YOUR PATHWAY

BOWEL CANCER

treatment

Bowel Cancer Australia

introduction

Bowel Cancer Australia has produced this booklet to help you understand the patient journey and make you aware of the various treatment options that might be available to you.

The following pages contain comprehensive, yet easy to understand information about bowel cancer and what treatment may be ahead of you in the coming months. We hope this information will help you at this difficult time and will be useful now, and in the future, as you learn more about your diagnosis and treatment options. For information on treatment of secondary bowel cancer in the liver and/or lungs, please ask us for a copy of our booklet *'Bowel Cancer Advanced: Liver Treatment'* or download it from our website.

A diagnosis of bowel cancer and subsequent treatment has huge implications for you, your family and your friends. We recognise help should not be solely limited to medical issues. Much more information on wide ranging issues is available on our website, www.bowelcanceraustralia.org, including diet and nutrition advice, practical and financial considerations and possible side effects of treatment (and what to do about them).

Cancer treatment has a whole new language which you are going to need to learn. It's going to be a while before you understand it all, so we have also included a jargon buster on our website to help you in the early days.

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Roche

Bowel Cancer Australia maintains editorial control over content within this booklet.

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Contents

being diagnosed with bowel cancer

There's no denying it, for even the most positive of people, being diagnosed with cancer will come as a terrible shock. Many bowel cancer patients describe everything being 'a bit of a blur' after they are told. If possible, it is important not to make hurried decisions about what happens next during your initial consultation with your specialist.

You will need to take time to consider what you have been told and to seek support from family and friends. You will also need the support and understanding of your clinical nurse specialist to help you understand what your needs and preferences are likely to be, as part of your treatment and care plan development.

Your choices

When you are ready to move onto considering treatment options, the most important thing to remember is that you have a variety of choices to consider. Certainly, your medical team are the experts in the disease but it is **your life, your illness, your body.** Don't be rushed into making decisions before you've had a chance to reflect and don't be frightened to ask about anything you don't understand. Be confident to ask about the choices available to you, and seek a second opinion to gain more information before making any decisions.

your multi-disciplinary team

Your first appointment at the hospital is likely to be with a general or colorectal surgeon and a specialist colorectal nurse. They are part of a specialist colorectal Multi-Disciplinary Team (MDT).

The MDT brings together all the key people involved in treating you, to ensure that all the different parts of your treatment are delivered as seamlessly as possible. This team meets regularly, once a week. Your case will be presented and your treatment options will be discussed at the MDT meeting, to ensure that you are offered the best possible care and support throughout your treatment.

Who are the colorectal team specialists?

Every person is unique, and will have their treatment and care planned according to their individual needs. Each specialist team is led by at least one consultant, including:

- **Surgeon:** A doctor with specialist training to remove cancers, and perform other operations which can help to repair and maintain body function and relieve other symptoms of illness or damage. Each surgeon will specialise in a particular problem, or area of the body, making them an expert in their field.
- **Clinical or Medical Oncologist:** A doctor who is skilled in non-surgical management of cancer patients. Clinical oncologists also specialise in radiotherapy treatment.
- **Diagnostic Radiographer/Radiologist:** uses X-rays and other specialised scanning machines (ultrasound, CT, PET and MRI scanners) to locate and measure the extent of a cancer.
- **Pathologist:** A specialist doctor who uses special techniques and equipment to examine and identify samples of tissue and confirm a diagnosis.
- **Colorectal Nurse Specialist:** has received additional training and qualifications in the care of patients with bowel conditions and bowel cancer, and has become an expert in this field. Nurse Consultants or Nurse Practitioners have additional qualifications at a very advanced level.
- **Cancer Care Coordinator (CCC)/Clinical Nurse Consultant (CNC):** Senior nurses who monitor a patient from diagnosis throughout treatment. They work closely with specialists and are a one-stop shop for your needs in hospital and a consistent source of information and support.
- **Stoma Nurse Specialist:** has experience and qualifications in the care and management of people with either a temporary or permanent stoma.

Surgeons and Oncologists will be supported by Senior Registrars – qualified doctors who are gaining more experience and developing their skills within a specialist area.

... and other health professionals

Other members of the hospital team who may be involved in your care include:

- **Chemotherapy Nurse Specialist:** has additional training and qualifications in the care and management of patients needing chemotherapy.

- **Therapeutic/Radiotherapy Radiographer:** A specialist trained to deliver radiotherapy treatments.

- **Palliative Care Specialist:** A doctor or nurse with additional experience and qualifications in supporting patients and families, and managing symptoms to improve quality of life for patients with very advanced cancer.

- **Pharmacist:** A specialist able to provide support and advice to the rest of the clinical team, and to patients, about the medicines that are being used to treat

Support from your specialist team is a very important part of your cancer pathway, and may be provided by a number of people, dependent upon your individual circumstances:

- **Counsellor:** Uses non-medical therapies and techniques to support you if you are struggling to deal with emotional issues and problems.

- **Dietitian/Nutritionist:** Supports you if you have problems with eating and/or drinking properly, or are having problems with maintaining or managing your weight.

- **Physiotherapist:** Helps you to regain strength, mobility, balance and control after surgery.

- **Occupational Therapist:** Helps you to regain your independence and cope with physical problems which affect your home or work life; provides specialist aids and equipment.

- **Clinical Psychologist:** Treats and supports you if you are coping with emotional problems.

- **Psychiatrist:** May help you if you have problems coping with psychological or emotional issues.

deciding your treatment plan

Just as everyone is different, so your treatment plan will be tailored to your individual circumstances. Your specialist team will discuss the options that are available to you, including where and when your treatment will take place. They will describe to you, step by step, what each stage of your plan might involve, the likely outcomes and who will be treating you.

Your surgeon, oncologist and specialist colorectal or stoma nurse will work together to help you to understand the facts about your cancer – if it has spread, and (if so) how much of the bowel and what other areas or organs in the body have been affected. They will also make an assessment of your general health and fitness – known as Holistic Needs Assessment – and consider any underlying health problems. It is also important that they understand what home and family issues need to be considered as well as any practical concerns, as these might also have an impact on your health and treatment choices. This process will also help you to manage your own care much more effectively so that you will know when and how to ask for help.

