



Bowel (Colorectal) Cancer

For people with cancer,
their family and friends



Bowel (colorectal) cancer

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Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call the Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call the Cancer Council Helpline through NRS 1300 555 727.

Generous Victorians who fundraise to fight cancer make many Cancer Council services, including the publication of this booklet, possible. For information on how you can help, visit www.cancervic.org.au or call 1300 65 65 85.

Introduction

This booklet has been prepared to help you understand more about bowel cancer. Bowel cancer is also known as colorectal cancer.

Many people feel understandably shocked and upset when they are told they have or may have bowel cancer. This booklet aims to help you understand how bowel cancer is diagnosed and treated. We also include information about support services you may like to use.

We cannot tell you which is the best treatment for you. You need to discuss this with your doctors. However, we hope this booklet will answer some of your questions and help you think about the questions you want to ask your doctors.

If you find this booklet helpful, you may like to pass it on to your family and friends who may also find it useful.

This booklet does not need to be read from cover to cover but can be read in sections according to your needs or interest. The words in **bold** are explained in the glossary.

*** Information about anal cancer is not covered in this booklet. Please call the Cancer Council Helpline on 13 11 20 or visit www.cancervic.org.au to find out about anal cancer.**

*** Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the inside back cover for details.**

Contents

What is cancer?	... 4
The bowel	... 6
Bowel cancer	6
Causes of bowel cancer	7
How common is bowel cancer?	8
Diagnosis	... 9
Screening for bowel cancer	9
Doctors and other health professionals you may see	11
How bowel cancer is diagnosed	12
'Staging' the disease	15
Tests for your family	16
Treatment	... 17
Surgery	17
Chemotherapy	20
Radiotherapy	21
Complementary and alternative medicines	22
Prognosis	23
When cancer can't be cured	24
Recovery and follow-up care	24
Life after treatment	25
Having a stoma	... 26
Stomal therapy nurses	27
Coping with a stoma	27
Ostomy support groups	28

Making decisions about treatment	... 29
Talking with doctors	30
Talking with others	30
A second opinion	31
Taking part in a clinical trial	31
Research into bowel cancer	32
Seeking support	... 33
Practical and financial help	33
Diet	34
Exercise	35
Relaxing	35
Sexuality and cancer	36
Cancer Council Helpline	36
Multilingual Cancer Information Line	37
Talk to someone who has been there	37
Living with Cancer Education Program	38
Caring for someone with cancer	... 39
Questions to ask your doctors	... 41
Glossary: what does that word mean?	... 42
Index	... 46

What is cancer?

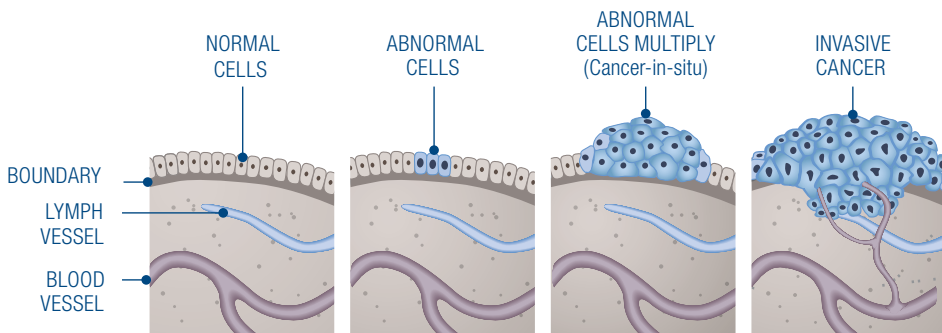
Cancer is a disease of the body's cells. Our bodies are always making new **cells**: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain **genes**. All cancers are caused by changes to these genes. Changes usually happen during our lifetime, although a small number of people inherit such a change from a parent.

Normally, cells grow and multiply in an orderly way. However, changed genes can cause them to behave abnormally. They may grow into a lump. These lumps can be **benign** (not cancerous) or **malignant** (cancerous).

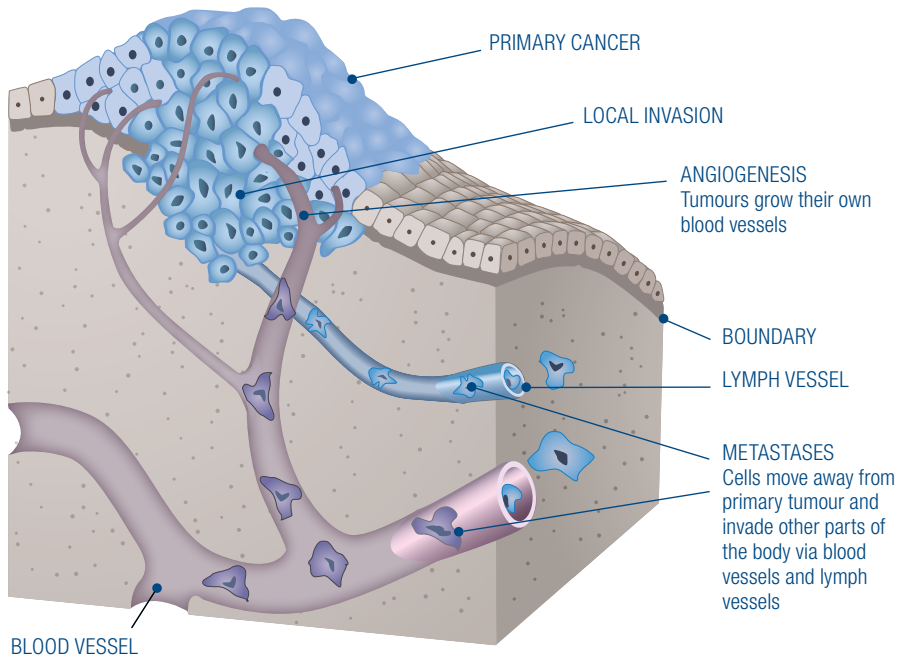
Benign lumps do not spread to other parts of the body.

A malignant lump (more commonly called a malignant **tumour** or a cancer) is made up of cancer cells. When it first develops, this malignant tumour is confined to its original site. If it is not treated, cancer cells can spread into surrounding **tissue** and to other parts of the body.

The beginnings of cancer



How cancer spreads



When these cells reach a new site they may continue to grow and form another tumour at that site. Such tumours are called secondary cancers or **metastases**.

For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This process is called angiogenesis.

The bowel

The bowel is the longest part of the digestive system (the 'gut').

The **digestive system** is the long tube that runs from the back of the mouth, forms the stomach and bowel, then ends at the **rectum** and **anus**. It winds around inside the body. Food passes through it and is digested and absorbed. The waste products are passed out as **bowel motions**.

The bowel is made up of two sections. The **small bowel** is where food is absorbed. This leads into the **large bowel**, where only water and salts are absorbed. The large bowel has two parts: the **colon**, which is about 1.5 m long, and the **rectum**, which is about 15 cm long. The rectum leads to the outside of the body through the **anus**.

