



Waitemata
District Health Board

Te Wai Awhina



A guide to colorectal cancer, treatment and recovery

Nga Tohu Tohu

About this booklet

Being diagnosed with colorectal (bowel) cancer is scary. You probably have lots of questions you want to ask. In this booklet you and your family or whanau will find a lot of information about colorectal cancer and the services you will receive.

North Shore and Waitakere hospitals have a specialised surgical team to treat your cancer. Please ask any questions that you or your family and whanau may have, and we will try to answer them.

At the back of this booklet you can also find information on support networks, services within the hospital and what to expect after treatment. You will also be given a Patient Follow-up Record.

Make sure you bring both the Patient Follow-up Record and this booklet to all of your appointments. The information in both these documents help us to work with you to help in your recovery.

You should also have a bowel cancer pack from the Cancer Society. This has a lot of useful information. If you don't have this please speak to our colorectal clinical nurse specialist (CNS). You'll find the contact details on page 2.

This is what patients who have used our services say:

"I accepted and took upon myself the challenge of 'beating' the cancer. I did not dwell on what might have been or what may never happen."

"The key to all this is to ask as many questions as you want to ask, ask 'why' at all stages, evaluate the answers and fit them into the pattern of healing and then get on with life and rejoice that you are there to enjoy it."

"After the initial shock and despair following diagnosis, I found I quickly accepted I was going to face the future with what I consider to be a chronic condition. As such, I found it easier to accept continuing treatment. This has enabled me to maintain hope and optimism thereby adjusting to this new change. "

Support is available

Colorectal clinical nurse specialist

The colorectal clinical nurse specialist (CNS) is available Monday to Friday, from 8am to 4:30pm to help and support you and your family/whanau with your health care. Please phone (see below) if you have any questions at all.

The colorectal clinical nurse specialist will:

- Make sure you get the right information to help you make decisions about your treatment and ongoing care
- Work with your surgical team to co-ordinate your care.

Stoma therapy service

The Colorectal CNS also provides a **stoma** therapy service for people who need a bag (**stoma**).

The nurse will:

- Give you and your family or whanau information and resources before your surgery, and also provide any counselling you may need
- Put you in touch with others who have a bag, and also with community support groups
- Co-ordinate your care and recovery while you are in hospital
- Co-ordinate and help with your discharge and support from community services.

CONTACT DETAILS:

Phone: (09) 486 8920 ext 2317

Fax: (09) 488 4621

ColorectalNurse@waitematadhb.govt.nz

Available: Monday to Friday

POSTAL ADDRESS:

North Shore Hospital
Private Bag 93503 Takapuna
Auckland 0740

If you or your family or whanau are worried about anything to do with your condition, treatment or care please contact us.

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Introduction

You have come in to hospital because your GP (general practitioner or family doctor) has referred you here, or you have come in through the Emergency Department.

We will let your GP know what treatment you receive and what progress you make. When you leave the hospital, your GP will continue to manage your care.

If you have any questions about your treatment or stay, please ask us. All our staff are here to help you.

Abbreviations

ACH – Auckland City Hospital

CNS – Clinical Nurse Specialist

NSH – North Shore Hospital

WTK – Waitakere Hospital

Glossary

We have highlighted some words in **bold** because you might not have seen them before. You can find an explanation of these words in the Glossary (page 29) at the back of the booklet.

Planning ahead

While you are in hospital our staff will assess your health and social needs. We will talk to you and your family or whanau about your care after you leave hospital. If you need help at home, we can discuss your options, which may be:

- Returning home with health and/or social support
- Receiving further short-term rehabilitation
- Residential or nursing home care (short or long-term).

Please talk to us at any time if you or your family or whanau are worried about what may happen when you leave hospital.

Frequently asked questions

You will have many questions after your diagnosis. These are some of the questions people often ask. If you have any other questions please ask your doctors or nurses. You will also find a useful list of suggested questions on page 36 of the Cancer Society booklet 'Understanding Cancer: Bowel Cancer'.

Q. Why did I get cancer?

A. The causes are complex and often involve a mix of inherited and environmental factors. There is no single answer, but we hope ongoing research will give the answers to this in the future (see page 8 "About colorectal (bowel) cancer").

Q. Will I need surgery?

A. Yes. In most cases we recommend surgery for colorectal cancer. Surgery removes the part of your bowel that the cancer is in (see page 14 "About surgery").

Q. When will I need surgery/how long before an operation?

A. The doctors and nurses will need as much information as possible about your colorectal cancer before your surgery. We will need to do several tests so the medical team can make the right decisions about your treatment (see page 12 "Investigations/tests").

Q. Will the cancer spread in the time before surgery?

A. Colorectal cancer grows very slowly. It takes years to grow and then spread, so it is very unlikely it will spread before your surgery, even if this is several weeks away.

Q. What other treatment will I need?

A. Some patients with rectal cancers will need to have chemotherapy and/ or radiotherapy before surgery. After surgery you may need chemotherapy depending on the results of your **histology** report. This report gives details of your cancer after surgery (see page 20 "Other treatment").

Q. Will I need a bag?

A. Only some rectal or anal cancer patients need bags, but you might need one if you need an acute (emergency) operation. Your surgeon will discuss this with you before surgery. Bags are often only temporary.

Q. What are the survival rates for colorectal cancer patients?

A. The earlier we find the cancer and treat it the better chance you have of being cured. Overall, about six out of every 10 people treated for colorectal cancer will be cured of the disease.

