



Follow-up of survivors of bowel cancer

This fact sheet is for people who have completed treatment for bowel cancer. It explains why follow-up appointments are important and possible effects from treatment.

You may know that when bowel cancer is found and treated early, the outcome is often very good.

In Australia:

- 5-year survival for people treated for very early-stage bowel cancer is about 90%. This means that for every 100 people treated for very early-stage bowel cancer, about 90 will still be cancer free 5 years later.
- For bowel cancers found and treated at a later stage (when the cancer has spread), survival rates are lower.
- For all people with bowel cancer (including people treated for later-stage cancers), the 5-year survival rate is 61% and the 10-year survival is about 56%. This means that for every 100 people treated for bowel cancer, about 56 will still be cancer free 10 years later.

For some people treated for bowel cancer, there is a chance the cancer could come back (recur).

Your doctor will schedule regular follow-up appointments to check on your health and look for any signs of bowel cancer recurrence.

Your doctor will also talk to you about possible effects from your bowel cancer or treatment.



Potential issues

As a bowel cancer survivor, you may have physical, emotional, social and practical concerns after completing treatment. Care from your health care team should address all of these issues.

Your medical care should include:

- good communication between your cancer specialist and GP about your health needs
- looking for any signs of cancer spread, recurrence or second primary cancers
- treating any side effects or late effects from your cancer and treatment

- advice about preventing new cancers and reducing your risk of your cancer recurring.

Follow-up frequency

Everyone who has been treated for bowel cancer should be followed up by a doctor.

Follow-up is intended to find any recurring cancer while it may still be cured.

Your doctor will talk to you about how you have been feeling, do a physical exam and may also use other scans and tests to look for signs of recurrence.



Example follow-up schedule for people treated for bowel cancer

Type of follow-up	Years 1 and 2	Years 3–5	After 5 years
History (talking about your health) and examination <ul style="list-style-type: none"> Digital rectal examination Sigmoidoscopy (if you had an anterior resection of the rectum) 	Soon after discharge from hospital Every 3–6 months Every 3–6 months	Every 6 months or every year	As advised by your doctor
Blood test to measure CEA (a cancer marker) CT scan	Generally every 3–6 months May be each year		As advised by your doctor
Colonoscopy (depends on your circumstances)	Your doctor will advise if you require a colonoscopy in this time	After 3–5 years	Every 3 or 5 years

Note: this schedule may vary, for example if your doctor suspects recurrence or if you have another illness.

When to contact your doctor

Contact your doctor if you notice a bowel change or any other symptom that concerns you. You don't have to wait for your follow-up appointment.

Contact your doctor if you notice:

- any sign of bowel obstruction (for example vomiting, bloating, constipation, not passing any wind)
- any signs of hernia (swelling or bulge under the skin on the stomach area [abdominal wall])
- any signs of abscess (tenderness, pain, warmth and redness in the area of your surgery; a high temperature of 38C or above; chills)

- bleeding from the bowel or altered bowel habit
- unexplained pain, discomfort or weight loss.

Coordinating follow-up

It is very important that your follow-up is properly coordinated and you do not attend excessive appointments.

Your specialist and GP should consult and decide on who will coordinate your follow-up.

Ideally, this will be documented on a survivorship care plan. If you don't have a survivorship care plan, please ask your GP, specialist or cancer nurse who should be able to provide this for you.

Possible long-term effects and late effects of treatment

Not everyone will have long-term or late effects. If you have had treatment for bowel cancer, this does not mean you will get all or even any of the effects described here. Long-term and late effects will vary depending on the stage of your bowel cancer as well as the treatment you had. Some effects from treatment for bowel cancer are more common than others. Some are rare. Some will become less severe over time and disappear completely whilst others may be permanent. Please speak to your doctor if you have any concerns about effects from your cancer treatment.





Possible long-term effects and late effects of treatment

All common cancer treatments (surgery, chemotherapy or radiotherapy) can cause both long-term and late effects. Possible long-term and late effects following treatment for bowel cancer and their causes include:

Long-term and late effects	Cause
Bowel obstruction	Sometimes occurs following surgery or radiotherapy
Abdominal wall hernia	Sometimes occurs following surgery
Abscess	Sometimes occurs from radiotherapy
Bowel function problems such as urgency, leakage, constipation, diarrhoea, farting	Removal of some of the bowel Nerve damage from radiotherapy and surgery affecting the anus
Problems with a stoma (for example skin problems, leakage, narrowing of the opening)	Having a stoma
Infertility	Radiotherapy to the pelvic area
Sexual problems Males: problems with erections Females: premature menopause, narrowing or shortening of the vagina, vaginal dryness	Cancer treatment and having a stoma can affect a person's libido, self-image and sexual confidence Surgery Radiotherapy to the pelvic area
Unhappiness with changes in appearance	Surgery, especially having a stoma
Urinary problems (for example urgency, difficulty passing urine, incontinence, infection)	Surgery, more so if resection to the bowel is a low resection Radiotherapy
Peripheral neuropathy (changes to feelings in your toes and fingers, numbness, pain)	Can be caused by some chemotherapy drugs
Pain	Surgery or radiotherapy
Fatigue (extreme tiredness that isn't helped by sleep or rest)	Sometimes occurs following treatment, however the reasons are not clear May be associated with anxiety or depression
'Chemo brain' or 'Chemo fog' which may include poor concentration and forgetfulness	May occur in people who have had chemotherapy but is not well understood
Depression and anxiety	Can occur following treatment, however the reasons are not clear
A second primary cancer	May occur rarely due to radiotherapy or chemotherapy

