is. If the letter X is used instead of a number, it means that it can’t be determined.

<table>
<thead>
<tr>
<th>T (Tumour)</th>
<th>Indicates how far the tumour has grown into the bowel wall and nearby areas. T1 is a smaller tumour; T4 is a larger tumour that has grown into another organ.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–4</td>
<td></td>
</tr>
<tr>
<td>N (Nodes)</td>
<td>Shows if the cancer has spread to nearby lymph nodes. N0 means that the cancer has not spread to the lymph nodes; N1 means there is cancer in 1–3 lymph nodes; N2 means cancer is in 4 or more lymph nodes.</td>
</tr>
<tr>
<td>0–2</td>
<td></td>
</tr>
<tr>
<td>M (Metastasis)</td>
<td>Shows if the cancer has spread to other, distant parts of the body. M0 means the cancer has not spread; M1 means the cancer has spread.</td>
</tr>
<tr>
<td>0–1</td>
<td></td>
</tr>
</tbody>
</table>
Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for any doctor to predict the exact course of the disease. In most cases, the earlier bowel cancer is diagnosed and treated, the better the outcome.

To come up with a prognosis, your doctor will consider:
- test results
- the type of cancer you have
- the rate and depth of tumour growth
- other factors such as age, fitness and medical history.

If bowel cancer is diagnosed and treated when it is still confined to the colon and/or local lymph nodes, it is known as early bowel cancer and has a good prognosis. If the bowel cancer has spread beyond the colon and local lymph nodes, it is known as advanced bowel cancer. The cancer may respond well to treatment, but a cure is less likely.
Key points

• There are many types of tests used to diagnose bowel cancer, but your doctor will only arrange the tests you need.

• A faecal occult blood test (FOBT) checks stool samples for traces of blood in people with no symptoms. It is often done as part of a national screening program. The FOBT can help find polyps or bowel cancer in its early stages. If blood is found during the FOBT, you should have a colonoscopy.

• A colonoscopy can be used to look for polyps and cancer in the entire large bowel.

• A bowel preparation will be needed before a colonoscopy. This cleans out the bowel so the doctor can see inside clearly. You will need to follow a low-fibre diet, take laxatives and only drink clear liquids.

• While these tests are not commonly used, some people have a virtual colonoscopy or flexible sigmoidoscopy.

• CT and MRI scans are painless tests that take pictures of the inside of your body. They may show the location of the cancer and whether it has spread.

• The specialist will use the test results to assign the cancer a stage. This describes the size and spread of the cancer. You will be told the stage of the cancer about a week after bowel surgery, when enough tissue and lymph nodes have been examined and tested.

• Your prognosis is the expected outcome of the disease. The earlier bowel cancer is diagnosed and treated, the better the likely outcome.

• You may see many health professionals who specialise in different areas of care and work together as a multidisciplinary team to diagnose and treat you.
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. Check with your doctor how soon your treatment should start, and take as much time as you need before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that’s based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask your doctor questions – see page 70 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.
A second opinion
You may want to get a second opinion from another specialist to confirm or clarify your doctor’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 doctor who provided the second opinion.

Taking part in 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.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of Understanding Clinical Trials and Research, or visit australiancancertrials.gov.au.
Treatment for early bowel cancer

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

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

The treatment options you are offered will depend on the guidelines for best practice in treating bowel cancer. For some people, the best option may be to join a clinical trial.

Treatment options by type of bowel cancer

Colon cancer – Surgery is the main treatment for early colon cancer. If cancer has spread to the lymph nodes, you may have chemotherapy after surgery. This is called adjuvant chemotherapy. Radiotherapy is not used for early colon cancer.

Rectal cancer – Surgery is the main option for early rectal cancer. If the cancer has spread beyond the rectal wall and/or into nearby lymph nodes (locally advanced cancer), you will have either radiotherapy or both radiotherapy and chemotherapy (chemoradiotherapy or chemoradiation). This is called neoadjuvant treatment, and the aim is to make the cancer as small as possible before it is removed. This will be followed by surgery and then adjuvant chemotherapy.
How the surgery is done

Different surgical methods may be used for bowel cancer. Each method has advantages in particular situations – your doctor will advise which method is most suitable for you.

Open surgery
This involves one long cut (incision) down your abdomen. Open surgery usually means a larger wound and slower recovery. It requires a longer hospital stay.

Open surgery is a well-established technique and is widely available in Australia.

Minimally invasive surgery
Also called keyhole surgery or laparoscopic surgery, this method involves several small cuts. It usually means less pain and scarring, a shorter hospital stay and faster recovery.

A thin tube (laparoscope) is passed through a cut in the abdomen. The laparoscope has a light and camera. Long, thin instruments are inserted through other small incisions to remove the section of bowel with the cancer. Robot-assisted surgery is a type of laparoscopic surgery. The instruments are controlled using robotic arms.
Surgery
There are different types of surgery for bowel cancer. The aim of surgery is to remove all the cancer and nearby lymph nodes.

