



UNDERSTANDING CANCER

Bowel Cancer Matepukupuku Puku Hamuti



A guide for people with bowel cancer



ANY CANCER, ANY QUESTION

0800 CANCER (226 237)

Cancer Information Helpline

Your general practitioner: phone _____

Your nurse: phone _____

Your local Cancer Society phone: _____

24-hour emergency: phone 111

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Publications statement

Our aim is to provide easy-to-understand and accurate information on cancer and its treatments. Our Living with Cancer information booklets are reviewed and updated by cancer doctors, specialist nurses and other relevant health professionals to ensure that the information is reliable, evidence based and up to date. The booklets are also reviewed by consumers to ensure they meet the needs of people with cancer and their carers.

Other titles from the Cancer Society of New Zealand/Te Kāhui Matepukupuku o Aotearoa

Booklets

Advanced Cancer/Matepukupuku Maukaha

Cancer Clinical Trials

Cancer in the Family

Chemotherapy/Hahau

Coping with Cancer

Eating Well During Cancer Treatment/Kia Pai te Kai te wā Maimoatanga Matepukupuku

Emotions and Cancer

Getting on with Life After Treatment/Te Hoki Anō ki tō Toioranga Whai Muri I te Maimoatanga

Living with Dry Mouth/Te Noho me te Waha Maroke

Radiation Treatment/Haumanu Iraruke

Sex and Cancer

Supporting Someone with Cancer/Te Manaaki i Tētahi e Māuiui ana nā te Matepukupuku

Brochures

Being Active When You Have Cancer

Questions You May Wish to Ask

Cancer Society information and support services

The Cancer Information Service is a Cancer Society service where you can talk about your concerns and needs with specially trained staff. Call your local Cancer Society and speak to support services staff or phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Your local Cancer Society offers a range of services for people with cancer and their families/whānau. These may include:

- information and support
- volunteer drivers providing transport to treatment
- accommodation while you are having treatment away from home.

The range of services offered differs in each region, so contact your local centre to find out what is available in your area.

“When I was diagnosed I was very frightened and vulnerable to misinformation and suggestion by well meaning people. I wanted, and mostly got, information and positive encouragement, which gave me hope.” - Phil

Talking with doctors

Before you see a doctor, it may help to write down your questions. See the next page for a useful list of questions you may wish to ask.

We suggest that you have a support person with you at your appointment with your doctor.

“I wasn’t ready to hear much and I’d let them know when I wanted more information.” - Syd

Te kōrero ki o rata

I mua i tō haere ki te kite i tētahi rata, tērā pea hē pai ki te tuhi i ō pātai ki tētahi pepa. [tirohia a whārangi 3] mō tētahi taurira rārangi pātai tērā pea ka hiahia koe ki te whakamahi.

Hē mea pai hoki mēnā ka whai tangata tautoko koe i tō haerenga ki te kite i tō rata matepukupuku.

Questions you may wish to ask

When you hear you have bowel cancer, you and your family/whānau may feel understandably frightened and you may have many questions. Having your questions answered can help you to feel more in control of your situation, and better able to make decisions regarding your care plan. Here is a list of questions to help you make the most of your time with your doctor.

Choose the questions that you want answers to and let your doctor know if there are things you do not want to be told.

1. What type of bowel cancer do I have?
2. How far has my cancer spread? What stage is it?
3. Can my cancer be cured?
4. What other tests do I need before treatment starts?
5. What treatment do you advise for my cancer, and why?
6. Are there other treatment choices for me?
7. What are the risks, benefits and possible side effects of each treatment?
8. Will I have to stay in hospital, or will I be treated as an outpatient?
9. How long will the treatment take?
10. How much will it affect what I can do?
11. How much will the treatment cost?
12. If I need further treatment, what will it be like and when will it begin?
13. How often will my check-ups be? What will they involve?
14. Are there any problems I should watch out for?

15. What will happen if I do not have treatment? What services will be available to support me and my family/whānau?
16. When can I return to work?
17. When can I drive again?
18. Will the treatment affect my sexual relationships?
19. I would like to have a second opinion. Can you refer me to someone else?
20. Are my children or family/whānau at increased risk of getting this cancer too?
21. What is my prognosis (outlook)?
22. What should I tell my family/whānau? (Many people do not wish to know the answer to this if it is likely to be bad news.)

If there are answers you do not understand, feel comfortable saying:

- can you explain that to me again?, or
- I am not sure what you mean, or
- could you draw a picture or write it down?

The Cancer Society has a brochure titled *Questions You May Wish to Ask* that has general questions and spaces in which you or your doctor can write answers. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

Ngā pātai tērā pea ka hiahia koe ki te whiu

Ka rongoa ana koe kua pā te matepukupuku puku hamuti ki a koe, Tērā pea, ka matakū koe, ka matakū tō whānau, tērā pea he maha āu pātai. Mā ngā whakautu koe e whakapakari ake kia taea ai te āta tiaki i a koe anō, kia kaha ake ai ki te whakatau rautaki e pā ana ki tō mahere maimoatanga.

Kei Te Kāhui Matepukupuku ētahi mātārere reo Māori, Ētahi Pātai Tērā Pea ka Hiahia Koe Ki Te Tuku, e whai ana i ētahi pātai whānui me ētahi pūare wātea hei tuhi whakautu. Ka taea he kape mā te waea atu ki te Waea-āwhina Pārongo Matepukupuku **0800 CANCER (226 237)** mō tētahi kape, mā te whakapā atu rānei ki te tari Kāhui Matepukupuku kei tō rohe. Ka taea hoki te tikiake tētahi kape mai i te paetukutuku o Te Kāhui Matepukupuku (www.cancernz.org.nz).

Suggested reading

Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped. Contact your Cancer Society library or local library for some good-quality resources.

Websites

You may be interested in looking for information about bowel cancer on the internet. While there are very good websites, be aware that some websites provide incorrect information. We suggest that you discuss any information you find with your medical team.

We recommend that you begin with the Cancer Society's website (www.cancernz.org.nz) and follow our links. The following may also be helpful.

Bowel Cancer New Zealand
www.beatbowelcancer.org.nz

Colorectal Surgical Society of Australia and New Zealand
www.cssanz.org

Cancer Council Australia
www.cancer.org.au

Cancer Research UK
www.cancerresearchuk.org

Macmillan Cancer Support UK
www.macmillan.org.uk

National Cancer Institute (USA)
www.cancer.gov/cancerinfo

The suggested websites are not maintained by the Cancer Society of New Zealand. We only suggest sites that we believe offer credible and reliable information, but we cannot guarantee that such websites have correct, up-to-date or evidence-based medical information.

For more information on using health websites and social media, see the Cancer Society's information sheet *Using the Internet for Cancer Information and Support*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

“After I was diagnosed with bowel cancer our computers ran hot. The research and discussions went on day and night. Both kids took the time to become very knowledgeable about all aspects of bowel cancer and its treatment.” - Anna

About this booklet

This booklet has been prepared to provide you with information about cancer of the large bowel (*colon*) and *rectum*. If you have cancer in the small bowel (ileum), we suggest you read Macmillan Cancer Support UK's online resource *Understanding Small Bowel Cancer*. To read it, go to www.macmillan.org.uk

Ngā āhuatanga o tēnei puka

I whakaritea tēnei puka hei whakarato pārongo mō te matepukupuku o te puku hamuti nui (*kōpiro*) me te tou. Mehemea kua pā te matepukupuku ki tō puku hamuti iti (ileum), ka whakataunaki mātou kia pānuitia e koe te rauemi ā-ipurangi a Macmillan, Cancer Support UK, *Understanding Small Bowel Cancer*. Ki te hiahia pānui koe, haere ki www.macmillan.org.uk

This booklet provides information about the diagnosis of, the treatment of, practical support for and the emotional impacts of cancer.

We cannot tell you which is the best treatment for you. You need to discuss this with your doctors. However, we hope this information answers some of your questions and helps you think about the questions you may want to ask your doctors.

The booklet is divided into sections. Some sections may not be about your present situation. You may like to ask your doctor or nurse which sections you will find useful, or you can phone our Cancer Information Helpline **0800 CANCER (226 237)** to talk about this.

- Section one is about understanding bowel cancer.
- Section two is about diagnosing and staging bowel cancer.
- Section three is about bowel cancer treatment.
- Section four is about the impacts of bowel cancer.

Read the appendices at the back of this booklet for information about cancer and how it grows. They also provide information about the bowel and how it works.

Information is summed up in key points at the end of each section of the booklet. We have translated our key points into te reo Māori for those who prefer to read information in this official language of New Zealand.

The words in *italics* are explained in the glossary at the end of the booklet.

If you find this booklet helpful you may like to pass it on to your family/whānau and friends to help them understand your bowel cancer. We suggest you also read our booklet *Coping with Cancer*.

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Section one: Understanding bowel cancer

What is bowel cancer?

Bowel cancer is cancer in any part of the large bowel (*colon* or *rectum*). Depending on where it starts, it may be called cancer of the colon (large bowel) or cancer of the rectum (lower end of the large bowel). Sometimes bowel cancer is also called colorectal cancer. Large bowel cancer occurs when *cells* grow abnormally and form a lump or *tumour*. Most bowel cancers are found in the colon.

He aha te matepukupuku puku hamuti?

I whakaritea tēnei puka hei whakarato pārongo mō te matepukupuku o te puku hamuti nui (*kōpiro*) me te *tou*. Mehemea kua pā te matepukupuku ki tō puku hamuti iti (*ileum*), ka whakataunaki mātou kia pānuitia e koe te rauemi ā-ipurangi a Macmillan, Cancer Support UK, *Understanding Small Bowel Cancer*. Ki te hiahia pānui koe, haere ki www.macmillan.org.uk

Ka puta te matepukupuku puku hamuti nui i ngā wā e tino rerekē ana te tipu o ngā pūtau, ā, ka puta he puku. Kitea ai te nuinga o ngā matepukupuku puku hamuti i roto i te kōpiro.

Cancer of the small bowel is very rare and is not discussed in this booklet. For more information, we suggest you read Macmillan Cancer Support UK's online resource *Understanding Small Bowel Cancer*. To read it, go to www.macmillan.org.uk

Types of bowel cancer

Most bowel cancer is adenocarcinoma. This means that the cancer started in the gland cells of the lining of the bowel. Rarer types of bowel cancer include:

- mucinous tumours
- signet ring
- squamous cell tumours
- carcinoid tumours (neuroendocrine tumours)
- sarcomas (mostly leiomyosarcomas)
- lymphoma.

Causes of bowel cancer

Bowel cancer is common in New Zealand. In most cases it is unclear why people have been affected by it.

Bowel cancer usually starts as a *benign polyp* that grows to become cancerous. A polyp is a mushroom-like growth that occurs inside the bowel. Only about five per cent of polyps develop into cancer.

While most people do not have a cause for their cancer, there are some things that might contribute to the cancer to a small extent. These include the following.

Family/whānau history of bowel cancer

Having a parent, brother, sister or child who has had bowel cancer may contribute to a small extent.

Most bowel cancer (as much as 90 per cent) is not inherited.

You cannot catch bowel cancer or pass it on through personal contact.

Rare genetic conditions

Some people have a family/whānau history of bowel cancer, or other cancers such as endometrial cancer, stomach cancer, brain cancer or pancreatic cancer. If you have a family/whānau history of cancer, please discuss this with your doctor.

If you have a strong family history of bowel or other cancers, your doctor may recommend additional genetic tests through the Familial GI Cancer Service. These can help work out if your immediate family members or relatives may also be at increased risk of cancers.

