

# A guide to help you understand your bowel cancer & treatment



## Introduction

The information contained within this booklet (“log book”) is specifically for patients who have been diagnosed with bowel, or colorectal cancer.

This log book contains information about your cancer treatment and the care that you can expect. We hope that having this information will help you have a clearer understanding of your cancer and any treatments.

The log book is quite a comprehensive document. However, you may find that it does not answer all of your questions. Please remember that you can always speak to a member of the team caring for you who will address any concerns or queries that you may have. As health care professionals, we often use medical terms and phrases. In order to help you understand these, we have included a glossary of terms towards the back of the log book (page 23).

Bring this log book with you each time you come to hospital and together we can add to it and write notes, so there is a clear record of what is happening.

### Acknowledgements:

Waikato Hospital staff: Mr Lolohea, colorectal surgeon; Mr Van Dalen colorectal surgeon; Judy Warren, CNS colorectal cancer

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Personal details

Name: .....

Address:

(Patient label)

Daytime telephone number: .....

Evening telephone number: .....

GP contact telephone number: .....

Past medical history that may affect your treatment:  
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.....

Allergies:  
.....  
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Current medication:  
.....  
.....

Other issues of importance to you (e.g. do you live alone, family support, disabilities, etc.):  
.....  
.....

Your useful contacts

Name / organisation

Telephone

Address

Email

Role

Name / organisation

Telephone

Address

Email

Role

Name / organisation

Telephone

Address

Email

Role

## What is bowel cancer?

- Bowel cancer is the growth of abnormal cells that develop from within the bowel lining.
- The exact cause of this problem is not known, but we do know that risk increases with age. Approximately 2500 cases are diagnosed annually in New Zealand with about 400-450 of these diagnosed and treated across the Waikato, Bay of Plenty and Lakes DHB areas.
- People with a family history of cancer may have an increased risk of developing the disease.

## How do we know you have colorectal (bowel) cancer?

We usually diagnose colorectal cancer using the results from a number of tests and investigations. (Please refer to the glossary, page 23).

You may already have had some of these tests/investigations.

- X-rays
- Rigid sigmoidoscopy
- Flexible sigmoidoscopy
- CT colonography
- Colonoscopy
- Biopsies
- Scans – Ultrasound, CT and MRI
- Blood tests.

The results of your investigations will have been discussed amongst the multidisciplinary team members and your treatment planned accordingly.

There may be occasions when we are unable to confirm your diagnosis before an operation. If this is the case, we will have to wait until the suspected cancer has been removed and analysed by the pathologist.

It is common to wait 2-4 weeks for tests and appointments but this will not cause your cancer to get worse. We understand though, that it is a very anxious time for you and your family. If you are concerned, please contact your cancer nurse specialist who will be monitoring tests and ensuring appointments are arranged.

## Who will be involved in your care?

There are numerous health professionals who will be caring for you, each with their own area of expertise. These include surgeons, oncology doctors, pathologists, radiologists, nurses, dieticians, physiotherapists, social workers and several others. We call this “the multidisciplinary team” (MDT).

## What treatments are available?

The main treatment for colorectal cancer is surgery (see page 12). However, some patients benefit from having other treatments as well as surgery. The other treatments we use are radiotherapy or chemotherapy. For some people these therapies are used before surgery, for others after surgery and for some people, not at all. Colon cancer is usually first treated by surgery.

Radiation therapy will be at the Regional Cancer Centre in Hamilton and chemotherapy treatments are usually given at your hospital's outpatient chemotherapy unit. If you need either, appointments will be arranged for you. You will not receive treatment at your first appointment and you will usually have several days to consider the treatment options.

Most people believe that radiotherapy and chemotherapy have some very unpleasant side effects. However, when they are used to treat colorectal cancer, these side effects tend not to be so severe and many people are able to lead a normal life whilst having treatment.

Depending on where you live, arrangements may be made for you to stay at the Lions Cancer Lodge in Hamilton from Monday to Friday. There is no charge for this. You will be given information about this by the Regional Cancer Centre.

Please note while you are having treatment at the Regional Cancer Centre or hospital chemotherapy unit, the oncologists are your primary health provider and any concerns regarding treatment can be addressed with them and the oncology nurses.

## What is radiotherapy?

Radiotherapy treatment uses high energy x-rays to destroy cancer cells. Some patients with colorectal cancer will have this treatment before their surgery and others may benefit from radiotherapy after surgery.

The treatment is individually planned and monitored by your radiation oncologist. Your first appointment with the radiation oncologist is to make sure you understand what type of cancer you have, how much it has grown and spread in your body and to explain what the goals and side effects of the radiation treatment will be. You will require another CT scan for planning the radiation treatment. This will be arranged for you.

## What is chemotherapy?

Chemotherapy treatment involves using drugs that are usually given as an injection into a vein. These drugs attack the cancer. Depending on what type of cancer you have and how far it has spread, chemotherapy may stop your cancer from growing further, shrink the cancer or sometimes get rid of it altogether.