Surgery for cancer in the colon
The most common type of surgery is called a colectomy. There are different types of colectomies depending on whether part or all of the colon is removed. Lymph nodes near the colon and some normal bowel around the cancer will also be removed.

The surgeon usually cuts the colon on either side of the cancer and then joins the two ends of the colon back together. This join is called an anastomosis.

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

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

After surgery, you will have a scar. Most people who have open surgery have a scar from above their navel to their pubic area. See page 29 for an illustration of the cut (incision).
Types of colectomies

- **Right hemicolectomy**: The right side of the colon is removed.*
- **Left hemicolectomy**: The left side of the colon is removed.*
- **Transverse colectomy**: The middle part of the colon is removed.
- **Sigmoid colectomy**: The sigmoid colon is removed.
- **Subtotal or total colectomy**: Most or all of the bowel is removed.
- **Proctocolectomy**: All of the colon and rectum are removed.

*If the transverse colon is also removed, it is called an extended right or left hemicolectomy.*
Surgery for cancer in the rectum

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

You may have an anterior resection or abdominoperineal resection (also known as an abdominoperineal excision). The surgery may be open style or minimally invasive (see page 29).

Resections in the large bowel

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

Abdominoperineal resection or excision (APR or APE)
The sigmoid colon and entire rectum and anus are removed. Your surgeon uses the descending colon to create a permanent stoma (known as a colostomy) for faeces to leave the body. The anal area will be stitched up and permanently closed.
An anterior resection is the most common operation. This will include creating a temporary stoma, which will be reversed later.

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

**Ultra-low anterior resection**
The lower left part of the colon and the entire rectum are removed, along with nearby lymph nodes and fatty tissue. The end of the bowel is joined to the lowest part of the rectum, just above the anal canal. In some cases, the surgeon creates another way for waste to leave the body (see right).

**Colonic J-pouch**
An internal pouch is made from the lining of the large bowel. This J-pouch will be connected to the anus and work as a rectum. You may have a temporary ileostomy (a stoma from the small bowel, see page 50), which will be reversed once the J-pouch heals.
Other types of surgery

Local excision – People who have very early stage bowel cancer or are not fit for a major operation may have a local excision. The surgeon inserts an endoscope into the anus to remove the cancer. This is called transanal endoscopic microsurgery (TEMS).

If the cancer is very low in the rectum, the surgeon may be able to remove the cancer by passing an instrument up the anus rather than using an endoscope. This is called transanal excision (TAE).

A less commonly used method is a colonoscopic excision, which can remove small tumours from the colon.

The type of surgery you have will depend on the location of the cancer. The surgeon will also consider your preferences.

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

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

The type of surgery your doctor recommends depends on several factors including the location of the tumours in the colon, genetic and other risk factors, and your preferences.
Surgery for a blocked bowel (bowel obstruction)

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

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

Sometimes the obstruction is cleared during surgery to remove the cancer. In some cases, the bowel obstruction will mean you have to have emergency surgery. It may be possible to close up the bowel during the surgery, but some people may need a stoma (see pages 50–55). Sometimes a stoma is made ‘upstream’ from the obstruction to relieve the blockage to allow time for staging scans of the cancer or chemoradiotherapy before surgery, to make sure the cancer is removed appropriately.

Not everyone with a blockage will want an operation or be fit enough to have it. To help keep the bowel open so that bowel motions can pass through again, your surgeon may be able to put in a small tube (stent). A stent may also help manage the blockage until you are well enough for an operation. A flexible tube with a light at the end, called an endoscope, is passed through the rectum. This helps the surgeon see the blockage, and the stent is inserted through it.

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

Drips and tubes
You will be given fluids through a drip (also called an intravenous or IV infusion) until you can start eating and drinking again. You may need a drip for a few days. You may also have other tubes – from your bladder to drain urine (catheter) or from your abdomen to drain fluid from around the surgical area.

Recovery time
This varies depending on the type of surgery. You will probably be in hospital for 5–7 days, but it can take 2–3 months to fully recover.

Pain relief
At first, you will need some pain relief. You will have patient-controlled analgesia (PCA), which delivers a measured dose of pain relief medicine when you push a button. Pain relief may also be given by a slow injection into a vein (intravenous or IV infusion) or by an injection into your spinal column (epidural or spinal anaesthetic).

Breathing exercises
You may also be shown some deep-breathing exercises to do to prevent a chest infection.

Blood clots
To reduce the risk of developing blood clots in your legs, you may wear compression stockings during surgery to apply pressure to your calves. Some people also wear a special cuff that applies intermittent pressure.
Side effects of bowel surgery

Changes in bowel and sexual function – Many people find that their bowel and bladder functions change. These usually improve within a few months but, for some people, it can take longer. See page 49 for more details. Erection problems are also an issue for some men.

Changes to your diet – See pages 56–60 for information.