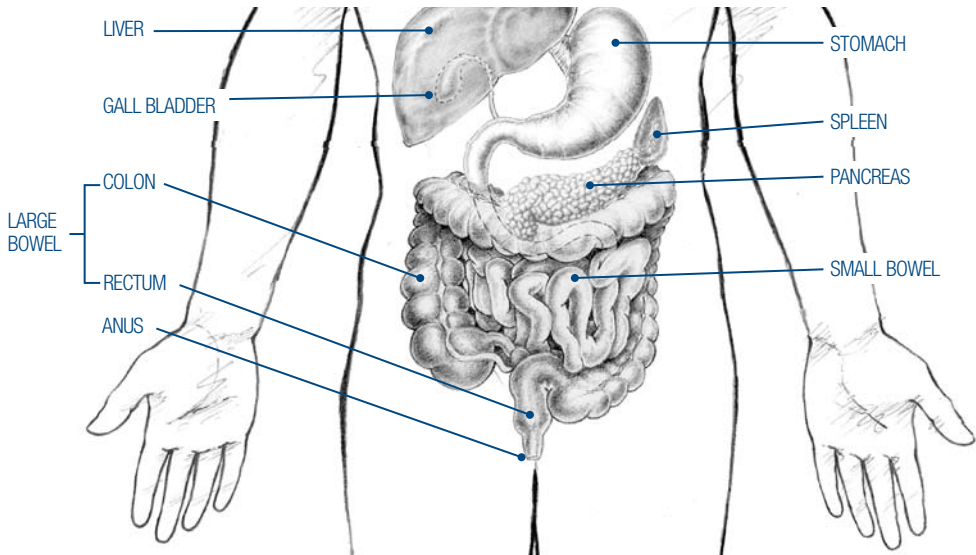
Bowel cancer

Bowel cancer generally affects the **colon** or **rectum**. Cancer of the **small bowel** is rare.

Bowel cancer starts in the lining of the bowel (the mucosa). If untreated it spreads deeper into the wall of the bowel. From there, it can spread to **lymph nodes** in the area. Later, bowel cancer can spread to other areas including the **liver** or **lungs**.

Sometimes bowel cancer starts in polyps that grow in the lining of the bowel. Polyps look like small mushrooms. These polyps are quite common in people over the age of 50 and are usually **benign**. However, some polyps can grow and become cancerous. People with **familial adenomatous polyposis (FAP)** have a lot of polyps in their bowel. They are at much greater risk of bowel cancer.

The digestive system



Causes of bowel cancer

The causes of bowel cancer are not clearly understood. Some **risk factors** make it more likely that a person will develop bowel cancer. These include:

- ageing: bowel cancer more commonly affects people over the age of 50
- a personal or family history of bowel cancer
- inheriting one of these uncommon genetic disorders: **familial adenomatous polyposis (FAP)** or **hereditary non-polyposis colorectal cancer (HNPCC)**
- having ulcerative colitis, where the lining of the **colon** is inflamed, for more than eight to 10 years.

How common is bowel cancer?

Bowel cancer is the most common cancer that affects men and women in Victoria. More than 3600 people are diagnosed each year. Bowel cancer mainly affects people over the age of 50 but can occur at any age.

Diagnosis



The most common symptoms of bowel cancer are:

- blood in **bowel motions** (either bright red or very dark in colour)
- mucus in bowel motions
- diarrhoea, constipation or feeling that the bowel does not empty completely, particularly if this is a change from normal habits
- general discomfort in the **abdomen** (feelings of bloating, fullness and/or cramps)
- constant tiredness
- weakness and paleness (anaemia).

If you have not been diagnosed with bowel cancer and are just looking through this booklet, please be aware that many of these symptoms occur without any serious disease being present. However, if you have any of the symptoms for more than two weeks, see your doctor for a check-up.

Screening for bowel cancer

National health guidelines recommend screening for bowel cancer at least every two years from the age of 50 for those without symptoms or a strong family history of bowel cancer. Regular screening is important

because bowel cancer can develop without noticeable symptoms. However, if detected early, nearly all bowel cancers can be cured.

Screening for bowel cancer involves completing a simple, at-home test called a faecal occult blood test (FOBT). An FOBT looks for traces of blood in the **bowel motion** that are often invisible to the naked eye and could be a sign of bowel cancer. The test involves taking tiny samples from two separate bowel motions, putting the completed test in the envelope provided and mailing it to a pathology lab for analysis.

An FOBT is 'positive' when traces of blood are found in the samples. Blood may be due to conditions other than cancer, such as polyps or haemorrhoids, but it needs to be investigated. If your FOBT is positive you will receive a letter asking you to speak to your doctor about follow-up tests, usually a colonoscopy, to determine the cause.

If your FOBT is 'negative' (meaning no traces of blood were found) you will need to do another test in two years.

*** See your doctor if you have symptoms of bowel cancer. If you have a strong family history of bowel cancer speak to your doctor to find out if you might benefit from earlier or increased testing.**

National Bowel Cancer Screening Program

Currently select age groups are eligible to receive a free FOBT in the mail as part of the Australian Government's National Bowel Cancer Screening Program. To find out if you are eligible, visit www.cancerscreening.gov.au/bowel or telephone 1800 118 868.

If you are over 50 and not yet eligible for the national program, speak to your doctor about having an FOBT or call the Cancer Council Helpline on 13 11 20.

*** The Cancer Council has an FOBT information sheet. Visit www.cancervic.org.au or telephone 13 11 20.**

Doctors and other health professionals you may see

Your doctor will examine you and refer you for tests to see if you have cancer. This can be a worrying and tiring time, especially if you need to have several tests.

If the tests show you have or may have cancer, your doctor will refer you to a specialist, who will advise you about treatment options.

You should expect to be cared for by a team of health professionals from the relevant major fields (see following list). Ideally, all your tests and treatment should be available at your hospital; however, this may not be possible.

Specialists and other health professionals who care for people with bowel cancer include:

- colorectal surgeons and general surgeons
- radiation oncologists, who specialise in radiotherapy (also known as **radiation** therapy)
- medical oncologists, who specialise in chemotherapy
- nurses and general practitioners, who will help you through all stages of your cancer
- gastroenterologists, who are doctors with an interest in problems of the gastrointestinal tract
- **stomal therapy nurses**, who specialise in caring for people who have **stomas**
- dietitians, who will recommend the best diets to follow during and after treatment
- social workers, psychologists, counsellors, physiotherapists and occupational therapists, who will advise you on support services and help you get back to normal activities.

How bowel cancer is diagnosed

This section lists common tests for bowel cancer. You may have had some of them already.

Rectal examination

This test helps the doctor to check the last 6 to 8 cm of your **bowel**.

Your doctor will insert a gloved finger into your **anus** to feel inside your **rectum** for anything unusual. The test will be a little uncomfortable and may make you feel like you are going to open your bowels, but you won't lose control.

Sigmoidoscopy

This test looks at the lower part of your **large bowel**, including the **rectum**.

Your doctor will put a firm or flexible lighted tube (sigmoidoscope) into your **anus** so they can see the lining of your bowel. This may be uncomfortable but should not cause severe pain. No **anaesthetic** is required. The test will only take 10 minutes.

You may have an **enema** to clean out your bowel before the test so all areas can be seen clearly. A fluid will be put into your rectum which will cause you to empty your bowel.

Barium enema and x-ray

Before the x-ray, you will have an enema (see 'Sigmoidoscopy', above).

A small tube will be put into your **anus** and up into your **rectum**. White liquid, called barium, will be put into your **bowel**. Then air will be pumped in to make the barium go into the creases in the bowel wall. This will show up the bowel lining clearly when x-rays are taken. This may be uncomfortable. The test will take about 30 minutes.

Colonoscopy

This test lets your doctor look for signs of cancer inside the whole of the **large bowel**.

