

# Understanding Bowel Cancer

A guide for people with cancer, their families and friends.



## Understanding Bowel Cancer

A guide for people with cancer, their families and friends.

First published January 2002

This edition July 2004

© The Cancer Council New South Wales 2004

ISBN 1 86507 053

### Acknowledgements

The Cancer Council New South Wales acknowledges the National Health and Medical Research Council for kindly permitting its publication, *Guidelines for the prevention, early detection and management of colorectal cancer: A guide for patients, their families and friends*, to be used as the main source of this booklet.

We also thank Professor Terry Bolin, Chairman of the Gastrointestinal and Liver Unit of Prince of Wales Hospital, Sydney; Associate Professor John Cartmill, Colorectal Surgeon, Nepean Hospital; Sue Westcott, of the Bowel Cancer Support Network; and Libby Weir, Coordinator, The Cancer Council's Hereditary Cancer Register, for their valuable help with this booklet.

Editor: Marge Overs

Cartoons: Greg Smith

### The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in New South Wales. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

This booklet is funded through the generosity of the people of New South Wales. To make a donation to help defeat cancer, visit The Cancer Council's website at [www.cancerCouncil.com.au](http://www.cancerCouncil.com.au) or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

The Cancer Council New South Wales  
153 Dowling Street  
Woolloomooloo NSW 2011

Cancer Helpline: 13 11 20  
Telephone: (02) 9334 1900  
Facsimile: (02) 9334 1741  
Email: [feedback@nswcc.org.au](mailto:feedback@nswcc.org.au)  
Website: [www.cancerCouncil.com.au](http://www.cancerCouncil.com.au)





# Introduction

This booklet has been prepared to help you understand more about bowel cancer.

Many people feel understandably shocked and upset when they are told they have bowel cancer. This booklet is intended to help you understand the diagnosis and treatment of bowel cancer. We also include information about support services.

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

You may like to pass this booklet on to your family and friends for their information.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you.

Some medical terms that may be unfamiliar are explained in the glossary.



# Contents

<b>What is cancer?</b> .....	4
<b>What is the bowel?</b> .....	6
How common is bowel cancer? .....	7
<b>How bowel cancer starts</b> .....	8
Finding bowel cancer early .....	8
Stages of bowel cancer .....	9
Prognosis .....	9
<b>Gathering information</b> .....	10
Which health professionals will I see? .....	11
A second opinion .....	12
Making a plan .....	12
<b>Diagnosis</b> .....	13
<b>Treating bowel cancer</b> .....	17
Know your options .....	17
Surgery .....	18
Types of surgery .....	20
Surgery for colon cancer .....	20
Surgery for rectal cancer .....	22
Surgery for two cancers .....	23
Having a stoma .....	24
Stomal therapy nurses .....	26
Chemotherapy .....	27
Radiotherapy .....	28
Alternative therapies .....	28
Clinical trials .....	29

<b>Secondary liver cancer</b> .....	30
Treatment options .....	30
<b>After treatment is over</b> .....	32
Can I stop the cancer coming back? .....	33
Checkups .....	33
If the cancer comes back .....	34
Treating symptoms of incurable cancer .....	34
<b>Seeking support</b> .....	35
Practical and financial help .....	36
Healthy eating .....	36
Exercise and relaxation techniques .....	37
Cancer support groups .....	37
The Cancer Helpline .....	38
Sexuality and cancer .....	39
Living with Cancer Education Program .....	39
Caring for someone with cancer .....	40
Information on the Internet .....	40
<b>Information checklist</b> .....	41
<b>Glossary</b> .....	42
<b>Cancer Council stores, NSW</b> .....	48
<b>Regional offices</b> .....	49



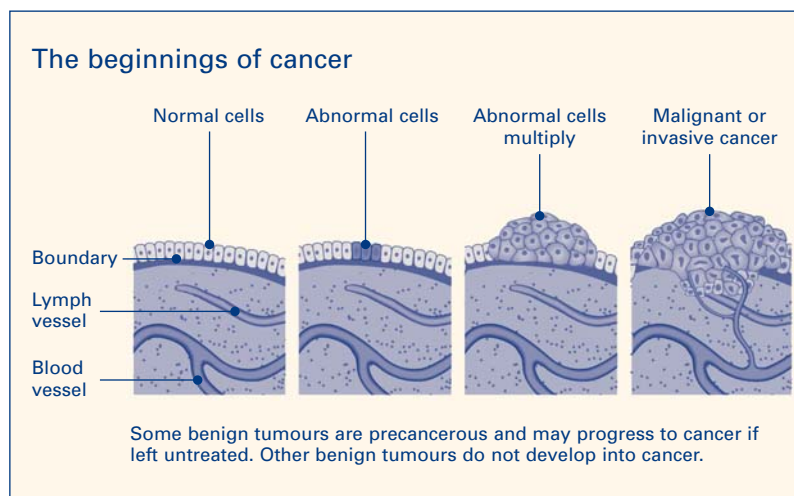
# What is cancer?

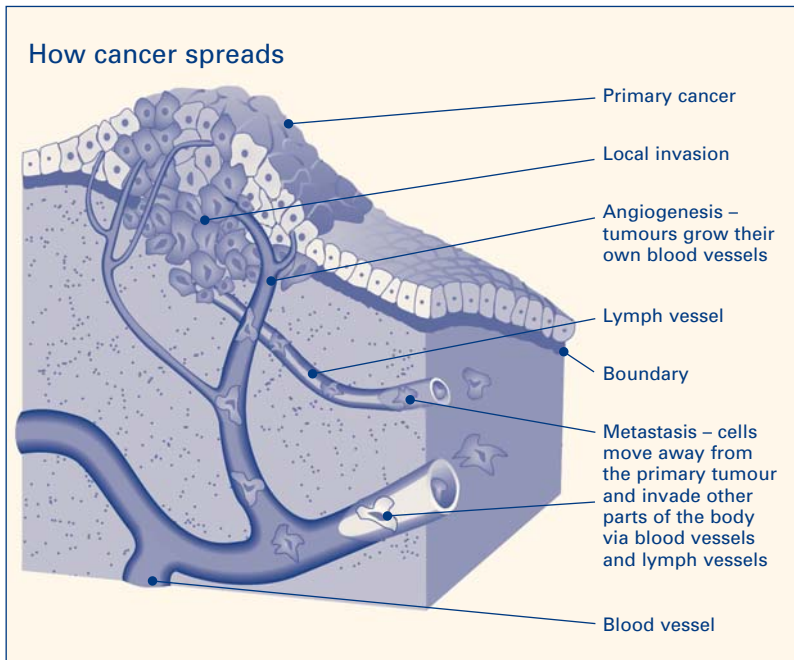
Cancer is a disease of the body's cells, which are the body's basic building blocks. Our bodies constantly make new cells: to enable us to grow, to replace worn-out cells, or to heal damaged cells after an injury.

