About Gastrointestinal Carcinoid Tumors

Overview and Types

If you have been diagnosed with a gastrointestinal carcinoid tumor or are worried about it, you likely have a lot of questions. Learning some basics is a good place to start.

- What Is a Gastrointestinal Carcinoid Tumor?

Research and Statistics

See the latest estimates for new cases of gastrointestinal carcinoid tumor in the US and what research is currently being done.

- What Are the Key Statistics About Gastrointestinal Carcinoid Tumors?
- What’s New in Gastrointestinal Carcinoid Tumor Research and Treatment?

What Is a Gastrointestinal Carcinoid Tumor?

Gastrointestinal carcinoid tumors are a type of cancer that forms in the lining of the gastrointestinal (GI) tract. Cancer starts when cells begin to grow out of control. Cells in nearly any part of the body can become cancer. To learn more about what cancer is and how it can grow and spread, see What Is Cancer?

To understand gastrointestinal carcinoid tumors, it helps to know about the gastrointestinal system, as well as the diffuse neuroendocrine system.
The gastrointestinal system

The gastrointestinal (GI) system, also known as the digestive system, processes food for energy and rids the body of solid waste. After food is chewed and swallowed, it enters the esophagus. This tube carries food through the neck and chest to the stomach. The esophagus joins the stomach just beneath the diaphragm (the breathing muscle under the lungs). The stomach is a sac-like organ that holds food and begins the digestive process by secreting gastric juice. The food and gastric juices are mixed into a thick fluid, which then empties into the small intestine.

The small intestine continues breaking down food and absorbs most of the nutrients. It
is the longest section of the gastrointestinal (GI) tract, measuring more than 20 feet. The small intestine then joins the colon. This is a wider, muscular tube about 5 feet long. The appendix is found near the junction of small intestine and colon. The colon absorbs water and mineral nutrients from food and serves as a storage place for waste. The waste left after this process goes into the rectum. From there it passes out of the body through the anus as stool (feces).

The diffuse neuroendocrine system

Carcinoid tumors start from cells of the diffuse neuroendocrine system. This system consists of cells that are like nerve cells in certain ways and like hormone-making endocrine cells in other ways. These cells don’t form an actual organ like the adrenal or thyroid glands. Instead, they are scattered throughout other organs like the esophagus, stomach, pancreas, intestines, and lungs. The digestive system is large and has more neuroendocrine cells than any other part of the body. This might be why carcinoid tumors most often start in the digestive system.

Neuroendocrine cells help control the release of digestive juices and how fast food moves in the GI tract. They may also help control the growth of other types of digestive system cells.

Neuroendocrine tumors

Like most cells in the body, GI tract neuroendocrine cells sometimes go through certain changes that cause them to grow too much and form tumors. These tumors are known as neuroendocrine tumors (NETs) and neuroendocrine cancers. In the past, most abnormal growths of neuroendocrine cells were called carcinoids. But in 2000, the World Health Organization (WHO) reclassified carcinoids as neuroendocrine tumors and neuroendocrine cancers.

Neuroendocrine tumors are growths that look benign but can possibly spread to other parts of the body. Neuroendocrine cancers are abnormal growths of neuroendocrine cells which can spread to other parts of the body.

Neuroendocrine cancers (also known as neuroendocrine carcinomas) are divided into groups based on the way the cells look under a microscope:

- **Well-differentiated** neuroendocrine cancers have cells that do not look very abnormal and are not multiplying rapidly. These tumors tend to grow and spread slowly. Well-differentiated neuroendocrine cancers can look identical to benign
neuroendocrine tumors when seen under the microscope. Sometimes the only way to know for certain that a mass is a neuroendocrine cancer (and not a benign tumor) is when it spreads to other organs or tissues.

- **Poorly-differentiated** cancers have cells that look very abnormal and are multiplying more rapidly. Poorly-differentiated cancers tend to grow and spread quickly.
- **Moderately-differentiated** cancers have features in between those of well-differentiated and poorly-differentiated cancers.

### Neuroendocrine tumors of the pancreas

Neuroendocrine tumors in the pancreas are known as *islet cell carcinomas* or *pancreatic neuroendocrine tumors*. Islet cell tumors are not the same as carcinoid tumors. They have a different prognosis (course of disease and outlook) and respond differently to treatment. Neuroendocrine tumors of the pancreas are not covered here, but you can find more information in *Pancreatic Cancer*.

### Carcinoid tumors

*Carcinoid* is the term used to describe well to moderately-differentiated neuroendocrine tumors in the stomach, intestine, appendix, rectum, and lung. Carcinoid tumors that start in the lungs are not covered here, but you can find more information in *Lung Carcinoid Tumor*.

Neuroendocrine tumors and cancers act like the cells they come from, often releasing certain hormone-like substances into the bloodstream. In most people with carcinoid tumors, the levels of these hormones are not high enough to cause symptoms. But in about 1 person out of 10 with a carcinoid tumor, the tumor spreads and grows enough to release high amounts of these hormones. This can cause a set of symptoms known as the *carcinoid syndrome*. Some symptoms of the carcinoid syndrome include flushing (redness of the skin with a feeling of warmth), wheezing, diarrhea, and a fast heartbeat.

