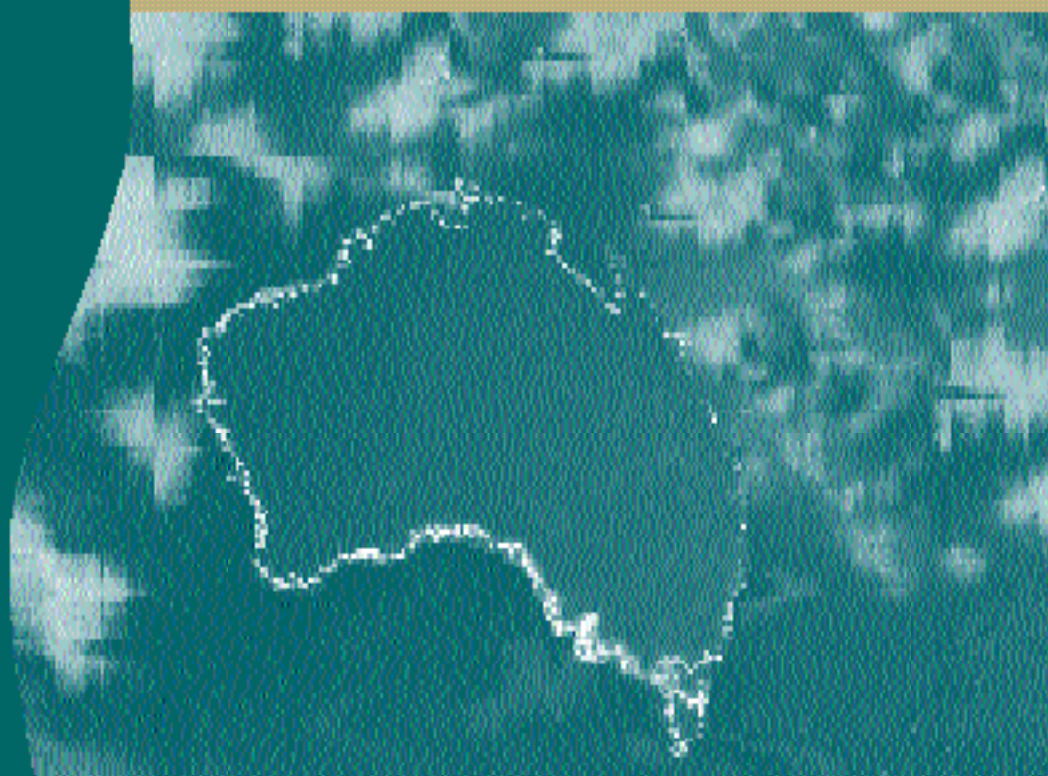




Guidelines for the  
prevention, early detection and  
management of colorectal cancer:  
*A guide for patients, their families  
and friends*



**NHMRC**

National Health and Medical Research Council



**Guidelines for the prevention,  
early detection and management of  
colorectal cancer: *A guide for patients,  
their families and friends***

Endorsed February 2000

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National Health and Medical Research Council

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## INTRODUCTION

This book has been prepared for people with bowel cancer, their families and friends. The first section is for people with bowel cancer, and is intended to help you understand what bowel cancer is, and the various treatments and diagnostic tests available for bowel cancer. This information will help you become well informed about your illness, and should assist you as you make decisions about treatment.

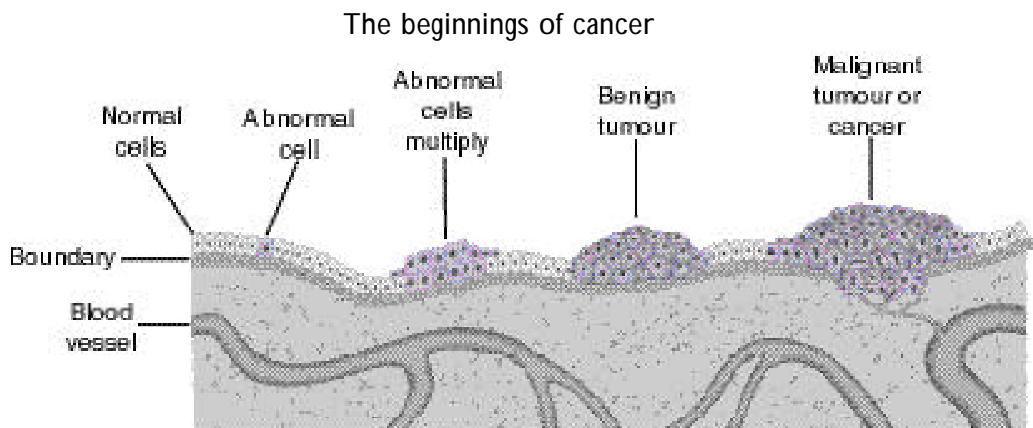
You may wish to refer to the first section of this book before you discuss important aspects of your treatment with your doctor. Your doctor should be familiar with the recommendations included. He or she should also be willing to discuss the pros and cons of different treatments, where more than one treatment is available.

The second section of the book is for the families and friends of people with bowel cancer. This section provides information on reducing your risk of bowel cancer through a healthy lifestyle, the importance of early detection, and bowel cancer in families.

The recommendations made throughout this book are by the National Health and Medical Research Council (NHMRC).

### **What is cancer?**

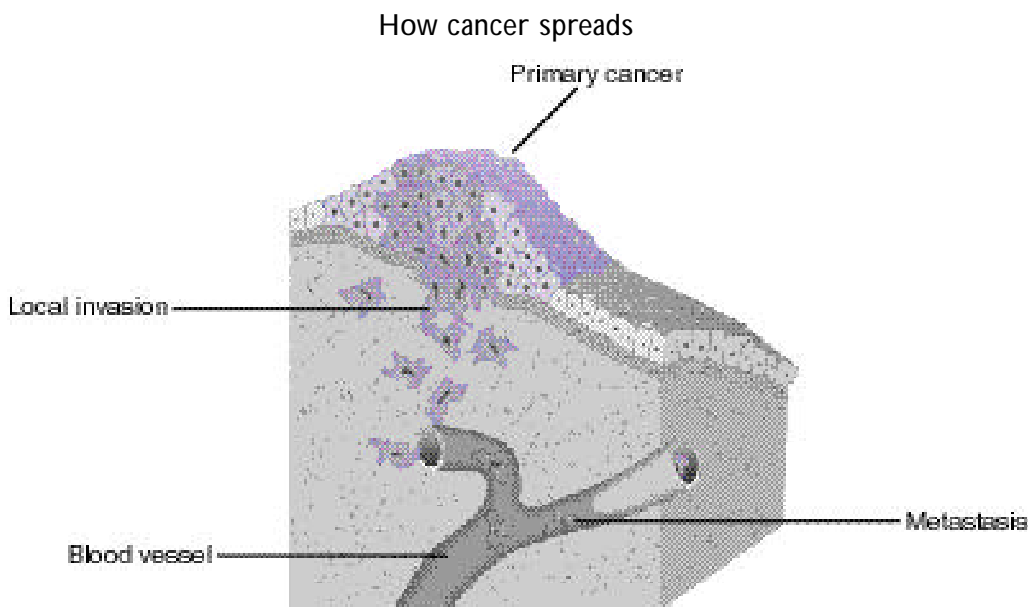
Cancer is a disease of the body's cells. Our bodies are constantly making new cells: to enable us to grow, to replace worn-out cells, or to heal damaged cells after an injury. Almost every cell in the body contains a complete set of genetic blueprints, which controls how our cells function. Normally cells grow and multiply in an orderly way. Occasionally however, if something causes a mistake to occur in these genetic blueprints, some cells behave abnormally. They multiply in an uncontrolled way, and may grow into a lump that is called a tumour.



*Some benign tumours are precancerous and may progress to cancer if left untreated. Other benign tumours do not develop into cancer.*

Tumours can be benign (not cancerous) or malignant (cancerous). Benign tumours do not spread outside their normal boundary to other parts of the body. A malignant tumour is made up of cancer cells. If these cells are not treated they may spread into surrounding tissues.

If cancer cells spread beyond their normal boundaries then the tumour is malignant, that is, it is a cancer.



Sometimes cells break away from the original (primary) cancer and spread to other organs. When these cells reach a new site they may continue to grow and form another tumour at the site. This is called a secondary cancer or metastasis.

### **What is bowel cancer?**

The bowel is part of the digestive tract which connects the stomach to the anus, the opening where waste materials (faeces) are passed out of the body. The function of the bowel is to finish digesting food by absorbing water and nutrients.

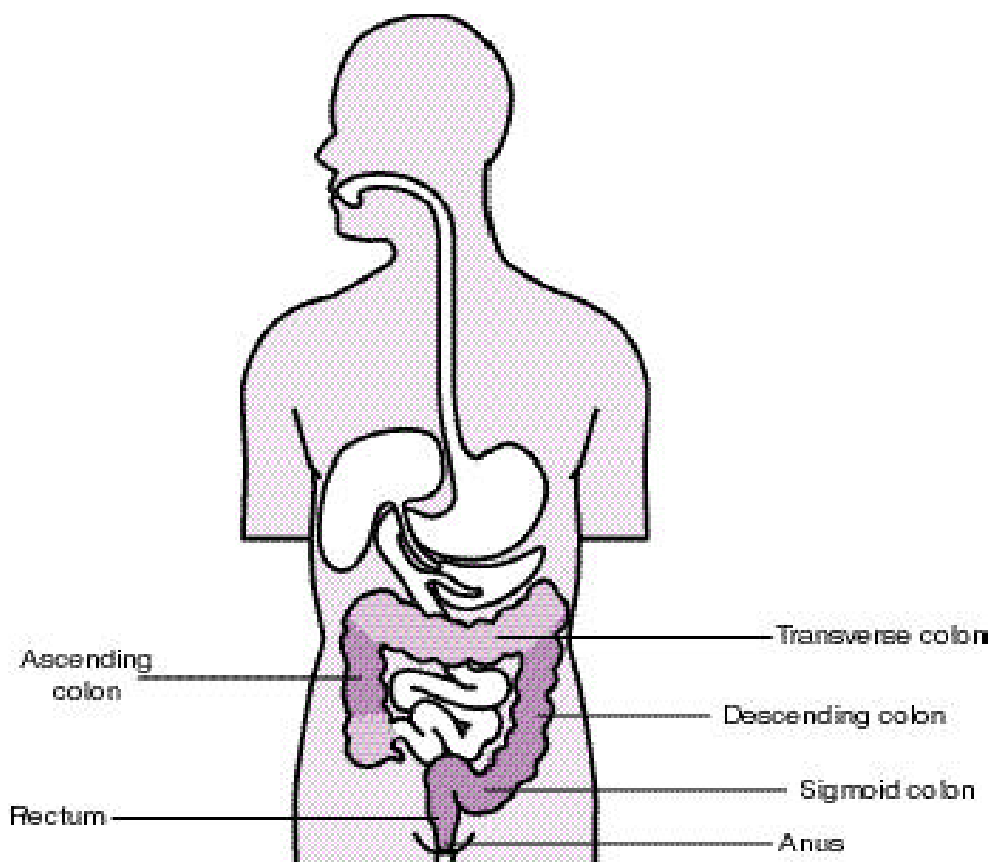
The bowel has three main parts:

- small bowel—this mainly absorbs nutrients from broken-down food
- colon—this mainly absorbs water
- rectum—this stores waste materials (faeces) until they are passed from the body through the anus.

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



This booklet also contains references to colon cancer and rectal cancer when specifically distinguishing one form from the other.



### **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, and there are about 10,600 new people diagnosed with bowel cancer each year. It is becoming a little more common, especially in men.

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. Occasionally, people develop bowel cancer while in their twenties and thirties, but this is very rare. Australia has one of the highest rates of bowel cancer in the world, along with North America and New Zealand.

### **What causes bowel cancer?**

There are a few people who carry faulty or altered genes that increase their risk of bowel cancer. Genes carry the instructions that control how our bodies grow and develop. We inherit these genes from our parents. Sometimes an altered gene can permit a cancer to develop. If your mother or father had an altered gene like this, it can make your chance of developing the same cancer much more likely. It is important to note that there has never been a family where *everybody* gets bowel cancer. 'Bowel cancer in families' (p65) discusses the risk of bowel cancer in your family.

For most people, it is not the genes we were born with, but our age and diet that contribute to developing bowel cancer. Section 2 discusses the benefits of a healthy diet and exercise for reducing an individual's risk of bowel cancer.

# SECTION 1

Information for patients

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## 1: HOW DOES BOWEL CANCER START?

Bowel cancer seems to start in two different ways. It can grow from the inner bowel lining, or from a small raised area that looks like a mushroom, known as a polyp. These polyps, are usually benign (harmless), however some polyps can become cancerous (malignant) and capable of spreading.

Polyps are important for people who have already had bowel cancer because they increase your risk of developing a second cancer later on. After being treated for bowel cancer, your doctor will give you regular check-ups to look for either new signs of cancer, or for benign polyps. (See **p19** 'What procedures might I have?').

These check-ups can also be arranged for members of your family if, after discussion with your doctors, they are thought to be at a higher than average risk of developing bowel cancer. For more information, see **p65** 'Bowel cancer in families' and **p19** 'What procedures might I have?'.

### 1.1 DOES BOWEL CANCER SPREAD?

Bowel cancer spreads (metastasises) beyond the bowel if it is not treated. But it spreads fairly slowly, more slowly than some other cancers. It can stay in the bowel for many months or years before moving outside it, first to the lymph nodes, then to other organs. This gives doctors a chance to completely cure the cancer by surgery.

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

Bowel cancer is highly treatable when it is detected in its earliest form, even if it has spread to regional (nearby) lymph nodes, but less so if it has spread to other organs such as the liver. When it has spread to other organs, there are many treatments that can help, but a cure is much harder to obtain. **That is what makes it so important to detect bowel cancer early, before it has spread to other organs.**

### 1.2 WHAT ARE THE DIFFERENT STAGES OF BOWEL CANCER?

Your chances of cure depend on the stage at which your cancer is diagnosed. There are a number of different ways to describe the different stages of bowel cancer, but one method uses the terms A, B, C and D.

- Stage A cancer is confined to the bowel wall.
- Stage B cancer has spread to the outer surface of the bowel wall and not beyond.
- Stage C cancer has spread to lymph nodes outside the bowel wall and not beyond.
- Stage D cancer is where there is known to be distant metastases.