Useful Tips

There will be a lot of information for you to remember and you will naturally have lots of questions for your specialist team. Don't worry about sounding stupid. Ask as many questions as you need to, so that you understand what you are being told and what the implications might be in the longer term.

Two heads are better than one – always try to take someone with you to these consultations. They can take notes for you to remind you what was said and what was decided. They can also help you to remember the questions you wanted to ask.

important questions to ask

There will be lots of uncertainties about what to expect and what the future holds for you at the start of your bowel cancer journey. Here are some of the questions that might be important for you and your family:

- Where is my bowel cancer, how advanced is it (stage), and can you draw me a picture to describe this?
- Who will be looking after me?
- What are my treatment choices?
- If I need to have surgery, what kind of operation will it be and how long will I be in hospital?
- Will I have to have a stoma? If I do, will it be permanent?
- If I need to have any other kinds of treatment, what are they likely to be?
- How long will these treatments take, and how long will I be in hospital for?

- If I need chemotherapy, can I have this treatment at home?
- What are the likely side-effects of my treatment, and how will you help me to cope with them?
- Will I need to be off work, or will I need extra help at home after I have had my surgery/treatment?
- How will my bowels be affected?
- How will my energy levels and appetite be affected?
- Will my treatment have any effect on my sexual function?
- If it is relevant - Will I still be able to have children after my treatment?
- Who can I contact in an emergency?
- Are there any clinical trials open to me?
- Am I being denied any treatments or medications because of cost?
- Are my family at increased risk of bowel cancer?
- What sort of follow up can I expect to have, once my treatment has finished?
- What other sources of support are available locally to help me and my family cope?

understanding bowel cancer staging

In order to determine the best treatment for your particular bowel cancer, you will undergo various tests to find out the size and position of the cancer, and whether it has spread. This process is called ‘staging’. You will probably also have blood tests to check your general health, and a CT (computerised tomography) scan, MRI (magnetic resonance imaging) scan or ultrasound scan that enables the doctors to look at the cancer in more detail.

The staging system for bowel cancer is the Australian Clinico-Pathological Staging System (ACPS):

- Stage **AO** - In stage AO, the cancer is found only in the innermost lining of the bowel. Stage AO cancer is also called carcinoma in situ.
- Stage **A** - the cancer is confined to the bowel wall.
- Stage **B** - the cancer has spread to the outer surface of the bowel wall.
- Stage **C** - cancer is found in lymph nodes near the bowel.
- Stage **D** - cancer is found at distant sites; e.g. in the liver or lungs.

You may also hear about the ‘Dukes’ system, which is like the ACPS. Dukes Stage A equals ACPS Stage A, and so on.

Stages of bowel cancer

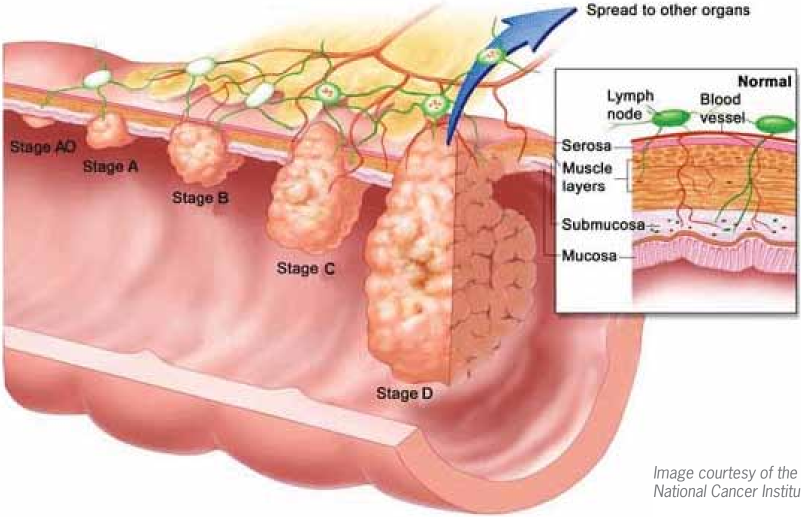
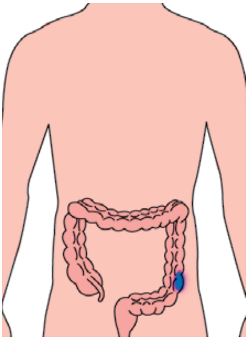
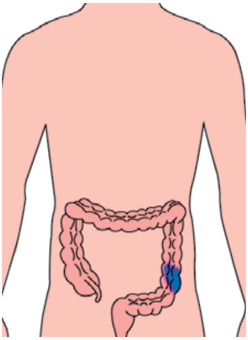
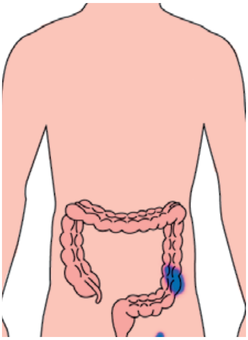
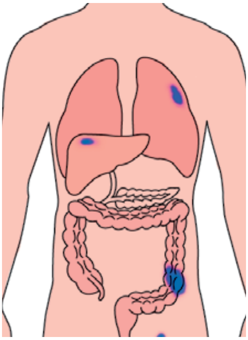


Image courtesy of the National Cancer Institute.

understanding bowel cancer staging

STAGE 1 (I) ACPS/DUKES' A T1 OR T2, NO MO	STAGE 2 (II) ACPS/DUKES' B T3 OR T4, NO MO	STAGE 3 (III) ACPS/DUKES' C ANY T, N1 OR N2 MO	STAGE 4 (IV) ACPS/DUKES' D ANY T, ANY N, M1
			
Tumour has invaded several layers of bowel but has not spread outside the wall.	Cancer has grown through the muscle layer of the bowel or rectum and invaded nearby tissue, but has not spread to the lymph nodes.	Cancer has spread to nearby lymph nodes, but not to other parts of the body.	This is also known as METASTATIC BOWEL CANCER. The cancer has spread from where it started in the colon or rectum, to other organs often the liver and lung.

TNM: is a shorthand description of the staging classification, which helps the specialists to understand very quickly what your cancer looks like.

T: describes tumour size and how far it has grown into - and through - the bowel wall, using a scale of T0 to T4.