Q. How long will it take until I recover?

A. Your hospital stay will be about three to five days after open or **laparoscopic** (keyhole) surgery. Each person has different recovery times, but it can take several months to fully recover. You should take about six weeks off work. By the time you leave hospital you will probably be able to shower, dress yourself and walk around. Your medical team will discuss what activities you should avoid at first. We will encourage you to move about while you are in hospital and gradually increase your activity once you go home.

Q. Who should I keep in touch with after I leave hospital?

A. Your family doctor will be responsible for your care once you leave hospital. If there are any changes in your health after treatment, go to your family doctor first. You will receive a telephone call from the ERAS (Enhanced Recovery after Surgery) nurse specialist two days after you go home. You will have met the ERAS nurse at clinic before you come to hospital (see page 18) Your hospital medical team will give you a Patient Follow-up Record.

My Questions

How do I feel?

It is completely normal to have days when you feel you are coping and other times that you are not so good. In the table below you can tick how you are feeling at each milestone. You may also want to add some of your own milestones.

Milestone	I'm OK ✓	I'm not OK ✓
I have received my diagnosis		
I have had the CT and results		
My operation day is booked		
I have received the histology report (after operation)		
First check-up four to six weeks after surgery		

If you have ticked any of the 'Not OK' boxes you may want to talk to someone about what you are going through. A good place to start is the colorectal clinical nurse specialist (you'll find contact details on page 2).



About colorectal (bowel) cancer

What is colorectal cancer?

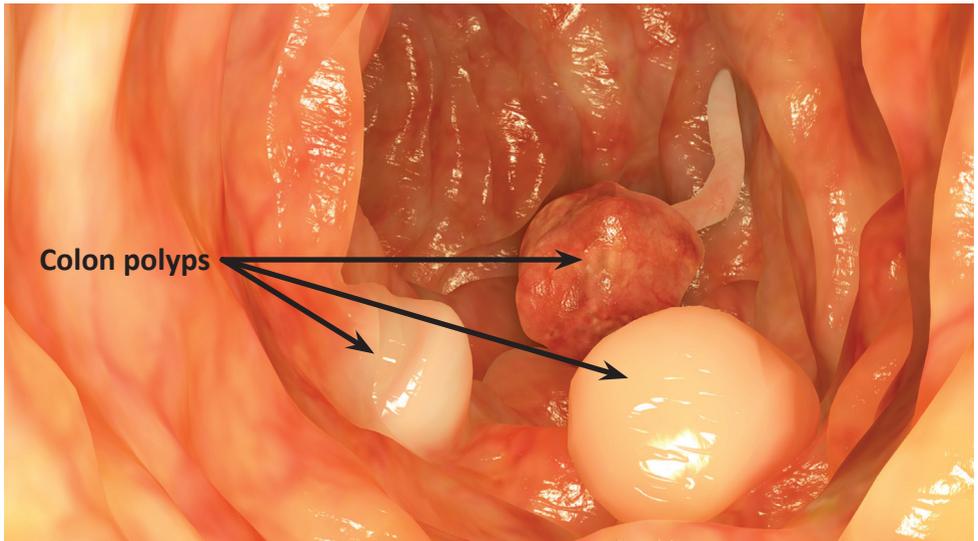
Colorectal (bowel) cancer is the name we use to describe cancer of the colon and rectum (large bowel). It is a **malignant** tumour that starts in the bowel wall. It is usually, but not always, confined to the place where it starts for a long time before it spreads.

Cancer is a growing health concern in New Zealand, and colorectal cancer is the most common cancer for both men and women. Each year nearly 3000 New Zealanders are diagnosed with colorectal cancer.

About six out of every 10 people treated for colorectal cancer will be cured.

How did I get colorectal cancer?

The causes of colorectal cancer are complex but are usually a combination of things you inherit and things in your environment. Usually colorectal cancer starts as a **polyp** in the bowel, which can then become **malignant**. It can take many years for the **polyps** to become **malignant**. Removing the **polyps** stops them from becoming colorectal cancer.



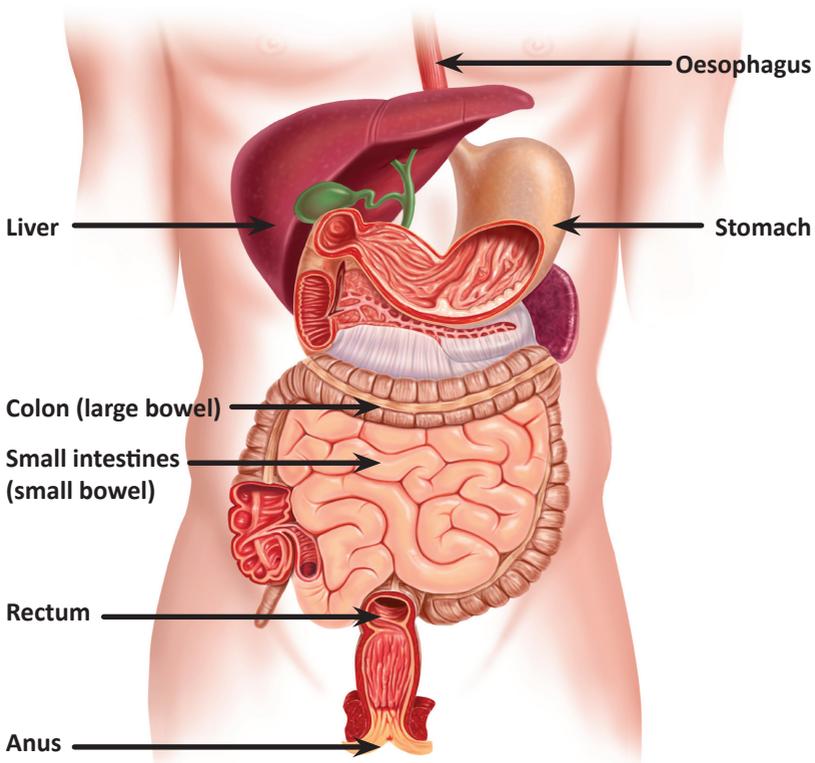
What are the symptoms of colorectal cancer?

