


Living beyond bowel cancer



Bowel Cancer
NEW ZEALAND

bowelcancernz.org.nz



The Koru is an integral symbol in Māori art. It symbolises new life, growth, strength and peace.

Now that treatment is over...

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Now that treatment is over...

The end of cancer treatment can bring relief and a readiness to put the experience behind you and yet there may be an undercurrent of worry and uncertainty about the future. It is normal to feel concerned.

One of the hardest things after treatment is not knowing what happens next and we hope this booklet will be a helpful companion as you begin to navigate the new terrain that is 'life after bowel cancer'.

Your feelings and responses to all that has happened, and what may occur in the future, can have a significant effect on you, and the transition back into the day to day can be challenging. You might want to live a healthier lifestyle, wondering what changes you should make, when to make them, and how.

It may feel like a safety net has been taken away when treatment finishes. You've been used to attending appointments, receiving support and information from your medical team, and now you may feel like you're on your own. It can take a while to adjust and you may find that life, as you knew it, is different.

Those who have gone through cancer treatment often describe the first few months as a time of change. It's not so much about 'getting back to normal' but finding out what is a 'new normal' for you. There is both physical and emotional healing to be done and there will be questions as you settle into your recovery.

Life can take on a new meaning and you may look at things in a different way. An experience of cancer can bring about an opportunity for personal change, family and whānau strengthening, spiritual growth, and a deeper appreciation of life. Some people choose to follow a new path or simply treasure the beauty to be found in each day. Many have learned to take better care of themselves and value those who care for, and about them, far more.

Follow up care

Knowing what to expect after treatment ends can help you make informed decisions about your ongoing health and wellbeing. Information can make you feel better and more confident because your questions are answered and your concerns attended to.

When hospital treatment is finished, your follow up care plan may be managed by your GP unless you are having ongoing treatment from your surgeon or oncologist.

The plan will ensure you receive hospital services at key points during your recovery, and, if necessary, timely medical intervention if problems occur between appointments.

A recurrence of bowel cancer (also referred to as colorectal cancer) is most common within the first few years after treatment and so your follow up visits will be more frequent during this time. If you have been diagnosed with metastatic (also known as 'secondary' or 'advanced') bowel cancer, or are having ongoing treatment, then you will have more appointments with your healthcare professionals.

After treatment ends, you'll receive a follow up care plan. A sample treatment summary and follow up plan is on page 42.

The plan will recommend a follow up visit with your medical team 4-6 weeks post treatment, 2-3 annual checks for three years, and then annual checkups thereafter.



You may find the following surveillance guidelines helpful too¹:

Surveillance: personal history of colorectal cancer

This content on surveillance for people who have undergone previous colorectal cancer resection is drawn from the guideline Management of Early Colorectal Cancer available at nzgg.org.nz

Follow-up after colorectal cancer resection: when to review

All people who have undergone colorectal cancer resection

- Should undergo clinical assessment if they develop relevant symptoms
- Should receive intensive follow-up. Follow-up should be under the direction of the multidisciplinary team and may involve follow-up in primary care.

People with colon cancer

- High risk of recurrence (Stages IIb and III): clinical assessment at least every 6 months from first 3 years after initial surgery, then annually for 2 further years.
- Lower risk of recurrence (Stages I and IIa) or comorbidities restricting future surgery: annual review for 5 years after initial surgery.

People with rectal cancer

- Review at 3 months, 6 months, 1 year and 2 years after initial surgery, then annually for a further 3 years.

Follow-up: specific components

People with colon cancer Stages I to III

Colonoscopy before surgery or within 12 months following initial surgery.

Follow-up should include:

- physical examination and CEA
- liver imaging at least once between years 1 and 3
- colonoscopy every 3 to 5 years

People with rectal cancer Stages I to III

Colonoscopy before surgery or within 12 months following initial surgery

Follow-up should include:

- physical examination and CEA
- liver imaging at least once between years 1 and 3
- digital rectal examination and sigmoidoscopy at 3 months, 6 months, 1 year and 2 years after initial surgery
- colonoscopy thereafter at 3 to 5-yearly intervals

¹Surveillance for people at increased risk of colorectal cancer: A primary care practitioner resource: January 2012. New Zealand Guidelines Group: Ministry of Health 2012

Make sure you have all the contact details for the people overseeing your follow up care. They will be responsible for coordinating your appointments, arranging tests if needed, and providing access to your medical team if necessary.

If you are not receiving the appropriate follow up care as planned, contact your GP or usual health provider for advice.