N: describes lymph node involvement - from N0 which means that no lymph nodes are affected, to N2 where there are 4 or more lymph nodes affected.

M: describes whether distant metastases (secondary tumours in other parts of the body) are present or not. M0 means that there is no evidence of the cancer having spread, while M1 means that there is.

Within any category of the TNM scoring system, the use of an X score means that it has not been possible to assess the presence of cancer within the area described.

what are my treatment options

Treatment for bowel cancer is decided by:

- Where the cancer is in your bowel
- How big the tumour is
- The number, size and position of any tumours outside the bowel (including lymph nodes)
- The type of cancer cells – their cell type and genetic makeup
- Your general health and fitness
- Your wishes as the patient.

It will also be determined by:

- The local and national guidelines for best practice in treating bowel cancer
- The availability of different treatment options within your local hospital
- The access to clinical trials available within your local hospital
- How well you respond to the treatments
- The impact of any side-effects you may experience as a result of treatment.

There is a combination of treatments given to treat bowel cancer, depending on where the cancer is within your body. The table below is a summary of what they might be, according to your own individual diagnosis. The details are described and explained further in this booklet.

Site/Spread	**Early stage limited to bowel**	**Local spread involving lymph nodes**	**Distant Metastases**	**Very advanced metastatic disease**
Colon (large bowel)	Surgery	Surgery, Chemotherapy	Surgery, Chemotherapy, Monoclonal Antibodies, Specialised Radiotherapy	Managed by oncology and specialist palliative care teams
Rectum (back passage)	Options will vary according to stage and position: Neo-adjuvant Radiotherapy and/or Chemotherapy, Surgery, Adjuvant Chemotherapy and/or Radiotherapy		Neo-adjuvant Chemotherapy & Radiotherapy, Surgery, Adjuvant Chemotherapy, Radiotherapy, Monoclonal Antibodies	Symptoms managed using medications, short doses of Radiotherapy and Chemotherapy, Surgery
Anus				Chemotherapy, Monoclonal Anitbodies

- Neo-adjuvant: treatment given to shrink and kill cancer cells, often before surgery
- Adjuvant: treatment given after surgery to kill any remaining cancer cells in the body
- Clinical trials may be available at every stage of treatment.

radiotherapy options

Radiotherapy is the use of controlled, high-energy radiation, usually X-rays, to destroy cancer cells. The treatment doesn't make you radioactive and it's perfectly safe to be with others during the course of your treatment.

If you have been diagnosed with cancer in your rectum, radiotherapy may be offered to you as a treatment option, either on its own or prior to surgery. It is sometimes given at the same time as chemotherapy – called chemo-radiation – which makes the cancer cells more sensitive to the radiation.

Chemo-radiotherapy is an effective alternative to surgery for anal cancer.

Radiotherapy can be given in two ways:

External radiotherapy is delivered from outside of the body by a machine and only takes a few minutes. Each time you are given radiotherapy you receive a 'fraction' of the full dose prescribed.

Internal radiotherapy involves positioning radioactive sources inside or near to the tumour. This treatment delivers a high dose of radiation directly to the cancer while limiting damage to surrounding tissues and organs. This treatment, also known as brachytherapy or contact radiotherapy.

The side-effects of radiotherapy will vary depending on length and intensity of treatment you have. It will affect the bowel and other local tissue, including your skin and other tissue close to the tumour. This can cause temporary pain, discomfort, and change your bowel habit.

Long term problems associated with the treatment may include chronic inflammation of the bowel (radiation enteritis). This can be difficult to cope with initially but there are specialist treatments available which may help. This condition often needs very careful monitoring and changes to diet and lifestyle to manage successfully.

The formation of scar tissue after the treatment is common, and - for women - the use of a vaginal dilator is recommended on a daily basis for several months - and possibly much longer - after completion of the treatment, to reduce the risks of painful narrowing and strictures forming in the longer term.

Your radiology team will be able to advise you on how to minimise and cope with any problems or side-effects associated with your treatment.

radiotherapy options

Radiotherapy can be used at several different stages of treatment

Neo-adjuvant (pre-operative) radiotherapy for rectal cancer is given before surgery to shrink the tumour in order to make it easier to remove and reduce the risk of the cancer coming back.

If you are prescribed external radiotherapy, the treatment could either be a short course (eg five treatments over a period of five days) or a long course (eg five treatments a week, for five or six weeks). Internal radiotherapy usually takes one to three sessions to deliver.

Whether you have external or internal radiotherapy, there will be a period of time between the radiotherapy treatment ending and your surgery.

This delay is intentional, as the radiotherapy continues to shrink the tumour for several weeks after the end of treatment.

Chemo-radiotherapy can also be used on its own to kill cancer cells as an alternative to chemotherapy and/or surgery.

Adjuvant (post-operative) radiotherapy

If you have not had radiotherapy before your surgery, you may be advised to have radiotherapy in conjunction with chemotherapy after surgery, to destroy any cancer cells that may be left behind:

- If the tumour was difficult to remove
- If your cancer has grown through the wall of the rectum or spread to nearby lymph nodes.

Palliative radiotherapy

Lower doses of radiotherapy, over a shorter period of time, can also be given if surgery is not an option to:

- Relieve symptoms
- Slow the spread of the cancer.

If your oncologist believes you will benefit from radiotherapy, he/she will discuss this with you. Ask them why they are recommending this treatment for you, how the radiotherapy will be given and what other choices you might have.

Specialist radiotherapy techniques

New treatments using specialist radiotherapy technology can also be used in to treat metastases (tumours that may have spread) in other parts of the body, eg the liver, brain or lung.

These treatments may offer individual patients a viable alternative, if the tumours cannot be removed safely by surgery.

Other specialist treatments include Radiofrequency Ablation (RFA) which uses heat from an electrode (probe) to destroy cancer cells by passing an electrical current (radiofrequency) to the tumour. The electrical current heats the cancer cells to high temperatures, destroying them (ablation).