The treatment is individually planned and monitored for each person by your medical oncologist. Your first appointment with the oncologist is to make sure you understand what type of cancer you have, how much it has grown and spread in your body and to explain what treatment options are available and the goals, risks and side effects of the treatment. You should also be advised of any new treatment options that may not be funded.

## Radiation and/or chemotherapy prior to surgery for rectal cancer

Rectal cancer sometimes needs to be treated with radiation and/or chemotherapy prior to surgery. The decision on who should receive this treatment is made after discussion at a multidisciplinary meeting attended by surgeons, medical oncologist/s, radiation oncologist/s, pathologist and a radiologist where x-rays and scans are reviewed. There are two main radiation regimes.

1. Short course - daily radiation for five days and surgery about 1 week afterwards.
2. Long course – radiation and chemotherapy treatment over 5 weeks and surgery about 5 weeks later. Your oncologist, surgeon and cancer nurse specialist will discuss your treatment in detail and answer any questions you may have.

## Understanding digestion

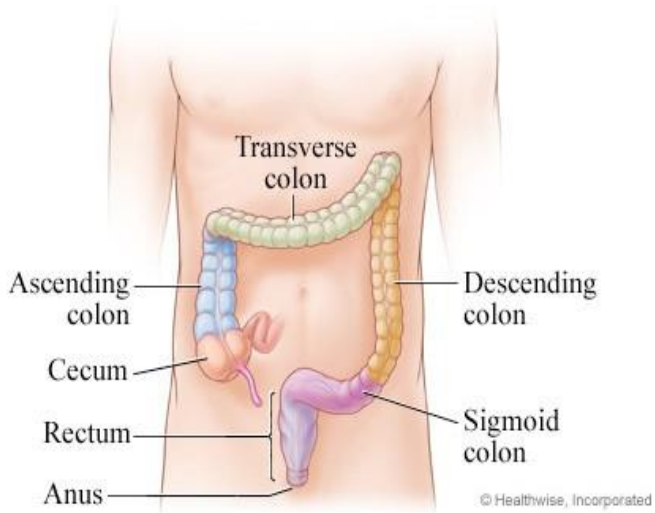
To understand your operation, it helps to have some knowledge of how your body works.

When food is eaten, it passes from the mouth down into the oesophagus (gullet) and into the stomach. Here it is broken down and becomes semi-liquid. It then continues through the small bowel (structured like a very long coiled tube), where digestion of nutrients takes place and where most of these are absorbed into the body.

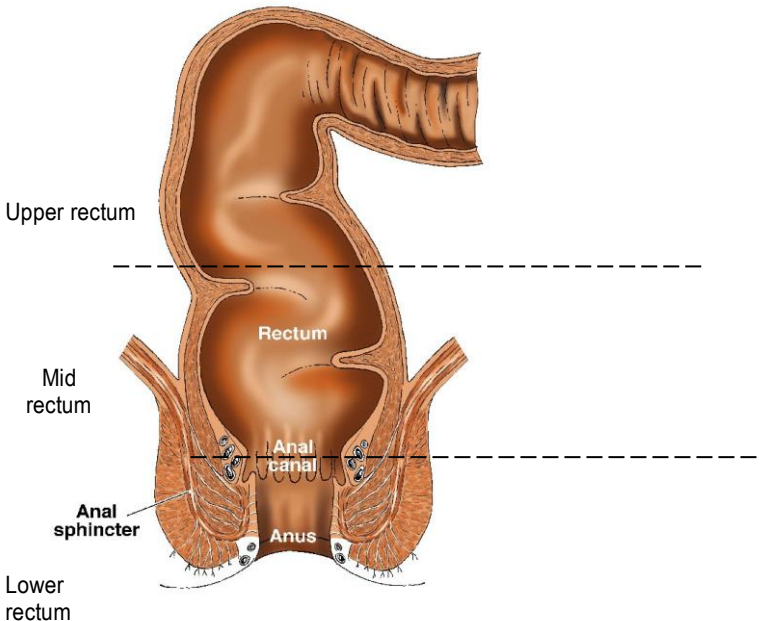
Following this, waste (faeces) passes through the large bowel (colon) into the rectum (back passage) and to the anus (back passage opening) for passing out of the body when going to the toilet.



Below are images of the colon and rectum.



The large intestine (colon) extends from the cecum to the anus and includes the ascending colon, the transverse colon, the descending colon, the sigmoid colon, and the rectum.



The rectum is divided into upper, mid and lower rectum

## Rectal cancer treatment plan

If you have been told you have rectal cancer, your case will be discussed at the multidisciplinary meeting and a treatment plan recommended. Your GP will also be sent a copy of this plan.

