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

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. A small number (about 10%) of all pancreatic cancers have an inherited genetic cause. This means that some families have more than one relative who gets pancreatic and other types of cancer. Sometimes a faulty gene is found, such as those shown in Table 1, which explains why these families get cancer. If a person has one of these faulty genes, their close relatives (e.g. children, brothers/sisters) have a 1 in 2 (50%) chance of also having the faulty gene. There are other families who also have many relatives with pancreatic cancer, but a faulty gene is not found (Table 2). These families are told that they have "Familial pancreatic cancer".

Table 1: Faulty genes that are known to cause pancreatic cancer

Faulty gene	Condition	Lifetime risk of pancreatic cancer*
STK11	Peutz-Jeghers syndrome	11-32%
PRSS1	Hereditary pancreatitis	20 – 40% (higher in smokers)
CDKN2A	Familial melanoma	17%
BRCA2	Hereditary breast and ovarian cancer	3 – 8%
PALB2	Hereditary breast cancer	Not known
MLH1/PMS2/MSH2/MSH6	Lynch syndrome	3.6%

Table 2: Pancreatic cancer risk based on family history

Familial pancreatic cancer	Lifetime risk of pancreatic cancer*
0 relatives with pancreatic cancer	0.96%
1 relative with pancreatic cancer	4%
Familial pancreatic cancer (2 relatives)	8-12%
Familial pancreatic cancer (3 or more relatives)	16-30%

* 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 risk of pancreatic cancer?

Talking to your relatives about your family history is an important first step. The answers to the questions below can help your GP 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 that found a faulty gene?
- Have any relatives been told that they have Hereditary 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, even if they don't have cancer. It might be easier to use a separate piece of paper to write down details about your mum's relatives and your dad's relatives. It would also help if you can find any medical records or death certificates from relatives who had cancer to confirm the type of cancer that they had.

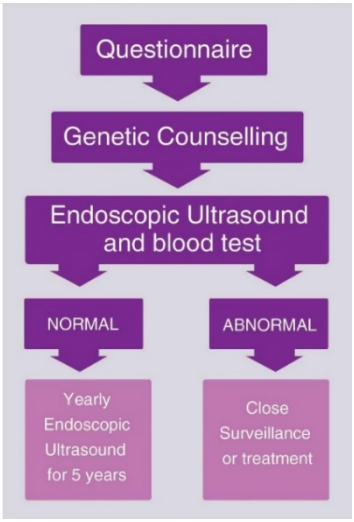
If you have a pattern of certain types of cancer in many relatives, your GP may recommend you see a genetic counsellor. A genetic counsellor can help you to understand your risk and may be able to arrange genetic testing to find out if your family has a faulty gene that causes cancer.

What tests can I have to screen for pancreatic cancer?

People who are at high-risk of pancreatic cancer can join a research study coordinated by the Australian Pancreatic Cancer Genome Initiative (APGI) at St Vincent's Hospital (Sydney) and Austin Hospital (Melbourne) that is trying to develop new ways of finding pancreatic cancer at an early stage. You can join the screening trial if you:

- Are 50-80 years (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 one of the faulty genes in Table 1 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 suggest that you have another test in 3-6 months, or they can do other tests to see if this is an early sign 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 after 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 will need to pay to have this test done.

Where can I get more information?

If you have any questions or you want to join the trial, please contact the screening trial coordinator: Tanya Dwarte: t.dwarte@garvan.org.au

You can read more about our research into Familial Pancreatic Cancer at our website**:** www.pancreaticcancer.net.au/

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