For further information, please download our booklet *“Bowel Cancer Advanced: Liver Treatment”*

treatment pathway

Initial investigations

Positive screening test

GP: It is very important that a positive screening test is followed up by a referral for colonoscopy

Referral to Specialist

Symptoms

GP: History, iFOBT & blood tests examined

Referral to Specialist

Emergency Admission

Acute Symptoms

Specialist investigations

Colonoscopy, Barium enema, Flexible sigmoidoscopy, Virtual colonoscopy (CT colonography), MRI, PET scan, blood tests → primary diagnosis

Primary diagnosis confirmed

Anal Cancer

Rectal Cancer

Colon Cancer

Very advanced Bowel, Rectal or Anal Cancer

Primary treatment

Neo-adjuvant Chemotherapy and/or Radiotherapy to downstage tumours & metastases

Surgery

Conservative Management & Palliative Care

Follow up & staging confirmed

Secondary treatment

Recovery & Rehab

Surgery

Adjuvant Chemotherapy

Recovery & Rehab

Follow up & symptom control

Follow up & third line treatment

Adjuvant Chemotherapy & Radiotherapy

Follow up & Re-staging

Recovery & Rehab

Follow up & re-staging

Recovery & Rehab

→ → → Information and support available as appropriate throughout your treatment pathway → → →

Regular follow up will continue for 5 years after diagnosis, and include a general history of your health, blood tests (for tumour markers, full blood count (FBC) and liver function tests (LFTs)) and a routine physical examination. Colonoscopy; CT and other scans will usually be performed during this period, depending on your own circumstances and any new symptoms.

surgery: what to expect

There are different methods of surgically removing a tumour from the bowel, depending on the exact location of the cancer, its size and type, and whether the cancer has spread. Your test results will affect the decision on the type of surgery that will be best for you. Once you understand what is going to happen, you will be asked to sign a consent form to allow the surgery to take place, and for the surgeons to do what they consider will offer you the best chance of a good quality of life and long term survival.

Surgery for cancer in the upper bowel (colon)

The exact location of the cancer in the colon will affect which type of surgery you will need. Ask your doctor to explain what type of operation you are having, and whether they can draw you a picture to make it easier for you to understand what they will be doing, and how your bowel – and your body - will look after the operation. This can also help you to understand how the surgery may affect your bowel habit and the position of any scar tissue or where a stoma* might be formed.

During the operation, the surgeon will remove the cancerous tumour and a small, healthy area around the tumour called the 'tumour margin'. This is very important, to ensure that all of the cancerous cells have been removed. The surgery can either be done via the traditional open surgery method or via a technique called laparoscopic (keyhole) surgery.

The surgeon will also remove nearby lymph nodes. Following the operation these will be examined in the laboratory to see if the cancer has spread. If it has, your specialist team will discuss what the next course of action might be.

After the part of the colon containing the tumour is removed, the ends of the colon will be joined back together in what is called an anastomosis. If it is not possible to rejoin the two ends of the colon immediately, the surgeons will form a stoma*, which may be permanent. At other times, they may want to give the anastomosis time to heal, so they will form a temporary stoma, which will be reversed a few weeks/months later.

*You can find more details on stomas (also known as colostomy or ileostomy) in our booklet *"Bowel Cancer Surgery: Your Operation"*.

surgery: what to expect

Surgery for cancer in the lower bowel (rectum or anus)

Colorectal surgeons will use both keyhole and open techniques for removing bowel cancers, depending on the exact location, its size, and type. These are advanced surgery techniques and your surgeon will have additional training and experience, and specialist equipment, to be able to do the operation safely and effectively.

Keyhole surgery techniques are becoming increasingly common, where it is possible to remove the cancer without having to make large surgical incisions. Newer rectal surgery techniques are also helping surgeons to avoid damaging or removing the anus and surrounding tissue whenever possible too. There are, however, occasions when it is necessary to perform an open operation in your abdomen or around your perineal area (groin).

Emergency surgery

Whilst many patients have time to plan for their surgery, some patients are diagnosed with bowel cancer following emergency admission to hospital with abdominal pain or other severe symptoms. In these cases, it can be difficult for the doctor to diagnose bowel cancer without undertaking exploratory surgery which is always done as an "open" procedure, and will depend upon your symptoms when you are admitted.

In cases where patients are admitted as an emergency, with a blockage in the bowel caused by a cancer, the surgeon may choose to insert a colonic stent as a temporary way of unblocking the bowel, before more extensive surgery can be planned.

For more information, please see our booklet *"Bowel Cancer Surgery: Your Operation"* or visit our website www.bowelcanceraustralia.org

post-op follow up and rehabilitation

Side-effects of surgery are common, but will affect people in different ways. Many effects are short lived and will settle with time. Other effects may last for several months, or longer, depending on your own circumstances.

As a general guide, some of the most common side-effects of surgery may include:

- Pain and reduced mobility - especially immediately after surgery
- A change in bowel function (diarrhoea, urgency or constipation)
- Nausea and / or vomiting
- Loss of appetite or bloating
- Tiredness and a lack of energy.treatments.

You may also experience other side-effects, depending on the specific surgery you have had, and whether it is in combination with other Taking regular pain killers and taking gentle exercise is an equally important part of your recovery. Drinking plenty of water, and eating small, light meals frequently will help too.

You will see your surgeon a day or two after the operation, to get an idea of how they thought the operation went, and what they think the outcomes are likely to be. A follow up appointment is also arranged, for around 3 - 6 weeks after the operation, to start considering the “what next?” By then, the results of your pathology tests will be back and your case will have been discussed at the Multi-Disciplinary Team meeting.

Bowel surgery is a major operation. It can take several weeks, or even months, to fully recover (often reflecting how long your operation took).

Contact your specialist team straight away if you develop any new symptoms, or are getting worse. They will help you to understand what is causing the problems and may be able to prescribe medication to reduce the effect or make changes to your treatment plan.

availability of drugs

In Australia we have a number of government bodies responsible for the regulation and availability of bowel cancer treatments.

The *Therapeutic Goods Act* 1989 provides a national framework for the regulation of therapeutic goods in Australia to ensure quality, safety and effectiveness of medicines. It also sets out the requirements for inclusion of therapeutic goods in the Australian Register of Therapeutic Goods (ARTG), including advertising, labelling and product appearance, for example.

The Therapeutic Goods Administration (TGA) carries out a range of assessment and monitoring activities to ensure therapeutic goods available in Australia are of an acceptable standard.