Colonoscopy biopsy result \_\_\_\_\_

CT results: \_\_\_\_\_

TNM staging from MRI (see page15):

Referral to oncology specialist?      Yes       No

Results and explanation given by: \_\_\_\_\_

When \_\_\_\_\_

Where \_\_\_\_\_

What is your treatment plan following the multidisciplinary meeting? \_\_\_\_\_

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Please note that after discussion at the MDT meeting, it may be 2-3 weeks before you are seen by an oncologist. This first appointment is a discussion between you, your family/support person and the oncology specialist where you will be given an explanation about the planned treatment and the risks and benefits to you. This appointment is not to begin treatment. If you need radiation, a further CT scan will be required before treatment can start. This is for planning where the radiation beam is to be directed.

## Colon cancer treatment plan

If you have been told you have colon cancer, your case will be discussed at the multidisciplinary meeting and a treatment plan recommended. Your GP will also be sent a copy of this plan.

Colonoscopy biopsy result \_\_\_\_\_

CT results: \_\_\_\_\_

Results and explanation given by: \_\_\_\_\_

When: \_\_\_\_\_

Where: \_\_\_\_\_

What is your treatment plan following the multidisciplinary meeting?

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### Do you need chemotherapy?

This will be discussed further on. Not all colon cancer needs chemotherapy. We will not know usually until after surgery. However if the CT scan has shown you have liver or lung metastases, then yes, chemotherapy may be considered. In these cases, discussion at a multidisciplinary meeting is required.

## Surgery Plan

|   |             |
|---|-------------|
| The name of your operation is:  |             |
| The part of your bowel that is being removed is:                                      |             |
| You will require a stoma:<br>Yes <input type="checkbox"/> No <input type="checkbox"/> | Stoma type: |

Note – if your surgery is likely to involve the formation of a stoma, additional information will be given as appropriate. A stoma is an artificial opening between an organ and the skin's surface, formed by surgery. There are different types, including an ileostomy (formed from the small bowel), colostomy (formed from the large bowel), and urostomy (which creates a new urinary bladder using a piece of intestine).

### Why is an operation necessary?

- Tumours of the bowel can partially or even totally block the normal function of the bowel causing an obstruction. This may mean that nutrients cannot be properly absorbed by the body.
- The tumour may bleed and eventually cause anaemia.

Surgery to remove the tumour may cure the problem or at least improve the symptoms related to a bowel tumour.

### When will the operation be done?

If you have colon cancer, surgery should be done 6-8 weeks after diagnosis but this can vary.

If you have rectal cancer, this depends upon the agreed treatment plan.

If you have a temporary ileostomy, a further operation will be required.

## Do bowel operations carry any risks?

As with any major operation, there are risks involved. Such risks may include:

- 1) the anaesthetic
- 2) there is a small risk of death resulting directly from the operation. Elderly patients with bowel tumours carry greater risks as do patients with pre-existing medical problems.

## Common problems following bowel surgery are

- change in bowel function/frequency.
- urinary problems
- wound infections
- chest problems
- in addition, a very small number of patients can have a leakage from the join in the bowel that has been stitched together. This can result in complications (e.g. abscesses, peritonitis) and may require further surgery
- possible sexual dysfunction following rectal surgery.

## Before your operation

You may be asked to attend a pre-admission clinic. At this clinic you will be assessed for your surgery by an anaesthetist and nurse. You will be given information about what to expect during your hospital stay and how you can help yourself to recover quicker after surgery. This may take about two hours. Blood samples may be taken and you may also be asked to go for a chest x-ray and ECG (heart tracing). At this clinic visit a number of questions will be asked about your home situation and who can support you once home. It is important you advise staff about any concerns you may have about going home after the operation so arrangements can be made with you. Your expected length of stay in hospital will be discussed with you. We encourage you to bring your own comfortable clothes to wear but leave your valuables at home.

If you are admitted without attending the pre-admission clinic, then the above will be done by the ward doctor when you are admitted to the ward. The doctor will also ask you to sign a consent form, if this has not yet been done.

Most people come in to hospital the same day of surgery, however if necessary arrangements will be made to admit you earlier.

## Immediately after your operation

When you return from theatre, you will have drip in your arm, possibly a drain from your abdomen, and an epidural or patient controlled analgesia (PCA). You may also have a tube in your bladder (catheter) that drains your urine. All of these are temporary measures that will be removed when requested by your doctor. Oxygen via a mask may sometimes be necessary.

## Pain control

Most people will experience some pain or discomfort in the bowels prior to passing wind or stools following surgery, for which you can have pain relief medication. The methods of giving pain relief include epidural, patient controlled analgesia (PCA), injections and tablets. These will all be discussed with you before your surgery. If you do have any pain, please let the nurses know immediately so that they are able to help you feel more comfortable.

## Eating and drinking

From the first day onwards you will be given free fluid and light meals as you can tolerate them. A dietitian will see you if you have dietary concerns.

