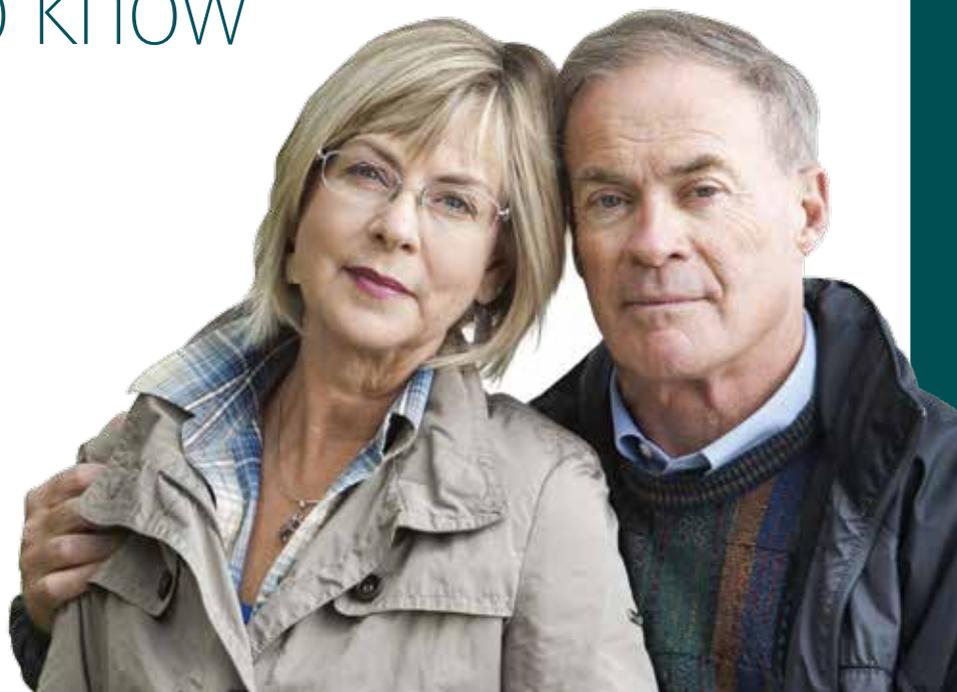


Pancreatic Cancer

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 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 pancreatic 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.

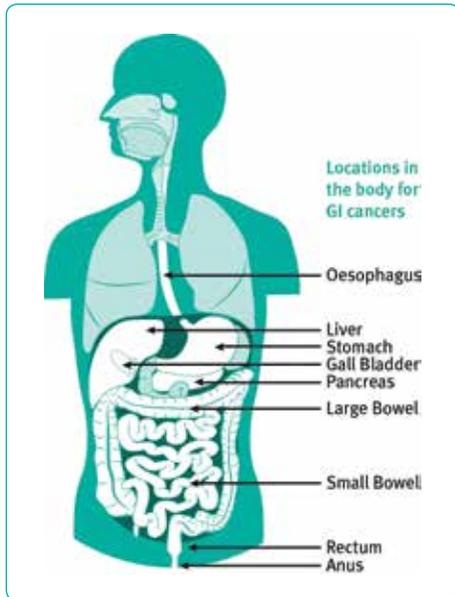
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The pancreas and pancreatic cancer

The pancreas is a small gland just behind the stomach, between the stomach and the spine. It's about 13cm long and is joined to the start of the small intestine or duodenum.

The pancreas produces hormones like insulin that control blood sugars, and enzymes that help the body digest food. Over 90% of pancreatic cancers are in these enzyme-producing cells – they're known as "exocrine" tumours. The minority that attack the hormone-producing cells are called "neuroendocrine" or sometimes "islet cell" tumours.



Cancers happen when abnormal cells start to divide uncontrollably, forming a malignant growth or tumour. Pancreatic cancer starts in the lining of the pancreatic duct, spreads into the body of the pancreas, then further into the blood vessels and nerves around it, blocking the bile duct. It may also spread through the lymph system or the bloodstream to other parts of the body.

