Just Diagnosed

with bowel cancer

What Happens Next?





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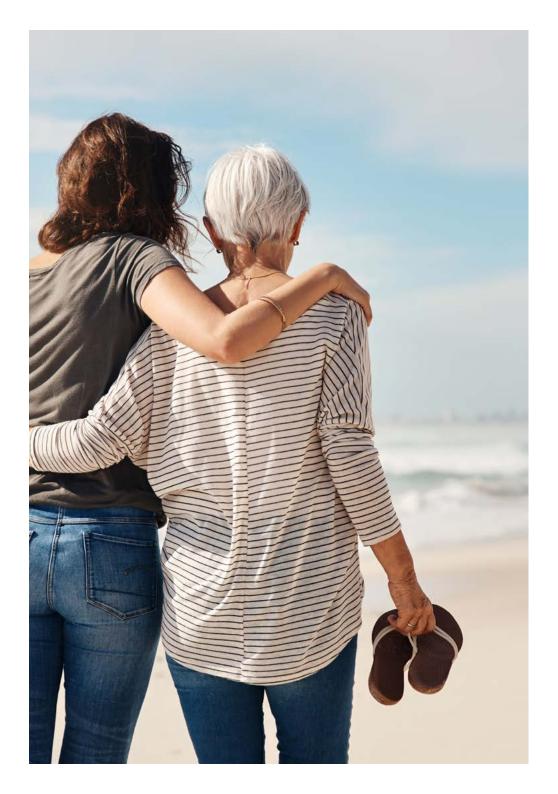
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Introduction

This booklet is for everyone diagnosed with bowel cancer as well as their whānau and friends. It will give you an overview of bowel cancer, how it can be treated, and what to expect during your treatment.

There's space to add your own notes and write down any questions you may have. You might like to keep this booklet handy when you meet with the doctors and other specialists who are helping with your treatment – so you can ask them to explain anything you would like to understand.

More help

On page 44, there's a list of resources, groups and free services that support bowel cancer patients in New Zealand.

For more information on the help that's available, see our website: bowelcancernz.org.nz > Support



The Bowel Cancer NZ Facebook support group has been a tower of strength and knowledge for me. When I got the diagnosis I was naturally in shock but after an initial cry and some anger, I switched into how do I make this journey my journey, without just being taken on it."

Julie Morse

Your healthcare team

Treating bowel cancer is a team effort that involves the skills of doctors, nurses and other highly trained healthcare professionals.

Here are the people who will most likely be closely involved in treating you:

Colorectal Nurse Specialist

A nurse with specialist training in the care of bowel cancer patients and other patients with bowel conditions.

Colorectal Surgeon

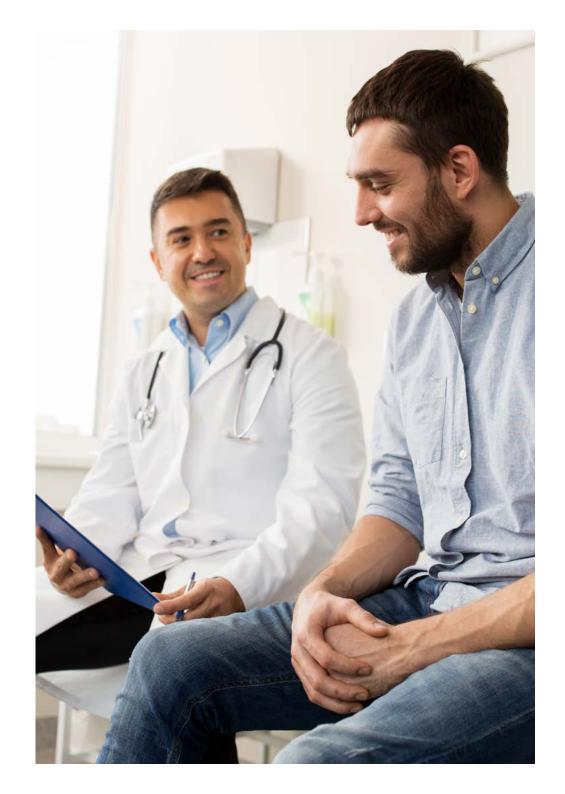
A doctor with specialist training in performing bowel surgery. Other specialist surgeons may also be involved if the cancer has spread to other parts of your body, such as your liver or lungs.

Medical Oncologist

Doctors who are skilled in treating cancer patients with chemotherapy and other advanced drugs.

Radiation Oncologist

A Clinical Oncologist who specialises in radiation treatments. This specialist prescribes, plans and supervises any courses of radiation required.



Radiologist

Specialists who use X-rays and other scanning machines, such as ultrasound, CT, PET and MRI machines to see inside the body. A Diagnostic Radiologist uses these scans to locate and measure the size of a cancer.

Stoma Nurse

A nurse with specialist training in the care of patients who have a stoma (temporary or permanent opening in the body after a section of bowel has been removed).

Oncology Nurse

A nurse with specialist training in the care of patients who are being treated for cancer.

Palliative Nurse

A nurse with specialist training to support patients and their whānau when cancer is very advanced, with the goal of improving quality of life.