According to figures collected in South Australia between 1977 and 1994, 88 per cent of people with Stage A bowel cancer are alive five years after they are diagnosed and treated. **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.** The figures for people at other stages are 70 per cent for Stage B, 43 per cent for Stage C and 7 per cent for Stage D.

Stage of cancer at diagnosis	Proportion of people alive five years after their diagnosis
A confined to the bowel wall	88%
B spread to the outer surface of the bowel wall and not beyond	70%
C spread to lymph nodes outside the bowel wall and not beyond	43%
D where there is known to be distant metastases	7%

Overall, about 56 per cent of people who have had their bowel cancer successfully removed are alive five years after their diagnosis. This figure seems to be improving slightly, both in Australia and in other parts of the world.

It is important to note that 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 an *individual's* prognosis, so these figures can at best only serve as a guide to a person's chance of cure.

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## 2: HOW MIGHT BOWEL CANCER AFFECT ME?

Bowel cancer can affect you physically, emotionally and socially. These effects are discussed below.

### 2.1 PHYSICAL EFFECTS

In the early stages before diagnosis, bowel cancer can cause four types of symptoms, but not everyone has all of them. These symptoms are described below.

**It is important to note that these symptoms can be caused by a number of medical conditions, not just cancer.** If you have an important or persistent change of this sort, you should see your doctor.

#### **Bowel bleeding**

When your bowel bleeds, the blood is passed from your ‘back passage’ or anus. Small amounts of blood may appear on the surface of, or mixed in with, your faeces, on the toilet paper or in the toilet prior to flushing.

There are many causes of bowel bleeding. Bowel cancer is the most worrying of these causes, however there are many other common causes for bowel bleeding not related at all to cancer, eg haemorrhoids (enlargement of the spongy, blood-filled cushions in the wall of the bowel), and fissures (tears in the lining of the bowel caused by straining). Bowel bleeding is caused by the bursting of a blood vessel in the wall of the bowel. The blood loss is not generally a problem, however it may be a symptom of a serious problem and should always be checked by a doctor.

#### **Anaemia**

Red blood cells contain haemoglobin that carries oxygen to the other cells in your body. When you have anaemia, there is a lack of red blood cells in the body. There are many causes of anaemia but one of the most common is bleeding from the bowel. The bleeding may be so slow that it is not noticeable, or from higher parts of the bowel so that you can’t see it in your faeces or in the toilet. It can sometimes be a warning of the presence of bowel cancer.

Having anaemia can make you feel tired and have a lack of energy. In more severe cases you may experience a shortness of breath and chest pain. However, generally anaemia is not serious and can be easily treated.

The first step in the treatment of anaemia due to blood loss is to identify the cause of the bleeding and treat it. Once this has been done, the iron lost from the body through the bleeding must be replaced so the body can make new red blood cells. This is usually done by either taking iron tablets, or having a blood transfusion.

### **Change in bowel habit**

There are many causes for a change in bowel habit—for instance, a change in dietary behaviour. However, some people who develop bowel cancer find that their usual bowel habit has changed over the past weeks to months for no apparent reason. You may become constipated (have difficulty passing faeces) more often, or after years of using your bowels once daily, you start going twice daily or more. It is also common for the shape of your faeces to change due to the presence of the cancer in your bowel. It is important to observe the general nature of your bowel movements so that if you notice any changes, they can be described to your doctor.

### **Abdominal pain**

There are many causes for abdominal pain, however some people with bowel cancer have pain in the abdomen. This pain may be constant, it may come and go, similar to a crampy, colicky pain, or it could be a gripping sharp pain. The pain may be in just one place or it may move around. It may be mild, or it may be more severe. The pain is usually due to a blockage in the bowel caused by the cancer, and results from the bowel pushing harder to move the faeces through. The pain should be completely relieved once the cancer is removed.

### **Other symptoms**

People with bowel cancer can develop other symptoms. They may include bloating, loss of weight, tiredness, or generally feeling 'out of sorts'. You should see your doctor if you have any of these symptoms.

## **2.2 EMOTIONAL EFFECTS**

The diagnosis of bowel cancer affects every person differently. For the majority of people, it will be a difficult time, however some people will manage with little upset to the routine of their daily lives.

Being told you have bowel cancer may come as a great shock, but it is not necessarily a death sentence. The chances of cure are high for people whose cancer has not spread.

After being told you have bowel cancer, you may encounter many very different, but normal, types of emotion.

In the beginning you may feel shocked. Some people overcome the shock quickly and accept what they have been told, while others go into denial. It is quite normal for you to deny what you have been told and believe it will 'go away', or 'the doctor' or 'tests' must have been wrong. This feeling of denial may last only a few days (or weeks). In some people however, it may not pass.

You may also find your feelings jumping between sadness and depression to anger, 'why me?', or 'how dare it invade my body'. It is important to know that depression is a very common reaction to being told you have cancer and should not be hidden from those closest to you. It is not a sign of weakness, and if it persists for more

than a short time, there are effective treatments available to help you overcome this. During this time you may feel that you don't know how to deal with the disease. You may feel concerned and threatened in many ways, even though the outlook for most people with bowel cancer is good.

You may worry about:

- your life and how long you will live
- the effects of both the disease and the treatment on your roles as a provider, mother or father, spouse or partner, grandparent or lover
- the effect on your family, work and other aspects of your life
- the medical implications for your 'blood' relatives
- how much this will change your life
- 'will I be a burden to those around me?'
- the possible spread of the cancer
- what to do about treatment.

All of these are important concerns. Your family, friends and doctors are important in providing support to help you cope.

Eventually you may come to accept the changes the cancer may have made to your life and continue as normally as possible. Going through the treatment may make you worry about your self-esteem, your sex life and your relationships. However, not everyone may experience all these emotions. It can continue to worry you for a long time after the diagnosis has been made. But as you get over the shock and as the treatment progresses, the worry will diminish and you will gradually adjust.

No matter what type of bowel cancer you have, your general health, your circumstances and your level of support will influence the emotional effect it has on you.

### **The effect on your family**

Bowel cancer affects not just you, but your family too. Partners or spouses, mothers, fathers, brothers, sisters and children will all be affected. Partners may feel anxious and distressed and uncertain about how they can help.

Younger children may be frightened about the change in the family, and might develop behavioural problems. Adult children may be concerned about their own risk of bowel cancer. The whole family will need to make adjustments.

Many families find that talking about the issues helps them cope. In some cases, discussion with your doctor, your best friend, spiritual or religious adviser, a counsellor or a member of a cancer support group may be helpful.

For people facing bowel cancer on their own, support and help can be provided by your doctor, medical adviser, counsellors and cancer support groups.



## **Relationships, sexuality and bowel cancer**

On the physical side, surgery for bowel cancer, even having a stoma, should not affect a couple's ability to enjoy sex. Occasionally, however, in men an operation to the rectum can damage the nerves that go to the sexual organs. This may prevent a man from having an erection. It can also cause problems with ejaculation. If you or your partner do have sexual problems, it may help to discuss them with your doctor.

For some people, surgery can change the way some people feel about themselves or their bodies. Or they may be very concerned about how their partner will cope. One person might feel no difference, or find that the cancer experience draws them closer to their partner. Another may be less interested in intimacy and sex, or may feel that these things are temporarily less important. It can affect their whole relationship.

Some people will be in a stable relationship when they have surgery. Try not to bottle up your concerns. Talk things over with your partner—this is one of the most important things you can do. Good, open communication goes a long way to sorting out any problems that exist. It will also reassure both of you of your affection and need for each other.

Other people will be single. Rarely, some will be in their teens or early twenties. This is a time for trying out relationships, meeting new people and deciding who and what you are. It's normal to feel uncertain of yourself—many people do, including those who appear very confident. Body image and the way you look can be very important.

Telling others about bowel problems can be difficult—who do you tell? When do you tell? It's probably best to know people well before you tell them. A bowel problem is a much smaller issue for someone who already knows and cares for you.

It's important to remember that people love others for who they are, not what they look like. Remember also, that you are in control of the situation. You can choose who to tell, and when to tell.

It can help considerably to discuss these problems with an independent person. Another person can see your situation differently and may suggest new ways to help you manage. This person may be your doctor, a stoma therapist (see **p34** 'Having a stoma'), or someone at home or in your community who can help. There are also excellent sexual counsellors available—these may be social workers, psychologists or psychiatrists. The Cancer Information Service (13 11 20) can put you in touch with specialists or someone within your community who may be able to help.

## 2.3 SOCIAL EFFECTS

Having bowel cancer can also interfere with your normal life, at least for some time. The cancer and its treatment might interfere with your work, housework, caring for children, partners or grandchildren, your sex life, sport, and anything else you do. You will probably feel more 'in control' when your treatment has finished.

Nearly all the treatments you will have for your cancer have side effects that affect different people in different ways. You may be just left feeling tired and with little energy to carry on as normal, or you may feel nauseated (sick) or have pain which takes time to get over. Whatever the extent of your side effects, having bowel cancer can affect the normality of your life.

Your cancer and its treatments might also be expensive. Apart from medical and other expenses, it is common to need time off paid work for treatments, recovery and medical appointments. There may also be extra medical, childcare and other expenses for you to consider. Information and support for bowel cancer patients is readily available. You may qualify for financial assistance from the government or for home help services through your local council and/or community health centres. Your doctor should be able to help you find any information or services to assist you through this time.

## 2.4 COUNSELLING AND SUPPORT

Most people cope with their illness better if they have good emotional support from family, spouse or partner and friends. But some people find it hard to accept support because they need to hide their fear, or act as if everything is alright. They may be used to providing support, not receiving it. If you find this a problem, it may be wise to seek professional help.

Many people find counselling helps. It can help you cope and make you feel less anxious and helpless. If you would like help, you could ask:

- your hospital, which may have staff specialised in counselling people with cancer
- your doctor, who could refer you to someone appropriate, if he or she does not have the skills to assist
- the Cancer Information Service on 13 11 20, which will put you in touch with a counsellor at your local cancer council.

Apart from counselling, many other forms of support may be available. These include:

- access to a support group
- help with looking after children, elderly parents or an elderly spouse
- help with transport
- care of the stoma, if you have one (refer to **p34** 'Having a stoma')
- hostel or other accommodation during treatment.

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### Recommendation:

For everyone dealing with bowel cancer there is a degree of difficulty, but most people find that they can cope with their illness better if they have good emotional support. It is recommended that patients seek emotional support at a level to suit their needs.

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## 2.5 SUPPORT SERVICES

There is a variety of support services that can help you cope with bowel cancer treatment at home. These include home help, meals on wheels and visiting nurses. These are provided by local councils, the Royal District Nursing Service and palliative care services. As well, there are organisations and groups that can provide you with information and support. Some of these, such as the Cancer Information Service in your state, can tell you about other services.

### **Cancer support groups**

Cancer support groups offer mutual support and information to people with cancer and, often to their carers (people who care for someone with bowel cancer). It can often help to talk with others who have gone through the same experience. A support group can offer the chance to share experiences, practical suggestions and ways of coping. Your hospital may run special cancer support groups: check with your doctor, nurse or social worker, or contact the Cancer Information Service.

## 2.6 CANCER INFORMATION SERVICE

The Cancer Information Service 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 specially trained staff. The staff can send you written information and can put you in touch with appropriate services in your own area. Telephone 13 11 20.

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## 3: DEALING WITH BOWEL CANCER AND ITS TREATMENTS

When you are first told you have bowel cancer, you may or may not understand much else. Hearing the word ‘cancer’ may come as a terrible shock, and 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 receive support from family and friends. This can help you understand the disease and choose the best form of treatment for you.

You can only decide which treatment you would prefer if you know which forms of treatment are most effective for people in your circumstances. Your doctors should provide you with such information automatically. If not, you can ask for it.

### 3.1 YOU NEED RELIABLE INFORMATION

To make decisions, you need reliable information. Your doctor may or may not provide much information at first. As you learn more, you will want to know more. Ask more questions as you go along, and encourage your family, partner, relatives or friends to do the same. You may want to take a list of questions along for other visits. See **p51** ‘What questions could I ask if I have bowel cancer?’. It may be better to ask them in stages, rather than all at the first visit.

It is important to remember to make a longer appointment with your doctor if you have a number of questions to ask. This ensures you have plenty of time to receive the information you need and your doctor will not have to rush with you. Most doctors are happy to spend more time with you if you request it. If you find your doctor is not helpful, then try to find a doctor who is.

Treat the information provided on the Internet with some caution. Even though this is a wonderful source of information on bowel cancer, it may not all be factual information supported by evidence, and could be just someone’s ‘personal experience’ or ‘theory’. Always check this information and any recommendations you receive with your doctor.

The National Health and Medical Research Council, which provides policy advice to the Commonwealth government, says that doctors should not avoid telling you things just because they think you’ll be upset by them. It also says:

- information should be provided in a form and manner which helps patients understand the disease and treatment options available, and which is appropriate to the patient’s circumstances, personality, expectations, fears, beliefs, values and cultural background
- doctors should give advice, but should not encourage you against your wishes towards a particular course of action

- patients should be encouraged to make their own decisions
- patients should be frank and honest in giving information about their health, and doctors should encourage them to be so.

### **Your doctor must tell you everything you want to know**

Of course, it can be hard to remember everything you're told, especially if you've just found out you have cancer. You might find it helps to:

- ask for more information at each visit to your doctor
- ask a relative or friend to go with you
- read pamphlets, notes and booklets—your doctor will be able to help you get these
- 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.

If you are not fluent in English, you may prefer to use a qualified interpreter, rather than a family or staff member. Interpreters are available free of charge, although you have to book them in advance.

## **3.2 WHO ARE THE DOCTORS?**

You will probably meet a number of doctors from different fields of medicine. They will include:

- your general practitioner, who has an important role in your ongoing care
- a surgeon, either a colorectal surgeon or a general surgeon who specialises in bowel care
- a radiation oncologist, also known as a radiotherapist, who uses radiotherapy (special types of X-rays) to treat cancer
- a medical oncologist, a doctor who specialises in the use of medication (such as chemotherapy, hormones and pain relieving drugs) to manage cancer
- a gastroenterologist, who specialises in colonoscopy or who has an interest in familial aspects of bowel cancer.