Fatigue – It is normal to feel tired after surgery. Try to rest and only do what is comfortable. You might have to remind your family and friends that it may take several months to recover from surgery.

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

Radiotherapy

Radiotherapy (also known as radiation therapy) uses radiation, such as protons, to kill cancer cells. The radiation is targeted to the specific site of the cancer, and treatment is carefully planned to do as little harm as possible to your normal body tissue near the cancer.

Commonly, radiotherapy is used before surgery for locally advanced rectal cancer. It is often combined with chemotherapy and radiotherapy (called chemoradiotherapy or chemoradiation). This is because chemotherapy makes cancer cells more sensitive to radiotherapy, and reducing the number of cancer cells will make it easier for the surgeon to completely remove the tumour. Radiotherapy is not used to treat early colon cancer.
Radiotherapy can be delivered in different ways, including IMRT (intensity-modulated radiation therapy) and VMAT (volumetric modulated arc therapy). These techniques deliver a dose to the affected area without damaging surrounding tissue. These improvements have reduced the side effects from radiotherapy.

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.

If radiotherapy is given with chemotherapy, you will have it once a day for 5–6 weeks. You may have a shorter course of radiotherapy if it is given by itself, usually for five days, Monday to Friday. To find out more, call 13 11 20 for a copy of *Understanding Radiotherapy*, or download a copy from your local Cancer Council website.

**Side effects of radiotherapy**

Common side effects of radiotherapy include:

- diarrhoea
- tiredness
- urinary or faecal incontinence (see page 49)
- redness and soreness in the treatment area
- reduced fertility (see opposite)
- problems with sexual function (see opposite).

People react to treatment differently, so some people may have few side effects, while others have more. Your treatment team will give you advice about how to manage radiotherapy side effects.
Effects on fertility and sexual function
Radiotherapy to the pelvis and rectum can affect your ability to have children (fertility) and sexual function.

<table>
<thead>
<tr>
<th>For men</th>
<th>For women</th>
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<tbody>
<tr>
<td>• Radiotherapy can damage sperm or reduce sperm production. This may be temporary or permanent.</td>
<td>• Radiotherapy may lead to damage and narrowing of the vagina, making sexual intercourse painful. The use of a vaginal dilator can help to gradually widen the entrance and prevent the side walls sticking together. Ask your doctor or a physiotherapist for advice on how to use a dilator.</td>
</tr>
<tr>
<td>• Most doctors suggest that men use contraception or abstain from unprotected sex during and after radiotherapy for one month.</td>
<td>• In some cases, radiotherapy can affect the ovaries and stop them producing female hormones. This can cause menopause and infertility. Menopause can be managed by hormone replacement therapy, which is safe for rectal cancer. After menopause you will not be able to conceive a child. Share your feelings about any fertility issues with your partner, a counsellor or a fertility specialist.</td>
</tr>
<tr>
<td>• You will be able to store sperm at a hospital or fertility clinic before treatment starts. Talk to your doctor about this.</td>
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Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer (cytotoxic) drugs. It aims to kill cancer cells while doing the least possible damage to healthy cells. If the cancer has spread outside the bowel to lymph nodes or to other organs, chemotherapy is usually needed. Chemotherapy may be used for several reasons:

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

**After surgery (adjuvant)** – Chemotherapy is used after surgery for either colon or rectal cancer to reduce the chance of the cancer coming back by eliminating any cancer cells that may have spread after surgery. You will probably start chemotherapy as soon as your wounds have healed and you’ve recovered your strength, usually within eight weeks.

If the cancer has spread to other organs, such as the liver or lungs, chemotherapy may be used to reduce symptoms and make you more comfortable (see page 44).

You may have chemotherapy injected into a vein (intravenously) or as tablets. If you have chemotherapy intravenously, you can have the drugs through a thin plastic tube called a central venous access device (CVAD). The CVAD may be placed under the skin with a local anaesthetic. This type of CVAD is called a port-a-cath.
Some people have chemotherapy through a portable bottle called an infusor pump. It is made of hard plastic and looks like a baby bottle. It is usually worn in a bag around your waist or on your hip. The bottle gives a continuous dose over 48 hours while you are at home. You will be shown how to care for the infusor pump.

You will probably have chemotherapy as a course of several sessions (cycles) over 4–6 months. Your medical oncologist will explain your treatment schedule.

**Side effects of chemotherapy**
Most chemotherapy drugs cause some side effects. The side effects depend on the drugs used and the dosage levels.

Common side effects include:
- tiredness
- feeling sick (nausea and vomiting)
- diarrhoea
- mouth sores and ulcers
- changes in appetite and loss of taste
- a drop in levels of blood cells (your blood count), which may increase the risk of infection
- sore hands or feet
- pins and needles, numbness, redness or swelling in the fingers and toes – more common if using the chemotherapy drug called oxaliplatin
- skin peeling and increased sensitivity to sunlight – more common if using the chemotherapy drug called fluorouracil (or 5-FU).
People react to chemotherapy differently – some people have few side effects, while others have many. Most side effects are temporary, and there are ways to prevent or reduce them. Your doctor will prescribe medication to prevent and manage the side effects. It is uncommon to need a break or change in your treatment.