Pharmacist

A specialist who can support and advise the healthcare teams about the medicines being used to treat cancer.

Dietician or Nutritionist

Professionals who support you if you have difficulties with eating and drinking, or if you have problems keeping weight on or off.

Physiotherapist

A professional trained to help you regain strength, movement and balance throughout treatment.

Clinical Psychologist

A professional trained to support you with your mindset while you are undergoing treatment and afterwards. They can provide you with tips and tools for dealing with the emotional side of cancer diagnosis and treatment.

GP

Your family doctor, who will likely be involved in your care throughout your diagnosis and treatment.

Ward Social Worker

Each hospital has a social worker on the ward. They are professionals who provide non-medical therapies to support people dealing with the practical and emotional issues they may face during treatment.

Contact details

You can write the names and details of your healthcare team members here:

Name	Name
Role	Role
Phone	Phone
Email	Email
Name	Name
Role	Role
Phone	Phone
Email	Email
Name	Name
Role	Role
Phone	Phone
Email	Email
Name	Name
Role	Role
Phone	Phone
Email	Email



Do you have any questions?

It's normal to have questions when bowel cancer is diagnosed. Here are some of the things people commonly ask. You may have other questions too.

You could make a list of questions you would like to ask at your next consultation. Bring a friend to take notes, or you could record the answers and play them back later (make sure you ask for permission from everyone in the meeting if you want to record it).



Where is my bowel cancer, and can you draw me a picture to show this?

How advanced is my bowel cancer (what stage)?

Who will be looking after me?

What are my treatment choices?

If I need to have surgery, what kind of operation will it be and how long will I be in hospital?

Will I have to have a stoma? If I do, will it be permanent?

If I need to have any other kinds of treatment, what are they likely to be?

How long will these treatments take, and how long will I be in hospital?

What are the likely side-effects of my treatment, and how will you help me cope with them?

Will I need to be off work, or will I need extra help at home after my treatment?

How will my bowel be affected?

How will my energy levels and appetite be affected?

Will my treatment have any effect on my sexual function?

Will my treatment affect my ability to have children?

Who can I contact in an emergency?

Are there any clinical trials open to me?

Are there any unfunded treatments or medication you would suggest for my cancer?

Can I get a second opinion about treating my bowel cancer?

Are my family at increased risk of bowel cancer?

What sort of follow-up can I expect once my treatment has finished?

What other sources of support are available locally to help me and my family cope?

My questions & notes

		
		
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The stages of bowel cancer

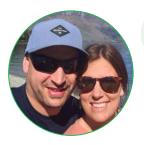
You will hear a lot about staging or the 'stage' your cancer is at. This is the system medical professionals use to describe the size of a cancer, where it is located and whether it has spread.

The stage of a cancer is determined at diagnosis and does not change over time, even if the cancer shrinks, grows, spreads or recurs. So the cancer is still referred to by the stage it was given when it was first diagnosed, although information about the current extent of the cancer may be added.

The treatment chosen for your bowel cancer depends on its stage.

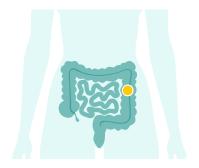
What does staging mean?

The stage of your bowel cancer can be described as stage 0-IV (or 0-4). Stage 0, or 'carcinoma in situ', means that the cancer cells are contained in the inner lining of the bowel, and there is very little risk of any cancer cells having spread.



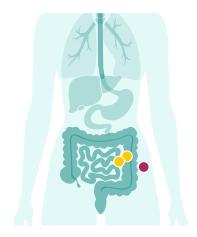
I knew the CT scan was crucial in determining my staging. Waiting for the results was probably the hardest part of the journey. I found out I had Stage 2 cancer and my tumour was large but treatable. The path forward was clear – surgery followed by chemotherapy."

Marcel Sandland



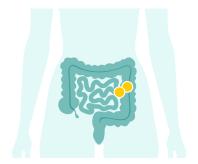
Stage I (1)

The cancer hasn't spread outside the bowel wall.



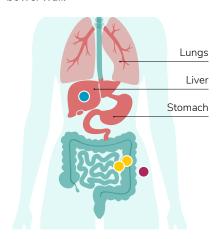
Stage III (3)

The cancer has spread to nearby lymph nodes.



Stage II (2)

The cancer has grown into or through the outer layer of the bowel wall.



Stage IV (4)

The cancer has spread to other parts of the body – often the liver or lungs. This is known as metastatic bowel cancer.

Key 🛑 Tumour 🌘 Nodes 🔵 Metastatic

Staging and the TNM system

A common tool specialists use to describe the stage of bowel cancer is the TNM system:

Tumour – information relating to the original (primary) tumour.

The number reflects the size of the cancer and ranges between 1-4, from smallest to largest.

Nodes – whether the cancer has spread to the nearby lymph nodes.

The number ranges from 0-3. 0 would mean no lymph nodes are affected. 1-3 is then used to indicate the size, location or number of affected lymph nodes.

Metastasis – refers to whether the cancer has spread from the primary tumour to other parts of the body.