## What happens after surgery?

Once you have had your surgery, the idea is to get you back to living as normal a life as possible. The colorectal specialist team will be on hand to answer any questions or problems that you may have in the future.

Plans for going home are based on the early assessment from your pre-admission clinic visit and on how your hospital stay and recovery has been. Ward staff will discuss and arrange a discharge plan with you and your support persons. Sometimes this requires an arranged meeting which your support people can attend.

Once you have been discharged, your follow-up care will be at the discretion of the individual consultant but it will be based on a common policy that is approved across the colorectal service (see page 30).

## Future treatment

You will be fully involved in discussions regarding your future treatment and will be given a clear assessment of the facts relating to your case.

We cannot say if you will need any further treatment after your surgery, as this will depend on what the pathologist finds when the part of your bowel that has been removed is examined.

Usually you will have gone home before these results are available. These results are discussed at another multidisciplinary meeting, and with your agreement the cancer nurse specialist will phone you with the results and ongoing treatment plan.

What are your histology results?

TNM staging:

Referral to oncology specialist? Yes D                  No D

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Results and explanation given by:

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When:

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Where

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What is the action plan following the multidisciplinary meeting?

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## Staging

When the pathologist examines the section of removed bowel, they describe the spread of cancer according to staging systems. Many staging systems are available which include Dukes system, Astler-Coller and TNM plus many others. However, TNM provides more information and it is the system that we use.

### TNM

The TNM system varies slightly for different types of cancers and an explanation in respect of colorectal cancer follows.

#### Tumour (T)

The description relates to the size of the primary cancer, i.e. where the cancer started. There are four stages in respect of size for colorectal cancer, ranging from T1 – T4. T1 being where the growth is limited to the inner layer of the bowel whilst at the other end of the staging scale for tumour size, T4 is where the cancer has grown into other structures in the body or through the outer lining of the bowel.

Some doctors may also refer to stage 0, or carcinoma in situ, which means that the cancer is at a very early stage. Unfortunately, with colorectal cancer this is unlikely as the tumour has usually grown more than this before any symptoms are recognised.

#### Nodes (N)

This indicates whether there are any lymph nodes involved and if so how many. For colorectal cancers there are three stages: N0, N1 and N2. N0 means there are no lymph nodes containing cancer, and N2 meaning there are 4 or more lymph nodes that are affected.

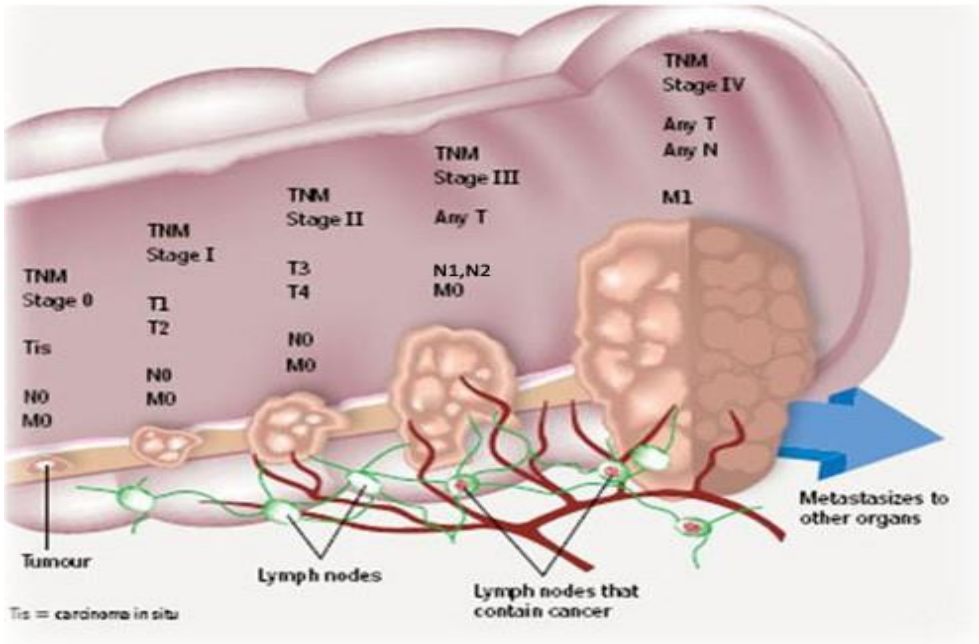
#### Metastases (M)

This indicates whether there is any spread into other parts of the body through the bloodstream. The stages are M0, where there has been no spread, and M1 where the cancer has spread to other parts of the body.

So a cancer described as T1, N0, M0 would be one that was still within the inner layer of the body, where no lymph nodes were involved and when it had not spread to other organs.

Whichever staging system is used, it will be discussed in more detail with you by the team who are caring for you.