Further information related to effects of treatment for bowel cancer

- Bowel obstruction, hernia or abscess is serious but not common. Your doctor or specialist cancer nurse will explain what signs for you to look for and how to contact them.
- Bowel problems such as constipation, diarrhoea, leaking and farting can be treated. Your doctor or specialist cancer nurse can advise about diet and treatments. Referral to a specialist dietitian can be arranged.
- If you have a stoma, be aware of problems that may happen and see your doctor if any symptoms arise. Your doctor or specialist cancer nurse can refer you to a stomal therapist or stomal nurse who understands the physical, emotional and social concerns that can result from having a stoma. Consider joining a stoma support group (call the Cancer Council Helpline 13 11 20).
- Urinary problems can be dealt with. Your doctor can advise you about things that you can do to manage these and refer you to a continence nurse if needed.
- A small number of people have an inherited bowel cancer. If this affects you and your family, your doctor will discuss referral to a family cancer clinic for advice about prevention and screening.
- You may have particular needs if your fertility has been affected. You may have sought advice about sperm banking or egg harvesting before surgery and may want further advice or counselling now that your treatment is finished. Your doctor may suggest that you see an infertility specialist.
- If you are experiencing sexual problems as a result of your cancer or cancer treatment your doctor may suggest referral to a sexual counsellor and/or a menopause specialist (for women) or erectile dysfunction specialist (for men).
- Depression and pain can contribute to fatigue and can be treated.



Further information related to effects of treatment for bowel cancer

- You may feel unhappiness with the changes to your body and with having had cancer. You may begin or continue to have fears about the future. You may be feeling worried, sad or unable to get through the day. Many of these feelings are normal when adjusting to life after a cancer diagnosis and usually lessen with time. You may find it helpful to attend a support group and/or speak with a fellow survivor. Contact via the Cancer Council Helpline (13 11 20). If you feel low in mood or depressed for long periods, it is very important that you speak to your doctor and get treatment.

Getting help and support

Any change in how your body looks, feels or functions can be very hard to deal with. Certain late or long-term effects may be annoying but manageable. However others can be more severe and have a big effect on your quality of life.

There are things that can be done to help control or treat many long-term and late effects from treatment for bowel cancer. It is important you find the right support to help you manage and cope with any side-effects you have or may develop.

For you and your partner, there may be relationship effects, including issues about changed roles, fear of recurrence of bowel cancer and fear of 'being a burden'.

Survivors who go through and beyond cancer treatment without partners or close family and friends may experience great loneliness.

Speak with your doctor or specialist nurse about how you are feeling. Support groups and/or contact with a fellow survivor through a service such as Cancer Connect may be helpful. Contact via the Cancer Council Helpline (13 11 20).

Staying well

Having cancer and treatment often makes people think about their health in different ways. Some people decide they want to live a healthier lifestyle than they did before getting cancer. Some people look for ways to reduce the chance of their cancer coming back and preventing a new cancer developing. It's a great time to make some changes and commit to staying healthy. This includes:

- having a healthy diet
- maintaining a healthy weight
- stopping smoking
- increasing physical activity (most people need to do at least 30 minutes of moderate-intensity physical activity on most, preferably all, days).

These simple measures may help to prevent recurring bowel cancer or a new cancer. They may also reduce many of the physical and emotional effects of cancer treatment.

Screening

It's important to have screening for other cancers.

- Have regular Pap tests. (Women)
- Have a mammogram every 2 years if you are at average risk of breast cancer and aged 50–69. (Women)

In addition:

- Have your usual cholesterol, blood pressure and blood glucose checks.
- Have regular dental examinations.
- Take care to protect your skin from the sun.

Further information

The Australian Cancer Survivorship Centre – A Richard Pratt Legacy



The Australian Cancer Survivorship Centre – A Richard Pratt Legacy is a web-based centre. It is funded by Peter MacCallum Cancer Centre, The Pratt Foundation and the Victorian Department of Health. The Australian Cancer Survivorship Centre aims to help improve services and care for cancer survivors in Australia as well as focusing on increased awareness, especially about issues that affect survivors after their treatment ends. The information on this site is divided into four sections: Health Professionals, Survivors, Family & Friends and Research. There are links to useful information and reliable websites.

www.petermac.org/cancersurvivorship

Cancer Council



Contact the Cancer Council Helpline on 13 11 20 for information about side effects from treatment, or any other questions you have about cancer and surviving cancer. Cancer Council booklets include 'Living well after cancer: a guide for cancer survivors, their families and friends'. Call the Cancer Council to find out about Life after Cancer forums. Through the Cancer Council Helpline you can speak with a cancer nurse: ask about Family Cancer Connect and support groups and other support services that may help you. Cancer Connect is a free phone peer support service that puts people in touch with others who've had a similar cancer experience.

www.cancer.org.au

All of these services may be accessed through their websites

Australian Cancer Survivorship Centre

A Richard Pratt Legacy



Australian Cancer Survivorship Centre

Mailing address – Locked Bag 1,
A'Beckett Street, Melbourne VIC 8006
Phone: 03 9656 5207

Email: contactacsc@petermac.org

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