

# Carcinoid Syndrome

## What is carcinoid syndrome?

Carcinoid syndrome is the term used to describe a group of symptoms associated with some neuroendocrine cancers. Carcinoid syndrome most often occurs when neuroendocrine cancer is in the small bowel or lung and has metastasised to the liver. Carcinoid syndrome can also occur when neuroendocrine cancers are in other areas of the body, however this is less common.

Carcinoid syndrome is caused by neuroendocrine cancer producing excessive amounts of the hormones and peptides that are normally active during digestion and breathing. One of the most common hormones to be overproduced is serotonin. Overproduction of these hormones and peptides can lead to the group of symptoms known as Carcinoid syndrome. Neuroendocrine cancers that overproduce hormones are sometimes described as a *functioning neuroendocrine cancer*.

## Do all neuroendocrine cancers cause carcinoid syndrome?

No, not all neuroendocrine cancers cause carcinoid syndrome. Neuroendocrine cancers that do not overproduce hormones are often referred to as non-functioning neuroendocrine cancer.

Carcinoid syndrome is the most commonly occurring hormonal syndrome associated with neuroendocrine cancers. It is important to know there are several other less common hormonal syndromes that can occur (for example; excessive insulin production caused by an insulinoma and excessive gastrin produced by a gastrinoma).

## What are the symptoms associated with carcinoid syndrome?

The symptoms of carcinoid syndrome include:

- Flushing, intermittent or persistent, of the face, neck and upper chest. Flushing from carcinoid syndrome is usually a dry flush with no associated sweating.
- Diarrhoea multiple times a day, sometimes associated with urgency.
- Wheezing or shortness of breath (bronchospasm).
- Abdominal pain intermittent and/or cramping.
- Skin changes such as telangiectasia (spider veins) and pellagra (dark skin rash caused by niacin deficiency – Vitamin B3) occur in a small number of people with neuroendocrine cancer.

## Investigations for carcinoid syndrome

5HIAA 24-hour urine test; measures 5HIAA, a biproduct of serotonin breakdown

Chromogranin A (CgA) blood test; measures the levels of the CgA, a protein produced by neuroendocrine cancer cells and released into the blood. CgA is currently the blood test available to assist with neuroendocrine cancer diagnosis and monitoring.

## Essential knowledge

If you have been diagnosed with carcinoid syndrome it is essential, you are aware of:

### Carcinoid crisis

A life-threatening form of carcinoid syndrome that causes extreme changes in blood pressure due to excessive hormone release. It can occur when a person with neuroendocrine cancer experiences significant stress, undergoes biopsies, anaesthetic, liver directed therapies or peptide receptor radionuclide therapy (PRRT). If you have carcinoid syndrome and are having a procedure, it is essential healthcare professionals are made aware so that appropriate management is organised to prevent a carcinoid crisis.

For further information see

- [Carcinoid Crisis Fact Sheet](#)
- [Anaesthesia Fact Sheet](#)
- [Patient Medical Alert Card](#)



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## Carcinoid heart disease

A hormonal complication related to carcinoid syndrome caused by neuroendocrine cancer. If a person is diagnosed with or experiences carcinoid syndrome symptoms, it is vital to be assessed and monitored for carcinoid heart disease.

For further information see

- [Carcinoid Heart Disease Fact Sheet](#)

## Management and treatments for carcinoid syndrome

### Medication

Somatostatin Analogues are used to control the excessive hormone secretion and manage carcinoid syndrome symptoms.

Antidiarrhoea medication may be used under medical supervision however this does not treat the cause.

### Surgery

Surgery with an aim to remove all or some (debulking) of a neuroendocrine cancer can reduce the symptoms of carcinoid syndrome.

## Behavioural modifications

Diarrhoea and Flushing has sometimes been reported to be triggered by alcohol, certain foods, exercise and emotions. Assessment and education from a dietitian may be of benefit to identify any potential trigger foods as a way of reducing symptoms.

## Symptom diary

If carcinoid syndrome symptoms are persistent or have re occurred during or after treatment, a symptom diary is a helpful strategy to use to communicate with medical specialists the intensity and frequency of any symptoms.

If you need further information about carcinoid syndrome and neuroendocrine cancer, please contact your treating team or the **NET nurses at NeuroEndocrine Cancer Australia on 1300 287 363** Monday-Friday 9am-5pm.



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