



Leading
the fight...

Bowel (Colorectal) Cancer

For people with cancer,
their family and friends



**Cancer
Council
Helpline**
1311 20
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Bowel (colorectal) cancer

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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 information 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 at the back of this booklet.

 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.

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What is cancer?

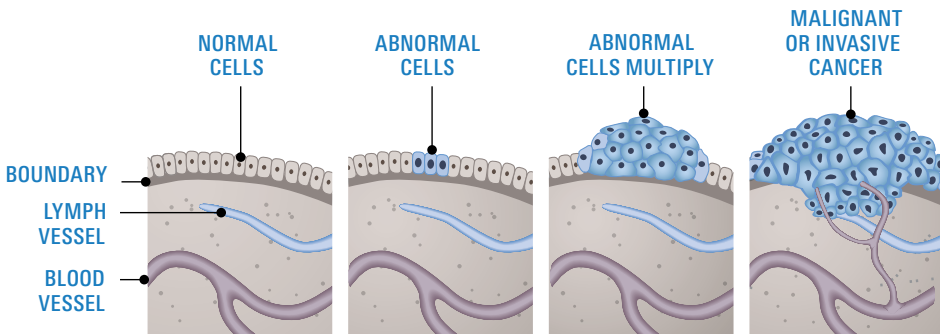
Cancer is a disease of the body's cells. Our bodies are always making new **cells**: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain **genes**. All cancers are caused by changes to these genes. Changes usually happen during our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

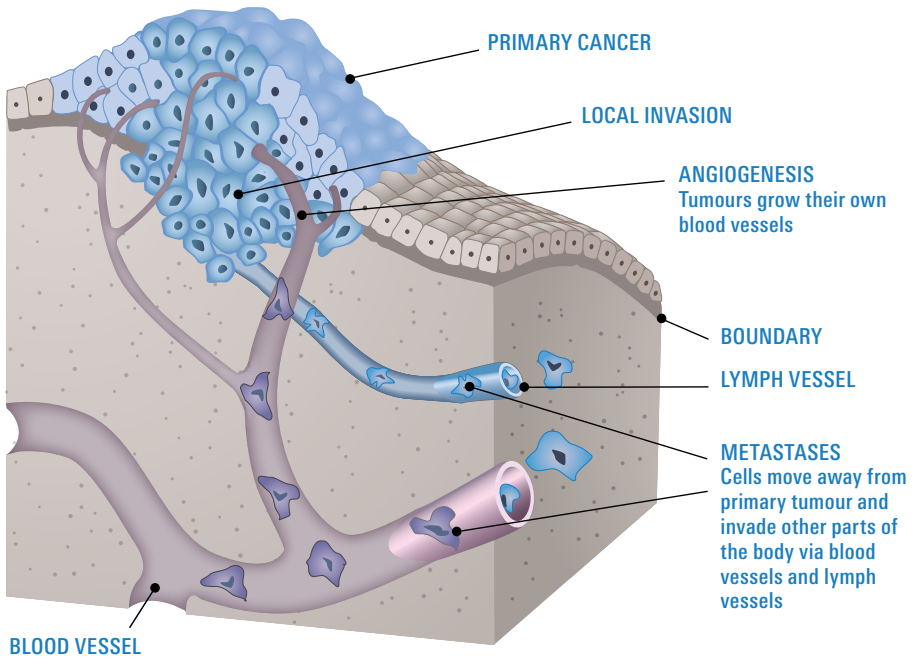
Benign lumps do not spread to other parts of the body.

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 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 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 **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 one and a half metres long, and the **rectum**, which is about 15 centimetres long. The rectum leads to the outside of the body through the **anus**.