## When you go home

### Day to day activities

Illness disrupts and changes your lifestyle. However, the best person to decide when you are ready to resume your normal social life, or return to work, is you. Of course this should only be when you feel ready to do so.

You are advised not to lift heavy objects for about 6 weeks after your operation. Exercise is important, but build up to this gradually after your operation. If it hurts, STOP!

Always accept offers of help with the shopping, housework or jobs around the house until you feel well enough to start yourself. If you live alone, inform the ward staff and they can organise some help for you. There are no hard and fast rules about resting; your body will let you know, but try not to sleep too much during the day as this can affect your night's sleep.

## Driving

You should not drive until you can do an emergency stop. That is, you must be able to do this without hesitation because of your fear that your wound will hurt. It is advisable to check your car insurance policy as there may be a restriction clause.

## Diet

Your diet should change very little. It is important to maintain a well balanced diet and eat regularly. Remember to eat small frequent meals and drink plenty of fluids. A dietitian could be asked for suggestions to help ensure that you are eating the correct foods in the correct quantities.

Following your surgery, you can expect to lose several kilograms in weight. This weight loss will of course vary from patient to patient. Weight gain may be slow and gradual and it may take up to three months to replace your weight loss.

## What about sex?

You may resume sexual intercourse when it is comfortable for you. This will depend on the surgery performed and will vary from individual to individual.

Following pelvic surgery, men may experience problems achieving an erection or ejaculation, and women may experience vaginal dryness and discomfort on intercourse. It is therefore important that you and your partner have open and honest discussions at this time.

Your cancer nurse specialist is used to discussing these matters and may be able to offer support and advice if needed, or refer you to someone who can help.

## Psychological issues

Being diagnosed with a serious illness or having an operation can be very stressful. Some days you may feel weary, tearful and generally not able to cope. This is perfectly normal and as your energy and fitness levels return, you will start to feel well again.

However, some patients find that these feelings persist. If you find that this is the case, please discuss this with your cancer nurse specialist. The Cancer Society holds regular support groups which can be of great benefit and may be able to refer you to a counsellor, if necessary.

## Bowel function

Immediately following your operation you are likely to have problems with excess wind and loose stools. Excess wind is normal after any bowel operation and should soon settle down. Eating regularly, chewing your food properly and closing your mouth when chewing will all help to reduce a build up of wind.

Loose stools should reduce once the bowel has settled down after surgery and you are eating normally. Slight adjustments to your diet may help in the short term. Sometimes, depending on the surgery, a more frequent bowel activity may now be normal. Medication can be prescribed to help slow the frequency and thicken the output.

Generally most people will develop a “new” normal bowel routine in time, perhaps over a few months and up to two years. Contact your cancer nurse specialist if you are having any bowel function problems.

## Post operative exercise

Restoring your physical health after an operation is vital to your mental and bodily recovery. Start by walking and build up gradually to your normal activities. Be gentle with yourself at first; swimming, aqua-aerobics or yoga will help to tone muscles affected by surgery and relaxation exercises will help to cope with the stresses you have undergone. The doctors can deal with your medical problems but you need to look after your daily wellbeing. Set yourself simple fitness targets to begin with and build up steadily from there.

## Clinical trials

Your doctor may offer you the chance to participate in a clinical trial. Clinical trials allow us to research new drugs or treatments and often help us to find out more about the disease. Without the clinical trials we would not have the cancer treatments we have today and we would not be able to safely develop new drugs and therapies in the future. Not everyone with colorectal cancer will be eligible to take part in a clinical trial, mostly for a medical reason, so your doctor will only mention it if they think you are eligible.

A clinical trial usually compares best treatment that is currently available against something new, that must be at least as good or hopefully better. Participating in a clinical trial is entirely voluntary. If you don't want to take part then you don't have to, and you will receive the same treatment and

care as everyone else. If you do decide to take part, then a specialist nurse called a clinical trials nurse will be on hand to help you participate.

## Living with and after cancer

A diagnosis of cancer can have an impact on many areas of your life, both during and after treatment. Your doctor and cancer nurse specialist are able to discuss and help you understand and manage these concerns. The Cancer Society is valuable for support and advice and has programmes and support groups that can help you and your family/support persons. There are other supports available which can be discussed with you. Reputable internet sites such as the MacMillan Cancer Support (United Kingdom) can also provide valuable information and advice.

Also refer to the Supportive Care Directory, Midland Cancer Network at [http://www.midlandcancernetwork.org.nz/page/pageid/2145862568/Supportive\\_Care\\_Services](http://www.midlandcancernetwork.org.nz/page/pageid/2145862568/Supportive_Care_Services)

## Your thoughts and questions

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If any of the below are of concern to you, please ask for help.

- **Symptoms and side effects**

Cancer and cancer treatments can cause a range of symptoms and side effects. These can often be effectively managed or controlled.

- **Financial issues**

A cancer diagnosis can have an effect on your income – but you may be able to get help.

