Australian Pancreatic Cancer Genome Initiative

Pancreatic Cancer: Am I at risk and what can I do about it?

What is pancreatic cancer?

The pancreas is an organ in the body that helps digest food. Sometimes the cells of the pancreas begin to grow out of control and a person develops pancreatic cancer. About 3000 Australians are told that they have pancreatic cancer each year. Most of the time, people have no signs of pancreatic cancer until it has spread to other parts of their body. This makes it harder to treat and many people die within a few months of being told that they have pancreatic cancer. Finding cancer at an early stage is the best way to improve survival.

What causes pancreatic cancer?

Most cancers occur by chance when our cells become damaged. About 1 out of every 100 people (1%) will get pancreatic cancer. Some lifestyle habits like smoking, drinking a lot of alcohol, and being overweight increase the chance of getting pancreatic cancer. A small number (about 10%) of all pancreatic cancers have a genetic cause. Sometimes a gene variant is found that explains why these families get cancer. If a person has one of these gene variants, their close relatives (e.g. children, brothers/sisters) have a 1 in 2 (50%) chance of also having the gene variant. There are other families who have "familial pancreatic cancer", which means that they have a strong family history of pancreatic cancer, but genetic testing has not been done, or a gene variant has not been found.

Table 1: Some of the main genetic causes of pancreatic cancer.

Condition	Gene name	Lifetime risk of pancreatic cancer*
Peutz-Jeghers syndrome	STK11	11-32%
Hereditary Pancreatitis	PRSS1	20 – 40% (higher in smokers)
Familial melanoma	CDKN2A	17%
Hereditary breast and ovarian cancer	BRCA2	3 – 8%
Hereditary breast cancer	PALB2, ATM	Increased
Lynch syndrome	MLH1/PMS2/MSH2/MSH6	3.6%
Familial pancreatic cancer (2 relatives)	Not known	8-12%
Familial pancreatic cancer (3 or more relatives)	Not known	16-30%

* The higher % number means a higher chance of getting pancreatic cancer by the age of 80 years

What should I do if I think I have a high risk of pancreatic cancer?

Talking to your relatives about your family history is an important first step. The answers to these questions can help your doctor to assess your chance of getting pancreatic cancer:

- Have you or any of your close relatives had cancer? What is their name, date of birth, what type of cancer did they have and how old were they when they were told they had cancer?
- Did any relatives have a genetic test? What was the result?
- Have any relatives been told that they have pancreatitis (an inflamed pancreas)?
- Do you/your relatives have lifestyle risks for pancreatic cancer? (e.g. Type-2 diabetes, smoking, or being overweight)

If possible, write down details about your parents, children, brothers, sisters, grandparents, aunts, uncles and cousins on both sides of the family, even if they don't have cancer. If you have a pattern of certain types of cancer in many relatives, your GP may recommend you see a genetic counsellor. A genetic counsellor can help you to understand your risk and may be able to arrange genetic testing.

References:

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What can I do to reduce my risk of getting pancreatic cancer?

Everyone can reduce their risk of cancer by not smoking, having a good diet and being a healthy weight. This is even more important for people with a genetic risk of pancreatic cancer. If you notice anything strange about your digestion, have tea coloured urine, lose weight quickly, or have unusual pain you should see your GP straight away.

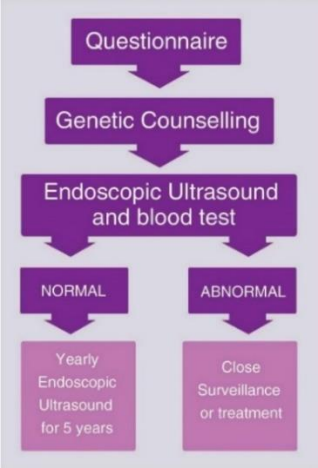
What tests can I have to screen for pancreatic cancer?

People who are at high-risk of pancreatic cancer can join the Australian Pancreatic Cancer Screening Trial, a research study that is trying to develop new ways of finding pancreatic cancer at an early stage. The best way to find out if you are eligible for the study is to gather information about your family history and contact the screening trial coordinator.

You may be eligible to join the screening trial if you:

- Are 50-80 years old (or 10 years younger than your youngest relative with pancreatic cancer), and
- Have at least two or more close relatives with pancreatic cancer, or
- Have a variant in one of the genes in the table and a close relative who has had pancreatic cancer, or
- Were told by a doctor that you have Peutz-Jeghers syndrome or Hereditary Pancreatitis, even if a faulty gene hasn't been found.

If you join the pancreatic cancer screening trial, you will be asked to do five things:



1. Answer a personal and family health questionnaire.
2. Attend an appointment with a genetic counsellor.
3. Have a yearly medical test called an endoscopic ultrasound (EUS). An EUS is a small ultrasound probe that is attached to a flexible tube. While you are asleep, a doctor will put the EUS into your mouth and direct it into your stomach to take images of your pancreas. If the doctor sees something unusual, they might do more frequent screening or other tests to look for early signs of pancreatic cancer.
4. Have a yearly blood test on the same day as the EUS to see if a marker in the blood can show that a cancer might be growing.
5. Answer follow-up questionnaires at 1 month, 1 year and 5 years from your first EUS.

If you do not want to join the research study, your GP may be able to send you to a specialist who can check your pancreas using an ultrasound or MRI, but you may need to pay to have this test done.

Where can I get more information?

There are some reliable websites online where you can find out more:
Australian Pancreatic Cancer Genome Initiative: www.pancreaticcancer.net.au/
Cancer Council Australia: www.cancer.org.au/about-cancer/types-of-cancer/pancreatic-cancer.html
Pancreatic Cancer Action Network: https://pancreaticcanceraction.org/

If you have any questions or you want to join the trial, please contact the screening trial coordinator:

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