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

For more information, call 13 11 20 and ask for a copy of *Understanding Chemotherapy*, or download a digital version from your local Cancer Council website.

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

• Surgery is the most common treatment for early bowel cancer. You may also have radiotherapy or chemotherapy.

• The type of surgery you have depends on where the cancer is in the bowel, the type and size of the cancer, and whether it has spread. Cancer in the colon and cancer in the rectum are treated differently.

• Colectomy is the most common surgery for colon cancer. There are different types of colectomies depending on whether part or all of the colon is removed.

• Operations for rectal cancer include anterior resection, but if the cancer is low in the rectum you may have an abdominoperineal resection.

• During bowel surgery, the surgeon cuts the colon on either side of the cancer and joins the two ends of the bowel back together.

• If it is not possible to join the bowel back together or if the bowel needs time to heal, a diversion is created for faeces to come through a hole (stoma) in the abdominal wall. Waste (faeces) will be collected into a bag.

• In some cases, you may be able to have minimally invasive surgery (keyhole, laparoscopic or robotic surgery).

• Radiotherapy is treatment with radiation. It is used to treat locally advanced rectal cancer. It is given before surgery (neoadjuvant), often with chemotherapy but sometimes alone.

• Chemotherapy is treatment with drugs. It may be used before or after surgery to reduce the chance of the cancer coming back.
Treatment for advanced bowel cancer

When bowel cancer has spread to the liver, lung or lining of the abdomen and pelvis (omentum and peritoneum), this is known as stage 4 bowel cancer.

To control the cancer, slow its growth and manage symptoms, such as pain, you may have a combination of chemotherapy, targeted therapy, radiotherapy and surgery.

Systemic treatment

Advanced bowel cancer is commonly treated with drugs that reach cancer cells throughout the body. This is called systemic treatment, and includes chemotherapy (see pages 40–42). Sometimes a targeted therapy is used together with chemotherapy.

Targeted therapy drugs work differently from chemotherapy drugs. While chemotherapy affects all rapidly dividing cells and kills cancerous cells (cytotoxic), targeted therapy drugs affect specific molecules within cells to block cell growth (cytostatic).

Two types of targeted therapy drugs are commonly used in Australia for advanced bowel cancer.

**Bevacizumab** – This drug blocks the growth of blood vessels that supply cancer cells. It is given as an injection into a vein (intravenously) every two weeks, with chemotherapy.

**Epidermal growth factor receptor inhibitors (EGFR-Is)** – These target special receptors on cancer cells. They only work for
people who have a normal RAS gene. You will be tested for changes (mutations) in these genes before you are offered these drugs. EGFR-Is are usually given with chemotherapy but sometimes on their own after other chemotherapy drugs have stopped working.

If your medical oncologist thinks that a targeted therapy may help, they will discuss this with you. However, some targeted therapy drugs may be available only through a clinical trial (see page 27).

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

**Side effects of targeted therapy**
The side effects of targeted therapy vary depending on the drugs used. Common side effects of bevacizumab include high blood pressure, tiredness, bleeding, low white blood cell counts, headaches, mouth sores, loss of appetite and diarrhoea. The most common side effects of EGFR-Is include acne-like rash, headache, tiredness, fever and diarrhoea.

**Radiotherapy**
Radiotherapy can also be used as a palliative treatment for both colon and rectal cancer. It can be used to stop bleeding and if the cancer has spread to the bone or formed a mass in the pelvis, it can reduce pain. For further details, see pages 37–39.
Surgery

If the cancer has spread to other parts of the body, you may still be offered surgery. This can help remove small secondary cancers (e.g. in the liver or lungs) or clear up a bowel obstruction.

You may have surgery to remove parts of the bowel along with all or part of other organs. This is called an en-bloc resection.

The type of operation used for advanced bowel cancer will depend on your situation, so talk to your surgeon about what to expect.

Your medical team will advise what kind of follow-up and treatment is recommended after surgery. Regular check-ups have been found to improve survival for people after surgery for bowel cancer, so you should have check-ups for several years.

Hyperthermic intraperitoneal chemotherapy

If the cancer has spread to the lining of the abdomen (peritoneum), you may have chemotherapy during surgery. This is called hyperthermic intraperitoneal chemotherapy (HIPEC). First, as many tumours as possible are removed (cytoreductive surgery) and then heated chemotherapy is delivered to the abdomen.

The chemotherapy circulates around the abdomen for a short time, and then it is drained and the cut closed. Heating the chemotherapy allows it to be better absorbed by the cancer cells and reduces side effects to other parts of the body. Cytoreductive surgery and HIPEC are best performed in a specialised centre.
Palliative treatment

If the cancer is advanced when it is first diagnosed or returns after treatment, your doctor will discuss palliative treatment for symptoms caused by the cancer, such as pain.

