CONDITION

Functioning carcinoid

A functioning carcinoid is a neuroendocrine tumor that releases hormones causing symptoms such as flushing and diarrhea.

WHAT IT IS
Hormone-releasing neuroendocrine tumor causing noticeable symptoms

BODY SYSTEM
Digestive system, lungs, heart, and circulation

MAIN SYMPTOMS
Skin flushing, diarrhea, abdominal cramping, wheezing

WHAT CAUSES IT
Hormone release from a neuroendocrine tumor

HOW IT IS DIAGNOSED
Biopsy, hormone tests, and CT, MRI, or receptor imaging

MAIN TREATMENT
Surgery and treatments controlling hormones or tumor growth

CAN IT BE CURED?
Sometimes - localized tumors may be removed

IS IT AN EMERGENCY?
Sometimes - severe breathing or circulation problems

LONG-TERM OUTLOOK
Often manageable, shaped by tumor spread and heart involvement

Overview

A functioning carcinoid is a neuroendocrine tumor that releases enough hormones or hormone-like chemicals to cause symptoms. Neuroendocrine cells receive nerve signals and make hormones. They are found throughout the body, particularly in the digestive system and lungs.

"Carcinoid" is an older term. Health professionals now often use neuroendocrine tumor , or NET. These tumors are classified by where they began, how quickly their cells are growing, and whether they have spread.

A tumor is functioning when its chemical release causes a recognizable symptom pattern. The most common is carcinoid syndrome , which may include skin flushing, watery diarrhea, abdominal cramps, wheezing, and a fast heartbeat. Serotonin and other chemicals contribute

to these symptoms.

Digestive NETs often do not cause carcinoid syndrome until they have spread to the liver, because the liver usually breaks down their chemicals before they reach the wider circulation. Tumors in the lungs or ovaries may cause symptoms without liver spread.

Both the tumor and its hormone release need treatment. Prolonged exposure to these chemicals can damage heart valves, but treatment can often control symptoms and slow tumor growth.

Symptoms

Symptoms depend on the chemicals released, the tumor's location, and whether it has spread. They may be intermittent or become more frequent over time.

Common features of carcinoid syndrome include:

Flushing may last minutes or longer. Alcohol, large meals, stress, exercise, or certain foods may trigger episodes. Persistent diarrhea can cause dehydration, weight loss, and abnormal salt levels.

The tumor itself may also cause symptoms. Digestive tumors can cause nausea, bleeding, intermittent pain, or bowel blockage. Lung tumors may cause cough, repeated chest infections, or chest discomfort.

Carcinoid heart disease may cause breathlessness during activity, ankle or leg swelling, tiredness, abdominal swelling, or reduced exercise tolerance. These usually develop gradually but need prompt assessment.

Many other conditions can cause flushing or diarrhea, so either symptom alone does not mean you have a functioning carcinoid.

- Sudden warmth and redness of the face, neck, or upper chest
- Frequent or urgent watery diarrhea
- Abdominal pain or cramping
- Wheezing, coughing, or shortness of breath
- A fast or forceful heartbeat

Causes and risk factors

A functioning carcinoid develops when changes in a neuroendocrine cell allow it to grow into a

tumor. The cause is usually unknown. The tumor then releases serotonin or other active chemicals.

Most NETs are not inherited. A small proportion occur with inherited conditions such as multiple endocrine neoplasia type 1. A relevant family history may lead to genetic counseling.

Some stomach NETs are associated with autoimmune atrophic gastritis or rare conditions causing high gastrin levels, although these tumors do not all produce carcinoid syndrome.

"Functioning" describes the effects of hormone release. A non-functioning NET does not necessarily become functioning.

Diagnosis

Diagnosis usually requires evidence of a NET and evidence that its chemical release explains the symptoms.

A 24-hour urine test for 5-HIAA , a serotonin breakdown product, is commonly used when carcinoid syndrome is suspected. Plasma 5-HIAA may be available. Foods, medicines, and supplements can affect results, so follow the laboratory's preparation and collection instructions. Do not stop medicines on your own.

Chromogranin A may also be measured, but it is not specific to NETs. Acid-suppressing medicines, kidney problems, and other conditions can raise it.

CT or MRI scans help locate the tumor and determine whether it has spread. Somatostatin-receptor imaging, often a PET scan using a specialized tracer, can identify tumor cells with particular receptors.

A biopsy confirms that a growth is a NET and establishes its grade , which indicates how quickly its cells appear to be growing. The report may include a Ki-67 index measuring the proportion of dividing cells.

Other tests may include endoscopy, colonoscopy, chest imaging, or an echocardiogram to examine the heart. Blood tests may assess kidney and liver function, hydration, nutrition, and possible heart strain.

Treatment and management

Treatment addresses both the tumor and its hormone effects. Care may involve specialists in cancer, endocrinology, digestive health, surgery, radiology, nuclear medicine, and cardiology.

Surgery may remove a localized tumor and nearby affected tissue and can sometimes be

curative. It may also help selected people with tumor spread by reducing symptoms or preventing bowel problems.

Somatostatin analogues can reduce flushing and diarrhea and may slow some tumors. Short-acting medication may be used for breakthrough symptoms or around procedures, while longer-acting forms provide ongoing control.