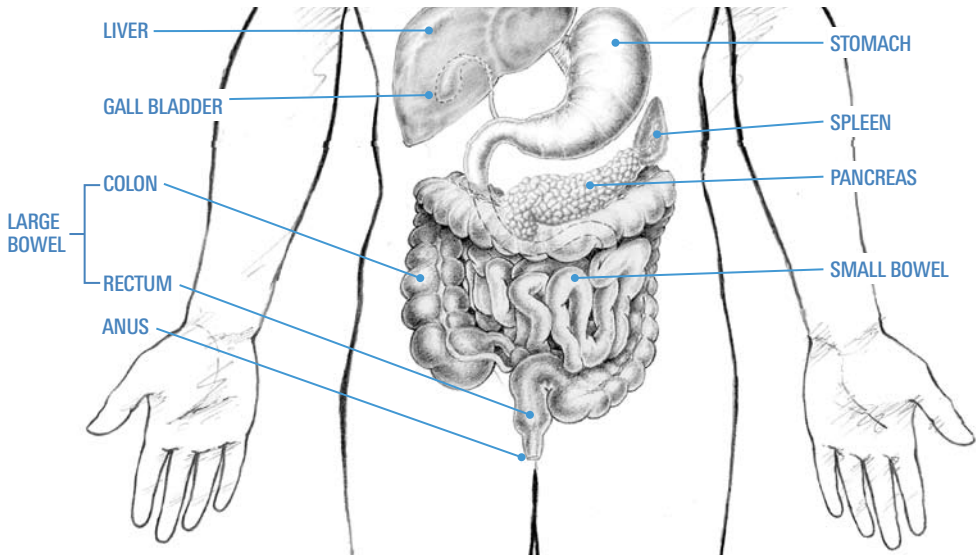
Bowel cancer

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 the **liver** or **lungs**.

Sometimes bowel cancer starts in polyps, which 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 ten years.

How common is bowel cancer?

Bowel cancer is the most common cancer that affects men and women in Victoria. More than 3400 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.

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.

A faecal occult blood test (FOBT) is available to test for early signs of bowel cancer. People aged 50 with no symptoms or family history should do a FOBT every two years. See your doctor to arrange this.

 The Cancer Council has an information sheet on faecal occult blood tests. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

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. This may not be possible in some non-metropolitan areas.

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 while you are in treatment and recovery
- 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 six to eight centimetres 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. 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. This will give you watery diarrhoea, which will empty your bowel. This is called bowel preparation.

Barium enema and x-ray

Before the x-ray, you will have a bowel preparation (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 (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 its beginning at 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 into 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 your organs appear white on 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 (transducer) 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 transducer 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**.

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 which 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 (for example) if you have had injuries to the eyes or elsewhere that were caused by metal.

Positron emission tomography (PET) scan

This is used to build up more information after an MRI or CT scan. 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 then 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 ring-shaped scanner. The tube may make some people feel claustrophobic. If you think you are likely to be affected in this way, please 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. 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.

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**).

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.

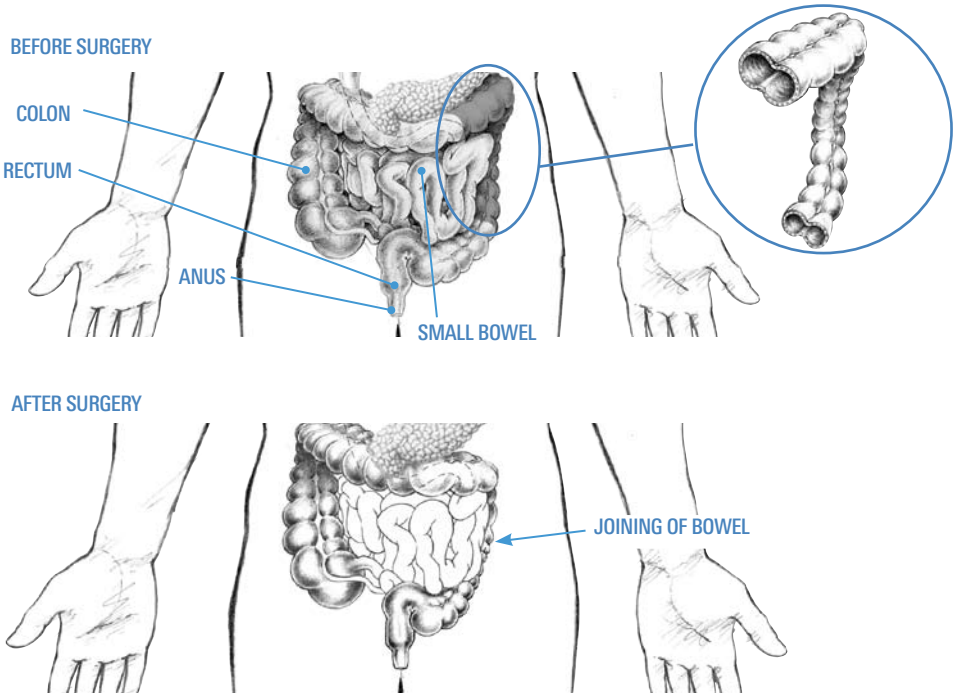
Surgery

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 facing page) is an operation for cancer in the **colon**. It removes the part of the colon where the cancer is and