All treatments used to prevent, cure or alleviate bowel cancer must be entered on the Australian Register of Therapeutic Goods (ARTG) before they can be supplied in Australia. Once approved and entered on the ARTG, they are available for human use and can be accessed privately (at a cost to the patient).

Some treatments can then be recommended by the Pharmaceutical Benefits Advisory Committee (PBAC) to be listed on the Pharmaceutical Benefits Scheme (PBS) as a subsidised treatment. Once a drug has been listed on the PBS, the government subsidises the cost of the treatment (the patient pays a lower cost to access the treatment).

The Scheme is available to all Australian residents who hold a current Medicare card.

In summary, the TGA registers a drug to be sold within Australia which can still be accessed and paid for privately but may not necessarily be government funded through the PBS.

availability of drugs

The issue of drug availability has received a lot of media attention and can be confusing and complicated.

You should discuss all the options with your oncologist, and if a drug would be of benefit but it is not available via the PBS, you may consider accessing this privately or applying to a manufacturer to see if you are eligible to enter an access program or request the drug be made available on compassionate grounds.

Also, ask about clinical trials. The drugs mentioned here are approved for use in Australia. You may be asked to participate in clinical trials with drugs not mentioned here or with unlicenced combinations of drugs listed in this booklet.

performance status

Doctors use the World Health Organisation (WHO) performance status to describe how well you are. They also call it your ‘performance status’.

The WHO designed a scale that doctors use most often. It has categories from 0 to 4. Here is what they mean:

- **0,1** – you are active but you cannot carry out heavy physical work, but can do anything else
- **2** – you are up and about more than half the day; you can look after yourself, but are not well enough to work
- **3** – you are in bed or sitting in a chair for more than half the day; you need some help in looking after yourself
- **4** – you are in bed or a chair all the time and need a lot of looking after

Clinical trials often include performance status as one of the criteria you must meet to join the trial as researchers have to make sure people are well enough to take part.

Most drug trials involves WHO categories 0, 1, and a small number of category 2 groups.

Similarly, a patient’s WHO performance status is often a criteria you must meet to be eligible for some PBS-subsidised bowel cancer treatments.

chemotherapy explained

Chemotherapy is the use of 'anti-cancer' (also known as cytotoxic) drugs to destroy cancer cells in the body. Chemotherapy is used at different stages of treatment, and can be used in combination to make other treatments more effective.

- **Neo-adjuvant** – to shrink the tumour(s) before surgery in order to get a better outcome following the operation.
- **Adjuvant** – to destroy any microscopic cancer cells that may remain after the cancer is removed by surgery and reduce the possibility of the cancer returning.
- **First-line** – chemotherapy that has been shown, through extensive clinical trials and research, to be the best option for the type of cancer being treated. A monoclonal antibody may be recommended in addition to chemotherapy.
- **Second-line** – alternative chemotherapy treatment for disease which has not responded to first-line chemotherapy, or has recurred. A monoclonal antibody may be recommended in addition to chemotherapy.
- **Third-line** – certain monoclonal antibodies have been shown to have benefit when given alone after chemotherapy has stopped working.
- **Palliative** – to relieve symptoms and slow the spread of the cancer, if a cure is not possible.

How is chemotherapy given?

Chemotherapy drugs can be given in several different ways:

- **Oral chemotherapy** – chemotherapy drugs available as capsules to be taken at home every day.
- **Intravenous (IV) infusion** – the treatment is given directly into a vein. There are a wide range of schedules for chemotherapy, from a small injection over a few minutes, a short infusion of up to 30 minutes, or longer infusions over the course of a couple of hours or even a couple of days.

  IV chemotherapy can be given via four different methods, depending on how often you will need treatment to be given:

- **Cannula** – A small tube inserted into a vein in the back of your hand, or your arm.
- **Central Line** – A thin, flexible tube inserted through the skin of the chest into a vein near the heart, which can stay in place for many months. Hickman® or Groshong® lines are common types.
- **PICC Line** – A thin, flexible tube passed into a vein in the bend or upper part of your arm and threaded through the vein until the end of the tube lies in a vein near the heart. PICC lines can stay in place for many months.
- **Portacath** – A thin, soft plastic tube that is put into a vein. It has an opening (port) just under the skin on your chest or arm.

chemotherapy explained

If your oncologist believes you will benefit from chemotherapy, he/she will discuss the best treatment plan options with you. You may be prescribed one drug or a combination of drugs. Depending on the stage of your bowel cancer, you may also be recommended treatment with monoclonal antibodies.

The chemotherapy drugs licensed for treatment of bowel cancer in Australia are:

- 5-FU (5-fluorouracil)
- Capecitabine (Xeloda)
- Oxaliplatin (Eloxatin)
- Irinotecan (Camptosar)

A combination of two or more drugs is common, for example:

- FOLFOX (5-FU + Oxaliplatin)
- FOLFIRI (5-FU + Irinotecan)
- FOLFOXIRI (5-FU + Oxaliplatin + Irinotecan)
- XELOX (Capecitabine + Oxaliplatin).

Each drug dose is calculated initially according to your body surface area. Each drug has certain characteristic side-effects to be aware of. These side-effects can be "risk assessed" for likelihood by your oncologist, and dosages can be altered to suit your own circumstances.

These standard drugs are considered to have a moderate risk for developing common side-effects associated with bowel cancer chemotherapy, including nausea and vomiting, diarrhoea and febrile neutropaenia.

