

A man with a beard and tattoos is wearing a tropical tank top. He is looking directly at the camera. The background is a simple indoor setting with a window.

YOUNG-ONSET BOWEL CANCER

A GUIDE FOR THE UNDER 50s



Bowel Cancer
AUSTRALIA

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ABOUT THIS BOOKLET

‘You have bowel cancer’. Four words you don’t expect to hear when you’re young. Yet each year over 1,413 young Australians do.

Mainstream support services and resources can often be aimed at older people. Leaving young-onset bowel cancer patients feeling that their needs are not being met.

Bowel Cancer Australia is different.

We provide essential support services uniquely designed for younger bowel cancer patients and their families via our confidential Helpline with telephone and email support, as well as a national Peer-to-Peer Support Network and Buddy Program.

Our services are underpinned by an unrivalled range of information booklets and factsheets for patients and healthcare professionals, and world-first Bowel Cancer App.

This booklet has been designed specifically for younger bowel cancer patients, their family and friends. Giving an introduction to how bowel cancer can affect your body, emotions, relationships and daily life. We’ve also included some personal experiences of younger people diagnosed with bowel cancer.



DON'T FORGET

Please speak to your healthcare team if you have any questions about how the information in this booklet affects you.

NEVER TOO YOUNG

It is a common misconception that bowel cancer is ‘an old person’s disease’, but the reality is that you should never be told that you are too young to have bowel cancer.

Although a large majority of newly diagnosed bowel cancer cases occur in people aged 50 years and over, 1 in 11 Australians diagnosed with bowel cancer are under the age of 50.






At Bowel Cancer Australia we hear from younger people who have had problems getting a diagnosis and who find it hard to get information and support that’s relevant to them.

So, we launched our Never Too Young campaign in 2014, which is leading change for younger bowel cancer patients.

Bowel Cancer... You’re Never Too Young provides resources uniquely designed for younger people, helping them to better understand their bowel cancer risk and to take appropriate action.

The initiative aims to raise community awareness of young-onset bowel cancer and provide better support to young people diagnosed with the disease. Giving younger patients a voice and changing clinical practice and policy.

FIND OUT MORE AT:

-  bowelcanceraustralia.org
-  [@bowelcanceraust](https://twitter.com/bowelcanceraust)
-  [@bowelcanceraustralia](https://www.instagram.com/bowelcanceraustralia)
-  [Bowel Cancer Australia](https://www.facebook.com/BowelCancerAustralia)
-  [#Never2Young](https://twitter.com/never2young)



“I have always tried to remain positive and have found there are more up days than down days. The support available is amazing and my advice to anyone embarking on this journey would be to take all the help you can get.”

Ainslie, diagnosed at age 37



KNOW YOUR HEALTHCARE TEAM

You'll be looked after by healthcare professionals who specialise in different areas of your care. They form a team, called a multidisciplinary team (MDT). In this booklet, we call them your healthcare team.

It's important to know the names of the healthcare professionals looking after you so you can contact them if you need to. It can also help to avoid delays if you can tell other members of the team the names of the healthcare professionals you've seen. We've listed some of the professionals you're likely to see but you may not have contact with all of

them. There's also space for you to add other healthcare professionals and an emergency contact.

Bowel Cancer Australia's Bowel Care Nurses and Nutritionist. Support for You - What Matters Most.

Tel: 1800 555 494

Email: bowelcanceraustralia.org/nurse

COLORECTAL CLINICAL NURSE SPECIALIST

A nurse with specialist knowledge of bowel cancer. They are your main point of contact with your healthcare team. They offer information and support.

NAME:

TEL:

EMAIL:

COLORECTAL SURGEON

A doctor who treats bowel cancer with surgery.

NAME:

TEL:

EMAIL:

CLINICAL OR MEDICAL ONCOLOGIST

A doctor who specialises in radiotherapy, chemotherapy and other drug treatments.

NAME:

TEL:

EMAIL:

STOMAL NURSE

A nurse who specialises in stoma care.

NAME:

TEL:

EMAIL:

OTHER HEALTHCARE PROFESSIONALS

You may also come into contact with physiotherapists, social workers, dietitians and other professionals. If you have chemotherapy, you will also be given a phone number you can call at any time during the day or night.

NAME:

TEL:

EMAIL:

NAME:

TEL:

EMAIL:

NAME:

TEL:

EMAIL:

EMERGENCY CONTACT

Ask your medical team who you can contact outside office hours for urgent help.

NAME:

TEL:

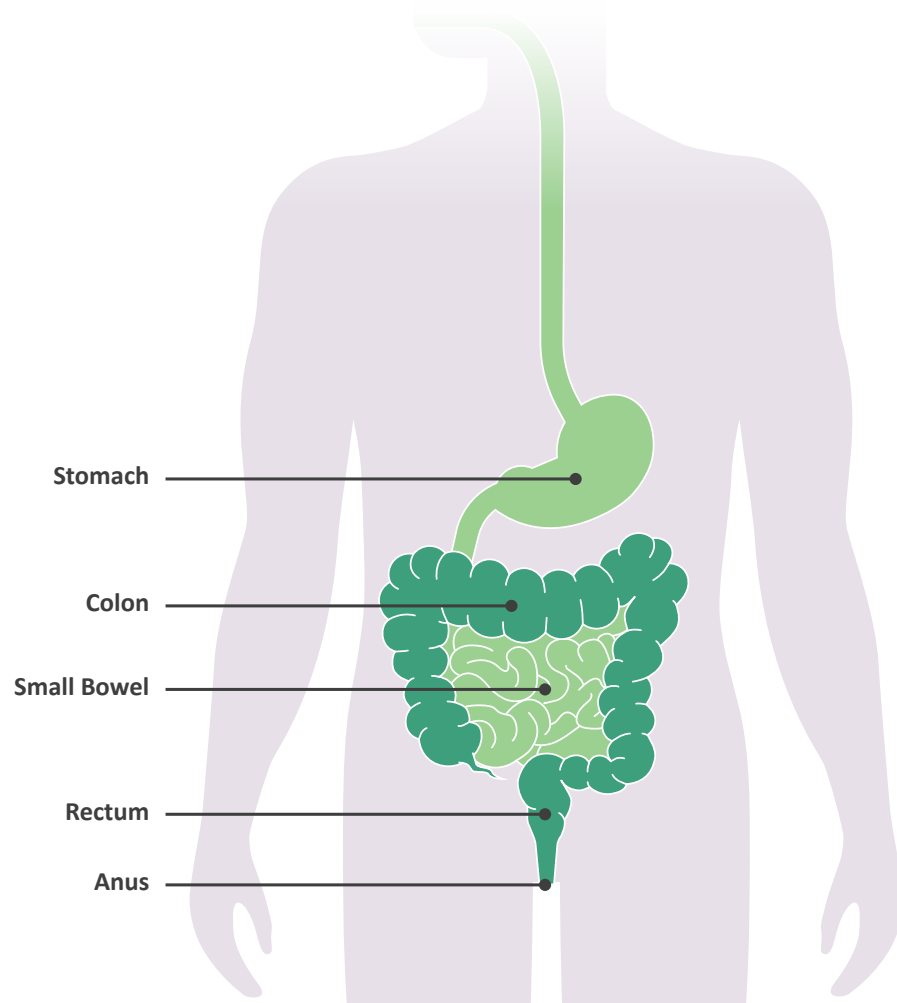
EMAIL:

WHAT IS BOWEL CANCER?

Bowel cancer is also called colorectal cancer. It affects the large bowel, which is made up of the colon and rectum, shown in the picture below.

The cells in your body normally divide and grow in a controlled way. When cancer develops, the cells change and can grow in an uncontrolled way. Bowel cancer starts in the colon or rectum.

The cancer cells might stay within the bowel or they might spread to the lymph nodes or other parts of the body, such as the liver or lungs.



"It all began last year with all the tell-tale signs. Sore stomach, bloating, IBS symptoms, then progressed to bleeding and mucus in my stools. I went to three different GP's and it was dismissed by all of them as "haemorrhoids" or a "fissure" or "piles etc." Can't be cancer, your too young I heard a lot. Don't Google your symptoms they said it all lead to cancer! Ha what a joke. I knew inside I wasn't well, so off I went for the 4th visit to the doctors. I demanded a colonoscopy"

Grant, diagnosed at age 35



YOUR DIAGNOSIS

DIAGNOSIS

You may have been diagnosed with bowel cancer after being referred by your GP. Some people are diagnosed after going to hospital as an emergency with pain in the abdomen and vomiting.

You may have had a procedure, which looks at the left side of the colon and rectum (flexible sigmoidoscopy) or the whole of the colon and rectum (colonoscopy). During the procedure, the specialist can take samples of tissue (biopsies) to be looked at later under a microscope. They also check the health of the rest of the colon and rectum.

If the biopsies show cancer, you will need more tests to find out the size of the cancer, where it is and whether it has spread. This is called staging the cancer.

You will have a CT scan of your chest, abdomen and pelvis.

If the CT scan shows that the cancer may have spread outside the colon or rectum, you may need other tests, like an MRI scan or a PET scan.

If the cancer is in your rectum, you will also have an MRI scan. This will show whether all of the cancer can be removed with surgery or whether you need to have other treatment first, such as radiotherapy or chemotherapy.

The results will help you and your healthcare team decide on the best treatment.

"I had been experiencing weight loss over a 12-month period (20kgs) and was continually told by a doctor that I was suffering from an eating disorder. One night I was suffering from severe stomach cramps and went to the emergency department, shortly after I was taken into the operating theatre with the possibility of appendicitis. Once I was on the operating table a large tumour was discovered and removed. I later found out my tumour had been growing for over 18 months."

Rebecca, diagnosed at age 17



"I was diagnosed with Stage 4 terminal bowel cancer at 34. Symptoms presented 10 weeks earlier, consisting of severe abdominal pain. I had multiple visits to the doctor and four Emergency Room visits resulting in misdiagnosis on three visits. The 4th visit was my diagnosis. My advice is to listen to your body. If something doesn't feel right and you are not satisfied with the answers you get, keep pushing and looking for that correct diagnosis. Even if it takes 10 different doctors and hospital visits. It's your life you're fighting for and nobody knows it better than yourself."

Marisha, diagnosed at age 34



You may want to take someone with you to your hospital appointments to help you remember what has been said. You could also take a list of questions that you want to ask and a pen to write down the answers. This can help you remember the information once you get home. We've suggested some questions throughout this booklet. Your healthcare team may use words that you haven't heard before. Don't be afraid to ask for information to be repeated or explained until you feel comfortable that you understand what is being said. We've explained the medical words used in this booklet on page 69.

You should be put in touch with a specialist who you can contact with any questions you have about your cancer or your care. Ask your healthcare professional if there are any booklets you can take home with more information about your condition. You can also contact our Bowel Care Nurses and Nutritionist by emailing bowelcanceraustralia.org/nurse or calling **1800 555 494**.

FIND OUT MORE AT:

Read more about cancer staging systems and tests for bowel cancer at bowelcanceraustralia.org

YOUR DIAGNOSIS

YOUR FEELINGS

Many younger people experience delays in getting a diagnosis or are given the wrong diagnosis at first. Your GP might not expect someone so young to get bowel cancer.

In the early days following diagnosis, you may feel all sorts of emotions. People have described feeling shocked, numb, sad, scared, angry or a sense of disbelief. Sometimes people lose interest in things they used to enjoy or have trouble sleeping or eating. Most of these feelings

will ease off in time. Talking to family and friends can help.

If you have any difficult feelings that don't go away or are hard to cope with, speak to your healthcare team or GP. They can refer you to a counsellor or psychologist, or they may offer you medicines that can help.