Surgery for bowel cancer: colectomy

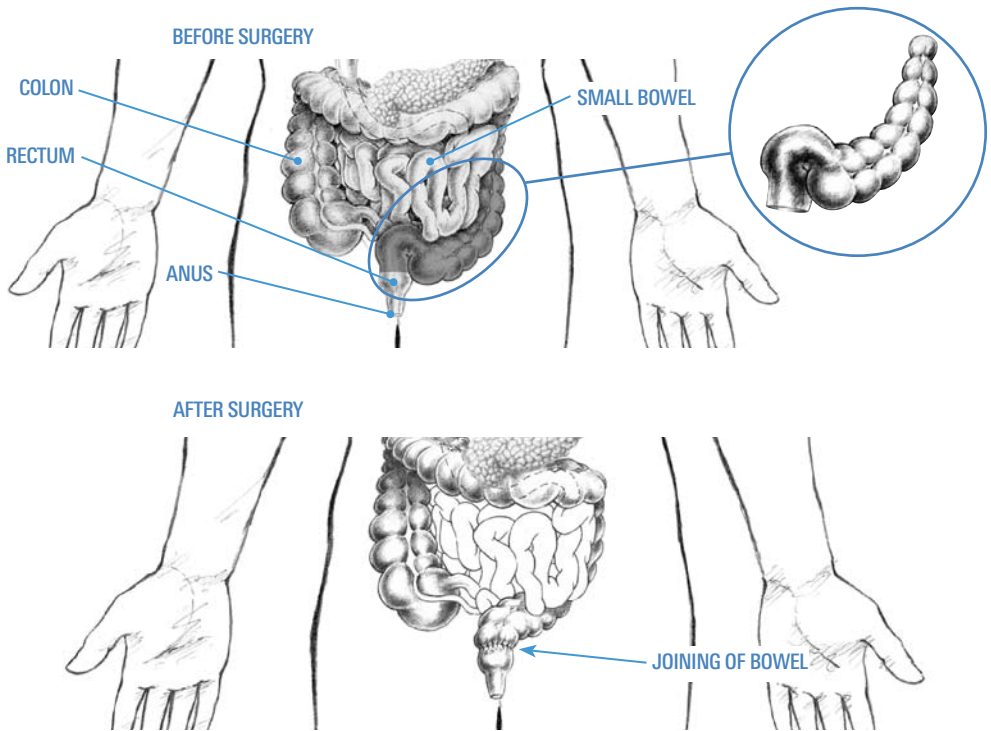


then joins the two ends of the colon together. After the operation, you will have a scar on your lower **abdomen**, a catheter (tube) to collect urine until your wound begins to heal, and a shorter colon.

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** for a time (see 'Having a stoma').

There are two types of surgery for cancer in the **rectum**. In an anterior resection (see picture on page 18), 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

Surgery for bowel cancer: anterior resection



bowel heals. In the other type of surgery, an abdominoperineal (AP) resection, you will have two wounds: one on 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').

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.

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 drugs used in chemotherapy can cause side effects. They may include feeling sick (nausea), vomiting, feeling unwell and tired, 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. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

Radiotherapy

Radiotherapy treats cancer by using radiation to destroy cancer cells. 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**.

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 may be used in addition to radiotherapy.

Side effects of radiotherapy

Side effects of radiotherapy may include tiredness, skin redness and tanning, nausea, 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 experience symptoms of **menopause**). 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. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

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 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.


The Cancer Council website www.cancervic.org.au has more information, as does the US National Center for Complementary and Alternative Medicines <http://nccam.nih.gov/>.

When cancer can't be cured

If your cancer has spread and it is not possible to cure it by surgery, 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 further information, contact the Cancer Council Helpline on 13 11 20 or Palliative Care Victoria on 9662 9644.

 The Cancer Council has a booklet on advanced cancer for people with cancer and a booklet for carers of people with advanced cancer. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

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 information about your own **prognosis**, you need to speak to your doctor, who is familiar with your full medical history.

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.

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.

Having a stoma

Some people who have surgery for bowel cancer need to have a stoma.

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**.

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 runnier.