Normally, cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in a lump called a tumour.

Tumours can be benign (not cancer) or malignant (cancer). A benign tumour does not spread outside its normal boundary to other parts of the body.

A malignant tumour is made up of cancer cells. When it first develops, this malignant tumour may be confined to its original site. This is known as a cancer in-situ (or carcinoma in-situ). If these cells are not treated, they may spread beyond their normal boundaries into nearby tissues, becoming invasive cancer.





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

Sometimes cells move away from the original (primary) cancer, either by the local tissue fluid channels (lymphatics) or in the bloodstream, and invade other organs. When these cells reach a new site, they may continue to grow and form another tumour at that site. This is called a secondary cancer or metastasis.

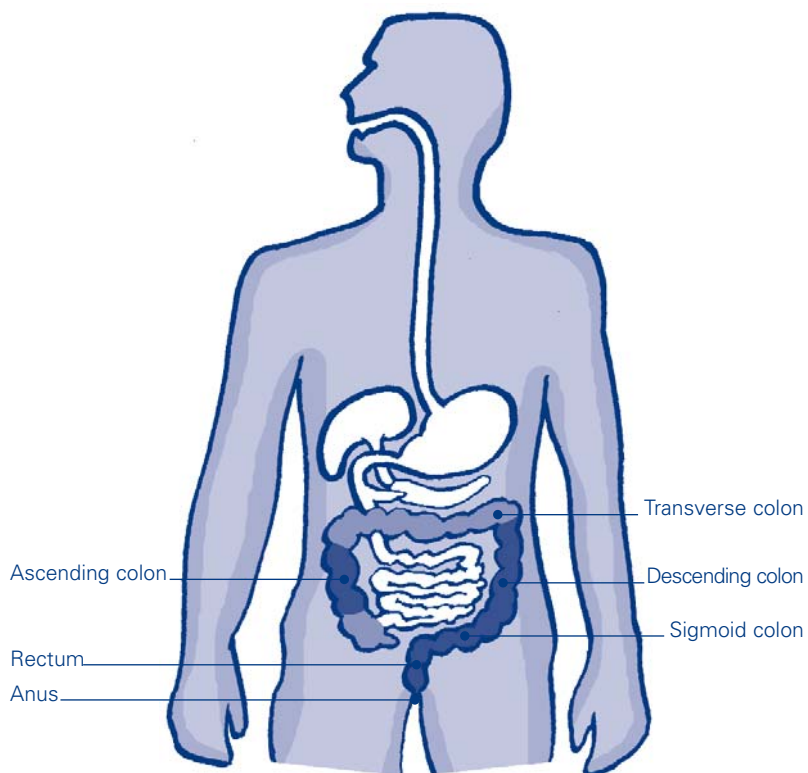


# What is the bowel?

The bowel is part of the digestive tract. Its function is to finish digesting food by absorbing water and nutrients, and to get rid of remaining waste.

The bowel has three main parts:

- Small bowel – mainly absorbs nutrients from broken-down food.
- Colon – mainly absorbs water.
- Rectum – stores waste materials (faeces) until they are passed from the body through the back passage (anus).





The colon and rectum together are known as the large bowel. When we talk about bowel cancer, we generally mean cancer of the colon or rectum because cancer of the small bowel is rare. Bowel cancer is also known as colorectal cancer.

## How common is bowel cancer?

Bowel cancer is a major problem in Australia. Apart from skin cancer, it is the most common cancer affecting both men and women. About one in 18 men and one in 26 women will develop bowel cancer before the age of 75.

The older you are, the greater your chance of developing bowel cancer – it affects mainly people over 50 but can occur at any age.

Some people who develop bowel cancer inherit damaged genes from their parents but, for most people, age and diet contribute to developing bowel cancer.



# How bowel cancer starts

Bowel cancer seems to start in two ways. It can grow from the inner bowel lining or from a small raised area that looks like a mushroom and is called a polyp. These polyps are usually harmless (benign) but some can become cancerous (malignant) and spread.

If you have already had bowel cancer, polyps increase your risk of developing a second cancer. After being treated for bowel cancer, your doctor will give you regular checkups to look for new signs of cancer or polyps.

These checkups can also be arranged for members of your family if your doctor thinks they have a higher-than-average risk of developing bowel cancer.

## Finding bowel cancer early

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, first to the lymph nodes, then to other organs. This gives doctors a chance to remove and cure the cancer using surgery.

Lymph nodes are more commonly known as glands. We have them in many parts of our body and can feel them in our neck, groin and under arms. We also have them around our bowel.

Bowel cancer is highly treatable when detected early, even if it has spread to nearby lymph nodes. When it has spread to other organs, such as the liver, many treatments can help, but a cure is more difficult (see *Secondary liver cancer*, page 30). That is why it is so important to detect bowel cancer early, before it has spread to other organs.

## Stages of bowel cancer

Your chance of cure depends on the stage at which your cancer is diagnosed. One way to describe the stages of bowel cancer is listed below:

- Stage A: the cancer is confined to the bowel wall.
- Stage B: the cancer has spread to the outer surface of the bowel wall and not beyond.
- Stage C: the cancer has spread to lymph nodes outside the bowel wall and not beyond.
- Stage D: the cancer has spread to liver and bones.

## Prognosis

The sooner bowel cancer is diagnosed, the better the likely outcome (prognosis). Survival statistics have shown that 88% of people with stage A bowel cancer and 70% of people with stage B bowel cancer will be alive five years after their diagnosis.

Overall, about 56% of people who have had their bowel cancer successfully removed are alive five years after their diagnosis.

But these survival statistics represent the average number of people alive five years after their diagnosis and do not represent a single person's chance of survival. Many factors influence prognosis and it is best to talk to your doctor about your own situation.

Although it is not a hard and fast rule, bowel cancer is unlikely to come back in people who are well and have no signs of it after five years.

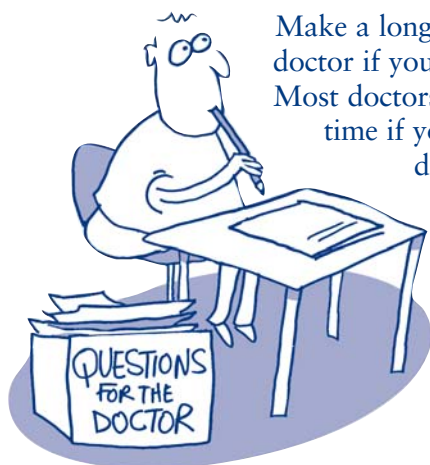


# Gathering information

Hearing the word cancer may come as a shock. Some people find it hard to think of anything else for some time. You need time to collect information, to think about it, and to get support from family and friends. This can help you understand the disease and choose the best treatment for you.

