Bowel Cancer
What you and your family need to know
The GI Cancer Institute is Australia’s only independent, non-government, non-profit organisation with the specific aim of raising funds to carry out clinical research trials to test and improve treatments for gastro-intestinal (GI) cancers: those of the oesophagus, stomach, liver, pancreas, gallbladder and bowel (including rectum and anus).

These trials are conducted by the Australasian Gastro-Intestinal Cancer Trials Group (AGITG), a multi-disciplinary collaborative group of medical and research professionals. For more than 23 years this group has been working to improve medical treatments for people with GI cancers. The GI Cancer Institute was established by the AGITG to raise funds for these trials, and also to raise public awareness about these cancers.

Our clinical trials can make a difference in three key ways:

1. they can help the trial subjects by giving them access to the latest cutting-edge treatments;
2. they can deliver significant findings that will improve future treatments; and
3. whatever the major findings, the trials can provide information that influences the direction of best medical practice.

Recent and current AGITG trials on bowel cancer have examined:

- effectiveness of latest chemotherapy and radiotherapy treatments in different combinations;
- individual targeting and refining of treatments for particular patients for best results;
- testing of treatment options both before and after surgery;
- best ways of prolonging survival, and also of minimising side-effects to improve quality of life.
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The bowel and bowel cancer

The bowel is the part of the body's digestive system connecting the stomach to the anus – via the small intestine and the large intestine (consisting of the colon and rectum).

The bowel has to complete the process of digestion – by absorbing the nutrients and water from the food and then getting rid of the waste.

Fortunately, improvements in treatment are changing bowel cancer from a deadly disease into an increasingly curable one.

Most bowel cancers are abnormal cell growths that develop on the inner surface of the large intestine – starting as small growths called polyps. Not all of these turn into cancers – and if they can be detected early and removed during a colonoscopy, the risk of cancer is much reduced.

New and better treatments are being discovered through research – changing bowel cancer from what was once nearly always a deadly disease into an illness that can be cured more often than not.

Since the 1980s, survival chances have improved from 50% so that now, two-thirds of all people in Australia diagnosed with bowel cancer survive beyond five years.

There are approximately 15,000 new cases of bowel cancer diagnosed in Australia each year – making it the second most common cancer after prostate cancer. The average age of people at time of diagnosis is 69 – but some are diagnosed much earlier.

Bowel cancer claims around 4,000 Australian lives a year.
Can bowel cancer be prevented

The risk of bowel cancer increases with age – but it takes time to develop, so prevention and screening are important ways to reduce the risk.

The earlier bowel cancer is diagnosed, the better the chance of successful treatment.

It is likely that most cases of bowel cancer can be prevented by:

- Eating a healthy diet with plenty of fruit, vegetables, wholegrain foods and fish, and reducing your consumption of fatty foods, red and processed meats
- Participating in regular exercise and maintaining a healthy weight
- Reducing consumption of alcohol and not smoking
- Have a better understanding of your gastro-intestinal health and learn about the way your body naturally functions so that you can recognise any changes in bowel habits
- Participate in screening programs after the age of 50

A positive way of responding to a bowel cancer diagnosis might be to encourage your family to be aware of healthy choices.

Educating your family about gastro-intestinal health offers a constructive opportunity for them to contribute to shopping, food preparation and family meals and to make a difference in their own future wellbeing. But it’s important to remember that even if someone “does all the right things”, they can still develop bowel cancer – even at a young age.

Screening for bowel cancer

The Australian Government has a bowel cancer screening program for various age groups over 50. People over this age should be screened at least every two years. Talk to your GP about doing a Faecal Occult Blood Test or a colonoscopy.
Detecting bowel cancer

**Family history**

Genetic inheritance is a factor in bowel cancer – especially if someone is diagnosed in early middle age, or if cancer is common in the family. There may be a genetic abnormality that’s being passed on through the genes. In a case like this, close relatives like children or siblings may be referred to a specialist for advice. If there’s a high risk, some family members may be advised to have a regular colonoscopy.

Inherited conditions can make someone more likely to get bowel cancer. These conditions are not very common. One is called Familial Adenomatous Polyposis (FAP) – which causes lots of polyps to develop inside the large bowel, ramping up the risk of cancer. This can be treated early to stop cancer developing.

There’s also Lynch Syndrome or HNPCC, which mutates certain genes, causing higher risk.

**What can be done about family history?**

If you think you have a strong family history of bowel cancer, make an appointment with your GP to talk about your concerns. You may be referred to a genetic specialist or a bowel specialist to talk about what types of screening might be appropriate.

Unlike some malignant tumours, bowel cancer can often be cured by surgery – and new treatments are being found which make survival even more likely. The earlier it’s diagnosed, the more likely it can be cured.