Palliative treatment aims to manage symptoms without trying to cure the disease. It can be used at any stage of advanced bowel cancer to improve quality of life. It is not just for people who are about to die and does not mean giving up hope. Rather, it is about living for as long as possible in the most satisfying way you can.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include surgery, radiotherapy, chemotherapy, targeted therapy or other medicines.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs. For more information, visit your local Cancer Council website or call 13 11 20 for free copies of Understanding Palliative Care and Living with Advanced Cancer.
Key points

- Advanced cancer means the cancer has spread from where it started to another part of the body.

- Recurrent cancer means the cancer has come back some time after you were first treated.

- Drug treatment that reaches the cancer cells throughout the body is commonly used for advanced bowel cancer. This is called systemic treatment. It includes chemotherapy and targeted therapy drugs.

- Two types of targeted therapy drugs are commonly used in Australia for advanced bowel cancer.

- The drug bevacizumab blocks the growth of blood vessels that supply cancer cells.

- Epidermal growth factor receptor inhibitors (EGFR-Is) target specific receptors on cancer cells. They only work for bowel cancer that have a normal RAS gene.

- Radiotherapy may be used for advanced cancer of the colon or rectum. It can help stop bleeding and reduce pain.

- In some cases, surgery can remove small secondary cancers or a blockage in the bowel. If the cancer has spread to the lining of the abdomen, you may have chemotherapy during surgery. This is called hyperthermic intraperitoneal chemotherapy (HIPEC).

- People with advanced cancer might be offered palliative treatment, such as radiotherapy and chemotherapy. Palliative treatment is given to ease the symptoms of the cancer.

- All of the treatments can cause side effects, such as pain, fatigue or diarrhoea. Talk to your doctor about how to manage any side effects.
After treatment for bowel cancer, many people find that they need to adjust to changes to their digestion or bowel function.

**Incontinence**

The movement of waste through the large bowel can become faster after surgery or radiotherapy. This can mean you need to go to the toilet more urgently and more often. It may also result in a loss of control over bowel motions (faecal incontinence).

Bowel surgery or radiotherapy may weaken the anus, making it difficult to hold on when you feel the need to empty your bowels, particularly if you have loose stools (diarrhoea).

Some people have difficulty controlling when they pass urine (urinary incontinence), and find they need to urinate more often or don’t fully empty the bladder. For example, radiotherapy can irritate the lining of your bladder, because the bladder is located near the large bowel. This can cause temporary urinary incontinence.

If you have bladder or bowel changes, you may feel embarrassed, but there are ways to manage the symptoms. Incontinence issues usually improve in a few months, but sometimes take years. Talk to your health care team about whether any bowel or bladder changes are likely to be permanent. For more information, contact the Continence Foundation of Australia on 1800 33 00 66, or visit continence.org.au. To locate public toilets near you, visit toiletmap.gov.au. You can also download the National Public Toilet Map iPhone App from the iTunes App Store.
Having a stoma

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

The two types of stoma are a colostomy (made from the large bowel) and an ileostomy (made from the small bowel).

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

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

Stomas vary in size and can change shape during the weeks after surgery. A stomal therapy nurse (see page 55) can give you advice about any changes to your stoma or the skin around it. Most people need time to adjust to having a stoma (see page 54).
Types of stoma

Colostomy

Opening of the colon onto the surface of the skin to form the stoma

Ileostomy

Opening in the ileum onto the surface of the skin to form the stoma

Area that may be removed

Coping with bowel and dietary changes
Paul’s story

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

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

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

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

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

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

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

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

Having a colostomy hasn’t stopped me travelling – I’ve been able to holiday in Bali a couple of times.
How the stoma works

When the bowel moves, wind and waste matter (faeces) come out through the stoma. You cannot control when this happens, but a small disposable bag is worn on the outside of the body to collect the waste. This is called a stoma bag or an appliance.

Stoma bags have adhesive on the back so they stick firmly to the skin and provide a leak-proof, odour-proof system. A filter lets out any wind (but not the odour), which should stop the wind inflating the bag. The bags usually can’t be seen under clothing.

Attaching the bag – A stomal therapy nurse (see page 55) will help you choose an appliance that suits your body shape and the stoma, and will explain how to attach it securely.

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

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

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

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

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

To help the stoma settle and to avoid blockages, you may need to make some dietary changes (see pages 56–60). Over time, most people find they can eat a normal healthy diet.

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

See a stomal therapy nurse – If there is a chance you could need a stoma, the surgeon will probably refer you to a stomal therapy nurse before surgery. Stomal therapy nurses are registered nurses with special training in stoma care. They can:

• talk to you about the best place for the stoma to be located
• answer questions about your surgery and recovery
• provide you with printed, online and audiovisual resources
• give you information about adjusting to life with a stoma.