Your doctor must tell you everything you want to know, but it can be hard to remember everything you're told, especially if you've just found out you have cancer. These tips may help:

- Ask for more information at each visit to your doctor.
- Ask a relative or friend to go with you.
- Read pamphlets and booklets.
- Tape-record your visits so you can go through what the doctor said later.
- Write down questions as they come to mind, so you can ask your doctor at your next visit, or in stages at each visit.



Make a longer appointment with your doctor if you have a number of questions. Most doctors are happy to spend more time if you ask for it. If you find your doctor is not helpful, try to find a doctor who is.

## Which health professionals will I see?

A number of doctors and health care workers will care for you, including:

- Your GP – has an important role in your ongoing care.
- A surgeon – either a colorectal surgeon or general surgeon who specialises in bowel care.
- Radiation oncologist – is responsible for radiotherapy.
- Medical oncologist – is responsible for chemotherapy.
- Gastroenterologist – specialises in colonoscopy.
- Dietitian – recommends the best diets to follow while you are in treatment and recovery.
- Nurses – assist you through all stages of your hospitalisation and cancer experience.
- Social workers, physiotherapists and occupational therapists – advise you on support services and help you get back to your normal activities.

These health care workers, with their collection of different skills, are a team. You and your family are part of that team. Communication keeps the team working well.

## A second opinion

You may want to ask for a second opinion from another specialist. This is understandable and can be a valuable part of your decision-making process.

Your specialist or GP can refer you to another specialist and you can ask for results to be sent to the second-opinion doctor.

You can ask for a second opinion even if you have started treatment or still want to be treated by your first doctor.

## Making a plan

Once you have all the information you need – and a second opinion if you wish – you and your doctor will make a treatment plan. This can spell out issues like order of treatment, tests and maintaining communication with your doctor.

But it won't be possible to plan everything until you have had an operation.

When I learnt I had bowel cancer, I felt very alone because not even my husband knew how frightening it was. Thanks to the very caring medical staff and other patients I spoke to, I learnt that I wasn't the only one going through such a difficult time.



# Diagnosis

This chapter lists the tests and procedures you might have. You may have already had some, while others may still be to come.

The three types of tests are:

- General tests: include simple procedures such as blood tests to check your body functions.
- Tests to look at the cancer: include a rectal examination, sigmoidoscopy, barium enema, colonoscopy, computerised tomography (CT) scan, magnetic resonance imaging (MRI), and an endorectal ultrasound. These tests help doctors to look at the position of the cancer in the bowel and are explained in this chapter.
- Tests to look for cancer that may have spread: the process to find out if your cancer has spread and how far is called staging. Most staging is done after surgery and involves the removed cancer and bowel. Other tests involve the liver and lungs, where bowel cancers tend to spread first.

## Sigmoidoscopy

This test involves your doctor putting a rigid or flexible tube into your anus to examine your rectum and lower colon for cancer. The test only takes 10 minutes and may be uncomfortable but should not cause severe pain.

A gastroenterologist or surgeon usually performs a rigid sigmoidoscopy after a rectal examination. Flexible sigmoidoscopy might be done in a specialist's rooms or in a hospital day surgery unit.

This test may involve a bowel preparation called an enema, which cleans out your bowel before the test, so any unusual areas can be seen clearly. It involves drinking a large amount of special drink, which gives you a watery diarrhoea that empties out your bowel.

## Rectal examination

Your doctor will examine your rectum by inserting a gloved finger into your anus to feel around the inside of your rectum for any abnormalities. A rectal examination is an essential test used to examine the lowest 6-8cm of the bowel. The test is a little uncomfortable and feels like you are going to open your bowels, but you won't lose control.

## Barium enema

A barium enema is a type of x-ray investigation. Before the examination, you will have a bowel preparation to clean out your bowel. A small tube is inserted through your anus and up into your colon. White liquid, called barium, is inserted, then air is pumped in to make the barium go into the creases in the bowel wall and show up the bowel lining clearly when x-rays are taken. This can be a little uncomfortable. The test takes about 30 minutes.

Like all tests, it is not always accurate. It detects about 90% of bowel cancers, but can easily miss small growths in the bowel known as polyps. It is less accurate than colonoscopy for small cancers. Most patients should have a sigmoidoscopy and a barium enema to fully examine the rectum.

Patients who have a barium enema should be sure to have a rigid sigmoidoscopy to look at the lowest part of the rectum, which is not well shown by a barium enema.

## Colonoscopy

A colonoscopy involves inserting a long, flexible tube, with a tiny lens on the tip, through your anus and rectum then around your colon to its beginning at the small bowel. It is used to look for cancer. Before the test, you will have a bowel preparation to clean your bowel.



You will be given a sedative that will make you feel drowsy and comfortable. You may feel some discomfort during or after the procedure but this should settle quickly. The test takes about 20 to 30 minutes. During the colonoscopy, the doctor can remove polyps and take out tissue (a biopsy) to test for cancer.

Colonoscopy is more accurate than a barium enema, but it can still miss about 5% of cancers and polyps.

Doctors who do a lot of colonoscopies are more likely to see more of the bowel than doctors who don't do them as frequently.

## Chest x-ray

A chest x-ray is a precaution before any surgery to check for lung or heart disease. Chest x-rays are also used to see whether bowel cancer has spread to the lungs.

## Computerised tomography (CT) scan of the abdomen

The CT scan is a special type of x-ray that gives a picture of the organs and other structures in your body. CT scans are useful for providing information about the extent or stage of the cancer and if it has spread.

This painless test usually takes 10 to 40 minutes. You will lie flat on a table that moves in and out of the scanner, which is a large machine shaped like a doughnut. The CT scan picks up 70% to 80% of secondary cancers in the liver or abdomen.

## Virtual colonoscopy

A virtual colonoscopy is a type of CT scan that gives a picture of the colon. It does not allow polyps or cancer to be removed or biopsied. If a virtual colonoscopy shows a problem, more tests may be needed.

## Ultrasound

An ultrasound uses high-frequency sound waves to build up images of structures in the body. In an abdominal ultrasound, a technician will pass a probe over your stomach several times to check the structure of the liver and other organs and to look for any signs that cancer has spread to the liver.

An endorectal ultrasound uses sound waves to form a picture to look at cancer in the rectum. A short probe inserted into the rectum detects the sound waves and allows the surgeon to assess the size and spread of the cancer. The procedure, which takes about 10 minutes, is not painful but can be uncomfortable.

The test can also help the surgeon plan the surgery and to see whether any extra treatment, such as radiotherapy, is needed. An endorectal ultrasound is more accurate than a CT scan or MRI to determine the spread of a cancer in the rectum.

## Liver function test

This blood test measures chemicals that are normally found in your liver or made there. An abnormal result can be a sign that a cancer has spread to the liver.

