



Understanding Bowel Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



Understanding Bowel Cancer

A guide for people with cancer, their families and friends

First published January 2003. This edition February 2015.

© Cancer Council Australia 2015. ISBN 978 1 925136 45 6

Understanding Bowel Cancer is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

Editor: Jenni Bruce. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Mr Chip Farmer, Colorectal Surgeon, The Alfred Hospital, Cabrini Hospital and The Avenue Hospital, VIC; Mervyn Bartlett, Consumer; Dr Andrew Haydon, Medical Oncologist, The Alfred Hospital and Cabrini Hospital, VIC; Jackie Johnston, Palliative Care and Stomal Therapy Clinical Nurse Consultant, St Vincent's Private Hospital (Darlinghurst), NSW; Dr Shahrir Kabir, Fellow in Colorectal Surgery, Royal Brisbane and Women's Hospital, QLD; Steve Pratt, Nutrition and Physical Activity Manager, Cancer Council WA; Cassie Riley, Cancer Nurse Coordinator – Colorectal, WA Cancer and Palliative Care Network, WA; Mary Shanahan, Cancer Genetics Nurse Coordinator, Peter MacCallum Cancer Centre, VIC; A/Prof Andrew Stevenson, Head of Colorectal Surgery, Royal Brisbane and Women's Hospital, University of Queensland; Pat Walls, Clinical Nurse Consultant Stomal Therapy/Wound Management, Holy Spirit Northside Private Hospital, QLD. We also thank Paul Zuideryk for sharing his story, the reviewers who have worked on previous editions, and the National Health and Medical Research Council for permission to use *Clinical Practice Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer* as source material for earlier editions.

Note to reader

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

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

Cancer Council

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



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101

Email info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

Introduction

This booklet has been prepared to help you understand more about bowel 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 National Health and Medical Research Council's clinical practice guidelines for bowel cancer.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
The bowel	6
Key questions	8
What is bowel cancer?	8
How common is it?.....	8
What are the symptoms?.....	9
What are the risk factors?.....	10
Can bowel cancer run in families?	11
Diagnosis	12
General tests	12
Tests to find cancer	15
Further tests	19
Staging bowel cancer.....	22
Prognosis	22
Which health professionals will I see?.....	24
Making treatment decisions	27
Talking with doctors	27
A second opinion	28
Taking part in a clinical trial	28
Treatment	29
Surgery.....	30
Chemotherapy.....	38
Targeted therapies.....	41
Radiotherapy	42
Palliative treatment.....	44

Coping with dietary and bowel changes	46
Incontinence.....	46
Having a stoma	48
Coping with a stoma	52
Diet after treatment	54
Looking after yourself	61
Relationships with others	62
Life after treatment	63
Seeking support	65
Practical and financial help	65
Talk to someone who's been there.....	65
Caring for someone with cancer	67
Useful websites	68
Question checklist.....	69
Glossary	70
Notes.....	75
How you can help	76



What is cancer?

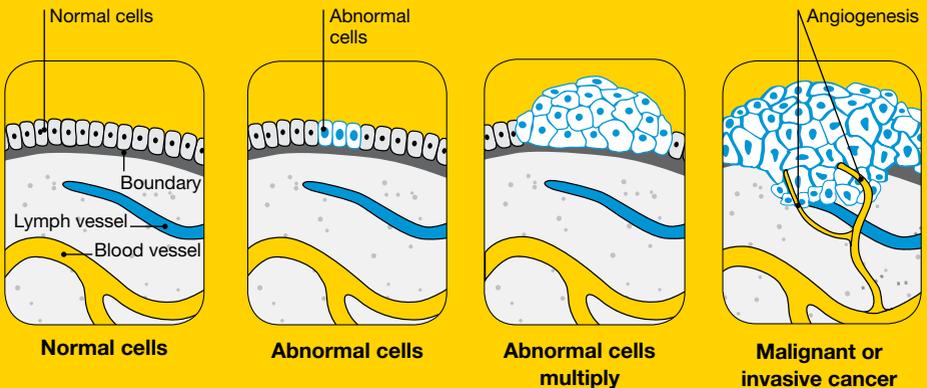
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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



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 (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

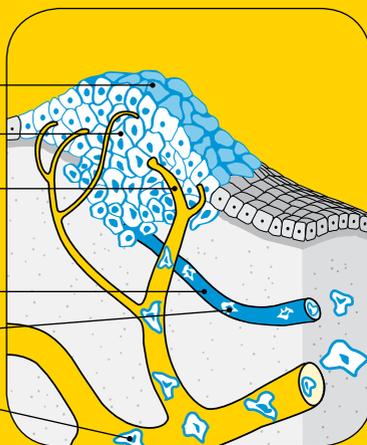
Primary cancer

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





The bowel

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.

Duodenum	The first section of the small bowel; receives food from the stomach.
Jejunum	The middle section of the small bowel.
Ileum	The final and longest section of the small bowel; transfers waste to the large bowel.

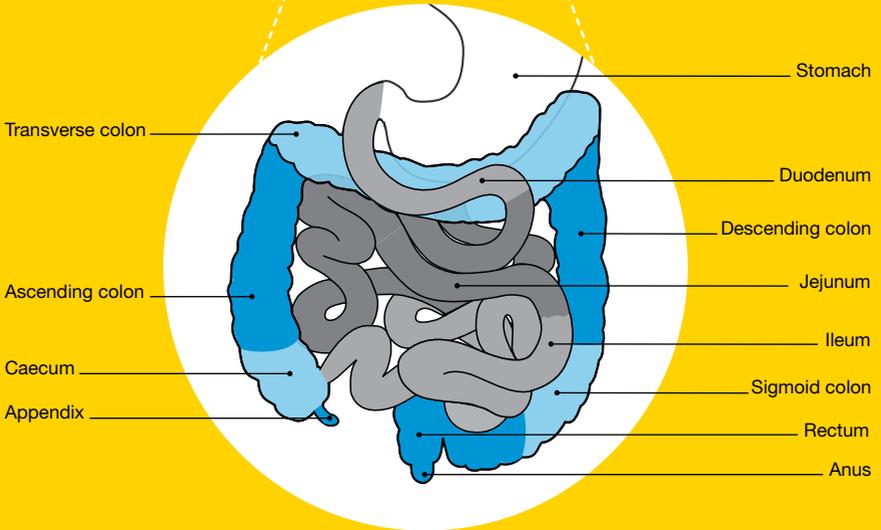
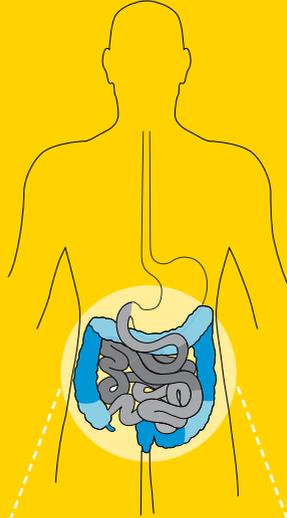
Large bowel

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.

