

GI cancer

What you and your family need to know



◀ FACTS YOU SHOULD KNOW



**GI CANCER
INSTITUTE**

GASTRO-INTESTINAL CANCER RESEARCH



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 Trials Group (AGITG), a multi-disciplinary collaborative group of medical and research professionals. Since 1991 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 participants 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 have examined:

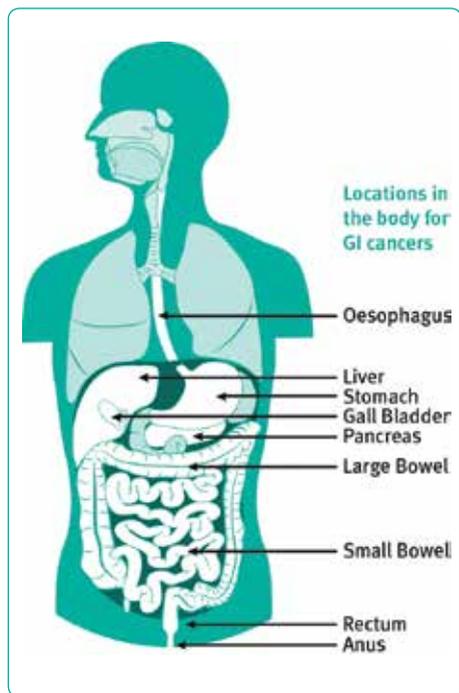
- effectiveness of latest chemotherapy and radiotherapy treatments in different combinations;
- individual targeting and refining of treatments for particular patients for best results;
- testing of treatment options both before and after surgery; and
- best ways of prolonging survival, and also of minimising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

In this booklet.....

What is GI cancer	1
Types of GI cancer	2
Can GI cancers be prevented.....	5
How to support someone with GI cancer	6
Dealing with depression and anxiety	7
Supporting the family	8
Changes at home	9
Treating GI cancer	10
Changing the odds: our research	11
Make a difference	12

What is GI cancer

Gastro-intestinal (GI) cancer is a term for the group of cancers that affect the digestive system. These include cancer of the oesophagus, stomach, gallbladder, liver, pancreas, bowel, rectum and anus.



Gastro-intestinal cancer is Australia's most common form of cancer – with close to 25,000 new diagnoses each year, or 3 every hour. GI cancers in Australia cause more than 12,000 deaths a year – 33 per day. This is more than the combined total of breast and prostate cancer and melanoma.



Low survival rates

Survival rates for GI cancers remain unacceptably low. The average five-year survival rate for GI cancer is just 49%. And the outlook for some GI cancers is much worse – as low as 6% for pancreatic cancer.

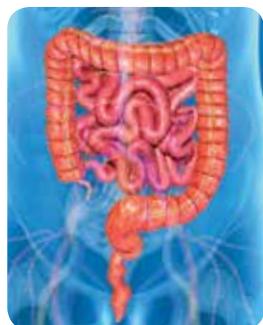
Five-year survival rates for GI cancers 2007–11:

Bowel	67%
Anal	65%
Stomach	27%
Gallbladder	19%
Oesophageal	18%
Liver	16%
Pancreatic	6%

Source: Australian Institute of Health and Welfare, January 2015

Types of GI cancers

Bowel and Anal Cancer



Bowel cancer is sometimes known as colorectal cancer. The bowel is part of the body's digestive system, which connects the stomach to the anus. Together

the colon (large and small intestine) and rectum are known as the bowel. Bowel cancer is a diseased growth that usually develops inside the large bowel. Most bowel cancers develop from small growths inside the colon or rectum called polyps, which look like small spots on the bowel lining or like cherries on stalks.

Not all polyps become cancerous. A test called a colonoscopy, involving a tube inserted into the bowel, is used to test for polyps. If polyps are detected and removed, the risk of bowel cancer is reduced.

Bowel (or colorectal) cancer is the most common internal cancer in Australia, with over 15,000 new cases diagnosed each year.

Of these, small intestine cancer is relatively rare, with just over 400 cases diagnosed each year.

Anal cancer is also rare, with just under 400 new diagnoses a year.

Gallbladder Cancer



Gallbladder cancer is cancer of the biliary tract including the bile duct. It affects the digestive organ that stores bile (produced in the liver). The gallbladder digests and absorbs fats in

the intestines. One risk factor for cancer of the gallbladder is gallstones.

