

About Carcinoid - A Quick Guide

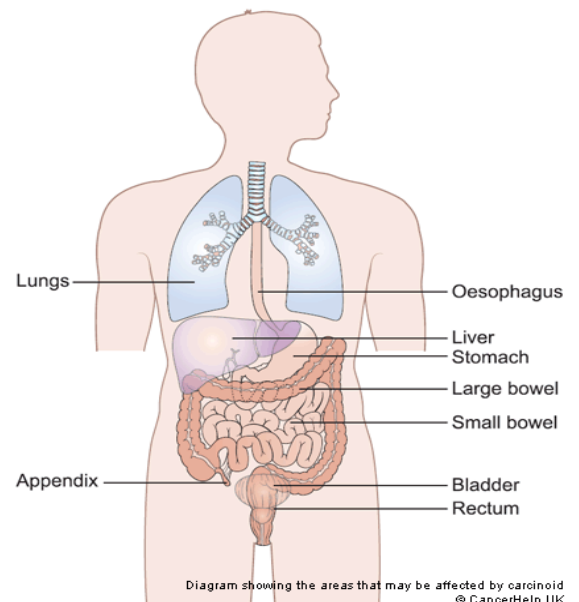


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This is a brief summary of the information on 'About carcinoid' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

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What are carcinoid tumours?

Carcinoids are rare, slow growing tumours that may not cause any symptoms for several years. Most of these tumours occur in people over the age of 60. Carcinoid tumours are also sometimes just called 'carcinoid'. They are one type of tumour of the neuroendocrine system.

Most carcinoid tumours are found in the digestive system. But they can also develop in the lung, pancreas, kidney, ovaries or testicles.

Carcinoid tumours and the neuroendocrine system

The neuroendocrine system is made up of nerve and gland cells. It makes hormones and then releases them into the bloodstream. There are neuroendocrine cells in the gut, including the food pipe (gullet or oesophagus), in the lungs and in the pancreas. Carcinoid tumours develop when these neuroendocrine cells become cancerous.



What is carcinoid syndrome?

Some carcinoid tumours release hormones that cause particular symptoms. Doctors call this collection of symptoms 'carcinoid syndrome'. About 1 in 10 people with a carcinoid tumour (10%) have carcinoid syndrome.

Risks and causes of carcinoid

Risk factors for carcinoid

Carcinoid tumours are rare. They are slightly more common in men than women. They are most common in middle aged people, although anyone can develop carcinoid at any age. More women than men develop carcinoid under the age of 50. But more men develop it after 50.

There is very little information about what causes carcinoid, or increases your risk of developing it. Doctors think that most cases happen by chance. But there are a few things that increase the risk.

Carcinoid is slightly more common in black men of African descent than it is in other ethnic groups. People who smoke may also have an increased risk of certain types of carcinoid.

Family history

Carcinoid is more common in people who have a rare family syndrome called multiple endocrine neoplasia type 1 (MEN1) or who have a condition called neurofibromatosis. People whose parents have carcinoid have a higher risk of developing it. Having a parent with certain other types of cancer slightly increases the risk. Having a brother or sister with bowel cancer also slightly increases the risk.

Other medical conditions

Having a stomach condition where the stomach produces too much acid also increases the risk of carcinoid.

Screening for carcinoid

Screening means testing for early stages of a disease before there are any symptoms.

We do not screen for carcinoid in the UK. At the moment we don't have a proven test that can safely and reliably find carcinoid tumours. And because these tumours are rare, very few would be found and the cost of screening everyone would be high.

If you believe that you may be at a higher than average risk of developing a carcinoid tumour, for example if you have a particular medical condition, you can explain this to your doctor. They may be able to give you regular check ups. If you have inherited a rare family syndrome called multiple endocrine neoplasia your doctors may suggest that you regularly have tests to check for a number of different types of cancer. Doctors know that some people with this family syndrome will go on to get carcinoid.

Symptoms of a carcinoid tumour

Many people don't have any symptoms in the early stages. Doctors often diagnose carcinoid when doing tests for something else. Your symptoms will depend on where the carcinoid develops in the body.

In carcinoid of the lung, symptoms may include cough, coughing up blood, breathlessness, wheezing, chest pain, tiredness, feeling sick and weight gain.



Carcinoid of the stomach may cause pain, weight loss and fatigue (feeling tired and weak).

Carcinoid of the bowel does not usually cause symptoms. If it does, it can cause abdominal pain or blockage of the bowel. With blockage of the bowel you may have constipation, watery diarrhoea and feel or be sick. Some people with carcinoid of the bowel have vague symptoms for many years. Doctors sometimes diagnose these as irritable bowel syndrome.

Symptoms of carcinoid syndrome

Some carcinoid tumours produce large amounts of hormones and cause 'carcinoid syndrome'. Your symptoms will depend on the hormone that your tumour is making. You may have flushing of the skin, abdominal pain, diarrhoea, loss of appetite, fast heart rate, wheezing, and changes in blood pressure.

Should I see a carcinoid tumour specialist?

It can be very difficult for GPs to decide who may have a carcinoid tumour and who may have something more minor that will go away on its own. With many symptoms, your GP is perfectly right to ask you to wait to see if they get better. But, if your GP thinks your symptoms could be due to a cancer or carcinoid, they should refer you to a specialist urgently. According to Department of Health guidelines for urgent referrals, you should ideally get an appointment within 2 weeks.

About NICE guidelines

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines to help GPs decide who should be seen urgently by a specialist.

There aren't any specific guidelines for carcinoid because it is so rare and the symptoms can be so varied. So your doctor will look at your symptoms to decide which kind of specialist you need to see. For instance, if you have bowel problems, you will see a doctor specialising in diseases of the bowel. If you are diagnosed with carcinoid you will be referred to a team of doctors who have expertise in treating carcinoid tumours.

If you are still worried

If you are concerned that your GP is not taking your symptoms seriously enough, it might be helpful to print this PDF and ask your GP to talk it through with you.

Questions for your doctor about carcinoid

- Can you explain what carcinoid is?
- How will I know if I have carcinoid?
- What increases my risk of getting carcinoid?
- Can I have any tests to detect carcinoid?
- Should I give up smoking?
- Could my symptoms be caused by carcinoid?
- My father had carcinoid - does this mean I am more likely to get it?
- What is carcinoid syndrome?



Notes

More information

For more information about carcinoid, visit our website
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in September 2010. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor.
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