### Other gastrointestinal tumors

Carcinoids and other neuroendocrine tumors are different from the more common tumors of the GI tract. Most GI tract tumors start from the glandular cells that produce mucus and make up the inner lining of the digestive system. When these tumors are benign, they are called *adenomas*. When these cells develop into cancer, the tumors are known as *adenocarcinomas*.

These tumors differ quite a lot from carcinoid tumors in their symptoms, their outlook,
and their treatment. For these reasons, it is important to know what type of tumor you have: a neuroendocrine tumor, a neuroendocrine cancer, an adenoma, an adenocarcinoma, or some other type of tumor. Information about adenocarcinomas of the GI tract can be found in *Esophagus Cancer*, *Stomach Cancer*, *Small Intestine Cancer*, and *Colorectal Cancer*.

In general, neuroendocrine tumors and neuroendocrine cancers grow slower than other cancers in the GI tract. But how they grow and whether or not they spread to other areas varies widely. This depends to some extent on which part of the body the tumor starts in.

- References
See all references for Gastrointestinal Carcinoid Tumor

What Are the Key Statistics About Gastrointestinal Carcinoid Tumors?

Although the exact number isn’t known, about 8,000 neuroendocrine tumors and cancers that start in the gastrointestinal tract (the stomach, intestine, appendix, colon, or rectum) are diagnosed each year in the United States. These tumors can also start in the lungs (see *Lung Carcinoid Tumor* for more information) and the pancreas, and a small number develop in other organs.

The number of carcinoid tumors diagnosed has been increasing for many years. The reason for this is unknown. Some think it may be a byproduct of doing more medical tests to look for something else and finding carcinoid tumors. Since many carcinoids never cause any symptoms, there are probably many people with carcinoid tumors that are never found. These tumors might only be seen during an autopsy when a person dies of something else, or when someone has surgery or imaging tests for an unrelated condition.

The most common location of gastrointestinal carcinoid tumors is the small intestine,
often in the section near the appendix (called the *ileum*). Other common sites include the rectum, the colon (large intestine), the appendix, and the stomach.

The average age of people diagnosed with carcinoid tumors is in the early 60s. Carcinoid tumors are more common in African Americans than in whites, and are slightly more common in women than men.

- References

See all references for Gastrointestinal Carcinoid Tumor

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What’s New in Gastrointestinal Carcinoid Tumor Research and Treatment?

There is always research going on in the field of gastrointestinal (GI) carcinoids. Scientists keep looking for the causes of, ways to prevent, and new approaches to diagnose and treat GI carcinoid tumors.

Genetics

Researchers are looking for the causes of GI carcinoid tumors in the hope that this knowledge can be used to help prevent or treat them in the future. A great deal of progress has been made in recent years. For example, scientists have found that changes in the *MEN1* gene (the gene that causes multiple endocrine neoplasia, type 1) are seen in many people with GI carcinoids. Other genetic changes that seem to make tumors more aggressive are now being explored as well.

Diagnosis and staging
Because the outlook and treatment of GI carcinoid tumors and other cancers of the digestive tract are very different, accurate diagnosis is important. Researchers have made great progress in developing tests that can detect specific substances found in the cells of carcinoid tumors. Most of these tests treat tissue samples with special antibodies made in the lab. The antibodies are designed to recognize specific substances that appear only in certain types of tumors.

OctreoScan® is an imaging test commonly used to look for GI carcinoid tumors in the body. Researchers are now looking at other radionuclide methods to see if they can detect carcinoid tumors early.

**Treatment**

Surgery is the main treatment option for carcinoid tumors when possible. But better approaches are needed when surgery can’t remove all of the tumors. Chemotherapy has had limited success. New chemotherapy drugs and combinations of drugs are being studied, but true advances are likely to come from other approaches.

**Targeted therapy**

Several newer types of drugs, known as targeted therapies, are now being studied for use against neuroendocrine tumors. Targeted therapy uses drugs or other substances to identify and attack cancer cells while doing little damage to normal cells. These therapies attack the parts of cancer cells that make them different from normal, healthy cells. Each type of targeted therapy works differently, but all alter the way a cancer cell grows, divides, repairs itself, or interacts with other cells.

Everolimus (Afinitor®) is a targeted drug that works by blocking a cell protein known as mTOR, which normally helps cells grow and divide. It is approved by the FDA to treat advanced pancreatic neuroendocrine tumors. It is also being studied to see if it can help patients with GI carcinoids. In one study, adding everolimus to octreotide (Sandostatin) was better than octreotide alone in halting tumor growth.

Bevacizumab (Avastin®) is a type of targeted drug that attacks a tumor’s blood supply. It is already being used against some types of cancer and is being studied for carcinoid tumors.

Other targeted therapies block the molecules that increase the growth of cancer cells. Some of these (such as erlotinib, temsirolimus, and sorafenib) are used in other types of cancer and are now being tested against carcinoids.
Netazepide is a new drug that blocks the hormone gastrin. In early studies of patients who have carcinoid tumors of the stomach and high gastrin levels, this drug helped the tumors shrink. More studies are planned.