Before the test, you will have a bowel preparation. This is a drink given the day before your colonoscopy which will give you watery diarrhoea to empty your bowel and allow all the large bowel to be seen clearly. You may also need an enema (see ‘Sigmoidoscopy’, above).

A long, flexible, lighted tube (colonoscope) will be put into your **anus**. It will be gently pushed through your large bowel to examine all of the large bowel to the beginning of the **small bowel**.

If the doctor sees anything unusual, they can pass small tools into the colonoscope and take out some **tissue**. The tissue can be examined under a microscope. This is called a biopsy.

You will have a sedative or **anaesthetic**; this will make you feel drowsy. You may feel some discomfort during or after the test but this should settle quickly. The test will take about 20 to 30 minutes. You should arrange to have someone take you home.

Chest x-ray

You may have a chest x-ray to check for lung or heart disease before surgery. Chest x-rays can also show if bowel cancer has spread to the **lungs**.

Computerised tomography (CT) scan

A CT scan is a type of x-ray that gives a picture of organs and other structures (including any **tumours**) in your body. It is used to see if cancer has spread to areas such as the **lymph nodes, liver or lungs**. CT scans are usually done at a hospital or a radiology clinic. It usually takes 30 to 40 minutes to complete this painless test.

You will be asked not to have a meal before the scan. You will have a liquid dye before the scan, in a drink and in an injection. This dye makes it easier to read the scans that are taken, so anything unusual will show more clearly. You will be asked to lie on a table that slowly moves through the CT scanner, which is large and round like a doughnut. Most people can go home as soon as their scan is over.

There is a small possibility of the injected dye causing an allergic reaction. You should tell your doctor if you are allergic to iodine or to contrast dyes, or if you are diabetic or have abnormal kidney function.

Ultrasound scan

In this test, sound waves are used to create a picture of your bowel and organs nearby. An ultrasound scan is mainly used to see if cancer has spread to the **liver**.

You will be asked to uncover your **abdomen** and lie on a table. Once you are comfortable, a gel will be spread on the skin over the area being scanned.

A small device will be moved across your abdomen. It makes sound waves and receives echoes. A computer makes a picture of the echoes produced when the sound waves meet something dense, like an organ or a **tumour**.

This test is painless and takes 15 to 20 minutes.

Endorectal ultrasound scan

If a cancer is found in the **rectum** by other tests, your doctor may ask you to have an endorectal ultrasound.

The small device will be inserted into your rectum to see how large the cancer is, and whether it has spread.

This test is used to help 'stage' the disease (read about staging later in this chapter). It can help the doctor decide whether you should have radiotherapy before surgery.

Liver function test

This blood test measures chemicals that are normally found or made in your **liver**. The test may be abnormal if cancer has spread to your liver.

Carcinoembryonic antigen (CEA) test

This blood test looks for a substance (CEA) that is produced in high quantities by some cancer **cells**, especially in bowel cancer.

Magnetic resonance imaging (MRI)

This test is like a CT scan, but it uses magnetism instead of x-rays to build up pictures of the organs in your **abdomen**. It is often used in bowel cancer to help 'stage' the disease (see below for more details).

Like a CT scan, MRI is painless and the magnetism is harmless. You will be asked to lie on a table inside a large metal tube that is open at both ends. The test may take up to an hour. The tube makes some people feel claustrophobic (afraid of being in a small space). If you think you are likely to feel this way, please tell the treatment centre in advance: you may be able to take someone into the room with you for support. The machine can be quite noisy.

Because the MRI scanner uses a powerful magnet, people with certain types of metal in their bodies should not have MRI scans. You should tell your doctor if you have any metal objects in your body (like a pacemaker), or clips from past operations, or if you have had injuries to the eyes or elsewhere that were caused by metal.

Positron emission tomography (PET) scan

This test is used to help determine how far the cancer has spread after an MRI or CT scan. It may or may not be available at your hospital.

You will be asked to not eat or drink anything before the PET scan. A small amount of radioactive material will be injected into a vein in your arm one hour before the scan. You will be asked to lie or sit in a darkened room until the scan. For the scan, you will lie on a table and be moved through a large doughnut-shaped scanner. The tube may make some people feel claustrophobic. If you think you are likely to feel this way, tell the staff at the treatment centre before your scan.

'Staging' the disease

The tests described in the previous pages will show whether you have bowel cancer. Some can also show if it has spread.

The cancer may have spread into blood vessels or **lymph nodes** near the bowel, or into organs further away, like the **liver** or the **lungs**. This is called metastasis.

Knowing if and how far the cancer has spread is called ‘staging’ the disease and is related to your prognosis. Staging helps your doctors to work out the best treatment for you.

In Australia, the staging system for bowel cancer is the Australian Clinico Pathological Staging System (ACPS). You may also hear about the ‘Dukes’ system, which is like the ACPS: Dukes stage A equals ACPS stage A, and so on.

- Stage A: the cancer is confined to the bowel wall.
- Stage B: the cancer has spread to the outer surface of the bowel wall but no further.
- Stage C: cancer is found in lymph nodes near the bowel.
- Stage D: cancer is found at distant sites: for example, in the liver or lungs.

Ask your doctor to explain the stage of your cancer in a way you can understand. This will help you to choose the best treatment for your situation.

Another staging system being used more often is called the TNM system. It records how far the **tumour** (T) has spread through the bowel wall, if **lymph nodes** (N) are affected by the cancer and whether the cancer has spread to other parts of the body (M, for **metastases**).

Tests for your family

Having a family history may slightly increase the risk of bowel cancer in your family. Your doctor may recommend that your family members (brothers, sisters, parents and children) should have a screening **colonoscopy** as a precaution. The age your family needs to have their colonoscopy depends on what age you were when you were diagnosed with bowel cancer. The routine colonoscopy should be at 50 years of age, or 10 years before the age when you were diagnosed with bowel cancer, whichever comes first.

Speak to your doctors about this.

Treatment



Many years of treating cancer patients and testing treatments in clinical trials has helped doctors know what is likely to work for a particular type and stage of cancer. Your doctor will advise you on the best treatment for your cancer. This will depend on the type of cancer you have, where it is and how far it has spread, your general health, and what you want.

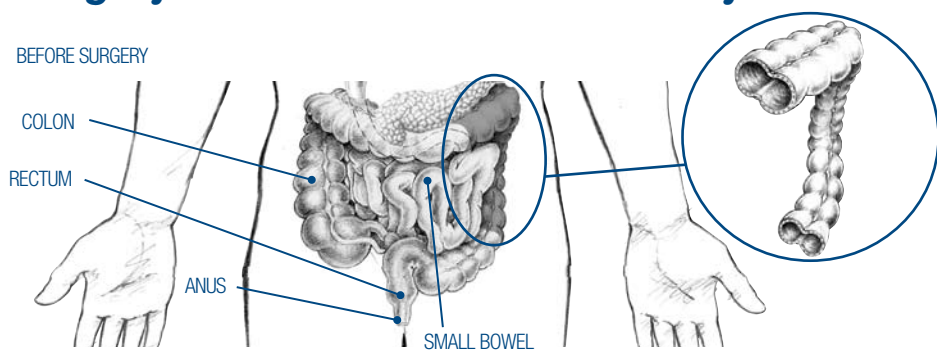
The main treatment for bowel cancer is surgery. Chemotherapy and radiotherapy may also be used.