These doctors should all work in a team. In some hospitals, they do. In others, they do not. Communication between doctors occurs at different levels. You should ask your specialist doctors to communicate with your local doctor, to ensure he or she is kept up to date with your treatments and results.

### 3.3 CHOOSING A SPECIALIST

Choosing the right specialist can be difficult. Some people have no choice—there is only one specialist in town. Others feel they have no choice. Still others find they can ask around, get recommendations from different doctors, and make a choice.

Some people are willing and able to travel long distances for specialist care. Others either cannot travel or prefer to remain at home, close to family and friends. Some people prefer specialists who deal with them as equals, while others prefer their doctors to take the lead.

You are probably already seeing a specialist. You may be happy with the person you are seeing, but if not, it is always possible to get a second opinion.

### 3.4 GETTING A SECOND OPINION

Before you make a decision about a treatment, you may want to seek an opinion from another doctor. Getting an opinion from another doctor about your disease and treatment can help you settle in your own mind that you are doing the right thing.

There are two ways to get a second opinion. One is to tell your specialist you want to see someone else. The other way is to ask your GP to refer you to another specialist. If someone you know has seen a specialist whom they recommend, and you wish to see that specialist, ask your doctor for a referral. Your GP or specialist is obliged to help you get a second opinion if you would like one.

### 3.5 DECIDING ABOUT TREATMENT

Some people want their doctors to decide what to do. Some people want to decide what to do on their own. Some may find it useful to use their GP as a 'health advocate' to help them sort through all the information they collect about various treatments and decide which is the best option.

Gathering information can take time, and thinking about the right approach can take time. Except in very rare circumstances, taking a few weeks to decide what to do will not make any difference, although it would not be wise to take months to decide, as symptoms may worsen and require more treatment.

The important thing is to be comfortable with the approach you take. Whatever you decide to do, there is no extreme rush unless you have abdominal pain, other symptoms or you need emergency surgery.

### 3.6 UNDERSTANDING RISK

Your doctor may talk to you about the chances of, for example, your treatment being successful and totally curing your cancer.

Chance means the *risk* of a particular thing happening. It may be scary to be told that you have what sounds like a big risk: for example a one in five (or 20 per cent) risk of a serious illness. It can be reassuring to turn the statistic around and

remind yourself that this also means that you have a four in five (or 80 per cent) chance of *not* developing the serious illness.

For example, a 50-year-old man may be told that he has a one in 18 chance of developing bowel cancer before the age of 75. This means that one in 18 Australian men develop bowel cancer before the age of 75; it does not mean that *he* will develop bowel cancer. He may be among the 17 men of every 18 who *do not* develop bowel cancer before the age of 75.

If you don't understand your doctor when he or she is discussing your risk of a certain thing happening, ask for an explanation. Understanding your risk can help you make decisions about your treatment.

### 3.7 MAKING A PLAN

Once you have all the information you need, and have had a second (or third) opinion if you wish, you and your doctor will make a treatment plan. This should spell out:

- what treatments, if any, come first
- what treatments, if any, follow
- what tests you should have, at what stage, to see how you are going
- what to do if problems arise
- what to do if emergencies arise at night or on weekends
- how to maintain communication between your specialists and you
- who will be the doctor coordinating all your treatment
- how many specialists you will need to see.

Of course, it is not possible to plan everything at this stage. You may not know everything about the extent of the cancer until you have had an operation. So keep asking these questions until the rest of the plan is worked out.

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## 4: WHAT PROCEDURES MIGHT I HAVE?

This chapter lists all the possible tests and procedures that you might have. Some of these tests you may already have had, while others may still be to come. Please note that you will not necessarily have all of these tests—this is just a list of what you might have.

There are three types of tests you might have:

- general tests
- tests to look at the cancer
- tests to look for cancer that may have spread.

General tests include simple procedures such as a blood test of electrolytes and liver function to generally see how your body is functioning.

Tests to look at the cancer may include a rectal examination, sigmoidoscopy, barium enema, colonoscopy, computerised tomography (CT) scan or endorectal ultrasound. These tests help doctors to look at the position of the cancer in the bowel.

If you have cancer, you and your doctor will want to know how far advanced it is. This process is known as staging. Most staging is done after surgery when the cancer has been removed from your bowel. However it is still important to find out if it has spread to other parts of the body. The main areas of interest for these tests are the areas around the bowel where the cancer was first detected, and the liver and lungs, as these are where bowel cancers tend to spread to first. For this reason, you may have tests to look for cancer in other parts of your body. These tests may include a chest X-ray, abdominal ultrasound, CT scan, or CEA test.

All of these tests are described in more detail below.

### 4.1 RECTAL EXAMINATION

Your doctor will examine your rectum by inserting his or her 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 6–8 centimetres of the bowel. The test is a little uncomfortable and feels like you are going to open your bowels, however you do not lose any control.

### 4.2 SIGMOIDOSCOPY

This test involves your doctor inserting either a flexible or rigid tube into your anus to examine your rectum and lower colon for possible signs of cancer. The test may be uncomfortable but should not cause severe pain. You may feel bloated and uncomfortable, but the test only takes 5 to 10 minutes.



### **Rigid sigmoidoscopy**

A specialist doctor such as a gastroenterologist or surgeon usually performs this test in his or her surgery after you have had a rectal examination. The sterile, disposable tube is about 25 centimetres long, and you don't need any preparation for it.

Your doctor may arrange for you to have a flexible sigmoidoscopy or colonoscopy after, or instead of, having this test.

### **Flexible sigmoidoscopy**

This test may be done in a day room as an outpatient or by some specialist doctors who have the facilities to do this test in their rooms. The sterilised tube can be between 35 and 65 centimetres long, and unlike the rigid sigmoidoscope, is not disposable. This test may involve a bowel preparation (called an enema) which cleans out your bowel before the test, so any unusual areas can be examined thoroughly.

Complications during sigmoidoscopy are rare, although in less than one in 5,000 cases, the lining of the bowel or the bowel wall may be damaged and may need to be surgically repaired.

## **4.3 BOWEL PREPARATION**

Whether you have a colonoscopy, barium enema or in some cases a sigmoidoscopy, you may need to clean out your bowel before the test. This is called a bowel preparation.

A typical bowel preparation involves drinking a large amount of a special drink that cleans your bowel. This gives you excessive watery diarrhoea which cleans and empties out your bowel.

With some preparations, it can cause dehydration, and often in older people intravenous fluids are given in hospital while having the bowel preparation.

## **4.4 BARIUM ENEMA**

A barium enema is a type of radiological (X-ray) investigation for which you lie on a table in the X-ray department. Prior to the examination, you will have to have a bowel preparation to clean out your bowel. A small tube is then inserted into your anus and up into your colon and a quantity of white liquid—barium—is poured in. The table may be tilted to wash the barium around inside you. Then a series of X-rays are taken.

The barium shows up the lining of your bowel clearly on the X-rays. It is essential for the doctor to pump air into the bowel to give a better contrast for the X-ray. This can be a little uncomfortable and leave you feeling bloated. The test takes about 30 minutes from start to finish.

Like all tests, it is not always accurate. It detects about 90 per cent of bowel cancers, but can easily miss small polyps. It is less accurate than colonoscopy (see below) for small cancers. In most patients, a sigmoidoscopy should complement the barium enema to fully examine the rectum.

Complications from barium enemas are rare. About three people in 10,000 have serious complications, and it is estimated that about three people in 100,000 may die due to the test.

#### 4.5 COLONOSCOPY

A colonoscopy involves inserting a long, flexible tube, with a TV-like lens on the end, through your anus and rectum then around your colon to its beginning at the small bowel. The doctor can have a good look for cancers. Before the test, you will have a bowel preparation which should totally clean out your bowel. You will be given a sedative that will make you feel very drowsy, and much more comfortable. You may however feel some discomfort during or after the procedure, but this should settle quickly. The test takes about 20 to 30 minutes.

Unlike barium enema, colonoscopy has the extra benefits of being able to remove polyps and biopsy cancers during the same test.

Colonoscopy is more accurate than a barium enema, but it can still miss about 5 per cent of cancers and polyps due to an incomplete examination. Also, doctors who do a lot of colonoscopies are more likely to see more of the bowel than doctors who don't do it as frequently.

Like all tests, colonoscopy has risks. The risks associated with having a colonoscopy are higher than those associated with having a barium enema or a sigmoidoscopy, however the accuracy of this test is higher, and the benefits are better as previously mentioned. About three people in every 1,000 may have serious bleeding, one in 1,000 may have bowel damage or tears, and about one in 10,000 may die.

#### 4.6 CHEST X-RAY

You may have a chest X-ray for two reasons. One is that you will probably have an operation, and a chest X-ray is a precaution before any surgery to check for any lung or heart disease. The other is that occasionally bowel cancers spread to the lungs, and an X-ray is an easy way to check that the lungs are free of cancer.

A chest X-ray is a simple, painless procedure that takes just a few minutes. You will stand in front of an X-ray screen in a radiology department and have a picture of your chest taken. The dose of radiation you receive is very low, and there are no harmful side effects.

#### 4.7 COMPUTERISED TOMOGRAPHY (CT) SCAN OF THE ABDOMEN

Most patients with bowel cancer will not need a CT scan before their operation. The CT scan (sometimes called a CAT scan) is a special type of X-ray, which gives a picture of the organs and other structures in your body. CT scans are not very useful for detecting early stages of bowel cancer as they are not very sensitive, however they are very useful for giving information about the extent or stage of the cancer and if it has spread (see **p43** 'What treatments will I have for secondary liver cancer?').

This painless test usually takes 10 to 40 minutes. You will be asked to lie flat on a table that moves in and out of the CT scanner—a large, round machine that is shaped like a doughnut. One to two hours before the scan, you may be asked to drink a liquid called gastrograffin or barium, and later have a dye injected into a vein, often on the back of the hand or on the forearm. These will improve the quality of the images. You will be asked not to eat or drink for a while before you have your scan. Most people are able to go home as soon as their scan is over.

CT scans are also used to check if the cancer has spread anywhere else in the body. The CT scan will pick up 70 to 80 per cent of secondary cancers in the liver or abdomen, but like all tests it's not perfect.

#### 4.8 ABDOMINAL ULTRASOUND

**Ultrasound** is sound waves of a very high frequency (higher than the human ear can hear). If ultrasound is directed at the body, it is reflected back differently by different types of tissue. In an ultrasound scan, these differences are measured and used to build up images of structures in the body. Ultrasound examination is usually performed by an ultrasound technician, who guides the scanning by watching the images on a screen like a television.

The ultrasound technician will pass a probe over your abdomen several times to check the structure of the liver and other organs and to look for any signs that the cancer has spread to the liver.

Ultrasound is widely available around Australia.

#### 4.9 ENDORECTAL ULTRASOUND

An **endorectal ultrasound** is a technique in which sound waves are used to form a picture to look at cancer in the rectum. A short probe is inserted into the rectum and this detects the sound waves and allows the surgeon to assess the size and spread of the cancer. The procedure takes about 10 minutes, and is not painful, but you may feel uncomfortable.

The test may also help the surgeon plan what type of surgery to perform, and whether any form of additional therapy, such as radiotherapy, may be appropriate. An endorectal ultrasound is more accurate than a CT scan or magnetic resonance imaging (MRI) (explained in this section) when determining the local spread of a cancer in the rectum.

Endorectal ultrasound is not required for everybody with rectal cancer. Also, being a fairly new technique, only a small number of surgeons have been trained to use it properly, although this number will grow. It is not available in all parts of Australia.

#### 4.10 ELECTROLYTES TEST

This blood test measures the amount of sodium, potassium and other elements and molecules in your blood. Its main role is to check that your kidneys are functioning properly.

#### 4.11 FULL BLOOD EXAMINATION (FBE)

A blood test is a simple procedure performed by a doctor or nurse who takes a sample of blood from your arm using a syringe. The test only takes a few minutes and is only briefly painful. The blood taken can be used for several tests described below.

People having treatment for bowel cancer will probably have full blood examinations (or blood tests) quite regularly. This is especially the case for those having chemotherapy, as chemotherapy temporarily damages blood cells.

Full blood examinations are used for:

- liver function tests; and
- carcinoembryonic antigen tests (see below).

#### 4.12 LIVER FUNCTION TEST (LFT)

This blood test measures various chemicals that are normally found in, or made by, your liver. This test is important for people with bowel cancer because if the cancer spreads, it often spreads to the liver. Abnormal results from a liver function test can be one of the signs that a cancer has spread to the liver. It is usually done as a routine test in the early stages of trying to work out where the cancer is and whether or not it has spread.

#### 4.13 CARCINOEMBRYONIC ANTIGEN (CEA) TEST

CEA stands for carcinoembryonic antigen, and is a molecule produced by your bowel and some cancer cells. A CEA test is a simple blood test and can only be used as a guide.

In some cases, 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.

Although some doctors take regular blood tests for CEA, it is not a certain test to prove whether the cancer is growing or not. CEA is most likely to be used after surgery to determine if the cancer has come back (recurrence).

#### 4.14 MAGNETIC RESONANCE IMAGING (MRI)

The procedure for MRI is similar to a CT scan, but it uses a change in the magnetic field in tissues of the body instead of X-rays to build up a series of clear and detailed cross-sectional pictures of your body. It does not often provide any additional information to the CT scan.

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## 5: WHAT ARE THE TREATMENT OPTIONS?

If you have bowel cancer, there are some decisions to be made regarding what type of treatment to have (or not have).

The choices you have will depend on whether or not the cancer has spread, or is at risk of spreading. You are likely to have a full physical examination and a series of tests to see if the cancer has spread (see **p19** 'What procedures might I have?').

To put it simply, the choices are:

- to have surgery (which will be needed by the great majority of patients)
- to have chemotherapy
- to have radiotherapy
- to have adjuvant therapy
- to take part in a clinical trial
- to do nothing for now.

While surgery is the main treatment for bowel cancer, there are other treatments that can help.

People with colon or rectal cancer may get help from chemotherapy or radiotherapy (or both). Chemotherapy involves the use of strong drugs to kill or slow the growth of cancer cells. Radiotherapy uses strong X-rays to kill or slow the growth of cancer cells.

You may choose to have your treatment as part of a clinical trial. Clinical trials are discussed later in this chapter (see **p41**).

Whatever treatment you have, you should ask your doctor whether the treatment planned for you has any risks.