Rare genetic conditions:

- Hereditary non-polyposis colorectal cancer (HNPCC) is a condition in some families/whānau where the tendency to develop cancer is inherited.
- Familial adenomatous polyposis (FAP) is a condition that causes hundreds of small growths (known as polyps) in the bowel of the person affected. If left untreated, FAP always turns into bowel cancer.

Other possible factors

Some factors may increase your risk of bowel cancer, including getting older, smoking, being overweight, consuming alcohol and having an inactive lifestyle. Having *Crohn's disease* or *ulcerative colitis* for more than 10 years may also be a contributing factor.

Symptoms of bowel cancer

Common signs and symptoms of bowel cancer include:

- blood in your *bowel motions* (this may look like red blood or black bowel motions)

- a change in bowel habit (particularly a tendency to looser or more frequent bowel motions)
- diarrhoea, constipation or feeling that your bowel does not empty completely
- general abdominal discomfort (frequent gas pains, bloating or cramps)
- unexplained weight loss
- tiredness
- anaemia.

Bowel symptoms that last for more than six weeks should be checked by your doctor.

Most people with bowel symptoms do not have bowel cancer. However, these symptoms are important and may need diagnosis and treatment. If you are experiencing them, you should discuss these with your doctor without delay.

When you are diagnosed with bowel cancer, you may also be concerned about your family/whānau's risk of bowel cancer. You can ask your doctor whether your family/whānau members are at increased risk of bowel cancer, and what they should do about it. Anyone with new bowel symptoms that are worrying, or that last more than six weeks, should see their doctor.

How common is bowel cancer?

Bowel cancer is the second most common cancer in New Zealand. 93 per cent of cases are found in people over the age of 50.

(Source: Ministry of Health, *Cancer: New Registrations and Deaths 2013*)

Should people at increased risk be checked?

In some cases, people who have a higher-than-average risk of developing bowel cancer are advised to be checked.

Each person has a right to make an individual decision on whether or not to be checked.

Key points: Understanding bowel cancer

- Bowel cancer is named according to where it is found—for example, cancer of the colon or cancer of the rectum.
- Most cancers in the large bowel are called adenocarcinoma.
- Cancer of the small bowel is uncommon.
- Common signs and symptoms of bowel cancer include:
 - blood in your bowel motions (this may look like red blood or black bowel motions)
 - a change in bowel habit
 - diarrhoea, constipation or feeling that your bowel does not empty completely
 - bowel motions that are narrower than usual
 - general abdominal discomfort (frequent gas pains, bloating or cramps)
 - unexplained weight loss tiredness
 - anaemia

Bowel symptoms that last for more than six weeks should be checked by your doctor.

Ngā kōrero matua: te mōhio ki te matepukupuku puku hamuti

- Whakaingoatia ai te matepukupuku puku hamuti e ai ki te wāhi kitea ai - hei tauira, matepukupuku o te kōpiro, matepukupuku o te tou rānei.
- Kīia ai te nuinga o ngā matepukupuku ki roto i te puku hamuti nui, ko te adenocarcinoma.
- Kāore e tino kitea ana te matepukupuku o te puku hamuti iti.
- Kei roto i ngā tohu noa me ngā tohu mate o te matepukupuku puku hamuti, ko enei:
 - he toto kei roto i tō tiko (tērā pea, he rite ki te toto whero, he pango rānei te tiko)
 - ka rerekē te āhua o tō haere ki te tiko
 - korere, kōreke, te wā e kore tō puku hamuti e mahi tika
 - kua whāiti haere te tiko e puta ana i tō tou
 - ka auhi whānui te puku (te hia patero, te pupuhi o te puku, te kōpiropiro rānei)
 - te heke ohore o tō taumaha
 - te hiamoe
 - anaemia

Ki te haere tonu ngā tohu mate puku hamuti mō te ono wiki nui ake rānei, me haere kia tiroirohia koe e tō rata.

Section two: Diagnosing and staging bowel cancer

How is bowel cancer diagnosed?

You will probably see many doctors, nurses and health professionals, who will work together as a multidisciplinary team to diagnose and treat you. It may be helpful to keep together documents about your appointments, information, letters and useful contacts. This will make it easier for you to know who to call and which doctors you have seen.

For most people, their bowel cancer is found after having symptoms. For others it may be discovered following a medical check-up. If you have symptoms, your general practitioner may arrange a test that involves having the inside of your bowel looked at. This could be with a short tube (sigmoidoscope) or a long tube with a small camera on the end (*colonoscope*). Sometimes a *CT scan (computerised tomography scan)* can be used to look at the inside of the bowel (*CT colonography*).

It can be a worrying time waiting for results, especially if you need several tests. If these tests do not rule out cancer but concern persists, it is usual to be referred to a bowel specialist. They will arrange further tests and advise you about treatment options. The purpose of these tests is to find out the type of bowel cancer you have and if the cancer has spread to other parts of your body. You may need to travel to another hospital for some tests.

Screening

In New Zealand, a bowel cancer screening programme is now being rolled out region by region for those without symptoms. For more information, talk to your doctor or visit the Ministry of Health's website: www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/national-bowel-screening-programme

Ngā whakamātautau

I Aotearoa nei, kua hōrapa tētahi hōtaka whakamātautau i te matepukupuku puku hamuti ki ia rohe, ki ia rohe, mō te hunga kāore e whai tohu mate ana. Mō te roanga ake o ngā kōrero, kōrero ki tō rata, me haere rānei ki te paetukutuku a te Manatū Hauora: www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/bowel-cancer-programme/national-bowel-screening-programme.

Several tests can be performed to diagnose bowel cancer. You may have some or all of the following tests:

Abdominal examination

The doctor feels the surface of your *abdomen* to check for any lumps.

Rectal examination

The doctor inserts a gloved finger into your rectum to check for any lumps, swelling or bleeding.

Tests

X-rays, CT scans or *PET (positron emission tomography)* scans and *MRI (magnetic resonance imaging)* scans are used to make images of the inside of your body to see if you have a lump and if it has spread. These can be done before or after surgery.

Blood count

A sample of your blood is taken to count the number of red cells in your blood (a low level [anaemia] can be a sign of bowel cancer).

Carcinoembryonic antigen (CEA)

CEA is a blood test that looks at a protein in your blood. The protein level is sometimes raised in people with bowel cancer; however, there are some conditions that are not cancer (for example, smoking) that can cause it to be raised.

CEA on its own does not diagnose bowel cancer, but if you have been diagnosed with bowel cancer, it can be useful for tracking progress.

A test for blood in the bowel motions (faecal occult blood)

This is most commonly used as a screening tool as part of a screening programme for bowel cancer. It is less helpful if you have abdominal symptoms. A normal faecal occult blood test does not exclude bowel cancer.

Barium enema

This is an older test using barium and X-rays to look at the lining of your bowel. There are now better tests than this available, and most doctors do not recommend this test anymore.

CT colonography (also known as virtual colonoscopy)

This X-ray technique is increasingly replacing barium enemas. The colon is emptied with a laxative. Air is then gently pumped into your bowel via your *anus* (the entry to your rectum). CT scans are taken of your abdomen. If abnormalities are found, this usually leads to a *colonoscopy*.

Sigmoidoscopy

The doctor examines your rectum and the lower part of your bowel using a short tube (which is usually straight, but it may be flexible) called a sigmoidoscope. The doctor may also take a *biopsy* (a small sample of tissue).

Colonoscopy

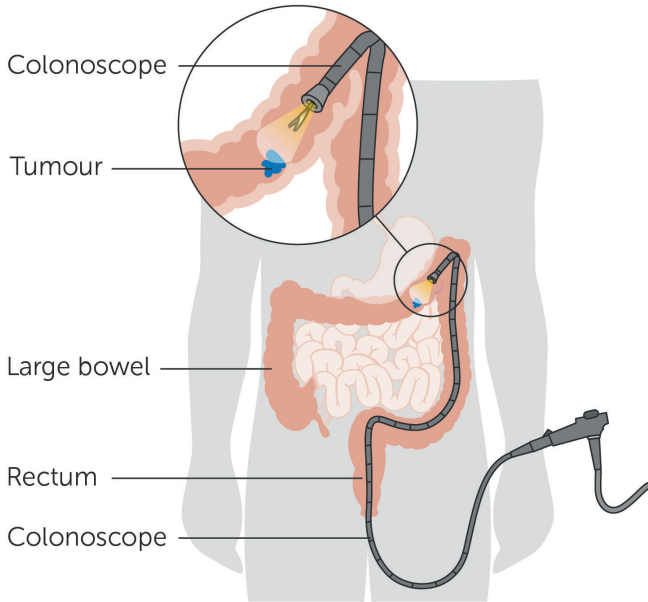
Before your test you are given instructions on how to prepare your bowel for a colonoscopy. The doctor or nurse inspects the entire length of your large bowel by gently inserting a long, flexible tube with a video camera in it (called a colonoscope). This is passed through your anus and rectum into your colon (see the diagram on page 23). You may be offered medication to help you relax during the colonoscopy.

Removing polyps at colonoscopy

If you have a pre-cancerous lesion, such as an adenomatous polyp of the colon or rectum, your surgeon or gastroenterologist may just remove the polyp from the bowel lining. A border of healthy tissue will also be removed. This is called a local *resection*.

Removal of a polyp

Diagram showing a local resection of an early-stage bowel cancer



Cancer Research UK

(Copyright: Cancer Research UK)

If there are any cancer cells within the polyp, your surgeon may decide that you need a second, larger operation. This is to remove any cells that may have been left behind, and to make sure that the cancer is unlikely to come back.

CT scan (sometimes called a CAT scan)

CT scans use X-rays to take three-dimensional (3D) pictures of the inside of your body. CT scans are usually done at a hospital or radiology service, and can be used to find smaller cancers than those found by X-rays. CT scans can also show enlarged *lymph nodes* or may show cancer in other parts of your body.

You may be asked to not eat or drink for a few hours before the CT scan. A dye (iodine contrast) may be injected into your arm to make the scan pictures clear. For some scans you may be asked to drink a lot of water. This is so that the kidneys can cope easily with the dye. Before the scan, tell your medical team if you are allergic to iodine, fish or dyes, or if you have kidney problems. A CT scan may take 10 to 30 minutes. You lie flat on a bench, which moves you through the centre hole in the CT scanner, a machine shaped like a doughnut.

MRI (magnetic resonance imaging)

This is a scan using magnetic fields and radio waves to build a picture of the organs inside your body.

The MRI machine is similar to a CT scanner, but has a longer central hole, more like a cylinder (tube). Scanning is very noisy. You will be offered earphones (with or without music) to reduce the sound. Some people feel claustrophobic (closed in) when they are having a scan. If you think this may happen to you, let your doctor know when they book your appointment as they may be able to prescribe medication to help you relax before the scan.

PET (positron emission tomography) scan

PET scans are only available in a few New Zealand cities. A PET scan can be used to help stage bowel cancer (see page 26) and look for cancer that may have spread to other parts of your body. Most people do not need PET scans, but they can be helpful—particularly if other tests are inconclusive or if doctors are considering removing secondary cancer.

Before the scan, a radioactive glucose (sugar) solution is injected into your arm. It takes 30 to 90 minutes for the body to absorb the radioactive solution. Then you have two types of scan. One scan looks for where in the body the radioactive glucose solution has built up. The other is a CT scan to match these areas to the different parts within your body. This combination of scans is sensitive and will find areas of the body affected by bowel cancer.

If you are diabetic, it is important to have good diabetic control before this test. Talk to your doctor or nurse if your sugar levels are high.

Staging the bowel cancer to see how far it has spread

If you've had an operation, the laboratory examines the tumour and surrounding tissue to assess the stage (size and extent) of the cancer, and whether it has spread to the lymph nodes or other organs, such as the liver.