Radionuclide scans, such as the I-131 MIBG scan, can help find neuroendocrine tumors because they use substances that are attracted to neuroendocrine cells. These substances are attached to slightly radioactive elements so that they can be detected with special cameras. Using higher doses of I-131 MIBG delivers more radiation to the tumor cells and is used in Europe to treat neuroendocrine tumors and cancers. But doctors are now studying the use of a form of octreotide (or a similar drug called edotreotide) that has been attached to a radioactive form of the element yttrium called 90-Y. When injected into the body, the drug homes in on the tumor cells, allowing the radiation from the 90-Y to kill them. So far, results have been promising, but this approach is still only available in the United States as a part of a clinical trial.

- References
  See all references for Gastrointestinal Carcinoid Tumor

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Causes, Risk Factors, and Prevention

Risk Factors

A risk factor is anything that affects your chance of getting a disease such as cancer. Learn more about the risk factors for gastrointestinal carcinoid tumors.

- What Are the Risk Factors for Gastrointestinal Carcinoid Tumors?
- Do We Know What Causes Gastrointestinal Carcinoid Tumors?

Prevention

At this time, there is no known way to prevent gastrointestinal carcinoid tumors. Since smoking might increase the risk of carcinoid tumors of the small intestine, not starting or quitting smoking may reduce the risk for this disease.

- About Gastrointestinal Carcinoid Tumors
- Causes, Risk Factors, and Prevention
- Early Detection, Diagnosis, and Staging
- Treatment
- After Treatment

What Are the Risk Factors for Gastrointestinal Carcinoid Tumors?

A risk factor is anything that affects your chance of getting a disease such as cancer. For example, exposure to strong sunlight is a risk factor for skin cancer, while smoking is a risk factor for cancer of the lung and several other cancers.

But risk factors don’t tell us everything. Someone without any known risk factors
can still develop cancer. And someone can have a risk factor, but still not get the disease. Only a few risk factors for gastrointestinal (GI) carcinoid tumors are known.

**Genetic syndromes**

**Multiple endocrine neoplasia, type I**

This is a rare condition caused by inherited defects in the gene *MEN1*. People with this syndrome have a very high risk of getting tumors of 3 glands: the pituitary, parathyroid, and pancreas. They also have an increased risk of carcinoid tumors. Some studies estimate that inherited mutations of the *MEN1* gene are responsible for about 10% of carcinoid tumors. Most of these are gastric (stomach) carcinoids. Children have a 50/50 chance of inheriting this syndrome from an affected parent.

If your family is affected by the MEN1 syndrome, you might want to talk to your doctor about the pros and cons of getting tested for it. Although the gene that causes tumors in people with the MEN1 syndrome has been found, genetic testing for MEN1 is not widely available. Because the results of genetic testing are not always clear cut, it is important that the test is done along with genetic counseling to help you make sense of the results.

**Neurofibromatosis type 1**

This disease often runs in families and is characterized by many *neurofibromas* (benign tumors that form in nerves under the skin and in other parts of the body). It is caused by defects in the *NF1* gene. Some people with this condition also develop neuroendocrine tumors of the small intestines.

**Other genetic syndromes**

Neuroendocrine tumors are also more common among people with tuberous sclerosis complex and von Hippel Lindau disease. Tuberous sclerosis complex can be caused by a defect in the *TSC1* or *TSC2* gene. People with this condition can also develop tumors of the heart, eyes, brain, lungs, and skin. People with von Hippel Lindau disease have an inherited tendency to develop blood vessel tumors of the brain, spinal cord, or retina, as well as kidney cancer. It is caused by changes in the *VHL* gene.
To find out more on being tested for genetic syndromes, see Genetic Testing: What You Need to Know.

Race and gender

Carcinoid tumors are more common among African Americans than whites. Outcomes are also not as good for African Americans. Researchers do not yet know why. Carcinoid tumors are also slightly more common in women than men.

Other stomach conditions

People with certain diseases that damage the stomach and reduce the amount of acid it makes have a greater risk of developing stomach carcinoid tumors, but their risk for carcinoid tumors of other organs is not affected.

Factors with uncertain or unproven effects

Smoking

Smoking may increase the risk of getting a carcinoid tumor of the small intestine, according to some research. But further studies are needed to confirm this.

Diet

The risk of developing GI carcinoid tumors does not appear to be increased or decreased by any specific foods.

- References

See all references for Gastrointestinal Carcinoid Tumor

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Do We Know What Causes Gastrointestinal Carcinoid Tumors?

Researchers have made great progress in understanding how certain changes in DNA can cause normal cells to become cancerous. DNA is the chemical in each cell that carries our genes, which control how our cells function. We look like our parents because they are the source of our DNA. But DNA affects more than the way we look.

Some genes control when our cells grow and divide. Certain genes that help cells grow, divide, and stay alive are called oncogenes. Genes that slow down cell division or cause cells to die at the right time are called tumor suppressor genes. Cancers can be caused by DNA changes that turn on oncogenes or turn off tumor suppressor genes.