Stomal therapy nurses

Usually 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 and regain confidence. 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.

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 other support groups are available for people over the age of 35. Contact the Cancer Council Helpline on 13 11 20 for the association 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 treatment 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. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been advised.

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. 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 37 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 chaplain, 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 looking for information about 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. 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

Your doctor may suggest that you think about taking part in a clinical trial.

Clinical trials are a vital part of the search to find better treatments for cancer. Doctors conduct clinical trials to test new or modified treatments and see if they are better than existing treatments. Many people all over the world have taken part in clinical trials that have resulted in improvements to cancer treatment. However, the decision to take part in a clinical trial is always yours.

Clinical trials improve knowledge about cancer treatments and help people being treated for cancer in the future. They do not necessarily help people who join a trial.

If you are thinking about 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:

- Which treatments are being tested and why?
- Which tests are involved?
- 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?
- How much time will I need to spend having tests and filling out forms?

Ask the doctor or researcher to explain anything you don't understand. Ask them to explain in words that you understand.

If you decide to join a randomised clinical trial, you will be given 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 Cancer Council has information on clinical trials. Telephone 13 11 20 for a copy or visit www.cancervic.org.au

Research into bowel cancer

Research into all aspects of bowel cancer is occurring in Australia and around the world. The information from these research studies is made available to doctors through medical journals and meetings of medical societies. New treatments become available when it is clear they are more effective than existing treatments. Ask your doctor about any new research results that might be relevant to your illness.

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 8 pm.

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 **colostomy** if you have one. Foods such as fruit and vegetables may give you loose stools and make your colostomy 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 and each person needs 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.

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. Telephone 13 11 20 or visit www.cancervic.org.au

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.

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. Telephone 13 11 20 or visit www.cancervic.org.au

Sexuality and cancer

Cancer treatment and the emotional effects of cancer may affect you and your partner in different ways.

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.

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 like to seek 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.

 The Cancer Council has information on sexuality and cancer.
Telephone 13 11 20 or visit www.cancervic.org.au

Cancer Council Helpline

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

Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a free and confidential service of the Cancer Council. You can call and speak to a cancer nurse with the help of an interpreter. 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.

Cancer Support Groups

Cancer support groups offer support and information to people with cancer, their family and friends. It can help to talk with others who have gone through the same thing. Support groups can also offer many tips and ways of coping. Your hospital may run cancer support groups: check with your doctor, nurse or social worker, or contact the Cancer Council Helpline.

Cancer Connect

Cancer Connect is a program run by the Cancer Council. It connects people who have bowel cancer or other cancers with volunteers who have had the same type of cancer. All volunteers are trained and supported by a program coordinator and the nurse counsellors from our Cancer Council Helpline. If you would like to talk with a Cancer Connect volunteer, call 13 11 20.

Living with Cancer Education Program

The Cancer Council's Living with Cancer Education Program provides information on cancer and ways of coping with it. 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.

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 some one 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.

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 How will it affect me physically, mentally and socially?
- 4 Will it affect my sex life and my fertility?
- 5 Which tests might I have?
- 6 Are there any risks of complications?
- 7 What are the options for treatment?
- 8 What happens if I do nothing?
- 9 Which surgery would I have? What are the risks?
- 10 How long would I be in hospital?
- 11 How long before I could get back to my normal life?
- 12 Do I need a stoma?
- 13 How does radiotherapy work? What are the risks?
- 14 How does chemotherapy work? What are the risks?
- 15 Is it painful and are there any side effects?
- 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 Is my family a bowel cancer family?

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 lower part of the body between the chest and hips, which contains major organs involved with digestion, bowel motions, and reproduction, including the stomach, liver, bowel, kidneys and bladder.

advanced cancer Cancer that has spread and/or is unlikely to be cured.


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 millions 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.

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.

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.

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 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.

lymphatic system The tissues and organs that produce, store, and carry white blood cells, which fight infections and other diseases. This system includes the bone marrow, spleen, thymus, lymph nodes and lymphatic vessels (a network of thin tubes that carry lymph and white blood cells). Lymphatic vessels branch, like blood vessels, into all the tissues of the body.

lymph nodes Also called lymph glands. Small, bean-shaped structures that form part of the lymphatic system. 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 eventually 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 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. The plural form of metastasis is metastases.

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 centimetres 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. 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 your 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.

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Cancer information in other languages

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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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