With this information, the doctor decides if further treatment is needed. This can be an anxious time, as it may take a week or two for your results to come back. For more information about managing these feelings, read the Cancer Society's

information sheet *Coping with waiting*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

Stages of bowel cancer	
Stage 1	The tumour is still confined to the inner lining of the bowel.
Stage 2	The tumour has spread to the outer layers of the bowel wall.
Stage 3	The tumour has spread to lymph nodes next to the bowel cancer.
Stage 4	The cancer cells have spread to distant parts of the body, such as the liver or lungs.

Key points: Diagnosing and staging bowel cancer

- Doctors use tests to diagnose bowel cancer and help to develop a treatment plan.
 - Tests (colonoscopies, X-rays, CT scans or PET scans, and MRIs) are used to make images of the inside of your body to see if you have a tumour and if it has spread. Most people need a CT scan; only some people need an MRI or PET scan. Discuss this with your doctor.

- A piece of the cancer may need to be sampled (a biopsy) to determine which type it is. There are many ways that a biopsy can be taken.
- When your test results are available, your doctor talks to you about your prognosis (the expected outcome for you) or what may happen in your future. This is based on the type of cancer, how fast it is growing and its stage.
- You will probably see many doctors, nurses and health care professionals, who will work together to diagnose and treat you. For more information, see page 31 “Your treatment team”.
- It may be helpful to keep together documents about your appointments, letters, information and useful contacts. This will make it easier for you to know who to call and which doctors you have seen.
- Staging tells you the size of the cancer in your bowel and if it has spread to other parts of your body.
- It may be helpful to keep together documents about your appointments, letters, information and useful contacts. This will make it easier for you to know who to call and which doctors you have seen.
- Staging tells you the size of the cancer in your bowel and if it has spread to other parts of your body.

Ngā kōrero matua: Te whakatau me te whakawāhanga i te matepukupuku puku hamuti

- Ka whakamahia e ngā rata ngā whakamātau hei whakatau i te matepukupuku puku hamuti, hei āwhina hoki i te mahi whakarite mahere maimoatanga.
- Ka whakamahia ngā whakamātau (colonoscopies, X-rays, CT scans or PET scans, and MRIs) hei waihanga ata o ngā mea kei roto i tō tinana ki te tiro tiro mēnā kua puta he puku ki roto, kua rauroha rānei. Me whai te nuinga i te Matawai Roro, ko ētahi anake ka whai i te matawai MRI, PET rānei. Kōrerotia tēnei kaupapa me tō rata.
 - Tērā pea ka hiahiatia he wāhanga o te matepukupuku hei whakamātau (he biopsy) ki te whakatau ko tēhea momo matepukupuku. He nui ngā huarahi e tango biopsy ai.
 - Ka kōrero tō rata ki a koe inā puta ai ngā whakamātautau, e pā ana ki tō waitohu (te āhua o tō mate), tae atu ki te āhua o ngā rā ki mua. Ka hāngai tēnei ki tō momo matepukupuku, me te tere o te tipu, me te wāhanga kua eke.
 - Kāore e kore ka maha ngā rata, ngā tapuhi, ngā mātanga tiaki hauora e mahi ngātahi ai ki te āta tātari i tō mate me te whakarite maimoatanga. Mō te roanga ake o ngā kōrero, tiro ki te wharangi 31 “tō rōpū maimoatanga”.

- He mea nui te pupuri i ō pepa e pā ana ki ō haerenga, ō reta, ngā pārongo me ngā tāngata whakapānga pai. Mā konā e māmā ake ai te kōwhiri ko wai te tangata hei whakapā atu, ko ēhea hoki o ngā rata kua kitea e koe.
- Mā te mahi whakawāhanga koe e tohu mō te rahi o te matepukupuku kei roto i tō puku, mehemea kua rauroha ki wāhi kē o te tinana.

Section three: Bowel cancer treatment

Making decisions about treatment

If you are given a choice of treatment, including no treatment for now, you will need to think about your options. You may want to ask your doctor questions, such as:

- what is the goal of the treatment?
- can I expect to live longer if I have treatment?
- if I have treatment, is there a risk that my quality of life will be affected by the treatment?
- are there other treatments for me?
- what is the chance of the treatment working?

For more information on this subject, you can read the Cancer Society's information sheet *Making decisions about your cancer treatment*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by

contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

“At first I wondered if ignorance was bliss, but after a week I thought, ‘No’. It’s my body and I want to know what is going to happen, and I want to know, if I make a decision, what will happen.” Silei

A second opinion

You may want to ask another doctor about your cancer or treatment. You can ask your *oncologist* or general practitioner to refer you to another cancer doctor. You are entitled to a second opinion if you want one.

Treatment options for bowel cancer

In most cases there are several ways of treating bowel cancer. These treatments include:

- surgery
- chemotherapy
- radiation treatment
- targeted therapies.

Most people have surgery.

Some people receive a combination of two or more treatments. Your treatment will depend on the size of your

cancer, its location and whether it has spread. Your general health and your wishes are also important in the decision-making. The list of questions at the front of this booklet may help you to discuss your treatment with your doctor. In some cases you may want to seek a second opinion (see page 30).

Ngā kōwhiringa maimoatanga mō te matepukupuku puku hamuti

I te maha o ngā wā, he nui ngā huarahi maimoa i te matepukupuku puku hamuti. Anei ētahi o aua maimoatanga:

- hāparapara
- hahau
- Maimoatanga iraruke
- Ngā haumanu whakahāngai.

Whai ai te nuinga i te mahi hāparapara.

Your treatment team

You will be cared for by a range of health professionals, known as a multidisciplinary team. Each focuses on a different part of your treatment. Working with you, the team will develop a treatment plan that offers you the best care.

Your multidisciplinary team is likely to include:

- a general practitioner—is responsible for your general health and referring you for specialist treatment

- a general surgeon or colorectal surgeon—is responsible for diagnostic tests and surgery to remove cancer from your bowel
- a medical oncologist—specialises in cancer treatment using medication. They are responsible for prescribing any chemotherapy and other treatment options, such as targeted therapies
- a radiation oncologist - specialises in radiation treatment. This person arranges, prescribes, plans and supervises any course of radiation
- a radiologist—uses diagnostic imaging methods (such as CT scans) to see inside the body
- a pathologist—analyses samples of body tissue to help with diagnosing and staging your bowel cancer
- cancer nurses and care coordinators—provide assessments, support and information throughout your treatment
- a *stomal therapist*—helps you if you have a *stoma* bag (*colostomy* or *ileostomy*)
- a social worker—provides support and information about emotional and practical problems (such as employment and financial issues, home help and childcare)
- a pharmacist—gives advice on medication
- a dietitian—gives advice on nutrition to help you to manage the effects on the bowel after surgery and during other cancer treatments
- *palliative* care doctors and nurses—work closely with your general practitioner and oncologists to provide supportive and palliative care. Their aim is to help you to manage the effects of your cancer at home and in hospital.

As well as the multidisciplinary team, hospitals have pastoral and spiritual care workers, and whānau and Pacific health care workers. They are available on request to talk to you throughout your treatment.

“I’m the type of person to ask questions. They [the team] were really kind—not patronising ‘kind’. They were very patient explaining to me.” Silei

Surgery

The surgical removal of a tumour offers the best chance of a cure for patients who have early-stage cancer. The surgeon, with your multidisciplinary team, will determine if the cancer is only in your bowel, assess your general wellbeing and fitness for an operation, and discuss with you what the surgery involves. How you recover from bowel surgery will depend on many factors.

An operation on your bowel is a major procedure, and you may feel tired for weeks or even months afterwards. You may find that you need to take four to six weeks off work, and most surgeons recommend that you do not lift heavy objects. You may have altered bowel habits after surgery (for example, more frequent, looser motions). It can take up to a year for your bowel habits to settle into a routine because the bowel has been shortened. You may also find that your bowel produces more wind than before, and this can sometimes build up in the abdomen and cause pain. If you are struggling with this, talk to your doctor; they can suggest some ways of managing it. Some people find that their bowel is always more active than before their surgery.

Hāparapara

He pai ake te tango ā-hāparapara i te puku hei whakaora i te nuinga o ngā tūroro e whai ana i te matepukupuku i te wāhanga-tīmatatanga. Ka whakatau te mātanga i te taha o te rōpū hauora ngaio) mehemea kei tō puku anake te matepukupuku, me te aromātai i tō oranga whānui me tō pakari ki te whai haparapara, me te kōrerorero ki a koe mō ngā piki me ngā heke o te hāparapara. He maha ngā āhuetanga e hāngai ana ki te tere o tō whakaora, whai muri i te hāparapara puku.

He mahi nui te mahi pokanga ki te puku, ā tērā pea ka tino hiamoe koe mō ngā wiki, ngā mārama tini rānei whai muri mai. Tērā pea kāore koe e āhei ki te hoki ki te mahi mō te whā ki te ono wiki, ka tohu hoki ngā mātanga kia kua koe e hikihiki mea. Tērā pea ka rerekē te āhua o tō tiko whai muri i te hāparapara (hei tauira atu, ka nui ake, ka ngāwari ake hoki tō tiko). Tērā pea, tekau mā rua marama rā anō te roa kia tau te mahi tiko, i te mea kua whakapotoa te puku. Tērā pea ka nui ake te mahi pāterotero, ā, i ētahi wā ka puta te mamae nā te nui o te hau kino kei roto i te puku. Mehemea he uaua mōu, kōrero ki tō rata; mā rātou e hoatu tohutohu mō ētahi huarahi whakahaere i tēnei māmāe. E kite ana ētahi, ka nui ake te mahi o te puku hamuti e ai ki ngā rā i mua i te mahi hāparapara.

However, there are two things you can do to help your recovery from surgery:

- Increase your physical activity before your surgery if you can (for example, walk short distances).
- Aim to stop smoking well before any surgery is performed, if you currently smoke.

When planning for your hospital stay, consider the following:

- your transport—how you will get to hospital and home again
- your support person—arrange to have someone at home with you for at least two or three days after you leave hospital. They can help with tasks such as shopping, laundry and housework
- your medical certificates—request medical certificates from your doctor if needed

There are several things the surgeon and anaesthetist need to know about you before your surgery. A few days before surgery you will be asked:

- if you have had problems with a general anaesthetic before or if you have any allergies
- if you have diabetes. If you have diabetes, make sure you tell your doctor. Your blood sugar levels will need to be checked during your stay in hospital
- what medications you are taking (names, doses and times of day that they are taken).

You will be told what day and time you need to stop eating or drinking before surgery.

The type of operation you have will depend on:

- where the cancer is in your bowel
- the type and size of your cancer
- whether your cancer has spread.

How long you stay in hospital will depend on the type of operation you have.

Surgery to remove part of the bowel is called a colectomy. If the left side of the bowel is removed, it is called a left hemicolectomy.

Left hemicolectomy

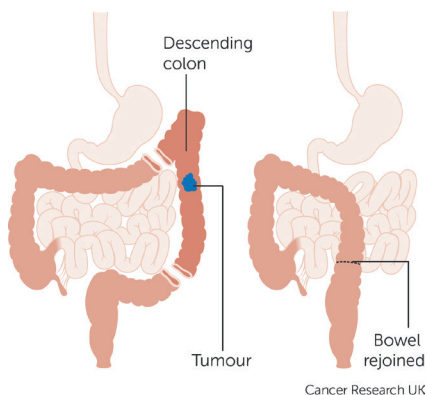
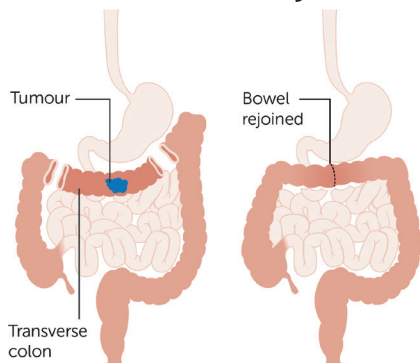


Diagram showing the part of the bowel removed with a left hemicolectomy

(Copyright Cancer Research UK)

If the middle part of the bowel is removed (the transverse colon), it is called a transverse colectomy.