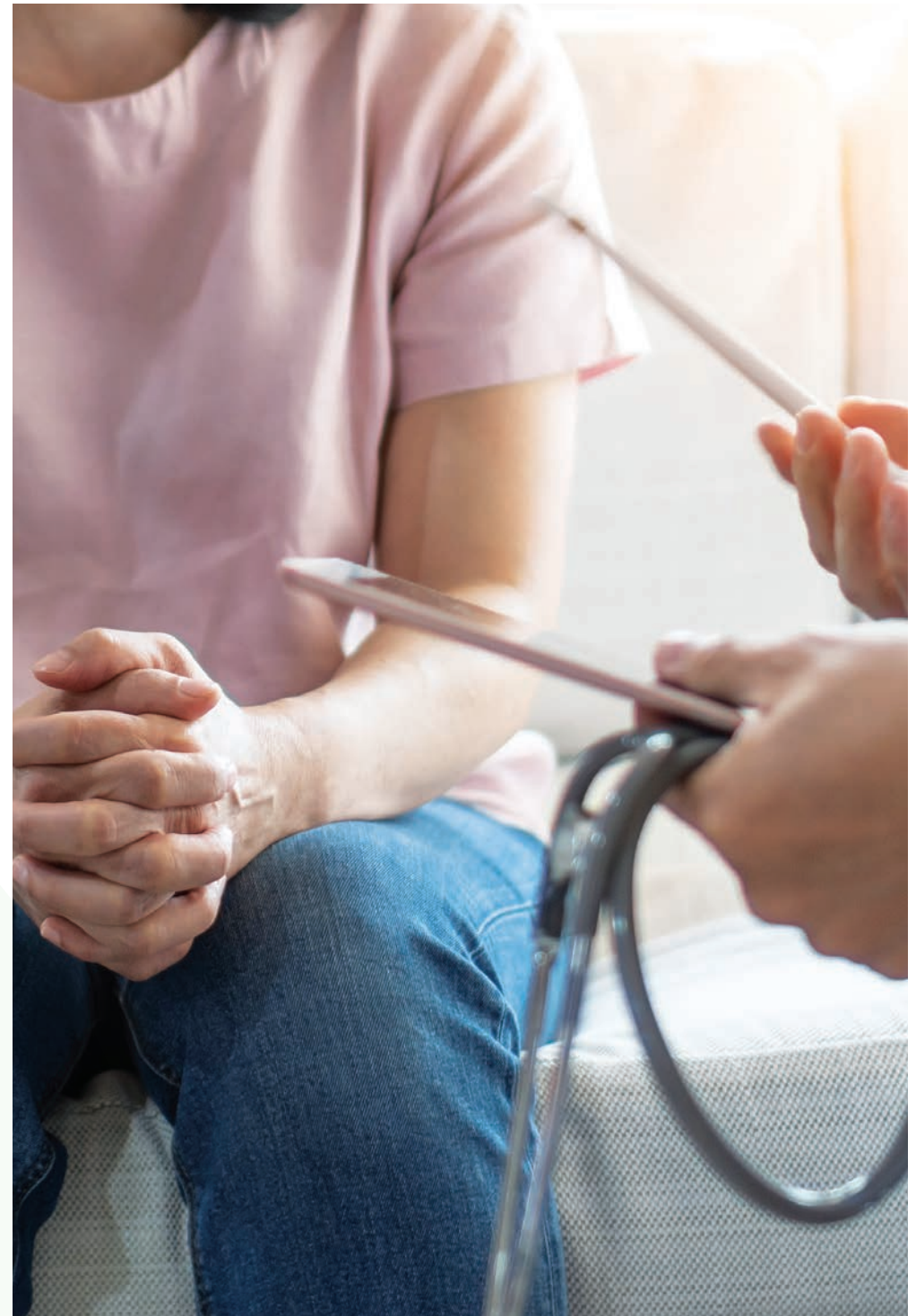
As a consumer of health services, whether you are paying for them or not, you are entitled by law to receive care and support from registered health professionals, and you have clearly defined rights (as per the Code of Health and Disability Services Consumers' Rights). If you feel you have been treated unfairly, you may make a complaint to the Health and Disability Commissioner and you can access free support from the Health and Disability Advocacy Service. More information about this service is on page 41.



**Do attend your follow up visits.
They are an important part
of your recovery.**



**Your mind and spirit may need
healing too so don't be afraid
to ask for help.**





What happens at a follow up consultation?

Your follow up appointments provide an opportunity for you to discuss your treatment and care with your healthcare team. You can talk about your concerns, review progress, and mention any symptoms that worry you.

Be open, honest, and actively seek information. This approach works well for you, your doctor, and other members of your healthcare team.

Here are some tips to help you make the most of the time with your team:

- Before your appointment, write down a list of symptoms, concerns, and any side effects or problems you are experiencing.
- Take along your own personal treatment record (see page 42) to refer to.
- Bring someone with you who can take notes and debrief with you afterwards.
- Ask for explanations to be made in terminology you can understand. Repeat back in your own words what you think the doctor meant, and keep asking questions until you understand what is being said.
- Be honest. Tell your doctor how you're feeling, physically and emotionally.
- Discuss any changes you've noticed in your body (e.g. pain, discomfort, new symptoms). Ask for solutions or plans of action.
- Ask for referrals to other service providers e.g. dieticians, exercise programmes for cancer recovery, and counseling.
- Sometimes people make dietary changes or include other health practices such as acupuncture, reiki, and tai chi in their recovery from bowel cancer. Mention any nutritional supplements you are taking (vitamins, herbal remedies, and dietary changes) or complementary health practices to your health care team so they have a full picture of your health.
- Give a summary of your overall health at the time: sleep and diet quality, energy level, emotional/mental state, mobility, bowel habits, your relationships, intimacy with your partner, and ability to cope day to day.
- If you need more time, ask for it. If that's not possible at the consultation, ask for another appointment to be made.