Caecum	A pouch that receives waste from the small bowel. The appendix is a small tube hanging off the end of the caecum.
Colon	The main working area of the large bowel. Takes up most of the large bowel's length and has four parts: ascending colon, transverse colon, descending colon and sigmoid colon.
Rectum	The last 15–20 cm of the large bowel.
Anus	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.

The digestive system

- Small bowel
- Large bowel





Key questions

Q: What is bowel cancer?

A: Bowel cancer is cancer in any part of the large bowel (colon or rectum). It is sometimes known as colorectal cancer and might also be called colon cancer or rectal cancer, depending on where it starts. Cancer of the small bowel is very rare 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 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 (glands). These small, bean-shaped masses are part of the body’s lymphatic system. If the cancer advances further, it can spread to other organs, such as the liver or lungs (metastasis).

In most cases, the cancer develops slowly and stays in the bowel for months or years before spreading.

Q: How common is it?

A: Bowel cancer is the second most common cancer affecting people in Australia. It is estimated that about 17,000 people are diagnosed with bowel cancer every year.¹ About one in 19 men and one in 28 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 often has no symptoms. However, some people with bowel cancer do experience persistent symptoms. These can include:
- a change in bowel habit, such as diarrhoea, constipation or smaller, more frequent bowel movements
 - a change in appearance of bowel movements (e.g. narrower stools or mucus in stools)
 - a feeling of fullness or bloating in the bowel or rectum
 - a feeling that the bowel hasn't emptied completely after a bowel movement
 - blood in the stools or on the toilet paper
 - 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 tears in the anal canal, and some foods or medications, can also cause these changes.

Short-term changes in bowel function are very common and usually do not indicate a serious problem. However, if you have any of the above symptoms for more than four weeks, see your doctor for a check-up.

Q: What are the risk factors?

A: The exact cause of bowel cancer is not known. However, some factors increase the chance of developing it.

Risk factors include:

- **age** – bowel cancer most commonly affects people over the age of 50
- **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 increase the risk
- **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
- **strong family history** – see opposite
- **rare genetic disorders** – see opposite.

Being physically active, maintaining a healthy weight and eating a high-fibre diet may help protect against bowel cancer.



Although the average age at which bowel cancer is diagnosed is 69 years, about 7% of bowel cancers are in people younger than 50.²

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 will 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 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.



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 14).

To diagnose bowel cancer, your general practitioner (GP) will examine you and 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.

Waiting for the test results can be a stressful time. It may help to talk to a friend or family member or to a health care professional, or you can call Cancer Council 13 11 20.

General tests

Physical examination

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

To check for problems in the 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), and it helps the doctor detect problems in the lowest part of the bowel.

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. It might make you feel like you are going to have a bowel movement, but it is very unlikely that this will happen.

The doctor may also insert a small, rigid telescope into the anus to see the lining of the rectum. You do not need an empty bowel or anaesthetic for this examination. Depending on the type of telescope used, the procedure is called a proctoscopy or rigid sigmoidoscopy.

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.

Most doctors also measure the levels of carcinoembryonic antigen (CEA), which is a protein produced by some cancer cells. If your blood tests 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.

“ I started to have some bleeding when I went to the toilet. There were no other warning signs – it just happened out of the blue, so I went to see my GP. ” *Andrew*

Screening 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 it helps your doctor decide whether to do further tests, such as a colonoscopy (see opposite).

People over 50 should have an FOBT every two years. Because the test helps catch bowel cancer early, this can significantly improve the chance of surviving the disease.³

Through the National Bowel Cancer Screening Program, many people 50 and over are automatically sent free FOBT

kits – phone **1800 118 868** or see cancerscreening.gov.au. Kits can also be purchased from some pharmacies. You complete the test at home.

The FOBT is only for low-risk people without symptoms of bowel cancer. Anyone with symptoms of bowel cancer (see page 9) should 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 as a precaution. 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. It should be repeated every one to two years.

Tests to find cancer

Flexible sigmoidoscopy

This test allows the doctor to see the rectum and lower part of the colon. To have a flexible sigmoidoscopy, you will need to have an empty bowel (see page 18).

Before the test, you may be given a light anaesthetic or sedation. You will lie on your side while a thin, flexible tube with a light and camera at the end, called a sigmoidoscope, is inserted gently into your anus and guided up through to the bowel.

The sigmoidoscope blows carbon dioxide or air into the bowel. This inflates the bowel slightly and allows the doctor to see the bowel wall more clearly. The camera and light at the end of the tube show up any unusual areas. The doctor can also use the sigmoidoscope to remove a piece of tissue for examination. This is called a biopsy.

A sigmoidoscopy takes about 10–20 minutes. Though it may feel uncomfortable, the test should not be painful. You may experience cramping and pressure in your lower abdomen. This will ease as you clear the remaining air by passing wind.

Colonoscopy

A colonoscopy examines the whole length of the large bowel. This is generally the most accurate test to examine the large bowel for cancer and polyps. 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 clear.

- Before a colonoscopy, you will have a bowel preparation to clean your bowel (see page 18). 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 examination.
- During the procedure, the doctor will insert a flexible tube with a camera on the end, called an endoscope, 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), which will be removed for further examination (biopsy).

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. Overall, the test is safe and the benefits far outweigh the risks for most people.

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.

Virtual colonoscopy

A virtual colonoscopy uses a CT or MRI scanner (see pages 19–20) to create images of the colon and rectum and display them on a screen instead of putting an endoscope into your bowel.

Your bowel needs to be empty for the virtual colonoscopy, so you will have a bowel preparation (see page 18). You will probably lie on your back or stomach and a thin tube will be inserted into your rectum to fill your colon with air. This may feel uncomfortable.

After your colon is inflated, you will be moved into the scanner. The scanner will create 3D images of your colon while you hold your breath for short intervals. The procedure takes 10–15 minutes.

Virtual colonoscopies are not used often because they are not as accurate as colonoscopies and they involve exposure to radiation. They are covered by Medicare only in some circumstances when a colonoscopy isn't feasible. Although the test is less invasive than a colonoscopy and shows your bowel in detail, your doctor may not be able to see small abnormalities and cannot take tissue samples.

Barium enema

Barium is a white contrast liquid that shows up on x-rays, and a barium enema is a type of bowel x-ray procedure. This test has been largely replaced by colonoscopy, but it might be used in particular circumstances.

