

Carcinoid lung tumour

A patient's guide

What is a carcinoid lung tumour?

Lung carcinoid tumours are unusual tumours that starts in neuroendocrine cells in your lungs. They account for 1-2% of all lung cancers. They tend to grow slower than other types of lung cancers.

Carcinoid tumours are a type of tumour of the neuroendocrine system. This system is made up of special types of nerve and gland cells called neuroendocrine cells. They make hormones like adrenaline that are released into the bloodstream. Cells in this system don't form as an organ but are scattered throughout the body in organs like the lungs, intestine and stomach.

Carcinoid tumours develop more in the digestive tract than the lungs. With only 2 out of 10 carcinoid tumours developing in the lungs.

Types of carcinoid tumour **There are two types of lung carcinoid:**

- Typical carcinoids grow slowly and only rarely spread.

- Atypical carcinoids are much rarer, tend to grow faster and are more likely to spread to other parts of the body than typical carcinoids.

Doctors can only tell the difference by looking at the cells under the microscope. 9 out of 10 (90%) lung carcinoids are typical in nature. A carcinoid tumour may form in the walls of the large airways (bronchi) near the centre of the lungs, or develop in the smaller airways (bronchioles) towards the outer edges of the lungs and is called peripheral. The tumour's location may affect which symptoms a patient has and how the carcinoid can be treated.

What are the symptoms of lung carcinoid tumours?

Because typical carcinoid lung tumours tend to grow slowly they may not cause any symptoms for many years. Sometimes they are found by medical tests carried out for other reasons.

If a carcinoid is present in the large airways symptoms may include:

- Cough and sometimes blood in the phlegm or sputum
- Wheezing

- Shortness of breath
- Chest pain

Lung carcinoid tumours can cause partial or complete blockage of an air passage that can lead to a chest infection. Carcinoid syndrome is a condition related to over-production of certain hormones by the neuroendocrine cells of the tumour. It is very uncommon to have carcinoid syndrome from a lung tumour.

What tests may be done?

Imaging (chest X-rays)

Computed tomography (CT scan) - uses x-rays taken from different angles, which are combined by a computer to make detailed pictures of organs. It can provide information on the size, shape and position of the carcinoid tumour and show any enlarged lymph nodes.

Radionuclide scan

Positron Emission Tomography (PET) scan. This is a type of nuclear medicine imaging and uses a small amount of radioactive material called radiotracers. Cancer cells are more metabolically active and absorb the radiotracer at a higher rate so show up brighter on the scan.

Prior to this scan you will be injected with a small dose of a radioactive glucose (sugar) solution. You will be advised to avoid close contact with infants and pregnant women for at least 12 hours after you receive this medication. You will be asked to rest for about 40 minutes to allow the glucose to move around your body. The scan will take around 30 minutes to perform.

There are two different types of PET scans used in neuroendocrine tumours (NETs) –

Fluorodeoxyglucose (FDG) and Gallium-68 Dotatate. Which type of scan you will have will be determined by your doctor and dependent on the type and grade of tumour you have.

Prior to your PET CT scan you will receive a patient information leaflet that identifies in more detail preparation and potential complications.

MRI Liver

May be considered to get more detailed information regarding the liver which may not show up well on the other scans.

Biopsy

The only way to know for sure if a person has a carcinoid tumour is to remove cells from the tumour and look at them under a microscope. This is called a biopsy.

Ways to obtain a lung biopsy.

1. Bronchoscopy + biopsy
2. EBUS (Endobronchial ultrasound biopsy)
3. CT Needle biopsy
4. Surgical biopsy

Your clinical team will discuss with you the most appropriate method of obtaining a biopsy.

Blood and urine tests

Blood and urine tests may find substances that carcinoid tumours secrete eg serotonin or chromogranin-A in the blood may be a sign of a typical carcinoid tumour. The level of 5-HIAA a byproduct of serotonin can show up in urine.

How are lung carcinoid tumours staged?

The staging system most often used for lung carcinoid tumours is the American Joint Committee on Cancer (AJCC) TNM system, which is based on three

key pieces of information:

- The size and extent of the main tumor (T): How large is the tumor? Has it grown into nearby structures or organs?
- The spread to nearby lymph nodes (N): Has the tumour spread to lymph nodes within the chest?
- The spread (metastasis) to distant sites (M): Has the tumour spread to distant organs?