For some people there can be a sense of relief that they finally know what's wrong with them. Some people deal with their diagnosis in a practical way and focus all their energy on getting better.

"I was first diagnosed with bowel cancer a few weeks before my 28th birthday, and a month before my wedding. It was found by accident. I had never been tested for it because no-one considered for a second that someone of my age and basically healthy would ever have bowel cancer. There is no family history at all. After many months of abdominal pain I went in for surgery to remove adhesions and fibroids on my uterus. When they opened me up the surgeon basically said, "What the heck is that?!" It was a total shock for everyone.

I refused to start my treatment until after my honeymoon in New Zealand because I had spent too long planning all those Lord of the Rings tours. The day after I got home I had my portacath inserted and the day after that I started six months of chemo. Every time I was in the clinic I was waiting for someone to tell me to get out of the chemo chair because they were only for patients.

My nurses were wonderful, but I never felt comfortable and I refused every bit of support that was offered to me because I was convinced I didn't deserve it. I was a young woman, but I didn't have breast cancer so there was no information or resources for me."

Sarah, diagnosed at age 27



Your mind will be busy processing all the new information about diagnosis and treatment, so it's normal to have problems concentrating or remembering things.

Waiting for treatment and test results can be stressful and worrying. Finding something to keep you busy can help. This doesn't need to be anything too tiring but could be something like visiting family if you feel up to it, or a hobby that you can do for short periods of time. Finding out what to expect from the treatment can help you feel more in control.

If you'll be spending time in hospital, you could take something to help you pass the time, like magazines, a phone, tablet, or audio relaxation exercises. Earplugs and an eye mask may help you to sleep better.

People who have been through treatment often say that once treatment starts it's a bit like being on a rollercoaster. There can be ups and downs, but they know that their healthcare team is there to support them. Your team is interested in how your diagnosis and treatment is affecting your emotions and your daily life so let them know if you think you need some help.

TELLING PEOPLE

Talking about your cancer can sometimes help you feel closer to the people who are important to you and can help you cope with your diagnosis. But people aren't always used to talking about cancer and there can be many strong emotions or difficult situations that make it harder.

Choose who you want or need to tell. If possible, start with telling those who are likely to react in a supportive way – people you think might help you. Sometimes people are upset, shocked and may struggle to think of what to say. If you're feeling uncomfortable with any silence you could let the person know that you don't expect them to know what to say and return to the conversation later. Or you could ask them to help you with a particular task.

YOUR DIAGNOSIS

Friends and family can be a great support, even if you've had a difficult relationship before your diagnosis. Don't be afraid to take up their offers or to ask for help. If you're used to managing by yourself, this can take a bit of getting used to. But by accepting help, you can save your energy for the things that are most important to you.

If you have a lot of people to tell, friends or family may help you.

Or you might want to send a group email or text. Some people write blogs or set up WhatsApp groups so they can update everyone on their progress at the same time.

There may be some people you don't want to talk to about your cancer. You might want to practise a few things to say, so you can use them if you need to. One example might be, "I'm not bad thanks, how are you getting on?" to turn the attention away from you and on to the other person.

YOU AND YOUR PARTNER

Your relationship with your partner may change when you're diagnosed with bowel cancer. You may feel a closer bond between you as you deal with your diagnosis together. Or one or both of you might be finding it difficult to cope. Your usual roles at home may have changed, for example if you stop working or if

you're not able to do things around the house that you used to. You might find it difficult to get used to these changes.

Try to keep talking and listening to each other. Suggest ways your partner can help you, for example, by answering phone calls from friends and family. You may want to ask your partner to go to your hospital appointments with you. This gives you both the chance to be involved in discussions about test results and treatments. Your healthcare professional may also find it helpful to talk to you both together and to get to know your partner.

Your partner might need support themselves. Our Peer-to-Peer Support Network for loved ones is a good way for partners to share experiences with others: bowelcanceraustralia.org/buddy

COPING ON YOUR OWN

If you live alone, there may be times when you feel you don't have the support you need. Joining a support group or Bowel Cancer Australia's Peer-to-Peer Support Network can help you meet others who are going through similar experiences to you.

I post daily posts on Instagram, and that started out as making me do something every day to keep me positive, currently I'm up to day 950 and counting. I post a photo of my support person and I each treatment, and an update of where I'm at. The love, support and kindness I have received from my family and friends has been totally amazing, has never wavered, and has been instrumental in me keeping a positive attitude throughout this little journey we are all on together. For this, I will be eternally grateful."

Loretta, diagnosed at age 49



YOUR DIAGNOSIS

TALKING TO CHILDREN

Whether you have children of your own or young children in your family, talking to them about cancer can be difficult and upsetting for you both. Some people are unsure what the 'right' things to say or do are and may try to protect the child from upset by not telling them what's happening. But even very young children will sense when something is wrong in the family and they can get more worried when they're not told what is going on. They may even fear that something worse is happening. Talking to children stops them getting wrong information from other places like the television or internet.

You don't need to tell the child everything at once. Tell them in a language that they will understand and be prepared to answer their questions. You can check

that they've understood by asking them to tell you what's happening, in their own words. If you don't have an answer, it's okay to say you don't know.

Ask how they're feeling and try to find out what they're worried about. Generally, children need to be reassured that they will still be loved and cared for. Young children may want to know who will make dinner or take them to school if the person who normally does this is unwell.

You may want to tell your child's school or any clubs they go to. This will help the staff to support your child and understand any changes in their mood or behaviour.

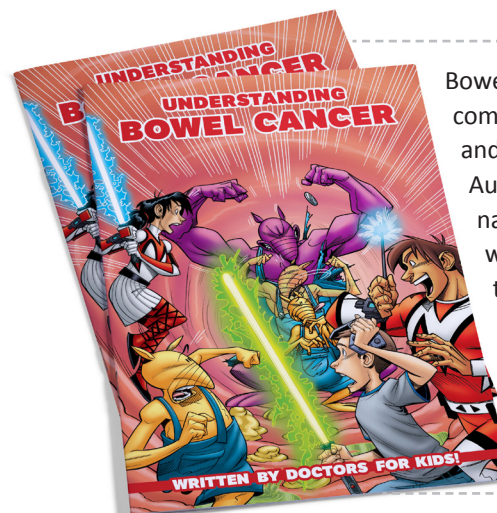
"My husband and I sat down and told the kids what was going to happen, we were honest to them. Three different reactions from our three kids. Telling my parents was hard, I dreaded it. I feel like my loved one's where taking the diagnoses harder than me. Social Media made the news easier to relay to our wider circle of friends and family via personal messenger or a post."

Steph, diagnosed at age 32



"A cancer recovery with young children is a niche' area of recovery, and one that requires a lot of support. Your role of mum, parent, caregiver does not simply stop because you are unwell or debilitated. Your partner (if you have one) must wear the breadwinner, carer, psychologist, chef, cleaner, driver, and playdate organiser hat. Not to mention- manage their own grief, fatigue and sadness. It is a mammoth undertaking, hugely straining and can often seem like mission impossible. Remember to think of your carers- say thank-you every day and strongly encourage them to take respite."

Sally, diagnosed at age 38



Bowel Cancer Australia has developed a new comic book to explain bowel cancer to children and loved ones. The comic, based on a real Australian family, tells the story of a young boy named Angus, whose mum was diagnosed with bowel cancer. It's a great tool for getting the whole family together to talk about bowel cancer diagnosis, answer questions and learn together.

<https://shop.bowelcanceraustralia.org/collections/patient-resources/products/understanding-bowel-cancer-comic>

YOUR DIAGNOSIS

TELLING A PARENT

Your parent may already know that you've been having tests for a medical problem. They may have no idea that you've been worried about your health or they may have noticed that something was wrong. Whatever the situation, telling a parent or older family member that you have cancer can be difficult. You may worry about upsetting them or you may need to think about their health. For example, if they have dementia, they may find it difficult to understand.

You may decide that you don't want to tell your parent. Be aware that someone else may tell them or your parent may notice that something is different. You know your own family best. You may want to talk to another member of the family or friend about what to do.

You can't make difficult or bad news good, but these things may make it a bit easier for you and your parent.

- Think about whether you want to tell your parent straight away or wait until there's a treatment plan to talk about. This can give you something positive to focus on.
- Is there a good time of day to tell your parent? If you tell them earlier in the day they may have more time to take the news on board or contact someone else for support. If you tell them nearer the end of the day, both of you may find it difficult to sleep.

- Think about taking a booklet that explains your cancer.
- Sometimes parents can feel helpless because they haven't been able to protect their child from cancer. You can let them know how they can help. For example, by asking them to look after grandchildren, help with housework or just be there for a cup of tea and a chat.
- If your parent is in a care home or hospital you may want to tell the staff so that they can support your parent.
- If your parent has personality or behavioural changes caused by an illness, such as dementia, they may react by saying something that seems insensitive or irrelevant. These reactions can be difficult to cope with but they can be easier to deal with if you prepare yourself for them. You might want to ask someone else to repeat the information to your parent later on.
- Think about what may help you after you've told your parent. Perhaps having quiet time on your own, or having someone supportive to turn to.

GETTING SUPPORT

A diagnosis of bowel cancer can bring with it all sorts of challenges. You may find that you don't come across many other people your age when you go to your hospital appointments. You might even feel as though you're the only younger person with bowel cancer.

There are ways you can get in touch with other people your age to share experiences and support. Many of these sources of support are online but you could ask your healthcare team if there is any local support for people your age.

Your specialist will be your main point of contact with your healthcare team. They will tell you how you can get in touch with them if you have any questions or worries. You can keep a note of their contact details at the front of this booklet so they're easy to find when you need them.

Your GP can also give you information and support. They can assess what support you need and give you the chance to ask any questions about your diagnosis and treatment.

I never realised how isolating disease and illness are. Even chemotherapy is quite a lonely experience, on top of everything else. So, the Peer-to-Peer Network was really great, because I could talk and vent and complain to somebody who'd been through it, who knew what I was going through, which was important. Being able to call up and talk to the Bowel Care Nurses was great too, because I could ask for help and get advice on the treatment, even when I was too tired and unwell to get out of bed or leave the house."

Peter, diagnosed at age 34



YOUR DIAGNOSIS

"Bowel Cancer Australia has helped me enormously, and I am truly grateful to them. Through the Peer-to-Peer Support Network I met and became friends with the Bowel Babes. Bowel Cancer Australia and the Bowel Babes have been the silver lining to the cloud that is cancer. The staff at Bowel Cancer Australia are all so friendly and personable, and they always help in whatever way they can - sometimes even in ways I yet haven't realised I needed! With Bowel Cancer Australia I feel that I belong, and that I am included as much as I want to be with research, new developments and speaking to the media. It's great to have access to nurses and a nutritionist that have so much knowledge about bowel cancer."

Danielle, diagnosed at age 34



GENETIC RISK

Some bowel cancers are caused by a change or fault in one or more genes. The changed gene can be passed down through a family. If you have the changed gene, you have a higher risk of getting bowel cancer at some point in your life. Around one in every 20 bowel cancers is caused by a change in a known gene.

The genetic conditions we know about include Lynch syndrome, familial adenomatous polyposis (FAP) and MUTYH associated polyposis (MAP). People with these conditions have a much higher chance of developing bowel cancer and they're more likely to be diagnosed at a younger age.

LYNCH SYNDROME

Lynch syndrome used to be called hereditary non-polyposis colorectal cancer (HNPCC). It causes up to one in 30 bowel cancers. Both men and women with Lynch syndrome have a higher risk of bowel cancer. Lynch syndrome also increases the risks of other cancers, such as cancer of the womb, ovary, stomach, small bowel, urinary tract, brain, pancreas and a type of skin tumour.