Transverse colectomy



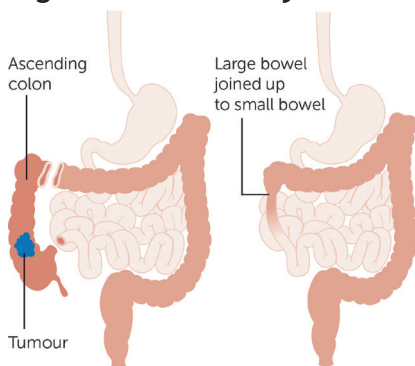
Cancer Research UK

Diagram showing the part of the bowel removed with a transverse colectomy

(Copyright Cancer Research UK)

If the right side of the bowel is removed, it is called a right hemicolectomy.

Right hemicolectomy



Cancer Research UK

Diagram showing the part of the bowel removed with a right hemicolectomy

(Copyright Cancer Research UK)

If the sigmoid colon is removed, it is called a sigmoid colectomy.

J pouch

For cancers in the lower part of the rectum, the surgeon removes the rectum. If possible they join the end of the colon to the anus. This join is called a colo-anal *anastomosis*. Sometimes the surgeon uses the end of the colon to make a pouch, called a J pouch. This acts like the rectum to store bowel movements before you go to the toilet. In such situations you may need to have a stoma while your bowel heals. In most cases the stoma can be reversed after a few months.

(Source: Bowel Cancer UK)

If your tumour is in the middle part of your rectum, your surgeon may remove most of the rectum and attach the colon to the anus. Sometimes the surgeon makes a small pouch by folding back a short section of colon or by enlarging a section of colon. This small pouch then works like the rectum did before surgery.

Anterior resection/high anterior resection

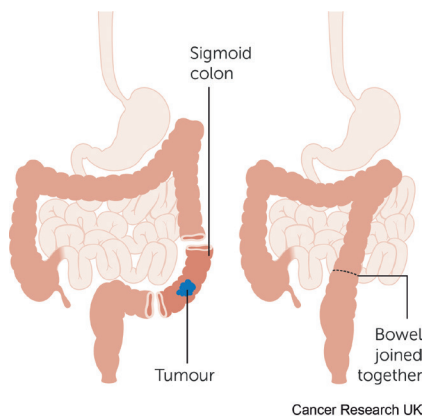


Diagram showing the part of the bowel removed with a sigmoid colectomy

(Copyright Cancer Research UK)

After your surgeon removes the part of the bowel containing the tumour and the surrounding lymph nodes, the ends of the colon are joined back together. The place where they join is called an anastomosis. Sometimes, to give the area time to heal, the surgeon makes a temporary colostomy or ileostomy higher up the bowel (see below for explanations of colostomy and ileostomy). You may have the stoma reversed in another operation several months later to rejoin the bowel. This is called a stoma reversal. In the meantime you will have a stoma bag over the opening of the bowel.

If you have a large amount of colon removed (total colectomy), your surgeon may not be able to join the ends of the bowel that are left. You may need to have a permanent ileostomy or stoma.

Colostomy

If the bowel cannot be rejoined, the upper end can be brought out to the skin of the abdominal wall. This is called a colostomy, and the opening of the bowel is known as a stoma. A bag is worn over the stoma to collect bowel motions. The operation to rejoin the bowel is known as a stoma reversal. If it is not possible to reverse the colostomy, the stoma is permanent.

Ileostomy

Some people need to have an operation in which the end of the small bowel (ileum), or a loop of ileum, is brought out to the right side of the abdominal wall, called an ileostomy. As with a colostomy, bowel motions are then collected in a bag worn over the stoma.

(Sources: Cancer Research UK and Macmillan Cancer Support UK)

A stomal therapist will see you before and after surgery to teach you to manage your stoma. There are many stoma products available and the therapist will work with you to find the one that suits your individual needs.

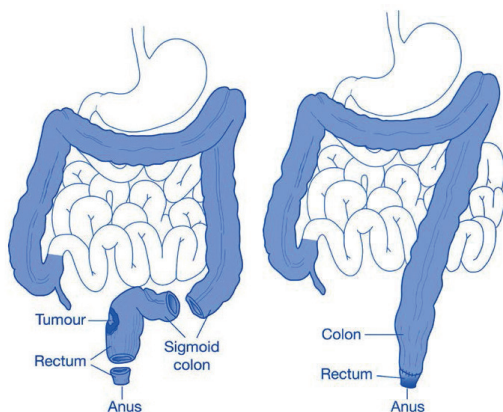
Ostomy bags and appliances are supplied free if you are a New Zealand citizen. You may find it helpful to get in touch with someone else who has had a stoma and talk to them about how they manage theirs. Your stomal therapist, local Ostomy Society or Cancer Society will be able to help. Visit the Ostomy Society website (www.ostomy.org.nz) or call the Cancer Information Helpline **0800 CANCER (226 237)**.

Surgery for rectal cancer

You may have radiation treatment or chemotherapy, or both, to shrink a tumour before surgery to make it easier to remove.

If the cancer is in the upper part of your rectum, your surgeon removes the part of the rectum containing the tumour. This is called a low anterior resection.

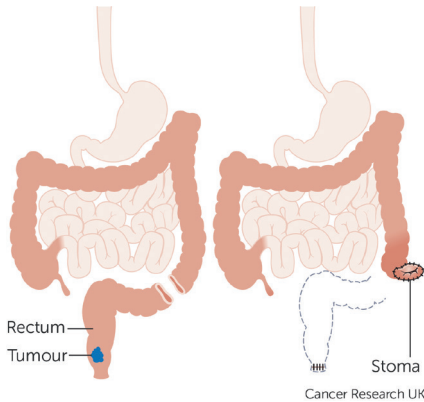
Low anterior resection



(Copyright Cancer Research UK)

If the cancer is in the lower part of your rectum, your surgeon cannot leave enough of the rectum behind for it to work properly, so they remove your anus and rectum completely. This is called an abdominoperineal resection (AP resection). Then the surgeon diverts the remaining bowel to make an opening on your abdomen. This is called a colostomy.

Abdominoperineal resection



*Diagram showing an abdominal resection of the bowel
(Copyright Cancer Research UK)*

For people who have an AP resection, their colostomy will be permanent.

Keyhole bowel surgery (laparoscopic resection)

For a small cancer, the surgeon may use keyhole surgery (laparoscopic resection). The surgeon makes several small cuts in your abdomen instead of making one large cut. The surgeon passes a long tube called a laparoscope and other instruments through these cuts. They look through the laparoscope to do the operation. The surgeon then removes the tumour through a small cut. This type of surgery may take a bit longer but your stay in hospital is likely to be shorter.

If the cancer blocks the bowel

Usually, your surgery for bowel cancer will be planned in advance. But sometimes the cancer completely blocks the bowel; this is called a bowel obstruction. In this situation you need an operation straight away. The surgeon may put a tube called a stent into the bowel. The stent keeps the bowel open so that it can work normally again. You may have immediate surgery to remove the cancer from the bowel, or a stoma may be formed to relieve the obstruction.

Side effects of surgery

An operation on your bowel is a major procedure, and you may feel tired for weeks or even months afterwards. You may find that you need to take four to six weeks off work, and most surgeons recommend that you do not lift heavy objects. You may have altered bowel habits after surgery (for example, more frequent, looser motions). It can take up to a year for your bowel habits to settle into a routine because the bowel has been shortened. You may also find that your bowel produces more wind than before, and this can sometimes build up in the abdomen and cause pain. If you are struggling with this, talk to your doctor; they can suggest some ways of managing it. Some people find that their bowel is always more active than before their surgery.

(Source: Macmillan Cancer Support UK)

Talk to your doctors and nurses about what you can expect. You may find it helpful to talk to a dietitian about what to eat. There are medications available to help manage changes in your bowel habits.

For advice on suitable foods to eat and other tips, read the Cancer Society's booklet *Bowel Cancer and Bowel Function*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

For some people, bowel surgery affects their sexual function. See our booklet *Sex and Cancer* for information.

After surgery

You will be encouraged to start moving around as soon as possible. Even if you have to stay in bed, it is important to move around to help your circulation and prevent blood clots. You may be given special support stockings to wear before and after your operation.

Chemotherapy

Chemotherapy is the treatment of cancer with anticancer (cytotoxic) medicine. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells. There are many types of chemotherapy treatment and different combinations can be used.

Chemotherapy may be given in a number of situations.

- Before surgery to try to shrink the cancer and make the operation easier
- During radiation treatment (chemo-radiation) to increase the effectiveness of the radiation treatment
- After surgery to reduce the chances of the cancer coming back
- As palliative treatment for a large cancer in the bowel, or for cancer that has spread beyond the bowel, to reduce symptoms and improve your quality of life or extend your life

Chemotherapy is usually given as a day procedure, which means you arrive and go home on the day you have treatment (outpatient).

Usually treatment is given in cycles, spread over weeks or months. Chemotherapy is given by injection or drip into a vein, or via a portable infusion pump worn on the body to deliver the medicine continuously into the veins. Some chemotherapy treatments are given as tablets or capsules that you take every day. The number of treatments you have depends on the type of bowel cancer you have. It also depends on how well your body is handling the side effects.

For more information on this subject you can read the Cancer Society's booklet *Chemotherapy/Hahau*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

There are treatments that are not fully funded by the government that may offer you an additional benefit. They can be expensive. Ask your oncologist if these therapies might be helpful for you, and what the cost might be.

Hahau

He maimoatanga matepukupuku te hahau e whakamahi ana i ngā whakapōauau ārai matepukupuku (cytotoxic). Ko te whāinga, ko te patu i ngā pūtau matepukupuku me te whai kia iti ake te kino ka pā ki ngā pūtau pai. He maha ngā momo huarahi maimoatanga hahau, i ētahi wā ka whakamahia te maha o ngā kōwhiringa.

He nui ngā wā ka whakamahia te hahau.

- I mua i te hāparapara, hei tīngongo i te matepukupuku kia māmā ake ai te mahi pokanga
- I te wā o te maimoatanga iraruke (hahau-iraruke) hei whakapiki ake i te papātanga o te maimoatanga iraruke
- Whai muri i te pokanga, hei whakaiti ake i te hokinga mai anō o te matepukupuku
- Hei maimoatanga mō tētahi matepukupuku nui kei roto i te puku hamuti, mō te matepukupuku kua rauroha rānei ki waho o te puku hamuti, ki te whakaiti ake i ngā tohu mate e puta ana me te whakapiki i te kounga o tō oranga, ki te whakaroa ake rānei i tō oranga.

Kāore e kore ka puta he papātanga ki te taha nā runga i ngā mahi hahau. He mea nui ki te whāki i tō rata, e pēhea ana tō āhua. Ki te puta he kirikā (ka nui ake te pāmahana o tō tinana i te whakarautanga 38) ka āhua mate rānei koe ahakoa te pai o te waeine mahana, kaua e tatari - kia tere tonu te whaiwhai. Whakapā atu ki tō rata, ki tō tapuhi rānei ka whakarongo ki ō rātou tohutohu.

Side effects of chemotherapy

Side effects usually go away within a few months of finishing treatment. Some people manage to continue with their normal lives at home and work throughout their chemotherapy.