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### Recommendation:

Your doctor should inform you of the likely impact various treatment choices might have on your quality of life.

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### How to make the decision

As a patient, you should be involved in the decision-making process about your treatment. Your doctors should explain to you everything they know about your cancer and you should be asked whether you are in agreement with the proposed treatment. Take your doctors' advice but be aware of your options. This is your decision.

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? (see **p15** 'You need reliable information').

The next step is to work out whether a cure is possible, or whether it is not. Your doctor can advise you of this. Armed with his or her 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.

The following sections discuss these treatments.

## 5.1 SURGERY

The aim of an operation for bowel cancer is to remove the cancer and enough of the tissue around it to make sure no part of the primary bowel cancer is left behind.

This is major surgery. It takes time, and you will need time to recover from it.

### **Will it cure me?**

If your colon cancer has not spread outside the bowel then surgery can remove the cancer, and cure you. Approximately 70 to 80 per cent of colon cancer patients 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 (upwards of 70 per cent).

Unfortunately, surgery is unlikely to cure the majority of patients whose cancer has spread to other organs such as the liver, but the surgery might ease any problems the cancer is causing. However, in a small percentage of patients where the cancer has spread only to the liver, surgery to remove that part of the liver may cure you.

### **Before surgery**

If you are having surgery for bowel cancer, you will go through a few procedures first. These are:

- a discussion of your full medical history
- a full physical examination of your heart, lungs and liver
- a blood test to check for anaemia and assess your kidney function.

Then there is a range of issues (some of which may or may not be relevant to your circumstances) for you to think about and talk to your doctor about. These include:

- who should do the operation?
- informed consent

- preparing for a stoma (if required)
- preparing the bowel
- storing blood
- preventing blood clots
- preventing infection
- what type of surgery will I have?

These issues are discussed below.

### **Who should do the operation?**

There is some research showing that surgeons who have had specialist training and a lot of experience in bowel cancer may produce fewer complications during surgery, and maybe a lower death rate, compared to less experienced surgeons. You should ask about the surgeon's expertise in colon and rectal surgery separately as they are different operations. The only way for you to know how much experience your surgeon has had is to question him or her or ask your general practitioner.

Therefore, especially if you are having surgery for rectal cancer, you should see a surgeon with specialist training and experience in cancer of the rectum.

### **Informed consent**

Before anybody can operate on you, you must agree to have the operation and this involves providing written consent. This involves more than just saying 'OK, doctor, whatever you think'. Giving informed consent, as it is called, involves understanding:

- the reasons for the operation
- the risks involved in both the operation and the anaesthetic, and how large or small those risks are
- what may happen if you don't have the operation
- the likely outcome after the operation
- anything else you want to know.

Your doctor may give you some written material to read. If it is not clear and you do not understand the information, tell your doctor so that he or she can answer any questions you have.

You may have a lot of questions to ask. Your relatives and close friends may also have questions they want to ask. This may take time or even more than one consultation. Do not hesitate to have additional consultations and seek a second opinion if you need to.



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## Recommendation:

Before the operation, it is essential you have a full discussion with the surgeon and anaesthetist.

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### **Preparing the bowel**

If you are going to have surgery for bowel cancer, you are likely to have a bowel preparation (see **p20** 'Bowel preparation').

Recently, research has shown that having a bowel preparation before surgery does not reduce your risk of wound infection or breakdown of the wound. Therefore you should discuss with your surgeon whether or not a bowel preparation is necessary for your circumstances.

### **Storing blood**

Up to 50 per cent of people having surgery for bowel cancer have a blood transfusion before, during or after their surgery. Blood can be collected from other people, or you can 'donate' it to yourself before the operation. This is known as having an 'autologous blood transfusion'. It is important to check with your doctors if you wish to use your own blood as in some cases, the blood must be taken at the same place where you are going to have the operation (for example, sometimes the blood cannot be transported from one clinic to another).

You may wish to use your own blood for personal reasons or religious beliefs. Using your own blood is also safer, because there is little or no risk of infection, and fewer complications. If you wish to store your own blood for possible use while in hospital, you can discuss this option with your doctor two to three weeks before you are to have surgery.

The procedure for donating blood is simple and painless. Your doctor or a nurse puts a needle into your arm, and collects your blood into a bag or in tubes. The procedure can vary in length from 15 minutes to one hour depending on how easily and how much blood is collected. You may feel weak or tired for a short period of time afterwards, however a rest and something to eat or drink can quickly make you feel better.

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## Recommendation:

If you are having elective surgery for bowel cancer, consider storing blood for a blood transfusion.

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### **Preventing blood clots**

People with cancer are prone to getting blood clots in their legs, as are people having any abdominal surgery. So if you are having surgery for bowel cancer, you have a much higher risk of getting blood clots.

Blood clots can be dangerous during any type of surgery. The clots can break away from where they initially form and travel through your bloodstream, lodging in your lungs or heart where they can cause life-threatening complications.

Surgeons take the risk of blood clots very seriously and may use either or all of three proven methods to reduce your risk of getting blood clots.

These include:

- having regular injections of a blood-thinning substance called heparin, or a similar substance
- intermittently compressing your calves while you are having the surgery
- encouraging movement as early as possible after surgery.

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### **Recommendation:**

Everybody having surgery for bowel cancer should have treatment to help prevent blood clots.

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### **Preventing infection**

Antibiotics are now given routinely with bowel surgery. People who have antibiotics have fewer problems after surgery and don't need to stay as long in hospital.

Many types of antibiotics are effective against bowel organisms—there is no research showing which is the best. It is important for you to tell your doctor if you have any allergies to antibiotics before you have surgery so as to avoid any complications.

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### **Recommendation:**

Everybody having surgery for bowel cancer should have antibiotics.

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### **Surgery**

There are several things that you and your surgeons will consider both before and during your operation for bowel cancer. These are:

- what type of surgery might you have?
- what if they find two cancers?
- what else might happen?

### **What type of surgery might I have?**

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

The main types of surgery are:

- a colectomy, for colon cancers
- an anterior resection or low anterior resection, mainly for rectal cancers
- an abdominoperineal (AP) resection, (less common) for very low rectal cancers close to the anus.

All of these types of surgery are described in more detail below.

### **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 then rejoining the two ends of the bowel. You will end up with a scar across your lower abdomen, a temporary catheter to collect urine until your wound begins to heal, and a 'shorter' colon. Depending on how much of your bowel is removed, you may or may not defecate more often, or have diarrhoea. You may also need to have a temporary colostomy (see **p34** 'Having a stoma').

There are four possible types of surgery you can have for colon cancer (colectomies), depending on the position of your cancer (see diagram on **p31**). If your cancer is:

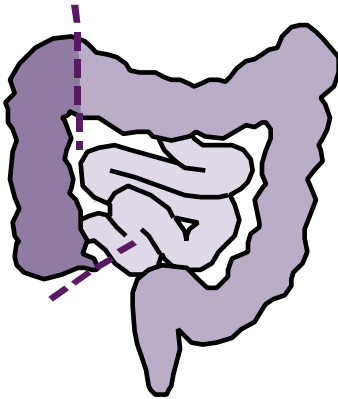
- on the right side of your colon—a right hemicolectomy
- on the left side of your colon—a left hemicolectomy
- in the middle of your colon—a transverse colectomy
- in the sigmoid colon—a sigmoid colectomy.

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 (see **p32** 'Anterior resection'). This type of surgery involves joining your bowel together in the upper area of the rectum.

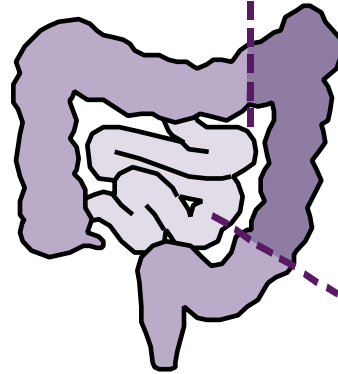
Some surgeons have also used laparoscopic ('keyhole') surgery on people with colon cancer. The idea is that having a smaller wound will allow people to recover more quickly from the surgery.

This is an experimental treatment, and so far the evidence is unclear as to how effective this treatment may be, or what complications could arise.

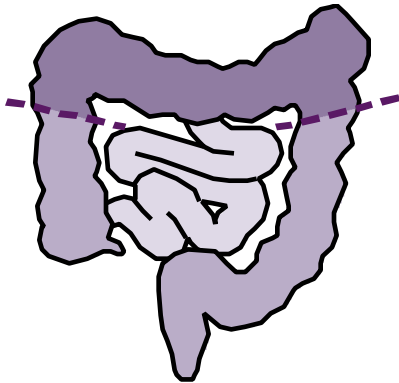
### Types of colectomies for colon cancer



*Right hemicolectomy*



*Left hemicolectomy*



*Transverse colectomy*



*Sigmoid colectomy*

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

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### Recommendation:

You should not have laparoscopic surgery unless it is part of a clinical trial.

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### **Surgery for rectal cancer**

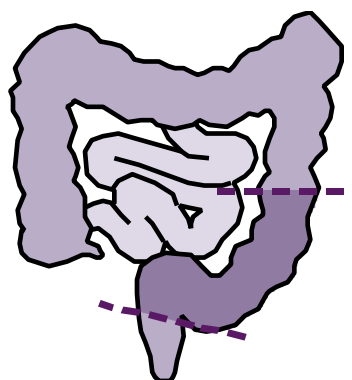
There are two types of surgery you could have for cancer in the rectum: an abdominoperineal (AP) resection or an anterior resection, depending on the position of the cancer in your rectum (see diagram on the next page).

Men having surgery for rectal cancer should consider having sperm storage if fertility is an important consideration. For more information on this, ask your doctor or a fertility counsellor.

### Types of surgery for rectal cancer



*Abdominoperineal (AP) resection*



*Anterior resection*

The main types of surgery you might have for rectal cancer are either the low or ultra-low anterior resection, depending on where your cancer is in the rectum. These operations require only one wound and you will not need a permanent stoma. The muscle that controls the opening and closing of the anus (anal sphincter), is not touched so it is unlikely you will lose control of your bowels (incontinence). A new version of the low anterior resection, a total mesorectal excision (TME) is now being trialed around the world. Preliminary results indicate that TME may be a better operation but this is not yet certain.

A less common approach for rectal surgery is to have 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 **p34** 'Having a stoma').

There is no difference in survival between people having the different types of surgery. People having a low or ultra-low anterior resection have a better quality of life than those having an AP resection.

However, low anterior resection is not always possible, particularly if the cancer is already near the anal sphincter.

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### Recommendation:

Most patients with rectal cancer will be able to have a low or ultra-low anterior resection to remove their cancer. However, an individual will have an AP resection if the anus cannot safely be kept.

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### **What if they find two cancers?**

About 5 per cent of people with bowel cancer find they have two separate cancers in their bowel at the same time. Sometimes this is discovered before surgery, and sometimes this is discovered during surgery. In general it is important to have a total colonoscopy before surgery to check for a second cancer.

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

1. take out the two smaller sections and rejoin all the bowel
2. take out one larger section containing both cancers, or
3. take out 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 check-ups with colonoscopy for the rest of their life. If you have two cancers at once, your chances of another cancer developing are higher than average.

### **What else might happen during surgery?**

There are three things that surgeons keep in mind when operating on people with bowel cancer—attachment, and secondary liver and ovarian cancer.

#### ***Attachment***

In about 10 per cent of people with bowel cancer, the cancer seems to be attached to another organ, such as the uterus or bladder. Half the time, this is because the cancer has invaded that organ and joined it to the bowel, but the other half of the time, the apparent attachment is only due to inflammation.

Research shows that the best thing for surgeons to do if the cancer is attached to another organ is to remove the attached organ with the bowel. People live longer that way, rather than if the surgeon tries to separate the bowel from the other organ.

However, a woman who has her uterus removed is no longer fertile. For premenopausal women, this can be an important issue that you may wish to discuss with your doctor or a fertility counsellor. Having your uterus removed can also be significant for postmenopausal women, who may also wish to discuss this issue with their families, friends or counsellor.

#### ***Secondary liver cancer***

Between 10 and 20 per cent of people having surgery for bowel cancer will already have secondary cancers in their liver. They may know this already, or the surgeon may discover it during the operation.

Usually, the best thing to do at the time is nothing, and wait for a couple of months, before working out the best approach (see **p43** 'What if I have secondaries in my liver?'). But occasionally, if there seems to be only one secondary cancer in

the liver, if it is in the right position, and the surgeon has done the operation successfully before, it can be removed.

### ***Secondary ovarian cancer***

About 5 per cent of women with bowel cancer will 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 to make sure.

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 ovaries are still functional, and the issue of removing the ovaries is more complicated and should be discussed with your doctor or a fertility counsellor.

## **5.2 HAVING A STOMA**

For some people having bowel surgery there is the chance of having a permanent or temporary stoma.

The word 'stoma' comes from the Greek word meaning 'opening' or 'mouth'. A stoma is an artificial opening into the body created by surgery to act as an exit for body wastes (faeces). The piece of bowel chosen is brought out onto the abdomen or 'tummy' through a hole the surgeon has made, opened out onto itself and stitched to the skin. The location of the hole has been previously marked by the stomal therapy nurse. The opening onto the abdomen allows the faeces to be diverted and collected in a bag.

You are likely to need a stoma if you:

- have an emergency operation because your bowel is blocked—the stoma could be either temporary or permanent.
- need to divert faeces away from the join that your surgeon has made when removing your cancer—this is usually a temporary stoma.
- need to bypass your cancer—the stoma could be either temporary or permanent.
- have most of your bowel removed—this is usually a permanent stoma.
- have a very low rectal cancer and your rectum and anus need to be removed—this is a permanent stoma.

Occasionally, the need for a stoma cannot be foreseen before surgery, so some people go into an operation thinking they will not need a stoma, but awake from the anaesthetic with a stoma. It is recommended that a stomal therapy nurse sees all people who might have a stoma before the operation, as well as after. It helps to know what you might be in for, rather than waking up to a surprise. You should discuss this possibility with your surgeon.

### **A stomal therapy nurse**

If there is a chance you will need a stoma, you should be seen by a nurse with specialist training in the management of stomas. He or she will explain the surgery and management of the stoma with the surgeon and identify the best place for the surgeon to place it. Your stomal therapy nurse will also help you adjust to having a stoma and regain confidence. Ongoing care, support and advice are available after discharge from your stomal therapy nurse or you will be referred to another specialist in your district.