Medical guidelines recommend everyone diagnosed with bowel cancer under age 70 have their cancer tested for Lynch syndrome. But this doesn't always happen.

If you have Lynch syndrome, your family members may be able to have genetic testing. There's a one in two chance of your children, brothers and sisters having Lynch syndrome. But this doesn't always happen. It is therefore important to ask your surgeon or specialist to ensure the test is performed.

If any of your family members have Lynch syndrome, they'll be offered regular colonoscopies from the age of 25 or 5 years younger than the youngest affected family member if they were diagnosed under age 30.

This allows any growths (polyps) to be removed and cancer to be picked up early. Specialists don't usually start screening family members under this age because the risks of the colonoscopy are greater than the chance of picking up a cancer. They might be offered other preventative measures, such as taking aspirin, making lifestyle changes or having surgery to remove part of the colon (colectomy). Ask your healthcare team for more information on what screening is available.

"After my treatment ended, I found out my bowel cancer was genetic - I have Lynch Syndrome. No history of bowel cancer. After having genetic testing done, I have helped a lot of family members find out they to also have Lynch Syndrome."

Sarah, diagnosed at age 33



YOUR DIAGNOSIS

FAP

Less than one in every 100 bowel cancers is caused by FAP (familial adenomatous polyposis). People with FAP have a large number of growths (polyps) in the lining of the bowel. If these are left untreated, there's a high chance of bowel cancer developing. Most people with FAP have surgery to remove the colon, and sometimes the rectum, to reduce their risk of developing bowel cancer. FAP isn't always inherited from a parent. About a quarter of cases are caused by a new change in the FAP gene.

MAP

MAP (MUTYH associated polyposis) is similar to FAP but is passed down through a family in a different way. To develop MAP, you must inherit two copies of the changed gene – one from each of your parents. Your parents may not have MAP themselves but may carry one copy of the changed gene.

GENETIC TESTING

If genetic testing shows you have an inherited bowel cancer syndrome, your family members may also be offered testing to see if they carry the gene variant. If they do carry the gene variant, they will be offered regular bowel screening. If your relatives don't want to have a genetic test, they can still have regular screening if they have a one in two chance of carrying the gene variant.

In most cases, people diagnosed with bowel cancer don't have any known gene faults and so their family members don't need genetic testing. But current guidelines recommend that your

first-degree relatives should have a colonoscopy from age 50, or earlier if other members of your family have bowel cancer.

All family members should tell their GP if they have:

- one first-degree relative (parent, brother, sister or child) diagnosed with bowel cancer before the age of 55, or
- two or more first-degree relatives diagnosed with bowel cancer at any age, or
- one or more relatives with a known genetic (inherited) condition linked to bowel cancer

"It is a year since I received my stage 4 bowel cancer diagnosis. I suppose I had been showing symptoms that something wasn't quite right for some time, but I'd always had issues with irregular bowel movements since I was a child. I was initially given an end date of two years from diagnosis. Although some people have said doctors shouldn't give time frames like that, I'm glad that my surgeon and oncologist did speak so honestly with me. Don't get me wrong, it was the hardest thing I've ever had to hear, and I had it delivered to me twice within a week. Even though I understand and accept my diagnosis, it doesn't mean I accept their prognosis. Everyone is entitled to their own opinion, I just believe that I can live with this cancer longer than another 12 months. Probably one of the hardest things I've had to come to terms with is not only that I have cancer but also Familial adenomatous polyposis (FAP). FAP is rare and hereditary, so after my surgery I was referred for genetic testing, as was my daughter, brother and my parents. Luckily my brother and parents were given the all clear, but I had a 50% chance of passing FAP on to my daughter and unfortunately, she drew the short straw."

Benita, diagnosed at age 41



"My biggest symptoms were rectal bleeding and constipation, which for many years prior to my diagnosis of FAP (a genetic predisposition to bowel cancer) were put down to haemorrhoids and having poor eating habits. It made sense due to my age and I felt like I had brought it on myself because of bad habits. Yet at no stage was I offered to have any further checks like a rectal exam to confirm haemorrhoids. Years later, my symptoms were only getting worse and thankfully I finally found a new GP who was fantastic, listened to my symptoms and got me the referrals I needed. Because of that I was only almost diagnosed with bowel cancer and got my bowel removed just in time."

Sofiah, diagnosed at age 25



YOUR DIAGNOSIS

FERTILITY

Bowel cancer treatment can come with fertility risks and understanding the preservation options available is an important consideration for many bowel cancer patients.

Just as all other side effects are discussed, possible impacts on fertility should be part of any discussions with your treating specialist before starting treatment for bowel cancer.

Women who receive a bowel cancer diagnosis before beginning or completing their families will often have many questions about how cancer treatment will affect their ability to have children in the future.

Bowel Cancer Australia has put together some helpful information about how bowel cancer surgery and treatment can

affect reproductive health, what options exist to help preserve fertility before treatment begins, and what alternatives can be considered for building a family after treatment ends.

Some treatments for bowel cancer carry a risk of infertility for women and men. Your specialist should discuss this risk with you when you are diagnosed.

Even if you're not ready to have a child now, you might want the option to begin or grow your family in the future. Coping with a cancer diagnosis as well as possible infertility can be hard. You might feel that things are moving very quickly with little time to make important decisions. Your specialists can refer you to a counsellor or a fertility specialist.

"As my doctor started talking about my treatment options, I was asked question I hadn't expected - 'Are you in a long-term relationship and do you want to have children?' While Jason and I have been together for 3.5 years and we had talked about having children 'someday', that was definitely not a day anytime soon! I explained my situation and then she recommended I talk to a fertility doctor about options for getting my eggs or an embryo frozen, just to be safe, as the chemotherapy treatment can kill eggs and, in some cases, make a person infertile. This had to be decided and done before any chemotherapy treatment started. She booked me in with the fertility nurse the next day so I could find out all my options."

Marisa, diagnosed at age 32



"My symptoms first showed when I became pregnant with my little boy. I was 35, fit, healthy, basking in the joy of a much wanted first pregnancy. Hearing the words "chemotherapy" was almost as hard to swallow as the original cancer diagnosis. This can't be happening to me, this happens to other people, people in magazines, people on TV, not me. I have a baby! How can I possibly have chemo?"

Angel, diagnosed at age 36



YOUR DIAGNOSIS

FERTILITY IN WOMEN

Many women diagnosed with cancer during their childbearing years will be able to have children naturally after treatment, but some are at risk for losing their ability to conceive a child or carry a pregnancy.

Surgery that involves removal of the uterus and/or both ovaries in women will cause infertility. In addition, it may cause scarring that can make it difficult to conceive.

Radiation treatment to the pelvic area also damages the ovaries, which are very sensitive to even low doses of radiation. The amount of damage depends on the size of the radiation field, the dose of radiation given and the number of treatments. If the uterus is included in the radiation field, it can be damaged, making it difficult for a woman to conceive and carry a pregnancy.

Chemotherapy can cause temporary or permanent infertility, depending on the drugs and doses used. Your periods may become irregular or stop during treatment. The younger you are, the more likely you are to carry on having monthly periods. If the infertility is temporary, your periods may return six months to a year later. If the infertility is permanent, you may go through menopause and your periods will stop.

The newer biological therapies may affect your fertility, depending on which drug you are having. Speak to your oncologist if you are worried about this.

Your fertility options will depend on how much time you have before your cancer treatment starts and how well you are. The chances of having a baby after fertility treatment vary from person to person. Your fertility specialist can give you an idea of how successful the different fertility treatment options are likely to be.

If you have a partner, you may be able to have your eggs fertilised using in vitro fertilisation (IVF). This will take two to four weeks once you have been referred to a fertility specialist. The embryos can then be frozen and used once you are ready to start a family.

If you don't have a partner, you may be able to store unfertilised eggs, which you can use in future fertility treatment. This procedure is less likely to result in a pregnancy than using frozen embryos. Some women use donated sperm so they can freeze embryos, rather than eggs.

If there isn't time to freeze embryos or eggs before your treatment starts, you may be able to freeze tissue from one of your ovaries.

The storage of ovarian tissue and its use in fertility treatments is still fairly new. Your fertility specialist will be able to tell you about this and other possible treatments, if you would like to know more.

FERTILITY IN MEN

Surgery can cause erection and ejaculation issues and so may affect your fertility. Radiotherapy to the pelvic area can interfere with fertility.

Chemotherapy can cause your body to slow down or stop the production of sperm. This can be temporary or permanent, depending on the drug and the dose. If it is temporary, sperm production can take several years to fully recover. If you are having more than one chemotherapy drug, you are more likely to have a low sperm count or stop producing sperm completely.

You will be offered the chance to store some sperm before you start your treatment, and your specialist can tell you more about this.

WHEN TO TALK TO YOUR SPECIALIST ABOUT YOUR FERTILITY

Although you can talk to your specialist about your fertility concerns anytime, it is best to discuss them early during diagnosis and treatment planning, and before you start any treatment. This allows time for referral to a fertility specialist to learn about your risk of infertility and pursue fertility preservation, if you desire.

PRESERVING OVARIAN FUNCTION AFTER BOWEL CANCER

Chemotherapy and radiation treatment can impact fertility in women with bowel cancer, however there are several standard and investigational treatment options that may be available to preserve fertility among newly diagnosed women.

One surgical procedure, called ovarian transposition, can help protect a woman's ovaries from being damaged during radiation therapy for rectal cancer by permanently moving them outside the field of treatment.

This minimally invasive procedure reduces the exposure of the ovaries to radiation with the goal of keeping the ovaries working properly and increasing the chances that a woman can conceive a child after cancer treatment, will not go into early menopause, or both.

Even when the ovaries are moved, they may still be exposed to some radiation. Adding chemotherapy to a patient's treatment plan may increase the likelihood of eggs being destroyed.

In order to improve the chances of having a biological child, patients may also want to consider egg or embryo freezing before treatment.

YOUR DIAGNOSIS

CONTRACEPTION

Both men and women should use contraception during radiotherapy and chemotherapy and for about a year after treatment ends. This is because these treatments can damage sperm and eggs or harm a developing baby.

ASSESSING FERTILITY AND FERTILITY TREATMENT

Fertility options after cancer treatment will depend upon your age and whether you have been through premature ovarian failure or early menopause.

When you are ready to start a family, you may need fertility treatment to have a baby.

Although there are no tests that can reliably predict whether you will be able to fall pregnant and if the pregnancy will be successful, a cancer or fertility specialist will be able to talk to you about your likely fertility status after treatment and any fertility treatment options available.

FAMILY BUILDING OPTIONS AFTER BOWEL CANCER TREATMENT

Not all women will be able or want to freeze eggs or embryos before beginning cancer treatment. However, if you are no longer fertile after treatment, there are still ways to become a parent.

Alternative routes to parenthood can include using donor eggs, surrogacy, and adoption.

The legal and financial implications of these options can be considerable. However, patients should be informed about all the options available to them before beginning treatment, so as to make the best decision they can for their current and future personal circumstances.



"My life changed forever, when I was told that I had bowel cancer. At the time, I was 39 and living my best life. The hardest thing I've had to do was explain to my 7 year old son that I have cancer but the doctors hope they can make me better. While I am not happy to have cancer, I am grateful for the lessons it has taught me - to make the most of each day I have on this earth; not to sweat the small stuff; and to tell my family and friends how much I love them often."

Donna, diagnosed at age 39



YOUR DIAGNOSIS

PREGNANCY AND MOTHERHOOD

Bowel cancer in pregnancy is distinct from bowel cancer in the general population.