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**Early signs**

In its early stages, bowel cancer often has no symptoms – that’s why it’s important to screen.

Bowel cancer can often cause symptoms similar to other unrelated conditions.

If you experience any of the following symptoms, you should consult your doctor:

- A recent, persistent change in bowel habits to looser, more diarrhoea-like motions, going to the toilet more often, or trying to go
- Blood (either bright red or very dark) in the stool
- Diarrhoea, constipation, or feeling that the bowel does not empty completely
- Frequent gas pains, bloating, fullness or cramps
- Stools that are narrower than usual
- A lump or mass in your tummy
- Weight loss for no known reason
- Persistent, severe abdominal pain, new and recent (especially in older people)
- Feeling very tired
- Vomiting
How to support someone with bowel cancer

Staying informed

A diagnosis of bowel cancer can be a big shock. It may take time to accept the news and be ready to talk about it.

Support may come from family, friends, health professionals and/or special support services.

For the main carer, family and supporters, it’s important to be positive and sensitive to the feelings of the person with the cancer. There can’t be too much understanding and love – though sometimes a person with cancer may not want to be overwhelmed or pitied.

As new screening programs and treatments develop, more people are surviving bowel cancer. There’s good reason to be hopeful – and clinical trials are offering more hope still.

Whether you’re someone with bowel cancer, or supporting someone with it, try to inform yourself and your family about its symptoms, treatments, new research and ways of coping. Treatments are changing all the time, so check that what you’re reading is up to date.

Not everything you find out will apply to the person you’re caring for. New trials or treatments may apply to some cancer types but not others. Keep discussing what you read with your medical team.
Dealing with depression and anxiety

Being diagnosed with cancer leads to a wide range of reactions in different people. Many people have strong emotional and psychological responses to cancer and its treatment. There can be fear, anger, fatigue, anxiety, fear of recurrence – sometimes lasting longer than the disease or the treatment.

After being diagnosed, a period of sadness is normal – combined with concern for their family and well being. They may worry about financial or legal matters, or about their body image, work, hobbies or social life. In many cases, good listening and support may be all that’s needed.

But if this sadness continues and seems to overwhelm the person, it may be a sign of depression. It may be hard to tell whether symptoms like loss of sleep or appetite, fatigue, pain or low moods are because of the cancer or because of depression – or both. Longer-lasting symptoms of this kind, and particularly thoughts of suicide, are indicators of depression.

You may need medical or community help to deal with this. Ask for advice from your medical team who can refer you to specialist psychologists or psychiatrists, or point you to sources of good information.
What to do about depression

For the main carer and family, sometimes being a sympathetic listener may be enough to help a loved one through the first stages of sadness and adjustment. If the person with cancer doesn’t seem to find relief, you may need to ask for help from your medical team – they may be able to come up with helpful strategies to improve the patient’s sense of control and reduce their feelings of helplessness. Or they may point you to good information, or refer you to specialists or community organisations that have experience in dealing with depression.

In the longer term

Going through cancer can have lasting impacts on the mind and emotions of the person with the cancer or their family members. Whatever the outcome, anxiety, depression, fatigue and fear of recurrence can last for a long time afterwards – and may need to be handled with patience and persistence.

Some useful websites

Beyond Blue
beyondblue.com.au

Black Dog Institute
blackdoginstitute.com.au

Cancer Council
cancercouncil.com.au
Supporting the family

Talking with the children

A cancer diagnosis in the family can cause many emotional responses in children, some of them unexpected.

But both adults and children can and do learn to cope with cancer and its treatments.

Some general suggestions:

- Don’t hide the truth from children. It is best if they find out from you in a sensitive way rather than in some other way that might be less accurate or that might lead to far worse imaginings.

- Give them straightforward, truthful information, without too much detail all at once, in words they can understand appropriate to their age.

- Use some basic cancer terms and explain what they mean.

- Be balanced – encourage facing the negative but working on the positive.

- Be prepared to cope with a range of reactions from children. Seek professional help if needed.

- Give children plenty of chances to ask questions and have them answered, and to express their feelings.

- Don’t be afraid to say “I don’t know.”

- Weekly family meetings are a good way to manage anxiety that can build up and provide an opportunity for all family members to air their concerns and others a chance to address them.

- Keep your children informed, involved and able to feel they're being useful.

Children are exposed to a lot of information about illness and health – from peers, social media and the internet, TV or elsewhere. Not all of this information is accurate! Ask your kids what they've heard and talk to them about cancer, pointing them towards reliable sources of information.