For more details, visit the Australian Association of Stomal Therapy Nurses at stomaltherapy.com or call Cancer Council 13 11 20.

Join a stoma association – With your consent, the stomal therapy nurse will sign you up to a stoma (or ostomy) association. For a small annual membership fee, you will be able to obtain free stoma appliances and products. Stoma associations also provide assistance and information to members and coordinate support groups for people of all ages.


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 be eligible 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.
Diet after treatment

Immediately after treatment – particularly surgery – you might be on a low-fibre or soft diet. During and after recovery from treatment, you may find that some foods cause discomfort or diarrhoea (see pages 57–58).

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

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

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

The Australian Government’s booklet *Improving Bowel Function After Bowel Surgery* provides some helpful tips. Visit the website [bladderbowel.gov.au](http://bladderbowel.gov.au) to download a copy, or call 1800 330 066.
Diarrhoea
Diarrhoea, the frequent passing of loose, watery faeces, may be caused by different types of treatment:

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

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

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

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

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

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>fruit (fresh or dried)</td>
<td>grapes, stone fruit (such as apricots, peaches and plums), most berries</td>
</tr>
<tr>
<td>vegetables and legumes</td>
<td>capsicum, cabbage, onions, beans, peas, corn, broccoli, lentils, dried beans, baked beans, peas, brussels sprouts</td>
</tr>
<tr>
<td>alcohol</td>
<td>beer, wine, spirits (these can cause dehydration)</td>
</tr>
<tr>
<td>bran, nuts, seeds and fibre</td>
<td>multigrain, wholemeal and high-fibre breads, some breakfast cereals</td>
</tr>
<tr>
<td>fatty foods</td>
<td>butter, cream, fatty meats, fried foods</td>
</tr>
<tr>
<td>lactose</td>
<td>dairy foods (such as milk, cream, yoghurt and soft cheeses)</td>
</tr>
<tr>
<td>spicy foods</td>
<td>garlic, onion, chilli, curry</td>
</tr>
<tr>
<td>caffeine</td>
<td>coffee, tea, chocolate, cola-type soft drinks, energy drinks</td>
</tr>
<tr>
<td>sugar-free foods and drinks</td>
<td>the sweetener sorbitol has a laxative effect</td>
</tr>
</tbody>
</table>

Tips for reducing diarrhoea

- Eat low-fibre foods, such as white rice, white pasta, white bread, rice-based cereal, potatoes, fish and lean meat.
- Well-cooked vegetables without seeds, husks or skin, such as carrots, potato and pumpkin, are good choices.
- Eat three small meals a day and snack often.
- If you suspect that a food causes diarrhoea, avoid it for 2–3 weeks. Reintroduce one food at a time. If the diarrhoea flares up again, you may want to avoid that food.
Wind (flatulence)

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

### Foods that may produce wind

<table>
<thead>
<tr>
<th>Foods</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>eggs</td>
<td>prepared any way</td>
</tr>
<tr>
<td>vegetables (raw or cooked)</td>
<td>broccoli, cabbage, onions, cauliflower, corn, asparagus, brussels sprouts</td>
</tr>
<tr>
<td>legumes</td>
<td>lentils, beans</td>
</tr>
<tr>
<td>dairy products</td>
<td>strong cheeses, large serves of dairy products (such as milk and cream)</td>
</tr>
<tr>
<td>fizzy (carbonated) drinks</td>
<td>some soft drinks, beer</td>
</tr>
<tr>
<td>raw and dried fruit</td>
<td>pears, dates, raisins, figs, prunes, grapes, pineapple, apples, bananas</td>
</tr>
</tbody>
</table>

### Tips for reducing wind

- Try chewing charcoal tablets, eating natural yoghurt and/or drinking peppermint tea.
- Cut food into small, bite-sized pieces.
- Chew your food slowly and thoroughly.
- When you have a drink, take small sips.
- Talk to your doctor about doing light exercise to relieve bloating and gas.
Blockages
For people with a stoma, some foods can cause blockages. This means solids, fluids and gas can’t move through as they normally would. It can be uncomfortable and cause a bloated feeling or nausea. If you experience symptoms of a blockage for more than two hours or you start vomiting, contact your nurse or hospital.

<table>
<thead>
<tr>
<th>Foods that may cause blockages</th>
</tr>
</thead>
<tbody>
<tr>
<td>high-fibre foods</td>
</tr>
<tr>
<td>raw vegetables</td>
</tr>
<tr>
<td>cooked vegetables</td>
</tr>
<tr>
<td>seeds or kernels</td>
</tr>
<tr>
<td>spicy foods</td>
</tr>
<tr>
<td>fruit and vegetable skins</td>
</tr>
<tr>
<td>meat casing</td>
</tr>
</tbody>
</table>

Tips for avoiding blockages

- Eat regular meals.
- Try to maintain a balanced diet so your body is well nourished.
- Drink up to eight glasses of fluid a day so you stay well hydrated.
- Cut food into small, bite-sized pieces, and chew slowly and thoroughly.
- If you have trouble eating a certain food, talk to a dietitian about alternatives.
Key points

- After treatment for bowel cancer, most people find their bowel function changes.