## Carcinoembryonic antigen (CEA) test

Carcinoembryonic antigen is a molecule produced by your bowel and some cancer cells. The level of CEA in your blood can reflect the number of cancer cells you have in your body but it is not a very reliable marker. A CEA test is most likely to be used after surgery to see if the cancer has come back.

## Magnetic resonance imaging (MRI)

MRI is a diagnostic test that uses a combination of magnetism and radio waves to build up detailed cross-section pictures of your body. The test involves lying on a couch inside a metal cylinder – a large magnet – that is open at both ends.

# Treating bowel cancer



The choice of treatment will depend on whether the cancer has spread or is at risk of spreading. While surgery is the main treatment for bowel cancer, chemotherapy and radiotherapy can also help. Chemotherapy uses drugs, and radiotherapy uses x-rays, to kill or slow the growth of cancer cells.

## Know your options

As a patient, you should be involved in decision-making about your treatment. You should ask your doctor whether the treatment planned for you has any risks. Your doctors should explain everything they know about your cancer and you should be asked whether you agree with the proposed treatment. Take your doctor's advice but know your options.

The first step is to find out as much as you can about the cancer. Where is it? How big is it? Has it spread? If so, where to? The next step is to work out whether a cure is possible. Your doctor can advise you of this.

Armed with your doctor's opinion, you can decide whether you should:

- Have treatment that will try to cure you.
- Have treatment that will help ease problems, without trying to cure you.
- Do nothing for now.

“After the surgery I was back to normal in 3-4 weeks. As long as I didn't overdo things, I slotted back into my normal routine very quickly.”

# Surgery

The aim of an operation for bowel cancer is to remove the cancer and enough of the nearby tissue to make sure that no part of the cancer is left behind. This is major surgery and you will need time to recover from it.

## Will it cure me?

If your cancer has not spread outside the bowel, surgery can remove the cancer and cure you. About 70% to 80% of people with colon cancer with no cancer in the lymph nodes are alive five years later.

If your rectal cancer does not involve the full thickness of the bowel wall and has not spread to the lymph nodes, you have a good chance of surviving (more than 70%).

Unfortunately, surgery is unlikely to cure most people whose cancer has spread to other organs such as the liver, but it might ease some problems the cancer is causing. However, in a small percentage of people where the cancer has spread only to the liver, surgery to remove that part of the liver may cure them.

## Who should do the operation?

Research has shown that surgeons who have a lot of experience in treating bowel cancer may produce fewer complications during surgery, and their patients may have a lower death rate, compared to less experienced surgeons. Likewise, if you are having surgery for rectal cancer, you should see a surgeon with specialist training and experience in cancer of the rectum.

You should ask about the surgeon's expertise in colon and rectal surgery separately because they are different operations.

## Informed consent

Before surgery, you must agree in writing to have the operation. This involves giving informed consent, which involves understanding:

- The reasons for the operation.
- The risks of the operation and the anaesthetic.
- What may happen if you don't have the operation.
- The likely outcome after the operation.
- Anything else you want to know.

## When things go wrong

Your doctor will explain things that could go wrong during your treatment. A leak from the bowel, bleeding and infection and other things can occur. It is good if your relative or support person can be at this meeting. The doctor explains these things because they know they can happen. Sometimes one of your team can make a mistake. Keep this in mind; cross-checking and reminding can help keep you safe. Say something if you think things might be going wrong. You or your family may well be the first to notice.

## Preventing blood clots

People with cancer and people having abdominal surgery are vulnerable to getting blood clots in their legs. So if you are having surgery for bowel cancer, you have a much higher risk of getting blood clots. The clots can travel through the bloodstream, lodging in your lungs or heart where they can be life-threatening.

Surgeons may reduce your risk of getting blood clots by:

- Giving you regular injections of a blood-thinning substance called heparin, or a similar substance.
- Compressing your calves during surgery.
- Encouraging movement soon after surgery.

## Types of surgery

Your doctors and surgeon will decide the best type of surgery to remove your cancer. This will depend on where the cancer is and how far it has spread.

In some cases, surgeons may have to perform additional surgery if they operate and find something different to what they expected. Tests do not always tell surgeons all they need to know about your cancer, and only when they can see inside you can they make these decisions.

## Surgery for colon cancer

A colectomy is the most suitable surgery for cancer in the colon. This type of surgery involves removing the section of the bowel containing the cancer, and rejoining the two ends of the bowel.

You will end up with a scar across your lower abdomen, a temporary catheter (tube) to collect urine until your wound begins to heal, and a shorter colon.

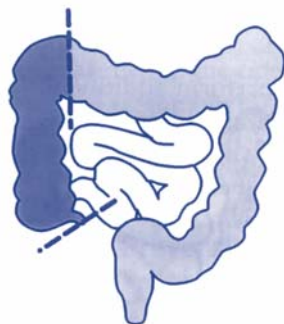
Depending on how much bowel is removed, you may have to open your bowels more often or you may have diarrhoea. You may also need a temporary colostomy (see *Having a stoma*, page 24).

There are four types of colectomies, depending on the position of your cancer. If your cancer is:

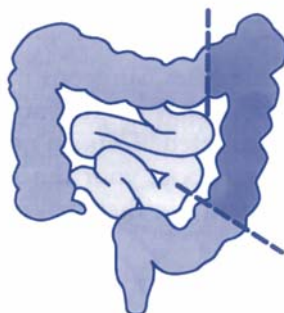
- On the right side of your colon – a right hemicolectomy.
- On the left side of your colon – a left hemicolectomy.
- In the middle of your colon – a transverse colectomy.
- In the sigmoid colon – a sigmoid colectomy.

If your cancer is low in the sigmoid colon or close to the rectum and sigmoid, another type of surgery you might have is a high anterior resection. This type of surgery involves removing a section of bowel and rejoining the bowel together in the upper area of the rectum.

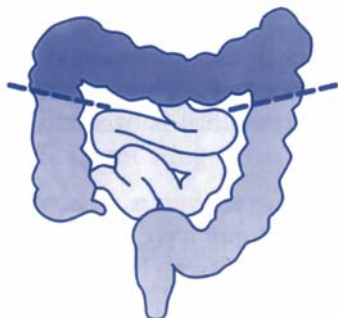
## Types of colectomies for colon cancer



Right hemicolectomy



Left hemicolectomy



Transverse colectomy



Sigmoid colectomy

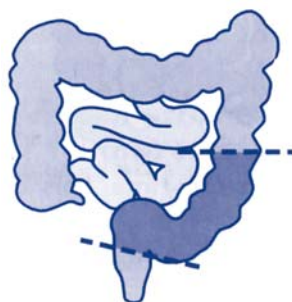
A colectomy may be done anywhere within the shaded areas of the diagrams.

