FLaNET

NET Light Guide

Volume 3 | Carcinoid Heart Disease

NET Light Guide

Getting to the Heart of the Matter:

Understanding Carcinoid Heart Disease in People Living with Neuroendocrine Tumors

Living with a neuroendocrine tumor (NET) often means learning to recognize new symptoms and navigate complex treatment decisions. But for some people with carcinoid syndrome, changes such as increasing shortness of breath, fatigue, or swelling may signal something beyond their cancer.

Carcinoid heart disease is a rare but important complication caused by long-term exposure to hormones released by some neuroendocrine tumors. Left untreated, it can lead to significant heart valve damage. Fortunately, advances in screening, surgery, and NET treatments have dramatically improved outcomes over the past two decades.

The key is recognizing the signs early. In this month's NET Light Guide, we'll explain what carcinoid heart disease is, who may be at risk, how it is diagnosed, and why timely treatment can help patients regain their quality of life.

Key Takeaways
CARINOID HEART DISEASE

- Carcinoid heart disease most often occurs in patients with carcinoid syndrome.
- Long-term exposure to serotonin can damage the heart valves.
- Symptoms often develop gradually and may be mistaken for cancer-related fatigue.
- Echocardiograms play an important role in early detection.
- Early diagnosis and treatment can significantly improve quality of life.

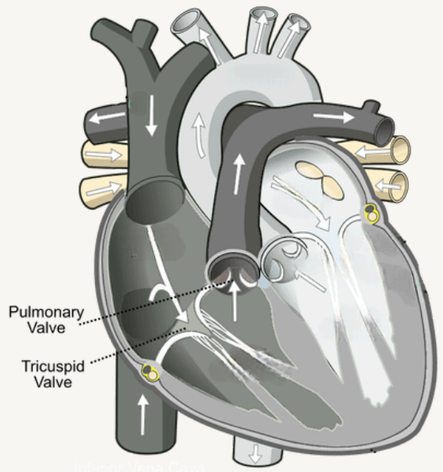
What Is Carcinoid Heart Disease?

Carcinoid heart disease is a condition in which hormones produced by certain neuroendocrine tumors damage the heart valves over time.

Unlike many heart conditions that affect the heart muscle itself, carcinoid heart disease primarily affects the valves responsible for directing blood through the heart. Continuous exposure to serotonin and other substances can cause these valves to become thickened, stiff, and unable to open and close properly.

The condition most commonly affects the two valves on the right side of the heart:

- **Pulmonary valve**
- **Tricuspid valve**



This occurs because blood carrying these hormones reaches the right side of the heart before traveling to the lungs, where many of the hormones are naturally broken down.

Who is Most at Risk?

Not everyone with a neuroendocrine tumor develops carcinoid heart disease. **Patients are generally at higher risk if they have:**

- Carcinoid syndrome
- Long-standing hormone-producing tumors
- Persistently elevated serotonin or urine 5-HIAA levels

Fortunately, modern treatments that better control hormone production have reduced the number of patients who develop advanced carcinoid heart disease compared with previous decades.

Why Early Detection Matters?

Heart valve damage usually develops gradually, and many patients adjust to worsening symptoms without realizing their heart is being affected. By the time symptoms become severe, significant valve damage may already be present. Routine monitoring allows healthcare teams to identify changes before permanent heart dysfunction occurs.

Could Your Symptoms Be Related to Your Heart?

One of the challenges of carcinoid heart disease is that its symptoms often resemble those caused by cancer itself or by everyday aging.

Common Symptoms:

- **Fatigue**
- **Difficulty climbing stairs**
- **Shortness of breath during activity**
- **Reduced exercise tolerance**
- **Swelling in the legs**
- **Abdominal swelling caused by fluid buildup**

While these symptoms do not always indicate heart disease, they should never be ignored, particularly in patients with carcinoid syndrome.

SYMPTOMS OFTEN MISTAKEN FOR OTHER CONDITIONS:

Patients frequently assume symptoms are caused by:

- Cancer-related fatigue
- Aging
- Being out of shape
- Treatment side effects

If symptoms continue to worsen or interfere with daily life, speak with your healthcare team.

Jill's Story

"I THOUGHT IT WAS JUST THE CANCER."

When Jill Samson was diagnosed with a metastatic small bowel neuroendocrine tumor, she assumed every symptom she had experienced over the previous several years was related to her cancer.

She had gradually lost the ability to do activities she once enjoyed: climbing stairs left her breathless, running with children at work became impossible, even walking uphill required frequent stops to catch her breath.

> "I really feel like I got my life back.."
>
> — Jill Samson

Before receiving her NET diagnosis, Jill sought answers from 14 different physicians and received multiple diagnoses, but none fully explained what she was experiencing.

After meeting with her NET specialist, simple cardiac testing raised immediate concern. She was referred to a cardiologist, where an echocardiogram revealed severe carcinoid heart disease affecting both her tricuspid and pulmonary valves. Within weeks, she underwent surgery to replace both valves.

Although her recovery included complications, including temporary kidney failure requiring dialysis, Jill ultimately regained her strength and returned to many of the activities she thought she had lost forever.

How Is Carcinoid Heart Disease Diagnosed?

The most important screening tool for carcinoid heart disease is an echocardiogram, an ultrasound that allows physicians to examine how well the heart valves are functioning.

Depending on a patient's individual situation, additional testing may include:

- Urine 5-HIAA to monitor serotonin production
- Blood tests that evaluate cardiac stress
- Transesophageal echocardiography (TEE)
- Additional cardiac imaging when needed

Patients with carcinoid syndrome or persistently elevated serotonin levels may benefit from routine heart monitoring, even before symptoms develop.

Treatment and Looking Ahead

Today's surgical techniques, combined with improvements in NET therapies and multidisciplinary care, have dramatically improved outcomes for patients living with carcinoid heart disease.

Successful treatment often involves close collaboration between:

- NET specialists
- Cardiologists
- Cardio-oncology teams
- Cardiac surgeons

Because heart damage can progress over time, experts emphasize treating severe valve disease before irreversible heart dysfunction develops.

Questions to Discuss

WITH YOUR CARE TEAM

Am I at risk for carcinoid heart disease?

Should I have regular echocardiograms?

How often should my urine 5-HIAA levels be monitored?

Could my symptoms be related to my heart rather than my cancer?

Should I see a cardiologist with experience caring for patients with NETs?

Connect, Understand, and Move Forward with FLaNET

Living with a neuroendocrine tumor can be overwhelming, but you don't have to navigate it alone. At FLaNET, we are committed to providing patients and caregivers with trusted educational resources, expert-led webinars, and opportunities to connect with a supportive community.

Whether you are newly diagnosed or have been living with NETs for years, staying informed can help you recognize important symptoms, ask informed questions, and partner with your healthcare team to make confident decisions.

Explore educational resources, attend upcoming webinars, and connect with NET specialists when you join the growing FLaNET community.

- Watch Our Carcinoid Heart Disease Webinar
- Explore educational resources
- Watch Upcoming Webinars
- Connect With NET Specialists
- Make A Donation

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