Changes in 2 tumor suppressor genes are responsible for many inherited cases of neuroendocrine tumors and neuroendocrine cancers. Most inherited cases are due to changes in the MEN1 gene. A smaller number are caused by inherited changes in the NF1 gene.

Most neuroendocrine tumors and neuroendocrine cancers are caused by sporadic changes (mutations) in oncogenes or tumor suppressor genes. Mutations are called sporadic if they occur after a person is born, rather than having been inherited. The mutations that cause carcinoid tumors often affect the MEN1 gene, the same gene responsible for most familial neuroendocrine tumors and neuroendocrine cancers. But not much is known about exactly what causes these gene changes.

Doctors do know that carcinoid tumors start out very small and grow slowly. When patients have parts of their stomach or small intestine removed to treat other diseases, taking a close look under the microscope often shows small groups of neuroendocrine cells that look like tiny carcinoids. Researchers still do not know why some stay small but others grow large enough to cause symptoms.

- References
  
  See all references for Gastrointestinal Carcinoid Tumor

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Can Gastrointestinal Carcinoid Tumors Be Prevented?

At this time, there is no known way to prevent gastrointestinal carcinoid tumors. Since smoking might increase the risk of carcinoid tumors of the small intestine, not starting or quitting smoking may reduce the risk for this disease.

- References
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Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Gastrointestinal Carcinoid Tumors Be Found Early?
- Signs and Symptoms of Gastrointestinal Carcinoid Tumors
- How Are Gastrointestinal Carcinoid Tumors Diagnosed?

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- How Are Gastrointestinal Carcinoid Tumors Staged?
- Survival Rates for Gastrointestinal Carcinoid Tumors

Questions to Ask About Gastrointestinal Carcinoid Tumors

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- What Should You Ask Your Doctor About Gastrointestinal Carcinoid Tumors?

Can Gastrointestinal Carcinoid Tumors Be Found Early?

Because carcinoid tumors usually grow and spread slowly, about half of all gastrointestinal carcinoid tumors are found in an early or localized stage, usually before
they cause any problems.

Carcinoid tumors often are found incidentally (by accident). These tumors aren’t causing any symptoms but are found when tests are done for other diseases. They may also be found when parts of the gastrointestinal system are removed to treat other diseases.

For example, a person with stomach pain or bleeding may have a test called an upper endoscopy to look for an ulcer. In this test, the doctor looks at the stomach lining through a flexible lighted tube. During this test, the doctor may notice a small bump in the stomach wall that turns out to be a carcinoid tumor.

Sometimes during colorectal cancer screening, a routine sigmoidoscopy or colonoscopy (looking at the large bowel through a flexible lighted tube) will incidentally find a small carcinoid tumor.

Sometimes when the appendix is removed (to treat appendicitis or as part of a larger operation), a small carcinoid is found at the tip. This happens in about 1 of every 300 people who have appendix surgery done for other diseases. Most of these carcinoids were too small to have caused any symptoms.

- References
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**Signs and Symptoms of Gastrointestinal Carcinoid Tumors**

Most gastrointestinal (GI) carcinoids grow slowly. If they do cause symptoms, they tend to be vague. When trying to figure out what’s going on, doctors and patients are likely to explore other, more common possible causes first. This can delay a diagnosis, sometimes even for several years. But some do cause symptoms that lead to their diagnosis.
Symptoms by location of the tumor

The symptoms a person develops from a GI carcinoid tumor often depend on where it is.

The appendix

People with tumors in their appendix often don’t have symptoms. If it is discovered, it is usually when they have their appendix removed during an operation for some other problem. Sometimes, the tumor blocks the opening between the appendix and the rest of the intestine and causes appendicitis. This leads to symptoms like nausea, vomiting, and abdominal (belly) pain.

The small intestine or colon

If the tumor starts in the small intestine, it can cause the intestines to kink and be blocked for a while. This can cause cramps, belly pain, weight loss, fatigue, bloating, diarrhea, or nausea and vomiting, which might come and go. This can sometimes go on for years before the carcinoid tumor is found. A tumor usually needs to grow fairly large before it completely blocks (obstructs) the intestine. When that happens, patients have severe belly pain, nausea and vomiting.

Sometimes a carcinoid tumor can block the opening of the Ampulla of Vater, which is where the common bile duct (from the liver) and the pancreatic duct (from the pancreas) empty into the intestine. When this is blocked, bile can back up, leading to yellowing of the skin and eyes (jaundice). Pancreatic juices can also back up, leading to an inflamed pancreas (pancreatitis), which can cause belly pain, nausea, and vomiting.

Sometimes, a carcinoid can cause intestinal bleeding. This can lead to anemia (too few red blood cells) with fatigue and shortness of breath.

The rectum

Rectal carcinoid tumors are often found during routine exams, even though they can cause pain and bleeding from the rectum and constipation.

The stomach

Carcinoid tumors that develop in the stomach usually grow slowly and often do not
cause symptoms. They are sometimes found during an exam of the stomach by an endoscopy looking for other things. (Endoscopy is described later in this section.) Some can cause symptoms such as the carcinoid syndrome.