- **Emotional effects**

A cancer experience can trigger a range of emotional responses for you, your family and friends, but there are a number of ways to manage them and get support.

- **Life after cancer**

When your treatment is over, it's important to give yourself time to adjust to any physical or emotional changes.

- **Eating well**

Cancer and its treatment can sometimes cause problems with eating. There are tips to help you manage different eating problems and maintain a healthy diet.

- **Practical issues**

It can help to think ahead when going to work, planning a holiday, getting travel insurance or arranging care for your pets.

- **Relationships and communication**

Cancer can have an emotional and physical impact on your relationships, but there's help available for you, your family and friends.

- **Advanced cancer**

It's usually a shock if a cancer comes back. There may be decisions and plans you want or need to make to if this happens.

## List of useful addresses and telephone contacts

|                              |                             |
|------------------------------|-----------------------------|
| Waikato Hospital             | 07 839 8899                 |
| Rotorua Hospital             | 07 348 1199                 |
| Thames Hospital              | 07 868 6550                 |
| Tauranga Hospital            | 07 579 8000                 |
| Whakatane Hospital           | 07 306 0999                 |
| Taupo Hospital               | 07 376 1000                 |
| Cancer Society (Waikato)     | 07 838 2027 or 0800 226 237 |
| Cancer Society (Tauranga)    | 07 571 2035                 |
| Cancer Society (Rotorua)     | 07 349 4556                 |
| Ostomy Society (Eastern BOP) | 07 308 8195                 |
| Ostomy Society (Western BOP) | 07 576 5736                 |
| Ostomy Society (Rotorua)     | 07 348 9749                 |
| Ostomy Society (Waikato)     | 07 871 4997 or 07 826 3655  |

### Websites

Please discuss your information needs with your cancer nurse specialist. You will be given additional information as appropriate e.g. from oncology.

| Source                        | Website  |
|-------------------------------|--|
| Midland Cancer Network        | <a href="http://www.midlandcancernetwork.org.nz">www.midlandcancernetwork.org.nz</a> |
| NZ Cancer Society             | <a href="http://www.cancersociety.org.nz">www.cancersociety.org.nz</a>               |
| Beating Bowel Cancer          | <a href="http://www.beatingbowelcancer.org">www.beatingbowelcancer.org</a>           |
| Beat Bowel Cancer NZ          | <a href="http://www.beatbowelcancer.org.nz">www.beatbowelcancer.org.nz</a>           |
| Cancer Research (UK)          | <a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a>               |
| MacMillan Cancer Support (UK) | <a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>                       |
| Lance Armstrong Foundation    | <a href="http://www.livestrong.com">www.livestrong.com</a>                           |
| Cancer Backup (UK)            | <a href="http://www.cancerbackup.org">www.cancerbackup.org</a>                       |

## Medical words and terms (Glossary)

These are some of the medical words and terms you may come across during your appointments for colorectal investigations/tests.

|                                    |   |
|------------------------------------|---|
| abscess                            | a collection of pus in a cavity formed by the decay of diseased tissues   |
| acute                              | sudden onset of symptoms  |
| adjuvant therapy                   | chemotherapy and/or radiotherapy in addition to surgery   |
| aetiology                          | the cause of a disease  |
| anaemia                            | too few red blood cells in the body   |
| analgesia                          | pain relievers such as paracetamol and morphine   |
| anastomosis                        | the joining together of two ends of healthy intestine or blood vessels  |
| anus                               | the opening of the back passage   |
| barium enema                       | an enema that contains barium. When the patient is x-rayed, it allows the colon to be seen  |
| benign                             | non-cancerous   |
| biopsy                             | removal of small pieces of tissues from the body for examination under the microscopes for diagnosis                                  |
| caecum                             | the first part of the large intestine, just after the small intestine. It is on the right side of the body                            |
| CEA (carcinogen embryonic antigen) | a blood test that can indicate bowel cancer   |
| chemotherapy                       | drug therapy used to attack cancer  |
| chronic                            | symptoms occurring over a long period of time   |
| colitis                            | inflammation of the colon   |
| colon                              | the large intestines, from the caecum to the rectum   |
| colorectal                         | one word that refers to the colon and rectum  |
| colonoscopy                        | examination of the colon by inserting a tube that houses a camera and light – a colonoscope. This tube is about the width of a finger |

