

# I have a family history of PC - what are the risks and what should I do?

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It is very important to distinguish risk as defined by population statistics from the risk you might face as an individual. You may well hear reports that having a relative with pancreatic cancer increases your risk of developing this disease by three fold or even greater. This is very misleading.

The vast majority of people who have relatives with pancreatic cancer are at no greater risk of developing the disease than any other person. However, there are a small proportion of families where there is a genuine and significant predisposition for this disease. This small number of families means that on average a person with an affected relative is at several fold greater risk than someone with no affected relative. A bit like the concept of someone living in Australia having much greater risk of being eaten by a shark than someone from the UK. While true, it ignores the fact that many Australians do not live near the coast, let alone go swimming in shark infested waters.

An individual in one of the highest high risk families could have a risk as high as 50:50 that one day they will develop this terrible disease. We estimate that this is approximately 120 fold the risk of someone with no family history. Even in these families this frightening sounding risk needs to be put in context, but certainly there is much that can and should be done by individuals in such a family to improve their chance of avoiding developing and dying of cancer.

The majority of people with a family history should be reassured that they need not live in constant fear of the disease.

The question is how you know whether your family is one of the unlucky few. An obvious indication is the number of cancer cases, but this is again often described in the literature in overly simplified terms (based on population risk and not individual risk). So you may read that two relatives with cancer signifies that you have a risk 38 fold greater risk than the general public. Again this average is made up of a small (albeit significant) proportion of families with 120 fold greater risk and the majority with no increased predisposition.

The European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer (EUROPAC) works with families to offer the best possible estimate of risk, based on the number of family members who have developed cancer and the equally important figure of the number of people in a family who have reached a ripe old age without developing cancer. While we can never be certain that a family history means a familial risk, there are some families (we know of at least 100 in the UK) where risk is considered to be enough to mean vigilance and even screening to pick up the disease early is advisable. The disease is not incurable if detected early enough.

In most of these families there is no known genetic reason for the increased risk but in approximately 1 in 5 there is a known genetic mutation that people inherit. If these mutations are not inherited then an individual in such a family will again be at no greater risk than anyone else. Even if the mutation is inherited or there is no known mutation in a particular family but high risk is assumed, this does not mean that you are likely to develop cancer tomorrow. It appears that the age at which people are at greatest risk is dependent on the age relatives developed the disease.

Brothers and sisters tend to develop the disease at similar times while children of affected parents tend to develop the disease a little earlier. Pilot screening programmes have been developed to give the greatest possible security at the ages of greatest risk.

If you are worried about your risk of pancreatic cancer please contact EUROPAC ([Europac@liv.ac.uk](mailto:Europac@liv.ac.uk), 0151 706 4168), they will be happy to advise you. Other than that the best advice is to stop smoking (if you ever started) and be aware of the warning signs that should be brought to the attention of your GP along with your family history. These include abdominal pain, jaundice, loss of weight and onset of diabetes; but always remember that in most cases these will be explained by less threatening conditions than pancreatic cancer.

**The following references may be of interest.**

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