Numbers or letters after T, N, and M provide more details about each of these factors. Higher numbers mean the carcinoid tumour is more advanced. Once a person's T, N, and M categories have been determined, this information is combined in a process called stage grouping to assign an overall stage.

Staging for lung carcinoid tumours can be complex, so ask your doctor to explain it to you in a way you understand.

Knowing the stage and position of a carcinoid tumour helps the doctors decide on the most appropriate treatment.

What are the main treatments for lung carcinoid tumours?

The method of treatment will depend on the type of carcinoid (typical or atypical) and its staging. It may also depend on your overall health. You may not have any treatment straight away if your carcinoid is not causing symptoms or is not growing. Your doctor will monitor you with regular check-ups and you will be offered treatment if you develop symptoms. This approach is sometimes called “watchful waiting”.

Surgery for carcinoid tumours

Many lung carcinoid tumours can be treated with surgery alone. You may have surgery if you:

- Have early stage or localised carcinoid in the lung.
- Are generally well.

When the aim of this surgery is to completely remove the carcinoid, it is known as curative or radical surgery. If the tumour is peripheral a segmentectomy or lobectomy would be required to remove it completely plus the local lymph nodes. For central carcinoids there are specialised

procedures that aim to remove the entire tumour called bronchial sleeve resection or sleeve lobectomy.

Other types of treatment

Chemotherapy

Chemotherapy uses drugs to destroy tumour cells. This works by disrupting their growth. Chemotherapy isn't generally the first choice of treatment for typical carcinoid tumours.

Radiotherapy

Radiotherapy is treatment with high energy x-rays that are aimed at the tumour to destroy tumour cells, or sometimes to the place from which the tumour was removed surgically.

What are the other treatments for carcinoid tumours?

When a carcinoid tumour is present in the airways it is called endobronchial. There are various forms of endobronchial treatment using a bronchoscope. This is a special scope with either a laser or freezing probe fitted to it. This can be used to destroy the tumour cells. It can open up an airway, and can result in excellent local control of the tumour.

In some cases this can be curative. The use of a freezing method is known as cryotherapy.

What happens after initial treatment?

Lung carcinoid tumours are often cured by the initial treatment but sometimes they can come back (recur) many years later. If you have completed your treatment, your doctor will still want to monitor you closely. Your doctor will want to see you regularly for follow-up. The time between visits may be extended if there are no problems.

It is very important to go to all of your follow-up appointments. During these visits, your doctor will ask about any problems you are having. They may arrange imaging tests such as chest x-rays or CT scans, or a check bronchoscopy for endobronchial disease. Generally, the prognosis of lung carcinoids is very good.

Recurrent carcinoid tumours
Carcinoid tumours can sometimes come back, even years after initial treatment. If this happens, further treatment options will depend on where the cancer is and what treatment has been used already.

Further information can be obtained on carcinoid tumours from the following sources

NET Patient Foundation
netpatientfoundation.org

Cancer Research UK
cancerresearchuk.org

Macmillan Cancer Support
macmillan.org.uk

Contact details

Clinical nurse specialist team
Monday to Friday 09:00 – 17:00
(except bank holidays)
01223 639898

Ward contacts

5 South West 01223 638515
5 South East 01223 638535

Consultant secretaries

Monday to Friday 09:00 – 17:00
(except bank holidays)
Mr Aresu 01223 639766
Mr Coonar 01223 639874
Mr Peryt 01223 639775
Ms Rogers 01223 639775

Royal Papworth Hospital NHS Foundation Trust

A member of Cambridge University Health Partners



Papworth Road
Cambridge Biomedical Campus
CB2 0AY



royalpapworth.nhs.uk



01223 638000

Alternative versions of this leaflet

Large print copies and alternative language versions of this leaflet can be made available on request.

View a digital version of this leaflet by scanning the QR code.



Become a member

As a member of Royal Papworth Hospital Foundation Trust, you could have your say on how the organisation is run, now and in the future. You will receive regular information and news from Royal Papworth and get invited to exclusive events. Membership allows you to vote for your representatives on the Council of Governors, talk to your Council of Governor representatives and stand as a governor.



Scan the QR code or head to royalpapworth.nhs.uk/membership to find out more.

| | |
|-----------------|---------------------------|
| Author ID: | Clinical nurse specialist |
| Department: | Oncology |
| Printed: | April 2025 |
| Review date: | April 2027 |
| Version: | 3 |
| Leaflet number: | PI 178 |