Pregnancy-associated cancer refers to the instance when the initial diagnosis of cancer is made during pregnancy or within 12 months of delivery.

Cancer is a leading cause of death in women in childbearing ages, and bowel cancer is among the eight most common malignancies in pregnancy.

Pregnant patients typically present with advanced bowel cancer, which is usually due to delayed diagnosis.

Patients frequently delay self-referral. Common presenting symptoms of bowel cancer include abdominal pain, constipation, vomiting, anaemia, and rectal bleeding; most of these symptoms might be attributed to pregnancy itself and are therefore overlooked. Rectal bleeding can also be attributed to haemorrhoids, which are common in pregnant women.

Specialists may delay diagnostic tests because of inattention to the potential significance of symptoms owing to the relative rarity of bowel cancer in this young population, and potential foetal risks.

For these reasons, most cases of bowel cancer are diagnosed later in pregnancy when more widespread metastasis has occurred.

Arguably, pregnancy should provide an opportunity to diagnose bowel cancer earlier than usual in the general population because of frequent routine doctor visits by the pregnant patient to the specialist. However, this often is sadly not the case.

As the presenting features of bowel cancer can overlap with those of pregnancy itself, there is a risk of development of advanced disease, with poorer prognosis at diagnosis.

You are never too young to have bowel cancer, and bowel cancer is being diagnosed in women while pregnant or shortly afterwards.

No one knows your body better than you, so regardless of whether you are pregnant or not, if something isn't right and you are experiencing any possible bowel cancer symptoms, discuss your concerns with your doctor as soon as possible.

If caught in time, 98 per cent of bowel cancer cases can be successfully treated.

It is important not to miss critical diagnoses that might put both mother and baby at serious health risk.

"I had no obvious symptoms before I was diagnosed. My diagnosis came about when I was 35 weeks pregnant and all of a sudden, I had severe shoulder tip pain in my right shoulder one night, which I initially put down to referred abdominal pain from the baby. The pain was so severe that I admitted myself to the labour ward in the middle of the night, despite the midwives trying to dismiss my pain as simply being muscle soreness. Fortunately, my obstetrician was not so dismissive and ordered a CT scan because he thought that there was something wrong with my lungs. That initial CT scan showed up shadows on my lungs and shadows on my liver. A specialist maternity specialist was called in and checked me over and was insistent that there was nothing wrong with me. We left it that I would deliver the baby in a few weeks' time, when he was full term and then do some further investigation into the dark shadows across my liver and lungs! My obstetrician, my husband and I had a sixth sense that all was not actually ok, and we decided together that the baby should be delivered early at 37 weeks and we would in fact start the further investigations then. So, I delivered a perfectly healthy baby boy by caesarean section and had two perfect days with him before our family life changed forever. On the day of Lenny's birth, he said to me "we are all a bit worried about what is going on with you, but let's not forget that today you are having a baby – so let's focus on that celebration today. Two days after Leonard was born, I was sent for a liver biopsy, which confirmed that the dark shadows were cancer and the primary source was bowel cancer."

Jaime, diagnosed at age 36



YOUR DIAGNOSIS

BOWEL CANCER DIAGNOSIS AND TREATMENT DURING PREGNANCY

Pregnancy affects the clinical presentation, evaluation, therapy, and prognosis of bowel cancer.

When diagnosis of bowel cancer is made during pregnancy, multidisciplinary involvement of the obstetrician, perinatologist, colorectal surgeon, and radiation and medical oncologists is essential to achieving the goal of early delivery that allows for the earliest treatment of the patient's cancer.

In situations in which therapeutic intervention is necessary at patient diagnosis, the stage of the pregnancy can have an impact on the types of procedures (e.g. radiologic and endoscopic intervention) and medications used (e.g. sedatives). However, once diagnosed, the evaluation of pregnant patients with bowel cancer is similar to the evaluation of nonpregnant patients.

Treatment and prognosis by cancer stage are not different from those in the general population. However, there are several factors to consider when planning management of the cancer treatment, the types of treatments used and when they are administered, including the location of the cancer, gestational age, elective versus emergency presentation, the stage of the tumour, complications of tumour or pregnancy, and the patient's decision.

THERE ARE STILL LOTS OF UNANSWERED QUESTIONS

The exact reasons for why bowel cancer is often diagnosed in more advanced stages during pregnancy is still associated with lots of unanswered questions.

A possible association between neoplastic cell growth and proliferation and gestation may have a role in the pathogenesis of bowel cancer in pregnancy. Maybe the increased levels of estrogen and progesterone during pregnancy stimulate the growth of tumoral cells with such receptors. Similarly, the enzyme cyclooxygenase-2 (Cox-2), and tumour suppressor protein p53 have been implicated in the carcinogenesis of bowel cancer in pregnancy. However, further research is required.

Research indicates that most diagnosed cases of bowel cancer in pregnancy are rectal carcinomas, below the peritoneal reflection. However, this may reflect a detection bias due to rectal exams performed during routine antenatal care.

Cases of familial adenomatous polyposis have also been reported to be first diagnosed during pregnancies.

QUESTIONS TO ASK AFTER YOUR DIAGNOSIS:

What happens next? Who do I need to see and when?

When will my healthcare team discuss my treatment at their meeting (MDT meeting) and how will I know the outcome?

Should I be referred for genetic testing?

Will my treatment cause early menopause or affect my fertility?

Can you refer me to a fertility clinic?

What emotional support is available?

Can you put me in touch with other people my age who have been diagnosed with bowel cancer?

What support or information is there for my family or children?

Who can I speak to about getting help with childcare during my treatment and recovery?

Where can I get information and advice about work and money?

YOUR TREATMENT

YOUR TREATMENT OPTIONS

The healthcare professionals looking after you meet regularly as a team, called a multidisciplinary team (MDT). They will talk about your test results and your options and wishes for treatment. You will have an appointment with a member of the team to talk about your test results and the benefits and risks of the treatment options.

Possible treatments include surgery, chemotherapy, radiotherapy and biological therapies. You may be offered more than one of these. The treatments you can have will depend on where your cancer is and whether it has spread.

SURGERY

The most common treatment for bowel cancer is surgery. This may be laparoscopic (keyhole) or laparotomy (open surgery). Ask your surgeon to explain the benefits and risks of each type of surgery.

If you were diagnosed with bowel cancer after being taken to hospital with a obstruction (blockage) in your bowel, you may have had emergency surgery to remove the cancer. Sometimes, surgeons put in a stent (flexible tube) to open the blocked section of bowel instead. If you have a stent, you may need another operation to remove the cancer later on.

Usually surgery involves removing the segment of bowel containing the cancer and joining the bowel back together. You may have a temporary stoma for a few months to rest the bowel while the join heals. If the bowel can't be re-joined, you will have a permanent stoma.

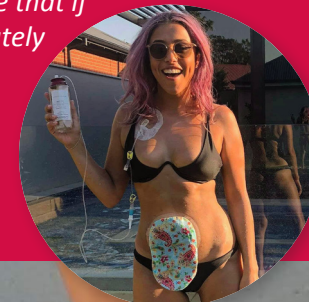
If you have FAP or MAP, your surgeon may advise removing the whole of the colon, and sometimes the rectum as well. This is to prevent you getting other bowel cancers. It may be possible to join the remaining bowel together, in which case you won't need a permanent stoma.

If you have Lynch syndrome, you will have yearly colonoscopies to monitor the remaining colon. Women with Lynch syndrome who have bowel cancer surgery around or after the menopause may also be offered a hysterectomy at the same time. This is to avoid the risk of womb and ovarian cancer.



"Don't be concerned about having an ileostomy/colostomy bag. Honestly after around three weeks I was fully adjusted. I truly believe that if I had to have this for the rest of my life I would absolutely cope. It's nothing to be ashamed of, I literally make jokes daily now. Being public about my diagnosis has led to me meet some truly inspirational people."

Dahlia, diagnosed at age 27



YOUR TREATMENT

STOMAS

Your surgeon should tell you if you're likely to need a stoma, which is where a section of bowel is brought out through an opening on your abdomen. Your bowel motions (poo) are collected in a pouch or bag attached to the skin around your stoma.

There are two types of stoma - a colostomy is formed from the large bowel and an ileostomy is formed from the small bowel. Both types can be temporary or permanent. Your surgeon or specialist will explain why you need a stoma, what type of stoma you might have and how long you might need it for. The stomal nurse will show you how to look after your stoma and will offer you practical and emotional support.

STAGING AND GRADING

Your healthcare team will have got an idea of the size and spread (stage) of your cancer from the tests you've had. After surgery, your team will have more information about the stage of the cancer, whether it has spread to the lymph nodes and whether you need more treatment.

A pathologist will look at the cancer cells under a microscope to see how normal or abnormal they look. This is called grading the cancer and it can help to show whether the cancer is likely to spread and how quickly.

RADIOTHERAPY

External radiotherapy uses high-energy X-ray beams to kill cancer cells. Radiotherapy is a treatment option for rectal cancer but it's not usually used to treat colon cancer.

Your healthcare team may offer you radiotherapy before surgery to shrink the tumour and make it easier to remove. Or, you may have radiotherapy after surgery if there's a chance the cancer could come back in the same place.

A course of external radiotherapy can last a few days or several weeks. You may have radiotherapy together with chemotherapy (chemoradiotherapy).

Your healthcare team may offer you internal radiotherapy (brachytherapy), depending on the size of the cancer and where it is in the rectum.

FIND OUT MORE AT:

You can read more about these treatments on our website: bowelcanceraustralia.org



"My main side effects from both the chemoradiation and chemotherapy was fatigue, and at times it was extreme. It would hit me 2 days after I was disconnected from my chemo pump and I would be useless for between 24-48hrs. That said however, I continued working full time during treatment, only taking time off for surgery, and every second Monday when I had to go to the infusion centre. For me, keeping busy made it seem like it was 'business as usual', even though it was anything but."

Geoff, diagnosed at age 33



YOUR TREATMENT

CHEMOTHERAPY

Chemotherapy uses drugs to kill cancer cells. You may have chemotherapy after surgery if the cancer has spread to the lymph nodes or if there's a high risk of it coming back. This is called adjuvant chemotherapy. If your cancer has spread, you may have chemotherapy to keep the cancer under control or ease symptoms.

Some chemotherapy drugs are given as an injection or drip into a vein. Others are tablets that you take by mouth.

IF YOUR CANCER HAS SPREAD

Bowel cancer most commonly spreads to the liver or lungs but it can spread to other parts of the body.

If your cancer has spread to your liver, your healthcare team may offer you surgery to remove the cancer from your liver, biological therapies or chemotherapy. If you're thinking of having surgery, your doctor will refer you to the hepatobiliary (liver) surgeons who will tell you whether surgery is suitable for you and, if so, will plan your treatment. Or you may be able to have other treatments such as radiofrequency ablation, microwave ablation or stereotactic radiotherapy.

If your cancer has spread to your lungs, your healthcare team may refer you to the thoracic (lung) team. You may be offered chemotherapy, biological therapies, surgery, radiofrequency ablation, microwave ablation or stereotactic radiotherapy, depending on where else the cancer is in your body.

BIOLOGICAL THERAPIES

Biological (targeted) therapies can be used with chemotherapy to treat bowel cancer that has spread to other parts of the body. They are drugs that help your body control the way cancer cells grow. They can be given as a drip into a vein or you may take them as tablets, depending on which drugs you're having. This is called personalised medicine, because your treatment is being tailored to the genetic make-up of your cancer.