Side effects may include:

- tiredness
- diarrhoea (this can become severe, so let your doctor or nurse know straight away if you develop diarrhoea)
- redness of, pain in and peeling of hands or feet (sometimes called hand and foot syndrome)
- numbness and tingling in fingers and toes (peripheral neuropathy)
- infections (the medicine can lower your ability to fight infections)
- a sore or dry mouth
- loss of appetite or taste changes
- constipation
- feeling sick or vomiting, but this is not common
- weight loss
- for women, less regular periods or no periods at all
- hot flushes, a dry vagina, mood swings or other symptoms of menopause
- vaginal itch, burning or infections.

Hair loss is not common for people having chemotherapy for bowel cancer.

You and your partner should use a contraceptive during treatment because the treatment can cause birth defects or miscarriage.

If fever develops (your temperature is 38 degrees or over) or you feel unwell even with a normal temperature, do not wait to see what happens—take action quickly. Contact your doctor or nurse and follow the advice given.

Radiation treatment

Radiation treatment is used to kill cancer cells by using X-ray beams that target the area affected by cancer.

It is often given in combination with oral chemotherapy to treat:

- locally advanced rectal cancer (cancer that has spread to areas close to the rectum) before surgery, to try to shrink the cancer and make surgery easier, and also to help reduce the risk of the cancer coming back
- metastatic rectal cancer (cancer that has spread to other distant parts of the body [for example, the liver]), either before surgery, to try to shrink the cancer and make the operation easier, OR when surgery is not planned, to get control of the cancer and slow down its spread.

Less commonly it is given with oral chemotherapy after surgery for rectal cancer to reduce the chances of your cancer coming back.

It may be given on its own:

- as a palliative treatment to treat cancer that has spread to other organs beyond the bowel
- to reduce symptoms and improve your quality of life
- to extend your life.

Radiation is usually given each day, Monday to Friday. Treatment for rectal cancer is normally over a period of five to six weeks. This may vary slightly, depending on the size of the tumour, the kind of treatment being used, the dose required, and the aim of your treatment.

The following can help with planning your treatment: routine blood tests, an MRI scan and a CT scan.

Blood tests are done regularly during treatment, and an MRI scan is repeated before surgery. You will be seen by your doctor or oncology nurse throughout treatment.

At the planning CT scan, your radiation therapist makes a few pin-sized marks (tattoos) on your skin. This is to ensure your body is in the right position and the same area of your body is treated each time.

During treatment you lie on a treatment bench (very similar to a CT scan bench). A machine delivering radiation is positioned around you. The treatment session takes 10 to 15 minutes. Radiation treatment is painless and there is no sensation of heat. The radiation therapist will make you as comfortable as possible.

Maimoatanga iraruke

Whakamahia ai te maimoatanga iraruke hei patu i ngā pūtau matepukupuku mā te whakamahi i ngā hihi whakaata roto ka hāngai ki te wāhi kua pā te matepukupuku.

I ētahi wā ka hoatu i te taha o te hahau ā-waha hei maimoa:

- te matepukupuku maukaha ā-tou (ko te matepukupuku kua rauroha ki ngā wāhi noho tata ki te tōu) i mua i te hāparapara, ki te tīngongo i te matepukupuku kia māmā ake te mahi pokanga, me te whakaiti ake i te mōrea o te hokinga mai o te matepukupuku.
- Te matepukupuku ā-tou metastatic (ko te matepukupuku kua rauroha ki ngā wāhi o te tinana (hei tauira, ki te ate), i mua i te hāparapara, ki te tīngongo i te matepukupuku kia māmā ake ai te pokanga, i te wā kāore i te whakaarotia te mahi pokanga rānei, hei whakahaere, hei whakapōturi hoki i te rauroha o te matepukupuku.

I ētahi wā, ka hoatu ki te taha o te hahau ā-waha whai muri i te pokanga, mō te matepukupuku ā-tou

Tērā pea ka hoatu me tōna kotahi anake:

- hei maimoatanga taurima mō te maimoa i te matepukupuku kua rauroha ki ētahi atu whēkau kei tua atu i te puku hamuti
- hei whakaiti i ngā tohu mate, hei whakapai ake i te kounga o te oranga
- Hei whakaroa ake i tō oranga



For more information on this subject, you can read the Cancer Society's booklet *Radiation Treatment/Haumanu Iiraruke*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

“It’s like an X-ray machine. No worries. You’ve got a comfortable room, music going, then it’s over.”
- Milly

Side effects of radiation treatment

Although radiation treatment is not painful, there are side effects, which may build up over the course of your treatment. Usually these are temporary. It is important to discuss any side effects with your multidisciplinary team, who can advise you on how to manage these effects.

Side effects may include:

- tiredness
- skin irritation/broken skin (sometimes broken skin in the anal area)
- loss of pubic hair
- diarrhoea
- loss of appetite
- nausea or vomiting.

Because of the difficulty of shielding ovaries from radiation, pre-menopausal women may find their periods stop during treatment or for a few months afterwards, and may not return. They may also have hot flushes, a dry vagina or other symptoms of menopause. Menopausal symptoms can be controlled.

If pre-menopausal women have radiation to the pelvis it is very likely that they will no longer be able to get pregnant naturally. If this is of concern to you, please discuss it with your doctor.

Men who are treated in the pelvic or abdominal area are less likely to have sexual problems because it is much easier to shield the testicles from radiation.

Skin care (practical advice for a raw, sore bottom)

When bowel motions are frequent and loose, the skin around the anus can become raw, sore, itchy and prone to bleeding.

Keeping your skin clean and protected will improve the situation.

Cleaning your skin

Use products that do not contain alcohol or soap. Alcohol-free baby wipes can be used to clean the anal area after a bowel motion. Using soap and water to clean the area around your anus can alter the pH of your skin and increase the risk of breaks in the skin.

Clean the skin frequently and always after a bowel motion. Use warm water and a mild pH-balanced cleansing product, such as baking soda in warm water. Ask your chemist for a suitable product. Unscented toilet paper is also recommended.

Protecting the skin

The first step is to avoid or reduce contact with bowel motions. Use a barrier cream to protect your skin. Apply a thick layer to get a good coverage of the area.

To absorb leakage, a range of pads and absorbent products is available. These contain super-absorbent (and odour-reducing) substances to protect the skin from damage. You can buy these products at supermarkets and pharmacies, or you may get a discounted price from a supplier. It is best to avoid using women's sanitary products because these are not designed to absorb leakage from the bowel.

Treating raw, sore skin

Raw skin around the anus is prone to fungal infection. Your doctor may prescribe an anti-fungal or cortisone-based cream to heal your skin. These creams tend to wipe off easily. To help them last, you can combine them with an equal amount of protective barrier ointment/cream.

Applying creams and ointments

Always cleanse and dry the skin well before applying any creams or ointments.

Apply the cream according to the instructions (for example, some anti-fungal creams should be applied sparingly).

Using a salt-water solution

To soothe skin and help with healing, sit with your bottom in a shallow bath of weak salt-water solution for five minutes several times a day.

Salt-water-solution recipe:

1 teaspoon of salt per cup of boiling water. Allow this to cool before use.

Chemo-radiation (chemotherapy and radiation treatment together) before surgery for rectal cancer

Research has shown that, for many people with rectal cancer, a combination of chemotherapy and radiation treatment before surgery is effective in reducing the risk of cancer coming back. This treatment may be done over a five-week period, and is usually followed by a break of several weeks to give the person time to recover from the radiation treatment. After this break, surgery is usually done.

Hahau-iraruke (te maimoatanga hahau me te iraruke ngātahi) i mua i te pokanga mō te matepukupuku ā-tou

E kitea ana i roto i ngā mahi rangahau mō te nuinga o te hunga whai matepukupuku tou, he whai kiko te whiriwhiringa raupapa o te maimoatanga hahau me te iraruke, i mua i te pokanga, hei whakaiti ake i te mōrea o te hokinga mai o te matepukupuku. Tērā pea ka whai ēnei maimoatanga i te rima wiki, me te whai wā whakatā mō te maha o ngā wiki kia āhei ai te tūroro ki te whai oranga anō mai i te maimoatanga iraruke. Whai muri mai ka whai te mahi hāpara pokanga.

Treatment for advanced cancer

If your cancer has spread, your doctor will discuss various treatments for specific problems caused by the cancer.

These may include:

- surgery to remove the cancer or to bypass any obstruction so that your bowel continues to work normally
- surgery to remove the cancer in other parts of your body, such as the liver or lungs
- chemotherapy and radiation treatment, which can shrink the cancer and control symptoms such as pain and bleeding
- targeted therapies (see below)
- ablation therapy, which includes *radio frequency* or *alcohol ablation* and *cryotherapy* (freezing treatment), for areas of cancer in the liver
- *stenting* to relieve bowel obstruction
- nerve blocks for pain.

Maimoatanga mō te matepukupuku maukaha

Mehemea kua rauroha te matepukupuku, ka matapaki tō rata i ngā momo maimoatanga e hāngai ana ki ngā raruraru ka puta nā te matepukupuku.

- maimoatanga hahau me te iraruke, he mea tīngongo i te matepukupuku me te whakahaere i ngā tohumate pērā ki te mamae me te heke o te toto
- haumanu whakahāngai (kei raro ake nei)
- haumanu ablation, kei roto ko te *ia irirangi*, ko te *ablation waipiro*, ko te *cryotherapy* rānei (maimoatanga whakatio), mō ngā wāhanga matepukupuku i roto i te ate
- te mahi *stenting hei whakahirihiri ake i ngā tauārai kei te puku hamuti*
- tāiha io mō te mamae

Targeted therapies

Targeted therapies aim to stop ('block' or 'inhibit') bowel cancer cells growing, by targeting changes (mutations) in the *genes* of the cells. These changes may be either on the surface of the cells or on the growth pathways inside the cells.

Not all bowel cancers respond to targeted therapies. Your doctor may test cells from your cancer for specific genes to decide if this is a treatment option that may work for you.

Targeted therapies are often given in combination with chemotherapy, as they work differently. They are usually injected into a vein.

Many of these are not free in the public health system.
Please check with your doctor for more information.

Some targeted therapies can cause an allergic reaction.
The most common side effect is skin rash. Other side effects may include:

- high blood pressure
- protein in your urine (your doctor may test your urine for protein and adjust your treatment if levels become too high)
- diarrhoea
- delayed wound healing
- tiredness.

Ngā haumanu whakahāngai

Ka hāngai te whāinga o ngā haumanu whakahāngai ki te puru (te tāiha, te tautāwhi rānei) i te tipu o ngā pūtau matepukupuku puku hamuti, mā te whakahāngai ki ngā panoni (iranoi) ki ngā ira o ngā pūtau. Tērā pea kei runga tonu i te mata o ngā pūtau ēnei panoni, i runga rānei i ngā huarahi tipu kei roto i ngā pūtau.

Taking part in a clinical trial

Your doctor may suggest that you consider taking part in a clinical trial. You could also ask if there is a clinical trial for your kind of cancer. Clinical trials are a vital part of the search to find better treatments for cancer and to test new or modified treatments and to see if they are better than existing treatments. Many people all over the world have taken part in clinical trials that have improved cancer treatments. The decision to take part in one is yours. If you are asked to take part in a clinical trial, make sure that you

fully understand the reasons for the trial and what it means for your treatment. You could ask:

- what is the standard treatment if I do not participate in the trial?
- what is the possible benefit?
- which treatments are being tested and why?
- what tests are involved?
- what are the possible risks or side effects?
- how long will the trial last?
- will I need to go into hospital for treatment?
- what will I do if any problems occur while I am in the trial?
- if the treatment I receive in the trial is successful for my cancer, is there a possibility of carrying on with the treatment after the trial?

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

You will be chosen at random by computer to receive one treatment or the other, but either treatment will be right for your condition. In clinical trials, people's health and progress are carefully monitored. If you do not want to take part, your doctor will discuss the best current treatment options with you.

