NeuroEndocrine Cancer Australia

Carcinoid Heart Disease

What is carcinoid heart disease?

Carcinoid heart disease is a hormonal complication related to neuroendocrine cancer that causes carcinoid syndrome.

When neuroendocrine cancer causes carcinoid syndrome it can cause high levels of circulating serotonin. The heart, and in particular the heart valves, have many serotonin receptors. When the heart is exposed to high levels of circulating serotonin from a neuroendocrine cancer, overstimulation of connective tissue signalling pathways occur and heart valves that are normally elastic tissue, instead thicken and stiffen (fibrosis). This occurs most commonly on the right side of the heart. Fibrosis can affect the way the heart valves open and close and can result in blood flows problems through the heart and lungs. The impact can be significant on the heart's ability to function. In some circumstances it can lead to a decrease in the overall function of the heart and right sided heart failure.

What are the symptoms?

- Fatigue
- Shortness of breath on exercise (dyspnoea)
- Swelling of lower legs (oedema)
- Fluid collecting in the abdominal region (ascites)
- Unintentional weight loss
- Irregular heartbeat (Atrial fibrillation)

Who is at risk of carcinoid heart disease?

People that have carcinoid syndrome from a neuroendocrine cancer are at risk of developing carcinoid heart disease. It is understood that between 20-50% of people with carcinoid syndrome will have carcinoid heart disease.

How is carcinoid heart disease diagnosed

Some people are diagnosed with CHD following investigation of reported symptoms.

However, many people with carcinoid heart disease do not experience any symptoms.

It is vital that people with carcinoid syndrome have their risk of carcinoid heart disease assessed by a medical specialist such as a medical oncologist or cardiologist.

Investigations for carcinoid heart disease

 5HIAA 24-hour urine test (measures 5HIAA; a biproduct of serotonin breakdown in the urine)

- NT-pro BNP blood test (screens for heart stress)
- Echocardiogram (ultrasound of the structure and function of the heart)

Management of carcinoid heart disease

- People with carcinoid syndrome who have symptoms suspicious of carcinoid heart disease require monitoring with an Echocardiogram
- If changes are identified on echocardiogram, early referral to a cardiologist should be considered
- Diet modification is sometimes recommended
- Medication management may be considered under medical guidance (eg; diuretics)
- Neuroendocrine cancer treatments such as; somatostatin analogues, liver directed therapies and surgery, that decrease excessive hormone production and control the cancer can minimize carcinoid syndrome and in turn prevent further deterioration in carcinoid heart disease.
- Replacement of damaged heart valves through surgery is sometimes necessary. If surgery is required pre surgery management is required to prevent carcinoid crisis.

For further information and support about neuroendocrine cancer contact the **NET nurses at NeuroEndocrine Cancer Australia on 1300 287 363** Monday-Friday 9am-5pm.