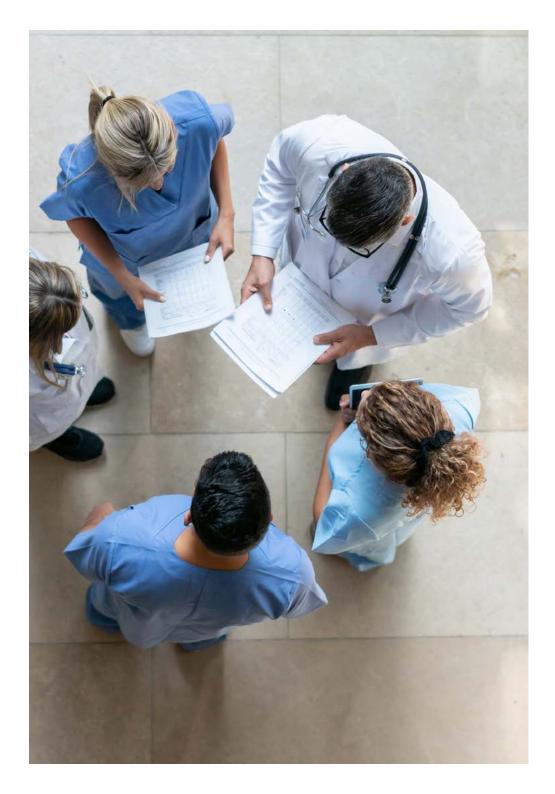
0 means there is no spread, and M1 means it has spread to other organs or tissue.

More information

If you want to know more about the way cancers are described, and what staging means, you can ask your healthcare team to explain.

You can also find further information at $\underline{\mathsf{bowelcancernz}.\mathsf{org}.\mathsf{nz}}$

> About bowel cancer > Treatment options > Staging and grading



How is bowel cancer treated?

There are three main types of treatment – surgery, chemotherapy and radiation. Your treatment may involve any combination of these at different times.

Surgery

Surgery is the most common way to treat bowel cancer, although it is not suitable for everyone. Your healthcare team will discuss what's best for you.

There are many different surgical techniques for bowel cancer. Here are a few:

- Keyhole (laparoscopic) surgery where several small incisions are made, and the surgeon inserts a long thin tube with a camera and uses surgical instruments to remove the cancer.
- Open surgery where a single, larger incision is made and the cancer is cut out.
- Colectomy where the surgeon removes part of the bowel and then sews up the two open ends.

The surgeon will usually remove the nearby lymph glands at the same time, to check whether any cancer cells have spread outside the bowel.

The location of the tumour will affect the type of operation you have, and whether you have a temporary or permanent stoma afterwards. This is where a section of the bowel is brought out through an opening on your belly, so waste then empties into a stoma bag stuck on your skin.

A temporary stoma will be left in place long enough to let your bowel heal after the surgery. Some people will need a permanent stoma if the ends of the bowel can't be joined back together.

More information is available at bowelcancernz.org.nz

> About bowel cancer > Treatment options > Ostomy information

Types of surgery

If you have a very small, early-stage bowel cancer, the surgeon may remove it from the lining of the bowel without the need to remove an entire section of bowel. This is called a local resection.

Here are some other types of surgery to remove bowel cancer.





1. Right hemicolectomy







3. Abdominoperineal resection (APR)

4. Anterior resection



5. Sigmoid colectomy



6. Hartmann's procedure



7. Total colectomy



8. Pan proctocolectomy

Recovery after surgery

As with any operation, you will be kept under close observation in the recovery area. You may spend some time in a high-dependency unit with specialist care until you are well enough to go back to the ward.

You will usually be encouraged to eat and drink as soon as you feel able to after surgery. Most people find that small portions of bland and low-fibre foods are easier to digest at first. In addition, eating will help you recover from the operation more quickly and get your bowel working again.

You will also be encouraged to start moving around as soon as possible. Even if you have to stay in bed, it's important to do regular leg movements and deep-breathing exercises. A physiotherapist or nurse will explain these to you.

To reduce the risk of blood clots, you may need to wear compression stockings, known as TED stockings. The nurse may also give you drugs to prevent blood clots. These are usually given as injections under the skin.



Painkillers will help you get up and move around. You should let the medical team know if your pain is not controlled.

If you have a stoma, the stoma nurse will visit you on the ward, to show you how to look after your stoma and give you advice on what you can eat and drink.

The day will come when you are well enough to go home. However, it will still take some time for your energy levels to improve, your appetite to return and for life to become more 'normal' again.

Don't hesitate to talk to your healthcare team if you have any concerns or unexpected side effects, such as a high temperature, lack of appetite, persistent diarrhoea, nausea, constipation or pain.

Practical tips when recovering at home

Many people look forward to returning to the comforts and familiarity of home. It's a real milestone in recovery.

Remember that your energy levels will likely be low for many weeks. Even simple tasks may be exhausting, so make sure you have plenty of help. And don't expect too much of yourself!