Surgery

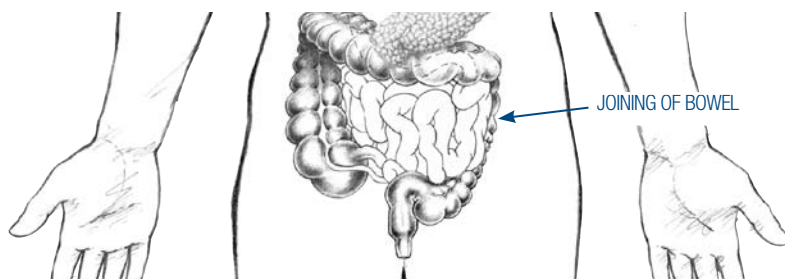
An operation for bowel cancer aims to remove the cancer and nearby **tissue** that could be affected by cancer. This is major surgery. You will need time to recover from it. In recent years, more people with bowel cancer are having keyhole surgery to remove the part of the **colon** where the cancer is. It is less invasive than the operations described below. (This means it is done using smaller incisions/cuts.) Speak to your doctor to see if this is possible for you.

A colectomy (see picture on next page) is an operation for cancer in the colon. It removes the part of the colon where the cancer is and then joins the two ends of the colon together. After the operation, you will have a

Surgery for bowel cancer: colectomy



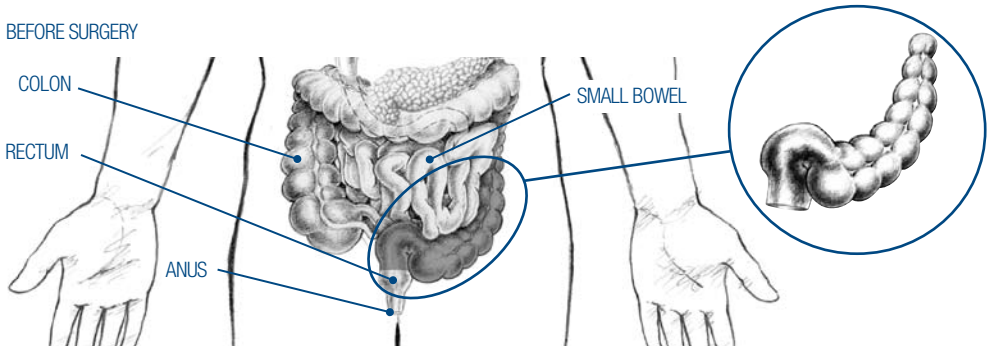
AFTER SURGERY



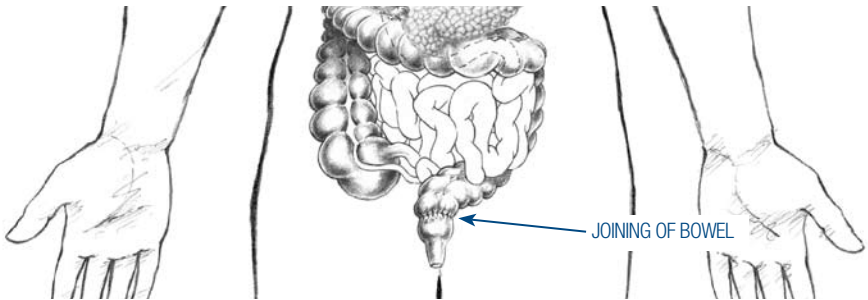
scar on your lower **abdomen**, a catheter (tube) to collect urine until your wound begins to heal, and a shorter colon. Depending on how much of the colon is removed, you may have to open your bowels more often or you may have diarrhoea. You may also need a **colostomy**, which may not be permanent (see 'Having a stoma'). There are two types of surgery for cancer in the rectum. In an anterior resection (see picture on next page), the surgeon removes the part of the bowel where the cancer is, then joins the two ends of the bowel together. Anterior resection leaves one scar. A permanent **stoma** is not needed, although you may need a stoma for a time while your bowel heals. In the other type of surgery, an abdominoperineal (AP) resection, you will have two wounds: one on

Surgery for bowel cancer: anterior resection

BEFORE SURGERY



AFTER SURGERY



your abdomen and one where your **anus** was removed. You will need to have a permanent stoma because you no longer have a **rectum** or anus (see 'Having a stoma'). Your surgeon may recommend constructing a colonic pouch in place of the rectum. This allows the rectal cancer to be removed and the bowel 'remade' so that you can pass bowel motions normally.

Early cancers and cancers that are not too invasive can often be removed during endoscopy. The surgeon uses techniques that safely remove the cancer without damaging the bowel wall. This is called a transanal endoscopic mucosal resection. Careful staging of the cancer is needed to make sure this is the best approach for your cancer.

In a small number of people who have bowel cancer, the cancer is attached to another organ, such as the uterus or bladder. If this happens in your case, the doctor may remove part of the attached organ with the bowel. Very rarely, a woman's uterus needs to be removed. This means she can no longer have children. Your doctor should discuss this with you before the surgery, so that you can talk with a fertility counsellor or another specialist if you wish.

After the operation

You will discuss your care after the operation with your surgeon.

You will need to have pain relief. This is usually by **epidural anaesthetic**, which dulls feeling below the waist. Some people will have morphine by a slow injection into a vein (infusion). Morphine is safe for short-term use. Other people will have patient-controlled analgesia (PCA), which means you control the dose you take.

You will need to rest for a couple of days and then start eating and drinking in a normal way again. Most people are able to move around again within four to five days and can go home about seven to 10 days after surgery. It takes two to three months to recover from the surgery.

Chemotherapy

Chemotherapy is often used to treat bowel cancer. You may be referred to see a medical oncologist to talk about possible chemotherapy:

- before surgery and sometimes with radiotherapy
- after surgery to increase the chance of cure, or
- to reduce symptoms and improve quality of life and survival if the cancer has spread (**advanced cancer**).

Chemotherapy is the use of anti-cancer drugs. It can be used to increase the chance of cure or to shrink the size of the cancer when cure is not possible. When cancer can't be cured, chemotherapy can improve survival, reduce symptoms and improve quality of life.

The aim is to destroy all cancer cells while doing the least possible damage to normal cells. The drugs work by stopping cancer cells from growing and reproducing.

Chemotherapy can be used before or after surgery and is usually given by injecting the drugs into a vein (intravenous treatment). There are other ways of having chemotherapy, including tablets.

Side effects of chemotherapy

Some chemotherapy drugs can cause side effects. The side effects depend on what drugs you are treated with. Different chemotherapy drugs are used to treat bowel cancer. The more common side effects may include feeling sick (nausea), vomiting, feeling unwell, tiredness, and some thinning or loss of hair from your body and head. Generally, these side effects are temporary and can be prevented or reduced.

The medical oncologist will discuss these and other side effects and risks with you.

★ **The Cancer Council's booklet *Coping with Chemotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or telephone 13 11 20.**

Radiotherapy

Radiotherapy treats cancer by using **radiation** to destroy cancer **cells** in a part of the body. Radiation can be targeted to cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body **tissue** around the **tumour**.

Radiotherapy is often part of the treatment for rectal cancer. It can be given before or after surgery. It reduces the chance of cancer coming back.

The treatment is given over a number of weeks, with a small dose of radiation each day from Monday to Friday. Each treatment only takes a few minutes.

Chemotherapy is often used with radiotherapy.

Side effects of radiotherapy

Side effects of radiotherapy depend on what part of the body is being treated. Treatment to the **bowel** may cause tiredness, skin redness, soreness around the bottom, diarrhoea and frequent urination. Side effects usually get better within a few weeks of ending treatment.