chemotherapy drugs

Treatment	At what stage is this treatment used?	What are the main side effects?	Is this treatment PBS subsidised?
5–Fluorouracil (5-FU)	At any stage of bowel cancer. It is usually combined with folinic acid (leucovorin). Adjuvant treatment of stage III (Dukes C) colon cancer after complete resection of primary tumour. Treatment of metastatic colorectal cancer.	5-FU/LV can cause tiredness, nausea, mouth ulcers, drop in immune cells, hair thinning, soreness and redness on palms of hands and soles of feet, diarrhoea. Not everyone will get these side effects – you may have none or several.	Yes
Oxaliplatin (Eloxatin)	Adjuvant treatment of stage III (Dukes C) colon cancer after complete resection of primary tumour. Treatment of metastatic colorectal cancer.	Oxaliplatin may cause gastrointestinal side effects, including nausea, vomiting and diarrhoea, and haematological side effects, such as bleeding gums, nose bleeds and bruising. Oxaliplatin can also give rise to sensations including pins and needles and numbness in the hands and feet and make you more sensitive to cold air and cold drinks.	Oxaliplatin in combination with 5-FU and folinic acid (FOLFOX) is PBS-subsidised as a treatment option for the adjuvant treatment of patients with stage III (Dukes C) colon cancer following complete resection of the primary tumour. Oxaliplatin in combination with 5-FU and folinic acid (FOLFOX) or capecitabine (XELOX) is PBS-subsidised as a treatment option for metastatic colorectal cancer in patients with a WHO performance status of 2 or less. Oxaliplatin is not PBS-subsidised for the treatment of patients with stage II (Dukes B) colon cancer. Oxaliplatin is not PBS-subsidised for the adjuvant treatment of patients with rectal cancer. From 1 December 2011, capecitabine in combination with oxaliplatin (XELOX) will be listed on the Pharmaceutical Benefits Scheme (PBS) as a subsidised treatment option for the adjuvant treatment of stage III (Dukes C) colon cancer. This will allow Xeloda to be reimbursed as both monotherapy and as part of the XELOX combination.

Treatment	At what stage is this treatment used?	What are the main side effects?	Is this treatment PBS subsidised?
Capecitabine (Xeloda)	Adjuvant treatment of stage III (Dukes C) colon cancer. Treatment of advanced or metastatic bowel cancer alone or in combination.	The most common side effects are diarrhoea, vomiting, nausea, a sore mouth, and an increased risk of infection. Hand Foot syndrome which causes redness, pain and swelling is also very common, and can be minimised by use of other drugs and special moisturising creams applied regularly to prevent the skin drying and cracking. Capecitabine may also affect the muscle tissue of the body so leg weakness and tiredness are common, but should be discussed with your nurse/doctor if it is becoming a problem for you. Any chest pain/angina type symptoms should be reported to your doctor straight away.	Capecitabine is PBS-subsidised as a treatment option for advanced or metastatic colorectal cancer. It is also PBS-subsidised as a treatment option for adjuvant treatment of stage III (Dukes C) colon cancer, following complete resection of the primary tumour. Capecitabine is not PBS-subsidised for the treatment of patients with Stage II (Dukes B) colon cancer. Capecitabine is not PBS-subsidised for the adjuvant treatment of patients with rectal cancer. From 1 December 2011, capecitabine in combination with oxaliplatin (XELOX) will be listed on the Pharmaceutical Benefits Scheme (PBS) as a subsidised treatment option for the adjuvant treatment of stage III (Dukes C) colon cancer. This will allow Xeloda to be reimbursed as both monotherapy and as part of the XELOX combination.
Irinotecan (Camptosar)	1st line combination and 2nd line monotherapy treatment of advanced colorectal cancer.	Patients may experience increased sweating, production of saliva, stomach cramps and diarrhoea, which is known as an “acute cholinergic syndrome” response. This is fully reversible with other medications, but should always be reported to the doctor. In addition, nausea and vomiting, delayed diarrhoea, muscle weakness, tiredness and lethargy may occur, as can bruising, bleeding and anaemia. Sometimes, it can also cause hair loss.	Irinotecan is PBS-subsidised as a treatment option for metastatic colorectal cancer in patients with a WHO performance status of 2 or less. Note: In first-line usage, effectiveness and tolerance may be improved when Irinotecan is combined with an infusional 5-fluorouracil regimen.

side-effects of chemotherapy

Chemo Induced Nausea & Vomiting (CINV)

Nausea and vomiting are two side-effects of cancer treatment that people often worry about the most. About 50% of people who undergo chemotherapy for bowel cancer suffer from nausea and vomiting, which might also cause dehydration, fatigue, loss of appetite and difficulty concentrating.

Some patients are more vulnerable to CINV than others. These include women (even more so if they experienced these symptoms during pregnancy), young people under age 50, and patients who have received previous chemotherapy treatments. Other risks include a personal history of motion sickness, or problems with anxiety.

Many new medications are available to control CINV and it can now be prevented in the majority of people by carefully assessing your risk of developing these side-effects before you start treatment.

How can I help manage chemotherapy induced nausea and vomiting?

- Avoid eating solid foods immediately before and after treatment
- Avoid caffeine and alcoholic drinks
- Drink clear liquids such as sports drinks, ginger ale, lemon-lime sodas, or dilute, unsweetened fruit juices
- Start with bland foods such as dry toast or crackers, then gradually increase to small, frequent meals throughout the day
- Avoid spicy or greasy foods
- Avoid favourite foods on days you are sick so they don't become nausea triggers
- Avoid strong smells that may upset your stomach such as cooking odours, smoke, or perfume
- Avoid lying flat for at least 2 hours following meals
- Contact your specialist team if vomiting is severe or if you cannot keep anything down
- Try doing some relaxing activities such as reading, puzzles, yoga, watching TV, or listening to music
- Alternative therapies such as selfhypnosis, guided imagery, progressive muscle relaxation, acupuncture,

Increased risk of infection and neutropaenic sepsis

Infection at any time during your bowel cancer treatment can have a significant effect on how well you tolerate your treatment and can slow down your recovery times.

Neutropaenic sepsis – or febrile neutropaenia – means that you have a fever caused by infection linked to low levels of neutrophils (white blood cells) in the blood. This is a serious condition, and one of the potential side-effects of chemotherapy for cancer. Chemotherapy for bowel cancer carries a moderate risk of neutropaenia.

Infection as a result of side-effects of chemotherapy – when the body is already compromised – is considered to be a medical emergency which often results in hospital admission for treatment with antibiotic intravenous (IV) infusions.

It is possible to assess your personal risk of developing this side effect before starting a new treatment.

You can manage your personal risk actively by careful attention to personal hygiene and limiting contact with other potential sources of infection: other people, pets, food and washing hands after touching hard surfaces (especially in busy, communal areas).

Who is most at risk?

The people most at risk of developing this serious problem are often older patients (over 65 years) who also have poor general health and other underlying health issues with heart, kidney or other problems with major organs. Other factors known to increase risk of infection include a low baseline blood cell count as a result of previous chemotherapy treatments, along with current chemotherapy regimes that are being given in high doses.