You will still have the support of your healthcare team – especially the Colorectal Nurse Specialist and your GP. If you have a stoma and bags, you may be referred to a community stoma nurse who can visit you at home. You can also download our free booklet on coping with a stoma after bowel surgery:

<u>bowelcancernz.org.nz</u> > Support > Resources

Your physiotherapist may give you exercises to build up your strength. Make sure you follow their instructions and don't be afraid to ask for guidance.

If your bowels aren't settling into a new routine, or you have trouble eating and maintaining a healthy weight, talk to your GP or other members of the medical team.

Bear in mind that it may take up to a year for things to settle down. You probably won't go straight back to the way things were before. So be patient, but don't hesitate to ask your medical team if anything is bothering you.

Check out our Facebook support groups and online resources in the More Help and Resources section on page 44. Many people find it really helpful to connect and share tips with those who have also been through bowel cancer treatment.

Follow-up appointments

You will see the surgeon soon after your operation. It's also normal to have a follow-up appointment a few weeks later to check your progress and discuss the next steps.

Your oncology team and other medical teams will also review your situation as and when necessary. If you feel like you need a review, you can contact the clinic or nurse specialist to organise one.

Depending on the type or stage of your cancer, you may need to have further tests, blood tests and scans to check progress.

Keep in mind that each bowel cancer patient will have a different schedule of tests, scans and follow-up appointments. Your case is unique, so don't worry if others are having more (or fewer) follow-up appointments than you are.

Contact your GP or specialist

If you experience any of these symptoms:

- A high temperature.
- Unable to eat or drink for any reason.
- Persistent diarrhoea, nausea or vomiting
- Constipation for three days or more.
- Pain, swelling, redness or unexpected leakage around your wound or stoma.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

When bowel cancer is caught early (Stage 0 or Stage I), surgery is often all that is needed to remove the cancer. Chemotherapy is not necessary.

In Stage II (2), after surgery, the tissue will be examined under a microscope. Depending on whether the cancer has spread through all four layers of the gut wall, into the blood vessels, or there is no adequate number of retrieved lymph nodes, adjuvant chemotherapy may be recommended to minimise or eradicate the chance of micrometastatic disease.

If, after surgery, cancer is found in the removed lymph nodes, then your cancer is Stage III (3), and adjuvant chemotherapy is readily recommended to reduce the risk of recurrence. In Stage IV (4), as your bowel cancer has spread to other organs, your healthcare team may still recommend surgery, almost certainly chemotherapy and sometimes radiation to target the cancer.

When is chemotherapy given?

Every patient is different, and your healthcare team will explain when and why chemotherapy might be the preferred option at any stage. Here's an overview:

Before surgery

To shrink the tumour

After surgery

To prevent cancer from coming back.

As the main treatment

If the bowel cancer has spread to other parts of the body, such as the lungs or liver.

In combination with radiation therapy

If you have rectal cancer.

How is chemotherapy given?

If your healthcare team thinks you would benefit from chemotherapy, they will talk to you about the drugs and the ways they are given.

Oral chemotherapy

Capsules which can be taken at home every day.

Intravenous (IV) infusion

The treatment is given directly into a vein. It might be a small injection over a few minutes, a short infusion of up to 30 minutes, or longer infusions over a couple of hours or even a couple of days.

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

Intravenous (IV) cannula

A small tube is inserted into a vein in the back of your hand or your arm.

Central line

A thin, flexible tube is inserted through the skin of the chest into a vein near the heart, which can stay in place for many months.

PICC line

A thin, flexible tube is passed into a vein in the bend or upper part of your arm and threaded through the vein until the end of the tube lies in a vein near the heart. PICC lines can stay in place for months.

Portacath

A thin, soft plastic tube is put into a vein. It has an opening just under the skin on your chest or arm.

Chemotherapy drugs used in New Zealand

Here is an overview of the fully funded chemotherapy drugs used for bowel cancer in this country.

FOLFOX regimen

Named after the initials of the drugs used for treatment:

- FOL folinic acid (leucovorin, calcium folinate or FA)
- F fluorouracil (5FU)
- OX oxaliplatin.

Given intravenously (IV).

CAPOX or XELOX regimen

Different names for the same combination of chemotherapy drugs. They are named after the initials of the drugs used for treatment:

- CAP or XEL capecitabine (Xeloda®)
- OX oxaliplatin

Given as a combination of IV and tablet.

FOLFIRI regimen

The name of a chemotherapy combination that includes:

- FOL- folinic acid (leucovorin, calcium folinate or FA)
- F- fluorouracil (5FU)
- IRI (irinotecan)

Given IV.

FOLFOXIRI regimen

A combination of previously mentioned folinic acid, 5FU, oxaliplatin and irinotecan.

Given IV.

5 FU alone

Given weekly in a four-weekly cycle x 7.

Given IV.

Capecitabine alone

Given daily via tablet for two weeks, followed by a one-week break.

Either 5FU alone or Capecitabine alone is usually given to those patients intolerant of multidrug regimens. This is to destroy any microscopic cancer cells that may remain after surgery (adjuvant treatment) or to reduce the burden of Stage IV (4) disease. It can also be given as maintenance (ongoing) treatment after initial treatment with a multidrug regimen for metastatic cancers.