Before having a barium enema, you will need a bowel preparation to clean out your bowel (see page 18). During the procedure, you will lie on an x-ray table while a barium-filled tube is inserted into your rectum and releases barium into your colon. The barium will show up any lumps or swellings, and x-rays of your inflated colon will then be taken. If an abnormal area is found in the bowel, you will probably need to have another test such as a colonoscopy.

Bowel preparation

Before some diagnostic tests, you will have to clean out your bowel. This will help the doctor see inside the bowel clearly.

The cleaning 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.

Having a bowel preparation may involve:

- **an enema** – One common way to clear the bowel is using an enema. This is liquid that is inserted 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.
- **laxatives** – Another type of bowel preparation is an oral laxative (in tablet or liquid form), which will cause you to have watery diarrhoea.

- **diet changes** – 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.

- **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.

Consider using soft toilet paper, wet wipes or barrier cream so your skin does not become irritated by the cleaning process.

Talk to your doctor if you have any concerns about the bowel preparation process.

Further tests

If any of the tests on pages 15–17 show you have bowel cancer, you will have one or more of the following scans to see if the cancer has spread to other parts of your body.

A scan is painless and is usually done as an outpatient. Most people are able to go home as soon as the test is over.

CT scan

A CT (computerised tomography) scan uses x-ray beams and computer technology to create a detailed, cross-sectional picture of the inside of the body.

Before the scan, dye is injected into a vein to make the pictures clearer. This 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.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. It takes about 30 minutes to set up the machine, but the CT scan itself takes only 5–10 minutes.



The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, let the person performing the scan know in advance. You should also tell the doctor if you're diabetic, have kidney disease or are pregnant.

MRI scan

An MRI (magnetic resonance imaging) scan uses radio waves and magnetism to create cross-sectional pictures of the body. Sometimes, dye will be injected into a vein before the scan to help make the pictures clearer.

You will lie on a table that slides into a metal cylinder that is open at both ends. During the test, the machine makes a series of bangs and clicks and can be quite noisy.

Some people feel anxious lying in the narrow cylinder. Tell your doctor beforehand if you are prone to anxiety or claustrophobia. You may be given a mild sedative to help you relax.

Before arranging the test, your doctor will check your medical history. People who have a pacemaker or any other metallic object in their body usually cannot have an MRI due to the effect of the magnet. However, some newer pacemakers are MRI-compatible.

PET scan

During a PET (positron emission tomography) scan, you will be injected with a small amount of radioactive glucose solution. It takes 30–90 minutes for the solution to circulate around your body. You will be left alone in a small room and asked to rest quietly during this time.

Your body is then scanned for high levels of radioactive glucose. Cancer cells show up brighter on the scan because they are more active and take up more of the glucose solution than normal cells do.

Though it may take a few hours to prepare for a PET scan, the scan itself usually takes only about 30 minutes.

Ultrasound

An ultrasound is a test that uses soundwaves to build up a picture of your body. A device (transducer or probe) is placed on or in your body. This sends out soundwaves that echo when they meet something dense, like a tumour, and images are projected onto a computer screen. Two types of ultrasounds may be used:

- **Abdominal ultrasound** – This may be done to see whether bowel cancer has spread to the liver. A gel is spread over your abdomen to conduct the soundwaves, and the transducer is passed over the abdominal area to create the image. The test takes 15–20 minutes.
- **Endorectal ultrasound (ERUS)** – A probe is inserted through the anus into your rectum. This can be uncomfortable but is usually not painful, and there may be some light bleeding from the rectum. The test takes only about 10 minutes.

An ERUS is often done if other tests show there is cancer in the rectum or anus. It helps the doctor work out the size of the cancer, whether it has spread, and what treatments to recommend.

A chest x-ray may be taken to check if the cancer has spread to the lungs or lymph nodes in your chest.



Staging bowel cancer

The tests described on pages 15–21 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.

The most common bowel cancer staging systems are Australian Clinico-Pathological Staging (ACPS) and TNM (see opposite). When staging is done before surgery, it is known as clinical staging – it represents your doctor’s estimate of the extent of the disease and is based on the tests used to diagnose the cancer. Pathologic staging is based not only on those early tests, but also on tests on the cancer and lymph nodes removed during surgery (see pages 30–35). These results are usually available about a week after the surgery.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease. 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
- how well you respond to treatment
- other factors such as age, fitness and medical history.

Australian Clinico-Pathological Staging

Developed in Australia for bowel cancer, the ACPS system uses all available information to work out the cancer's stage.

Stage A	Cancer is found only in the bowel wall.
Stage B	Cancer has spread to the outer surface of the bowel wall.
Stage C	Cancer has spread to the lymph nodes near the bowel.
Stage D	Cancer has spread beyond the lymph nodes to other areas, such as the liver or lungs.

TNM staging

Used for many forms 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.

T (Tumour) 1-4	Indicates how far the tumour has grown into the bowel wall and nearby areas. T1 is a smaller tumour; T4 is a larger tumour.
N (Nodes) 0-2	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.
M (Metastasis) 0-1	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.

Which health professionals will I see?

Your GP plays a key role in your care throughout your treatment for bowel cancer. They will arrange the first tests to assess your symptoms, or further tests if you have had a positive FOBT (see page 14). If these tests do not rule out cancer, you will usually be referred to a colorectal surgeon or a gastroenterologist, who will arrange more tests and treatment.

MDT health professionals

GP	explains information provided by specialists; assists you with treatment decisions; helps you obtain practical and emotional support; and works in partnership with your specialists in providing your ongoing care
colorectal surgeon	diagnoses bowel cancer and operates on the bowel
gastroenterologist	diagnoses bowel cancer and specialises in the digestive system and its disorders
medical oncologist	prescribes and coordinates the course of chemotherapy
radiation oncologist	prescribes and coordinates the course of radiotherapy
cancer care coordinator or clinical nurse consultant (CNC)	supports patients and families throughout treatment and liaises with other members of your health care team
operating room staff	include anaesthetists, technicians and nurses who prepare you for surgery and care for you during the operation and recovery

Once your treatment for bowel cancer begins, you will be looked after by a range of health professionals who specialise in different areas of your care.

The health professionals involved in your treatment will take a team-based approach and form a multidisciplinary team (MDT). The following health professionals may be in your MDT.