## Surgery for rectal cancer

There are two types of surgery for cancer in the rectum, depending on the position of the cancer.

### Anterior resection

Most patients with rectal cancer are able to have a low or ultra-low anterior resection to remove their cancer. These operations produce only one wound and a permanent stoma is not needed. The muscle that controls the opening and closing of the anus (anal sphincter) is not touched.



Anterior resection



Abdominoperineal (AP) resection

### Abdominoperineal (AP) resection

A less common type of rectal surgery is an abdominoperineal (AP) resection. In this operation, you will have two wounds – one on your abdomen and one where your anus has been removed. You will need to have a permanent stoma because both your rectum and anus have been removed (see *Having a stoma*, page 24).

There is no difference in survival between people having the different types of surgery. Low anterior resection is not always possible, particularly if the cancer is near the anal sphincter.



## Attachment to another organ

In about 10% of people who have bowel cancer, the cancer seems to be attached to another organ, such as the uterus or bladder.

In half of this group, this is because the cancer has invaded that organ and joined it to the bowel, but in other people the apparent attachment is only due to inflammation.

Research shows that the best thing for surgeons to do is to remove the attached organ with the bowel. A woman who has her uterus removed is no longer fertile, so women who want to have children should talk to their doctor or a fertility counsellor.

## Surgery for two cancers

About 5% of people with bowel cancer have two separate cancers in their bowel at the same time. This can be discovered before or during surgery. In general, it is important to have a colonoscopy before surgery to check for a second cancer.

If you have two cancers, there are three options for surgery:

1. Remove the two smaller sections and rejoin all the bowel.
2. Remove one larger section containing both cancers.
3. Remove the whole colon to prevent any chance of another cancer forming.

There is no research yet to show which choice is best. People who have had two cancers at the same time need to have regular colonoscopies for the rest of their lives because their chances of developing another cancer are higher than average.

## Secondary ovarian cancer

About 5% of women with bowel cancer have secondary cancers in the ovaries, usually found during the operation. If cancer is found in one ovary, it is recommended that both be removed.

Some doctors have suggested taking out both ovaries as a precaution to protect against developing ovarian cancer later on, even if there are no signs of cancer. There is no evidence to support this idea and it is not recommended.

In postmenopausal women, the ovaries can be removed with few side effects. However, in premenopausal women, the issue of removing the ovaries is more complicated and should be discussed with a doctor or a fertility counsellor.

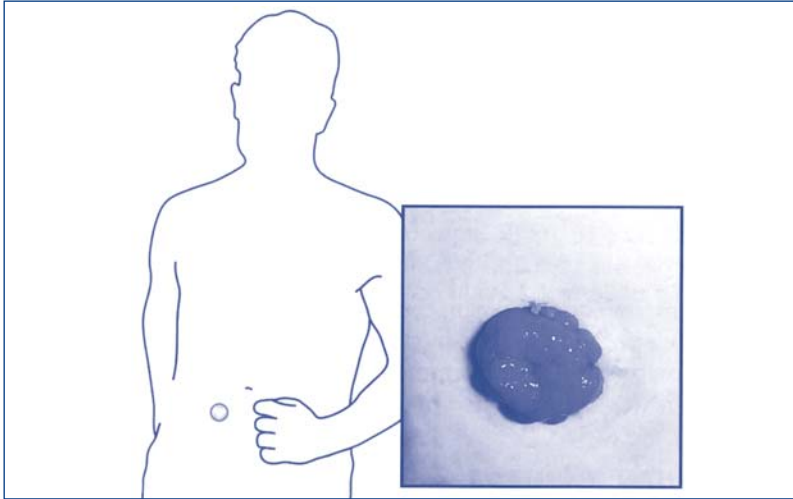
## Having a stoma

Sometimes after bowel cancer has been removed, it is not possible to reconnect the bowel as it was before. The body still needs to remove waste material, so the surgeon may make a small hole in the abdominal wall and bring one end of the bowel out through that hole and sew it to the skin. This creates an ostomy or stoma (from the Greek word meaning ‘mouth’).

If it is an opening from the colon (large bowel), it is called a colostomy. If it is an opening from the ileum (small bowel), it is called an ileostomy.

A stoma is roughly the size of a 20¢ coin and is usually located on the front of the abdomen, half way between the navel and the hip bone. It is soft, moist and red in colour and is made of the same type of tissue as the inside of the mouth.

A permanent stoma is needed in less than 10% of cases. Usually it is a temporary measure for about three months.



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 so it forms a spout. When the bowel acts, wind and waste material come out through the stoma so 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 has an adhesive on it that sticks firmly to the skin around the stoma and provides a leak-proof, odour-proof system. When a bag has been used, it is discarded and a new one is fitted.

Some people don't like to wear bags and may be taught how to manage by giving themselves 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 waste escaping at inconvenient times. These methods are not suitable for an ileostomy because its output is more fluid.

## Stomal therapy nurses

If there is a chance you could need a stoma, the surgeon will probably ask a stomal therapy nurse to see you before the operation, to discuss the best place for it to be located.

Stomal therapy nurses have specialist training and will answer your questions about the surgery and management of the stoma. They will help you adjust to having a stoma and regain confidence. They can give you ongoing care and support after discharge from hospital.

Stomal therapy nurses work in many city public and private hospitals, in country base and large private 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 surgeon, GP and the Cancer Helpline (13 11 20) can all help you find a stomal therapy nurse.

## Coping with a stoma

Having a stoma, even temporarily, is a big change in a person's life and takes some adjustment. Your stomal therapy nurse will discuss all aspects of living with a stoma and provide you with written material, booklets and videos. You will also be able 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 include them in these discussions.

About 20,000 people have a stoma in Australia and most enjoy a normal family, social and work life.

You will be advised to join an Ostomy Association so you can obtain free bags and related products. Each State has a separate support group for young people up to the age of 35. Call the Cancer Helpline on 13 11 20 for contact numbers.

# Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer drugs. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to your normal cells.

Chemotherapy can be given either 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.

Some drugs used in chemotherapy can cause side effects, including diarrhoea, vomiting, feeling off colour and tired, and some thinning or loss of hair. Some people have mouth problems such as ulcers, and some people find their skin becomes red and itchy. These side effects are temporary and can be prevented or reduced.

## Chemotherapy for colon cancer

Chemotherapy is often effective for people whose cancer has spread into the lymph nodes but no further (stage C cancer). If your cancer has spread into the liver and bones (stage D cancer), chemotherapy can help reduce some symptoms and prolong life but will not cure your cancer.

People whose cancer has not spread from the inside of the bowel (stage A colon cancer) are not commonly advised to have chemotherapy.