Early cancers may have no symptoms at all, which is why Waitemata DHB has a bowel cancer screening pilot programme. However, you might have several different symptoms, including:

- Bleeding from your bottom (rectal bleeding) with or separate from a bowel motion (poos). The blood might be mixed with the bowel motion
- Mucus from your bottom, with or without a bowel motion
- Recent changes in how often you do poos, especially doing it more often
- Iron deficiency (anaemia), which causes tiredness and pale skin.

How does the digestive system work?

To understand colorectal cancer it helps to know about the normal digestive tract and how it works.



Digestion starts in your mouth where enzymes start to break down food so you can absorb it. When you swallow food it moves into your oesophagus and then into your stomach. In your stomach the food is churned by muscles and acid and enzymes break it down further. Once the food is broken down, it is pushed in to your small intestine (small bowel) where you absorb most of it.

You continue digesting and absorbing food all the way down your small intestine. This is where you absorb all the nutrients. At the end of your small intestine (known as the ileum) the leftover waste passes through into your large intestine (large bowel, colon). Your colon absorbs the remaining salt and water and stores the waste in your rectum until it is time to **defecate** (have a poo).

Who is most at risk of developing colorectal cancer?

The average New Zealander has only a small chance of developing colorectal cancer – just 0.6% by the age of 55 years and 5.6% by the age of 75 years.

People with a personal history of colorectal cancer, colorectal **adenomas** (colon **polyps**) and ulcerative colitis have more risk of getting colorectal cancer. People with a family history of colorectal cancer (ie, immediate family such as a parent, brother or sister) may have a higher risk of developing the disease.

We recommend genetic counselling for all colorectal cancer patients who are younger than 50. Genetic testing is available for at-risk family members, such as brothers, sisters and children.

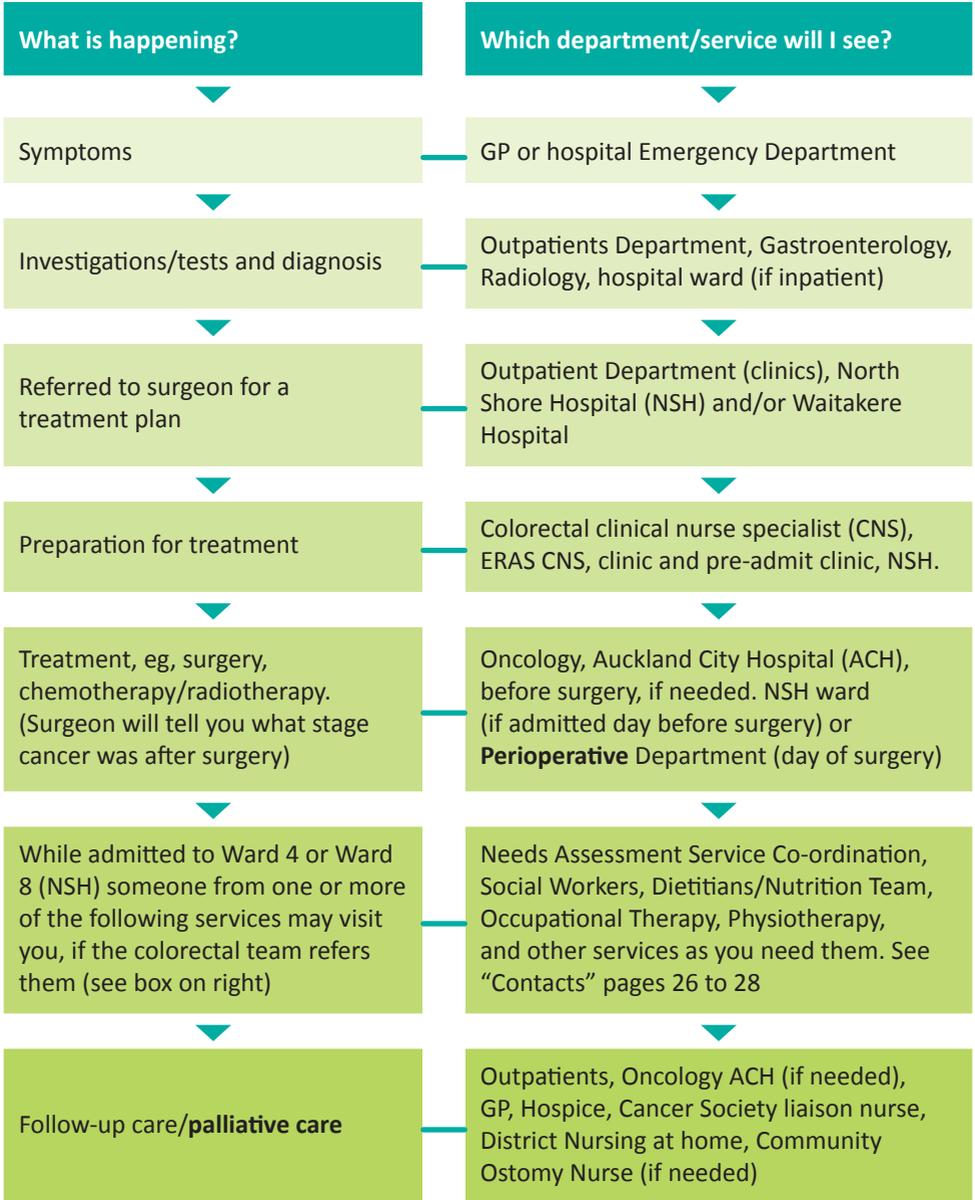
What can be done to reduce the risks?