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



Key points

- There are many types of tests used to diagnose bowel cancer, but you will only have the tests you need.
- A faecal occult blood test (FOBT) checks stool samples for traces of blood. It is often done as part of a national screening program. The FOBT is for people with a low risk of bowel cancer and can help find polyps or bowel cancer in its early stages. If blood is found during the FOBT, you will probably have a colonoscopy. A colonoscopy can be used to look for polyps and cancer in the entire large bowel.
- A flexible sigmoidoscopy is used to view the last 50 cm of the bowel. A rigid sigmoidoscopy looks at the rectum only.
- A bowel preparation may be needed before some tests. This cleans out the bowel so the doctor can see clearly.
- X-rays, CT scans, MRI scans, PET scans and ultrasounds are painless procedures that take pictures of the inside of your body. They may show the location of the cancer and whether it has spread.
- The doctor will assign the cancer a stage. This describes the size and spread of the cancer. You may 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 will probably 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 can 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. Others want to make sure the benefits outweigh the side effects so that 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 for further explanation – see page 69 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

Your medical team will recommend treatment based on:

- what will give you the best outcome
- the location of the cancer in the bowel
- whether the cancer has spread
- your general health
- your preferences.

The most common treatment is surgery, usually performed by a colorectal surgeon. You may also have chemotherapy, targeted therapies and radiotherapy, which will be coordinated by your oncologist. Different types of treatment may be combined.

Minimally invasive surgery

Minimally invasive surgery, also called keyhole or laparoscopic surgery, means the operation is done with several small cuts (incisions) instead of one large cut (open technique). This may include robotic surgery.

The surgeon passes a thin tube (laparoscope) through an incision in the abdomen. The laparoscope has a light and camera. Long, thin instruments are inserted through the other incisions to remove the cancer.

Compared to open surgery, the minimally invasive method usually means less pain and scarring and a faster recovery.

There are advantages to both types of surgery – your surgeon will advise which is suitable for you. Whether or not minimally invasive surgery is recommended depends on the size and location of the cancer, and if the surgery is available at your hospital or treatment centre.

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 where the cancer is located and how much of the bowel is removed (see opposite).

The surgeon may use an open or minimally invasive technique (see previous page). You will be given a general anaesthetic, then the surgeon will make a cut in the abdomen to find and remove the part of the colon containing the cancer. Lymph nodes near the colon and some normal bowel around the cancer will also be removed.

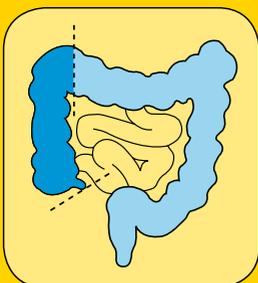
The surgeon usually joins the two ends of the bowel back together with stitches or staples. Sometimes the bowel isn't joined together; instead, one end is brought through an opening made in your abdomen and stitched onto the skin. This procedure is called a colostomy (if made from the colon in the large 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.

The surgeon may later be able to do another operation to rejoin the bowel. In some cases, this isn't possible and the stoma will be permanent. For information about stomas, see pages 48–54.

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

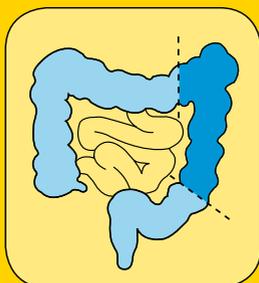
Types of colectomies

● Area removed



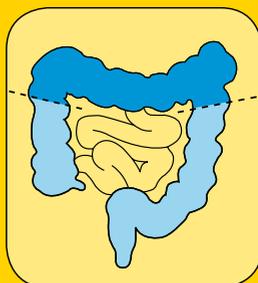
Right hemicolectomy

The right side of the colon is removed.*



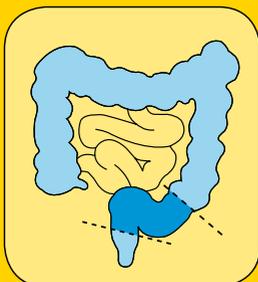
Left hemicolectomy

The left side of the colon is removed.*



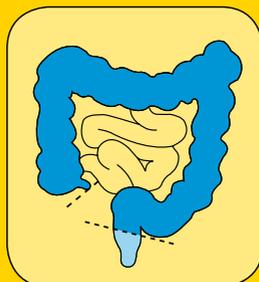
Transverse colectomy

The middle part of the colon is removed.



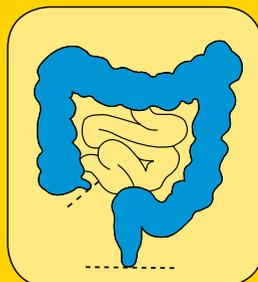
Sigmoid colectomy

The sigmoid colon is removed.



Subtotal or total colectomy

Most or all of the bowel is removed.



Proctocolectomy

All of the colon and rectum are removed.

**If the transverse colon is also removed, it is called an extended right or left hemicolectomy. For information about anterior resections, see pages 32–33.*

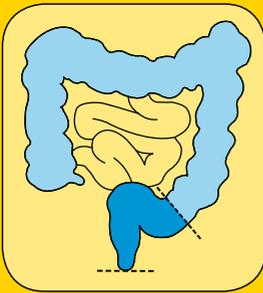
Surgery for cancer in the rectum

If you have rectal cancer, you may be advised to have an abdominoperineal resection (also known as an abdominoperineal excision) or an anterior resection. The abdominoperineal resection is also sometimes used for anal cancer (see page 34).

A resection or excision is the total removal of something by surgery. Abdomino refers to the abdomen, perineal refers to the area around the anus, and anterior refers to the front of the body.

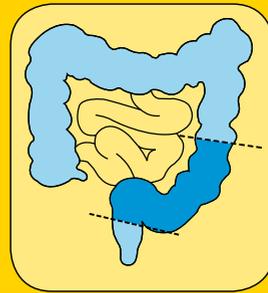
Resections in the large bowel

● Area removed



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.

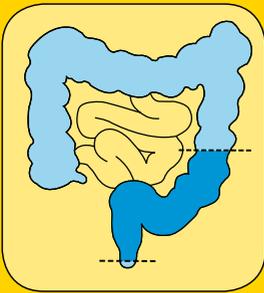


High anterior resection

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.

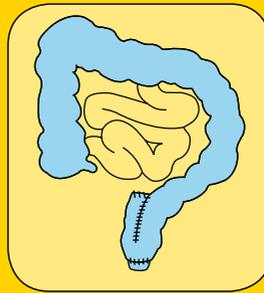
The type of operation you have depends on where the cancer is located. This will also determine whether the bowel can be rejoined, and where in the rectum the join can be made. The surgery may be open style or minimally invasive (see page 29).

Surgery that involves the lower part of the bowel can cause injury to nearby nerves, leading to conditions such as incontinence (accidental loss of urine or faeces) or erectile dysfunction. 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 a colonic J-pouch (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 48), which will be reversed once the J-pouch heals.

Anal cancer

Anal cancer is a rare cancer that affects the tissues of the anus. About 350 people in Australia are diagnosed with anal cancer every year, and most are 50 to 60 years old.⁴ Risk factors include smoking and sexually transmitted infections.