**Signs and symptoms from hormones made by carcinoid tumors**

Some carcinoid tumors can release hormones into the bloodstream. This can create different problems depending on which hormones are released.

**Carcinoid syndrome**

About 1 out of 10 carcinoid tumors release enough hormone-like substances into the bloodstream to cause the symptoms of carcinoid syndrome. These include:

- Facial flushing (redness and warm feeling)
- Severe diarrhea
- Wheezing
- Fast heartbeat

Many people find that factors such as stress, heavy exercise, and drinking alcohol trigger these symptoms. Over a long time, these hormone-like substances can damage heart valves, causing shortness of breath, weakness, and a heart murmur (an abnormal heart sound).

Not all GI carcinoids cause the carcinoid syndrome. For example, rectal carcinoids usually do not make the hormone-like substances that cause these symptoms.

Most cases of carcinoid syndrome occur only after the cancer has already spread to other parts of the body. Normally, blood coming from the GI tract first flows through the liver, where substances made by GI carcinoid tumors are broken down before they can reach the rest of the body. This prevents carcinoid symptoms. But if the cancer spreads outside the intestine (such as to the liver or lungs), the substances it makes can enter the main bloodstream and reach other parts of the body, where it can cause symptoms.

**Cushing syndrome**

Some neuroendocrine tumors produce ACTH (adrenocorticotropic hormone), a substance that causes the adrenal glands to make too much cortisol. This can cause *Cushing syndrome*, with symptoms of:
• Weight gain
• Muscle weakness
• High blood sugar (even diabetes)
• High blood pressure
• Increased body and facial hair
• Hump of fat on back of neck
• Skin changes like stretch marks (called *striae*)

**Zollinger-Ellison syndrome**

Carcinoid tumors can make a hormone called *gastrin* that signals the stomach to make acid. Too much gastrin can cause Zollinger-Ellison syndrome, in which the stomach makes too much acid. High acid levels can lead to irritation of the lining of the stomach and even stomach ulcers, which can cause pain, nausea, and loss of appetite.

Severe ulcers can start bleeding. If the bleeding is mild, it can lead to anemia (too few red blood cells), causing symptoms like feeling tired and being short of breath. If the bleeding is more severe, it can make stools black and tarry. Severe bleeding can itself be life threatening.

If the stomach acid reaches the small intestine, it can damage the intestinal lining and break down digestive enzymes before they have a chance to digest food. This can cause diarrhea and weight loss.

• References
See all references for Gastrointestinal Carcinoid Tumor

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**How Are Gastrointestinal Carcinoid Tumors Diagnosed?**

If you have *symptoms* that might be from a gastrointestinal (GI) carcinoid tumor, you
should see a doctor. He or she will take your medical history and examine you. If the doctor suspects some type of tumor or cancer, some tests will be ordered.

**Medical history and physical exam**

In taking your medical history, the doctor asks you questions about your general health, lifestyle habits, symptoms, and risk factors. The doctor also will probably ask about symptoms of the carcinoid syndrome, as well as symptoms that might be caused by a mass (tumor) in the stomach, intestines, or rectum.

Some patients with neuroendocrine tumors also have cancers or benign tumors of other organs, so doctors may ask about symptoms that might suggest other tumors are present. A thorough physical exam will provide information about signs of neuroendocrine tumors and other health problems. The doctor may pay special attention to the abdomen, looking for a tumor mass or enlarged liver.

If your medical history and physical exam give the doctor reason to suspect you might have a GI carcinoid, some tests will be ordered to find out if the disease is present.

**Imaging tests**

Your doctor may order one or more types of imaging tests to help determine the cause of your symptoms.

**Barium x-ray**

These tests use a barium-containing solution that coats the lining of the esophagus, stomach, and intestines. The coating of barium helps show abnormalities of the lining of these organs. This type of study is often useful in diagnosing some GI carcinoid tumors. It is least effective in finding small intestine carcinoids.

Barium studies can be used to examine the upper or lower parts of the digestive system. You will probably not be able to eat or drink anything (other than water) the night before the test. If the colon is being examined, you may need to take laxatives and/or enemas to cleanse the bowel the night before or the morning of these exams.

**Barium swallow:** This test is used to examine the lining of the esophagus. The patient drinks a barium solution that coats the lining of the esophagus. Then x-ray pictures are taken.
**Upper GI series:** This test is used to examine the lining of the stomach and the first part of the small intestine. The patient swallows the barium solution, and then may be moved around a bit so that it coats the inside of the stomach. Over time, it will leave the stomach and coat the first part of the small intestine. More x-rays can be taken over the next few hours as the barium travels through the rest of the small intestine. This is called a *small bowel follow-through.*

**Enteroclysis:** This is another way to look at the small intestine. In this test, a thin tube is passed from the mouth or nose down through the stomach to the start of the small intestine. Barium contrast is sent through the tube, along with a substance that creates more air in the intestines, causing them to expand. X-rays of the intestines are then taken. This test may be quicker and give clearer images of the small intestine than a small bowel follow-through, but the use of a tube to give the barium makes it more uncomfortable.