For more information, you can read the Cancer Society's booklet titled *Cancer Clinical Trials*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

Other treatments

Often, people with cancer think about using complementary therapies, alternative therapies or traditional healing. Many people feel it gives them a greater sense of control over their illness, and that it is 'natural' and low risk. They just want to try everything that seems promising. For many it is their usual cultural practice (for example, rongoā). It is important to talk to your doctor about any other therapies you are using or thinking about, because they may interfere with hospital treatment.

Complementary and alternative therapies

Complementary therapies are massage, meditation, acupuncture and other relaxation methods that are used alongside medical treatments. They may help you to feel better and cope more easily with your cancer treatment.

Alternative therapies include some herbal and dietary methods that are used instead of medical treatment. Many are promoted as cancer cures; however, none of these methods has been proven to be effective in treating cancer.

For more information on this subject you can read the Cancer Society's booklet *Complementary and Alternative Medicine*. You can download a copy from the Cancer Society's website (www.cancernz.org.nz).

“When it was painful I transported myself to the market at home with fresh fruit. I remembered songs that have no words that reminded me of home, like streams and natural sounds. I imagined myself at moments throughout my lifetime—special places on the beach, certain things we did as children. I took myself there.” - Silei

Traditional healing

Traditional Māori healing

Traditional healing has always been an integral part of Māori culture. Values, belief systems and teachings from kaumātua and tohunga alike have seen Māori focus on total wellbeing encompassing taha tinana, taha hinengaro, taha wairua and taha whānau (the physical domain, the domain of mind and behaviour, the spiritual domain and the family/whānau or social domain).

When Māori are faced with tough decisions on health care or treatment, some opt for traditional healing methods. These can include rongoā Māori, romiromi or mirimiri to name a few customary remedies based on native plants, massage therapy and spiritual healing.

Hauora Māori

Mai rā anō te hauora Māori i noho ai hei wāhanga o te ahurea Māori. Nā ngā uaratanga, te pūnaha whakapono me ngā akoranga a ngā kaumātua me ngā tohunga i kitea ai te arotahi a te Māori ki te oranga kotahi e rarawhi ana i te taha tinana, te taha hinengaro, te taha wairua me te taha whānau.

Ka huri ētahi Māori ki ngā kaupapa hauora Māori i ētahi wā mēnā he uaua ki te whakatau ko tēhea, ko tēhea o ngā momo maimoa me whai. Tae noa rā ki te rongoa Māori, te romiromi, te mirimiri rānei, hei taura atu. Ka hāngai katoa ki tarutaru otaota whenua me ngā rākau, te haumanu romiromi me te whakaoranga ā-wairua.

Mehemea he uaua ki te korere i o hiahia ki ngā kaiwhakarato maimoatanga, rapua tētahi tangata hei kaitaunaki mōu, kia āhei ai ngā tohunga hauora me matanga maimoa o ngā hōhipera ki te mahi ngātahi.

Pacific traditional healing

Traditional healing has long been used by Pacific people to help in their recovery. It involves taking a holistic approach to treating the person, where the mental, emotional, physical and spiritual aspects of their wellbeing are looked after together, rather than as separate parts. The treatment offered to each person depends on their needs.

Medicinal plants and herbs may be used during the treatment process, as well as stones and massage. Pacific people may choose to complement Western treatments with traditional healing.

It is possible to use both Western and traditional medicine as part of your healing journey. Each has its place and benefits.

You may think that the doctor and the traditional healer do not need to know about what each other is doing. But it is important that they do in order to make sure that the medicines you are taking are working well together and they are not causing any problems. Traditional plant medicines can sometimes react with Western medications.

If you find it hard to tell your doctor or nurses about the traditional healing methods being used by your healer, it may be helpful for your doctor or nurses to talk directly to your healer or even a close family/whānau member who knows what treatments you are receiving.

Palliative care

Palliative care focuses on improving quality of life—it is not just about care at the end of life. Care can be offered in the community, in a hospital, in a rest home, at home or in a hospice. Palliative care is provided by specialist doctors, nurses, social workers, spiritual care workers, whānau and cultural health services. Palliative care aims to:

- help you enjoy the best quality of life you can for as long as possible
- help make sure that your physical, practical, emotional and spiritual needs are met as well as possible
- help manage symptoms of bowel cancer
- help manage side effects of treatment

- help you feel in control of your situation
- help make the time that you have as positive as it can be for you and your family/whānau.

It is a good idea to ask for palliative care early—it can help to reduce stress for both you and your family/whanau if you are able to deal with issues early rather than wait until they become difficult to manage.

You may also have to make some difficult decisions during your illness. The palliative care team may be able to explain things to you, and help you to find answers.

In general, palliative care services are free. However, there may be a charge for the hire of some equipment for home care.

Palliative care and hospice services are funded by both the government and voluntary donations.

For more information on advanced cancer, you can read the Cancer Society's booklet *Advanced Cancer/Matepukupuku Maukaha*. You can download a copy from the Cancer Society's website (www.cancernz.org.nz).

Atawhai Taurima

Ka arotahi te atawhai taurima ki te whakapiki i te kounga oranga - kua ko te atawhai anake mō te wā e whakamatemate ana rātou. Ka taea te whakarato i roto i te hāpori, i tētahi hōhipera, tētahi kāinga whakatā, ki te kāinga, ki tētahi ratonga 'hospice' rānei.

After treatment

After your treatment you may need to have regular check-ups. Your doctor will decide how often you need these check-ups, as everyone is different. Check-ups will gradually become less frequent if you have no further problems.

Many people worry that any pain or illness is a sign that their cancer is coming back. This is usually not the case, but if you are worried about whether your bowel cancer is going to come back, ask your doctor about what to expect. You may feel less worried if you know exactly what to look out for and what you do not need to worry about.

If your bowel cancer returns, you may need further treatment. It is important to report any new symptoms to your doctor.

You may also feel worried or depressed when your treatment is over and you have time to understand what has happened to you. If you are feeling this way, you may find it helpful to join a cancer support group to help you through the months ahead

Whai muri i te maimoatanga

Ka mutu ana tō maimoatanga, tērā pea me kaha tonu tō haere kia tirohohia koe. Mā tō rata e whiriwhiri te auau o tō haere kia tirohia koe nā te rerekētanga o tēnā, o tēnā e mate ana. Ā tōna wā, ka iti ake tō haere kia tirohia mēnā kāore i te ara ake anō he raruraru.

He nui rātou ka māharahara kua hoki anō te matepukupuku nā te rongo anō i te mamae. I te nuinga o te wā, e hē ana tērā, heoi, mehemea kei te āwangawanga koe kei hoki mai anō tō matepukupuku, uiuitia tō rata mō ngā tūmanakotanga tērā ka puta. Ka iti ake pea tō māharahara, ki te mōhio koe mō ngā tūmanakotanga me ngā āhuetanga me kua noa iho e whakaaro.

Ki te hoki atu anō te matepukupuku, tērā pea me whai maimoatanga anō koe. He mea nui kia kōrero koe ki tō rata mēnā ka puta he tohumate hōu.

Tērā pea ka māha tō ngākau ka mutu ana ngā maimoatanga, ā, ka mārama ake koe ki ngā piki me ngā heke o tō mate. Mehemea e whakaaro pēnei ana koe, tērā pea hē mea pai mōu te whakauru atu ki tētahi rōpū tautoko matepukupuku, hei āwhina tonu i a koe i ngā marama kei mua i a koe.

Key points: Bowel cancer treatment

- In most cases there are a number of ways to treat bowel cancer. These treatments include:
 - surgery (most people have surgery)
 - chemotherapy
 - radiation treatment
 - targeted therapies.
- There are different types of surgery, and your surgeon will recommend the kind you should have. It will depend on several factors, including where the cancer is in your bowel.

Ngā pūwahi matua: Ngā maimoatanga mō te matepukupuku puku hamuti

- I te maha o ngā wā, he nui ngā huarahi maimoa i te matepukupuku puku hamuti. Anei ētahi o aua maimoatanga:
 - hāparapara (whai ai te nuinga i te mahi hāparapara)
 - hahau
 - maimoatanga iraruke
 - ngā haumanu whakahāngai.
- He maha ngā momo āhukatanga pokanga, ā, mā tō rata mātanga hoki e taunaki te momo pokanga me whai koe. Ko taka ki ētahi tini take hei whakaaro, tae noa ki te wāhi e noho ana te matepukupuku ki roto i tō puku hamuti.

Section four: The impacts of bowel cancer

Looking after yourself

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve your wellbeing. Addressing changes in your emotions and relationships early on is also very important.

For more information on this subject, you can read the Cancer Society's booklet *Coping with Cancer*. You can download a copy from the Cancer Society's website (www.cancernz.org.nz).

The Cancer Society also has a telephone support service, Cancer Connect, where we can introduce you to someone who is going through a similar cancer experience. For more information about Cancer Connect, phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Te tiaki i koe anō

Tērā pea ka puta he taumahatanga ā-tinana, ā-kāre nā te matepukupuku. Mā te kai pai, me te korikori tinana, me te whakangohe e āwhina i a koe ki te whakaitit ake i ngā taumahatanga me te whakapiki i tō oranga. He mea nui te tere whakatau i ō kāre-ā-roto me ōu nā hononga tangata.

Mō te roanga o ngā pārongo e pā ana ki tēnei kaupapa, pānuihia te puka a Te Rōpū Matepukupuku o Aotearoa *Coping with Cancer*.

Emotional support

People react in different ways when they learn they have bowel cancer. Feelings can be muddled and change quickly. Having tests for, or being diagnosed with, bowel cancer can be distressing for yourself and those close to you. It can also be difficult talking about bottoms and bowels, although many of us can laugh at a bit of ‘toilet humour’.

It may be helpful to talk about your feelings with family/whānau, friends or a health professional.

For more information about emotional support, you can read the Cancer Society’s booklet *Emotions and Cancer*. You can download a copy from the Cancer Society’s website (www.cancernz.org.nz).

Talking to friends and family/whānau

Sometimes you may find that your family/whānau and friends do not know what to say to you when you have cancer—they may have difficulty with their feelings as well. Some people may feel so uncomfortable they avoid you. Others may expect you to lead the way and tell them what you need. You may feel able to approach people directly and tell them what you need, or you may prefer to ask a close family/whānau member or friend to talk to other people for you.

For more information about talking to friends and family/whānau members, read the Cancer Society’s booklet *Cancer in the Family* and our information sheet *Telling others about your cancer diagnosis*. You can get copies by phoning the

Cancer Information Helpline 0800 CANCER (226 237) or by contacting your local Cancer Society office. You can also download copies from the Cancer Society's website (www.cancernz.org.nz).

Psychological, counselling and social worker support

When you are diagnosed with bowel cancer, suddenly you are faced with decisions and emotions you never thought you would have to deal with. The thought of bowel cancer can be frightening in different ways. Your first thoughts may be:

- how serious is this?
- am I going to die?
- will I be cured?
- will I be able to do the things I usually do?

In the time after diagnosis, you may experience a range of feelings. Common reactions are anxiety, fear, sadness and, sometimes, anger. Such strong emotions can make you feel as if you are losing control of your emotions or your life.

When you have bowel cancer you have to deal with many things for the first time. No matter how you are feeling, support services are available to you. If you speak to your general practitioner or medical team, they can refer you to someone such as a counsellor or psychologist, who can help you manage these feelings.

Psychologists and counsellors

A psychologist or counsellor:

- encourages you to talk about any fears, worries or emotions you may be feeling
- helps you to work through feelings of loss or grief
- helps you resolve problems so that you can find more pleasure in your life
- teaches you ways to handle any anxiety you have
- shows you meditation or relaxation exercises to help ease physical and emotional pain
- helps you to communicate better with your family/whānau and friends.