That is why you will have your blood levels checked before each new cycle of treatment. Your pre-treatment assessment should also include checking your temperature and blood pressure as these can also help to identify potential problems ahead, as will picking up undiagnosed, underlying respiratory infections, and other local infections at the site of IV ports, for example.

Your chemotherapy team should give you a special card with the signs and symptoms to look out for, and an emergency contact number to call if you notice any problems or have any concerns.

Where the personal risk is considered to be high, specialised medications can be prescribed to increase the production of these white cells where necessary, supporting the body and helping it to recover more quickly from the chemotherapy treatments.

understanding monoclonal antibodies

Monoclonal antibodies are a separate group of drugs used in the treatment of advanced (metastatic) cancer, usually in combination with other standard chemotherapy treatments.

Treatment with the most appropriate monoclonal antibodies will depend upon the results of specific genetic tests (called bio-markers) on the tumour tissue, known as the K-RAS test.

K-RAS testing does not affect the way your chemotherapy is prescribed. Instead, it gives your oncologist the information they need to work out which other medicine from the monoclonal antibodies group may work for you.

Some monoclonal antibodies are given at the same time as your chemotherapy, whilst others are given on their own.

There are three monoclonal antibody treatments currently approved for advanced bowel cancer in Australia:

- Bevacizumab (Avastin)
- Cetuximab (Erbitux)
- Panitumumab (Vectibix)

Monoclonal antibodies work to stop the cancer cells growing and developing by interfering with their reproduction processes (anti-EGFR) or by cutting off their blood supply (anti-VEGF).

Up to 60% of bowel cancer samples tested have wild-type genes which may be treated successfully with the anti-EGFR monoclonal antibody therapies Cetuximab and Panitumimab. Bevacizumab is also effective and regularly used to treat patients with wild-type genes.

Around 40% of bowel cancers may have mutated (changed) genes which will not respond to this anti-EGFR therapy, but may respond to the VEGF blocker Bevacizumab.

Treatment	At what stage is this treatment used?	What are the main side effects?	Is this treatment PBS subsidised?
Bevacizumab (Avastin)	Used for first and later treatment lines of advanced or metastatic colorectal cancer in combination with a fluoropyrimidine based chemotherapy. Use of bevacizumab is not dependent on KRAS status.	The most common side effects are tiredness, diarrhoea, nausea or pain. Also, some patients may experience a rise in blood pressure, nosebleeds or a delay in wound healing.	On 1 July 2009, Bevacizumab was added as an initial PBS-subsidised treatment, in combination with first-line chemotherapy, of a patient with previously untreated metastatic colorectal cancer with a WHO performance status of 0 or 1. Bevacizumab is also listed as a continuing PBS-subsidised treatment, in combination with first-line chemotherapy, of a patient with metastatic colorectal cancer who has previously been issued with an authority prescription for bevacizumab and who does not have progressive disease and who remains on first-line chemotherapy. Bevacizumab is not for use as monotherapy.

Treatment	At what stage is this treatment used?	What are the main side effects?	Is this treatment PBS subsidised?
Cetuximab (Erbitux)	Used for the treatment of patients with epidermal growth factor receptor (EGFR)-expressing, KRAS wild-type advanced or metastatic colorectal cancer in combination with chemotherapy. Cetuximab can also be given as a single agent in patients who have failed or are intolerant to oxaliplatin-based therapy and irinotecan-based therapy.	You may experience a skin reaction, of a variable nature. Your doctor will have guidelines for the management of this reaction. Skin reactions generally resolve following appropriate intervention by dose delay, reduction or completion of treatment. Reactions to the infusion occasionally occur. Diarrhoea and low magnesium (that might need replacement) are also side effects.	On 1 September 2011, cetuximab was added as an initial PBS-subsidised treatment, as monotherapy or in combination with an irinotecan based therapy, of a patient with a WHO performance status of 2 or less and with K-RAS wild type metastatic colorectal cancer after failure of first-line chemotherapy. Cetuximab was also listed as a conitnuing PBS-subsidised treatment, as monotherapy or in combination with an irinotecan based therapy, of a patient with K-RAS wild type metastatic colorectal cancer who has previously been issued with an authority prescription for cetuximab and who does not have progressive disease. Cetuximab is not PBS-subsidised for use in combination with bevacizumab or oxaliplatin based therapies.
Panitumumab (Vectibix)	As monotherapy for the treatment of patients with EGFR-expressing metastatic colorectal carcinoma with non-mutated (wild-type) KRAS after failure of irinotecan and oxaliplatin containing regimens.	The main side effect which may present is a skin reaction of variable nature. Your doctor and nurse will have guidelines for the management of this skin reaction. Skin reactions generally resolve following appropriate intervention by dose delay, reduction and completion of treatment. Reactions to the infusion are occasionally observed. Diarrhoea and low magnesium (that might need replacement) are also side effects.	In November 2008, the PBAC rejected a submission to add Panitumumab to the list of subsidised drugs under the PBS for patients with advanced bowel cancer, citing uncertain clinical benefit and the resultant high and highly uncertain cost effectiveness. The (unsibsidised) drug is available privately to patients via their oncologist.

taking part in a clinical trial

Advances in bowel cancer treatment offer new opportunities as we understand more about how the disease behaves. These newer treatments go through extensive testing at several different stages before they are approved for use in Australia.

Part of this testing process involves clinical trials, where patients are offered the opportunity to use these new drugs and treatments to see how they respond and to compare the results with existing treatments. For many patients, clinical trials offer an opportunity to try new drugs or techniques that have shown promise as being effective in treating bowel cancer, but there are no guarantees.

What are the different phases of clinical trials?

- **Phase I:** First trial in humans in the life of a new drug/treatment, to look at safety, toxicity and the dosages required. Involves a small number of patients.
- **Phase II:** Examines if a new treatment might work in a specific type of cancer. Involves more patients.
- **Phase III:** Follows phase II and compares a new treatment to an existing standard treatment to see if it might be better. Involves hundreds of patients, with treatments being chosen randomly (not by the doctor or patient).

What are the different types of cancer clinical trials?

- **Treatment trials:** test new treatments, such as new drugs, drug combinations and new approaches to surgery and radiotherapy.
- **Prevention trials:** test new approaches to lifestyle and certain medicines that may lower the risk of developing certain types of cancer.
- **Screening trials:** test the best way to detect cancer as early as possible.
- **Quality of life trials:** explore ways to improve comfort and quality of life for cancer patients.