### **Where can I find a stomal therapy nurse?**

Stomal therapy nurses are employed in many metropolitan public and private hospitals, in country base and large private hospitals. In the community, some district nursing services have specialist stomal therapy nurses who can be consulted. Many Ostomy Associations, which supply the bags, also have stomal therapy nurses on a sessional basis. Your surgeon and GP can help you find a stomal therapy nurse, and so can the Cancer Information Service on 13 11 20. Don't hesitate to contact one with any of your concerns.

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### **Recommendation:**

People with bowel cancer who may need a stoma should be informed about this and should have the opportunity of seeing a stomal therapy nurse before surgery as well as having follow-up visits.

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### **What does a stoma look like?**

A stoma is roughly the size of a 20 cent coin. It is soft, moist and red in colour with a puckered appearance. In fact it is the same type of tissue as the inside of your mouth. There is no feeling in the stoma itself—but the skin around it can be felt. It may be at skin level or raised a little.

### **Types of stomas**

There are two major types of stomas, named according to the place in the bowel they have been taken from. The first type of stoma is a colostomy, which comes from the large bowel. This can be either a transverse colostomy or a sigmoid colostomy (see diagrams on the next page). The second type of stoma is an ileostomy, which comes from the small bowel.

The faeces are collected in a discreet disposable bag, which sticks to the skin with special wafer backing. Modern bags are leak proof and do not smell. The bag cannot be seen under clothing and no one will know if you have one unless you choose to tell them. Some people are suitable for stomal washouts and may only need to wear a bag from time to time. See your doctor or stomal therapy nurse for more information on stomal washouts.

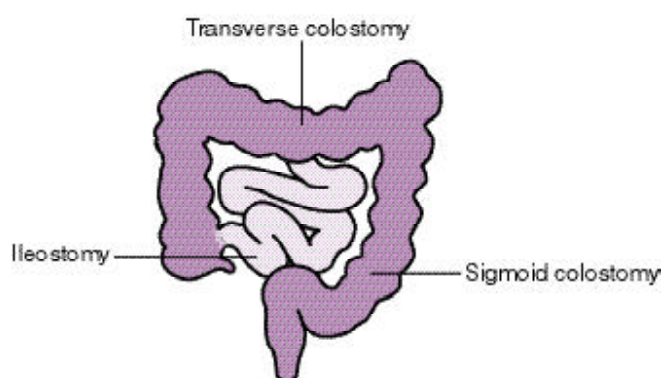


Each situation is different, and there are different bags for each. Some bags are changed once or twice a day; others stay on the skin for several days and are emptied from the bottom several times per day. Your stomal therapy nurse will advise you and teach you how to manage.

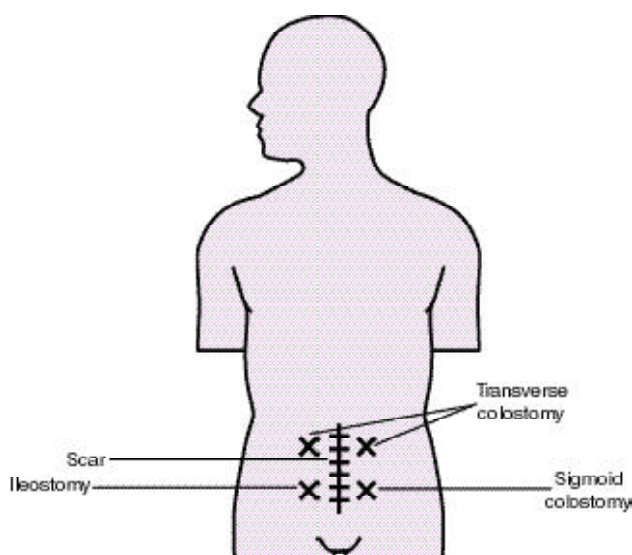
### **Where will they put it?**

Depending on the type of stoma needed, it can be placed in one of four different positions. The stomal therapy nurse will discuss this with the surgeon and mark a suitable place, taking into consideration the surgery, waistline, skin folds and visibility for you to be able to manage and attend to the bag.

### **Stoma types and positions**



*Types of stomas*



*Stoma positions*

### **Closure of a temporary stoma**

As mentioned earlier, not all stomas are permanent, and some can be removed. A temporary stoma is often removed two to three months after the initial surgery, when the join in the bowel is healed. Usually this is checked with an X-ray using a small amount of radio-opaque dye.

Your stay in hospital will be a lot shorter (four to seven days) than your initial surgery. The wound is usually just at the stoma site where the surgeon has freed up the bowel, closed the hole in it and placed the bowel back into position in the abdomen.

It may take a few days for the bowel to work and you may experience some urgency to go to the toilet, as everything is settling down and you recommence your normal diet again.

### **Coping with a stoma**

Ideally you will know before your operation if you will have a stoma, but sometimes it cannot be foreseen and you may wake up with an unexpected stoma. Adjustment to the situation under these circumstances is naturally more difficult than having time before the operation to prepare for the change.

Of course having a stoma, even temporarily, is a big change in a person's life and takes adjustment. Your stomal therapy nurse will discuss all aspects of living with a stoma and provide you with written material, booklets and videos. Many aspects of your life, such as gaining confidence to go out, managing when travelling, and sex will be covered. You will also be able to speak to another person with a stoma if you find that helpful.

Your family may also need information and support, and the stomal therapy nurse will be happy to include them in these discussions. You may like a family member to be your backup person as you gain confidence in management to learn about the stoma so they can support you until you can manage on your own.

In some areas, it is possible to buy custom-made garments that hold a bag neatly and firmly—for instance, attractive underwear for women, bathers and underpants for men. Ask your stomal therapy nurse for more information or contact the Cancer Information Service on 13 11 20.

There are between 20,000 and 22,000 people in Australia with a stoma. There is no reason why a stoma should keep a person from enjoying a normal family, social and business life.

### **Support groups**

If you are interested, your stomal therapy nurse can put you in touch with a support group near you. It will probably be attached to the Ostomy Association that you may wish to join. You will receive a quarterly informative magazine as well, to help in your adjustment. Each state has a support group for young people up to the age of 35.

### 5.3 CHEMOTHERAPY

This is the treatment of cancer with special anti-cancer drugs. The aim of chemotherapy is to kill all your cancer cells while doing the least possible damage to your normal cells. The drugs treat cancer cells by stopping cancer cells from multiplying.

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

#### **Side effects of chemotherapy**

Some drugs used in chemotherapy can cause side effects. The main side effect is diarrhoea, but can also include feeling sick, vomiting, feeling off colour and tired, and some thinning or loss of hair from your body and head. Some people experience mouth problems like ulcers, and some people find their skin becomes red and itchy. These side effects are temporary, and steps can be taken to prevent or reduce them.

While taking chemotherapy, you have a higher risk of infection and having problems with bleeding. Report the following symptoms to your doctor: excessive tiredness, bruising or bleeding easily. If you have a temperature over 38 degrees Celsius (100 degrees Fahrenheit), contact your doctor or nurse immediately, and go straight to hospital.

While taking chemotherapy, it is important to find out from your doctor how best to look after your health, and try to avoid people with coughs, colds and other infections. Sometimes this will not be practical.

#### **Chemotherapy for colon cancer**

Chemotherapy with the right drugs can help some people with colon cancer. It is often an effective treatment for people whose cancer has spread into the lymph nodes but no further (known as Stage C cancer).

If your cancer has spread into the liver and bones (Stage D cancer), chemotherapy can help to reduce some symptoms and prolong your life, although it 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 with Stage B cancer (cancer which involves the whole of the bowel wall) might benefit from chemotherapy. It is recommended that if you have Stage B cancer and, after talking to your doctors, want to have chemotherapy, then you should take part in a clinical trial of the treatment.

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## Recommendation:

The preferred chemotherapy in people with Stage C colon cancer is 5-FU plus low-dose leucovorin for six months.

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### **When should I have chemotherapy?**

If you are going to have chemotherapy for colon cancer, it is recommended that you start it four to six weeks after surgery. This gives you a chance to recover from the surgery and for your wounds to heal.

### **Portal vein infusion**

Portal vein infusion is a method of giving chemotherapy straight into the liver. This should reduce the risk of secondary cancers growing in the liver, which is the most likely spot for them.

This is done by inserting a catheter (a fine, flexible tube) into the portal vein (which leads into the liver) at the time of surgery. Chemotherapy is injected into the catheter. The catheter is removed after all the treatment is finished. The side effects may be less severe than those experienced with standard chemotherapy (see **p38** 'Side effects of chemotherapy').

Having chemotherapy by portal vein infusion increases the survival of people with Stage C bowel cancer, that is, cancer that has spread only to the nearby lymph nodes and no other organs. However, because it does not reduce the incidence of secondary liver cancers, most specialists do not recommend this approach.

## 5.4 RADIOTHERAPY

Radiotherapy treats cancer by using X-rays to kill or injure cancer cells. This radiation can be precisely targeted onto cancer sites in your body. 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.

### **Side effects of radiotherapy**

Radiotherapy can cause temporary side effects, including diarrhoea and nausea (which can be helped by medication) and tiredness. Mild headaches are also quite common.

If you are having radiotherapy, your skin in the treatment area may become red and sore after two or three weeks of treatment. From the start of your treatment, you will need to take care washing and avoid shaving the area or wearing clothing that can rub. Check with your doctor or nurse before using any talcs and lotions. Ask a member of your radiotherapy treatment team for a cream to ease the burning sensation.

Women having radiotherapy to the pelvis may go through menopause, if they haven't already done so. This means that you may become infertile (unable to become pregnant). Premenopausal women who are advised to have radiotherapy to the pelvis may wish to discuss the issue with their surgeon, a fertility counsellor, or a local IVF (in vitro fertilisation) clinic. Infertility can affect some men if they have radiotherapy to the pelvis: if you are concerned about this, you may wish to seek counselling.

It is fairly uncommon for men who have had radiotherapy to the pelvis to have difficulties getting an erection. However, if you find you do have this difficulty there are many ways to overcome this problem—your doctor will be able to advise you.

A small number of people who have radiotherapy to the pelvis will develop permanent problems with the bowel, like bleeding, narrowing of the small bowel or rectum, inability to absorb food and nutrients properly, bowel or urinary incontinence and a desire to go to the toilet very often. These problems can affect people differently, and if you find you are having problems, these should be discussed with your doctors.

All state cancer councils have information on what to do about the side effects of radiotherapy. Please contact them for information, or call the Cancer Information Service on 13 11 20.

### **Availability of radiotherapy**

Radiotherapy is available in all major Australian cities and increasingly in rural centres. Radiotherapy Outreach clinics are performed in many country centres. State governments and some charities provide assistance with travel and accommodation for country patients who need radiotherapy away from their home. There are longish waits in a few radiotherapy (Radiation Oncology) centres. This may play an important part in your decision-making about treatment, especially for country people.

## **5.5 CHEMOTHERAPY AND RADIOTHERAPY FOR RECTAL CANCER**

If you have rectal cancer that can be operated on, in some circumstances you may get help from treatments other than surgery. The best results come from having surgery, plus radiotherapy and chemotherapy. Chemotherapy and radiotherapy are commonly given after surgery (post-operative). This form of treatment reduces the chance of the cancer coming back in the rectum, and may reduce the risk of it spreading to other parts of the body.

### **Side effects of combined treatment**

If you have combined treatment—chemotherapy and radiotherapy—the chances of the treatments working are higher. But the risk of side effects is also higher.

Around one third of people having combined treatment experience serious problems. Combined treatment is also more likely to cause bowel problems such as diarrhoea and incontinence.

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## Recommendation:

It is recommended that people with high-risk rectal cancer have 5-FU based chemotherapy and radiotherapy after surgery.

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### 5.6 TAKING PART IN A CLINICAL TRIAL

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

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

- What treatments are being tested and why?
- What extra tests apart from my normal treatment will I be involved in?
- 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?

If you decide to join a clinical trial, you will be given either the best existing treatment according to your doctors or a promising new treatment. In a randomised controlled trial, you will be assigned at random ('like a toss of a coin') to receive one treatment or the other. The trial is likely to be double blind, meaning that neither you nor your doctor will know which treatment you are on.

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

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## 6: WHAT IF I HAVE SECONDARIES IN MY LIVER?

Nearly 50 per cent of all people treated for bowel cancer will develop secondary cancers in their liver within five years.

### 6.1 SYMPTOMS OF SECONDARY LIVER CANCER

The main signs and symptoms of secondaries in the liver are:

- pain on the right side of the abdomen
- shoulder pain
- tenderness on the right side of the abdomen
- bloating
- nausea
- jaundice (a yellowish discolouration of the skin, which might be itchy)
- dark urine.

### 6.2 TESTS TO FIND SECONDARY LIVER CANCER

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

To work this out, your doctors will talk to you about how you feel, examine you carefully and arrange a number of tests. These tests include:

- blood tests such as a full blood count and liver function tests (see **p23** 'Full blood examination', and **p23** 'Liver function test')
- a scan of your liver by ultrasound, CT scan or MRI (see **p22** 'CT scan of the abdomen', and **p24** 'MRI')
- depending on your progress so far, bone scans, CT scans of your abdomen and X-rays.

### 6.3 WHAT TREATMENTS WILL I HAVE FOR SECONDARY LIVER CANCER?

If your bowel cancer has spread to other parts of your body, apart from the liver, then there is no treatment that can cure you of the cancer. However, many treatments can relieve your symptoms.

The options for someone with secondary cancer in their liver include:

- surgery
- standard chemotherapy

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

If you have a few nodules of cancer in your liver, and you have no signs of cancer anywhere else, then surgery can be considered in addition to the other treatments listed.

If you have many cancers in your liver, say five or more, then treatment is unlikely to cure you and surgical removal of these tumours is not usually helpful. But treatment can still help with specific problems.

The usual treatment for a person with secondary liver cancer (if surgery is not suitable) is to first have chemotherapy. Usually this involves standard chemotherapy, but in some cases this may be given through the hepatic artery (see **p38** 'Chemotherapy').

Other forms of treatment to destroy the metastases can be used. These include cryotherapy and, less frequently, laser therapy and alcohol injection. These treatments are described in more detail below. However, the advantages of laser therapy and alcohol injection are not yet clear and should only be done as part of a clinical trial.