- You may need to go to the toilet more urgently or lose control over bowel motions (faecal incontinence).

- There are many ways to manage incontinence. For support and information, contact the Continence Foundation of Australia at continence.org.au.

- Some people will need to have a stoma, which is a surgically created opening in the abdomen. Waste (faeces) passes out of the body through this opening. The two types of stoma are a colostomy, which takes part of the large bowel out to the abdomen, and an ileostomy, which creates a stoma from the small bowel.

- A stoma may be temporary or permanent.

- A stomal therapy nurse can help answer any questions you have and help you adjust to life with a stoma.

- Becoming a member of an ostomy association entitles you to free stoma supplies through the Australian Government’s Stoma Appliance Scheme.

- Diarrhoea and wind are common problems after treatment for bowel cancer. You may need to change your diet, especially if the diarrhoea or wind is ongoing, or if you have a blockage.

- Drinking plenty of fluid throughout the day will help avoid dehydration and reduce constipation and blockages.

- 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. It’s important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and what your doctor advises. Cancer Council’s *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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.

Alternative therapies are used instead of conventional medical treatments. These therapies can include coffee enemas and magnet therapy. These can be harmful or may mean you decline treatment that is known to offer benefit. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or visit your local Cancer Council website.
Relationships with others
Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility
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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if surgery, radiotherapy or chemotherapy will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call 13 11 20 for free copies of Sexuality, Intimacy and Cancer, Fertility and Cancer and Emotions and Cancer, or download the booklets from your local Cancer Council website.
Life after treatment

For most people, the cancer experience doesn’t end on the last day of treatment. Life after cancer 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’, but they don’t want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace. Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 22 4636 to order a fact sheet.
Follow-up appointments
After your treatment, you will need regular check-ups to confirm that the cancer hasn’t come back. You may have a physical examination, blood tests including checking of CEA levels (see page 20), a scan or a colonoscopy.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.

What if bowel cancer returns?
For some people, bowel cancer does come back after treatment, which is known as a recurrence or relapse. This is why it is important to have regular check-ups.

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

If bowel cancer has spread beyond the bowel (advanced or metastatic bowel cancer), you may be offered treatment, such as surgery, chemotherapy, targeted therapy or radiotherapy, to remove the cancer, or help control its growth (see pages 44–48). Contact Cancer Council 13 11 20 for more information.

If you have advanced bowel cancer, your bowel may become blocked (bowel obstruction). This can cause serious complications and needs prompt treatment. For more information, see page 35.
Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

**Practical and financial help**

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can’t afford to pay – call 13 11 20 to ask if you are eligible.

**Talk to someone who’s been there**

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.
In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in a support setting because they aren't trying to protect their loved ones.

**Types of support**
There are many ways to connect with others for mutual support and to share information. These include:
- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at cancercouncil.com.au/OC.

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“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
Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You may find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit carersaustralia.com.au or call 1800 242 636 for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers’ services and to get a free copy of the Caring for Someone with Cancer booklet.
Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

**Australian**

Cancer Council Australia..........................cancer.org.au  
Cancer Australia........................................canceraustralia.gov.au  
Carer Gateway........................................carergateway.gov.au  
Carers Australia........................................carersaustralia.com.au  
Department of Health ..................................health.gov.au  
Department of Human Services .................humanservices.gov.au  
healthdirect..............................................healthdirect.gov.au  
beyondblue............................................beyondblue.org.au  
Colorectal Surgical Society of Australia and New Zealand ................cssanz.org  
Australian Association of Stomal Therapy Nurses....................stomaltherapy.com  
Australian Council of Stoma Associations ................australianstoma.com.au  
Continence Foundation of Australia ................continence.org.au  
Australian Government bladder and bowel........bladderbowel.gov.au  
National Public Toilet Map........................toiletmap.gov.au  
Dietitians Association of Australia..................daa.asn.au  
Cancer Screening........................................cancerscreening.gov.au

**International**

American Cancer Society.............................................cancer.org  
Cancer Research UK ......................................cancerresearchuk.org  
Macmillan Cancer Support (UK) ......................macmillan.org.uk  
National Cancer Institute (US) ..........................cancer.gov
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don’t understand, ask for clarification.

- What type of bowel cancer do I have?
- Where in the bowel is the cancer?
- Has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- Will I need a stoma? If so, will it be temporary or permanent? Will you refer me to a stomal therapy nurse?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?
abdomen
The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

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

adjuvant treatment
A treatment given with or shortly after another treatment to make it more effective.

advanced cancer
Cancer that may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

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

anal cancer
A rare cancer affecting the tissues of the anus.

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

anterior resection
A surgical procedure to remove cancer in the rectum with the bowel being rejoined to leave a functioning anus.