|                      |  |
|----------------------|--|
| colostomy            | an opening between the colon and the surface of the body. Part of the colon is brought out of the abdomen, creating a stoma. A bag is then placed over the opening to collect waste material |
| constipation         | difficulty in emptying the bowels or not being able to do this as often as usual   |
| CT scan              | a type of x-ray. A number of pictures are taken and fed into a computer to form a detailed picture of the inside of the body   |
| defaecation          | the act of passing faeces/bowel motions  |
| diagnosis            | a judgement about what a particular illness or problem is  |
| diarrhoea            | an increase in the frequency, of loose watery stool  |
| distal               | in relation to bowel problems this means further down the bowel towards the anus   |
| diverticular disease | a condition in which small pouch-like sacs develop in the large intestines. When these are inflamed it causes diverticulitis   |
| dysplasia            | alteration in the size, shape and organisation of cells indicating possible development of cancer  |
| electrolytes         | salt in the blood e.g. sodium, potassium etc   |
| enema                | a liquid introduced into the rectum to encourage the passing of bowel motions  |
| endoscopy            | a collective name for visual examinations of the inside of the bowel using a tube that contains a light and camera   |
| epidural             | a form of pain relief involving injection of drugs through a small tube placed into the epidural space in the spinal canal   |
| exacerbations        | an increase in the intensity of symptoms   |
| faeces               | bodily waste matter. Can also be referred to as stools, motions  |
| fistula              | an abnormal connection usually between two organs, or leading from an internal organ to the body's surface   |
| haemorrhoids         | swollen blood vessels around the anus which bleeds easily and may prolapse.  |
| heredity             | the passing of characteristics from parent to child  |
| histology            | the examination of tissues under the microscope to help make the diagnosis   |



|                 |   |
|-----------------|---|
| ileostomy       | when the open end of healthy ileum is diverted to the surface of the abdomen, creating a stoma  |
| inflammation    | a natural defence mechanism of the body where blood rushes to any site of damage or infection leading to reddening, swelling and pain. The area is usually hot to touch.  |
| laxatives       | medicine or tablets to cause emptying of the bowels   |
| lesion          | an area of tissue which is damaged as a result of disease or wounding   |
| malignant       | cancer cells. A tumour which invades tissues and can spread   |
| mucous          | a clear or cloudy jelly like substance produced by the small and large bowel  |
| neutropaenia    | a reduction in the number of white cells that fight infection   |
| oedema          | build up of excessive amount of fluid in tissues resulting in swelling  |
| oncologist      | a doctor who specialises in cancer care using drugs (medical oncologist) and/or radiotherapy (radiation oncologist)   |
| palliative care | it is a term when patients cannot be cured but they can have their pain and symptoms controlled. Palliative care concentrates on the quality of life and that of the patient's family. It focuses on controlling pain and other symptoms and meeting a person's social, emotional and spiritual needs |
| pathologist     | a specialist consultant who examines tissue and cells under a microscope  |
| pathology       | the study of the cause of the disease   |
| perforation     | a tear in the bowel wall that cause the content to spill into the abdominal cavity. This may cause peritonitis  |
| peritoneum      | membrane lining the abdominal cavity  |
| peritonitis     | inflammation of the peritoneum often due to a perforation   |
| polyp           | a growth that protrudes from the lining of the bowel. Generally non cancerous   |
| prophylaxis     | treatment to prevent a disease occurring before it starts   |
| proximal        | in relation to bowel problems this means further up the bowel towards the mouth   |
| radiologist     | a doctor who interprets x-ray pictures to make a diagnosis  |

|                    |   |
|--------------------|---|
| radiotherapy       | the use of high energy rays to attack cancer cells  |
| rectum             | the area of large intestine above the anus  |
| relapse            | the return of symptoms of the disease after a period of improvement   |
| remission          | a lessening of symptoms of the disease and return to good health  |
| sigmoid            | the part of the colon above the rectum. Shaped like an "s" or "c"   |
| sigmoidoscopy      | inspection of the lower bowel by inserting a tube that contains a camera light.   |
| stricture          | narrowing of the bowel  |
| stoma              | an artificial opening the bowel to the skin surface   |
| supportive care    | any care that helps the patient and their family to cope with cancer and its treatment, helping the patient gain the most benefits from treatment |
| suppository        | a bullet shape solid medication put into the rectum.  |
| tenesmus           | a persistent urge to empty the bowels   |
| terminal ileum     | the last part of the ileum joining the caecum via the ileocaecal valve.   |
| tumour             | an abnormal growth which may be benign or malignant   |
| ulcerative colitis | ulceration and inflammation of the large bowel  |
| ultrasound         | use of high pitched sound waves to produce pictures of organ on a screen for diagnostic purposes.   |
| urethra            | the tube that conveys urine from the bladder to the outside of the body   |
| urostomy           | this is a surgically created opening that allows urine to flow out of the body. It is sometimes called a urinary diversion                        |

# Your thoughts and questions

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## Your thoughts and questions

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# Your follow-up care.

# Colorectal cancer follow-up log book

## What is follow-up and who needs it?

The primary goal of follow-up examinations (surveillance) is to find and remove cancer that may recur after treatment. It is also an opportunity to assess how you are doing physically and emotionally following your cancer diagnosis and treatment and to assist you with any changes or problems you may experience. *It is important that you discuss any concerns you may have.*

Follow-up care is required but not everyone needs to be closely followed up. If you do need surveillance, it may be shared between your general practitioner, your specialist and cancer nurse specialist. Regular visits with your doctor or nurse help increase the likelihood of finding a treatable recurrence and/or may provide you with some reassurance.