There is a chance that a few people whose cancer involves the whole of the bowel wall (stage B cancer) may benefit from chemotherapy. Chemotherapy usually starts four to six weeks after surgery. This gives you a chance to recover from the surgery and for your wounds to heal.

## Radiotherapy

Radiotherapy treats cancer by using x-rays to kill or injure cancer cells. Treatment is carefully planned to do as little harm as possible to your normal body tissues.

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.

Radiotherapy can cause temporary side effects, including diarrhoea, nausea, tiredness and mild headaches. The treatment area may become red and sore. You will need to take care washing and avoid shaving the area or wearing clothing that can rub. Ask a member of your radiotherapy treatment team before using any skin preparations.

For more information on radiotherapy and chemotherapy, call the Cancer Helpline on 13 11 20 for free booklets.

Radiotherapy to the pelvis may cause infertility in some men and menopause in some women. Also, it can occasionally cause permanent bowel problems, such as bleeding, narrowing of the small bowel or rectum, inability to absorb food and nutrients properly, and bowel or urinary incontinence.

## Alternative therapies

There are many alternative therapies available. If you are considering an alternative therapy, always discuss it with your doctor first as these therapies can affect the treatment your doctor orders.

The Cancer Council has an information sheet on making an informed decision about alternative therapies. Call 13 11 20 for a free copy.

## Clinical trials

Your doctor may suggest you consider taking part in a clinical trial. Clinical trials are a vital part of the search to find better treatments for cancer. They test new or modified treatments and see if they are better than existing treatments.

Clinical trials are conducted under strict ethical supervision. Your doctor will only suggest you consider taking part if all the possible treatments in the trial are suitable for you.

The decision to take part in a clinical trial is always yours. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What treatments are being tested and why?
- What extra tests will I have?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?

If you decide to join a clinical trial, you will be given either the best existing treatment or a promising new treatment.

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

For more information about clinical trials, call the Cancer Helpline on 13 11 20 for a free copy of *Understanding Clinical Trials*.



# Secondary liver cancer

People treated for bowel cancer may develop secondary cancers in their liver. The main signs and symptoms are:

- pain on the right side of the abdomen
- shoulder pain
- bloating and nausea
- jaundice (a yellowish discolouration of the skin)
- dark urine.

If you have secondaries in your liver, there are two important questions. How many cancers are there in your liver? Do you have cancer anywhere else?

To work this out, your doctors will talk to you about how you feel, examine you and arrange a number of tests including blood tests, a liver scan and, depending on your progress, bone scans, CT scans of your abdomen and x-rays.

## Treatment options

The treatment options for secondary liver cancer include:

- surgery
- standard chemotherapy
- hepatic arterial infusion
- cryotherapy, alcohol injection, laser treatment
- do nothing for now.

**Surgery:** It may be possible to remove the part of the liver with the secondary cancers. This operation is suitable for people who have four or fewer small cancers in their liver, have no signs of cancer anywhere else and are reasonably healthy. In some cases it may be possible to do the operation again if the cancer returns to the liver and still has not appeared anywhere else.



**Chemotherapy:** Chemotherapy is given in most circumstances for secondary cancer in the liver. An alternative to standard chemotherapy is to have the chemotherapy injected directly into the liver. This is called hepatic arterial infusion.

**Cryotherapy:** This is an operation in which surgeons use a probe to freeze and kill cancers that have spread to the liver. Cryotherapy is a fairly new treatment. We don't know whether it is better or worse than surgery, or the other forms of treatments.

**Alcohol injection:** This is a less common form of treatment for liver metastases. Injecting alcohol into the cancer has been used successfully with small cancers that have started in the liver, rather than spread there from the bowel. It has also been used at times for people with small cancers that have come from the bowel.

**Laser treatment and radiofrequency treatment:** It may be possible to kill some cancers with laser treatment. This is a new technique that is not widely available. One benefit of this treatment is that it can be done through the skin rather than needing a full operation. There is little research to show how effective it is.

**Do nothing for now:** Having no treatment may be the right choice for some people with:

- Cancer in other parts of their body.
- A lot of cancer in the liver.
- Not many problems from the cancer in the liver.

The decision not to have treatment should only be made after talking to your doctor and family. You can always leave treatment for now, and have it later.



## After treatment is over

Probably the most important thing you can do after the treatment is to give yourself time. Finding out you have cancer and having treatment for it is tiring, apart from any other effects. Surgery, chemotherapy and radiotherapy are all tiring.

You need time to get your strength back. If you're responsible for the house, you'll need some help for a while. If you work, you'll 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.



## Can I stop the cancer coming back?

There is not much research about ways to prevent the cancer coming back. However, there is a lot of research that says the right sort of diet and regular exercise can reduce your risk of getting cancer in the first place.

An appropriate diet can help maintain your health in an attempt to prevent further bowel cancer developing. For more information about diet and cancer, contact the Cancer Helpline on 13 11 20.

## Checkups

People who have been treated for bowel cancer need regular checkups. This allows the surgeon and GP to monitor your health. You may find this reassuring after your treatment.

If your surgeon couldn't see your whole bowel 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.

“Even though I found the chemotherapy easy to cope with, I really felt alone when the treatments were finished and worried about the cancer coming back. This is when talking to a former bowel cancer patient is so important.”

## If the cancer comes back

If your cancer returns, you will have a number of tests to find out where it is. These tests will allow your doctor to tell you whether it is possible to have an operation to remove the cancer, or at least a large part of it. The tests may include a CT scan, MRI scan and/or endorectal ultrasound.

If it is possible for you to have an operation, it can be useful to help relieve some symptoms and delay others.

Radiotherapy and chemotherapy can also help people with a recurrence of bowel cancer. Having radiotherapy before

Sometimes an operation can remove all the cancer and give hope of a cure.

surgery can mean that the cancer shrinks enough to be taken out more easily. Chemotherapy after surgery might delay the return of the cancer.

## Treating symptoms of incurable cancer

Cancer that has spread beyond the liver is often incurable. In this circumstance, treatment is aimed at dealing with symptoms caused by the cancer.

If you have cancer that has spread beyond the liver, and the cancer is not causing any problems, you may decide to postpone treatment, although this decision should not be made without first consulting your doctor.



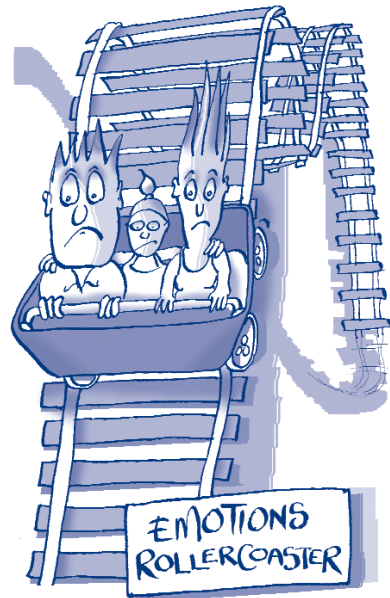
# Seeking support

When you are first diagnosed with cancer, it is normal to experience a range of extreme emotions, such as fear, sadness, depression, anger or frustration. It will help to talk about your feelings with your partner, family members and friends or, if you prefer, talk to a hospital counsellor, social worker, psychologist, your religious or spiritual adviser, or a support group.