### **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 fairly small cancers in their liver, have no signs of cancer anywhere else and are reasonably healthy. Between 15 and 50 per cent of such people are alive five years after the operation.

It may be possible, in some cases, to do the operation again if the cancer returns to the liver, and still has not appeared anywhere else.

Removing part of the liver is a major operation. In major cancer treatment units, under 5 per cent of people who have liver surgery do not survive the operation. That figure is likely to be higher outside major units.

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### **Recommendation:**

People with up to four cancers in their liver, who have no signs of cancer anywhere else, and who are otherwise healthy, could consider surgery to remove cancers.

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### **Standard chemotherapy**

Standard chemotherapy is given in most circumstances for secondary cancer in the liver (see **p38** 'Chemotherapy'). An alternative to having standard chemotherapy is to receive your chemotherapy directly into the liver. This is called hepatic arterial infusion.

### **Hepatic arterial infusion (HAI)**

Hepatic arterial infusion (HAI) is a form of chemotherapy in which the drugs are injected directly into the liver. HAI could be considered by people who have had bowel cancer and have:

- secondary cancers in their liver
- no secondary cancers anywhere else
- more than five cancers, or they are too big for surgery.

If you choose to have HAI, you will have an operation in which a form of tubing (a catheter) is put into your hepatic artery, the artery that runs to your liver. That tubing is connected to a pump, which is placed under your skin and used to deliver the chemotherapy directly into the liver.

Usually, during the operation, the surgeon will take out your gallbladder to prevent inflammation. There are minimal side effects associated with not having a gallbladder.

HAI does not make people feel any better or live longer than does standard chemotherapy. Complications from the operation occur in 5 to 8 per cent of patients. Up to 1 per cent die from the operation, and between 5 and 10 per cent of people have complications from the chemotherapy including inflammation of the bile duct, gastritis (a painful inflammation of the stomach), formation of a stomach ulcer and diarrhoea.

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### **Recommendation:**

Hepatic arterial infusion has been shown to increase the survival of patients compared to those who have the best supportive care. Even though more patients respond to having HAI than standard chemotherapy, there is still little evidence to show that people who do have HAI actually live longer than when they have chemotherapy.

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### **Cryotherapy**

Cryotherapy is an operation whereby surgeons use a probe to freeze and kill cancers that have spread to the liver.

The main side effects of cryotherapy are the same as those experienced after having any major operation; you will have a scar on your abdomen that will be painful and need time to heal. Probably 1 to 2 per cent of people who have this operation experience serious complications and die.

Cryotherapy is a fairly new treatment. Only about 2,000 people in the world have had it, so there is still quite a bit to learn. For example, we don't know whether it is better or worse than surgery, or the other forms of treatment.

### **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 from the bowel. It has also been used at times for people with small cancers that have come from the bowel. It does not seem to be quite as effective as HAI, however, some people have lived quite a few years after having such treatment.

### **Laser treatment**

It may be possible to kill some cancers with laser treatment. This is a very new technique which is currently not widely available.

One benefit of this treatment is that it can be done through the skin, rather than needing a full operation. But there is little research to show how effective it is.

### **Do nothing for now**

People whose cancer has spread to their liver, and have no treatment for it, find that the cancer eventually spreads and results in death. Approximately 10 to 15 per cent of people with liver secondaries who have no treatment are alive after three years, and fewer than 3 per cent are alive after five years.

Still, having no treatment maybe the right choice for some people with:

- cancer in other parts of their body, or
- a lot of cancer in the liver, or
- not many problems from the cancer in the liver.

The decision to have no treatment at all should not be made without first having a detailed and careful discussion with your doctor and family. You can always leave treatment for now, and take it up several weeks later if you wish.

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## 7: AFTER THE TREATMENT IS OVER

### 7.1 WHAT CAN I DO TO HELP MYSELF?

Probably the most important thing you can do is give yourself time. Finding out you have cancer, and having treatment for it, is tiring, apart from anything else. Surgery is tiring, and so are chemotherapy and radiotherapy.

You need to give yourself 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 you won't be fit enough, for a while, to do all the things you used to do.

Many people take time to adjust to the idea that they have had cancer. It can be a shock, especially as many of us think nothing serious is ever going to happen to us.

If you have a stoma, it may also take time to get used to it. Learning how to look after your stoma can take time, as can the idea of having it.

### 7.2 CAN I STOP THE CANCER COMING BACK?

There is not much research about ways you can prevent the cancer coming back. There is however, 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 Information Service on 13 11 20 or your local doctor.

### 7.3 CHECK-UPS

It is recommended that people who have been treated for bowel cancer have regular check-ups. This allows the doctor to monitor your health: you may find this reassuring following your treatment.

#### **Which doctor should I see?**

If you are having regular check-ups, the best approach is for your surgeon and GP to keep an eye on you. You could visit one or other in turn for your check-ups.

#### **What tests should I have?**

This section is for people who have no signs or symptoms that suggest their cancer has returned. If you have concerns that your cancer has returned, then you will have appropriate tests.

If you seem to be free of cancer, your surgeon will recommend that you have regular check-ups. This may involve a check-up soon after leaving the hospital, then each six months for two years, and once a year after that.

At each check-up you should have:

- a talk about how you're feeling
- a physical examination
- a rectal examination (see **p19** 'Rectal examination')
- a sigmoidoscopy, where appropriate (see **p19** 'Sigmoidoscopy')
- and in some cases, a CEA test (see **p23** 'Carcinoembryonic antigen test').

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, then you should have a colonoscopy every three to five years.

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## 8: WHAT IF THE BOWEL CANCER COMES BACK?

### 8.1 TESTS

If your cancer returns, you will have a number of tests to find out where the cancer is. These tests will allow your doctor to tell you whether it is possible for you 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. All are good at picking up cancer, however no one test is perfect. See **p19** ‘What procedures might I have?’ for details.

### 8.2 WHAT IF AN OPERATION IS POSSIBLE?

If it is possible for you to have an operation, then it can be useful to help relieve some symptoms and delay others. Occasionally, an operation could remove all the cancer, and give hope of a cure. But usually, operations for rectal cancer that has come back are intended to ease and delay symptoms.

Radiotherapy and chemotherapy can also help people with a recurrence of rectal cancer. Having radiotherapy before surgery can mean that the cancer shrinks enough to be taken out more easily. Chemotherapy after surgery might delay the return of the cancer.

### 8.3 WHAT IF AN OPERATION IS NOT POSSIBLE?

Most people whose bowel cancer comes back find it has spread too much to be able to be cured. There are many forms of treatment that can help—they can ease pain, ease other symptoms and buy time. Research has shown that chemotherapy can improve both how long you live and your quality of life.

### 8.4 TREATING THE 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 until you need it, although this decision should not be made without first having careful discussions with your doctor.

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## 9: WHAT QUESTIONS COULD I ASK IF I HAVE BOWEL CANCER?

Here is a list of questions you might like to ask your doctor(s). You don't have to ask these questions, and you will probably have others that you want to ask. But it is a start.

You may find it easier to ask some of these questions at each visit to your doctor, rather than trying them all in one go.

There is space at the end of Chapter 9 for you to write down any additional questions you think of.

### **The first step**

- How do you know I have bowel cancer?
- What is bowel cancer?
- Has it spread? If so, how far?
- Can I be cured?
- What are my chances of cure?

### **How will it affect me?**

- Is there anyone else with bowel cancer I could speak to?
- How will it affect me physically? Mentally? Socially?
- Will it affect my sex life and my fertility?
- Is my family a 'bowel cancer family'?

### **Tests**

- What tests might I have?
- What will they tell you?
- Do they hurt?
- Are there any risks of complications?

### **Options for treatment**

- What can I do to help myself?
- What can you do to help me?
- What are the options for treatment?

**Doing nothing for now**

- What happens if I do nothing? Will I get sick quickly? Could I still be cured?
- If I do nothing now, could I have treatment later?
- If I do nothing now, and have treatment later, will it affect my chances of cure?

**Surgery**

- What operation would I have?
- What are the risks?
- For how long would I be in hospital?
- What would you take out?
- Where would the scars be?
- How long before I could get back to my normal life?
- Would it cure me?

**Stoma**

- What's a stoma?
- Would I need one?
- If I did need one, would it be permanent?

**Radiotherapy**

- How does radiotherapy work?
- What does it do?
- How long does it take?
- Do I have to be in hospital?
- What are the risks?
- Can I get help if I need to travel?
- Would it cure me?
- Is it painful, and are there side effects?

**Chemotherapy**

- How does chemotherapy work?
- What does it do?
- How long does it take?
- Do I have to be in hospital?

- What are the risks?
- Will my hair fall out? When will it grow back?
- Would it cure me?
- Is it painful and are there any side effects?

**Check-ups**

- Would I need check-ups?
- How often?
- Who would do them?
- What tests would I have?
- If the cancer is picked up in a check-up, before it's causing me any problems, does that make any difference?

**What if the cancer comes back?**

- How would I know the cancer has come back?
- If the cancer comes back, could I still have treatment?
- Would the cancer still be curable?
- What sort of treatments could I have?
- What is palliative treatment?
- Can I control the pain?

**Where can I get help?**

- What do I do if I get sick and need help?
- How about if it's at night or on the weekend?
- Where can I get more information?
- Are there counsellors or nurses I could talk to?
- Are there other people with bowel cancer I could talk to?

**Other questions:**

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# SECTION 2

Information for family and friends

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## 10: REDUCING YOUR RISK OF BOWEL CANCER

While we do not fully understand the causes of bowel cancer, we do know that there are several important things you can do to reduce your risk of developing bowel cancer. These include certain lifestyle factors, such as maintaining a healthy weight, having a healthy diet, getting enough regular exercise and having regular check-ups if you find you are at a higher than average risk of developing bowel cancer.

It is believed that 66 to 75 per cent of bowel cancer cases could be prevented by eating a healthy diet and exercising regularly.

If you would like more information about reducing your risk of bowel cancer, contact the Cancer Information Service on 13 11 20.

### 10.1 IS BOWEL CANCER PREVENTABLE?

No cancer is completely preventable, but the chances of developing one can sometimes be greatly reduced.

### 10.2 A HEALTHY DIET

Food and nutrition have an important role to play in modifying the risk of developing bowel cancer.

#### **Fruit and vegetables**

The most important thing we can do to provide protection from bowel cancer is to eat five or more servings each day of fruit and vegetables. One serving of vegetables weighs about 60–90 grams, and one serving of fruit weighs about 120–140 grams.

Vegetables have been shown to provide strong protection against bowel cancer, therefore you should eat a wide variety of fruit and vegetables, especially cruciferous vegetables such as bok choy, broccoli, brussels sprouts, cabbage, cauliflower, chinese cabbage, collards, kohlrabi, mustard greens, swedes and turnips.

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### Recommendation:

Eat five or more portions per day of a variety of vegetables and fruits all year round.

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## **Fibre**

Eat plenty of fibre, especially wholegrain cereal fibres and wheat bran (also known as *poorly soluble cereal fibres*). Eating plenty of cereals is good for your general health and may also protect you against bowel cancer. Cereals contain dietary fibre and starch, important components of a healthy diet.

Cereals do not just include the commercial cereals many of us eat for breakfast. They also include wholegrain rice and pasta and wholegrain breads. Wheat bran in particular has been shown to protect against bowel cancer. You can find wheat bran in your supermarket as 'unprocessed' or 'natural' bran.

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### **Recommendation:**

Ensure your diet contains a selection of wholegrain cereal fibres and wheat bran, especially if you are at a high risk of developing bowel cancer.

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## **Energy and fat intake**

In general, Australians eat too much fat. There is evidence that a high intake of fat and obesity increase the risk of bowel cancer.

It is important to eat a low fat diet—reduce your dietary fat intake to less than 25 per cent of the energy you consume. It is equally important to eat a low calorie diet—fewer than 2,500 kilocalories (10,480 kJ) a day for men and fewer than 2,000 kilocalories (8,360 kJ) a day for women.

However, some uncommon fats may protect against bowel cancer. These are omega-3 fatty acids (found mainly in fish and fish oil).

---

### **Recommendation:**

Reduce dietary fat intake to less than 25 per cent of the energy you consume.

Eat a low energy diet—fewer than 2,500 kilocalories (10,480 kJ) a day for men and fewer than 2,000 kilocalories (8,360 kJ) a day for women.

---

## **Meat**

There is inconclusive evidence (evidence that doesn't lead to a clear recommendation) about the effect of a high intake of red meat and a person's risk of developing bowel cancer.

It may be important to avoid charring and heavily browning when frying or grilling meat, poultry or fish.

### **Dairy products and calcium**

At present there are no special recommendations about dietary calcium intake and bowel cancer.

In the past, calcium was thought to offer a moderately protective effect against bowel cancer, but recent studies have shown this not to be the case.

In keeping with general healthy diet guidelines, it is recommended you eat and drink plenty of foods containing calcium (eg milk, yoghurt, low fat cheese)—ensuring an intake of between 1,000 and 1,200 mg of calcium per day.

---

#### **Recommendation:**

Ensure a dietary calcium intake of 1,000–1,200 mg per day.

---

### **Other factors**

There are a few other things that may prove to be useful in the future. For example, in population studies, aspirin reduces people's risk of bowel cancer, but doctors aren't sure of the right dose yet, and are too worried about side effects to recommend it for everybody. Regular doses of selenium supplements, which can be obtained naturally from eating whole grains and vegetables, might turn out to be useful but currently the benefits of taking them have not been proven. It is therefore advised that vitamin and selenium supplements are not to be taken. Research is continuing to determine the benefits of these products. Evidence that antioxidant vitamins are protective is poor and beta-carotene in particular is not recommended as it may actually promote some cancer types.

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#### **Recommendation:**

On the basis of available evidence, aspirin, selenium and antioxidant vitamin supplementation are not currently recommended.

---

## **10.3 A HEALTHY LIFESTYLE**

There is now convincing evidence that regular physical activity, especially throughout your life, can offer protection against bowel cancer. While we do not yet know exactly how much activity you need to do to reduce your risk, we do know there are many other benefits to making regular exercise a part of your daily life.

Regular physical activity reduces your risk of cardiovascular disease and helps with the management of other conditions such as osteoporosis, arthritis, non-insulin dependent diabetes and obesity.