Keeping your own treatment record

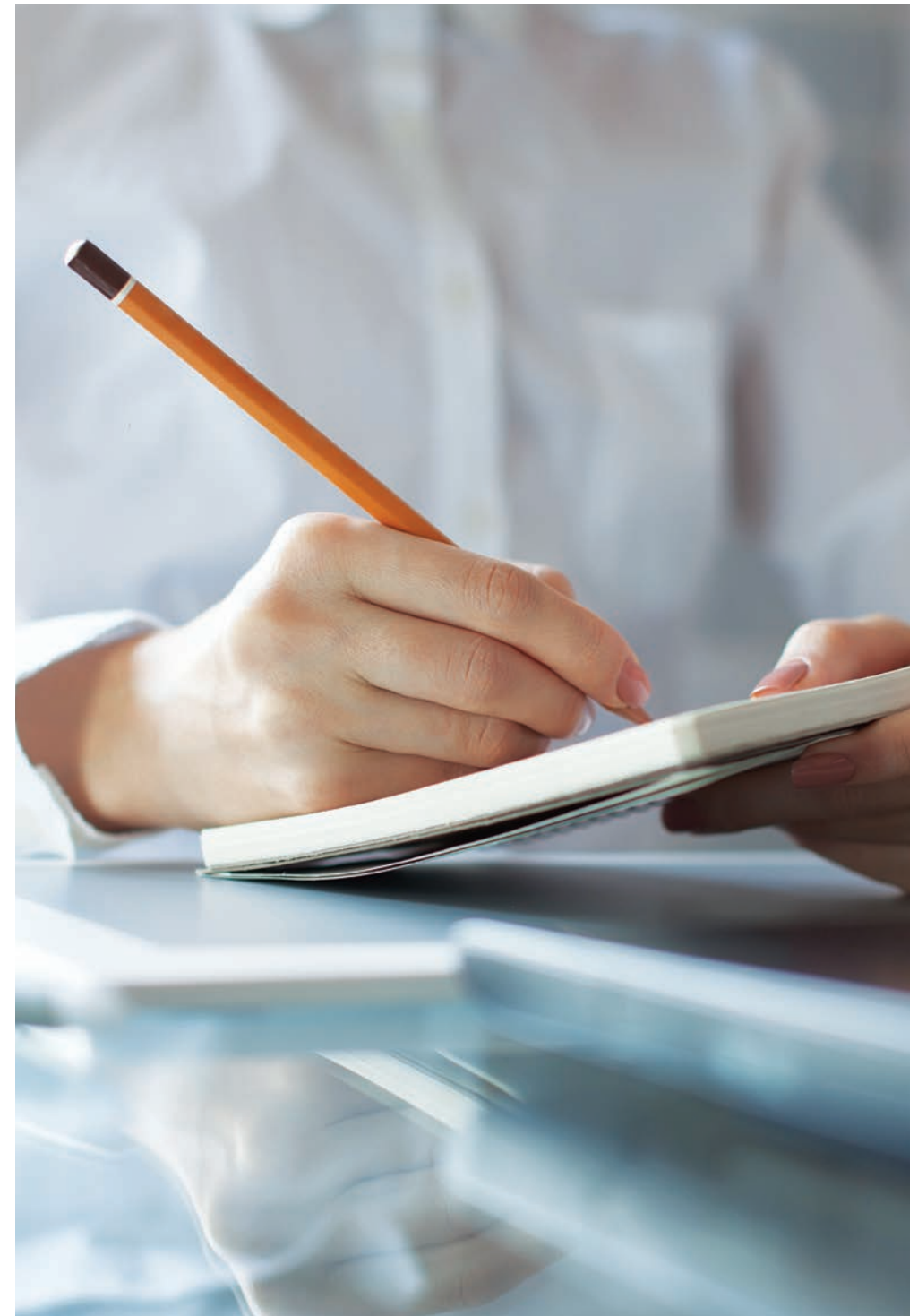
It's really helpful to have a written summary of your treatment so you can share this with other health care professionals you see. You can keep the information all in one place, perhaps in a notebook or binder, so it's easy to access during a consultation. There's a sample Treatment Record on page 42 that may be helpful.

A treatment record should include key facts and information:

- Date of diagnosis.
- Pathology report of your cancer.
- Dates of surgery or other treatment, and locations of health care providers (e.g. hospital or clinic).
- Sites and amounts of radiation therapy.
- Names and doses of chemotherapy and other drugs.
- Key lab reports, X-ray reports, CT and MRI scans.
- Any recommendations from your oncologist or other members of the health care team for enhancing your health and wellbeing.

You may also wish to include these in your records:

- List of things to watch out for (e.g. side effects of treatment or physical symptoms).
- Contact details for all members of the health care team involved in your treatment and follow up care.
- A record of any problems you experienced during or after treatment.
- Information about any supportive care you may have received (e.g. nutritional supplements, counseling, special medications).





Practical

Exercise and staying active

Keeping active and exercising regularly can help you recover health and mobility after treatment is finished. Even a 30-minute walk each day can boost energy levels and help you feel better.

It is thought that regular exercise, and keeping your weight within a healthy range, can reduce the risk of disease recurrence.

You may have been given specific exercises to strengthen your pelvic floor muscles and those in your abdomen and lower back. These exercises will help you regain bowel control and increase strength and stamina.

Keep in mind the advice you've received about more strenuous activities, such as driving and heavy lifting. The strain can have an adverse effect on healing muscles and skin so introduce these activities gradually. Housework can be more physical than you think, so take it easy!

There are exercise programmes specifically designed for recovery from cancer. Many of these are available locally, so check with your GP or health professional to see what is accessible for you. Programmes like this provide an opportunity not only to feel better but also to meet other people sharing a similar experience.



Plan ahead when out walking or exercising. Know where the toilets are and take along some spare clothing just in case.



Eating for recovery

A well-balanced diet with an emphasis on plenty of fresh fruit and vegetables, whole grains, good protein and essential oils is important for all of us and even more so in a recovery from cancer. Good nutrition and exercise enhance healing and build a solid foundation for a return to health.

A low-fibre or 'soft' diet may be recommended for a period of time, particularly if you have a stoma. Nuts, seeds and fibrous foods can cause a blockage in the stoma, and the level of stoma output will vary depending on how much you eat and when. Sometimes there is a bit of trial and error at the start as you identify foods that irritate the stoma. There can be considerable variation: a food that bothers one person may be fine for another.