You may find that your friends and family don't know what to say to you. They may have difficulty with their feelings as well. 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.

Some people may feel so uncomfortable that they avoid you. They may expect you to 'lead the way' and tell them what you need. This can be very difficult to handle and can make you feel lonely. The Cancer Council's booklet, *Emotions and Cancer*, may help at this critical time. Ring 13 11 20 for a copy.



## Practical and financial help

A serious illness often causes practical and financial difficulties. You don't need to face these alone.

Many services are available to help:

- Financial assistance, through benefits and pensions, can help pay for the cost of prescription medicines and for travel to medical appointments.
- Home nursing care is available through community nursing services, or through the local palliative care service.
- Meals on Wheels, home care services and aids and appliances can make life easier.

Contact the hospital social worker, occupational therapist or physiotherapist, or the Cancer Helpline for information.

## Healthy eating

Eating nutritious food will help you to keep as well as possible and cope with the cancer and treatment side effects. Depending on the kind of treatment you have had, you may have special dietary needs. A dietitian can help to plan the best foods for your situation – ones that you find tempting, easy to eat and nutritious.

The Cancer Council's booklet, *Food and Cancer*, has tips on diet during and after cancer treatment.

## Exercise and relaxation techniques

You will probably find it helpful to stay active and to exercise regularly if you can. The amount and type of exercise will depend on what you are used to and how well you feel. Discuss with your doctor what is best for you.

Some people find relaxation or meditation helps them feel better by releasing tension and anxiety. The hospital social worker or nurse will know whether the hospital runs any programs, or may know about local community programs. Your community health centre may also be able to help.

## Cancer support groups

Cancer support groups offer mutual support and information to people with cancer and their families. It can help to talk with others who have gone through the same experience. Your hospital may run a support group: check with your doctor, nurse or social worker. Joining a consumer advocacy group can also be a rewarding experience for some people.

Call the Cancer Helpline on 13 11 20 for information on advocacy groups or support groups, such as the Bowel Cancer Support Network.

“Being able to talk with someone who has experienced bowel cancer is the most marvellous feeling. With that person I can be completely honest with my feelings and fears.”

## The Cancer Helpline

The Cancer Helpline is a service of The Cancer Council NSW. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. The nurses can send you written information and put you in touch with appropriate services in your own area.

You can call the Cancer Helpline on 13 11 20, Monday to Friday, 9am to 5pm, for the cost of a local call. The tele-typewriter (TTY) number for deaf or hearing-impaired people is (02) 9334 1865.

As well as English, the Helpline is offered in the following languages:

Cantonese and Mandarin .....	1300 300 935
Greek .....	1300 301 449
Italian .....	1300 301 431
Arabic .....	1300 301 625

To access the Cancer Helpline in languages not on this list, call the Translating and Interpreting Service on 13 14 50.



## Sexuality and cancer

We are all sexual beings, and intimacy adds to the quality of our lives. Treatment and the psychological effects of cancer may affect you and your partner in different ways.

Some people may withdraw because of feelings of being unable to cope with the effects of chemotherapy and radiotherapy on themselves or their partner. Others may feel an increased need for sexual and intimate contact for reassurance.

Communication is essential to deal with concerns or problems that may arise. Talk about your feelings with your partner. Try different positions and practices to find out what feels right and is satisfactory for both of you.

If you have difficulties in continuing your usual sexual activities, discuss this with your doctor or with a counsellor.

## Living with Cancer Education Program

If you want to find out more about cancer and how to cope with it, you may find The Cancer Council's Living with Cancer Education Program helpful. The program runs for about two hours a week over eight weeks. Groups are small, with plenty of time for discussion. Courses are run by trained facilitators at hospitals and community organisations throughout NSW. Contact the Cancer Helpline for more information.

## Caring for someone with cancer

Looking after someone with cancer can be very stressful, particularly when it is someone you care about. Try to look after yourself during this time. Give yourself some time out, and share your worries and concerns with someone.

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 another member of the family or a close friend with them.

There are a variety of support services, such as home help, Meals on Wheels and visiting nurses that can help you cope with treatment at home. Call the Cancer Helpline to find out about the services in your area.

The Carers Association offers support and information for carers. Call 1800 242 636.

## Information on the Internet

The Internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of reliable information.

The Cancer Council NSW ..... [www.cancercouncil.com.au](http://www.cancercouncil.com.au)

The Cancer Council Australia ..... [www.cancer.org.au](http://www.cancer.org.au)

CancerBACUP ..... [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

CancerNet ..... [www.cancer.gov/cancer\\_information](http://www.cancer.gov/cancer_information)

American Cancer Society ..... [www.cancer.org](http://www.cancer.org)

Canadian Cancer Society ..... [www.cancer.ca](http://www.cancer.ca)



# Information checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor. If there are answers you don't understand, it is OK to ask your doctor to explain again.

- 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 What tests will I have?
- 6 Is there a risk of complications?
- 7 What are the options for treatment?
- 8 What happens if I do nothing?
- 9 What surgery will I have?
- 10 How long will I be in hospital?
- 11 How long before I can 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 How often do I need checkups?
- 16 What if the cancer comes back?
- 17 Is there anyone else with bowel cancer I can speak to?
- 18 Is my family a bowel cancer family?



# Glossary

## **abdomen**

The belly or tummy.

## **abdominoperineal (AP) resection**

An extensive operation for rectal cancer, which involves removal of the rectum, sewing up of the anus and a permanent colostomy.

## **advanced cancer**

Cancer that has spread past the site of origin to other organs.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body. A general anaesthetic puts a person to sleep for a period of time.

## **anal sphincter**

The muscle used to control bowel motion.

## **anterior resection**

A less extensive operation for rectal cancer, which involves an abdominal scar. The anus remains and there is no permanent colostomy.

## **anus**

The entrance to the back passage, through which bowel motions are passed.

## **ascending colon**

The part of the bowel on the right side.

**barium enema**

A test to look for cancer in the bowel. A white chalky liquid is put into your rectum and x-rays are taken.

**benign**

Not cancer. Not malignant.

**biopsy**

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

**bowel preparation**

An enema and/or oral medication to clean out the bowel.

**carcinoembryonic antigen (CEA)**

A chemical in the blood which, in part, reflects the amount of cancer cells in your body.

**catheter**

A tube passed into the bladder (or other organ) to remove fluid.