Remember, even if you currently do little or no exercise, it is never too late to start. In fact, significant health benefits are to be gained by being moderately active most days of the week even if you have previously been inactive.

It is also wise to restrict the amount of alcohol you drink as alcohol consumption may increase your risk of developing bowel cancer. Men should have no more than four standard drinks per day and women should have no more than two standard drinks per day.



Smoking is also associated with a higher risk of developing bowel cancer. It is recommended that you don't smoke.

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### Recommendation:

Avoid smoking, limit alcohol consumption and be physically active to protect against bowel cancer.

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## 11: EARLY DETECTION

Screening for bowel cancer can reduce the risk of death from bowel cancer in people over the age of 50.

### 11.1 SCREENING TESTS FOR BOWEL CANCER

See your doctor and have regular bowel check-ups if you are over 50 years of age or have:

- any of the warning signs for bowel cancer (listed on **p63**)
- a lot of bowel cancer in the family, or
- a condition known as FAP or HNPCC. (See **p65** 'Bowel cancer in families' for details).

Your doctor should begin your bowel check-up by taking a thorough history focusing on your risk factors. In particular he/she may ask about:

- your symptoms
- your family history of bowel cancer
- your history of benign bowel conditions (eg polyps and adenomas)
- your history of bowel cancer
- any other conditions of the bowel you may have had, eg inflammatory bowel disease.

Your doctor will then perform a physical examination, feeling for any areas in your abdomen that may be enlarged, followed by a rectal examination where the doctor feels inside your rectum with a gloved finger to find any abnormal lumps or swelling (see **p19** 'Rectal examination' for more information).

If further screening for bowel cancer is required, there are two possible tests which you may have, a faecal occult blood test (FOBT) or a sigmoidoscopy. In some cases you may have both. These tests are described in more detail below.

#### **Faecal occult blood test (FOBT)**

The faecal occult blood test (FOBT) is a test used to screen people for bowel cancer.

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#### Recommendation:

It is recommended that people over the age of 50 have an FOBT every two years (or every year if possible).

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### ***What does the test involve?***

The FOBT involves collecting three small samples of faeces (bowel motions) collected on different occasions, smearing them on a slide and sending them to a laboratory to be checked. You do the test in your own home, and return the samples to your doctor or laboratory for analysis.

The test can detect microscopic amounts of blood in faeces. If there is blood present, this may have come from a cancer in the bowel. Your doctor will advise you if you need to follow any special dietary restrictions during the testing period.

### ***What if I have a positive screening test?***

An FOBT can detect up to 80 to 90 per cent of bowel cancers if the recommended dietary restrictions are followed accurately. A positive screening test using FOBT means that blood has been detected in a sample, and bowel cancer *may* be present.

Everyone who has a positive test should have further tests to find out whether or not they have bowel cancer. Most will not have cancer, but a few will, and early diagnosis will greatly improve their chance of cure. Remember, there is a 90 per cent chance of cure if the cancer is found at an early stage.

### ***Where can I get my test?***

You can ask your doctor about having an FOBT, or call the Cancer Information Service on 13 11 20 for more information.

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## **Recommendation:**

Provided there has been a full discussion of the risks involved, it is recommended that people over the age of 50 who are concerned about their risk of developing bowel cancer, and who do not have a family history of bowel cancer, have an FOBT.

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### **Sigmoidoscopy**

This is another test which can be used to screen for bowel cancer. Sigmoidoscopy involves a doctor examining your rectum and lower colon through a flexible or rigid tube which is inserted into your anus. For more information on sigmoidoscopy refer to **p19** 'Sigmoidoscopy'. The benefits of screening by sigmoidoscopy are not as well established as with FOBT, but it is likely to be highly protective.

It is advisable for people over the age of 50 to have screening by flexible sigmoidoscopy every five years. However, it is important that if you develop symptoms in between screening tests, or if any other risk factors become evident (such as a close member of the family developing bowel cancer), you should see your doctor.

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## Recommendation:

In addition to having FOBT screening, people over the age of 50 years are advised to have flexible sigmoidoscopy every five years.

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### 11.2 WARNING SIGNS

There are several warning signs you can watch for which may indicate the presence of bowel cancer.

**It is important to note that these signs can be caused by a number of medical conditions, not just bowel cancer**. If you have a persistent change of this sort, you should see your doctor.

The most common symptom of bowel cancer is bleeding from the anus (or back passage).

Other symptoms include:

- persistent change in your normal bowel pattern, such as diarrhoea or constipation
- feeling that your bowel does not empty completely
- recurring pains or cramps in your abdomen or rectum
- loss of weight without any obvious reason
- general weakness, tiredness and breathlessness. These may be due to anaemia caused by a lack of iron, and this type of anaemia can be a result of bowel cancer.

Everyone over the age of 40 should watch out for warning signs of bowel cancer. See your doctor promptly if you notice any of the above symptoms. For more information about these symptoms, see **p9** 'How might bowel cancer affect me?'.

---

## Recommendation:

All people with suspicious bowel symptoms or rectal bleeding should be investigated, especially if other risk factors (such as older age or family history) are present, or in any person over the age of 40.

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People under the age of 40 should be investigated if there is a positive family history, if there is not an identified cause of symptoms, or if symptoms are persistent.

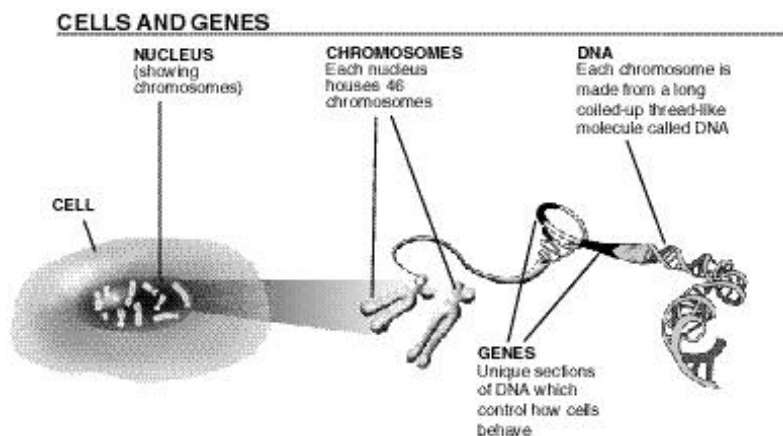


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## 12: BOWEL CANCER IN FAMILIES

### 12.1 INTRODUCTION TO GENETICS AND INHERITANCE

The human body is made up of billions of cells (such as skin cells, brain cells, nerve cells, etc). Almost every cell in the body contains a complete set of genetic instructions (chromosomes). These genetic instructions are made up of almost 100,000 genes, all linked together like tiny beads on a necklace and wound up into tight little packages that fit inside the centre (or nucleus) of a cell. Each gene in the body is made of DNA (deoxyribonucleic acid) and they carry the instructions that control how our bodies grow, develop and work. For example there are genes whose job is to make sure our cells grow at the right time, or genes that control the colour of our eyes, or hair.



*A human cell*

Inheritance is the transfer or 'passing on' of genetic information from a parent to a child. Genes come in pairs, and sperm cells and egg cells contain only *half* the genes needed to make a new human being. When the two come together, the new life contains a complete set of genetic information, half being from the mother and the other half from the father. Sometimes the genes act together in the same way, but if the two genes contain conflicting information, one gene may dominate over the other, eg a gene for dark hair and a gene for light hair will result in the darker hair being dominant.

When we talk about cancer that 'runs in the family' we often assume that everyone in the family will develop the cancer. This is not true. In fact, if your parent has an altered gene that causes bowel cancer, you are at risk of having the altered gene—that is, you have a 50:50 chance of having the altered gene that can cause cancer. If you have a brother or sister with the altered gene, you may also be at risk of having the altered gene.

If you have an altered gene that causes a high risk of bowel cancer, all your children are at risk. Each has a 50:50 chance of inheriting the altered gene from you—like tossing a coin, heads or tails. Remember that because genes are inherited in pairs, if you have an altered gene that causes a high risk of bowel cancer, you will have one copy of the altered gene and one copy of the normal gene. When you have a child you will pass on one or the other of the two genes but not both.

## 12.2 HAVE I INHERITED AN INCREASED RISK OF BOWEL CANCER?

Most people with bowel cancer will not have inherited a high risk altered gene from their parents. In fact 98 per cent of the population have only an *average* risk of developing bowel cancer. These are people who have never had a history of bowel cancer or a condition known as ulcerative colitis, and have no confirmed family history of bowel cancer. People with only one first-degree relative (parent, sibling or child) or second-degree relative (grandparent, aunt, uncle, niece or nephew) with bowel cancer diagnosed after the age of 55 are at a slightly increased risk.

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### Recommendation:

Based on family history, people who have an average (or slightly above) risk of developing bowel cancer should have an FOBT every year and consider having a sigmoidoscopy every five years from the age of 50.

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Some people are thought to be at a *moderately increased* risk of getting bowel cancer. This accounts for only 1 to 2 per cent of the population. These are people who have a first-degree relative (parent, sibling or child) with bowel cancer diagnosed before the age of 55, or two first-degree or one first-degree plus one second-degree relative (grandparent, aunt, uncle, niece or nephew) on the same side of the family with bowel cancer diagnosed at any age. If you are at increased risk, consult your doctor about having regular bowel checks.

---

### Recommendation:

Based on family history, people who have a moderately increased risk of developing bowel cancer should have a colonoscopy every five years starting at age 50 or at age ten years younger than the first diagnosis of bowel cancer in the family, whichever comes first. You should have an FOBT in each of the intervening years.

---

Other people are at a *potentially high* risk of getting bowel cancer. This accounts for less than 1 per cent of the population. These are people with three or more family members who have been diagnosed with bowel cancer, and people whose families have the inherited disorders known as hereditary non-polyposis colorectal cancer (HNPCC) and familial adenomatous polyposis (FAP). These conditions are described in more detail below. If you are at high risk of developing bowel cancer,

you will need to have regular bowel checks. Your doctor may advise genetic testing.

People with relatives who have had bowel cancer can consider having tests that diagnose signs of early bowel cancer. You will have a better chance of being cured if a cancer is detected at an early stage (see **p61** 'Screening tests for bowel cancer').

### 12.3 TYPES OF INHERITED BOWEL CANCER

Two types of inherited conditions, if left untreated, may result in bowel cancer. These are familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC).

FAP accounts for less than 1 per cent of all bowel cancers and is very rare. HNPCC is only marginally more common, accounting for about 1 per cent of all bowel cancers. These figures show that it is uncommon to actually have inherited an altered high risk gene associated with bowel cancer.

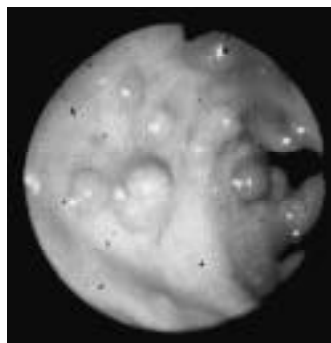
#### **Familial adenomatous polyposis (FAP)**

Familial adenomatous polyposis (FAP) is caused by a change in a gene known as the APC gene. People with this change in every APC gene in their body are referred to as 'having the FAP gene mutation'.

FAP causes polyps to grow inside the bowel. These polyps always turn into cancer if left untreated. Polyps are small growths, often on stalks like a mushroom, and they vary in size from a tiny pinhead to 2 centimetres or more.

Polyposis simply means a lot of polyps. The polyps in FAP are 'adenomatous', which means they can develop into cancer. FAP is also 'familial' which means the condition is passed on through families. If one of your parents has FAP, you have a 50:50 risk of developing FAP.

Most people with FAP develop bowel polyps during their late teens or early adult years. The polyps may start at any age, but rarely before the age of 10.



*Multiple bowel polyps*

### ***What can be done?***

There is much that can be done for someone with FAP.

### ***Gene testing***

For most people at risk of FAP, gene testing is now available. This can tell you whether you have the altered gene which causes FAP. People without the gene will not develop FAP, and their risk of developing bowel cancer is the same as the rest of the population (that is, it increases with age). Gene testing is discussed in more detail on **p70** 'Genetic testing for bowel cancer'.

### ***Regular check-ups***

People with FAP, and at-risk people who have not yet had gene testing, should have regular check-ups with the doctor. These should start when you are around 12 years of age, well before bowel cancer is likely to appear. When you have a check-up for FAP, it will generally involve having a sigmoidoscopy and maybe a barium enema (see **p19** 'Sigmoidoscopy', and **p20** 'Barium enema').

There is evidence showing that deaths due to bowel cancer are significantly reduced in families with FAP that have regular check-ups.

### ***Treatment to prevent cancer***

Treatment can remove polyps by removing all or most of the large bowel (the colon and sometimes the rectum) through surgery. The aim is to prevent cancer from developing, and at the same time, to keep your digestive system working as normally as possible. It is important to discuss the impact of this surgery with your doctor or professional counsellor before and/or after the operation. This type of help can be obtained through your hospital, or by phoning the Cancer Information Service on 13 11 20.

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## **Recommendation:**

Individuals having surgery for FAP should have an operation to remove all or most of the large bowel. It is not recommended that people with FAP routinely take nonsteroidal anti-inflammatory drugs.

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

Hereditary non-polyposis colorectal cancer (HNPCC) is also caused by an altered gene (as with FAP).

The normal function of the HNPCC gene is to repair any problems within the cell, but when a person carries an altered HNPCC gene, the problems are not repaired and this causes bowel cancer to develop. Currently there are five known HNPCC genes, all of them called mis-match repair genes. Each family has a unique HNPCC gene mutation.

People with HNPCC have very few, or no, polyps, which can make this condition more difficult to diagnose than FAP. The cancers which occur in individuals with HNPCC however, do still tend to develop from polyps.

HNPCC most commonly occurs when people are in their thirties or forties or older. Sometimes it occurs in the twenties, and very rarely in teenage years. Unfortunately, without genetic testing, it is impossible to tell in advance who will get bowel cancer, and genetic tests cannot tell when cancer will develop.

### ***What can be done?***

Many things can be done for families with HNPCC.

### ***Gene testing***

For some families, the altered gene can be identified. However, present tests will not identify the altered gene for all families, so regular check-ups are vital. New tests will become available in the future.