Your healthcare team should offer you a biomarker test to find out which biological therapies would work best and which

ones are unlikely to work for you. The test looks for changes (mutations) in groups of genes, such as the RAS genes.

Not everyone is offered the biomarker test, so we're campaigning for this to change. If your cancer has spread, ask your healthcare team if you can be tested.

Biological therapies are not all available as subsidised treatments on the Pharmaceutical Benefits Scheme (PBS). If you and your healthcare team think you would benefit from these drugs, your team can apply to the manufacturer for access through a compassionate program. Or you may be able to have them as part of a clinical trial.

"As I entered the arena for my first chemo session, it was hard not to notice that I was the youngest one there. Some with family members sitting by them for support, others on their own. We bought my son in with us once. We felt it was important that he understood where mum was going when she was having her medicine that made her feel incredibly sick and tired. 1 day of chemo in hospital then I chose the option to have chemo at home for another 2 days. A nurse would come to my house and remove the chemo bottle. It was all very well hidden, so it wasn't too obvious for my son. I had a port inserted into my chest wall so it was all hooked up under my clothing so you couldn't really tell that I had a continuous 3 days of poison being pushed throughout my body. 3 days on chemo. 2 weeks rest. 3 days chemo. 2 weeks rest. 6 months of this."

Chantelle, diagnosed at age 36



YOUR TREATMENT

CLINICAL TRIALS

Medical research trials that involve patients are called clinical trials. The aim is to compare different treatments to see if they're safe, if they work and how they work best. There are different types of clinical trials, looking at prevention, diagnosis, treatment and quality of life.

If you'd like to take part in a clinical trial, ask your healthcare team if you are suitable for any trials in your area.

The benefits of taking part in a clinical trial include possibly having a treatment that isn't normally available and having extra check-ups and support. Some people feel it's a good way of taking control over their cancer. You might also like the idea of helping to improve treatment and care for people in the future.

Possible disadvantages include not being able to choose which treatment you have or not knowing which treatment you're getting. Some people find the extra check-ups tiring or difficult to fit into their daily life. There might also be a risk of side effects that the researchers don't know about yet.

The research team will give you detailed information about the trial before you agree to take part and they will answer any questions you might have. You can leave a trial at any time without giving a reason.

If you're thinking about taking part in a clinical trial, ask your healthcare team for information on:

- what the trial is testing – for example, a new treatment or combination of treatments
- how long the trial will last
- whether you will get the new treatment
- the benefits and risks
- what support you will get during the trial
- what expenses will be paid
- whether you can continue having the new treatment if the trial is successful
- whether you'll see your usual healthcare team during the trial
- whether you can have a copy of the trial results

"Nowadays the craziness of chemotherapy seems like a distant memory and at times feels like it never happened. Surreal, like it happened to someone else. I still have side effects and symptoms that plague my everyday life. Constant pins and needles in my fingers and toes, an electric jolt through my body every time I move my head up and down. Also due to the re-section I have to retrain my bowels. This is a very slow and painful process, but most of all, embarrassing. So it feels like I'm back at the beginning, if not further behind. I was warned at the beginning of my treatment the most difficult thing would be that I wouldn't look 'sick'. As strange as that sounds it is true. I look as I always do, until I see the menagerie of scars. It is a blessing and a curse, I can disguise in a crowd, but people expect me to be back to normal. It is a very frustrating place to be."

Bridget, diagnosed at age 33



COPING WITH SIDE EFFECTS

Many people don't feel fully prepared for the side effects of their treatment. Your healthcare team should give you written information about the possible side effects. But they won't be able to tell you in advance which side effects you'll get or how long they'll last.

At your hospital appointments, your healthcare team will ask you about the side effects you're getting. You may want to keep a diary to help you remember the details.

Most side effects get better a few weeks after you finish treatment. But some people may have side effects that last longer or they may get new side effects later on. You can read more about this on page 45.

YOUR TREATMENT

COMPLEMENTARY THERAPIES

Some people use complementary therapies alongside their medical treatment to help them cope with side effects and to relax.

Complementary therapies can't cure cancer and there's not much evidence to show that they improve symptoms or quality of life in people with bowel cancer.

But some people find that therapies like acupuncture, meditation, yoga and aromatherapy help them cope with their cancer.

Speak to your healthcare team before starting any complementary therapies to make sure they won't affect your medical treatment.

"I made the most of all the services provided. Attending counselling, alternative therapy sessions, yoga and a wellness retreat, all to make me feel better and all for free; I was almost sad when I couldn't attend anymore as these definitely got me through the hard times."

Nat, diagnosed at age 32



QUESTIONS TO ASK ABOUT YOUR TREATMENT OPTIONS:

What stage is the cancer?

What are my treatment options?

What are the benefits and risks of each treatment?

What other options do I have if I don't want to have the recommended treatment?

What is the aim of the treatment?

What does treatment involve?

How long does the treatment take? How many times will I visit the hospital for treatment?

What are the side effects?

If surgery is an option, will I need a stoma? How long for?

Can you tell me about the outcomes and success rates of surgery in this unit?

Who will treat me? How much experience do they have of this treatment?

After treatment finishes, what appointments will I have and what will they be for?
Who with and when?

Will you send details of my treatment (called a treatment summary) to my GP? Can I have a copy?

What support is available at the end of treatment?

AFTER TREATMENT

WORRIES ABOUT THE FUTURE

When you finish treatment it can feel like coming off a rollercoaster. The biggest part is over but you are still feeling 'wobbly'. You may have been putting all your effort into coping with treatment and now you have the chance to look back at what you've been through. At the same time, your hospital appointments may become less frequent and you may feel less supported.

Recovery from treatment often takes longer than people expect. Try not to push yourself too hard. Setting yourself small achievable goals can help.

You may worry about your cancer coming back or spreading and you may have lost confidence in your body. You may feel differently about yourself, in both positive

and negative ways. If your cancer can't be cured, you may be finding it hard to cope with the uncertainty of the future.

Most people feel stronger over time and get back to enjoying normal life again. But this isn't possible for everyone. If you feel you can't cope, your GP or specialist may refer you to a counsellor or clinical psychologist.

Friends, family and other people with cancer can be a great support. You could use our online forum or join our Peer-to-Peer Support Network. You can keep in touch with other younger people with bowel cancer by following us on Facebook (@BowelCancerAustralia), Instagram (@BowelCancerAustralia), or Twitter (@BowelCancerAust) using the hashtag #Never2Young.

"I still suffer legs cramps and I still have the numbness in my hands and legs, but my hair is growing nicely, and I am still here. I am still smiling. If I can tell you one thing, it's to be as positive as you can be throughout everything life throws at you. Yes, it's hard! It's damn hard. My life has changed forever, and it will never be the same but I'm still here. It's a hard road we each travel. We need to make the most of every minute we are here. Smile more, laugh more and love more. It's exactly what I have done!! I'm now living where I've always wanted to live, I visit the beach daily, I'm working part time, spending time and making memories with my 3 beautiful girls! Living my best life post cancer treatment!"

Sherryn, diagnosed at age 34



FOLLOW-UP

Your healthcare team will offer you regular follow-up appointments after you finish treatment. This is to find out how you are coping physically and emotionally. If you had treatment to cure the cancer, your team will check the cancer hasn't come back or spread. If the cancer does come back, regular checks will increase the chance of it being picked up early.

You may have a blood test to check the levels of a protein called CEA (carcinoembryonic antigen). It's not a perfect test and other things, like smoking and non-cancerous bowel conditions, can increase your CEA level. But, for some bowel cancers, it can give a good idea of whether your treatment is working.

You may have two or more CT scans in the three years after you finish treatment. You may also have a colonoscopy a year after treatment ends and then every few years to check for growths (polyps) and any new cancers developing in the colon or rectum. Ask your doctor when you will have these checks and how often.

Your follow-up appointments may be with a specialist or nurse at the hospital or over the phone. They should ask you about your bowel function, weight, appetite and your stoma, if you have one. The specialist or nurse will give you your test results and explain how they affect your future care and the risk of the cancer

coming back or spreading. If they don't give you this information, you should ask for it. You can use these appointments to tell the specialist if you're having trouble coping or if you need extra support.

When you have your appointment, you might want to take:

- a list of questions you'd like answers to – we've suggested some on page 53
- your latest medicines prescription
- spare stoma appliances, in case your specialist needs to examine your stoma
- a friend or family member for support

You will have follow-up appointments for as long as you and your specialist feel they're useful and the risks of the tests aren't greater than the risk of the cancer coming back.

If you have been diagnosed with advanced cancer, are having ongoing treatment with intensive monitoring, or lots of problems with side effects, you will find that you have more follow-up appointments with specialists, nurses and other healthcare professionals.

AFTER TREATMENT

SIDE EFFECTS

The side effects of treatment usually get better over time. But some people may have side effects that carry on for more than six months (long-term effects) or that start months or years after they've finished treatment (late effects).

Speak to your healthcare team if any side effects aren't getting better or if you're having any new problems. The team can offer treatment and support.

People cope with side effects in different ways. Things that members of our Peer-to-Peer Support Network say have helped them include:

- changing their work-life balance
- focusing on the positive things in their lives
- improving their diet
- taking more exercise
- using complementary therapies

"Cancer is a scary word. And fair enough. Navigating life with Stage 4 cancer is difficult. It's plagued with the 'what ifs', the constant interruptions to normal life for surgery, treatment, scans, blood tests; the days and nights spent away from my beautiful girls; the sudden changes to the schedule; the financial stress and the hardest part is seeing people you love worry about you. But there are so many positives too. Cancer made me appreciate every single second of every single day. It has made me love, open up to people, accept help and be grateful. Grateful for my amazing family, for the beautiful friends I have, for my divine - sometimes unruly - little girls. I have continued to live as normally as I can. I work when I can, do Pilates as often as the treatment schedule allows, meditate, catch up with my warrior girlfriends for coffee most days and soak up the love and the positivity. Knowing I have people who truly believe in me has been imperative to my survival."

Kim, diagnosed at age 36



TIREDNESS

Extreme tiredness is one of the most common effects of cancer and its treatment. It can feel completely draining and can affect all areas of your life. Tiredness can get worse if you're feeling stressed or low in mood. If you think this is the case, ask your healthcare team for help.

The following things can help you cope with fatigue.

- Making a plan of what you want to do each day
- Doing the most important things first
- Pacing yourself by taking regular rest breaks, even when you're having a good day. This can help you feel better in the long term
- Trying to keep physically active, even if you don't feel like it - see page 52

HERNIA

After surgery to your abdomen, your muscles will not be as strong as before and you may be at risk of getting a hernia.

This is caused by part of your insides pushing through a weak part of the muscle or tissue wall.

After surgery for colon or rectal cancer, part of your bowel can push through the wound. Some people develop a hernia around their stoma (para-stomal hernia).

Others may get a hernia after having their stoma reversed. You may not have any symptoms but you might notice a slight lump or bulge, especially when you cough or strain the muscle. Some people have some pain in the area.

To help prevent a hernia, avoid lifting anything heavy for up to three months after surgery. Once you have recovered from surgery, ask your healthcare team about abdominal exercises to build up your core muscles. They may also advise you to wear a support belt or garment.

If you have a hernia, you may not need any treatment or your healthcare team may offer you surgery to repair it.

NERVE DAMAGE

The chemotherapy drug oxaliplatin can damage the nerve endings in the hands, feet and lower legs. This is called neuropathy. In some people, neuropathy can last for months or years after treatment. You may get pins and needles, weakness or numbness. This can make it hard to do everyday things like writing, picking up small items and walking. Some people become sensitive to the cold and need to wear gloves when they use the fridge or freezer. Your symptoms may get worse before they get better.