Symptoms of anal cancer can be similar to those for bowel cancer (see page 9), and your doctors may carry out some of the same tests, including blood tests, a proctoscopy

or sigmoidoscopy (page 13), and scans (pages 19–21). Anal cancer is staged using the TNM system (page 23).

The main treatment for anal cancer is chemotherapy and radiotherapy. Surgery may also be used. Early stage cancer may need only a local resection, which just removes the tumour. More advanced cancer may require an abdominoperineal resection (page 32) and a permanent stoma (page 48).

Local excision

People who have early stage bowel cancer or are not fit for a major operation may have a local excision. Instead of cutting into the abdomen, the surgeon inserts an instrument into the anus to remove very small tumours from the bowel.

Transanal excision (TAE) and transanal endoscopic microsurgery (TEMS) are local excision techniques for rectal cancer. 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.

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 the cancer.
3. Remove the entire colon and rectum (proctocolectomy) to prevent any chance of another cancer forming.

The type of surgery you have depends on what your doctor recommends and what you want.

Surgery for advanced cancer

If the cancer has spread to other parts of the body (metastasised), you may still be offered surgery. This can help control or slow the growth of the cancer. The surgeon may remove:

- small secondary cancers (e.g. in the liver or lungs)
- a blockage in the bowel (see page 36)
- cancerous parts of the bowel that are attached to another organ, such as the uterus or bladder – the attachment can be caused by scar tissue that has formed after earlier surgery (adhesions) or by the cancer spreading.

The operation may involve the removal of parts of the bowel along with all or part of other organs. This is called an en-bloc resection. In rare cases, a woman may need to have her uterus removed (hysterectomy). This means she can no longer have children. Your

doctor will discuss your fertility with you before the surgery and can refer you to a counsellor or fertility specialist (see page 62).

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 will probably have check-ups for several years.

The type of operation used for advanced bowel cancer will depend on your individual situation, so talk to your surgeon about what to expect. You can also call Cancer Council 13 11 20 for information.

Bowel obstruction

Some people can get a blocked bowel (bowel obstruction) as the bowel cancer grows. Because waste matter cannot pass through easily, symptoms may include pain, nausea, vomiting and constipation.

Surgery to remove the cancer may help unblock the bowel. In some cases, you may need a stoma (see page 48).

Not everyone with a blockage will want an operation or be fit

enough to have it. In this case, your surgeon may be able to put in a small tube (stent) to help keep the bowel open. The stent is inserted through the rectum using an endoscope. A stent may also help manage your condition until you are well enough for an operation.

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

What to expect after bowel surgery

The recovery time after bowel surgery 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.

At first, you will need some pain relief. Most people will have patient-controlled analgesia (PCA). The PCA system allows you to press a button to release a measured dose of pain relief. (The system is timed to protect you from overdose.)

Less commonly, pain relief may be given by a slow injection into a vein (intravenous or IV infusion) or by an injection into your spinal column (epidural anaesthetic).

You will receive fluids through a drip (also called an intravenous or IV infusion) until you are able to start eating and drinking again. You may need a drip for a few days.

People who have abdominal surgery need to minimise the risk of developing blood clots in their legs, which can be life-threatening. During surgery, you may need to wear compression stockings to apply pressure to your calves, as well as a special cuff that applies intermittent pressure. Afterwards, you may be given regular injections of a blood-thinning substance. It is important to get out of bed and walk around as soon as you are able, and to move your legs if you cannot get out of bed.

You may also be instructed to do deep-breathing exercises to prevent a chest infection.

Common side effects of bowel surgery

- **Changes in bowel function** – Many people find they have softer and more frequent bowel movements. You may find that you need to go to the toilet as soon as you feel the urge. Bowel function usually improves within a few months but, for some people, it can take longer. It may help to talk to your surgeon, a continence nurse or a dietitian. See page 46 and pages 54–58 for more details.
- **Fatigue** – Try to get plenty of rest and only do what is comfortable. You may have to remind your family and friends that you are still recovering, even several months after surgery.
- **Changes in your diet** – See page 54 for information about your diet after an operation for bowel cancer.

To find out more about surgery, call 13 11 20 and ask for a copy of *Understanding Surgery*, or visit your local Cancer Council website.

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 is contained inside the bowel, it can usually be treated with surgery alone and chemotherapy is not needed.

If you have chemotherapy, the drugs may be injected into a vein (given intravenously) or supplied in tablet form. Some people have a small medical appliance called a port-a-cath or infusaport placed

beneath their skin through which they receive chemotherapy. You will probably have sessions of chemotherapy over several weeks or months. Your medical team will work out your treatment schedule. You may be advised to use contraception during chemotherapy because of the effects of the drugs.

Chemotherapy may be used at different times:

- **Neo-adjuvant therapy** – Some people who have surgery have chemotherapy (and/or radiotherapy, see page 42) beforehand to shrink the tumour and make it easier to remove during surgery. This is known as neo-adjuvant therapy.
- **Adjuvant chemotherapy** – Chemotherapy is often used for people after surgery if the cancer has spread through the bowel wall or into nearby lymph nodes. This adjuvant chemotherapy aims to reduce the chance of the cancer coming back by eliminating any cancer cells still present after surgery.

If you have chemotherapy after surgery, you will probably have 4–6 weeks to recover from the surgery before starting the treatment. Chemotherapy can begin only when your wounds are healed and you are strong enough.

- **Palliative treatment** – If the cancer has spread to other organs, such as the liver or bones, chemotherapy may be used to reduce your symptoms and make you more comfortable (see page 44). Palliative chemotherapy may shrink the tumours and extend life, but it is not able to cure the disease.

Side effects of chemotherapy

Some chemotherapy drugs can cause 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
- hair loss
- loss of appetite
- a drop in levels of blood cells (your blood count), which may increase the risk of infection
- sore hands or feet
- pins and needles or numbness in the fingers and toes, particularly after using a chemotherapy drug called oxaliplatin
- skin peeling and increased sensitivity to sunlight, particularly after using a chemotherapy drug called fluorouracil (or 5FU).

People react to treatment 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 may prescribe medication to manage the side effects, arrange a break in your treatment, or change your treatment.

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

To find out more, call 13 11 20 and ask for a copy of *Understanding Chemotherapy*, or visit your local Cancer Council website.



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

Targeted therapies

New drugs known as targeted therapies are used for bowel cancer only when the disease is advanced (metastatic). These drugs work differently from chemotherapy drugs by destroying or stopping the growth of cancer cells while minimising harm to healthy cells. Targeted therapies may be used together with chemotherapy or alone. They are usually injected into a vein.

Not all cancers respond to targeted therapies. Your doctor may arrange a RAS biomarker test. RAS genes play a key role in cell growth, so the test can help predict which therapies might help you.