Your surveillance regime will be discussed with you by your doctor and cancer nurse specialist. The following table shows your expected follow-up schedule. This may be changed to best suit your needs i.e. if you have ongoing bowel problems the team may prefer to see you more frequently. Your GP will be informed of your follow-up requirements.

## Understanding the follow-up tests

- Carcinoembryonic antigen (CEA) is a blood test. Increasing levels may indicate that cancer has spread to other parts of your body. It should be done every 3 months for the first 3 years.
- A colonoscopy may be done to check the inside of the remaining colon for further polyps or second cancers. A colonoscopy is usually arranged to be done 3 years after your surgery, then at 5 yearly intervals until the age of 75. If you had an incomplete colonoscopy before surgery, you will have another colonoscopy arranged and done within 6 months after surgery.
- If you had rectal cancer, a flexible or rigid sigmoidoscopy will be done at 1 year and 2 years after surgery. This scope is inserted into the rectum and lower colon to inspect where the bowel was joined (the anastomosis) and check for further polyps, second cancers or other abnormalities.
- A computerised tomography (CT) scan will be done to check the bowel and other organs. A CT scan will be arranged and done 18 months after your surgery. If there are concerns though it may be done earlier.

## Signs and symptoms which are of concern

- a change in bowel routine (this is expected after surgery however)
- blood or mucous in your faeces
- unexplained weight loss
- unexplained fatigue
- unexplained abdominal pains.

## Other important issues that may be discussed with you

There can be ongoing effects from your treatment such as fatigue, numbness in hands and feet, bowel or stoma management, urinary problems, fertility, sexual problems, social concerns, work and financial concerns, diet, fears about recurrence, advice on a healthy lifestyle, screening and risks for your family, and genetic counselling if required.

It is important that you discuss these with your doctor or your cancer nurse specialist.

## Your thoughts and questions

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The following table will document follow-up appointment dates and the results of your tests. It is important that you take your log book with you when you visit the doctor or nurse

|                      |                            |          |
|----------------------|----------------------------|----------|
| Site of your cancer  | Date of surgery            |          |
| Name of operation    | Before surgery radiation   | yes / no |
| Stage of your cancer | After surgery chemotherapy | yes / no |

| Frequency | Date Due | CEA result              | Colonoscopy | CT scan | Other tests                                | With whom |
|-----------|----------|-------------------------|-------------|---------|--|-----------|
| 4-6 weeks |          | Follow-up after surgery |             |         |  |           |
| 3 months  |          | X                       |             |         |  |           |
| 6 months  |          | X                       |             |         |  |           |
| 9 months  |          | X                       |             |         |  |           |
| 12 months |          | X                       |             |         | Rigid or flexi-sigmoidoscopy (rectal only) |           |
| 15 months |          | X                       |             |         |  |           |
| 18 months |          | X                       |             | X       |  |           |
| 21 months |          | X                       |             |         |  |           |
| 2 years   |          | X                       |             |         | Rigid or flexi-sigmoidoscopy (rectal only) |           |



| Frequency                   | Date Due | CEA result | Colonoscopy | CT scan | Other tests | With Whom |
|-----------------------------|----------|------------|-------------|---------|-------------|-----------|
| 2 years<br>3 months         |          | X          |             |         |             |           |
| 2 years<br>6 months         |          | X          |             |         |             |           |
| 3 years                     |          | X          | X           |         |             |           |
| 3 years<br>6 months         |          | X          |             |         |             |           |
| 4 years                     |          | X          |             |         |             |           |
| 4 years<br>6 months         |          | X          |             |         |             |           |
| 5 years                     |          | X          |             |         |             |           |
| 5 years<br>6 months         |          | X          |             |         |             |           |
| 6 years<br>(rectal)         |          | X          |             |         |             |           |
| 6 years<br>6/12<br>(rectal) |          | X          |             |         |             |           |
| 7 years<br>(rectal)         |          | X          |             |         |             |           |

You should then have a colonoscopy every 5 years until the age of 75. This will depend upon your state of health.

## Family history of cancer

Is your cancer genetic? Are your children or any other relatives at risk? Generally no, but if you have any concerns regarding this issue, please discuss it with your surgeon or cancer nurse specialist.

Your doctor and cancer nurse specialist will ask you about any other family members that have developed cancer. There are many cancers that have genetic links. Take time to think about parents, grandparents, and siblings that may have had a diagnosis of cancer. Also note the approximate age at which these family members were diagnosed with cancer. This information may help your doctor decide if genetic testing or counselling should be performed.

| Name of family member | Relationship | Type of cancer | Age at diagnosis |
|-----------------------|--------------|----------------|------------------|
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