Longer term effects of radiotherapy may occur months or years after treatment. Radiotherapy can sometimes cause persistent diarrhoea, narrowing of the bowel, bleeding, and not being able to absorb food properly. In women, it can cause **infertility** (no longer being able to conceive children naturally) and the end of menstruation (some women may have symptoms of **menopause**) as the ovaries also receive some of the **radiation**. For men, radiotherapy to the **abdomen** or around the rectum may cause infertility and erection problems.

The radiation oncologist will discuss with you these and other side effects and risks, and how to manage them.

★ The Cancer Council's booklet *Coping with Radiotherapy* discusses ways of managing side effects. Visit www.cancerciv.org.au or telephone 13 11 20.

Complementary and alternative medicines

It's common for people with cancer to seek out complementary and alternative treatments. Many people feel that it gives them a greater sense of control over their illness, that it's 'natural' and low-risk, or that they just want to try everything that seems promising.

Complementary therapies include massage, meditation and other relaxation methods, which are used along with medical treatments. Alternative therapies are unproven remedies, including some herbal and dietary remedies, which are used instead of medical treatment. Some of these have been tested scientifically and found to be not effective or even to be harmful.

Some complementary therapies are useful in helping people to cope with the challenges of having cancer and cancer treatment. However, some alternative therapies are harmful, especially if:

- you use them instead of medical treatment
- you use herbs or other remedies that make your medical treatment less effective
- you spend a lot of time and money on alternative remedies that simply don't work.

Be aware that a lot of unproven remedies are advertised on the Internet and elsewhere without any control or regulation. Before choosing an alternative remedy, discuss it with your doctor or a cancer nurse at the Cancer Council Helpline.

Visit the Cancer Council website www.cancervic.org.au or the US National Center for Complementary and Alternative Medicines <http://nccam.nih.gov/>. Quackwatch at www.quackwatch.com is also a reliable website.

★ **The Cancer Council has a booklet about complementary and alternative cancer therapies. Visit www.cancervic.org.au or telephone 13 11 20.**

Prognosis

Bowel cancer spreads (metastasises) outside the **bowel** if it is not treated. It spreads fairly slowly and can stay in the bowel for months or years before moving outside it, generally first to the **lymph nodes**, then to other organs. This gives doctors a chance to treat and cure the cancer. Bowel cancer treatment is most effective if it happens before the cancer spreads.

If you would like to know more about your own **prognosis**, speak to your doctor, who is familiar with your full medical history.

When cancer can't be cured

If your cancer has spread and it is not possible to cure it by surgery (**advanced cancer**), your doctor may still recommend treatment. In this case, treatment may help relieve any symptoms, can make you feel better and may allow you to live longer.

Whether or not you choose to have anti-cancer treatment, symptoms can still be controlled. For example, if you have pain, there are effective treatments for this.

General practitioners, specialists and palliative care teams in hospitals all play important roles in helping people with cancer. For more, contact the Cancer Council Helpline on 13 11 20 or Palliative Care Victoria on 9662 9644.

★ **The Cancer Council has information on advanced cancer for people with cancer and for carers. Visit www.cancervic.org.au or telephone 13 11 20.**

Recovery and follow-up care

People who have been treated for bowel cancer need regular check-ups. This allows your doctors to keep an eye on your health. It may also help you to feel more confident about your health after treatment.

If your surgeon couldn't examine your whole bowel before or at the time of the operation, you should have a **colonoscopy** within six months. If you had a colonoscopy before or soon after your surgery, you should have one every three to five years.

After the treatment, give yourself time. Finding out you have cancer and having treatment are tiring. You need to give yourself time to get your strength back. If you look after the house, you will need some help for a while. If you work outside the home, you will need to ease back into it slowly, rather than rushing back the week after leaving hospital.

'I'm very independent so I tried to do as much as I could myself. But I was so tired I had to ask for help.'

This means you might have to remind your family and friends that for a while you won't be fit enough to do all your usual activities. Ask your doctor for specific post-operation instructions for your recovery.

Life after treatment

Many people are surprised to discover that life after treatment presents its own challenges.

During treatment, you may have been busy with appointments and focused on treatment, but afterwards you may feel anxious rather than more secure. You might worry about every ache and pain and wonder if the cancer is coming back. Regular check-ups and talking to your doctor about what to expect if the cancer comes back may reassure you.

Some people feel pressure from their family and friends to get back to their 'normal life'. Everyone will eventually re-establish a daily routine, but it will be at their own pace and may be different to how things were in the past. Some people call this a 'new normal'.

Give yourself time to adjust to physical and emotional changes. You may not be fit enough to do your usual activities around the house. If you're returning to work, ease back into it slowly, rather than rushing back the week after leaving hospital.

Some people say that after cancer, they have changed priorities and see life with a new clarity. For example, you may decide to spend more time with family, start a new hobby, travel or get involved in advocacy or volunteer work.

Talking to someone who has had bowel cancer may help you deal with the changes in your life. Call 13 11 20 and ask to speak to a Cancer Connect volunteer.

★ The Cancer Council has a booklet about life after cancer for people who have finished treatment. Visit www.cancervic.org.au or telephone 13 11 20.

Having a stoma



Some people who have surgery for bowel cancer need to have a stoma. You may hear people refer to this as a ‘bag’.

Sometimes, after bowel cancer has been removed, it is not possible to reconnect the **bowel** as it was before. The body still needs to get rid of **bowel motions**. The surgeon can make a small hole in your **abdomen** and bring one end of the bowel out through the hole and sew it to the skin. This makes a **stoma** or ‘ostomy’.

An ostomy from the colon is called a **colostomy**. An opening from the **ileum** is called an **ileostomy**. This stoma may be permanent or temporary.

A stoma is roughly the size of a 20 cent coin. It is usually located on the front of the abdomen, half-way between the belly button and the hip bone. It is soft, moist and red and is made of the same type of **tissue** as the inside of the mouth.

There is no feeling in the stoma itself but the skin around it has feeling. The stoma may be at skin level or raised a little. When the bowel acts, wind and bowel motions come out through the stoma. A small, disposable, flat plastic bag – often called a colostomy bag – is worn over the stoma to catch the waste.

The back of the bag sticks firmly to the skin around the stoma and provides a leak-proof, odour-proof system. When a bag has been used, it is thrown out and a new one is fitted.

Some people don't like to wear bags. You can learn how to manage by giving yourself a type of **enema** into the colostomy daily or every other day. Some people are able to wear a type of tampon or plug in their colostomy to stop wind and bowel motions escaping. These methods are not suitable for an ileostomy because its output is more watery.

Stomal therapy nurses

With bowel surgery there is a small chance you could need a stoma. Most surgeons will talk about this before surgery, just in case this turns out to be needed. The surgeon may ask a stomal therapy nurse to see you before the operation. The nurse will discuss the best place for it to be located.

Stomal therapy nurses have special training. They will answer your questions about the surgery and looking after the stoma. They will help you adjust to having a stoma. They can give you care and support after leaving hospital.

Stomal therapy nurses work in many hospitals. In the community, some nursing services have stomal therapy nurses. Many ostomy associations, which supply the bags, can put you in touch with a stomal therapy nurse. Your doctor and the Cancer Council Helpline can help you find a stomal therapy nurse.

Coping with a stoma

Having a **stoma**, even just for a short time, is a big change in a person's life. It takes some adjustment. Your **stomal therapy nurse** will discuss all aspects of living with a stoma and provide you with booklets and videos if you wish.