Side effects of targeted therapies

The side effects of targeted therapies vary depending on the drugs used. The most common side effects include:

- high blood pressure
- protein in the urine (your doctor may test your urine for protein and adjust your treatment if levels become too high)
- rash
- diarrhoea
- delayed wound healing
- tiredness.

Radiotherapy

Radiotherapy uses high-energy x-rays or electron beams (radiation) to kill or damage cancer cells. The radiation is targeted to cancer sites in your body, and treatment is carefully planned to do as little harm as possible to your normal body tissue around the cancer.

Often part of the treatment for rectal cancer, radiotherapy can be given:

- before or after surgery, to reduce the chance of the cancer coming back
- instead of surgery, if you are not well enough for an operation
- at the same time as chemotherapy (chemoradiation).

Radiotherapy is also used as a palliative treatment (see page 44) for both colon and rectal cancer.

During treatment, you will lie under a machine that delivers x-ray beams to the treatment area. Each treatment takes only a few minutes once it has started, but setting up the machine and seeing the radiation oncologist may take more time.

If radiotherapy is given along with chemotherapy, you will most likely have it once a day, Monday to Friday, for about 5–7 weeks. You may have a shorter course of radiotherapy if it is given by itself. The number of treatments you have depends on your radiation oncologist's recommendation.

To find out more, call 13 11 20 and ask for a copy of *Understanding Radiotherapy*, or visit your local Cancer Council website.

Side effects of radiotherapy

Common side effects of radiotherapy may include:

- bleeding
- diarrhoea
- nausea
- tiredness
- mild headaches
- urinary or faecal incontinence (see page 46)
- redness and soreness in the treatment area
- reduced fertility (see below)
- problems with sexual function (see below).

People react to treatment differently, so some people may have few side effects, while others have many. Your treatment team can give you advice about how to manage radiotherapy side effects.

Effects on fertility and sexual function

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

For men, radiotherapy can damage sperm or reduce sperm production. This may be temporary or permanent. Most doctors suggest that men use contraception or abstain from unprotected sex for six months after radiotherapy. You may be able to store sperm at a hospital or fertility clinic before treatment starts.

Because radiotherapy can damage blood vessels, some men may have erection problems. Your doctor may prescribe medication or refer you to a specialist clinic to manage this problem.

For women, radiotherapy may lead to damage and shrinking of the vagina, making sexual intercourse difficult. It can also cause early menopause and infertility if the ovaries receive radiation.

If the treatment causes sudden menopause and you are no longer able to have children naturally, you may feel upset and worry about the impact on your relationship. Even if your family is complete, you may have mixed emotions. Talking to your partner, a counsellor or a fertility specialist about your concerns can help.

To find out more, call Cancer Council 13 11 20 and ask for free copies of *Fertility and Cancer* and *Sexuality, Intimacy and Cancer*, or visit your local Cancer Council website.

Palliative treatment

Palliative treatment aims to reduce symptoms without trying to cure the disease. It can be used at any stage of advanced cancer to improve quality of life. It is not just for people who are about to die and does not mean you have given 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 physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy, targeted therapies or other medication.

To find out more, call 13 11 20 and ask for our free booklet on palliative care, or visit your local Cancer Council website.



Key points

- The most common form of treatment for bowel cancer is surgery. You may also have chemotherapy, targeted therapies or radiotherapy.
- 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.
- The most common surgery for colon cancer is a colectomy. There are different types of colectomies depending on the tumour's location.
- Operations for rectal cancer include abdominoperineal and anterior resections.
- During bowel surgery, the surgeon removes the section affected by cancer and, where possible, joins the two ends of the bowel back together. If the bowel cannot be joined together again, the surgeon may create a stoma, an opening to the outside of the body. Waste (faeces) will pass through this stoma into a bag.
- Sometimes a temporary stoma is made to give the bowel time to heal. It is usually reversed later.
- In some cases, you may be able to have minimally invasive surgery (keyhole or laparoscopic surgery) or a local excision.
- Chemotherapy is treatment with drugs. It may be used before or after surgery, if the cancer has spread, or to stop the cancer coming back.
- Targeted therapies are new drugs that target cancer cells and minimise harm to healthy cells. They are used only for advanced bowel cancer.
- Radiotherapy is treatment with x-rays. It is often used to treat rectal cancer.



Coping with dietary and bowel changes

After treatment for bowel cancer, many people find that they need to adjust to changes to their digestion or bowel function.

While you don't have to follow a strict diet after treatment, many people find that certain foods cause them discomfort and could make bowel problems worse.

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).

It is common to have difficulty controlling when you pass urine (urinary incontinence), and you may find that you urinate more often or do not fully empty the bladder. For example, radiotherapy to the pelvis can irritate the lining of your bladder, which is near your 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 with time, although it can take months or even years. Talk to your health care team about whether any bowel or bladder changes are likely to be permanent.

Managing bowel and bladder changes

- Go to the toilet frequently to empty your bladder or bowels.
- Carry extra underwear and some non-alcohol cleansing wipes in case you accidentally soil yourself.
- Consider whether wearing a continence pad or disposable undergarment would give you peace of mind.
- Ask your doctor if there are any medications for your continence problems. You might be able to take something before going out when you know it will be difficult to reach a toilet quickly (e.g. at concerts).
- If the skin around the anus or bottom is sore, itchy or broken, ask your doctor or pharmacist to recommend a suitable cream to soothe and heal it.
- Use non-alcohol cleansing wipes rather than dry toilet paper after a bowel motion to help reduce irritation.
- Talk to a dietitian about changes to your diet that may help reduce incontinence. See also pages 55–57 for advice on diarrhoea and diet.
- Visit **toiletmap.gov.au** to locate public toilets. You can also download the National Public Toilet Map iPhone App from the iTunes App Store.
- Read *Improving Bowel Function After Bowel Surgery*, produced by the National Continence Management Strategy and available from **bladderbowel.gov.au** or **1800 33 00 66**.
- Talk to the continence nurse at your hospital for support and information.
- Contact the Continence Foundation of Australia on **1800 33 00 66**, or visit **continence.org.au**. Their nurses offer confidential advice and have pamphlets on strengthening exercises that may help you 'hold on'.

Having a stoma

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

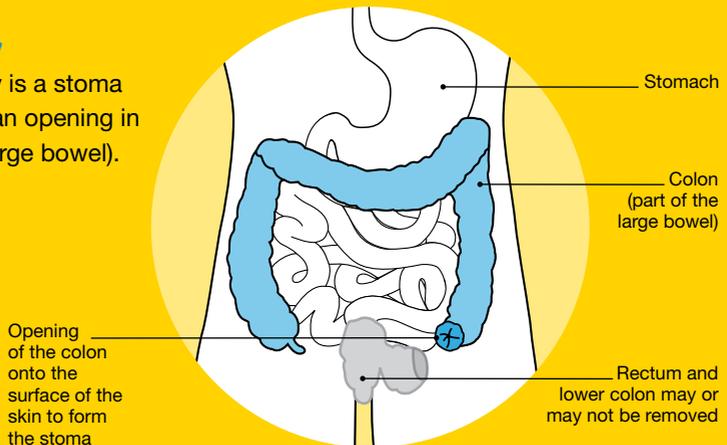
The two types of stoma are a colostomy (made from the large bowel) and an ileostomy (made from the small bowel) – see below.