Maintaining a healthy lifestyle may help cut the risks of getting colorectal cancer. Generally, people can reduce their risks by:

- Exercising every day, for 30 to 60 minutes
- Staying at a healthy weight
- Limiting how much alcohol you drink
- Not smoking
- Regular health checks if you are at risk of developing colorectal cancer.

What happens next?

What happens to each person as they are treated for colorectal cancer is different. However, most people go through the following steps:



Investigations There are several tests to find out if you have colorectal cancer and whether it has spread outside your bowel. You'll find a full list of these tests below.

Diagnosis This is when the doctor confirms with you whether you have colorectal cancer and whether it has spread outside your bowel.

Treatment We will talk about your treatment options with you, your doctor, and your family if appropriate, after you have had all your tests. Your treatment may include surgery, chemotherapy, radiotherapy or **palliative care**.

Staging This tells us how far advanced the cancer is. Your surgeon will talk to you about this information once the **histology** report is completed after surgery (see page 19).

Follow-up care This happens after you have completed your treatment. It involves regular check-ups and tests. You will be seen by your doctor or another senior doctor within his/her team, or the colorectal clinical nurse specialist.

Investigations/tests

Investigations are tests to find out if you have colorectal cancer (diagnosis) and whether it has spread outside your bowel. They usually take place before you come into hospital for surgery. The tests are carried out at clinics in the hospital's Outpatients Department, Gastroenterology Department and/or Radiology Department. If you are an outpatient, we will send you an appointment letter for these clinics. There are several different tests available and you may need one or more to give the right answers. After you have had ALL your tests you will get a diagnosis. These are the common tests for colorectal cancer:

Digital rectal examination

Digital rectal examination is done by a doctor and takes a few minutes. The doctor will insert a gloved finger into your bottom. The doctor is feeling for any lumps or swelling and checking for bleeding.

Sigmoidoscopy

Sigmoidoscopy is done to examine the lower end of your bowel. It takes about five minutes and is usually done after you have a digital rectal examination. A thin tube is inserted through your anus into your rectum and lower colon. Air is

blown into the bowel to enlarge it. You don't usually need to be sedated (given something to relax you). We may take a **biopsy** at this time and send it to the laboratory. Before you have this examination you may have to have an **enema** to help empty the lower part of your bowel. You will get more information and instructions about this when the test is booked.

Colonoscopy

Before this examination you will need to take a strong laxatives and you will not be able to eat certain foods for a couple of days. This will help to empty your bowel as it is very important that your doctor gets a clear view of the area. The day you take the laxative you will need to stay at home so that you can always be close to a toilet. We will give you more information and instructions about this when the test is booked.

Colonoscopies are done at North Shore and Waitakere hospitals by either a gastroenterologist or a surgeon and usually take about 30 to 60 minutes. They are the most accurate way to assess your colon and rectum. We will give you a sedative injection, then a colonoscope will be placed into you rectum and air will be pushed into your bowel. This might be a bit uncomfortable. If the doctor sees any abnormal areas they will take a **biopsy**. They might also take photographs of the area. The **biopsy** will be sent to the Pathology Department, where it will be examined closely under a microscope. It will take a few days before we know the results.



If you are going home after a colonoscopy it is important that someone collects you, as you will not be able to drive or use public transport for a while. If someone is with you they will be able to use the waiting room while you have your colonoscopy, or you can arrange for someone to collect you.

Side effects

You might notice some side effects after this test, such as wind and/or very loose, watery bowel motions (poos).

Other tests

While you are being diagnosed, we might also ask you to have:

- **Blood tests**
These check for anaemia, how well your liver is working, cancer markers and how well your kidneys are working before you have a **CT scan**.
- **CT scan**
This checks to see if the cancer has spread to other organs.
- **MRI scan**
This gives us more detailed information about the cancer. MRI scans are mostly done for rectal cancers or if the surgeon has asked for one.
- **CT Colonography**
This is a special **CT scan** for people who can't have a colonoscopy.

After all the tests and investigations have been done, the surgeon will give you a diagnosis and a recommended treatment plan.

About surgery

Types of surgery

Open surgery or laparoscopic surgery: Some patients will have open surgery, which is a large cut to the abdomen. Or we might offer you **laparoscopic** (keyhole) surgery. This is a relatively new approach to colorectal cancer surgery, and means we do the operation through small cuts using specialised equipment.

It's thought laparoscopic surgery has some advantages, such as helping you to recover and return to work more quickly, less scarring inside your abdomen and fewer breathing problems. Your surgeon will offer you **laparoscopic** surgery if it is suitable for you.

Open and laparoscopic just describes the way your operation is done. But there are different operations that you might have.

Anterior resection

This is for rectal cancer. The surgeon takes the cancer out and joins the end of your colon on to the remaining rectum or sometimes the anal canal. You might need a temporary bag (ileostomy) until the join has healed. This is more likely if the join is very low, or close to the outside. Your surgeon will talk to you about when you should have an operation to remove the bag, or a reversal. Some patients can have this just six weeks after their operation, but others might have to wait for a few months.

Abdomino-perineal resection

This is for anal and lower rectal cancer. The surgeon takes out all of the rectum and anal canal. Patients who have this need a permanent bag (colostomy).