Your medical team may suggest avoiding some foods during recovery because they can cause discomfort or diarrhoea. Experiment with different foods to determine those that cause problems for you. Try limiting intake of these foods rather than eliminate them altogether, as you may find that you can tolerate them as time goes on. Keeping a food and symptom diary can help.

The post treatment goal, even for those with a stoma, is to return to a healthy, balanced diet.

Even for special or prescribed diets, the following tips may be helpful:

- Avoid alcohol and carbonated drinks. They can irritate the bowel lining causing cramps, bloating, and diarrhoea.
- Drink water every day to stay hydrated, prevent constipation and to keep stools soft.
- Eat regularly. Smaller, lighter meals and snacks throughout the day may suit you better than three larger meals. This plan can be helpful if you are experiencing irregular bowel patterns or poor appetite.
- A short walk before mealtimes can help you feel hungry.
- Minimise intake of caffeinated drinks such as tea and coffee. They can increase bowel activity.
- If you have dietary concerns, ask for a referral to a dietician.

Changing your lifestyle

Lifestyle choices have an impact on our health and wellbeing and there are proven links between lifestyle and some diseases and illnesses.

After a diagnosis of cancer, you may want to do as much as you can to reduce your chance of recurrence and improve overall health. Many people make significant lifestyle choices to reduce their personal risk.

Here are some you may wish to try:

- Current research tells us that alcohol increases the risk of several cancers including bowel. Limit consumption or give up alcohol altogether.
- Giving up smoking can have significant health benefits and lower your risk of cancer returning.
- Combine at least 3 hours of exercise per week (minimum) with a healthy diet.
- Try some alternative practices such as meditation, reiki, and yoga, or relaxation techniques and exercise programmes designed for cancer recovery. Some people find that these activities can help reduce symptoms caused by stress and anxiety, and improve sleep.
- Add more fresh fruits and vegetables to your diet. Reduce your intake of refined and processed foods particularly those with a high salt, sugar, preservative, or fat content.
- Strong evidence supports a link between red meat consumption and bowel cancer. Eat less than 500gms of red meat (cooked weight) per week. Research points to processed meats such as salami, bacon, and ham increasing the risk of bowel cancer too. Avoid these if possible.
- Small portions of high quality protein every day can help with healing and repair, for example, small amounts of fish, chicken, or tofu for vegetarians.
- 'Follow your bliss'. If there is something you've always wanted to do, then make it happen. You'll feel great satisfaction with the accomplishment, and enrich your life at the same time.



Have fun with food. Try something different and experiment.

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Returning to work

Work gives us purpose and structure, and can provide a supportive platform in a return to life after treatment. The lingering effects of treatment may affect your ability to work so making practical, consultative decisions with your employer can facilitate a manageable return for you and for them.

A conversation with your employer may have already started at diagnosis so they are aware of your situation and will be supportive. Whether you worked through treatment, or stopped and are now ready to return, maintaining that dialogue with your employer will be helpful.

Here are some tips:

- Review your employment contract and make a long-term plan with your manager/employer in support of a return to work. This should include regular check-ins to monitor progress and to make reasonable adjustments as needed. Your contract will list your entitlements to sick leave, long-term leave without pay, and other company benefits.
- Keep a record of the discussions you have with your employer/manager, noting key points and decisions made.
- If you are unsure about working full time, ask if your job can be made part time for an agreed period or permanently.
- See if you can take on lighter duties or work reduced hours temporarily.
- Develop a flexible working schedule that allows time off to attend follow up appointments (ask your medical team for times that have less impact on your job responsibilities) and extra breaks at work if needed.
- See if you can work from home.
- Ask for a letter from your specialist, if needed, explaining how your cancer recovery can affect your ability to work.
- Check the availability and accessibility of toilet facilities in the work place.

The New Zealand Employment Relations Act (2000) requires employers to act in good faith, to treat you in a fair and reasonable manner, and to provide reasonable adjustments to help you in the workplace.

If you are applying for a new job, you are not required to disclose medical history; however, confirming that you can fulfil the duties and responsibilities of the job is a legal requirement. If you are unsure, check with your medical team about your ability to undertake the job.

The Employment NZ website has some good information about the rights and responsibilities of both employers and employees.

Visit www.employment.govt.nz





Personal

Emotions and feelings

It's normal to have lots of feelings after treatment because cancer affects us (and our family and whānau) physically, mentally, spiritually, and emotionally.

These feelings can be heightened after finishing treatment. The routine of hospital and doctor visits gave structure and the knowledge that 'something was being done'. Now you're on your own and that can be daunting.

Family and friends are getting on with life and you're still sitting on the sidelines. There may be pressure to 'get on with things' and 'be positive' and that may not be possible right now.

Treatments can leave you feeling vulnerable, anxious, fatigued, afraid, and lonely. Your self-confidence has taken a hit and you have learned you're not bulletproof or immortal. You may feel irritable, confused and foggy-headed.

It is normal to feel all of these things.

As a cancer type, bowel cancer brings with it some unique adjustments, and treatments can change how you feel about your body. You may worry about how a partner or someone close to you will react to surgical scars or a stoma bag. A changed bowel habit can take time to get used to, and you may think twice about going out or socialising.



There is no 'right' or 'wrong' way to feel. It takes time to adjust to this new place, not only physically but emotionally and spiritually too.