This cancer is quite rare in Western societies but more common in Asia-Pacific countries. In 2011, 771 Australians were diagnosed with biliary tract cancer, with half the cancers found in the gall bladder and the other half in the biliary tract.

Unfortunately, most people are diagnosed with biliary tract cancer once the tumour is too large to remove surgically or has spread to other areas of the body. This means that less than a third of people with the disease are eligible for surgery — with the aim of a cure. Even so, the survival rate for these people is still very low — the average five-year survival rate for all patients is only 18.5%. For those who are ineligible for surgery, chemotherapy remains the main treatment option. At present, there is no chemotherapy regimen that has been shown to specifically help people live longer.

Types of GI cancers

Stomach Cancer, GIST and NETs



The stomach is a muscular sack-like organ that receives and stores food from the oesophagus. Once the food is broken down, it is passed from the stomach to the small bowel, where nutrients

begin to be absorbed into the bloodstream.

Most stomach cancers develop in cells that line the mucosa and are called adenocarcinoma of the stomach. Stomach cancer (also known as gastric cancer) develops slowly – it may take many years before any symptoms are felt.

More than 2,000 people are diagnosed with stomach cancer each year. This includes a small number of people with gastro-intestinal stromal tumours (GIST) and neuroendocrine tumours (NETs) - relatively rare cancers that are mostly found in the stomach but can appear elsewhere in the digestive system. Their symptoms and progress vary widely.

Liver Cancer



The liver is a key organ in the body. It produces bile, which breaks down the fats in food so that they can be absorbed from the bowel. The liver helps process fats and proteins, some

of which are essential for blood clotting. The liver stores glycogen which is made from sugars to fuel the body. It also helps to process alcohol, some medicines, toxins and poisons to remove them from the body.

Over 1,400 people are diagnosed with primary liver cancer in Australia each year. These are cancers that arise from liver cells that have become malignant.

In addition there are those who have secondary liver cancers – originating from cancers from other organs such as the colon or rectum spreading (metastasising) to the liver. This will occur in about 40% of people with bowel cancer.

Oesophageal Cancer



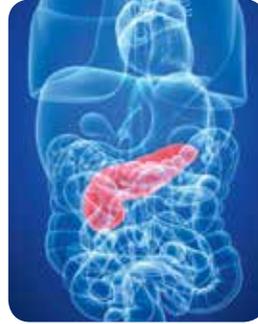
The oesophagus is the food pipe that carries food from your mouth to your stomach. The oesophagus has three main sections – the upper, middle and lower. Cancer can develop

anywhere along the length of the oesophagus.

Glands in the wall of the oesophagus produce mucus to help food slide down more easily when swallowing. These glands can become cancerous to produce adenocarcinoma of the oesophagus, which is the most common type of cancer seen in Western countries (the other most common type is squamous cell carcinoma).

There are around 1,400 new diagnoses of oesophageal cancer a year in Australia.

Pancreatic Cancer



The pancreas is a thin, lumpy gland that lies between the stomach and spine. It is about 13 cm long and is joined by a special duct (the pancreatic duct) to the first part of the small bowel (called the

duodenum). The pancreas plays two major roles in the body: to produce insulin, which controls the amount of sugar in the blood; and to produce enzymes, which help in food digestion.

Pancreatic cancer begins in the lining of the pancreatic duct. It spreads into the body of the pancreas before moving into the blood vessels and nerves around the pancreas, obstructing the bile duct. Cancer that develops in the pancreas may also spread via the blood or the lymphatic system to other parts of the body.

If diagnosed early, cancerous tumours in the pancreas are usually removed by surgery. However, this is not always possible as the cancer is often detected after it has spread from the pancreas to outlying tissues and organs.

More than 2,700 people in Australia are diagnosed with pancreatic cancer each year.

Can GI cancer be prevented

The earlier it's diagnosed, the better the chance of successful treatment.

The risk of developing most GI cancers is reduced 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. 90% of Australians are not eating enough fruit and vegetables
- Reducing consumption of alcohol and not smoking
- Participating in regular exercise and maintaining a healthy weight
- Being aware of your medical conditions that may increase your risk of developing GI cancers
- 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



Genetic inheritance (family history of cancer) can also be a factor in some GI cancers. In some of these cases, screening is available that may help to identify a cancer and allow surgery or treatment at an earlier stage. If you're aware of a strong family history of GI cancer, discuss this with your GP.

How to support someone with GI cancer

A diagnosis of cancer can be quite a 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 better treatments develop, many of them thanks to clinical trials, more people are surviving GI cancers.