Hartmann's procedure

This is usually performed in emergencies. The surgeon removes part of the colon or bowel with cancer, and does not rejoin it. Patients who have this need a temporary or permanent bag (ileostomy or colostomy).

Left hemi-colectomy

This is for cancer of the left colon. The surgeon takes out the section of the bowel with the cancer and joins both ends together.

Right hemi-colectomy

This is for cancer of the right colon. The surgeon takes out the section of the bowel with the cancer and joins both ends together.

Complications

About one-third of people having colorectal cancer surgery will have a complication (or something that doesn't go according to plan) related to their operation. Most of these are very small, but some are more significant and may even be life-threatening. But remember, without treatment colorectal cancer will kill you. Complications might be related to the anaesthetic or to the surgery. Your

anaesthetist will talk with you about the anaesthetic one. This booklet does not cover them.

These are some of the common or important complications you should know about before your surgery:

- **Infection** This can happen in several places, including inside the abdomen, the lungs, the bladder and in the wound. Colorectal cancer is dirty surgery and so we use several techniques to prevent infection. These include giving you antibiotics, using sterile wound dressings and isolating patients with bad infections. You can help by getting up out of bed as soon as you can and by taking deep breaths and coughing.
- **Bleeding** This can happen during surgery or even a few days later. If this happens, you may need a blood transfusion, but we will give you this only if you consent.
- **Deep vein thrombosis (DVT/leg clots)** This is the same as “travellers’ clots”, which passengers can get during long flights. It is caused by staying still for a long time. Being overweight, having cancer surgery, smoking, taking the oral contraceptive pill and not moving after surgery all increase the risk of clotting. Leg clots can break off and travel to your lungs, where they cause breathing problems and sometimes death. We can cut the chance of this happening by using anti-clotting agents (small injection under the skin on your stomach), specialised stockings and getting you up and moving as soon as possible.
- **Anastomotic leak** In any operation that takes out a piece of bowel and makes a join, it is possible there might be a leak. It is one of the most important complications that your surgeon will watch out for. Leaks happen in about 3% to 10% of patients (depending on what kind of operation they have) and almost always mean they have to have another operation. Often they will need to have a colostomy or ileostomy (bag). If a leak is going to happen, it will usually be in the first week after surgery.
- **Bowel obstruction** This is usually caused by internal scarring. It can happen after any abdominal operation, up to years later. Mostly it is treated with fluids (by drip) and pain relief, sometimes with a drainage tube in the stomach (nasogastric tube). It is quite common after an ileostomy is closed,

when it happens in up to 20% of patients. Most patients who get bowel obstruction don't need another operation, as it will settle with treatment.

- **Wound hernia** This may happen some years after your operation. Hernias are a weakness in the abdominal wall. They are more common in obese patients, smokers and after wound infections. Sometimes they need to be repaired surgically.
- **Death** The chance of dying as a result of your surgery is very low (less than 1%), but not zero. It is more of a risk for very old or sick patients, or for people who have emergency surgery for bowel obstruction or bowel perforation.

This covers the main complications but not all of them. If you are worried about anything, please talk about it with your surgeon or his/her team.

Bags/stomas

Stoma is the name for the end of a piece of bowel brought out on to the abdominal wall. The faeces (poos) drains into a bag.

There are two main types of bags, those for the small bowel (ileostomy) and those for the large bowel or colon (colostomy). These might be permanent or temporary, depending on what operation you need for your cancer.

If you need a bag (**stoma**) you will meet the colorectal clinical nurse specialist (CNS) before your operation to talk about how to use it and care for it, and to mark a site for it on your stomach. The colorectal CNS will plan with you for when you leave hospital. Sometimes patients who have emergency operations need a **stoma**. If this happens to you, you will meet the colorectal CNS after surgery.

- **Ileostomy**
Most ileostomies are temporary. The surgeon pulls out a section of the small bowel and stitches it on to the surface of the stomach. A bag then covers the bowel and collect the contents. Ileostomies are made to divert the poos away from where your colon or rectum has been joined, so it can heal properly. It also reduces complications. After you have left hospital you will go to an outpatient clinic for a barium x-ray, which will check how well the join has healed. Closing the ileostomy is a second operation and you will need four to five days in hospital.

- **Colostomy**

The surgeon pulls out a section of the large bowel and stitches it on to the surface of the stomach. A bag covers the bowel and collects the contents. This might be permanent but in some patients it can be temporary.

Before your operation

Pre-admit clinic

Shortly before surgery, we will ask you to attend a pre-admit clinic where we will assess you to make sure the operation is as safe as possible. You will meet the anaesthetist, who will answer any questions you have about the anaesthetic.

During the assessment you will be physically examined. You might also have blood tests and a recording of your heart (ECG).

The assessment can take two to three hours, and gives us the medical information we need to keep you safe in hospital.

Make sure you bring along all your medicines to the pre-admit clinic. Don't forget your Patient Held Record and also bring this booklet for each appointment and admission.

Admission

You will meet the ERAS (Enhanced Recovery After Surgery) nurse specialist at a clinic or at the pre-admit clinic. You will also get all the information about your admission, dates, times, where you need to come to and what you need to bring. We will also talk with you about your plans for when you go home after your operation.

Research

We do a lot of clinical trials at North Shore Hospital. We might ask you to take part in one. If we do, we will give you all the information you need to decide if you want to be involved. If you want to take part in or contribute to our research please talk about this with your surgeon or the colorectal nurse specialist (see page 2).

Appointments for clinics

Please contact North Shore Hospital (see details on page 26) and ask to speak with the booking clerk for your surgeon.. If you know it, have your NHI number ready to help us respond to your enquiry quickly.