Call the Cancer Council Helpline if you would like to arrange to speak to another person with a stoma. It can be helpful to hear how someone else coped with a stoma.

Your family may also need information and support, and the stomal therapy nurse will be happy to talk with them too.

Ostomy support groups

You will be advised to join an ostomy association so you can obtain free bags and related products. There are support groups for people of all ages. Support groups for young people up to the age of 35 are available in each state and territory, and other support groups are available for people over the age of 35. Contact the Cancer Council Helpline on 13 11 20 for the group nearest you.

Making decisions about treatment



Sometimes it is very hard to decide which is the right treatment for you. You may feel that everything is happening so fast that you do not have time to think things through. Waiting for test results and for treatment to begin can be very difficult.

While some people feel they have too much information, others may feel that they do not have enough. You need to make sure that you know enough about your illness, the possible treatments and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh up the good and bad points about each treatment. There is no right or wrong decision, only the decision that is best for you. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been advised. It is important to understand all the options available to you.

Some people with **advanced cancer** will always choose treatment, even if it only offers a small chance of cure. Others want to make sure that the benefits of treatment outweigh any side effects. Still others will choose the treatment they think offers them the best quality of life. Some may choose not to have treatment except to have any symptoms managed to maintain the best possible quality of life.

Talking with doctors

You may want to see your doctor a few times before making a final decision on treatment. It is often hard to take everything in, and you may need to ask the same questions more than once. If you feel comfortable, it may be helpful to bring a family member or friend with you to appointments for support and to write notes.

You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it.

*** Before you see the doctor, it may help to write down your questions. There is a list of questions to ask your doctor on page 41 which may help you. Taking notes during the session can also 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. Some people find it is helpful to tape record the discussion (but check with your doctor first).**

Talking with others

Once you have discussed treatment options with your doctor, you may want to talk them over with family or friends, with nursing staff, the hospital social worker, or your own religious or spiritual adviser. Talking it over can help to sort out which course of action is right for you.

You may be interested in searching for bowel cancer on the Internet. While there are some very good websites, you need to be aware that some websites provide wrong or biased information. We recommend that you begin with the Cancer Council's site (www.cancervic.org.au) and use our links to find other good cancer websites.

A second opinion

You may want to ask for a second opinion from another specialist. This is okay and can help you make your decision. It is important that you have all the information needed to make the decision that is right for you. Your specialist or local doctor can refer you to another specialist. You can ask for a copy of your results to be sent to the second doctor. You can still ask for a second opinion even if you have started treatment or still want to be treated by your first doctor.

Taking part in a clinical trial

Cancer Council Victoria supports participation in clinical trials. They are the most accurate way to determine the effectiveness of promising new treatments or new ways of combining cancer treatments. Always discuss treatment options with your doctor.

If your doctor suggests taking part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What is the standard (best available) treatment for my cancer if I don't go in the trial?
- Which treatments are being tested and why?
- Which tests are involved?
- What are the benefits of participating in a trial?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?
- What are the following requirements?

If you decide to join a randomised clinical trial, you will have either the best existing treatment or a promising new treatment. You will be allocated at random to receive one treatment or the other. In clinical trials, people's health and progress are carefully monitored.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not affect your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

The Victorian Cooperative Oncology Group and Clinical Trials Office have developed a clinical trial database to make it easier for people affected by cancer and health professionals to find suitable clinical trials. This database was funded by the Victorian Cancer Agency.

★ Visit www.cancervic.org.au/trials for more about clinical trials for bowel cancer.

Research into bowel cancer

Research for bowel cancer is ongoing. Recent clinical trials may have involved detection and screening methods, tests to predict the risks of cancer recurrence and immunotherapy. These may not be approved or available as standard treatment at this time. Always discuss diagnostic and treatment options with your doctor.

In some hospitals, you may be asked if part of your bowel **tumour** can be kept in a special **tissue** bank for future research. To find out more about clinical trials research in Victoria visit www.cancervic.org.au/trials or call 9635 5179.

Seeking support



When you are first told you have cancer, you may feel a range of emotions, such as fear, sadness, depression, anger or frustration. It may be helpful to talk about your feelings with your partner, family members or friends, or with a hospital counsellor, social worker, psychologist or your religious or spiritual adviser.

★ You can telephone the Cancer Council Helpline on 13 11 20, Monday to Friday, 8.30 am to 6 pm for cancer information and support.

Sometimes you may find that your friends and family do not know what to say to you. They may have trouble dealing with their feelings too. Some people may feel so uncomfortable that they avoid you. This can make you feel very lonely. You may feel able to approach your friends directly and tell them what you need. You may prefer to ask a close family member or a friend to talk with other people for you.

Practical and financial help

A serious illness may cause practical and financial problems. You do not need to face these alone. Apart from offering emotional support,

a social worker may be able to suggest useful tips to help. Ask at your hospital, your community health centre, or ring the Cancer Council Helpline.

Many services are available, including:

- financial assistance, which may be available for transport costs to medical appointments, prescription medicines, or through benefits or pensions. Contact the social worker at your hospital.
- home nursing care, which is available through district nursing, or through the local palliative care service: your doctor or hospital can arrange this.
- meals on wheels, home care services, and aids and appliances, which can make life easier: contact the hospital social worker, occupational therapist or physiotherapist, or your local council.

Diet

You will probably have to make some changes to your eating habits after treatment for bowel cancer. Your doctor or the hospital dietitian will advise you about the sort of diet that you need to follow.

At first you may notice that certain foods upset the normal action of your bowel or your **stoma** if you have one. Foods such as fruit and vegetables may give you loose bowel motions and make your stoma act more often than normal. This is often temporary and after a while you may find that the same foods do not have any effect. There are no set rules about the types of food to avoid; you will need to experiment. Some foods that disagree with one person may be fine for another. If you continue to have problems, it may help to talk to a dietitian at the hospital.

Depending on the type and extent of the surgery you have had, you may have diarrhoea. Tell your doctor or nurse if this happens as they can give you medicine to help control it. It is important to drink plenty of fluids if you do have diarrhoea.

It is very important that you try to eat as well as you can, to maintain your weight and strength. This is also true if you have chemotherapy or radiotherapy, although food may seem very unappealing at times.

No diet can cure cancer. In the longer term, plan to stick to a healthy diet and include regular exercise in your week. There is growing evidence that a good diet, staying a healthy weight and exercising regularly may reduce the chance of cancer coming back.

★ **The Cancer Council's booklet *Nutrition and Exercise* contains useful information. Visit www.cancervic.org.au or telephone 13 11 20.**

Exercise

You may find it helpful to stay active and exercise regularly. Exercise can help with fatigue. The amount and type of exercise you can do will depend upon what you are used to and how well you feel. Discuss with your doctor what is likely to be best for you. There is growing evidence that exercising regularly may reduce the chance of cancer coming back.

Relaxing

Some people find relaxing or meditating helps them to feel better. The hospital social worker or nurse will know whether the hospital runs any programs, or may be able to advise you on local community programs. Your local community health centre may also be able to help.

★ **The Cancer Council has information on relaxing and coping with anxiety. Visit www.cancervic.org.au or telephone 13 11 20.**

Sexuality and cancer

Cancer treatment and the emotional effects of cancer may affect you and your partner in different ways. Some people find after surgery, or with a **stoma**, that these changes to their body can affect their sexual drive.

Some people may withdraw through feelings of being unable to cope with the effects of treatment. Others may feel an increased need for sexual and intimate contact for reassurance. Every person copes differently.