More information

The oncology doctor, nurse, or other members of your healthcare team will be able to give you more details about the chemotherapy drugs they recommend for your treatment.

For more information on the types of chemotherapy that may be recommended, see the Glossary on page 46.

Immune and targeted therapies

A targeted therapy is a drug aimed at a particular gene or protein change in a cancer. An immune therapy (also known as immunotherapy) is designed to prime the immune system to recognise or kill cancer cells. They include Avastin (Bevacizumab) and Erbitux (Cetuximab) as targeted drugs and Keytruda (Pembrolizumab) as immunotherapy.

These therapies can help treat metastatic bowel cancer and can be used alone or with standard chemotherapy. They are currently not funded in New Zealand, and prices vary, with some pharmaceutical companies having cost-capped drug payment plans. However, as they need to be administered in a private clinic setting, there are additional administration fees.

To learn more about unfunded drugs and clinical trials, please visit our website at bowelcancernz.org.nz > About bowel cancer > Treatment options > Unfunded drugs and clinical trials.

What about side effects?

Chemotherapy drugs are powerful anti-cancer drugs, which means they may have side effects. Everybody reacts differently, too. The good news is that most side effects can be controlled with medicine.

Side effects may include:

- Fatique
- Diarrhoea
- Nausea and vomiting
- Sore mouth or throat
- Numbness or tingling in hands and feet
- Reduced blood cells which may cause anaemia, bruising, bleeding or an increased chance of infections
- Uncommon effects on the heart such as heart failure or a heart attack

Be sure to talk about them with your healthcare team – they will do their best to help you prevent or minimise them.

You can help combat some of the effects of chemotherapy by maintaining a good diet and adding in some gentle regular exercise. A great resource called 'Eating Well during bowel cancer' is available on bowelcancernz.org.nz > Support > Resources

You might like to make a note of any side effects you experience on the next page.

My notes & side effects

Recovery after chemotherapy

You will learn how your body responds to the anti-cancer drugs you are given. For example, you may have low energy levels after each course.

Your healthcare team may give you medicines to combat any side effects of chemotherapy, such as diarrhoea or nausea. Take any meds that are prescribed. If you find they don't work for you, then tell your oncologist, as there may be other options you can try.

Some people keep a diary to record the after-effects of each chemo course. A written record can be useful when discussing things with your oncologist and the other medical professionals involved.

Go easy on yourself, but don't hide away. Try doing some gentle exercise, such as going outside into the fresh air for a walk.

Check out the tips on page 37 for looking after yourself and restoring your health.

Radiation therapy

Radiation therapy is the use of controlled, high-energy radiation to destroy cancer cells. It is mainly used in rectal or anal cancers, but some specialised radiation techniques may be used to treat cancers in the colon.

The treatment does not make you radioactive, so it's safe to be with others while you're being treated.

Side effects

It's hard to predict what side effects the radiation may cause. Some people can tolerate the treatment very well and carry on working. Others may need hospital care. Your healthcare team will monitor your treatment closely and be on hand to help you cope with any side effects.

Short-term side effects may include:

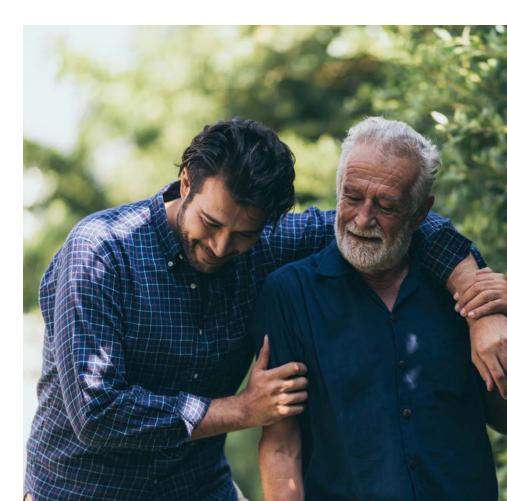
- Tiredness.
- Bowel irritation you may have discomfort, cramps and a change in bowel habits.
- Skin redness.
- Temporary loss of hair in the pelvic region (not head).

Long-term side effects may include:

- Weakened bones in the pelvis or hips, increasing the risk of fractures.
- There could be issues with erectile dysfunction, as the nerves that maintain an erection can be damaged.
- Female infertility or early menopause.

Please discuss any concerns with your healthcare team before starting radiation therapy.

For more information on the types of radiation therapy that may be recommended, see the glossary on page 46.





A word about clinical trials

Because bowel cancer is a common condition, many organisations and researchers are constantly looking for better ways to treat it. These trials are carefully monitored, and every patient who takes part must give their consent.

Cancer Trials New Zealand and clinical trial units in public hospitals run frequent trials to investigate new ways of preventing, diagnosing, treating and monitoring cancer. Some trials may involve new medicines that researchers hope will work better or have fewer side effects than current options.

If you agree to take part in a clinical trial, you will be helping advance research that can benefit others in the future.

Please speak to your medical team if you are interested in being considered for any clinical trials.



Looking after yourself

Being diagnosed with bowel cancer is a life-changing event.