CT appointments

Please contact North Shore Hospital (see details on page 26) and ask for Radiology bookings. If you know it, have your NHI number ready to help us respond to your enquiry quickly.

MRI appointments

Please contact North Shore Hospital (see details on page 26) and ask for MRI bookings. If you know it, have your NHI number ready to help us respond to your enquiry quickly.

Caring for your bag (stoma)

If you will need a bag or might need a bag (colostomy or ileostomy) the colorectal clinical nurse specialist (CNS) will teach you all about it at a clinic, and mark your stomach to show where the ileostomy or colostomy will go. If you have a bag the nursing staff will care for it straight after your operation. We will encourage you to start caring for it yourself, as soon as possible. When you are well enough, nurses will show you how to change your bag and generally care for your new routine. The colorectal CNS is here for you if you have any concerns or complications and will review your progress and plan your care with you.

What is my prognosis?

Histology

Histology reports are ready seven to 10 days after surgery. They include information about the size, stage, type, and appearance of the tumour. They also show if any of the **lymph nodes** around your bowel have cancer. The results will show if you need chemotherapy. If necessary, after surgery your surgeon, oncologist, radiologist and other specialists will have a team meeting to discuss your **histology** report. They will recommend if chemotherapy would help you.

they will also give you a **prognosis** and talk about any further treatment you might need.

What the “stages” mean

T stage: This refers to how far through the wall of the bowel the cancer has spread. It ranges from T1 (very early cancer) through to T4, where the cancer has spread into other organs next to the bowel.

N stage: This refers to whether the **lymph nodes** have cancer in them.

M stage: This refers to **metastatic cancer** or cancer that has spread from the bowel to other distant organs, like the liver or lungs.

You will be given a stage from Stage 1 through to Stage 4, depending on the combination of these three things (TNM). What stage your cancer is will determine your chance of survival (**prognosis**) and also what extra treatment you might need.

Transit lounge

You may be transferred to this area on the day you leave hospital if you have to wait for discharge papers, prescriptions or are waiting to be collected by relatives.

Other treatment

Surgery is the usual treatment for colon and rectal cancer. Not everyone needs extra treatment after surgery. However, some patients will benefit from other treatment as well as surgery to reduce the chance of the cancer coming back. This is known as **adjuvant** treatment. If you need more treatment it may be radiotherapy and/or chemotherapy. You might also have radiotherapy or chemotherapy before surgery to help make the cancer smaller.

Radiotherapy

Radiotherapy, usually given before surgery for rectal cancer, uses high-energy x-rays to kill or shrink cancer cells. The radiation usually comes from the outside of the body (external beam radiation).

Where will I have my radiotherapy?

Regional Cancer and Blood Services, Building 8, Auckland City Hospital.

Why is radiotherapy given?

For rectal cancer, radiation can stop the cancer from coming back in the place where it started. It can also treat local recurrences that are causing symptoms such as pain. Occasionally we use radiotherapy to treat **metastatic (secondary) colon cancer**.

How often will I need radiotherapy treatment?

This varies from five to 28 treatments (**fractions**). Treatment is usually Monday to Friday for as many weeks as your doctor prescribes.

What happens when I have radiotherapy?

You and your support person will be invited to attend a patient orientation session, held every Friday at 11am at the Cancer Society, Domain Lodge (opposite Auckland City Hospital). You will also get a patient information booklet about your treatment. You will have a planning session with staff at Auckland City Hospital, which involves **simulation**. Everyone is different, and **simulation** is when the radiation team plan which treatment you need. They take detailed images of your body and mark the exact areas that will receive beams of radiation. This minimises the amount of normal tissue in the way of the radiation. The treatment is like an x-ray taken from different angles. You will find more information on page 28 of the Cancer Society booklet 'Cancer Society Information and Support Services'.

What are the side effects?

Side effects of radiotherapy for colon or rectal cancer depend on what site is treated. They include diarrhoea, mild skin irritation, and possibly nausea. You may feel very tired from the treatment, and have a reduced appetite.

After radiotherapy?

You might continue feeling fatigue or tiredness for some weeks or even months. You might also develop anal or rectal irritation, known as **proctitis**. You could also develop a urinary tract infection, which we can treat.

Chemotherapy

Chemotherapy means using drugs to treat cancer. Many types of drugs are used

in chemotherapy, and they all attack cancer cells in different ways. Chemotherapy can be used alone or with radiotherapy and surgery. You will be able to attend a Patient Orientation organised by the Oncology Department, where you will discuss the details of your particular treatment.

How does chemotherapy work?

Chemotherapy works by stopping cancer cells from dividing and multiplying. The drug is injected into your vein or given by mouth. It enters your bloodstream and spreads throughout your body, so it is useful for cancers that have spread to other organs. Chemotherapy after surgery can make it more likely patients with some stages of colorectal cancer will survive. It can also help relieve symptoms of advanced cancer. Your chemotherapy will be tailored especially for your needs.

How is chemotherapy given?

Chemotherapy may be given, either

- **By mouth** as a tablet
- **By injection** into a vein, through a **peripheral venous line** (PVL) on the back of the hand as a **bolus**, or small infusion, or through **Portacath**. A Portacath is a tube placed into a large vein, which stays there for some time so we can give you drugs over the longer term.

How often will I need chemotherapy?

This depends on the type of treatment you are having. Each chemotherapy treatment is called a cycle. You will get more information about what you need from the Oncology Department before you start your treatment.

Where will I have my treatment?