AFTER TREATMENT

BOWEL FUNCTION

Your bowel habit will have changed after your cancer treatment and you may have:

- more frequent bowel motions
- looser poo
- wind
- constipation
- a feeling that you haven't completely emptied your bowel

These problems may be worse in the year after treatment but can carry on long-term.

If you have had surgery for rectal cancer that avoids a permanent stoma, you may have several bowel symptoms. This is due to a condition called low anterior resection syndrome (LARS). These symptoms often get better over six to 12 months but you may find them bothersome and they can affect your daily life. Having radiotherapy increases your risk of getting this syndrome.

FIND OUT MORE AT:

We have more information on diet, including coping with bowel problems, eating and drinking with a stoma and losing and gaining weight on our website.

If you have a temporary stoma, you will usually have it reversed after you finish treatment. Some people find it can take several months for their bowel habit to return to normal.

Tell your healthcare team about any bowel problems you're having or if your symptoms aren't getting better. Your specialist or Bowel Cancer Australia's Bowel Care Nutritionist can give you information on ways to improve bowel frequency and control. They can also help you find out which foods might cause you problems.

Your GP may refer you to a specialist if:

- you wake at night to empty your bowels
- you need to rush to the toilet to empty your bowels
- you ever have any leaks, soil yourself or lose control of your bowels
- your bowel symptoms stop you living a full life

If you have any of these problems, you may be referred to a continence specialist, a team who specialise in retraining the bowel and the muscles involved in emptying the bowel or a gastroenterologist who specialises in problems with the digestive system.

"I barely noticed any side effects from my first chemotherapy treatments. However, it was during a secondary and stronger round of chemotherapy (8 weeks of chemotherapy pills and fortnightly infusions) that the neuropathy kicked in and provided some interesting side-effects; loss of appetite and taste, I developed a penchant for sour lollies to make myself feel better. My throat would feel like it was closing if I had any cold drinks, so I would drink copious amounts of tea and hot cordial. My recommendation is to choose your second favourite flavour as you might not want to drink that tea again when you've recovered. My feet and fingers were very sensitive and would instantly develop painful pins-and needles if exposed to the cold, so I would wear gloves and slippers. My infusions were on Mondays and fatigue would increase until I was completely useless by the Friday. Thankfully I had a comfy sofa and Netflix to get me through the day. I would feel better with rest over the weekend and benefit greatly from the following week off. I would have significant pain on infusion day in that arm which was remedied by a heat pack.

A strange one I developed for about a year after the chemo was a kind of electric shock from my feet up my spine to the base of my skull whenever I looked down. I kept all my hair though, so that was nice. My brother is jealous because he lost all his in his twenties."

Steve, diagnosed at age 37



AFTER TREATMENT

BLADDER FUNCTION

Surgery for rectal cancer can affect the nerves to the bladder. You may not be able to fully empty your bladder and you might leak urine. Radiotherapy can irritate your bladder so you may need to pass urine more often or with little warning. Your healthcare team can give you information on how to manage bladder problems or they can refer you to a continence service.

SEXUAL FUNCTION

Cancer treatment affects your emotions and your relationships. This can lead to problems with intimacy and sex. If you have a stoma, this can add to any anxiety and change the way you see yourself as a sexual person.

If you have a partner, working together and being open about the effect of treatment on your sex life can help you both. Being physically and emotionally close with your partner may help you feel better able to cope with cancer. This doesn't need to lead to sex, but if you want to be sexually active or want to start a new relationship, there are professionals who can help. Whether or not you have a partner, a psychosexual therapist can also help you to understand and come to terms with any sexual problems.

Many people find it embarrassing to talk about their sex lives but your healthcare team are used to answering questions and talking openly about sexual matters and want to help.

Surgery and radiotherapy for rectal cancer can cause long-term problems getting an erection and problems with ejaculation in some men. These problems may get worse a few years after radiotherapy finishes. Possible treatments include tablets that increase blood supply to the penis, injections to help you get an erection, pellets that you insert into the end of the penis, vacuum pumps and penile implants. The success of the treatment will depend on whether the nerves or blood supply to the penis have been affected by the cancer treatment.

In women, surgery and radiotherapy can cause tightening and shortening of the vagina. This can make sex difficult and painful. Radiotherapy can also cause dryness of the vagina but lubricants can help with this. Regular intercourse or using a dilator after you've completed radiotherapy may help reduce the risk of vaginal shortening.

FIND OUT MORE AT:

Ask your stomal nurse for more information.

BODY IMAGE

Cancer and its treatment can change how you think and feel about your body. You may feel sad, angry or worried about any changes to your body. You may have scarring, weight loss, physical discomfort, numbness or other side effects of treatment that can make you feel self-conscious or affect your confidence. Talking about how you feel can help you cope. You could talk to someone close to you or you could ask your specialist nurse for help.

If you have a stoma, you may have strong feelings about the sudden and significant change to your body. Over time, and with support from your stomal nurse, you will learn to adapt to your new body.

Getting through the first few weeks can be tough and you may feel like you have a mountain to climb, but remember family, friends and healthcare professionals are there to help you. Talking about how you feel can help you cope.

Until you get used to looking after your stoma, you might worry about smells or leakage. You may worry that other people can see the pouch through your clothes and you may wonder how other people will respond to your new stoma. Your stomal nurse can help you with any worries you may have. Having a stoma should not stop you doing the things you enjoy. There are companies that sell underwear, swimwear and other products that can help you feel more comfortable.



AFTER TREATMENT

Diagnosed with stage 4 bowel cancer and secondary liver cancer at the age of 24, Hollie Fielder was told she had a 5% chance to be alive in 5 years. But in an inspiring story of 'beating the odds' - after two major operations on her bowel and liver, and six months of chemotherapy, Hollie was given the all clear.

Six years on from her diagnosis, Hollie is celebrating the wonderful news that she no longer needs to see her oncologist for check-ups. Now begins another journey.

As Hollie adjusts to her new normal the journey of self-acceptance and self-love begins.

A bowel cancer diagnosis and the treatments that follow not only have an impact on the physical, but the mental as well.

Coming to terms with scars from an operation, adjusting to the 'new normal' of bowel habits and possibly stoma (whether temporary or permanent) following surgery, living through some of the more extreme treatment side effects, and so on, all can have an impact on body image and how you feel about yourself.

As someone who has been through it all and is now making a concerted effort to focus on self-awareness and acceptance, we asked Hollie to share a few words about the journey to self-love and learning to accept and appreciate your body following a bowel cancer diagnosis.

"Your journey has gifted you a deeper connection and power to your body, your heart beats for you every day, be sure to feel that support and believe in who you are."

Hollie, diagnosed at age 24



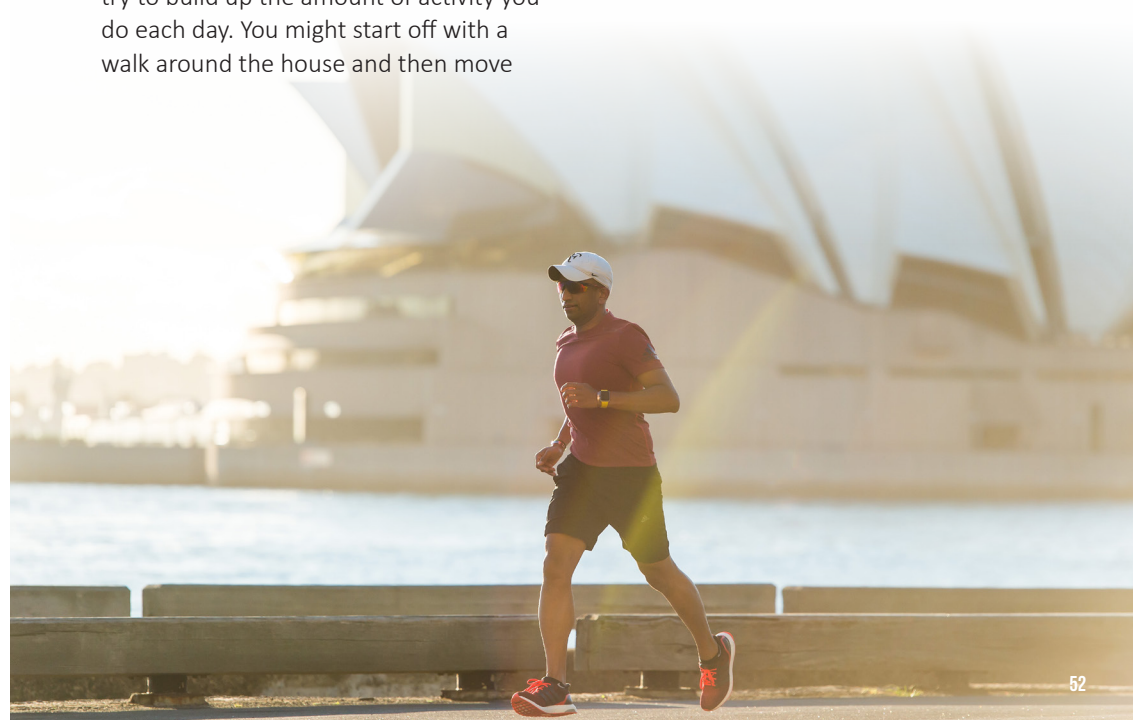
PHYSICAL ACTIVITY

You may not feel like exercising when you're having treatment but regular physical activity can help you stay at a healthy body weight and help you keep fit. It can also give you a sense of purpose. More evidence is needed about how helpful exercise may be for reducing side effects or improving survival in people recovering from bowel cancer treatment. But some studies have shown that it can improve fitness, mental wellbeing and quality of life. There's also some evidence of improved survival in people who are more physically active after curative bowel cancer treatment.

Start off gently and, when you're ready, try to build up the amount of activity you do each day. You might start off with a walk around the house and then move

on to a short walk outside. As you get your strength and energy back, you'll be able to do more. Try to build up to 30 minutes or more of moderate exercise, such as fast walking, at least five days a week. A pedometer can be helpful for setting daily step count targets, which you can gradually increase as your fitness improves.

Be careful not to lift anything heavy while you're recovering from treatment. Speak to a physiotherapist if your job involves manual work. They can also give you advice on when you can start exercising and what exercises would be best for you. You might like to try gentle forms of pilates, yoga or tai chi, which can help build strength in your abdomen.



AFTER TREATMENT

QUESTIONS TO ASK AT YOUR FOLLOW-UP APPOINTMENTS

What are the chances of the cancer coming back or spreading?

How and when will you check to see if the cancer has come back or spread?

What symptoms should I look out for that might show the cancer has come back or spread?

Who should I contact if I notice any new symptoms?

What long-term or late side effects might I get?

Where can I get help with dealing with side effects?

"Chemotherapy finally ended. It was such a relief, about six weeks later I had surgery to reverse my ileostomy and then two weeks after that I rolled back into work and pretty quickly it felt like some normality was returning to my life. Bowel cancer is a horrendous disease and my experience was beyond \$#!, however Sarah and I have since had our magical wedding and normality truly has returned."

Peter, diagnosed at age 28.



WORK AND LEGAL RIGHTS

After completing bowel cancer treatment, your focus may shift to returning to work.

Give yourself enough time to recover from your bowel cancer surgery and/or treatment and don't feel pressured into returning to work before you are ready.

Many patients describe a change in their worldview after having faced bowel cancer, resulting in their priorities shifting, especially in relation to their career goals and their definition of success.

Others express hesitation about returning to work due to fears of recurrence, a decreased sense of self-efficacy, and general anxiety related to re-integrating after being away.