To find a psychologist or counsellor, contact your general practitioner or your local Cancer Society office or phone the Cancer Information Helpline **0800 CANCER (226 237)**.

Social workers

Social workers are available to help support you and your family/whānau through the social and emotional changes a cancer diagnosis brings. If you do not already have a social worker, your hospital doctor or nurse can arrange a referral.

Social workers:

- provide information and support to help you and your family/whānau cope with your cancer diagnosis
- help set up support services so you can stay independent at home
- help with accommodation if you need to travel away from home for treatment

- help make travel arrangements if you are having treatment out of town
- offer advice and information about financial support available
- make referrals to other support agencies
- take part in multi-disciplinary meetings.

Financial assistance

Help may be available for transport and accommodation costs if you are required to travel some distance to your medical and treatment appointments. Your treatment centre or local Cancer Society can advise you on what sort of help is available.

Financial help may be available through Work and Income (**0800 559 009**). They will also have pamphlets and information about financial assistance.

Short-term financial help is available through Jobseeker Support. Longer-term help is provided through the Supported Living Payment. Extra help may be available, for example accommodation supplements and help with medical bills.

For more information about this subject, read the Cancer Society's information sheets *Benefits and entitlements* and *Benefits and entitlements: What happens when you apply for Work and Income support?* You can get copies by phoning the Cancer Information Helpline **0800 CANCER (226 237)**, or by contacting your local Cancer Society office. You can also download copies from the Cancer Society's website (www.cancernz.org.nz).

“It’s like a home away from home [Cancer Society accommodation]. We do all our own cooking and washing. You still have to look after those things yourself. It’s not like hospital. It’s really good to meet people, talk about it, but you’ve got your own room and your own time.” Melinda

Āwhina pūtea

Tērā pea ka wātea he āwhina utu mō ngā haerenga me ngā wāhi noho mehemea me haere tawhiti koe ki ō whakaritenga hauora, maimoatanga hoki. Mā tō pokapū maimoatanga, tō Kāhui Matepukupuku ā-rohe rānei koe e tohutohu i ngā momo āwhina e wātea ana.

Cultural and spiritual support

Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural and advocacy needs. Community health workers based at your local marae, or a community-based Pacific health service, may be good sources of support. Hospital chaplains are also available to people of all faiths and no faith, and offer support through prayer and quiet reflection. Talk with your health care team about the services available.

For more information on this topic, see our information sheet “Cancer and spirituality”.

Tautoko ā-ahurea, ā-wairua hoki

Ka whai ngā hōhipera huri noa i te motu i ngā kaimahi hauora kua whakangungutia hei tautoko i ō hiahiatanga ā-wairua, a-ahurea, ā-whaitaua hoki. Tērā pea, hē puna āwhina ngā kaimahi hauora kei tō marae ā-rohe, kei tētahi ratonga hauora Moana-nui-ā-Kiwa rānei. E wātea ana hoki ngā minita ō te hōhipera ki ngā tangata katoa, ahakoa te whakapono, te kore whakapono rānei, me tā rātou whakarato tautoko mā te karakia me te hurihuringa mārie. Kōrero ki tō rōpū atawhai hauora mō ngā ratonga e wātea ana. Mō te roanga o ngā pārongo e pā ana ki tēnei kaupapa, tirohia tā mātou whārangi pārongo “Cancer and spirituality”.

Interpreting services

New Zealand’s Code of Health and Disability Services Consumers’ Rights states that everyone has the right to have an interpreter present during a medical consultation. If you do not speak English as your first language or you are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. Speak to a member of your health care team about arranging interpreters in your local area.

For families/whānau

Cancer can affect your whole family/whānau. You may want to offer support but not know how. Here are some suggestions that may be useful:

- Learn about bowel cancer and its treatment. This will help you to understand what the person you are supporting is facing. But be careful about offering advice.
- Talk about your feelings together and be honest about what worries you.
- Try not to worry about what to say. Often listening while they talk, or just being there with them, is a good way to show you care.
- Offer to go to appointments with them as a support person. You can take part in the discussions, take notes or simply listen.
- Respect that your family/whānau member or friend may want to talk to their doctor alone.
- Do not try to do too much. Give the person the opportunity to do things for themselves—they will probably appreciate the chance to be useful.
- Look after yourself and give yourself time to rest. Taking care of yourself will help you to take good care of them.
- You may find that other people want to know about the health of your loved one. It may be useful to ask one person to be a spokesperson for your family/whānau, who will share this information with others. Or you may like to use email or text messaging rather than talk to everyone yourself.

- Accept that sometimes you will need help from others. Consider joining a local support group and do not be afraid to ask for help from other friends or relatives, or from the services available in your community.

When a loved one is diagnosed with cancer, your routines and family/whānau roles may change. The person who was the major source of income may now be unable to work and may be dependent on others. A partner who used to share responsibility for doing household chores may now have to take on extra tasks or get a job.

Maintaining your usual social life and hobbies may be difficult or impossible for a while. Cancer is not a normal event, so it is important to acknowledge this and not try to carry on with everything as before. There are a number of things you can do that may help you cope. For example:

- prepare simpler meals
- be more relaxed about housekeeping standards
- ask family/whānau to help more around the house.

“I said to them, ‘Look, you just have to support me now. It’s my time.’ It was role reversal.” Silei

For more information on this subject, you can read the Cancer Society’s booklet *Supporting Someone with Cancer/ Te Manaaki i Tētahi e Māuiui ana nā te Matepukupuku*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society’s website (www.cancernz.org.nz).

Advance care planning

While your health care professionals will do everything they can to cure your bowel cancer, factors (such as the stage of your cancer at diagnosis) sometimes mean that their best efforts cannot cure you.

Advance care planning is about helping you to think and talk about the end of life, and about what treatments and care you might want.

You and your health care providers should be working together to ensure that your future care choices fit your needs. This will then guide your family/whānau and doctors when you can no longer tell them yourself.

Advance care planning is voluntary—no-one can make you do it. For more information on advance care planning, visit www.advancecareplanning.org.nz

Relationships and sexuality

For some people, having cancer and cancer treatment has no effect on their sexuality. However, the anxiety and/or depression felt by some people can affect their sexual desire. We are all sexual beings and intimacy adds to the quality of our lives. Cancer treatment and the psychological effects of cancer may affect you and your partner in different ways.

Sex after treatment for bowel cancer

Most people are able to have satisfying sex lives after bowel cancer, but you will need time to get over surgery or other treatments. You should not have penetrative sex for at least six weeks after major surgery. This allows that area time to

heal and gives your stomach muscles time to recover. If you have had surgery involving the anus, you are advised to wait 10 to 12 weeks before having sex. But there is no reason why chemotherapy or radiation treatment should stop you having sex if you feel like it.

Many people do not feel like sex while they are having treatment. Side effects and general tiredness can get in the way. Surgery to the bowel or anus can affect the nerves to the sex organs.

Maintaining or keeping an erection may be difficult and your orgasm may be dry. Your ability to have an erection will depend on whether there is nerve damage. If you have any problems with sex after your treatment, you can discuss this with a health professional. There are a number of treatments available for erectile problems.

Anal sex can resume, or may start, when it is comfortable for patients and partners. For those who have had surgery to close the anus, this will not be possible.

Having sex when you have a stoma

If your surgery requires you to have a stoma formed for bowel cancer, there is a high chance of permanent damage to the blood and nerves that supply the genital area. This may cause problems with getting and maintaining erections.

A stoma can make some sexual positions uncomfortable, and needing to change a stoma bag before sex may spoil the moment. People may also worry that a stoma bag will fall off and/or they may have a bowel motion during sex.

Having a stoma may make you feel self-conscious about the change in your body. This can result in sexual difficulties with

your partner, or make you feel anxious about new relationships. Stomal therapists can give advice and help you with these kinds of issue.

Occasionally problems may arise because partners are struggling with change. It can be helpful to discuss it if you feel there is awkwardness between you. Your partner cannot damage the stoma, so go with the position you are comfortable with.

Practical tips if you have a stoma

People with stomas sometimes worry about whether their bags will get in the way. If a bag is emptied before sex, it can be folded up and secured with some tape to your body to prevent it moving around.

If a bag is not covered with fabric, some people choose to use a cotton cover during sex. This prevents the bag rubbing on you and your partner's skin. If you usually wear a transparent bag, the cover hides the contents. Some people choose to wear silky or cotton vest-like tops that cover the bags and the top halves of their bodies.

If your anus has been removed, the position of being on top of your partner may be uncomfortable for vaginal sex. One option is to enter the vagina from behind.

A finger, a penis or a sex toy should not be pushed into a stoma because this could damage the stoma.

If you have faecal oozing, use plugs designed for rectal use. Plan to have a spare stoma bag and toilet tissues or wet wipes on hand in case an accident does occur.

If you are worried about your bag making noises, try playing music during sex.

Ostomy Societies

These groups provide support and practical advice to people with ostomies (stomas). Some societies are not listed in the phone book, but your local Cancer Society can put you in contact with a group in your area.

For more information about sexuality, you can read the Cancer Society's booklet *Sex and Cancer*. You can download a copy from the Cancer Society's website (www.cancernz.org.nz).

Fertility and contraception

You may become infertile, either temporarily or permanently, during treatment. Talk to your doctor about this before you start treatment.

Despite the possibility of infertility, contraception should be used (if the woman hasn't gone through menopause) to avoid pregnancy. This is because there is a risk of miscarriage or birth defects for children conceived during treatment. If you are pregnant now, talk to your doctors about it straight away.

What can I do to help myself?

Many people feel that there is nothing they can do when they are told they have cancer. They feel not in control and helpless for a while. If you feel this way, there are practical ways you can help yourself.

Diet

A balanced, nutritious diet will help to keep you well and able to cope with any side effects of treatment. The Cancer Society's booklet *Eating Well during Cancer Treatment / Kia Pai te Kai te wā Maimoatanga Matepukupuku* provides useful advice about nutrition and diet during treatment. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

The hospital will also have a dietitian who can help you. If you have a stoma, your stomal therapist will give you tips on what to eat while your stoma is settling down.

Staying active

Research has indicated that people who keep active cope better with their treatment than those who do not. Ask your doctor what kind of exercise is best for you.

For more information, you can read the Cancer Society's brochure *Being Active When You Have Cancer*. You can get a copy by phoning the Cancer Information Helpline **0800 CANCER (226 237)** or by contacting your local Cancer Society office. You can also download a copy from the Cancer Society's website (www.cancernz.org.nz).

Relaxation techniques

Some people find that relaxation or meditation help them to feel better. The hospital social worker or nurse or your local Cancer Society may know whether the hospital runs any relaxation programmes. They may also be able to advise you on local community programmes.

The Cancer Society has some relaxation resources, which are available on CD or through our website.

- **Wellington Division's Relaxation and Visualisation see the link:**
<https://wellington.cancernz.org.nz/en/how-we-can-help/want-local-support/relaxation-and-meditation-cd>
- **Auckland/Northland Division's Relaxation and Mindfulness see the link:**
<https://auckland-northland.cancernz.org.nz/en/how-we-can-help-2/want-local-support/relaxation-and-mindfulness-cd>

Key points: The impacts of bowel cancer

- Cancer can cause physical and emotional strain.
- Eating well, exercising and relaxing may help to reduce stress and improve wellbeing.
- Addressing changes in your emotions and relationships early on is also very important.
- Having a stoma may make you feel self-conscious about the change to your body. Stomal therapists can give advice and help with all aspects of managing a stoma, including any changes to your sex life.