**chemotherapy**

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

**colectomy**

An operation to remove the colon or part of the colon.

**colon**

Part of the large bowel.

## **colonoscopy**

A test to examine the bowel. A long, slim, flexible tube with a light attached is inserted through the anus, and examines the bowel.

## **colostomy**

An operation where the colon is attached to an opening on the abdomen.

## **computerised tomography (CT) scan**

A technique that uses x-rays to build a picture of the body.

## **descending colon**

The part of the bowel on the left side of the abdomen.

## **endorectal ultrasound**

An imaging test to measure rectal cancer.

## **faecal occult blood test**

A test for the presence of blood in bowel motions.

## **faeces**

Bowel motions or stools.

## **familial adenomatous polyposis coli (FAP)**

A hereditary condition that causes hundreds of small growths (polyps) in the bowel. FAP always turns into bowel cancer if left untreated.

## **gastroenterologist**

A doctor who specialises in diseases of the digestive system.

### **hepatic arterial infusion**

Chemotherapy delivered directly through a tube into the artery to the liver.

### **hereditary non-polyposis colorectal cancer (HNPCC)**

A condition in some families where the tendency to develop bowel cancer is inherited. Up to 5% 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.

### **large bowel**

Lower part of the digestive tract, which consists of the colon and rectum. Also called the large intestine.

### **lymph**

A clear fluid that circulates throughout the body by means of the lymphatic system and carries cells that help to fight disease or infection.

### **lymph nodes**

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

### **magnetic resonance imaging (MRI)**

Similar to a CT scan, but this test uses magnetism instead of x-rays to build up pictures of the body.

### **malignant**

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

**medical oncologist**

A doctor who specialises in treating cancer with chemotherapy.

**metastasis**

A cancer that has spread from another part of the body.

**oncology or oncologist**

Oncology is the study of tumours or cancer. An oncologist is a doctor who specialises in tumours or cancer.

**palliative care**

Controlling the symptoms of a disease rather than curing it.

**polyp**

A lump in the bowel. Polyps are usually benign but can become cancerous.

**polypectomy**

Removal of a polyp.

**primary cancer**

The site where the cancer began.

**prognosis**

The likely outcome of a disease.

**radiotherapy**

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

**recurrent cancer**

A cancer that grows from cells of a primary cancer that has evaded treatment.



**rectum**

Back passage

**relapse**

The return of a disease after a time when there has been an improvement.

**sigmoidoscope**

A straight tube used to look in as far as the sigmoid colon.

**staging**

Tests to find out how far a cancer has progressed.

**stoma**

An artificial opening in the body that has been created surgically.

**stomal therapist**

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

**tissue biopsy**

Examination of tissue that has been removed from the body under a microscope so any abnormalities can be seen.

**total mesorectal excision**

An operation to remove the rectum and surrounding tissue.

**tumour**

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

**virtual colonoscopy**

A type of CT scan which looks closely at the large bowel.



# Cancer Council stores, NSW

## **Bondi**

Shop 5042  
Westfield Bondi Junction  
Oxford Street  
Bondi Junction NSW 1355  
Ph: (02) 9369 4199  
Fax: (02) 9369 3199

## **Chatswood**

Shop 442, Level 4  
Westfield Shoppingtown  
Victoria Avenue  
Chatswood NSW 2057  
Ph: (02) 9413 2046  
Fax: (02) 9413 2051

## **Hornsby**

Shop 3010  
Westfield Shoppingtown  
Pacific Highway  
Hornsby NSW 2077  
Ph: (02) 9987 0662  
Fax: (02) 9987 1778

## **Kotara**

Shop 106  
Westfield Kotara  
Cnr Park Avenue and  
Northcott Drive  
Kotara NSW 2289  
Ph: (02) 4965 5171  
Fax: (02) 4952 2604

## **Miranda**

Shop 3076, Upper Level  
Westfield Shoppingtown  
The Kingsway  
Miranda NSW 2228  
Ph: (02) 9525 9209  
Fax: (02) 9525 9593

## **Shellharbour**

Shop 228  
Shellharbour Square  
Lake Entrance Road  
Blackbutt NSW 2529  
Ph: (02) 4297 4777  
Fax: (02) 4295 1744

## **Sydney – City**

Shop C35  
Westfield Centrepoint  
Castlereagh Street entrance  
Sydney NSW 2000  
Ph: (02) 9223 9430  
Fax: (02) 9223 9437

## **Warringah Mall**

Shop 349, Level 1  
Warringah Mall  
Cnr Condamine Street and  
Old Pittwater Road  
Brookvale NSW 2100  
Ph: (02) 9939 2668  
Fax: (02) 9939 2208

# Regional offices



## Central Coast Region

127 Erina Street  
Gosford NSW 2250  
Ph: (02) 4325 5444  
Fax: (02) 4325 5688

## Far North Coast Region

120 Tamar Street  
Ballina NSW 2478  
Ph: (02) 6681 1933  
Fax: (02) 6681 1936

## Hunter Region

22 Lambton Road  
Broadmeadow NSW 2292  
Ph: (02) 4961 0988  
Fax: (02) 4961 0955

## Mid North Coast Region

121 High Street  
Coffs Harbour NSW 2450  
Ph: (02) 6651 5732  
Fax: (02) 6652 1530

## North West Region

Shop 2  
218 Peel Street  
Tamworth NSW 2340  
Ph: (02) 6766 1164  
Fax: (02) 6766 7053

## South West Region

40 Morrow Street  
Wagga Wagga NSW 2650  
Ph: (02) 6921 7760  
Fax: (02) 6921 3680

## Southern Region

1 Lowden Square  
Wollongong NSW 2500  
Ph: (02) 4225 3660  
Fax: (02) 4225 1700

## Sydney Metropolitan Region and Head Office

153 Dowling Street  
Woolloomooloo NSW 2011  
(PO Box 572  
Kings Cross NSW 1340)  
Ph: (02) 9334 1900  
Fax: (02) 9334 1739

## Western Sydney Region

43 Hunter Street  
Parramatta NSW 2150  
Ph: (02) 9687 1399  
Fax: (02) 9687 1118

## Western Region

84 Byng Street  
Orange NSW 2800  
Ph: (02) 6361 1333  
Fax: (02) 6361 1863

# Cancer Helpline 13 11 20

For support and information on cancer and cancer-related issues, call the Cancer Helpline. This is a free and confidential service.

Cancer Helpline .....	13 11 20 (cost of a local call)
TTY .....	(02) 9334 1865 for deaf and hearing-impaired
Cantonese and Mandarin ....	1300 300 935
Greek .....	1300 301 449
Italian .....	1300 301 431
Arabic .....	1300 301 625

For further information and details please visit our website:

[www.cancercouncil.com.au](http://www.cancercouncil.com.au)



*Building a  
Cancer Smart  
Community*