It is important to talk about your feelings with your partner. If it is difficult continuing with your usual sexual activities, discuss this with your doctor or with a trained counsellor. Your partner may also need support.

If you are without a partner, you may be worried about forming new relationships. Talking about this with a close friend, a family member, a social worker or phoning the Cancer Council Helpline on 13 11 20 may be useful.

★ For Cancer Council information on sexuality and cancer, visit www.cancervic.org.au or telephone 13 11 20.

Cancer Council Helpline

The Cancer Council Helpline is a confidential service where you can talk about your concerns and needs with cancer nurses for the cost of a local call. They can send you information and can put you in touch with support services in your area. Telephone 13 11 20.

‘I think one of the most important things is that although you feel you’re on your own, you don’t have to do it on your own. You need to ask questions and not try to be too stoic. There’s a lot of help available. We have to find out where it is and what sort of help suits us.’

Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a confidential service of the Cancer Council. You can call and speak to a cancer nurse with the help of an interpreter for the cost of a local call. It is for people with cancer, and people who are close to them. People who speak any language can use the service. See the inside back cover for details.

Talk to someone who has been there

Getting in touch with other people who have been through a similar experience can be very helpful. There are many ways to contact others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Support services available for patients, carers and family members include:

- Cancer Connect, a telephone peer support program that matches you with a volunteer who has been through a similar cancer experience, and who understands how you're feeling
- face-to-face support groups, which are often held in community centres or hospitals
- telephone support groups for certain situations or types of cancer, which trained counsellors facilitate
- online discussion forums, where people can connect with each other any time – see www.cancerconnections.com.au

Ask your nurse or social worker to tell you about support groups in your area. Visit www.cancervic.org.au or call the Cancer Council Helpline on 13 11 20 to find out how you can connect with others.

Joining a consumer advocacy group can also be rewarding for people who would like to use their experience to make a difference for others. Visit www.cancervoicesvic.org.au for more information.

Living with Cancer Education Program

The Cancer Council's Living with Cancer Education Program provides information on cancer and ways of coping. The program runs over one day or several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria. Contact your hospital social worker or the Cancer Council Helpline. The program is also conducted in languages other than English in some areas.

‘It’s good to talk to other people if you’re afraid, and try to look at ways to overcome the things you’re frightened about.’

Caring for someone with cancer



A carer is anyone, whether family or friend, who is helping to look after someone with cancer. Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. The person with cancer may have distressing emotions about their cancer diagnosis, side effects from treatment and mood changes from the effects of drugs.

Look after yourself during this time. Give yourself some time out, enjoy a cup of coffee with a friend, and share your worries and concerns with someone not involved. Make a list of 10 things you like to do and make sure that you do one enjoyable thing each day.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take with them another member of the family or a close friend. It also helps to write down questions before you go, and to take notes during the appointment.

Cancer Support Groups are usually open to patients and carers. A support group can offer the chance to share experiences and ways of coping. There is a range of support services such as home help, meals on wheels and visiting nurses that can help you cope with treatment at

home. These are provided by local councils, the Royal District Nursing Service and the palliative care services.

Call the Cancer Council Helpline on 13 11 20 to:

- be linked with another carer by telephone
- speak with a cancer nurse for further support and information
- be sent a carer's kit so that you can find out about financial assistance and other resources.

*** The Cancer Council has a booklet about caring for someone with cancer. Visit www.cancervic.org.au or telephone 13 11 20.**

Questions to ask your doctors

You may find the following list helpful when thinking about the questions you may want to ask your doctors about illness and treatment.

- 1 Has my bowel cancer spread? If so, how far?
- 2 What are my chances of cure?
- 3 Is there any further treatment that can increase my chances of a cure?
- 4 How will it affect me physically, mentally and socially?
- 5 Will it affect my sex life and my fertility?
- 6 Which tests might I have?
- 7 Are there any risks of complications?
- 8 What are the options for treatment?
- 9 What happens if I do nothing?
- 10 Which surgery would I have? What are the risks?
- 11 How long would I be in hospital?
- 12 How long before I could get back to my normal life?
- 13 Do I need a stoma?
- 14 How does radiotherapy work? What are the risks?
- 15 How does chemotherapy work? Are there different sorts of chemotherapy I could have? What are the risks of each one?
- 16 How often do I need check-ups?
- 17 What if the cancer comes back?
- 18 Is there anyone else with bowel cancer I can speak to?
- 19 Does my family need to have any tests done for bowel cancer?

If there are answers you don't understand, feel comfortable to say 'Can you explain that again?' or 'I am not sure what you mean by ...'

Glossary: what does that word mean?

Most of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

abdomen The part of the body between the chest and hips. The stomach, liver, bowel, kidneys and bladder are in the abdomen.

advanced cancer Cancer that has spread and/or is unlikely to be cured. Sometimes referred to as metastatic cancer.

anaesthetic A drug that is taken to stop a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic, which is used in many major surgeries, causes a person to lose consciousness for a period of time.

anus The opening at the end of the digestive system, from which bowel motions are passed.

benign Not cancerous. Benign cells do not spread like cancer cells.

bowel The part of the digestive system that extends from the stomach to the anus including the large and small bowel. Also known as the large and small intestine.

bowel motions Waste that remains after food has been digested and nutrients have been taken into the body. Bowel motions are passed from the body out of the anus. Also called 'faeces'.

cells The 'building blocks' of the body. A human is made of billions of cells, which are adapted for different functions.

colon The main part of the large bowel. It removes water and other substances from undigested food passed from the small bowel, and moves the bowel motions toward the rectum. The colon is divided into four parts: ascending (right), transverse, descending (left), and sigmoid colon.

colonoscopy A test to examine the bowel. A long, slim, flexible tube, with a light attached, is inserted through the anus, so the doctor can look at the bowel. Bowel preparation and anaesthetic are needed.

colostomy An opening into the colon from the outside of the body. A colostomy provides a new path for bowel motions to leave the body.

digestive system The organs that are responsible for getting food into and out of the body and for making use of food to keep the body healthy. The digestive system includes the stomach, liver, gall bladder, pancreas, small bowel, colon and rectum.

enema Where fluid is passed into the bowel via the anus (or stoma) in order to cause a bowel motion.

epidural anaesthetic A drug that is taken to stop a person feeling pain during a medical procedure. The drug is injected into the area located around the spinal cord.

familial adenomatous polyposis (FAP) A hereditary condition that causes hundreds of small growths (polyps) in the bowel of the person affected. If left untreated, one or more of the polyps always turns into bowel cancer.

genes The tiny factors that control the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. These genes are found in every cell of the body.

hereditary non-polyposis colorectal cancer (HNPCC) A condition in some families where the tendency to develop bowel (and some other) cancers is inherited. About 1% of all bowel cancer is due to HNPCC.

ileostomy Similar to a colostomy, but the operation brings part of the small bowel (the ileum) to an opening in the abdomen so bowel motions may leave the body.

ileum The last of the three parts of the small bowel.

infertility Not being able to have children naturally.

intestine Another name for the bowel.

large bowel The lower part of the digestive system, which consists of the colon and rectum. Also called the large intestine.

liver The organ that sits in the top right part of the abdomen behind the ribs. It has many important functions, including removing toxic substances from the body, making bile, storing fat and making various hormones.

lungs Two spongy organs within the chest cavity, made up of very large numbers of tiny air sacs. Through these sacs, oxygen is brought into the body and carbon dioxide is released from the body.