Here are some helpful tips:

- Allow yourself time to adjust. Treat yourself with compassion and kindness.
- Reach out to family and friends. Most people, even those closest to you, may find it hard to know what to do or say. Bowel cancer poses challenges because it involves bodily functions that are private and people may be fearful of saying the wrong thing. Talk about what is going on for you; deepen their understanding so they can feel more comfortable around you. It may take some work on your side but it is worth it. You'll feel less alone.
- Express yourself. We tend to keep to ourselves because we don't want to 'burden' or 'upset' anyone with our problems. Don't bottle up your feelings. Let out those fluctuating emotions. Talk it out with someone you trust. Keep a journal and write down how you feel or seek professional help if you need to.
- Stay calm, embrace humour. There's nothing like a good laugh to lift your spirits.
- Be alert to depression. A degree of 'feeling down' and unhappy comes with the territory, but if you feel depressed for long periods and it is affecting your quality of life, then talk to your doctor.
- Exploring ways to reduce stress will strengthen your ability to cope and provide insights into a different way of being. Have a go at meditation or mindfulness (there are some good courses and apps available), listen to music, or try some exercise programmes designed for cancer recovery.
- The psychological recovery from cancer can take far longer than the physical. It's not always easy accepting that you're not as independent and confident as you were before cancer. Try to be patient and gentle with yourself. You'll get there.
- Cancer can bring about a spiritual crisis. If religion has provided solace in the past but you now question those beliefs, talking to someone within your church or religious practice may help.
- Cancer brings us face to face with our mortality. Talking about your concerns, fears and feelings to those who haven't had cancer can be frustrating because they 'just don't get it'. Speaking with someone who has 'been there too' can be reassuring and comforting. Join a peer support group. Online or 'in person' groups can also be good sources of information but always discuss any medical advice offered with your specialists.
- See our section on Support Services for more information.



Worry about cancer returning

After treatment ends, worry about the bowel cancer returning can be very real for some people. Even the prospect of a follow-up appointment or hospital visit can trigger anxiety, and the waiting for test results can be tough for you and your family and whānau.

It's normal to feel this way, even if your prognosis is good, because a fear of recurrence doesn't always relate to the personal risk of cancer coming back. You may not want to know your risk of recurrence or survival statistics. It's an individual choice. If you do, your specialist can give you that information based on what they know about you and your cancer.

Sometimes the fear can be so strong that daily life becomes a struggle, making it hard to move on. Some say that life has 'stalled' and they don't know how to get started again, while others are reluctant to plan too far ahead.

Over time, you will think less about cancer returning. Acknowledging your feelings and talking them out with people you trust can help you 'take charge' and enjoy life again. If you are struggling to manage your fears, your GP or specialist can refer you to the most suitable support.

Routine tests and examinations at your follow up appointments may identify problems that require investigation and/or further treatment. These tests are often the most effective way to identify signs of early stage recurrence. There are physical symptoms you can watch out for too (your medical team may have provided you with a list), including,

- ongoing abdominal pain;
- bumps or swellings under the skin over the stomach area;
- a change in normal bowel habit that persists for two weeks or more (especially if you are waking up in the night with loose stools);
- reduced appetite, weight loss or weight gain around the waist and/or stomach;
- bleeding from the bowel (or in urine);
- any unexplained shortness of breath or cough lasting more than a week;
- bleeding or discharge from your wound site, or redness/tenderness around the area.

These symptoms don't necessarily mean a cancer recurrence. They may have another cause, one that can be treated with simple medications or other treatments. The important thing is to talk with your GP or specialist if you have any concerns.



Make an appointment with your GP or specialist if you have symptoms that concern you between scheduled follow-ups. If you experience acute pain or blood loss, call 111 for an ambulance or attend an emergency department at a hospital near you.



Fatigue and poor sleep

Fatigue is one of the most common side effects of treatment and recovery. A deep fatigue can last for several months post-treatment and you may be surprised to find that rest and sleep cannot dispel that 'worn out', lethargic feeling. It's frustrating when fatigue lasts longer than you think it should.

A lack of energy can make you irritable and impatient, and even the simplest tasks seem too hard. Somedays it's a struggle to get out of bed and the thought of going out to socialise, or have some fun, is an impossible dream. An inability to concentrate, feeling 'foggy in the head', and memory loss, are also common symptoms of fatigue.

So what causes this intense fatigue?

- Side effects of treatments.
- Ongoing pain and discomfort.
- Poor nutrition, dehydration.
- Anaemia.
- Stress and anxiety.

Discuss your energy levels during the follow up visits. Your doctor may suggest some tests to help determine the cause and treatments or lifestyle changes that might help.

Here are some things you can try yourself:

- Plan your day to be most active when you feel most alert and energetic.
- Develop a manageable routine: get up and go to bed at the same time each day.
- Choose how to spend your energy: let go of things that don't matter as much as they used to.
- Save your energy by changing how you do things: for example, try sitting on a stool while you wash the dishes.
- Take short naps and rest breaks between activities.
- Ask someone to help you: cook a meal, do the shopping, run an errand, clean the house, help with the kids.
- Exercise and fresh air can feel good: take a short walk, do some gentle yoga or stretching. Try to accomplish a little more each day.
- Stay with a healthy diet and drink plenty of water or diluted juices.
- Listening to music, reading a book, meditating, and other alternative therapies can lower stress levels and reduce fatigue.
- If you can't participate in an activity the way you used to, think of a way that is manageable so you can stay involved.
- It's OK to say 'no thank you' to invitations you can't manage. Don't feel guilty. Focus your energy on the things that really matter to you.

Poor sleep

Diagnosis and treatment have a profound impact on sleeping patterns. Post treatment worries can continue the disruption for some time with periods of insomnia, or waking in the early hours of the morning, unable to go back to sleep.