In Australia, there are over 2,800 people diagnosed with pancreatic cancer each year and over 2,400 people die from it. The disease affects both men and women equally.

Pancreatic cancer also accounts each year for over 25,000 "Disability Adjusted Life Years" from premature death and years of healthy life lost due to illness.

Can pancreatic cancer be prevented

Some factors increase the chances of getting pancreatic cancer, including:

- Smoking tobacco – smokers are 2-3 times more at risk of pancreatic cancer. This is an important message to give to your children, as most smokers take it up in their teens.
- Obesity – the risk of cancer is reduced by avoiding too much meat, especially smoked or barbecued, too much salt, saturated fat, dehydrated or fried foods. Eating plenty of fruit and foods with high folate content may help to protect against pancreatic cancer.

A positive way of responding to a cancer diagnosis might be to encourage your family to be aware of healthy food choices and the need for exercise.



Some medical conditions can also increase pancreatic cancer risk:

- Chronic pancreatitis
- Diabetes
- Previous surgery such as partial removal of the stomach or gall bladder

Age is also a factor – most people diagnosed are over 65.

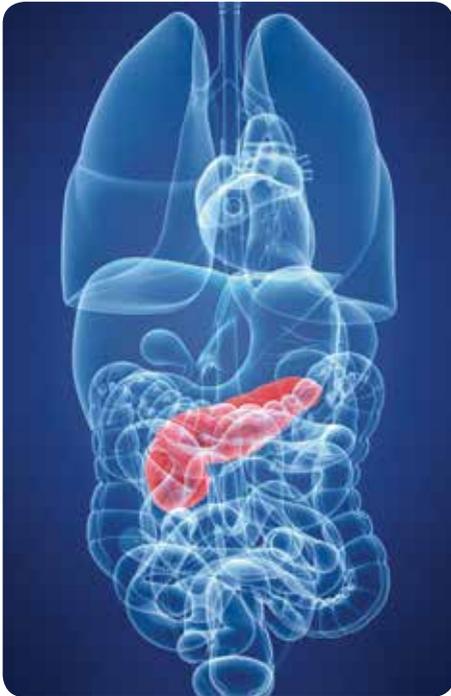
It's important to remember that even if someone has none of these risk factors, they can still develop pancreatic cancer.

Detecting pancreatic cancer

The prognosis (outlook) for someone with pancreatic cancer depends on the type and stage of cancer, their age and general health at the time of the diagnosis.

The five-year survival rate for people diagnosed with pancreatic cancer is just over 6%.

If pancreatic cancer is diagnosed and treated early enough, there's a modest chance it can be removed by surgery. In general the smaller the tumour, and the sooner it's diagnosed, the better the outlook.



When I was diagnosed with pancreatic cancer my children were only four, two, and three months old. For our family the only way to cope was to just get on with it, so if things were not important – like washing the floor – they didn't get done.

Jan Mumford, pancreatic cancer survivor

But it's difficult to diagnose early, because usually in the early stages there's no pain and no obvious symptoms - and there's no routine screening test. By the time it's diagnosed, the cancer has often spread to other organs - beyond what an operation can reach effectively.

As the disease progresses, some symptoms can emerge. These can include:

- pain in the upper abdomen
- loss of appetite
- nausea and vomiting
- weight loss
- changed bowel motions – either diarrhoea or severe constipation
- jaundice – yellowish skin and eyes, and dark urine

How to support someone with pancreatic cancer

A diagnosis of pancreatic cancer can be quite a shock, and coming to terms with surviving can be very confronting. The person with the cancer needs sensitivity and support from loved ones. Keep expressing your love and commitment – going through cancer can feel very lonely.

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



Staying informed

Whether you're someone with pancreatic 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. Discuss what you are reading with your medical team.

Be prepared to face some confronting information and reactions from all concerned that may include fear, anger, sadness and frustration.