The staff at Regional Cancer and Blood Services, Building 8, Auckland City Hospital will talk about your individual treatment with you. The Outpatient Clinic is on Level 5, and Radiotherapy Clinic on Level 4 of the same building.

Are there any side effects from chemotherapy?

Yes. While chemotherapy drugs kill cancer cells, they also damage some normal cells and this can lead to some unwanted effects. Most side effects are temporary, although some side effects may be permanent. It depends on the

type of drug you get, the amount, and how long the treatment lasts. You will be told all about the side effects of the drugs you will get before your treatment starts. You will also be carefully monitored while you are being treated to minimise any discomfort you feel. Side effects include diarrhoea, nausea and vomiting, skin sensitivity (particularly to the sun), skin rash, mouth ulcers, low blood counts (which can increase the chance of infection and fever), hair loss, sore hands and feet (known as hand/foot syndrome, it particularly happens with oral medication) and fatigue.

Palliative care services

Most bowel cancer is curable. But when it isn't, palliative care aims to make sure patients have the best quality of life possible.

Palliative care staff are experts in dealing with pain and other symptoms. They can offer emotional support for you and your family if your cancer is not curable and is no longer being treated.

What is palliative care?

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to speed up nor postpone death
- Looks after patients' psychological and spiritual needs, as well as the medical ones
- Offers a support system to help patients live as actively as possible
- Offers a support system to help the patient's family cope during their illness
- Involves a whole team of people in caring for patients and their families
- Will enhance quality of life, and may also positively influence the course of illness
- Can be used early in the course of illness, together with other therapies and treatments.

How do I get palliative care support?

In the hospital

The ward nurses, colorectal clinical nurse specialist or doctor can refer you to the **palliative care** team based at North Shore or Waitakere hospitals.

You can talk to the **palliative care** team about any symptoms or side effects of colorectal cancer. You do not have to put up with any unpleasant effects.

The **palliative care** team helps you manage symptoms like pain, nausea and vomiting, constipation, breathlessness, anxiety and depression. There may be issues other than physical ones that trouble you and they may be able to help with these. They can also make sure that the support you need is in place before you go home.

In the community

Community hospice teams work closely with your GP and district nurse. Before leaving hospital it is important that you understand your medication – the staff can help you with this and find out where you may need to collect your medication from. They may need to fax some prescriptions to your pharmacist before you go home.

Follow-up after surgery – the next five years

Understanding your Patient Follow-up Record (PFR)

As well as this booklet you have been given a PFR (blue card). This record tracks your follow-up treatment. This is because after surgery to remove the cancer from the colon, patients are still at risk of the cancer coming back, either in the colon or other organs such as liver or lung. Follow-up is important so we can pick this up early and offer early treatment to remove it.

Which patients should be followed up?

Everyone who has had surgery to cure cancer, and who would be fit for further liver or lung surgery, will be offered follow-up. Most patients with incurable cancer will also be followed up.

Who will perform the follow-up?

The surgeon who operates and your GP will start the follow-up. Your GP will be mainly responsible for your regular checks, and will tell your surgeon about any abnormalities. You will need to make the first appointment with your GP and take your Patient Follow-up Record with you. We will ask your GP to organise blood tests every three months and whatever follow-up you need.

What tests are done for follow-up?

Your specialist will arrange follow-up after treatment for colorectal cancer. For most patients this means outpatient visits, regular blood tests, and maybe scans and a colonoscopy. Your surgical team will complete your Patient Follow-up Record at each visit.

If you have any new symptoms or symptoms that worry you, such as loss of weight, tiredness, shortness of breath or new bowel symptoms (diarrhoea, constipation, bleeding) you should tell either your specialist team or you GP.

For most patients, follow-up of colorectal cancer consists of:

1. A blood test every three months for four years, then every six months for four years.
2. A **CT scan** one year after your operation and repeated as needed.
3. Colonoscopy before surgery followed by a check colonoscopy three years after your operation. Your surgeon will discuss this with you.
4. Regular clinical examination as arranged by your doctor.
5. After five to eight years (depending on the type of cancer) years you are considered cured of the cancer. Then you will need colonoscopy check-ups only once every five years.

Contacts

My family doctor/GP:.....

Name of Medical Practice:.....

Phone number:.....

Other details:.....

Waitemata DHB Support Services

		
All services/departments www.waitematadhb.govt.nz		
North Shore Hospital	(09) 486 8900 or Freephone 0800 80 93 42	124 Shakespeare Rd, Takapuna Private Bag 93-503, Takapuna AUCKLAND 0740
Patient Enquiries	(09) 486 8930	
Waitakere Hospital	(09) 839 0000 or Freephone 0800 80 93 42	55-75 Lincoln Road, Henderson Private Bag 93-115, Henderson AUCKLAND 0650
Asian Health Support Services		
North Shore Hospital	(09) 486 8314 or ext 2314/3863	
Waitakere Hospital	(09) 837 8831 or ext 6831/6017	
Chaplains	(09) 486 8900 (Ask for the chaplain on call)	
Colorectal Clinical Nurse Specialist / Stoma Therapist	(09) 486 8920 ext 2317 fax (09) 488 4621	North Shore Hospital Private Bag 93- 503, Takapuna, AUCKLAND