Your GP or nurse can recommend strategies to help with this, or even provide short-term medications to break the sleepless cycle if these strategies are unsuccessful. If the frequency or urgency of bowel movements at night is a problem, talk to your GP about slowing down your digestion with medication.



Here are some self-help suggestions:

- Stay with a routine for going to bed and getting up.
- Try a relaxing herbal tea before bedtime. Avoid caffeinated drinks in the evening.
- Make your bedroom environment quiet, calm, and comfortable.
- Try reading in bed before sleep, or listening to a guided relaxation or meditation.
- If you wake up in the early hours, try getting up rather than waiting it out. Have a herbal tea or read a book until you feel sleepy again.

Changes in body image

Cancer and its treatments affect our bodies and may change how we feel about them afterwards.

Surgery and treatment for bowel cancer produces scars, changes in shape, and in some cases, a stoma bag can create a small bulge under clothing.

Body image concerns and associated difficulties are a common experience. Some things may be more difficult to cope with than others so give yourself time to adjust. Think about what will make it easier, ask for help from your medical team, and make plans to help you manage.

Changes in your body may make you anxious, less confident, angry, or sad. You may feel,

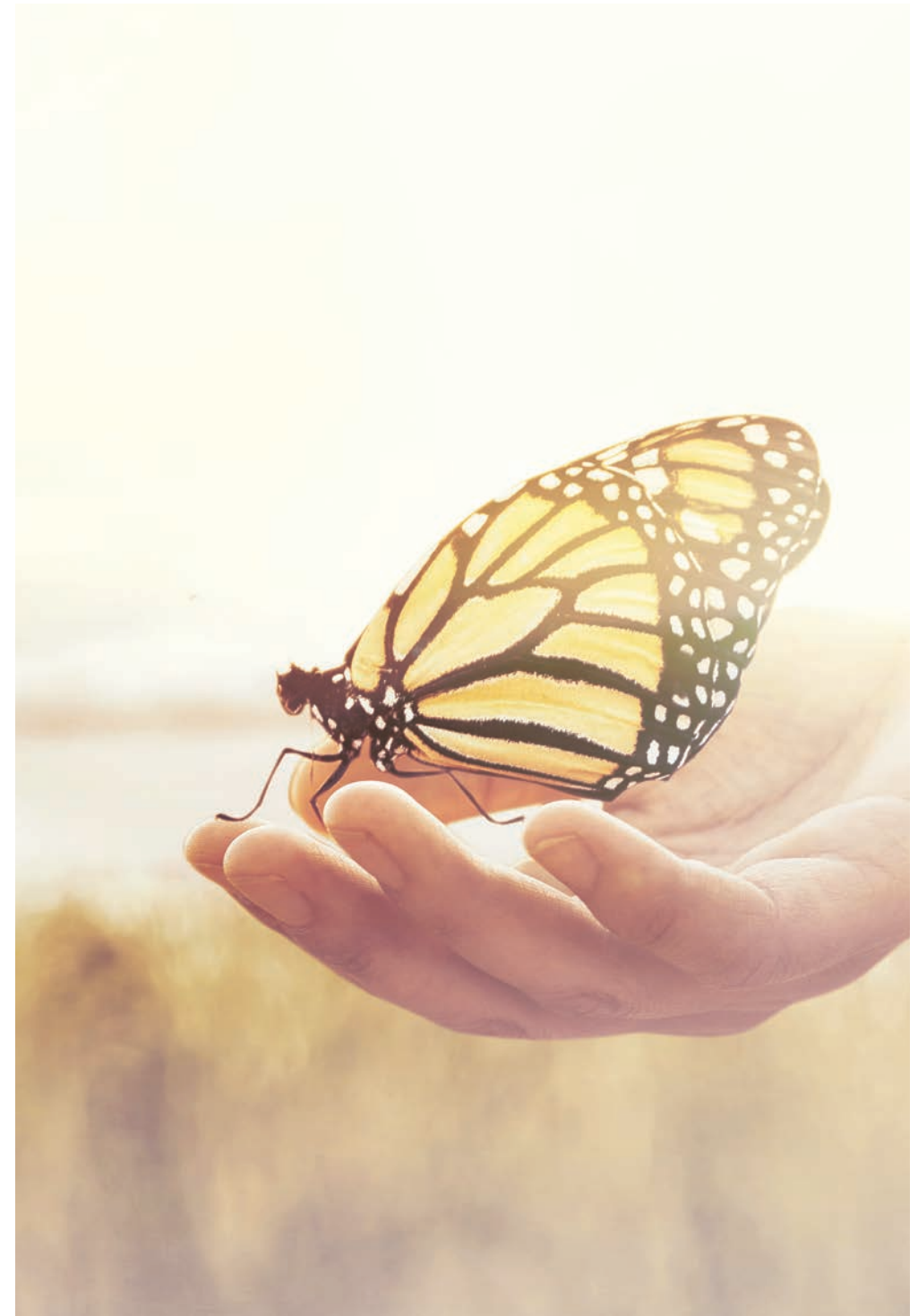
- you're not the person you used to be;
- afraid to go out, or return to work;
- anxious about your relationships;
- ashamed and embarrassed;
- unable to speak openly about how you feel.

Coming to terms with physical changes can take time.