**Barium enema:** This test (also known as a *lower GI series*) is used to look at the inner surface of the colon and rectum. The barium solution is given as an enema (through the anus) while the patient is lying on the x-ray table. When the colon is about half full of barium, the patient rolls over so the barium spreads throughout the colon. Then x-rays are taken. After the barium is put in, air may be blown in to help spread the barium toward the bowel wall and better coat the inner surface. This is called an *air contrast* (or *double contrast*) *barium enema.* X-rays are then taken.

Barium x-rays are used less these days than in the past. In many cases they are being replaced by endoscopy, where the doctor actually looks into the esophagus, stomach, or colon with a narrow fiber optic scope.

**Computed tomography (CT) scan**

A CT scan can help tell if the cancer has spread into your lymph nodes or other organs such as your liver.

The CT scan uses x-rays to make detailed cross-sectional images of your body. Instead of taking one picture, like a regular x-ray, a CT scanner takes many pictures as it rotates around you. A computer then combines these into images that look like slices of the part of your body that is being studied.

Before any pictures are taken, you might be asked to drink 1 to 2 pints of a liquid called *oral contrast.* This helps outline the intestine so that certain areas are not mistaken for tumors. You might also receive an IV (intravenous) line through which a different kind of contrast dye (IV contrast) is injected. This helps better outline structures in your body.
The injection can cause some flushing (redness and warm feeling that may last hours to days). A few people are allergic to the dye and get hives. Rarely, more serious reactions like trouble breathing and low blood pressure can occur. Medicine can be given to prevent and treat allergic reactions. Be sure to tell the doctor if you have any allergies (especially to iodine or shellfish) or if you have ever had a reaction to any contrast material used for x-rays.

A CT scanner has been described as a large donut, with a narrow table that slides in and out of the middle opening. You will need to lie still on the table while the scan is being done. CT scans take longer than regular x-rays, and you might feel a bit confined by the ring while the pictures are being taken.

When GI carcinoid tumors spread, it is often to the liver. To see if there are areas of cancer spread in the liver, a special type of CT known as a 3D-, 4D-, or multiphase CT scan is done. This means having one set of CT images taken before IV contrast is given. Then more sets of scans are taken as the contrast passes through the liver.

CT scans can also be used to guide a biopsy needle precisely into a suspected area of cancer spread. For a CT-guided needle biopsy, you remain on the CT scanning table, while a doctor moves a biopsy needle through the skin and toward the mass. CT scans are repeated until the doctor is sure that the needle is in the mass. A fine-needle biopsy sample (tiny fragment of tissue) or a core-needle biopsysample (a larger cylinder of tissue) is removed and looked at under a microscope.

**Magnetic resonance imaging (MRI) scan**

MRI scans use radio waves and strong magnets instead of x-rays to create detailed images of parts of the body. Like a CT scan, an MRI produces cross-sectional slices of the body. As with a CT scan, a contrast material might be injected into a vein, but it is not needed as often.

MRI scans take longer than CT scans, often up to an hour. You may have to lie inside a narrow tube which can feel confining and can upset people with a fear of enclosed spaces. Special, open MRI machine can help with this if needed, although the images might not be as sharp in some cases. The MRI machine makes loud buzzing noises, but some places provide headphones to help block the sound.

Sometimes MRI is used to look at blood vessels in the liver. This requires IV contrast and is known as **MR angiography (MRA)**.

**Radionuclide scans**
Scans using small amounts of radioactivity and special cameras can be helpful in looking for carcinoid tumors. They can help determine the extent of the tumor, as well as help locate it if doctors aren’t sure where it is in the body.

**Somatostatin receptor scintigraphy (OctreoScan®):** This is the scan most often used to look for carcinoid tumors. For this scan, a radioactive substance called *indium-111* is bound to a hormone-like substance called *octreotide*. When a small amount of this combined substance is injected into the blood, the octreotide causes it to attach to proteins on carcinoid cells. About 4 hours after the injection, a special camera can be used to show where the radioactivity has collected in the body. More scans may be done over the next few days as well.

**I-131 MIBG scan:** This is another test that can be used to find carcinoid tumors, but it is used less often than the OctreoScan. This test uses a chemical called *MIBG* that has radioactive iodine (I-131) attached. This substance is injected into a vein, and the body is scanned several hours or days later with a special camera to look for areas that picked up the radioactivity. These would most likely be carcinoid tumors, although other kinds of neuroendocrine tumors will also pick up this chemical.

**Positron emission tomography (PET) scan**

A PET scan is another imaging test that uses low levels of radioactivity to look for tumors. PET scans usually use a form of radiolabeled glucose (sugar) to find tumors. But to look for neuroendocrine tumors/cancers, a special type of PET scan is done, using a radioactive form of 5-hydroxytryptophan (5-HTP). This chemical is injected into the bloodstream and is taken up and used by carcinoid cells. After about an hour, a special camera is used to find the areas of radioactivity. Some doctors have found this type of PET scan to be more accurate than CT scans for detecting spread of disease. However, this type of PET scan is not available in every hospital (even some hospitals that have a PET scanner).