Your healthcare team are professionals with skills who can help you through this time. But only you know what it's really like. That's why it's vital to focus on the things that help you cope with the changes and challenges.

We asked people in our support groups what they found useful when they were diagnosed with bowel cancer.

"Listen to your body."

When your body tells you to rest, take a break. Go easy on yourself.

"Get outside into the fresh air."

A lot of people find that walking in nature is great for mental health.

"Eat what your body needs - and also what it wants."

A healthy diet is important, but you can also enjoy some treats.

"Reach out to friends, family and the medical professionals vou've come to know."

A few friendly words or just spending time with people you like, can be a great way to lift your mood. And, of course, you should always share any symptoms or changes to your normal condition with the medical team supporting you.

"Try mindful meditation."

Many people find that meditation or prayer – or simply sitting quietly – is a calming practice. You could try using some apps downloaded to your phone. Search for 'Calm', 'Headspace' or '5 Minute Journal.'

"Learn something new online."

Explore a topic or learn a new skill. There are many resources online.

"Treat yourself to a massage or bubble bath."

It's a nice way to relax and enjoy being pampered for a while.

"Keep a diary or journal."

The habit of writing down thoughts and experiences gets them out of your head and can help put things into perspective. A journal is also great for notes on any side effects after treatment, including your mood and any emotions you're feeling. Just jot down anything which is 'out of the ordinary' for you.

"Join our groups on Facebook."

Bowel cancer patients in New Zealand have their own private Facebook groups, with friendly support from people who understand what you're going through.

Learn more at bowelcancernz.org.nz > Support > Finding Support

On page 44, there's a list of the organisations and groups that support bowel cancer patients in New Zealand.

My notes & self-care

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After treatment

Once your treatment is complete, the focus shifts to recovery and restoring your general health. It's a gradual process, but your healthcare team are on hand to support you.

Coping with the change from being a patient

Strange as it might sound, you may have mixed emotions after your treatment finishes.

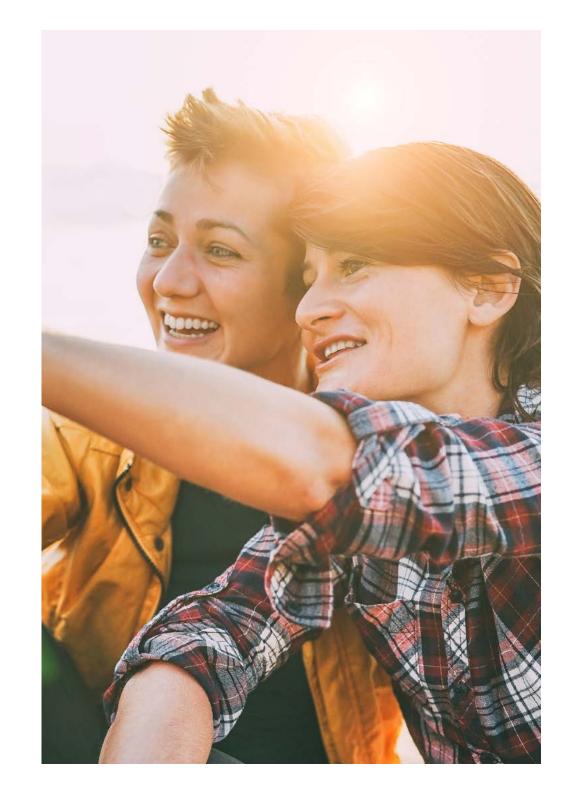
On the one hand, you have been through a lot, and you're ready to put it all behind you. On the other hand, you've been used to attending appointments and seeing a lot of your medical team. Now it may feel as if you're on your own.

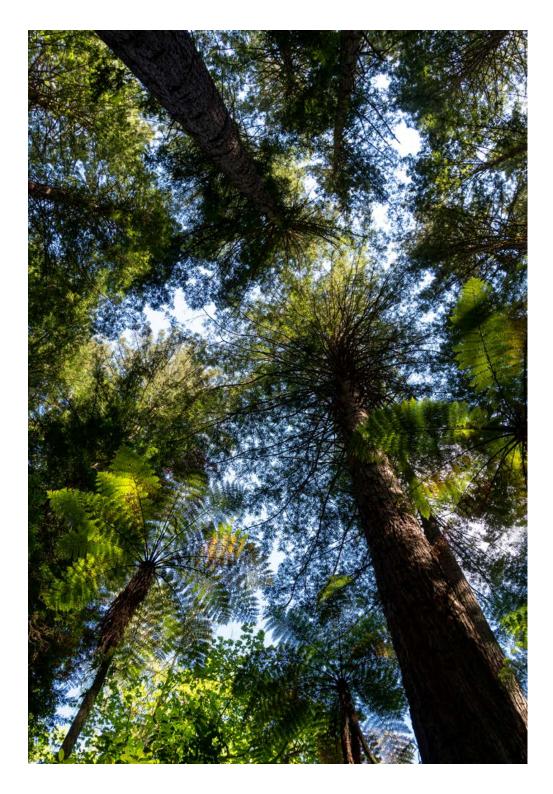
Many people find it takes a while to adjust. It's not about 'getting back to normal' but instead finding out what is a 'new normal' for you. Don't be surprised if it takes you anything from a few months to a year or more of physical and emotional adjustment.