A stoma may be temporary or permanent. A temporary stoma is needed only until the newly joined bowel has healed. The

Types of stoma

Colostomy

A colostomy is a stoma made from an opening in the colon (large bowel).



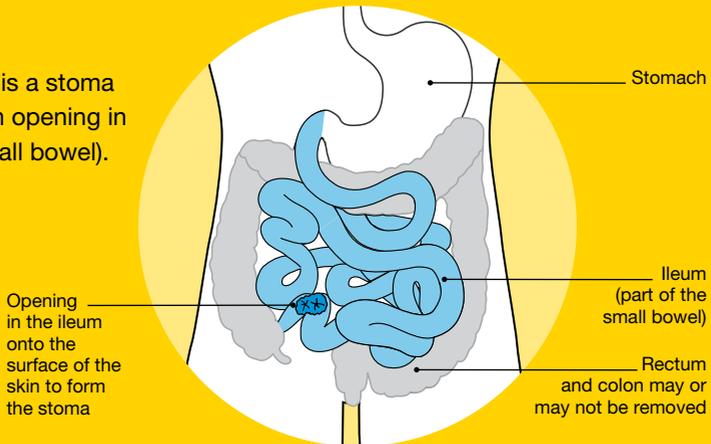
surgeon will determine the safest time to close your stoma. Less than 10% of people with bowel cancer need a permanent stoma.

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

Stomas vary in size and can change shape during the weeks after surgery. A stomal therapy nurse (see page 54) can give you advice about any changes to your stoma or the skin around it.

Ileostomy

An ileostomy is a stoma made from an opening in the ileum (small bowel).





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. 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 material (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 should 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 – Your stomal therapy nurse 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 material tends to be watery or soft. With a colostomy, the bag may be drainable or closed, depending on the consistency of your waste material. 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.

Coping 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 and how other people will react to your appearance. 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 also 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 page 59). Over time, most people find they can eat a normal healthy diet.

You can discuss changes to aspects of your everyday life with a stomal therapy nurse (see page 54). Your family may also need information and support, and can be included in discussions with the nurse if you wish. You could also talk to the hospital or your GP about seeing a counsellor if you feel like you need some emotional support.

Stoma Appliance Scheme

The Australian Government has a Stoma Appliance Scheme (SAS), which provides free stoma supplies to people with a temporary or permanent stoma. More than 40,000 people use the scheme.

To be eligible for the SAS, you must hold a Medicare card and belong to a stoma association. Your stomal therapy nurse will help you join an association, or you can contact them directly (see below).

The stoma supplies provided under the scheme include bags and appliances. Only certain products are covered and there is a limit to how many you can receive each month. If you need more than the maximum allowed, you can ask your GP or stomal therapy nurse to sign a certificate.

Visit health.gov.au and type 'Stoma Appliance Scheme' into the search box for more information.

Stoma associations

With your consent, your stomal therapy nurse will sign you up to a stoma (or ostomy) association. There is a small annual membership fee, but you will then 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.

If you would like to find out more about the stoma associations in your state or territory, visit the website of the Australian Council of Stoma Associations at australianstoma.com.au, or contact Cancer Council 13 11 20.

Stomal therapy nurses

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 and audiovisual resources
- give you information about adjusting to life with a stoma, including how to look after your stoma when you are out of hospital.

For more information, contact the Australian Association of Stomal Therapy Nurses at stomaltherapy.com, talk to a stoma association (see page 53), or call Cancer Council 13 11 20.

Diet after treatment

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

Your treatment team may tell you about some foods to avoid, but different foods can affect people differently, so you will probably 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 you to work out which foods tend to cause you trouble.

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. By trial and error, you might identify particular foods that irritate the stoma, but these vary considerably between people. Most people with a stoma end up eating a 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 to download a copy, or call **1800 33 00 66**.

Diarrhoea

Having loose or frequent bowel motions (diarrhoea) for long periods can be distressing. 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. Having diarrhoea that is hard to control can also make you feel tired.

Diarrhoea 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 do not form as solidly as before. This may need ongoing management.

- **Radiotherapy** – Radiotherapy often causes diarrhoea. It can take some weeks to settle down after treatment has finished. For a small number of people, diarrhoea is an ongoing issue.
- **Chemotherapy** – This treatment can cause diarrhoea and nausea. These side effects will go away after treatment and you can gradually resume a normal diet.

Diarrhoea can be exhausting, so rest as much as possible and ask family or friends to help out with chores. Eat at regular intervals throughout the day and try to maintain a balanced diet so your body is nourished.

Drink plenty of water so that you don't become dehydrated, and treat dehydration with a rehydration drink, such as Gastrolyte®. If your anus becomes sore, a pharmacist can recommend a cream.

Some people find it embarrassing to talk about diarrhoea. You may worry that diarrhoea means the cancer is still there or has come back. This is unlikely to be the case after treatment for bowel cancer.

It is important to talk to your doctor and nurses about diarrhoea. They will discuss ways to help control it, such as using medication, 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



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

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 makes them gassy. Reducing the foods that produce wind may be helpful. In particular, try restricting foods that are high in FODMAPs (Fermentable, Oligo-, Di-, Mono-saccharides And Polyols) – see table below.

Foods that may produce wind



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

Tips for reducing wind

- Try charcoal tablets, natural yoghurt and/or peppermint tea to reduce wind.
- Cut your food into small, bite-sized pieces.
- Chew 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.
- Ask a dietitian to help you with a low FODMAP diet.

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. This 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.

Foods that may cause blockages



high-fibre foods	oranges, strawberries, apples
raw vegetables	cabbage, celery, carrot, tomatoes
cooked vegetables	spinach, green beans, broccoli, cauliflower
seeds or kernels	popcorn, nuts, coconut, corn
spicy foods	chilli, curry
fruit and vegetable skins	apples, grapes, tomatoes
meat casing	sausages

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 to stay well hydrated.
- Chew food slowly and thoroughly.
- Cut your food into small, bite-sized pieces.
- If you have trouble eating a certain food, talk to a dietitian about your diet.