**Endoscopy**

Endoscopy tests use a flexible lighted tube (endoscope) with a video camera on the end. The camera is connected to a monitor, which lets the doctor see any abnormal areas in the lining of the digestive organs clearly. If needed, small pieces of the abnormal areas can be removed (biopsied) through the endoscope. The biopsy samples can be looked at under the microscope to find out if cancer is present and what kind of cancer it is.
Upper endoscopy

This test is also known as esophagogastroduodenoscopy or EGD. An endoscope is passed down through the mouth to look at the esophagus, stomach, and first part of the small bowel.

An upper endoscopy may be done in a hospital outpatient department, clinic, or doctor’s office. It usually takes 15 to 30 minutes, and most patients are given intravenous medicine to make them feel relaxed and sleepy. If you are sedated for the procedure, you will need someone to take you home (not just a cab).

Colonoscopy

This test is also called lower endoscopy. A special endoscope known as a colonoscope is inserted through the anus up into the colon. The doctor will be able to see the lining of the entire rectum and colon. For a clear view though, the colon must be completely cleaned out before the test. There are different ways to do this, but the most common is drinking a large amount of a laxative solution the night and the morning of the exam.

You will be given intravenous medicine to make you feel relaxed and sleepy during the procedure. A colonoscopy can be done in a hospital outpatient department, clinic, or doctor’s office. It usually takes 15 to 30 minutes, although it may take longer if a tumor is seen and/or a biopsy is taken. Because you will be sedated for the procedure, you will need someone you know to take you home afterward.

Proctoscopy

Proctoscopy can be used to look for a rectal tumor. This test uses a shorter, rigid, hollow tube (a proctoscope), which is about 10 inches long and about 1 inch across and may have a light on the end of it. The doctor coats the proctoscope with a lubricant and then gently pushes it into the anus and rectum. By shining a light into this tube, the doctor has a clear view of the lining of the rectum and anus. This test usually requires that you take laxatives or have an enema beforehand to make sure the bowels are empty.

Capsule endoscopy

Unfortunately, neither upper nor lower endoscopy can reach all areas of the small intestine, where many carcinoid tumors begin. A technique known as capsule endoscopy may help in some cases.
This test doesn’t really use an endoscope. Instead, the patient swallows a capsule (about the size of a large vitamin pill) that contains a light source and a tiny camera. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels (usually over about 8 hours), it takes thousands of pictures. These images are transmitted electronically to a device worn around the person’s waist, while he or she goes on with normal daily activities. The pictures can then be downloaded onto a computer, where the doctor can watch them as a video. The capsule passes out of the body during a normal bowel movement and is discarded.

**Double balloon enteroscopy**

This is another way to look at the small intestine. The small intestine is too long (20 feet) and has too many curves to be examined well with regular endoscopy. This method gets around these problems by using a special endoscope that is made up of 2 tubes, one inside the other. First the inner tube, which is an endoscope, goes forward about a foot, and then a balloon at its end is inflated to anchor it. Then the outer tube goes forward to near the end of the inner tube and it is then anchored in place with a balloon. This process is repeated over and over, letting the doctor see the intestine a foot at a time.

This procedure is done after the patient is given drugs to make him or her sleepy and may be even done under general anesthesia (where the patient is asleep). The main advantage of this test over capsule endoscopy is that the doctor can take a biopsy if something abnormal is seen. As with other tests that are done under sedation, you will need someone to take you home after this procedure (not just a cab).

**Endoscopic ultrasound (EUS)**

This test uses an endoscope with a small ultrasound probe on the end. This probe releases sound waves and then uses the echoes that bounce back to create images of the digestive tract wall (or nearby lymph nodes). Putting the ultrasound probe on the end of an endoscope lets it get very close to a tumor. Because the probe is close to the area being looked at, it can make very detailed pictures.

EUS can be used to see how deeply a tumor has grown into the wall of the esophagus, stomach, intestine, or rectum. It can also help see if certain lymph nodes are enlarged and help a doctor guide a needle into lymph node, tumor, or other suspicious area to do a biopsy. You will be sedated for this test, so you will need someone to take you home (not just a cab).
Biopsy

Even if an imaging test finds a mass, it can’t tell if the mass is a carcinoid tumor, some other type of tumor, or an area of infection. The only way to know for sure is to remove cells from the abnormal area and look at them under a microscope. This procedure is called a biopsy.

There are several ways to take a sample from a GI tumor. One way is through the endoscope. When a tumor is found, the doctor can use biopsy forceps (pincers or tongs) through the tube to take a small sample of it. Another way to sample a tumor is with a CT-guided needle biopsy, as described in the section on CT scans.

Bleeding after a biopsy of a GI carcinoid is a rare but potentially serious problem. If serious bleeding occurs, doctors can sometimes inject drugs into the tumor to constrict blood vessels and slow or stop bleeding.

In rare cases, neither endoscopic biopsy nor a CT-guided needle biopsy will be able to get enough tissue to identify the type of tumor. This is sometimes the case with tumors in the small intestine. In such cases, surgery may be needed to remove a tissue sample.

You can read more about biopsies and how they are tested in Testing Biopsy and Cytology Specimens for Cancer.