- It's OK to grieve the change.
- Talk to your GP and medical team about the changes to your body and how they make you feel. Don't be afraid or embarrassed to say, 'I'm struggling'. You have the right to be heard, treated with respect, and to receive the help you need.
- Don't be afraid to look at 'the new you'. Look at the area covered, then uncovered, either by yourself in the mirror, or with someone you trust.
- Resume your social activities. This will help rebuild confidence. Most people notice far less than you think.
- Consider connecting with a support group or someone who has had a similar experience.
- Do things in your own time.

It may take a while before you feel like socialising again and be prepared for mixed reactions. Some people may not hide their responses but others will put you at ease very quickly.

You don't have to tell people what has happened if you don't want to.



Changes in bowel habit

It is unlikely your bowel habit will return right away to what it was before surgery. It may take some time to settle into a 'new normal' so ask for help and advice if you are struggling to manage changed habits or if you have a stoma (either permanent or temporary).

Most changes in bowel habit (constipation, diarrhoea, wind and unpredictable bowel patterns) are caused by a change in the length and shape of your colon after surgery.

- A shortened bowel allows less time for reabsorption of water from faeces as it moves through, so movements can be loose and watery for a time. This is often a temporary problem as the body adjusts.
- Changes in the shape of the bowel can also affect the bowel's ability to hold faeces at the end, particularly if the rectum has been removed or impacted by surgery or radiotherapy. Other problems (leaking of urine or soiling) can arise if nerves controlling bowel movement and the muscles of the anus and bladder have been affected by surgery. This is usually a short-term problem but if it persists, you may need professional treatment to manage it.



Unpredictable bowel motions can be upsetting and embarrassing so if you're planning an outing, it can be reassuring to know the location of both public and private toilets ahead of time.

Sex and intimacy

Cancer treatments affect you physically and emotionally and may change how you feel about sex too. Even if you've been in a relationship for a long time, staying connected can be a challenge at first.

Talking openly about your sex life after cancer helps your partner understand how you're feeling and provides an opportunity for them to share as well. Start the conversation as soon as you can because a lack of communication may turn small issues into big ones.

Sexual problems arising from cancer treatments don't always resolve easily so you may need to get help from your GP or a medical specialist. Talking about it might be awkward at first, so take this booklet with you as a starting point, or write the problems down before you go.

Some intimacy problems are common for both men and women.

- ***I feel self-conscious and stressed by the thought of being seen with no clothes on.***

This is only natural, with or without a stoma: try soft lighting or keeping some clothes on during sex, and tell your partner how you feel about your body. Think of things that will help you feel more attractive and confident. Experiment and find other ways to enjoy an intimate relationship without full intercourse.

- ***I have no energy for sex.***

Fatigue is a common side effect of treatments and will reduce over time. If you haven't the energy for the sex you used to have, you can still kiss, hug, cuddle, touch, and talk.

- ***Will I still enjoy sex as much as I used to?***

Surgery, chemotherapy and radiotherapy can affect the nerve endings and blood vessels in the pelvic area causing localised inflammation and swelling. This can change the sensations you feel. It is most often a temporary problem, settling over time. However, there may be long-term loss of sensitivity around the pelvis and genital area.

- ***Can I still have anal sex after surgery?***

There may be issues with anal sex after treatment for bowel cancer, especially if surgery has involved removal of the anus. Some sexual acts may no longer be possible and so looking for other ways to express intimacy may help.

It may be reassuring to know that almost half of all men treated for bowel cancer will experience difficulties relating to sex and intimacy.

The physical and psychological effects of diagnosis and treatment can affect your desire to initiate sexual activity and you may feel anxious over whether you can achieve pleasure for your partner and for yourself. Talking to your partner can allay fears and worries, and together you can think of other ways to be intimate without full intercourse. Be imaginative, and have fun experimenting with new ways of giving pleasure that will not put pressure on healing areas.

Bowel cancer surgery can affect your ability to achieve or keep an erection, and this is more common than you might think. Surgery can damage nerve endings and blood vessels, affecting sensitivity in the pelvic area, and while this usually improves over time, it can become a long-term problem. If you have ongoing difficulties, see your GP or medical specialist for medication and practical advice to help you manage the changes and enjoy an intimate relationship with your partner.

In addition to the loss of sensitivity in the pelvic and genital area, surgery (of the rectum in particular) can make full penetrative sex uncomfortable for women.

This may last for several weeks or even months, and lessens with time. While you are healing, you and your partner could try experimenting with different positions, or other ways that pleasure both of you without affecting your wounds or stoma, or causing you emotional stress.

Radiotherapy can cause vaginal dryness and tightening, making intercourse painful. Try gently massaging the vaginal area with a water-based cream or lubricating gel. This will help moisten the vagina and keep it supple. A vaginal dilator can help prevent the formation of bands of scar tissue and keep your vagina open after surgery. If you are concerned about some aspect of your sexual recovery, an appointment with a gynaecologist will provide some practical tips and solutions.



Beginning a new relationship

Your recovery from bowel cancer may affect how you feel about finding a new partner. When, and how, do you tell a new person about the experience and the changes in your body? If the relationship becomes sexual, will this person understand that you need to take things slowly and gently?

Trust and friendship may 'open the door' to telling someone about your cancer experience, and having an idea beforehand of how you will explain it can help the conversation. Anticipate the response you would like to receive. If you don't get it, then that person may not be the one for you.

It's natural to be worried about a new person's reaction to your body after surgery and talking honestly about this is a good approach. Your partner will not be able to support you in the right way if they don't know. It may help to show them your body changes before sexual activity so you can both get used to how this makes you feel.

Be prepared for the reaction from your new partner. They may seem upset by what they see but this doesn't mean they don't want to have a relationship with you. Remember that this is new for them too.