lymph nodes Also called lymph glands. Small, bean-shaped structures that form part of the lymphatic system (the tissues and organs that produce, store and carry white blood cells, which fight infections and other diseases). The lymph nodes filter the lymph to remove bacteria and other harmful agents, such as cancer cells.

malignant Cancerous. A malignant tumour is the same as a cancer. It can spread, and often causes death if it is not treated.

menopause The end of ovulation and menstruation. The ovaries no longer produce oestrogen and the woman is no longer able to have children naturally.

metastasis/metastases The spread of cancer from one part of the body to another. A tumour formed by cells that have spread is called a ‘metastatic tumour’ or a ‘metastasis’. The metastatic tumour contains cells that are like those in the original (primary) tumour.

prognosis The likely outcome or course of a disease; the chance of recovery or recurrence.

radiation Energy in the form of waves or particles, including gamma rays, x-rays and ultraviolet rays. This energy can injure or destroy cells by damaging their genetic material. This ability is ‘used for good’ in radiotherapy (also known as radiation therapy).

rectum The last 12 to 15 cm of the large bowel, which opens to the outside at the anus. Faeces collect in the rectum before they are passed as a bowel motion.

risk factors Things that cause people to have a greater chance of developing an illness.

small bowel The upper part of the bowel. Includes the duodenum, jejunum and ileum. It mainly absorbs nutrients from food that has been broken down. Also called the small intestine.

stoma An ‘exit’ for bowel motions if the bowel can’t be joined properly after surgery. The surgeon makes a small hole in the abdomen, brings one end of the bowel out through the hole and sews it to the skin. This makes a stoma or ‘ostomy’.

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

tissue A collection of similar cells.

tumour A new or abnormal growth of tissue on or in the body.

Index

- abdomen 9, 14, 15, 18, 22, 26, 42, 44, 45
- abdominoperineal resection 18
- advanced cancer 20, 24, 29, 42
- anaemia 9
- anaesthetic 12, 13, 20, 42, 43
- anterior resection 18
- anus 6, 7, 12, 13, 19, 42, 43, 45
- biopsy 13
- bladder 20, 42, 43
- bleeding 22
- Cancer Connect 25, 37
- Cancer Council Helpline 10, 23, 24, 27, 28, 33, 34, 36, 37, 38, 40
- carcinoembryonic antigen (CEA) test 14
- carers 24, 37, 39
- check-ups 9, 24, 25, 41
- chemotherapy 11, 17, 20, 21, 35, 41
- clinical trials 17, 31, 32
- colectomy 17, 18
- colon 6, 7, 17, 18, 19, 26, 43, 44
- colonoscopy 10, 12, 13, 16, 24, 43
- colorectal surgeons 11
- colostomy 18, 26, 27, 43, 44
- complementary and alternative medicines 22
- computerised tomography (CT) scan 13, 15
- constipation 9
- diagnosis 9, 37, 39
- diarrhoea 9, 13, 18, 22, 34
- diet/dietitians 11, 22, 34, 35
- digestive system 6, 7, 42, 43, 44
- doctors 11, 16, 17, 23, 24, 30, 39, 41, 42
- endorectal ultrasound scan 14
- enema 12, 13, 27, 43
- erection problems 22
- exercise 35
- faecal occult blood test (FOBT) 10
- familial adenomatous polyposis (FAP) 6, 7, 43
- family history 7, 9, 10, 16
- fertility 20, 41
- gastroenterologists 11
- general practitioners 11
- hereditary non-polyposis colorectal cancer (HNPCC) 7, 44
- ileostomy 26, 27, 44
- infertility 22, 44
- keyhole surgery 17
- large bowel 6, 7, 12, 13, 43, 44, 45
- liver 6, 7, 13, 14, 16, 42, 43, 44
- liver function test 14
- Living with Cancer Education Program 38
- lungs 6, 13, 16, 44
- lymph nodes 6, 13, 16, 23, 44
- magnetic resonance imaging (MRI) 15

malignant 4, 44
 medical oncologists 11
 menopause 22, 44
 metastases/metastasis 5, 45
 morphine 20
 Multilingual Cancer Information
 Line 37
 nausea 21
 nurses 11, 23, 27, 28, 34, 35, 36, 37,
 39, 40
 occupational therapists 11
 ostomy support groups 28
 pain 12, 20, 24, 25, 42, 43
 paleness 9
 palliative care 24, 34, 40
 patient-controlled analgesia (PCA)
 20
 physiotherapists 11
 positron emission tomography (PET)
 scan 15
 prognosis 16, 23, 45
 psychologists 11
 radiation oncologist 11, 22
 radiotherapy 11, 14, 17, 20, 21, 22, 35,
 41, 45
 recovery 24, 45
 rectal examination 12
 rectum 6, 7, 12, 14, 18, 19, 43, 44, 45
 relaxing 35
 second opinion 31
 sexuality 36
 side effects 21, 22, 29, 31, 39
 sigmoidoscopy 12
 skin 14, 22, 26, 45
 small bowel 6, 7, 13, 19, 42, 43, 44, 45
 social workers 11
 staging 14, 15, 16, 19
 stoma 18, 19, 26, 27, 34, 36, 41, 43, 45
 stomal therapy nurses 11, 27, 28, 45
 support groups 28, 37, 39
 surgeons 11, 27
 surgery 13, 14, 17, 18, 19, 20, 21, 24, 27,
 34, 36, 41, 45
 symptoms 9, 10, 20, 24, 29
 tests 10, 11, 12, 14, 15, 16, 31, 32, 41
 tiredness 9, 21, 22
 TNM system 16
 tumour 4, 5, 13, 14, 16, 21, 32, 44, 45
 ulcerative colitis 7
 ultrasound scan 14
 urination 22
 uterus 20
 vomiting 21
 weakness 9
 x-ray 12, 13, 15, 45



Cancer information in other languages

خط معلومات السرطان باللغة العربية

إتصلوا بالخط
للتحدث الى ممرضة عن مرض السرطان
باللغة العربية على لرقم **9209 0160**

Polskojęzyczna Infolinia na Temat Raka

Aby móc porozmawiać z pielęgniarką na temat raka w języku polskim należy dzwonić pod numer **9209 0165**

廣東話癌症信息專線

用廣東話與護士談論癌症
請致電 **9209 0161**

Информационная линия по раковым заболеваниям на русском языкеЕсли вы хотите поговорить по-русски с медсестрой о раковых заболеваниях, то позвоните по номеру **9209 0166**

Ελληνική Γραμμή Πληροφοριών για τον Καρκίνο

Για να μιλήσετε σε μια νοσοκόμα σχετικά με τον καρκίνο στα Ελληνικά, τηλεφωνήστε στο **9209 0162**

Línea telefónica de Información sobre el Cáncer en el Idioma Español

Para hablar con un(una) enfermero(a) en español llame al **9209 0167**

Linea Informazioni sul cancro in italiano

Per parlare del cancro con un infermiere in italiano chiama il **9209 0163**

Đường dây Chỉ dẫn về bệnh Ung thư bằng tiếng Việt

Nói chuyện với y tá về bệnh ung thư bằng tiếng Việt, gọi số **9209 0168**

普通话癌症信息专线

若要用普通话与护士讨论癌症
请电 **9209 0164**

For other languages please call 9209 0169. Tell us which language you speak and an interpreter will help you talk to a nurse. To speak to a nurse in English, call 13 11 20.

INTERNET: For information in a range of languages please visit our multilingual website at: www.cancervic.org.au/other_languages



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