Key points

- After treatment for bowel cancer, most people find their bowel functions change.
- 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 will answer any questions you have and help you adjust to life with a stoma.
- If you become a member of an ostomy association, you will be entitled 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.
- It is important to drink plenty of fluid throughout the day to avoid dehydration and to 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 depend 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 could try 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, such as coffee enemas and magnet therapy, can be harmful. 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 treatment 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* and *Emotions and Cancer*, or download the booklets from the 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](http://beyondblue.org.au) 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 13), 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 relapse or recurrence. 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 (metastatic bowel cancer), you may be offered treatment, such as surgery, chemotherapy, targeted therapies or radiotherapy, to help control or slow the growth of the cancer (see pages 29–44). Sometimes small secondary cancers on the liver or lungs can be removed. 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 36.



Seeking support

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.

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 cancerconnections.com.au.

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



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 Home Help, Meals on Wheels or visiting nurses can help you in your caring role. 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. Phone 1800 242 636 or visit carersaustralia.com.au 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.

“Caring for my mum was deeply emotional. It was difficult, but it gave me a tremendous sense of caring and giving.” Sharyn



Useful websites

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

Australian

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

International

Macmillan Cancer Support.....	macmillan.org.uk
Cancer Research UK.....	cancerresearch.org.uk
American Cancer Society.....	cancer.org



Question checklist

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?



Glossary

abdomen

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

abdominoperineal resection (APR)

An operation for rectal cancer, which involves removing part of the colon and the rectum and anus and creating a permanent colostomy. Also used for anal cancer.

adjuvant therapy

A treatment given with or shortly after another treatment to enhance its effectiveness.

advanced cancer

Cancer that has spread into the surrounding tissues or away from the original site (metastasised).

anaemia

Deficiency in the number or quality of red blood cells.

anal cancer

A rare cancer affecting the tissues of the anus.

anal sphincter

See sphincter.

anterior resection

A surgical procedure to remove cancer in the rectum.

anus

The opening at the end of the bowel where solid waste matter normally leaves the body. The muscles that control it are called the anal sphincter.

appliance

See stoma bag.

ascending colon

The right side of the bowel.

barium enema

An examination of the bowel area using a white contrast liquid called barium. The barium is inserted into the rectum and x-rays are taken.

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 (removing faeces) 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 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.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

colectomy

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

colon

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

colonic J-pouch

An internal pouch surgically created using the lining of the large bowel. It may be formed during an ultra-low anterior resection.

colonoscopy

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

colorectal cancer

See bowel cancer.

colostomy

An opening (stoma) in the abdomen made from the colon (part of the large bowel). Also, the operation that creates this stoma.

Crohn's disease

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

CT scan

A computerised tomography scan. This scan uses x-rays to build a picture of the inside of the body.

descending colon

The left side of the colon.

digital rectal examination (DRE)

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

endorectal ultrasound (ERUS)

In this scan, a probe that generates soundwaves is inserted into the rectum. A picture of the rectum is built up from the echoes of the soundwaves.

endoscope

A flexible tube used to examine the bowel during a colonoscopy.

enema

A liquid solution that washes out the bowel.

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. The polyps will become cancerous if untreated.

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). Also, the operation that creates this stoma.

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.

infusaport

See port-a-cath.

large bowel

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

local excision

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

lymph nodes

Also called lymph glands. Small, bean-shaped structures that form part of the lymphatic system. They collect and destroy bacteria and viruses.

Lynch syndrome

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

malignant

Cancerous.

menopause

When a woman stops having periods (menstruating) and can't become pregnant anymore.

metastasis

A cancer that has spread from another part of the body. Also known as secondary cancer.

minimally invasive surgery

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

MRI scan

A magnetic resonance imaging scan. It uses magnetism and radio waves to take cross-sectional pictures of the body.

ostomy

See stoma.

palliative treatment

Medical treatment for people with cancer to help them manage pain and other symptoms.

PET scan

Positron emission tomography. A scan in which a person is injected with a small amount of radioactive glucose solution. Cancerous areas show up brighter in the scan because they take up more of the glucose.

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. Also called an infusaport.

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 expected outcome of a person's disease.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

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

The return of a disease after a period of improvement.

remission

When the symptoms of the cancer reduce or disappear. A partial remission is when there has been a significant improvement in the cancer. A complete remission is when there is no evidence of active cancer.

screening

Testing for signs of a disease in members of the public who do not have any symptoms.

sigmoid colon

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

sigmoidoscope

The 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.

sphincter

Strong muscles that form a valve. The anal sphincter muscles relax when a bowel movement occurs.

staging

The process of determining if the cancer is early or advanced.

stent

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

stoma (ostomy)

A surgically created opening to the outside of the body.

stoma bag

A pouch that collects waste from a colostomy or ileostomy.

stools

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

targeted therapies

Treatments that attack specific weaknesses of cancer cells while sparing healthy cells.

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.

ultrasound

A non-invasive scan that uses soundwaves to create pictures.

virtual colonoscopy

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

References

1. Australian Institute of Health and Welfare (AIHW), *Cancer incidence projections: Australia, 2011 to 2020*, AIHW, Canberra, 2012.
2. Australian Institute of Health and Welfare (AIHW), *Australian cancer incidence and mortality (ACIM) books: bowel cancer*, AIHW, Canberra, 2014.
3. MP Pignone et al., 'Costs and cost-effectiveness of full implementation of a biennial faecal occult blood test screening program for bowel cancer in Australia', *Medical Journal of Australia*, vol. 194, no. 4, 2011, pp. 180–85.
4. Australian Institute of Health and Welfare (AIHW), *Australian cancer incidence and mortality (ACIM) books: anal cancer*, AIHW, Canberra, 2014.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervec.org.au/glossary
- cancersa.org.au/glossary



How you can help

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

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and 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.



Cancer Council 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

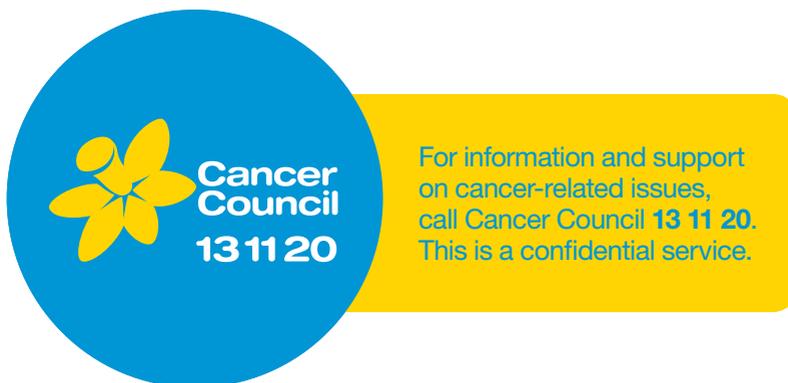
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.
www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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