Don't be hard on yourself, or try to do too much, too soon.

You may also find it helpful to download or order the Living beyond bowel cancer booklet from our website.

<u>bowelcancernz.org.nz</u> > Support > Resources





Palliative care

Palliative care is not the end; it is a change of focus.

The goal is to provide quality of life, control pain and manage symptoms to enable people to live every moment in whatever way is important to them. While physical needs like managing pain and symptoms are a priority, equal importance is placed on cultural, emotional, spiritual, and social needs.

Palliative care becomes an option when:

- As the patient, you decide you would rather manage the symptoms of your cancer than go through active treatment, so you can make the best of the time you have remaining.
- The medical team advise, following investigations, that the disease is too far advanced for you to benefit from active treatment to achieve a cure.

Palliative treatments may include medication, dietary changes, relaxation techniques, emotional support and other therapies. Other medical treatments such as palliative chemotherapy or radiation may also be used. You will still be regularly monitored, and new symptoms will be investigated and treated. The team works closely with you and your family to support your wishes

The terms palliative, terminal or 'lifelimiting' mean those conditions that cannot be cured and will at some point result in the person dying, even if that's years, months, weeks or days away. For instance, cancers that cannot be cured may still be responsive to drugs or radiation.

Palliative care can be helpful at all stages of life-limiting illness. It is often best introduced early on – sometimes even at the point of diagnosis. It can be beneficial even when someone has intensive treatments, for instance, chemotherapy for cancer.

In other words, palliative care is there to provide support, help and comfort to patients and families in those times when illness can be causing major problems or distress. It should also be available wherever the person with life-limiting illness may be – home, hospital (public or private), or rest home.

More help and resources

Bowel Cancer NZ nurse

Got a question? Call 0800 BCNZ NURSE (0800 226 968) or email here4you@bowelcancernz.org.nz

Online Support Groups

Join one of Bowel Cancer NZ's Facebook support groups for patients and their whānau. They're private, with a welcoming online community where you can share stories, ask questions, and, importantly, give and receive support.

Learn more at bowelcancernz.org.nz > Support > Finding Support

Bottoms Up

Bowel Cancer NZ runs virtual 'coffee groups' you can join through our online support groups or by emailing here4you@bowelcancernz.org.nz

Free Support Services



Physiotherapy

Physiotherapy helps with prehab and rehab for patients prior to or recovering from treatment and surgery. So, we fund up to three **free physio sessions** for patients.



Counselling

Need to talk? We understand the emotional toll bowel cancer can take on you and your whānau – that's why we offer three **free counselling sessions** for you and your loved ones.



Financial Assistance

For patients undergoing treatment and struggling to make ends meet. A one-off voucher for groceries or petrol is available.

To apply for the above services and for more information, please visit bowelcancernz.org.nz > Support > Free Services

Websites

Bowel Cancer New Zealand

<u>bowelcancernz.org.nz</u>

The NZ Familial Gastrointestinal Cancer Service

nzfgcs.co.nz

Cancer Society NZ

cancernz.org.nz

Colorectal Surgical Society of Australia and New Zealand

cssanz.org

Cancer Council Australia

cancer.org.au

Cancer Research UK

<u>cancerresearchuk.orc</u>

Macmillan Cancer Support UK

macmillan.org.uk

National Cancer Institute (USA)

cancer.gov/cancerinfo

(Bowel Cancer New Zealand only maintains the bowelcancernz.org.nz website. We have suggested sites we believe offer credible and reliable information but cannot guarantee that such websites have correct, up-to-date or evidence-based medical information.)

Glossary

Medical terms

Some of the specialist words and terminology you may come across when you're dealing with bowel cancer.

Chemotherapy treatments

Neo-adjuvant. To shrink the tumour(s) before surgery to get a better outcome following the operation.

Adjuvant. To destroy any microscopic cancer cells that may remain after the cancer is removed by surgery and to reduce the possibility of the cancer returning.

First-line. Chemotherapy that has been shown, through extensive clinical trials and research, to be the best option for the type of cancer being treated.

Second-line. Alternative chemotherapy treatment for disease which has not responded to first-line chemotherapy or has recurred.

Third-line. Chemotherapy given when both initial treatment (first-line therapy) and subsequent treatment (second-line therapy) don't work or stop working.

Palliative. To relieve symptoms and slow the spread of the cancer if a cure is not possible.

Radiation therapy treatments

Neo-adjuvant. To shrink the tumour(s) before surgery to get a better outcome following the operation.

Adjuvant. To destroy any microscopic cancer cells that may remain after the cancer is removed by surgery and to reduce the possibility of the cancer returning.

Palliative. Giving lower doses of radiation over a shorter period of time, or when surgery is not an option, to relieve symptoms or slow the spread of cancer.

External radiotherapy. Delivered by a machine outside of the body. Usually given as a course of several treatments over days or weeks.

Internal radiotherapy. Also known as brachytherapy or contact radiography. It involves positioning radioactive sources near to or inside the tumour itself.