With these challenges in mind, it may be hard to see the positive side of returning to work.

But it can be reassuring to resume your previous routine and get back to 'normality' after living through the disruption that cancer causes.

Work can also provide financial independence, a sense of purpose and a boost to your self-esteem.

In general, working is good for your health and returning to work can contribute to your overall wellbeing and recovery by providing an important source of friendship and social interaction, and something to think about other than your health.

RETURNING TO WORK

When you do return, you should ensure that you are given appropriate duties and assistance while you recover.

Employers have an obligation to help you return-to-work, including making reasonable adjustments to the workplace and ensuring you aren't treated unfavourably because of your illness.

You may find that you tire easily or have changes in bladder and bowel functioning; speak with your employer about possible options such as flexitime, job sharing, or working from home.

Options like these may help ease your mind and body back into the demands of your job.

It is important to be patient and take care of yourself.

TALK TO YOUR MEDICAL TEAM

Your medical team can advise you on the likelihood of your treatment and/or surgery affecting your ability to work, as well as when you will be ready to return-to-work.

The stage of bowel cancer and the treatment you had, as well as the type of job you hold, will all be factors in the timing of your return-to-work.

If your job is stressful or physically demanding, you may need to wait longer before returning to work.

Your doctor will fill out a Certificate of Capacity form with you which is like a medical certificate but includes details of your illness, expected time off work and any work restrictions that may enable you to return-to-work or stay at work.

Your initial Certificate of Capacity can only be obtained from a doctor and cannot be issued for longer than 14 calendar days.

You must continue to obtain valid Certificates of Capacity until you are able to return to your pre-illness duties and hours.

Ongoing Certificates of Capacity are usually valid for up to 28 calendar days unless otherwise approved and can be obtained from your doctor.

MEET WITH YOUR EMPLOYER

Returning to work is a team effort and communication between everyone involved in your return-to-work is essential.

Talk to your employer about planning your return-to-work and the types of duties you will be able to do when you return.

It can be helpful to talk to your employer shortly after you receive your cancer diagnosis and organize regular meetings or phone calls, so they know how you are doing.

You may also want to develop a written plan with your doctor or cancer care nurse that can serve as a guide for you and your employer regarding what you can consider to be reasonable goals and timeframes for your recovery and return-to-work.

You may be surprised by how supportive your employer will be.

By opening the line of communication early, you can assist them in managing your role and job allocations more effectively upon your return.

DAILY LIFE

RETURN-TO-WORK PLAN

A return-to-work plan is delivered according to medical guidelines.

The plan allows you to return-to-work in a safe and timely manner without exclusions due to your illness.

This might mean when you return-to-work you start on reduced hours and slowly build back up to your normal working week.

Alternatively, your role might be altered depending on the nature of the work you do.

This is done for the purpose of returning you to work successfully, in a supportive manner, with your health being the focus.

It is important to discuss the types of medications you might be on at the time of your return-to-work, because specific medications may not be suitable for those who are shift workers, causing a greater risk for your safety and those around you.

FIND OUT MORE AT:

Bowel Cancer Australia's Peer-to-Peer Support Network is a voluntary community of people affected by bowel cancer, whether personally or via a family member. To find out more, visit bowelcanceraustralia.org/buddy

REALISTIC EXPECTATIONS

It is important you set realistic expectations for yourself when working towards returning to work.

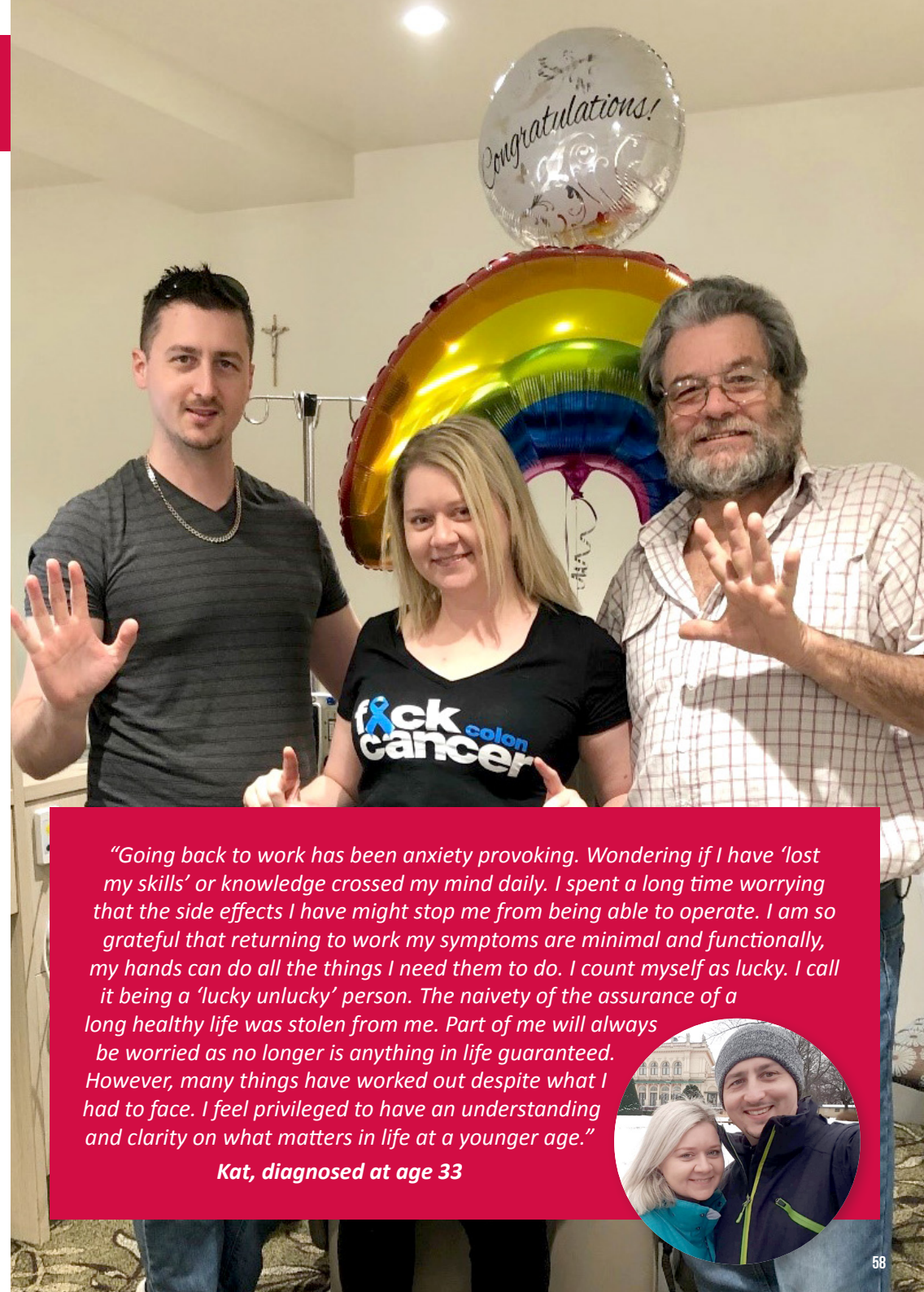
There are several factors you need to consider when recovering from bowel cancer, such as your emotional state, your physical limitations, fatigue levels after treatment or surgery, any financial concerns regarding sick leave and annual leave (or having no leave at all), and the flexibility of your roster.

All these factors, as well as your cancer diagnosis, are important and can cause concern throughout your recovery.

If you set realistic expectations from the beginning, it will make it easier for you mentally and physically.

In general, the longer a person is away from work the harder it is to return.

It is very important that you and your employer address any barriers to your return-to-work as early and effectively as possible.



"Going back to work has been anxiety provoking. Wondering if I have 'lost my skills' or knowledge crossed my mind daily. I spent a long time worrying that the side effects I have might stop me from being able to operate. I am so grateful that returning to work my symptoms are minimal and functionally, my hands can do all the things I need them to do. I count myself as lucky. I call it being a 'lucky unlucky' person. The naivety of the assurance of a long healthy life was stolen from me. Part of me will always be worried as no longer is anything in life guaranteed. However, many things have worked out despite what I had to face. I feel privileged to have an understanding and clarity on what matters in life at a younger age."

Kat, diagnosed at age 33



DAILY LIFE

LEGAL RIGHTS

National and state laws cover equal opportunity and anti-discrimination in the workplace. This means your employer must make any reasonable adjustments needed to allow you to continue working. For example, they could let you change your working hours or use your sick leave allowance for hospital appointments. If you've had time off work and are thinking of going back,

you may want to ask if you can start off with just a few hours, gradually building up your hours when you feel able to.

If you think you've been treated unfairly at work, you should speak to your employer first. If there's still a problem, you can contact the Fair Work Ombudsman or your union, if you belong to one.

SUPPORT

Additional support may be available through your employer, so be sure to ask if they offer resources such as a formal return-to-work management program, to help you make the transition.

It's also worth asking if they offer access to a consultation with a qualified mental health professional through an Employee Assistance Program (EAP) with whom you can confidentially discuss your adjustment back to the workplace.

Loved ones can also be an important source of support during recovery and when preparing to return to work.

In addition, you may find it useful to speak with someone who has been through bowel cancer and is going through or has gone through a similar situation.

MONEY AND INSURANCE

You may be worried about money, for example, if you're unable to work or you have extra costs, like childcare or travel to hospital.

Have a chat with your doctors about the likely cost of medical tests and treatments. Some factors that can impact upon the cost of treatments include:

- if you are treated at a public or private hospital
- if you are able to continue working or need to take leave
- if you need to travel for treatment due to living in a regional/rural area
- if you have private health insurance

A member of your healthcare team will be able to provide information about how you can access a social worker or welfare worker, who will be able to advise you on what financial and practical support services are available. You can also make contact with Medicare to ask about the 'safety net' on costs for your medications and medical bills.

If you have an insurance policy, such as critical illness cover, income protection or mortgage payment protection, you may be able to make a claim when you are diagnosed with cancer.

Some of the questions that might be useful to ask your health fund include:

- Which treatments are covered by my insurance?
- Which treatments are not covered by my insurance?
- If I claim for a particular treatment now, does that affect what treatments I can claim for later?
- What's the gap between the cost of treatment and my private medical insurance rebate?

CHILDCARE

There may be times during your treatment when you need extra help with childcare. Family and friends may be able to help or you may need extra childcare from a childcare centre, occasional care centre or childminder. A social worker will be able to tell you what help is available locally.

"I decided to focus on the positives during this experience. I took the treatment as a time for me to learn more about myself, for me to look after myself. Funnily enough, I had never been so happy. I got to know who I am, I allowed myself to be who I wanted to be. I took each day as it came. I read books about nutrition, cancer, yoga, meditation. I spent each day looking after myself and focussed on doing things that were good for my body, mind and soul."

Angelica, diagnosed at age 38



DAILY LIFE

TRAVEL

Often people living with bowel cancer think that they may be unable to continue travelling away on holidays, like they did prior to diagnosis.

If you enjoy travelling, having a holiday or trip to look forward to can be very positive and uplifting as you undergo treatment.

Although travel isn't advisable for some treatment plans and conditions, it can be possible with a little extra planning and by taking some factors into consideration.

Speak to your healthcare team if you're planning to travel during your treatment. They can tell you how your treatment might affect your plans. They can also give you a letter to take with you, listing the medicines you're taking and what they're for.

They can also offer helpful tips for travelling with a stoma. Always carry some supplies in your hand luggage in case of baggage delays.

There may be restrictions on the types and quantities of medications you can travel with, as some drugs are listed as controlled substances in certain countries. So be sure to research these before you travel, and plan ahead to ensure you have enough medication to cover your trip.