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

appliance
See stoma bag.

ascending colon
The right side of the colon.

barium enema
An examination of the bowel area using a white contrast liquid called barium and x-rays.

benign
Not cancerous or malignant.

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

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

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

bowel movement
Defecation. Evacuating waste matter from the bowels.

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

bowel preparation
The process of cleaning out the bowel before a test or scan to allow the doctor to see the bowel more clearly.

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

carcinoembryonic antigen (CEA)
A protein that may be found in the blood of a person with bowel cancer.
catheter
A hollow, flexible tube through which fluids can be passed into the body or drained from it.

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

chemotherapy
The use of anti-cancer drugs to treat cancer by killing cancer cells or slowing their growth.

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

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

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

colic J-pouch
An internal pouch surgically created using the last part of the large bowel.

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

colorectal cancer
See bowel cancer.

colostomy
An opening (stoma) in the abdomen made from the colon.

Crohn’s disease
A benign type of inflammatory bowel disease that may increase a person’s risk of developing bowel cancer.

CT scan
Computerised tomography scan. This scan uses x-rays to create a picture of the inside of the body.

descending colon
The left side of the colon.

dietitian
A university-qualified health professional who supports and educates patients about nutrition and diet during treatment and recovery.

digital rectal examination (DRE)
An examination in which a doctor puts a gloved finger into the anus to feel for abnormalities in the anus or rectum.

endoscope
A flexible tube with a light and camera on the end. It is used to examine the bowel during a colonoscopy.

enema
A liquid solution that washes out the rectum.

faecal incontinence
Inability to control bowel motions, resulting in accidental loss of faeces.

faecal occult blood test (FOBT)
A test that checks stools for
microscopic traces of blood.

**faeces**
Waste matter that normally leaves the body through the anus.

**familial adenomatous polyposis (FAP)**
A benign condition that causes polyps to form in the large bowel. Polyps can become cancerous if untreated.

**FDG-PET**
Fluorodeoxyglucose-positron emission tomography scan. A person is injected with a modified sugar molecule (fluorodeoxyglucose or FDG) to show up cancer cells. When combined with a PET scan it is called a FDG-PET.

**fertility**
The ability to conceive a child.

**flatulence**
Wind or gas.

**gastrointestinal (GI) tract**
The passage from the mouth to the anus that allows a person to digest food and eliminate waste. The lower GI tract includes the colon, rectum and anus.

**ileostomy**
An opening (stoma) in the abdomen made from the ileum (part of the small bowel).

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

**incontinence**
The accidental or involuntary loss of urine or faeces.

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

**large bowel**
The large bowel stores waste until it leaves the body as faeces. Its four parts are the caecum, colon, rectum and anus. Also called the large intestine.

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

**lymph nodes**
Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

**Lynch syndrome**
A disease that increases the risk of developing bowel cancer. Previously called hereditary non-polyposis colorectal cancer (HNPCC).

**malignant**
Cancer. 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 called secondary cancer.

**minimally invasive surgery**
A surgical technique that involves several small cuts. Also called keyhole, laparoscopic or robotic surgery.

**MRI scan**
Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.
neoadjuvant treatment
A treatment given before the main treatment to make the main treatment more successful.

palliative treatment
Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer. It is an important part of palliative care.

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

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

port-a-cath
A small medical appliance installed beneath the skin. A tube called a catheter connects the port to a vein so that fluids can be passed into the body.

primary cancer
The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

proctocolectomy
The surgical removal of the entire colon and rectum.

prognosis
The predicted outcome of a person’s disease.

radiotherapy
The use of radiation, usually x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

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

rectum
The last 15–20 cm of the large bowel, which stores faeces until a bowel movement occurs.

recurrent cancer
Cancer that has returned after treatment of the primary cancer. A recurrence may be local (in the same place as the primary) or distant (in another part of the body).

relapse
See recurrent cancer.

remission
When the symptoms and signs of the cancer reduce or disappear. This does not necessarily mean that the cancer is cured.

screening
A program to identify disease in people before any symptoms appear.

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

sigmoidoscope
A rigid or flexible tube used during a sigmoidoscopy.

sigmoidoscopy
A procedure in which a doctor inserts a sigmoidoscope into the anus to examine the rectum and lower colon.
small bowel
The middle part of the gastrointestinal tract, which takes food from the stomach and absorbs nutrients. It has three sections: the duodenum, the jejunum and the ileum. Also known as the small intestine.

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

staging
Performing tests to determine how far a cancer has spread.

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

stoma
A surgically created opening to the outside of the body.

stoma bag
A pouch that sticks to the surface of the abdomen and collects waste.

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

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

systemic treatment
Treatment that affects the whole body.

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

transanal endoscopic microsurgery (TEMS)
Removing part of the cancer using an endoscope inserted into the anus.

transanal excision (TAE)
Removing part of the cancer using an instrument inserted into the anus.

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

ulcerative colitis
A benign bowel disease that may increase the risk of bowel cancer.

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

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

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

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

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

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