They may want to know about effects of the cancer, side-effects of treatment, likely changes to family plans or routines, and the long-term outlook. They need to know enough to deal with their own fears and still be able to get on with things at home, at school and with their friends.
Supporting the main carer

The spouse, partner or other main carer for a person with bowel cancer can sometimes try to take the whole weight of the illness on their shoulders. The main carer can also suffer fear, fatigue, confusion and other effects – while trying to keep up responsibilities to a family, work or other commitments.

Having a family member with bowel cancer may mean changes to the family routines – especially to make sure no single person is left carrying the whole burden. Kids can take on extra chores and help prepare simple healthy meals. Friends and neighbours may be able to take a message, pick something up at the shop or help with transport.

The most important message is: if you’re struggling to cope, call for help – from family, friends or professionals.

Family counselling

This can offer a good chance for all members of the family to work through the emotions and problems.

Ask your medical team to refer you to family counselling services.

Or try your state/territory department of community services or human services, or contact Relationships Australia: relationships.org.au or tel. 1300 364 277
Changes at home

Having a family member with cancer can change some roles and relationships in the household. By taking on some specific responsibilities, children can feel they’re doing something to help – preparing healthy meals or doing extra chores. This can help counter feeling powerless.

Friends of the family can also help – we don’t want to impose on people, but it can be a way of letting friends know how important and valued they are.

Preparation healthy meals can be a good way of educating kids about the importance of healthy eating to reduce risks of cancer and also other gastro-intestinal disease.

Grant and Branka were both diagnosed with GI cancer, Branka with bowel cancer and Grant with oesophageal cancer. Together with their daughters, as a family they decided to get through this disease.

Branka and Grant sat their girls down and put a ‘family deal’ in place. They made a promise to their girls:

_We will be open and transparent with you and our job is to get better and to fight this disease BUT your job is to be a normal teenager - you must stay focused and on track with your studies, get through your schooling and keep up your sporting activities._
Treating bowel cancer

The treatment and care of people with bowel cancer is usually provided by a team of health professionals – sometimes called a “multidisciplinary team”.

Treatment for bowel cancer will depend on what stage the disease has reached, how severe the symptoms are, and the general health of the person with the cancer.

Treatment usually involves surgery, and it may also include radiotherapy and/or chemotherapy to destroy any remaining cancer cells.

There is research going on all the time to improve how quickly and accurately we can diagnose and treat bowel cancer. Some people may be offered a chance to participate in a clinical trial to test new treatments.

How we’re improving treatments

Scientific techniques to better understand bowel cancer are moving forward – thanks to worldwide research into treatments better targeted to the individual, and into better understanding of the genetics of the disease.

The GI Cancer Institute is the community division for the Australasian Gastro-Intestinal Trials Group (AGITG) – which is playing a leading role in new research. This includes taking part in worldwide collaborations into some of the most promising research into treatments and best clinical practices for bowel cancers and other cancers of the digestive system.

Some of the more promising research is concentrating on genetic and molecular studies, immunotherapy, targeted and genetic therapy, chemotherapy, stem cells and supportive care.

The best way to fight gastro-intestinal cancers is to develop better treatments and test them in clinical trials. That’s what we’ve been doing for 23 years - raising funds for this much needed research, as well as increasing awareness of the role of healthy living in reducing cancer risk.

Evidence shows we’re getting results - extending and improving the quality of patient lives.

Associate Professor Tim Price, Chair, GI Cancer Institute/AGITG
Changing the odds: Our research

Not only can bowel cancer be prevented in most cases, it can also be survived.

Thirty years ago, someone diagnosed with it had less than a 50/50 chance of surviving for five years. Now two out of three survive. This is because of early screening and better treatments made possible by research.

For more information about our clinical trials visit our websites:

www.gicancer.org.au  •  www.agitg.org.au

I’m alive today due to medical research - and the application of its findings in clinical and health care practice. AGITG trials, working with international collaboration, are major contributors to worldwide progress.

Dan Kent, Qld – bowel cancer survivor
We need to raise community awareness of gastro-intestinal cancers, and their research funding – to match their devastating burden of death and disease.

Russell Conley, Executive Officer, GI Cancer Institute / AGITG

Make a donation

By email: info@gicancer.org.au
By phone: 1300 666 769
Online: https://gicancer.org.au/donate/
Donations of $2 or more are tax deductible

Other ways to help

• Make an online donation at www.gicancer.org.au
• Run your own fundraising event or take the Gutsy Challenge. Call 1300 666 769
• Make a gift in your Will – for more information, call us (above) and ask for a confidential discussion
• Consider In Memory donations to honour a loved one
• Volunteer

More Information

Email: info@gicancer.org.au
Phone: 1300 666 769
Website: gicancer.org.au
FACTS YOU SHOULD KNOW ABOUT GI CANCER

3 **people** are diagnosed with GI cancer every hour

24,600 families are affected by GI cancer each year

33 Australians die every day of GI cancer

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