Depending on where you are travelling, travel vaccinations may also be a consideration. You will need to avoid any

live vaccines for the six months following chemotherapy, so speak with your doctor about any recommended vaccinations and your inoculation options.

Finding travel insurance after a bowel cancer diagnosis can be difficult but doesn't mean you have to stop travelling. Cancer is considered a pre-existing medical condition, so it may not be automatically covered in your travel insurance policy.

Difficulties can arise for people affected by cancer who want to obtain cover for cancer related medical costs. If you are looking for a policy that does include cover for pre-existing medical conditions such as cancer, contact the Insurance Council of Australia who may be able to refer you to an appropriate insurer. Some travel insurers will offer cover for cancer, provided you meet a few conditions. In some cases, you may have to pay an extra premium to receive cover for cancer on your travel insurance policy.

Many travel insurance policies exclude cover for cancer, but still offer many other benefits. Under these policies, cover for sudden or unforeseen non-cancer related medical expenses is provided (such as if you fall and break your leg), along with non-medical related complications such as travel delays, lost/stolen luggage and personal effects, and rental vehicle insurance excess.



"Whilst the journey isn't over just yet, I feel like I have already kicked bowel cancers ass, and I would not have been able to do it without the support of my amazing family and friends. They were so amazing throughout the whole process. During this experience I watched so many testimonies of other bowel cancer sufferers and seeing those men and women were truly inspirational and helped me to realise I wasn't alone in this fight."

Shelley, diagnosed at age 34



SUPPORT FOR YOU

SUPPORT FOR YOU

15,604 Australians are diagnosed with bowel cancer each year, 1,413 (or 9%) of whom are under the age of 50.

Mainstream support services and resources can often be aimed at older people. Leaving young-onset bowel cancer patients feeling that their needs are not being met.

Bowel Cancer Australia is different.

We provide essential support services uniquely designed for younger bowel cancer patients and their families via our confidential Helpline with telephone and email support, as well as a national Peer-to-Peer Support Network and Buddy Program.

Our services are underpinned by an unrivalled range of information booklets and factsheets for patients and healthcare professionals, and world-first Bowel Cancer App.

bowelcanceraustralia.org/finding-support

BOWEL CARE NURSES

Bowel Cancer Australia's friendly team of Bowel Care Nurses are at hand to answer bowel cancer questions large and small.

Whether you have symptoms and you don't know what to do; or if you have been diagnosed or have questions about treatment options. Whatever the reason, please don't hesitate to contact one of our friendly, trained Bowel Care Nurses.

Bowel Cancer Australia's Bowel Care Nurses understand that the needs of younger bowel cancer patients can be different, adding an extra layer of support to the trusted relationship patients have with their treating medical team at a very difficult time.

Registered nurses provide information and support to anyone with a question or experience related to bowel cancer.

You can email Bowel Cancer Australia's Bowel Care Nurses any time for advice at **bowelcanceraustralia.org/nurse**

Alternatively, please call Bowel Cancer Australia's helpline on **1800 555 494** (10am-4pm weekdays).



BOWEL CARE NUTRITIONIST

A diagnosis of bowel cancer involves some major changes to diet and lifestyle.

Bowel Cancer Australia's Bowel Care Nutritionist, who is also a young-onset bowel cancer survivor, helps with practical advice on food choices during treatment and in recovery. Offering specific nutritional advice, recipes, menu planning and cooking tips are provided to patients, carers, families and friends.

bowelcanceraustralia.org/nutritionist

New high and low fibre recipes are also released online every month.

bowelcanceraustralia.org/recipes



PEER-TO-PEER SUPPORT NETWORK

Bowel Cancer Australia's Peer-to-Peer Support Network is a voluntary community of people affected by bowel cancer, whether personally or via a family member.

It is Australia's only national support group for patients diagnosed under the age of 55, and now living with or beyond bowel cancer, and their loved ones. Including young families and partners, women diagnosed during pregnancy, siblings and parents with children that have been diagnosed with young-onset bowel cancer.

Through the support network, we aim to put young people in touch with each other - matching them by age, gender, region and their stage of bowel cancer and treatment pathway.

Partners, relatives and friends of patients also benefit from this service as we are able to put them in touch with other people who have a loved one with young-onset bowel cancer.

bowelcanceraustralia.org/buddy



SUPPORT FOR YOU

PATIENT RESOURCES

There is no shortage of information on bowel cancer but when it comes to credible information, that's a different case.

Bowel Cancer Australia has developed a suite of publications covering all aspects of bowel cancer: prevention, early detection, diagnosis, surgery, treatment and care. Including resources uniquely designed for younger people. Bowel Cancer Australia publishes a wide range of patient information

Our resources are designed to increase understanding of bowel cancer, treatment (including managing side effects), and how to adjust to the 'new' normal for people living with and beyond bowel cancer.

bowelcanceraustralia.org/shop

BOWEL CANCER APP

The Bowel Cancer App is a comprehensive companion for patients, loved ones and carers; a useful resource for health professionals; and an educational tool for the Australian community.

Key features include the popular 'Need to Know', 'How to Test' 'Living With' and 'Need to Ask' sections, as well as 'Buddy Connect' and 'Motivate Me' features.

bowelcancerapp.org

BOWEL CANCER STORIES

Many young patients and loved ones choose to share their stories to help raise awareness that you're never too young to have bowel cancer and to provide support to others.

Often people can find it helpful to read about the experiences of others who have been affected by bowel cancer.

Our 'Never Too Young' Peer-to-Peer Support Network members have kindly shared lots of their stories, which you can read on our website.

bowelcanceraustralia.org/bowel-cancer-stories

BOWEL CANCER... YOU'RE NEVER TOO YOUNG

Launched in 2014, Bowel Cancer Australia's 'Bowel Cancer... You're Never Too Young' initiative was created to provide bowel cancer resources uniquely designed for younger people.

Offering practical and emotional support for the growing number of young people affected by bowel cancer (and their loved ones), championing what matters most to people living with or beyond young-onset bowel cancer, while challenging perceptions through dynamic campaigning that raises awareness and motivates action in all young Australians.

A highlight of the initiative is Never Too Young Awareness Week - a dedicated week during Bowel Cancer Awareness Month that highlights the unique challenges faced by people who are living with or beyond young-onset bowel cancer.

nevertotoyoung.org.au



N2Y
NEVER
TooYOUNG
FOR BOWEL CANCER

SUPPORT FOR YOU



"They're there to listen to you, support you and find you the help that you need. It's reassuring to know you're not alone."
Angel, diagnosed at age 36



"They were there for me during my treatment, regularly reaching out to see how I was."
Jamie, diagnosed at age 40



"They have been the silver lining to the cloud that is cancer, always happy to help in whatever way they can - sometimes even in ways I yet haven't realised I needed!"
Danielle, diagnosed at age 34

"They just understand. No-one else understands the struggles, physically and emotionally better than those who have been through the same trials."
Steve, diagnosed at age 37



"They have helped me in so many ways – from helping me spread awareness through their #Never2Young program to introducing me to a bunch of awesome people through their Peer-to-Peer Support Network."
Geoff, diagnosed at age 33



"As much as our family and friends offered support, no one truly understood what we were going through having not been through it."
Sarah, diagnosed at age 33

"They have been the three pillars of strength I needed to get through one of the darkest times in my life. Thank you just doesn't seem enough xx."
Jodie, diagnosed at age 35



"The Bowel Cancer Australia team have been an integral part of my journey and have had such a positive impact on my treatment pathway."
Makala, diagnosed at age 32



MEDICAL WORDS USED IN THIS BOOKLET

Abdomen	The part of the body underneath the ribs and above the hips.
Adjuvant	Treatment used together with, or after, the main treatment to improve the chance of controlling the cancer.
Biological therapies	Drugs that change the way cancer cells work to stop them growing. Also called targeted therapies.
Biopsy	A sample of tissue taken to check for cancer.
Brachytherapy	Internal radiotherapy that uses a source of radiation inside the body for a short period of time.
Chemotherapy	Treatment that uses drugs to kill cancer cells.
Colon	The longest part of the large bowel, which ends just above the rectum.
Colonoscopy	A test that uses a long thin tube with a camera on the end to look inside the colon and rectum.
Colostomy	Where a section of the large bowel is brought out onto an opening on your abdomen, allowing bowel motions (poo) to pass into a pouch or bag.
CT scan	Computerised tomography scan. A scan that uses X-rays to take a series of pictures of the body.
FAP	Familial adenomatous polyposis. A rare inherited bowel cancer syndrome that greatly increases the risk of getting bowel cancer. Causes a large number of growths (polyps) in the lining of the bowel.
Genes	A set of instructions that control how the cells in your body grow and work. Genes are inherited from your parents. They control things like eye colour.
Ileostomy	Where a section of small bowel is brought out onto an opening on your abdomen, allowing bowel motions (poo) to pass into a pouch or bag.
Lymph nodes	Small glands that make up part of the lymphatic system, which defends the body against infection. They are a common place for colon or rectal cancer to spread to.
Lynch syndrome	A rare inherited bowel cancer syndrome that increases the risk of bowel cancer and some other cancers.

MAP	MUTYH associated polyposis. A rare inherited bowel cancer syndrome that causes growths (polyps) in the lining of the bowel and increases the risk of bowel cancer.
MRI	Magnetic resonance imaging. A scan that uses magnets to produce pictures of the body.
Microwave ablation	Treatment for bowel cancer that has spread to the liver. It uses heat from microwave energy to kill cancer cells.
Neo-adjuvant	Treatment used before the main treatment to improve the chance of controlling the cancer.
Pathologist	A doctor who looks at cells under a microscope to see how normal or abnormal they look.
Pelvis	The area of the body between the hips.
Polyp	A non-cancerous growth. Polyps can grow in the lining of the body's organs, including the bowel. Some polyps may develop into cancer over time.
PET scan	Positron emission tomography. A scan that uses a low dose of radiation to take pictures of the whole body.
Radiofrequency ablation	Treatment for bowel cancer that has spread to the liver. It uses radio waves to heat cancer cells to a high temperature.
Radiotherapy	Treatment that uses high-energy radiation to kill cancer cells.
Rectum	Part of the large bowel that sits between the colon and the anus. Bowel motions (poo) are stored here before passing out of the anus.
Selective internal radiotherapy (SIRT)	Treatment for bowel cancer that has spread to the liver. It involves injecting millions of tiny radioactive beads into the liver.
Sigmoidoscopy	A test that uses a long thin tube with a camera on the end to look inside the rectum and sigmoid colon.
Stereotactic radiotherapy	Treatment for bowel cancer that has spread to other parts of the body, such as the liver or lungs. It uses thin beams of radiation to give a high dose to the tumour, while limiting the dose to the surrounding healthy tissue.
Stoma	An opening on the abdomen, where a section of bowel is brought out so bowel motions (poo) can be passed into a pouch or bag.
Ultrasound scan	A scan that uses sound waves to build up a picture of the body.



Please support Bowel Cancer Australia.

Your tax deductible donation will help make real change happen across the continuum of care, from prevention and early diagnosis to research, quality treatment and care for everyone affected by bowel cancer.

\$25

Provides a newly diagnosed patient and their family with empowering resources for living with bowel cancer

\$50

Assists in the delivery of practical education programs for the prevention and early detection of bowel cancer

\$100

Helps in the provision of essential Bowel Care Nurse and Nutritionist support for patients and their families

\$200

Contributes to vital bowel cancer research to save lives and improve patient outcomes



Bowel Cancer
A U S T R A L I A

bowelcanceraustralia.org

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