What happens if I am asked to take part in a clinical trial?

- Make sure you understand the patient information leaflet, that all your questions have been answered and that you understand everything that is involved, plus all benefits and risks.
- Discuss the trial with friends, family, your GP and any other member of the health care team with whom you feel comfortable.
- You must give written informed consent before any clinical trial procedure can take place.

Other questions?

Declining to take part in a clinical trial will not affect your treatment in any other way. You can withdraw from the clinical trial at any time without giving a reason.

After you have completed your cancer treatment, you will need to have regular check-ups. At first these will be every few months, to check that the cancer has not returned.

These check-ups will usually include tests that you had to diagnose the original cancer – such as blood tests, CT scans and maybe the occasional colonoscopy. The tests will be undertaken to check that the cancer has not come back or spread.

Will the bowel cancer come back?

If your bowel cancer was diagnosed and treated early, then there is a very good chance that it will not recur after treatment. If it has taken a long time to diagnose and treat, there is a greater chance that it might recur. However, even if your cancer does recur, it can still be treated with a combination of further surgery, chemotherapy and radiotherapy, depending on your personal treatment plan.

Different types of cancer have a different 'natural history'. Some cancers with more aggressive types of tumour are most likely to recur early (within the first 2 years after diagnosis). Other types, with slow-dividing tumours, may recur years later. Bowel cancer generally lies between these two extremes. Recurrence is uncommon after 5 years and very rare after ten years. You can almost certainly consider yourself cured and unlikely to relapse at this point.

Implications for your family?

Although bowel cancer is linked to a variety of causative factors (and in most cases the cause is unknown), there is evidence that some cases have a genetic link, and that bowel cancer can be more prevalent in some families.

For further information on the link between family history and bowel cancer, look at the 'Risk Factors - Family History' section on our website www.bowelcanceraustralia.org

Getting the all clear

Generally, if after five years the cancer has not returned, you are considered all clear and it's time to celebrate! Throw a big party with all your family and friends, or treat yourself and your loved ones to a holiday or a special night out.

Giving something back

Having been through the bowel cancer journey and received the all clear, some people want to put it all behind them immediately and resume life as normal. Others may find that they actually miss the doctors and nurses who have been such a big part of their lives over the last months, and feel slightly lost or alone. If you are one of these people, you may find it helpful to get involved with your local hospital or a bowel cancer charity, to help raise awareness about the disease and perhaps offer support to people who are going through what you have experienced.

further support and useful contacts

About Bowel Cancer Australia

Bowel Cancer Australia is a national charity, dedicated to raising awareness of the disease and to providing support and information for those affected by bowel cancer. Being diagnosed with bowel cancer will come as a terrible shock to most people. Whilst you will receive all your medical help and support from your healthcare professionals, you may also like to contact the charity to talk to other patients in a similar situation, speak to a nurse or nutritionist adviser, or receive further information about any aspect of your disease.

Patients, and their families, contact us at every stage of their bowel cancer journey, but many find us of particular help and comfort when they are having a break from treatment, or have finished treatment, and are no longer having that day-to-day support from the hospital.

‘Love My Family’ Community

The charity runs a national patient-to-patient network for people with bowel cancer, or relatives of bowel cancer patients. We can put people in touch with each other, by phone or email, matching them by age, geographical region, bowel cancer stage, or treatment received. Talking to someone else who has been through a similar experience can be hugely reassuring, and many patients who initially contact the Community for support go onto become members, providing support to others.

Nurse & Nutritionist Advisory Services

You will have a number of contacts at your local hospital who can answer specific questions about your treatment, and you should not be afraid to ask for help if you are worried at any stage of your bowel cancer journey. The charity also provides a Nurse and Nutritionist Advisory Service, which you may wish to call if you can’t get hold of your assigned nurse, or if you have any other questions or worries.

Information Resources

The charity publishes a range of patient information, all available to order free of charge from the charity.

Please call **1800 555 494** or visit **www.bowelcanceraustralia.org** for further information.

Bowel Cancer Australia

love

BOWEL CANCER AUSTRALIA

support our work

I would like to support the work of Bowel Cancer Australia.

Your donation will not only help us to save lives, but also improve the health and wellbeing of those living with bowel cancer.

Please accept my donation of $ ____________________ *(donations over $2 are tax-deductible).*

My cheque / money order is enclosed (payable to Bowel Cancer Australia).

Or please debit my: ☐ MasterCard ☐ Visa ☐ Amex ☐ Diners

Card number: ___ ___ ___ ___ /___ ___ ___ ___ /___ ___ ___ ___ /___ ___ ___ ___

Name on card: ______________________________ Expiry date: ___ ___/___ ___

Signature: ____

Please note, if you prefer to donate by phone or online,
please call **1800 555 494**
or visit **www.bowelcanceraustralia.org**

My contact details

Title:________ First Name: ____________________ Surname: ____________________

Postal Address: ____

Suburb: ____

State:______________ Postcode:______________ Phone: ____________________

Email: ____

Preferred method of contact: ☐ Post ☐ Email

Thank you on behalf of Bowel Cancer Australia.

Privacy statement: Your name will be placed on our mailing list and, from time to time, we will send you information about Bowel Cancer Australia. If you do not wish to receive such information, please tick this box ☐. Please call 1800 555 494 should you require any further information.

Bowel Cancer Australia is a national charity working to reduce the impact of bowel cancer in our society through awareness, education, support and research. We aim to help save lives from this common cancer, Australia's second biggest cancer killer.

Charity initiatives such as Bowel Cancer Awareness Week®, BowelScreen Australia®, and the Healthy Community Program raise awareness among health professionals and the community about the importance of early detection and intervention in the successful treatment of bowel cancer.

Through our 'Love My Family' Community, we provide support, resources and advocacy for bowel cancer patients, their carers, close relatives and friends.

To do all this we rely on public support. If you would like to get involved, or make a donation, please visit our website.

www.bowelcanceraustralia.org

Bowel Cancer Australia   BOWELSCREEN AUSTRALIA   love BOWEL CANCER AUSTRALIA   IT'S CRUNCH TIME™

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