Sometimes a loving and caring relationship can precede a sexual one. Kissing, cuddling and holding hands may be enough. Just being together can make it easier to move on to a greater intimacy when you are ready. The more you talk about your needs, and how cancer has changed you, the easier it will be for you and your new partner.

Some people may reject you because of your cancer and treatment and this could knock your confidence. Try not to let it stop you from going on to meet someone else. New relationships don't always work out, even without cancer in the mix. You haven't failed.

Communicating with family, whānau and friends

Those close to you need time to adjust after treatment is over. Many will have taken the emotional rollercoaster ride with you and have feelings of relief, worry, and exhaustion.

Whānau, family, and friends may not fully understand what you've been through or realise that the experience has not ended for you. Outwardly, you may be looking well but inside all is turmoil as you navigate the new landscape that is cancer recovery and survivorship.

Those closest to you will have carried the greatest level of stress and they may be worried about the cancer returning too. Everyone needs time to settle after treatment, and honest and open communication can help ease the transition. Tell them how you feel, discuss your needs, and ask them to share with you.

Some people may expect you to be the person you were before bowel cancer and become disappointed or frustrated to find that you're not. They might say things like, 'But you look fine, just like your old self' and 'The cancer's gone isn't it?' It's natural for them to want you to be well but sometimes their expectations can be difficult for you to handle. Tell them that your recovery is ongoing, you need time to process all that has happened and 'getting on with it' isn't that easy.

Keep having the age appropriate discussions you had with your children throughout diagnosis and treatment. Very young children will know that something serious has happened so maintain the conversation in an open and honest way, letting them know that even though things have changed you are still there for them. You may find it helpful to access support from other charities and organisations. The Bowel Cancer NZ website has up to date listings: please visit www.bowelcancernz.org.nz

Reach out, talk, and listen. Whānau, family, and friends were part of your treatment. Let them be part of your recovery as well.



Support services

Joining a local cancer support group, a private online support group, or a cancer rehabilitation exercise programme, offers opportunities to share with others in a safe environment, to pick up information and practical tips, and to be with people who understand 'how it is'.

Support group meetings are not just for talking about cancer but also places to make connections, form friendships and have fun. The group may be non-specific for cancer type but the experiences shared are common to most people.

If a group isn't for you, try some online support. Bowel Cancer New Zealand has a popular private Facebook group where people discuss bowel cancer and their individual journeys. Sign up by searching for 'Bowel Cancer New Zealand Patient & Family Support Group' on Facebook.

Bowel Cancer New Zealand

We are a national charity for people and their families and whānau affected by bowel cancer. We are working to raise awareness of symptoms, promote early diagnosis, and encourage fair and affordable access to treatment for you. We are committed to reducing the impact of bowel cancer on our community through awareness, education, support and research.

Bowel Cancer New Zealand Inc.
PO Box 301517
Albany, Auckland 0752

www.bowelcancernz.org.nz
info@bowelcancernz.org.nz

Bowel Cancer New Zealand Patient and Family Support Group

Our Facebook group provides a forum for people to discuss bowel cancer and their journeys with others going through similar experiences, all within a supportive environment. All are welcome and the closed group allows maximum privacy. Only members of the group can see the posts. Join the closed Bowel Cancer Patient Support Group by searching for 'Bowel Cancer New Zealand Patient & Family Support Group' on Facebook.

Bowel Cancer New Zealand Nurse Support

You are not alone. Our registered nurse is available to answer any questions you might have about your diagnosis, and to help you navigate your treatment path. We are here for you.

Here4you@bowelcancernz.org.nz

Health and Disability Commissioner

The Health and Disability Commissioner promotes and protects the rights of consumers as set out in the Code of Health and Disability Services Consumers' Rights. This includes resolving complaints in a fair, timely and effective way.

www.hdc.org.nz

Health and Disability Advocacy Service

The Nationwide Health and Disability Advocacy Service is a free service that operates independently from all health and disability service providers and agencies. If you want to know more about your rights when using health or disability services, get questions answered, or talk through your options for making a complaint, they can help.

www.advocacy.org.nz

Work and Income Entitlements

Work and Income (WINZ) may be able to provide financial benefits if you need to stop working for a period of time, or are unable to work, due to a health condition. It is important to contact WINZ as soon as possible as there may be a stand-down period.

www.workandincome.govt.nz

District Health Board (DHB) Social Services

DHBs throughout New Zealand employ social workers who can assist with a number of issues that may arise after a change in health. They can provide information, advice, counseling, and help to solve problems for those experiencing emotional stress, relationship issues (e.g. caregiver stress, changing roles and dynamics within the family and whānau), and complex social problems arising from ongoing health issues. You may self-refer to the service, or be referred by hospital staff, your GP, or a family member.

www.health.govt.nz

Treatment Summary Record

An example of the key information to include on your treatment summary record

GP	Hospital
Name	DOB
Address	
Operation	Date
Adjuvant Chemotherapy	Yes No
Colonoscopy Due	
Referred for Surveillance by	
Commenced Surveillance on	
Stage of Pathway	

Five Year / Seven Year Surveillance Plan	Rectal Cancer Only											
	6 wks	3 mths	6 mths	9 mths	1 year	18 mths	2 years	3 years	4 years	5 years	6 years	7 years
Dates												
Blood Test												
Scans												
Colonoscopy												

Treatment Notes

Area for treatment notes with horizontal dotted lines for writing.



Bowel Cancer
NEW ZEALAND

*Reducing the impact of
Bowel Cancer on our community*

E. info@bowelcancernz.org.nz

POST. PO Box 301517, Albany, 0752 Auckland

bowelcancernz.org.nz