Staying informed

Whether you're someone with a GI 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.

Supporting the main carer



The spouse, partner or other main carer for a person with GI 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 GI 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 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

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 and anxiety, sometimes lasting longer than the disease or treatment.

After being diagnosed, a period of sadness is normal combined with concern about 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 have them addressed.
- 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.

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.



Preparing 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.



Jilli Blackler, a former airline employee, was first diagnosed with rectal cancer in 2000 at the age of 48 and underwent surgery. The cancer had spread to her lung and brain. Several operations followed – including two craniotomies and years of radiotherapy and chemotherapy.

During this time Jilli was helped by family, friends and colleagues.

People don't talk about these cancers nearly enough. We have to get out more information about GI cancers and be more open about them.

Jilli Blackler,
GI cancer survivor

Treating GI cancer

Treatment and care of people with GI cancers is usually provided by a team of health professionals – sometimes called a “multidisciplinary team”.

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

There’s research going on all the time to improve how quickly and accurately we can diagnose and treat GI 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 GI 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 of 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 the best clinical practices for GI cancers. 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 since 1991. The GI Cancer Institute raises 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



Our research

AGITG clinical trials are not about laboratories and test tubes, they're about real people living with GI cancers and getting access to the most effective medical treatments.

Not all people or cancer tumours are the same, so we need clinical trials to test the effectiveness of different types and combinations of treatments for particular groups of tumours and people.

Our trials test the effectiveness of leading medicines, technologies and treatment practices – often comparing two treatments with each other.

Benefits of clinical trials to patients

These clinical trials:

- give patients immediate access to the latest treatments;
- allow standard treatments to be changed 3-5 years earlier if conducted in Australia;
- improve cure rates; and
- improve patients' quality of life during treatment – participating patients get the best available care during the trial.

For more information about our clinical trials, visit our website:

gicancer.org.au under "GI cancer / Research and clinical trials".



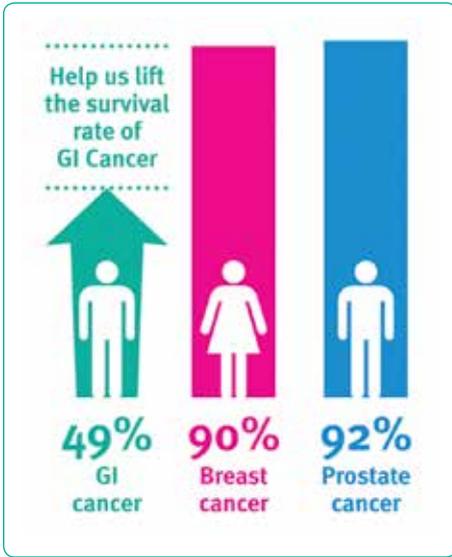
Are clinical trials safe?

No cancer treatment offers guaranteed success - most have side effects, and those given in clinical trials are no exception. But our trials must conform to several safety rules before being approved by an independent ethics committee. They must be scientifically sound, not produce more harm than good, keep patients informed of developments and results, and meet internationally agreed standards about the right way to carry out research involving people.

Before joining a trial, participants must be given accurate information about the study – its purpose, foreseeable benefits and risks (including side effects), full patients' rights and expectations of them.

Once all information about the trial is understood, the participant signs an information and consent form. Most importantly, they're free to opt out of the trial at any time for whatever reason, without any compromise to their future medical care.

Make a Difference



Ways to help

- Make a donation, online at www.gicancer.org.au or by phone 1300 666 769
- 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

Donations of \$2 or more are tax deductible



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

The funding gap

GI cancers are amongst the least funded in Australia, compared to their impact in lives lost, according to a report from Cancer Australia published in 2014.

Analysis of data from the report shows that from 2009-11, pancreas, liver, oesophagus, stomach and bowel cancer all fared significantly worse in funding than other major cancers such as leukaemia, melanoma, breast and prostate cancers, when compared to the number of deaths they caused.

Cancer Australia, *Cancer Research in Australia 2006-11*; AIHW, *Cancer Survival and Prevalence in Australia 1982-2010*



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

Source: AIHW Australian Cancer Database 2011, unpublished data

Locked Bag M250, Camperdown NSW 2050

P: 1300 666 769

E: info@gicancer.org.au

Donate Now www.gicancer.org.au 



**GI CANCER
INSTITUTE**

GASTRO-INTESTINAL CANCER RESEARCH