Ngā pūwahi matua: Ngā papātanga o te matepukupuku puku hamuti

- Tērā pea ka puta ngā taumahatanga ā-kiko, ā-kāre nā te matepukupuku.
- Mā te kai pai, me te korikori tinana, me te whakangohe e āwhina i a koe ki te whakaiti ake i ngā taumahatanga me te whakapiki i tō orange.
- He mea nui te tere whakatau i o kare ā-roto me ou nā hononga tangata.
- Tērā pea ka kiri hihira koe mō te rerekētanga ki tō tinana nā te whai stoma. Āhei ai kaihaumanu stoma_ki te whakarato tohutohu me te āwhina mō ngā āhuatanga katoa mō te whakahaere_stoma, tae noa ki ngā panoni ki tō mahi ai.

Appendix A: Understanding cancer

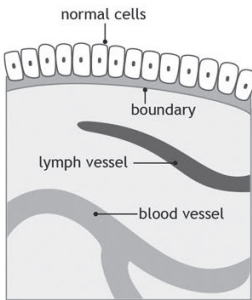
What is cancer?

Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells and heal damaged cells after an injury.

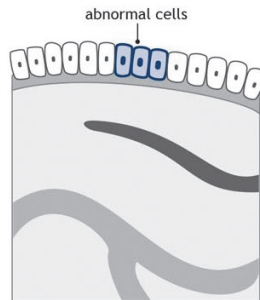
The process of making new cells is controlled by certain genes—the codes that tell our cells how to grow and behave. Cancers are caused by damage to these genes. These changes usually happen during our lifetime.

In a very small number of families, damaged genes may be passed through the generations. While these people have an increased risk of developing cancer, it does not mean they will definitely get cancer.

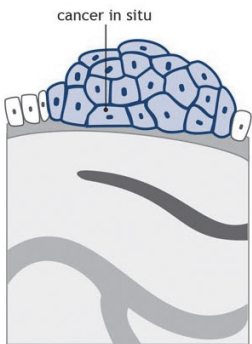
How cancer starts



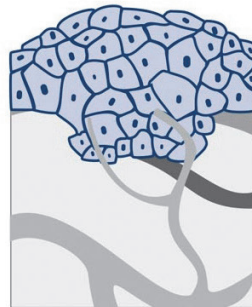
1. Normal cells



2. Abnormal cells



3. Abnormal cells multiply



4. Malignant or invasive cancer

Tumours can be benign (not cancerous) or **malignant** (cancerous). Benign tumours do not spread to other parts of the body.

How cancer spreads

A malignant tumour is made up of cancer cells. When it first develops, a malignant tumour is usually confined to its original site. This is known as the primary site. Some tumours can become quite large within their organs of origin, for example the bowel or rectum. With growth, the tumour may spread beyond the original organ boundaries and into surrounding tissues. This is called locally advanced cancer.

Sometimes cells move away from the original (primary) cancer through the bloodstream or lymphatic systems and start to grow in other body organs. When these cells reach a new site they may form another lump or mass. This is called a *secondary cancer* or *metastasis*. For example, if bowel cancer spreads to the liver, it is called a liver secondary (or metastasis).

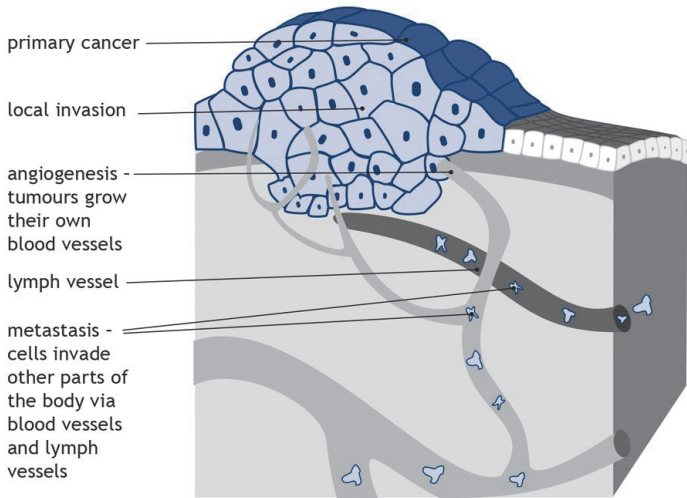
If the only place of spread is to nearby lymph nodes, this is called regional nodal spread. Your doctor will still refer to it as bowel cancer even though it has spread to another part of your body.

The sort of treatment you are offered for bowel cancer will depend on where in the bowel it began and whether it has spread. Your doctor will also take into account other things about you, such as your age and general health.

Treatment for cancer includes surgery, radiation treatment and chemotherapy (drug treatment). *Immunotherapy* and *targeted treatments*, which are now used to treat some cancers, will become more important in the future.

These modes of cancer treatment can be used individually or in combination.

How cancer spreads



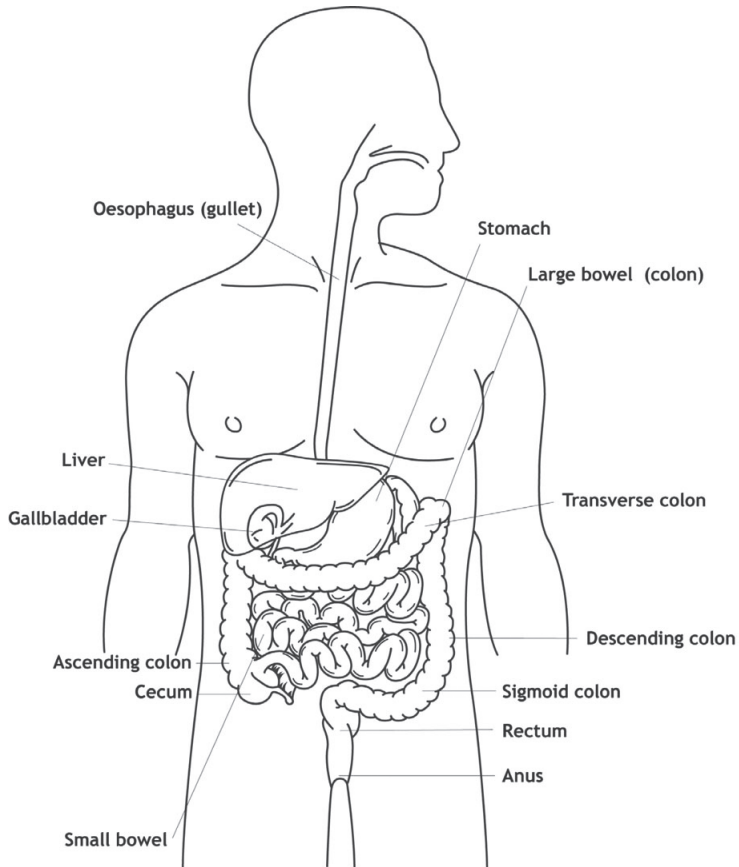
Appendix B: Understanding the bowel

The bowel

The bowel is a six-metre-long tube made of muscle, with a lining similar to the inside of the cheek. It is part of the digestive system and extends from the stomach to the rectum and anus. There are two parts of the bowel—the small bowel and the large bowel. Food and liquid are broken down in the stomach and then passed into the small bowel to be digested. From there, the nutritional parts of the food are absorbed into the bloodstream and the remains pass into the large bowel.

The large bowel is made up of two parts—the colon and the rectum. The colon is the first one and a half metres of the large bowel. The rectum is the last 12 to 15 centimetres, ending at the anus. The colon removes liquid from digested food, which is turned into solid waste. The rectum holds this solid waste until it is expelled as a bowel motion.

The digestive system



Glossary (What does that word mean?)

abdomen—The part of the body between the ribs and your groin, often called the stomach. It is also called the tummy.

alcohol ablation—An injection of ethanol (alcohol) directly into a liver tumour to destroy the cancer cells.

anastomosis—Where the bowel is rejoined after a section has been removed during surgery.

anus—The entrance to the rectum.

benign—Not cancerous. Benign cells are not able to spread elsewhere in the body.

biopsy—The removal of a small amount of cells or tissue from the body, which can then be examined under a microscope.

bowel motion—Also known as faeces, excrement, poo and stools.

cells—The ‘building blocks’ of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

colon—The large bowel.

colonoscope and colonoscopy—A colonoscope is a long, flexible tube inserted through the rectum into the bowel (a colonoscopy). A specialist can look down the tube to check for signs of cancer.

colostomy—If the bowel cannot be rejoined during surgery, the upper end can be brought out to the skin of the abdominal wall. This is called a colostomy and the opening of the bowel is known as a stoma. A bag is worn over the stoma to collect bowel motions.

Crohn's disease—A chronic inflammatory disease of unknown origin usually affecting the small or large bowel or both.

cryotherapy—Where liver tumours are frozen and destroyed using liquid nitrogen probes.

computerised tomography (CT) colonography—CT scan looking into the colon but not using a scope.

computerised tomography (CT) scan—Previously known as a CAT scan. A series of X-rays that are built up to give a picture of the part X-rayed.

genes (gene = singular) —The codes contained in the DNA in each cell that control the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. Genes are found in every cell of the body.

ileum—The small bowel.

immunotherapy—A treatment that uses the immune system to reject or kill cancer cells.

magnetic resonance imaging (MRI) scan—Similar to a CT scan, this test uses magnetism instead of X-rays to build up cross-sectional pictures of the body.

malignant—A tumour that is cancerous and is likely to spread if it is not treated.

metastasis—When a cancer has spread from the original site to another part of the body. It can also be called a 'secondary cancer'. It is sometimes shortened to 'mets'.

oncologist—A cancer doctor.

positron emission tomography (PET) scan—A scan that can be used to help stage bowel cancer and look for cancer that may have spread to other parts of the body.

palliative—Controlling the symptoms of a disease rather than curing it.

polyp—A small growth in the bowel. It can be either cancerous or not cancerous.

radio frequency ablation—A process that uses electrical current passed through a small needle placed directly into a liver tumour to destroy cancer cells with heat.

randomised clinical trial—A trial where people are put into groups by chance. One group is given the best current treatment or a placebo and their progress is compared with those having the treatment that is being tested. People are usually selected for each group by a computer.

rectum—The back passage/final section of the large intestine.

resection—The surgical removal of a portion of any part of the body.

secondary—The same as metastasis.

stent/stenting—When a tube made of metal or plastic is inserted into the bowel or a duct to keep it open and prevent closure when a tumour is growing rapidly.

stoma—An opening on the abdominal wall, which is made during surgery. A stoma can be permanent or temporary. A bag is worn over the stoma to collect bowel motions.

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

targeted therapies—treatment that aim to stop ('block' or 'inhibit') bowel cancer cells growing, by targeting changes (mutations) in the genes of the cells. These changes may be either on the surface of the cells or on the growth pathways inside the cells.

tumour—A swelling or lump. Tumours can be benign (not cancerous) or malignant (cancerous).

ulcerative colitis—A chronic, episodic, inflammatory disease of the large bowel and rectum.

virtual colonoscopy—See CT colonography.

Notes

You may wish to use this space to write down any questions you want to ask your doctor, nurses or health providers at your next appointment.

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We would like to read what you thought of this booklet, whether you found it helpful or not. If you would like to give us your feedback please fill out this questionnaire, cut it out, and send it to the Communications Officer at the address at the bottom of the following page.

1. Did you find this booklet helpful? (Tick box)

Yes No

Please give a reason(s) for your answer:

2. Did you find the booklet easy to understand? (Tick box)

Yes No

Please give a reason(s) for your answer:

3. Did you have any questions not answered in the booklet?

(Tick box)

Yes No

If yes, what were they?

4. What did you like most about the booklet?

5. What did you like least about the booklet?

6. Any other comments?

Personal information (optional)

Are you a person with cancer, or a friend/relative/whānau?

Gender: Female Male Age: _____

Ethnicity (please specify): _____

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