Sometimes, rather than dealing with the whole challenge all of the time, it can help to concentrate more on facing the needs and challenges of treatment, reducing the side-effects and maintaining quality of life.

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.

These feelings can sometimes end up in depression – 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.

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 pancreatic cancer can sometimes try to take the whole weight of the illness on their shoulders. Like the person with the cancer, their 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 pancreatic 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.



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.



Alberto was diagnosed with pancreatic cancer in December 2010. Surgeons removed the tumour and he began a year of chemotherapy. Cancer was then found in his liver and oncologist, Associate Professor Nick Pavlakis, who is leading an AGITG clinical trial, suggested that Alberto be treated with an additional chemotherapy agent. This completely shrank the tumour allowing him to have further surgery.

It is not until you are diagnosed with cancer that you think about research. Clinical trials are vital to uncovering the answers. I now feel great and I want to give back.

Alberto Marchetto,
pancreatic cancer survivor

Treating pancreatic cancer



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

Treatment for pancreatic 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 to remove part or all of the pancreas and affected organs, and it may also include radiotherapy and/or chemotherapy to destroy cancer cells.

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

How we're improving treatments

Scientific techniques to better understand pancreatic 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 face 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 best clinical practices for pancreatic 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.

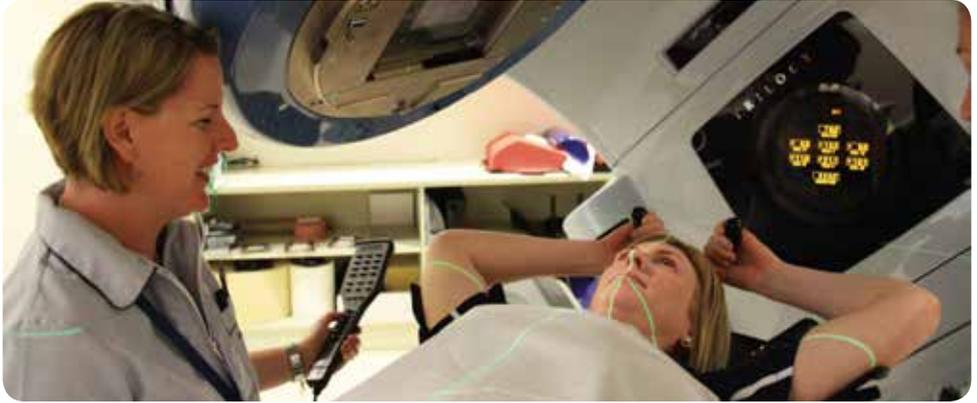
That's what we've been doing for 23 years - raising funds for this much-needed research, as well as increasing awareness of the role of healthy living in reducing cancer risk.

Evidence shows we're getting results - extending lives and improving their quality.

With your help we can continue to make a real difference.

Associate Professor Tim Price,
Chairman, GI Cancer Institute / AGITG

Changing the odds: Our research



Pancreatic cancer is aggressive and difficult to treat with a low survival rate.

There has been a considerable research effort into pancreatic cancer over the last decade, and small but real improvements in patient outcomes are starting to occur. However the progress that has been made in treatment of this disease is still slow. In fact, treatment for pancreatic cancer is currently at a similar point where bowel cancer was 5-10 years ago.

The scientific techniques to better understand pancreatic cancer and accelerate development of new approaches and better use of existing ones are now becoming available with the Australian contribution to the cancer genome project. The need to translate these laboratory findings into meaningful changes for patients through clinical research has never been greater.

For more information about clinical trials research go to our websites:

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



I personally know how important clinical trials are for saving lives of cancer patients. Embrace them with an open heart and an open mind...

Nick Goodall,
GI cancer survivor

Make a Difference



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

Locked Bag M250, Camperdown NSW 2050

P: 1300 666 769

E: info@gicancer.org.au

Donate Now www.gicancer.org.au 