### ***Regular check-ups***

For those who are known to carry an altered HNPCC gene and for people from HNPCC families who have not yet been able to have genetic testing, regular bowel check-ups are vital. It is recommended that testing begin at the age of 25 years, well before the cancer is likely to appear. These check-ups need to continue for life and should involve having a colonoscopy every one to two years (see **p21** 'Colonoscopy'). If you decide to have a colonoscopy every two years, it is important that every alternate year when you are not being screened, you have an FOBT (see **p61** 'Faecal occult blood test') to ensure a cancer does not grow during this period. Sometimes other tests might be needed and your doctor will provide more information if you need to have them.

For women with HNPCC, it is also important from the age of 35 to have regular gynaecological check-ups as having HNPCC can also increase your chances of developing uterine, ovarian, and other cancers. Your doctor will discuss these additional tests with you, or you can contact the Cancer Information Service on 13 11 20.

### ***Treatment to prevent cancer***

Cancers cannot develop if organs are removed. One option for people with HNPCC is to remove all or most of the large bowel (the colon and sometimes the rectum). The aim of surgery is to prevent cancer, and at the same time, to keep your digestive system working as normally as possible.

Women can also choose to have a hysterectomy (removal of the uterus) and possibly an oophorectomy (removal of the ovaries) to prevent gynaecological cancers, although this can be delayed until after they have had a family. It is important to discuss the impact of any preventative surgery with your doctor or professional counsellor before and/or after the operation. This type of help can be obtained through your hospital, or by phoning the Cancer Information Service on 13 11 20.

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## Recommendation:

Members of families with a proven link to HNPCC should be screened by yearly or two-yearly colonoscopy from the age of 25 years.

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### 12.4 GENETIC TESTING FOR BOWEL CANCER

Genetic testing can tell you whether or not you have the altered FAP or HNPCC gene(s) that may lead to bowel cancer.

The mutation in the particular HNPCC or FAP gene can differ from one affected family to another. Laboratory scientists need to find out which mutation is present in your family. The best way to do this is to take a blood sample from someone in the family who definitely has HNPCC or FAP, and identify the gene mutation. This is difficult to do, can take some time, and is not always successful.

Once the gene mutation has been found, anyone else in the family who is at risk of FAP can have the gene test once they reach the age of 12, or for HNPCC at 18. This involves only a blood test, and must be done at a specialist genetic clinic which will ensure you receive all the advice, support and help you need. Your doctor can arrange an appointment for you.

There are many implications to having genetic testing. These include:

- what if I do or don't have the altered gene?
- what if the scientists can't find the altered gene?
- when can I have genetic testing?
- how much does it cost?
- how long will it take?
- what if I don't want to know the result?
- what should I tell other family members?
- what if they don't want to know?
- what effects will a positive test result have on my life insurance?
- who needs to know the result?

All of these questions need to be considered before an individual or family has genetic testing. Genetic counsellors can help you work through these issues, answer questions, and help you come to a decision about having the test.

For more information on genetic testing, contact the Cancer Information Service on 13 11 20.

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## Recommendation:

Genetic testing should only be carried out under the supervision of a clinical genetics or cancer genetics specialist, and should always be supported by counselling.

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### **The FAP and HNPCC registers**

The FAP and HNPCC registers have been set up so that information about these genetic disorders can be recorded. Family trees of people with FAP or HNPCC are checked to identify people at risk of inheriting the altered gene. It could help the future medical care of you and your family if your gene test result is recorded on the FAP or HNPCC register.

If no one else in your family has had a gene test for FAP or HNPCC, your result will help give the correct advice to other family members. Your test could enable the laboratory to identify the family-specific HNPCC gene mutation. In any event, knowing that you do indeed have—or do not have—FAP or HNPCC could help others understand who else in the family may be at risk.

All information kept at both the registers is strictly confidential. It is never given to outside enquirers, including family members, without your permission.

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## 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.

### **abdomen**

The belly or tummy.

### **abdominoperineal (AP) resection**

Extensive operation for rectal cancer, which necessitates the use of a stomal bag. See the diagram on **p32**.

### **advanced cancer**

Advanced cancer is cancer that has spread past the initial site to other organs.

### **alcohol injection**

Technique used to permanently destroy nerves to relieve pain.

### **anaemia**

A lack of red cells in the blood. It can cause tiredness, paleness, weakness and sometimes heart problems.

### **anal sphincter**

Muscle used to control bowel motion.

### **anterior resection**

Less extensive operation for rectal cancer. Avoids the need for a permanent stomal bag. High anterior resection is performed for some colon cancers. See the diagram on **p32**.

### **antioxidant**

Type of chemical found in many foods and thought to protect against cell damage.

### **anus (the back passage)**

The opening of the bowel through which bowel motions are passed.

### **ascending colon**

The part of the bowel on the right side.

### **barium enema**

A test in which liquid barium is put into the bowel, via the anus, and a series of X-rays taken. The barium allows cancer in the bowel to show up on an X-ray.



**benign**

Not cancerous.

**beta carotene**

Nutrient chemical found in carrots etc.

**biopsy**

The removal of a small piece of tissue for examination in the laboratory, under a microscope. In bowel cancer, it is usually obtained during a colonoscopy.

**bone scan**

A test in which a radioactive chemical is injected, then X-rays trace its path throughout the body. The chemical goes to parts of the bone which are abnormal, such as areas of cancer or infection. Bone scans can be unreliable, and so are often used to give guidance, rather than answers, to a problem.

**bowel preparation**

Combination of enema and oral medication to clean out the bowel.

**cancer genes**

See oncogenes.

**carcinogen**

A cancer-causing substance.

**carcinogenic**

Cancer causing.

**carcinoembryonic antigen (CEA)**

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

**catheter**

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

**chemotherapy**

The use of drugs that are toxic to cancer cells. These drugs kill the cells or prevent or slow their growth. They may be taken in the form of tablets, intravenous injections or intra-arterial infusions.

**clinical trial**

Clinical trials test new cancer treatments or may compare existing treatments to determine the best way of improving health outcomes. The research is called a trial because it is uncertain whether a new treatment is better than existing ones.

**colectomy**

Operation to remove the colon or part of the colon. See **p30-31** .

**colon**

Part of the large bowel.

**colonoscopy**

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

**colostomy**

An operation which brings part of the colon through an opening in the surface of the abdomen. This allows faeces to come through the colostomy and be collected in a bag instead of through the rectum. The colostomy may be temporary or permanent.

**combination chemotherapy**

The use of two or more anti-cancer drugs together.

**complete remission (also, complete response)**

This is the term used when, after treatment, there is no sign of any cancer. It is not necessarily the same as 'cure', as some cancer cells may be hidden.

**computerised tomography scan (CT scan)**

A widely used X-ray technique which is good for looking at the brain and internal organs. The X-ray information, which is fed directly into a computer, is used to build up detailed cross-section pictures of the body.

**cryotherapy**

Treatment of tumour by freezing.

**descending colon**

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

**depression**

A general and long-lasting feeling of being down, often associated with tearfulness, guilt or irritability. Other features include loss of interest or pleasure in activities, lowered energy levels, poor concentration and troubles with sleep and appetite.

**differentiation**

A term in pathology meaning the degree of similarity to normal cells. Cells which resemble normal cells closely are described as well differentiated, while those which do not resemble normal cells are described as poorly differentiated. In general, these are more dangerous.

**endorectal ultrasound**

Medical imaging test used to measure rectal cancer.

**faecal occult blood test (FOBT)**

Chemical test for the presence of blood in bowel motions.

**FAP**

Familial adenomatous polyposis. People with this condition usually have hundreds of small adenomas (polyps or benign lumps) scattered throughout their bowel. These cause few problems in themselves, but they tend to turn malignant if not removed. It is caused by inheriting a damaged tumour suppressor gene.

**five-year survival rate**

A scientific measure used to determine the success of a treatment, because it is hard to know if someone is cured or not. It measures the number of people who are alive five years after a particular treatment. It *does not* mean you will only live for five years after having treatment. In general, if you are alive five years after treatment for bowel cancer, and have no signs or symptoms of the disease, you should probably think of yourself as cured.

**gastroenterologist**

Medical specialist in diseases of the digestive system.

**gene**

A large molecule, part of a cell's DNA, that controls the production of a protein molecule and through it, some action or function of the cell.

**general anaesthetic**

The technique of putting someone 'to sleep', so that an operation can be performed.

**genetic mutation**

An error in a gene caused by damage. This may result in a faulty or altered protein or no protein being produced.

**genetic testing**

A test that examines a family's genetic material to determine if it contains an altered gene that may increase an individual's risk of developing cancer. Genetic testing is only available to a small percentage of people with a strong family history of cancer.

**grading**

See differentiation.

**haemoglobin**

Pigment in red blood cells which carries oxygen, also levels of haemoglobin in blood detects anaemia.

**hepatic arterial infusion**

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

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

A type of colon or rectum cancer known or strongly suspected to be due to an inherited fault in a gene which runs through a group of relatives with extensive family histories of bowel, and perhaps, other cancers. It does not produce polyps like FAP.

**hormones**

Natural chemical substances that are produced by one body organ, and travel through the bloodstream to other organs where they exert their effects.

**ileostomy**

Similar to a colostomy (see **colostomy** ), but the operation brings part of the small bowel to an opening in the abdomen.

**incontinence**

Loss of control of bladder or bowel.

**inflammation**

Body reaction marked by redness, swelling and tenderness.

**laparoscopic surgery**

'Keyhole' surgery. Doctors use a number of hollow tubes, each with their own light and tools attached, to operate on your abdomen. In people with bowel cancer, it is still considered experimental.

**large bowel**

Lower portion of the digestive tract (consists of the colon and rectum). Also called large intestine. Bowel cancer generally refers to cancer of the large bowel.

**laser therapy**

Destruction of tissue by high energy light from a laser.

**left hemicolectomy**

Operation to remove part of the colon. See **p31** .

**liver biopsy**

A minor procedure, performed under a local anaesthetic, in which a piece of liver tissue is removed for examination by a pathologist.

**local anaesthetic**

The technique of making a small part of the body numb, so that minor operations can be performed without pain, while allowing the patient to remain awake.

**locally recurrent**

Cancer that has recurred (come back) after treatment, but which is confined to the bowel or nearby tissues only.

**lymph glands**

Lymph nodes.

**lymph nodes**

Small, generally pea-sized pieces of tissue found all over the body but easier to feel in the neck, armpits, and groins. They act as filters for harmful substances and commonly become inflamed if there is an infection nearby. They can also harbour cancer cells that have spread from elsewhere.

**magnetic resonance imaging (MRI)**

Medical imaging technique which uses a magnetic field instead of X-rays.

**malignant**

Cancerous.

**medical oncologist**

A specialist in the treatment of cancer using chemotherapy.

**metastasis**

The secondary or distant spread of cancer, away from its primary (initial) site in the body.

**metastatic**

Relating to secondary cancer.

**monitoring**

The process in which patients are followed up after initial diagnosis and treatment. It may include clinical examination and/or the regular performance of tests.

**oncogenes**

Genes that can cause cancer. Some are inherited, others are not.

**oncologist**

A specialist in the treatment of cancer.

**partial remission (or response)**

The situation when, following treatment, signs of the disease process have partially resolved but have not disappeared completely.

**polyp**

A small tumour in the bowel. Polyps are usually benign, but can turn malignant.

**portal vein**

Blood vessel running from bowel to liver.

**primary cancer**

The site where the cancer began.

**prognosis**

The course and likely outcome of a disease, as estimated by a person's doctor or treatment team.

**protocol**

A defined program for treatment.

**psychosocial**

Referring to the things psychological, social and spiritual.

**radiation oncologist (or radiotherapist)**

A specialist in the treatment of cancer using X-ray techniques.

**radio-opaque dye**

Substance injected to outline the body cavity.

**radiotherapist**

Doctor who treats cancer with radiation.

**radiotherapy**

The use of radiation, for example as X-rays, to kill or injure cancer cells.

**rectal examination**

Procedure used by doctors to feel inside the lower portion of the rectum with a gloved finger.

**rectum**

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

**recurrence**

The re-occurrence of cancer some time after it was first treated.

**resection**

Removal of part of the body in an operation.

**right hemicolectomy**

Operation to remove part of the colon. See **p31**.

**scan**

Medical imaging technique.

**secondary cancer**

Spread of cancer from where it began to another part of the body. The secondary cancerous growths are known as metastases or 'secondaries'. The process of spread is known as metastasis.

**selenium**

Trace element. A deficiency of selenium is linked to colon and other cancers.

**sigmoid colectomy**

Operation to remove part of the colon. See **p31**.

**sigmoidoscopy**

A test to examine the rectum and lower part of the colon. A short metal or plastic tube is inserted into the anus, and the doctor looks through.

**small bowel**

Upper part of digestive tract from the stomach to the colon.

**staging**

The process of determining the extent of the disease.

**stoma**

An artificial opening into the bowel created by surgery to act as an exit for faeces or body wastes. This opening onto the abdomen allows the faeces to be diverted and collected in a bag.

**stomal therapy nurse**

Specialised nurse with expertise in managing colostomies and other 'bag' drainage.

**symptoms**

Anything—whether it be physical, psychological or social—that causes you concern.

**syndrome**

A collection of symptoms and signs characteristic of a disease.

**systemic**

Relating to the whole body.

**total mesorectal excision**

Specialised operation removing rectum and surrounding tissue.

**transverse colectomy**

Operation to remove part of the colon. See **p31**.

**transverse colon**

The part of the colon at the top of the abdomen.

**tumour**

Any swelling. In the context of cancer, the word usually refers to malignant (cancerous) lumps.

**tumour suppressor gene**

A gene which, unless it is damaged, suppresses the development of cancer in a cell. When a tumour suppressor gene is damaged, other genes may get out of control and this can lead to cancer.

**ulcerative colitis**

Inflammatory disease of the large bowel, which causes an increased risk of cancer.

**ultrasound**

Medical imaging technique using high frequency sound waves.



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## **The National Health and Medical Research Council**

The National Health and Medical Research Council (NHMRC) is a statutory authority within the portfolio of the Commonwealth Minister for Health and Aged Care, established by the *National Health and Medical Research Council Act 1992*. The NHMRC advises the Australian community and Commonwealth; State and Territory Governments on standards of individual and public health, and supports research to improve those standards.

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