If diarrhea continues despite hormone-blocking treatment, another medicine may be added to reduce serotonin production. Doctors may first check for other causes, including infection, medicine effects, reduced pancreatic enzyme production, or previous bowel surgery.

Other tumor-directed options include:

Suitability depends on tumor site, grade, spread, scan findings, symptoms, general health, and previous treatment.

Carcinoid heart disease may require medicines for fluid buildup and, in selected cases, heart valve surgery. Controlling hormone release remains important.

Before surgery, anesthesia, or an invasive procedure, tell the team that you have a functioning NET. They may provide treatment to reduce the risk of carcinoid crisis , a sudden severe hormone-release reaction.

- Liver-directed procedures for tumors concentrated in the liver
- Peptide receptor radionuclide therapy for receptor-positive cells
- Targeted medicines that interfere with tumor growth
- Chemotherapy for selected or faster-growing tumors
- Radiation treatment in situations such as painful bone spread

Complications

Long-lasting diarrhea can cause dehydration, low salt levels, weight loss, and poor nutrition.

Carcinoid heart disease occurs when tumor chemicals cause thickening and scarring, usually in valves on the heart's right side. The valves may leak or narrow, potentially causing heart failure.

Some small-bowel NETs scar tissues supporting the bowel. This can narrow the intestine or its blood vessels, causing blockage or reduced blood supply.

A carcinoid crisis is an uncommon but serious episode of intense chemical release. It may cause major blood pressure changes, severe flushing, wheezing, a very fast heartbeat, confusion, or collapse. It may occur spontaneously but is more often associated with anesthesia, surgery, or another procedure.

Tumor spread may also affect the liver, bones, or other organs.

Prevention

There is no established way to prevent most functioning carcinoids because the cell changes that cause them are usually not linked to anything a person knowingly did.

Routine screening is not recommended for people at average risk. If an inherited tumor syndrome is suspected or confirmed, genetic counseling can explain the implications for you and your relatives and guide surveillance.

If you have a NET, attend planned follow-up appointments so hormone-related and heart complications can be identified early.

Living with it and what to expect

The outlook varies. Some NETs grow slowly and remain manageable for years; others are more active or have already spread when diagnosed. Tumor site, grade, extent, hormone control, and heart involvement all affect what to expect.

Long-term follow-up may include symptom reviews, blood or urine tests, scans, and checks for treatment effects. People at risk of carcinoid heart disease may need repeated heart blood tests or echocardiograms.

Symptoms can change even when scans are stable. Record flushing, bowel frequency, breathing symptoms, weight, and possible triggers. This can help the care team assess treatment and investigate other causes.

Avoiding personal triggers may reduce episodes, but restrictive diets are not necessary for everyone. If diarrhea affects weight or nutrition, seek help from a dietitian familiar with NETs rather than removing many foods without guidance.

Planning toilet access, carrying prescribed medicines, and coordinating travel with treatment can make daily life easier. Emotional support may help when symptoms are visible or unpredictable.

Contact your care team between appointments if symptoms become more frequent, treatment seems less effective, you lose weight, or side effects interfere with daily life.

When to get medical help

Arrange prompt medical advice for new or worsening diarrhea, flushing, wheezing, weight loss, abdominal pain, ankle swelling, or breathlessness. If you already have the condition, report a clear change from your usual pattern.

Seek urgent medical care for:

Call emergency services for severe trouble breathing, fainting, confusion, chest pain, collapse, or sudden intense flushing with a racing heartbeat. Severe abdominal pain with repeated vomiting or inability to pass stool or gas may indicate bowel blockage and also requires emergency assessment.

If sudden symptoms occur during or soon after a procedure, immediately tell the treating team about the functioning carcinoid because carcinoid crisis may require rapid treatment.

- Diarrhea with very little urine, marked dizziness, or other signs of dehydration
- New breathlessness, leg swelling, or rapid loss of exercise tolerance
- Persistent vomiting or worsening abdominal swelling
- Severe or increasing abdominal pain

Common questions

Is a functioning carcinoid cancer?

A carcinoid is a NET with the potential to spread, so it is generally managed as a form of cancer. Behavior ranges from slow-growing to aggressive. Grade and stage are more informative than the older word "carcinoid" alone.

Is functioning carcinoid the same as carcinoid syndrome?

Not exactly. "Functioning" means that a NET releases chemicals causing symptoms. Carcinoid syndrome is the common symptom pattern caused mainly by serotonin and related chemicals.

Can a functioning carcinoid be cured?

Sometimes. Complete removal of a localized tumor may be curative. If it has spread, treatment usually aims to control symptoms, slow growth, prevent complications, and maintain quality of life.

Why does carcinoid syndrome often mean the tumor has reached the liver?

Chemicals from a digestive tumor usually travel first to the liver, where they are broken down. Tumors that spread to the liver can release chemicals into the wider circulation. This pattern is common but not universal, particularly for tumors beginning outside the digestive system.

What foods trigger carcinoid flushing or diarrhea?

Triggers vary. Alcohol, large meals, spicy foods, and foods high in certain natural amines affect some people, but there is no single required carcinoid diet. Recording your reactions is more useful than avoiding long lists of foods without guidance.

Can stress make the symptoms worse?

Physical or emotional stress can trigger flushing, diarrhea, or palpitations in some people, but it does not cause the tumor. Increasing symptoms still need medical review rather than being assumed to be stress-related.

Sources

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