Waitemata DHB Support Services *continued*

		
ERAS Clinical Nurse Specialist	(09) 486 8920 ext 4607	
Maori Health Services Mo Wai Te Ora		
North/North Shore Hospital	(09) 486 8900	
West/Waitakere Hospital	(09) 839 0000	
Helensville	(09) 420 6357	
Warkworth	(09) 422 2700	
Whangaparaoa	(09) 427 0300	
Palliative Care We will refer you to the Palliative Care team if necessary.	(09) 486 8920 ext 2867/2097 The contact details of your Palliative Care team	
Social Workers	(09) 486 8920 x 3271	
For advocacy, counselling and links to a range of support agencies such as Home Help, Meals on Wheels, WINZ etc.		
Translation Services – WATIS (Waitemata Auckland Translation and Interpretation Services)		
North Shore	(09) 486 8314 or ext 2314/3863	
Waitakere	(09) 837 8831 or ext 6831/6017	
Auckland City Hospital Patient Enquiries www.adhb.govt.nz	(09) 367 0000 (09) 375 4300	Auckland City Hospital 2 Park Rd, Grafton Private Bag 92024 Auckland Mail Centre Auckland 1142

Community services and patient support groups



Auckland Cancer Society
www.akcansoc.org.nz

0800 226 237

These services are available if you would like to talk about cancer, get help in understanding treatment and side effects, and for emotional support and understanding.

District Nursing and Community Therapists – Community Ostomy

West/Waitakere	(09) 837 6620
North	(09) 486 8945
Helensville	(09) 420 8497
Warkworth	(09) 422 2700
Whangaparaoa/Rodney	(09) 427 0300

Nurses for each region are available through the West, North and Whangaparaoa (Rodney) numbers. There is only a limited service at weekends and on public holidays.

North Harbour Ostomy Society

(09) 445 2100

PO Box 31-574,
 Milford, Auckland.

Auckland Ostomy Society
akostomy@hotmail.com

(09) 828 2344
 (09) 271 4166

The ostomy societies provide friendship, understanding and support groups for people who have a bag (**stoma**).

Hospice

Warkworth/Wellsford Hospice	(09) 425 9535
Hibiscus Coast Hospice North Shore	(09) 426 0283
Hospice Trust West Auckland Hospice	(09) 486 1688
	(09) 837 1291

Amitabha Hospice Service
www.hospice.org.nz

(09) 828 3321



Glossary

You can find a full list of terms in the glossary in the Cancer Society booklet “Understanding Cancer: Bowel Cancer”. But these are some of the main ones.

Absorbable	The stitches will gradually dissolve over time, and be flushed out of the body. This usually takes a couple of weeks.
Adenomas	A benign (non-cancerous) tumour-like gland.
Adjuvant	Medical treatment added to another to make it more effective.
Anastamotic	The surgical join of the bowel or part of the intestine.
Biopsy	A sample of tissue that is taken to be examined in the hospital laboratory under a microscope.
Bolus	An injection of a drug into a vein.
CT Scan (or CAT scan)	A procedure that uses many x-ray images to create a computer image of a cross-section and 3-D images of the body’s organs. It is very low-risk. An iodine-based liquid is given in the vein, which makes many organs and structures much easier to see on the CAT scan. This may cause itching, a rash, hives, or a feeling of warmth throughout the body. This usually goes away quickly.
Defecation	Bowel motion, having a poo.
Discharge Summary	Gives you details on your diagnosis, name of operation you have, your recovery progress (including complications) while in hospital, recent blood results, histology report (if this is available when you are discharged) and advice about follow-up care.
Enema	The insertion of a liquid into the bowels through the rectum as a treatment, often used for constipation, or as an aid to diagnosis.
Epidural	Medication is put inside the spinal column just outside the sac that surrounds the spinal cord.
Fraction	Each separate radiation treatment. The number of fractions each person needs is different, as treatment is planned for your individual needs.

Histology	Science that studies animal and plant tissue at a very small, microscopic, level.
Infusional bottle	A container that holds a fluid medication that slowly infuses through a vein over time.
Laparoscopic	Otherwise known as keyhole surgery, this is surgery that is done through a small opening in the skin. Several operations can be performed in this way, without needing a large surgical incision (cut). Patients receive general anaesthesia (go to sleep) during the procedure. Generally, patients recover more quickly, and have less pain.
Lymph nodes	Small structures throughout the body that produce and store cells that fight infection.
Malignant	A tumour that invades the tissue around it (cancerous).
Metastatic (secondary) cancer	Cancer that has spread from the original tumour to other parts of the body.
Palliative care	Controls the symptoms of a disease rather than curing it. Please refer to page 23 for full details.
Perioperative	The period of time from when the patient enters the theatre for surgery until they leave the theatre area.
Peripherally inserted central catheter (PICC)	A PICC line is a line that is put in a vein in your arm around the elbow crease. The tip of the line rests in a large vein near the heart. It is a flexible tube and may stay in for several weeks or months. It is inserted by a doctor or radiology nurse specialist. If you need a PICC line you will get a patient information leaflet about it.
Peripheral venous line	A tiny tube (a catheter) that is put into a vein near the outside of your body to give fluids or medicine. This is the most common way to have intravenous (IV) fluids and IV medicine.
Polyps	A small stalk-shaped growth sticking out from the skin or inside the body. Polyps are usually harmless, but some can become malignant (cancerous).



Portacath	A small medical appliance that is installed beneath the skin. A catheter (tube) connects the portacath to a vein. Under the skin, the portacath has a channel through which drugs can be injected and blood samples can be drawn many times, which is usually more comfortable for patients than if we put needles in their skin all the time.
Proctitis	Inflammation of the rectum.
Prognosis	A medical opinion about the course and outcome of the disease.
Simulation	This copies what will take place during each ' fraction ' of treatment. This allows the radiation team to plan each patient's treatment in full before the first fraction takes place.
Staging	How far advanced the cancer is.
Stoma	A bag (it literally means "an opening" in your skin).