Intensity modulated radiotherapy (IMRT). Where both the radiation beam and the dose are shaped to match the tumour's shape and thickness.

Other medical terms

Abnormal. In medicine, an abnormal lesion or growth may be benign (not cancer), precancerous or premalignant (likely to become cancer), or malignant (cancer).

Adenocarcinoma. A cancer that starts in the mucus-producing cells in the lining of the internal organs. Most cancers of the breast, pancreas, lung, prostate and bowel are adenocarcinomas.

Adhesions. Scar-like tissue may form between two surfaces in your body, causing them to stick together. They can be caused by surgery, radiation or a tumour spreading into nearby tissue.

Analgesia. Pain relief.

Anastomosis. Surgery to connect healthy sections of tubular structures, such as the bowel, after the diseased portion has been surgically removed.

Antiemetic. A drug that helps to control nausea and vomiting.

Benign. A tumour that is not cancerous. It does not usually invade nearby tissue or spread to other parts of the body.

Bowel obstruction. When the bowel is blocked, and waste cannot pass through easily.

Cannula. A small tube inserted into a vein in the back of your hand or your arm.

Carcinoma. Cancer that starts in the skin or tissues that line the inside or cover the outside of internal organs.

Colostomy. An opening from the colon to the outside of the body. A colostomy provides a new path for waste to leave the body after part of the colon has been removed.

Complementary therapy/medicines. Treatments that are used along with standard treatments but are not considered standard. Examples include acupuncture, dietary supplements, massage therapy, hypnosis, and meditation. For example, acupuncture may be used

with certain drugs to help lessen

cancer pain or nausea.

Constipation. When bowel movements become difficult because the faeces are hard and dry. Bowel movements may be painful, and you may feel sluggish, bloated and uncomfortable.

Diarrhoea. Frequent and watery bowel movements. The opposite of constipation.

Enema. Liquid is introduced into your bowel through the anus.

Faeces. The solid waste you pass from your bowel. Also called stool or poo.

Ileostomy. An opening from a part of the small intestine (called the ileum) to the outside of the body (known as a stoma).

Immunotherapy. Cancer treatment designed to boost the body's natural defences to fight the cancer.

In situ. Cancer that has not spread to nearby tissue. Also called non-invasive cancer.

Informed consent. When patients are given important information, including possible risks and benefits, about a medical procedure or treatment, test or clinical trial. This is to help them decide if they want to be treated, tested, or take part in the trial.

IV. Short for 'intravenous.' Any drug or other substance given via your veins is said to be given intravenously.

Laxatives. A substance to get your bowel moving.

Malignant. Cancerous. Malignant cells can invade nearby tissue and spread to other parts of the body.

Mass. A lump that may be caused by the abnormal growth of cells, a cyst, hormonal changes, or an immune reaction.

Metastatic/metastasis. Refers to cancer that spreads from the place where it began to another part of the body. Cancer cells can break away from the primary tumour and travel through the blood or lymphatic system to the lymph nodes, bones and organs.

Micrometastasis. Cancer cells that have spread from the primary site to secondary sites and can only be seen under a microscope. **Nausea.** Feeling sick, wanting to vomit.

NED. 'No Evidence of Disease.' Another word for remission.

Ostomy. An operation to create an opening (stoma) from inside of the body to the outside. Colostomy and ileostomy are types of ostomies.

Pre-cancerous. Refers to cells that have the potential to become cancerous - also called premalignant.

Primary cancer. The original cancer.

Prognosis. Chance of recovery. A prediction of the outcome of a disease based on what's typically seen in other cases.

Recurrence. When cancer comes back after a period when it could not be detected. It may come back to the original cancer site or appear in another part of the body.

Remission. When the signs and symptoms of cancer disappear, but not necessarily the entire disease. The disappearance can be temporary or permanent.

Secondary cancer. This can be either a new primary cancer (a different type of cancer) that develops after treatment for the first type of cancer or cancer that has spread to other parts of the body from where it started (see metastasis).

Stoma. A surgically created hole in your abdomen. A piece of the bowel is brought through a small incision in the abdominal wall onto the skin surface. It is then turned back on itself like the cuff of a sleeve and stitched. Stomas can vary in size and location.

Targeted therapy. Treatment that targets specific genes, proteins or other molecules that contribute to cancer growth and survival.

Tumour. A mass formed when normal cells in your body start to change and grow uncontrollably. A tumour can be benign (noncancerous) or malignant (cancerous). Also called a nodule or mass.

Tumour markers. Substances found in tissue, blood, bone marrow, or other body fluids that may be a sign of cancer or certain benign (noncancer) conditions.

Bowel Cancer NZ is the leading bowel cancer charity in Aotearoa, New Zealand.

We're a nationwide, patient-focused charity dedicated to reducing the impact of bowel cancer in our communities through awareness, education, advocacy, research and support. Our goal is to lead the world with solutions to reduce New Zealand's bowel cancer statistics and free future generations from the impact of bowel cancer.

To find out more, donate, support or volunteer, see our website: bowelcancernz.org.nz







Reducing the impact of Bowel Cancer on our community

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