Blood and urine tests

Blood and urine tests can be very helpful in diagnosing carcinoid syndrome in patients who have symptoms that might be caused by it.

Many carcinoid tumors, especially those in the small intestine, make serotonin (also called 5-HT). It is probably the cause of at least some of the symptoms of carcinoid syndrome. The body breaks it down into 5-hydroxyindoleacetic acid (5-HIAA), which is released into the urine. A common test to look for carcinoid syndrome measures the levels of 5-HIAA in a urine sample collected over 24 hours. Measuring the serotonin levels in the blood may also give useful information. These tests can help diagnose many (but not all) carcinoid tumors. Sometimes, the tumors are small and don’t release enough serotonin for a positive test result.

In other cases, the tumors do not make much serotonin, but they do make its precursor, 5-HTP, which can be converted to serotonin in the urine. In patients with these tumors,
the blood serotonin level may be normal, but the urine levels of serotonin and 5-HTP are high.

Some foods, including bananas, plantains, kiwi fruit, certain nuts, avocado, tomatoes, and eggplant, contain a lot of serotonin and can raise 5-HIAA levels in the urine. Medicines, including cough syrup and acetaminophen (Tylenol), can also affect the results. Ask your doctor what you should avoid before having urine or blood tests for carcinoids.

Other common tests to look for carcinoids include blood tests for chromogranin A (CgA), neuron-specific enolase (NSE), substance P, and gastrin. Medicines that lower stomach acid called proton-pump inhibitors (such as omeprazole/Prilosec®, lansoprazole/Prevacid®, esomeprazole/Nexium®, and many others) can make CgA and gastrin levels high even when carcinoid tumors aren’t present. If you take any of these medicines, talk to your doctor about what you need to avoid before having these blood tests. Depending on the tumor’s location and your symptoms, your doctor might do other blood tests as well.

Some of these tests can also be used to show how well treatment is working, since the levels of these substances tend to go down as tumors shrink.

- References
  See all references for Gastrointestinal Carcinoid Tumor

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**How Are Gastrointestinal Carcinoid Tumors Staged?**

Staging — or determining the stage of disease — is the process of finding out if the tumor has spread, and if it has, how far. To help stage the tumor, doctors might use several types of imaging, endoscopy, or other tests described in “How are gastrointestinal carcinoid tumors diagnosed?”
The stage of the tumor, along with the place it started, can help determine the prognosis (outlook) for someone with a gastrointestinal (GI) carcinoid tumor. These 2 factors also help the doctor decide what treatment to recommend.

**Localized, regional, and distant stages**

GI carcinoid tumors can start in several different locations, and until recently there had been no standard system for describing their spread. In the past, many doctors simply divided GI carcinoid tumors into 3 general stages: localized, regional spread, and distant spread. This approach was fairly easy to understand and could be useful when choosing among treatment options.

It might not be possible to tell a benign tumor from a cancer when it is localized because the cells can look the same under the microscope. Any tumor that spreads, though, is a cancer (by definition).

**Localized**

The cancer has not spread beyond the wall of the organ it started in (for example, the stomach, intestine, or rectum).

**Regional spread**

The cancer has either spread to nearby lymph nodes or it has grown through the wall of the organ where it started to grow into nearby tissues such as fat, ligaments, and muscle (or both).

**Distant spread**

The cancer has spread to tissues or organs that are not near where the cancer started (such as the liver, bones, or lungs).

**The AJCC TNM system**

Modern staging of GI carcinoid tumors uses a system created by the American Joint Committee on Cancer (AJCC) that is known as the *TNM system*. The TNM system has 3 key pieces of information:
• **T** describes the size of the primary *tumor*, measured in centimeters (cm), and whether the tumor has grown into nearby organs.
• **N** describes the extent of spread to nearby (regional) *lymph nodes*.
• **M** indicates whether the cancer has *metastasized* (spread) to other organs of the body.

Numbers or letters that appear after **T**, **N**, and **M** give more details about each of these factors:

• The numbers 0 through 4 indicate increasing severity.
• The letter X means “cannot be assessed” because the information is not available.
• The letters “is” mean “carcinoma in situ”: the tumor is just in the top layer of cells and has not yet reached deeper layers of tissue.

The **T** categories for GI carcinoid cancers differ depending on where the cancer starts, but the **N** and **M** categories are the same.

### T categories for carcinoid tumors of the stomach

The **T** category describes how far down through the stomach layers the cancer has grown. The wall of the stomach is made of 5 layers. From innermost to outermost, they are:

• **Mucosa**: This innermost layer is where stomach acid and digestive enzymes are made. The mucosa has 3 parts: epithelial cells, a layer of connective tissue (the lamina propria), and a thin layer of muscle (the muscularis mucosa).
• **Submucosa**: This is a supporting layer under the mucosa.
• **Muscularis**: This is a layer of muscle that moves and mixes the stomach contents.
• **Subserosa and serosa**: These are the two outermost layers. They act as wrapping layers for the stomach.

**TX**: Primary (main) tumor cannot be assessed due to incomplete information.

**T0**: The primary tumor cannot be found.

**Tis**: The tumor is less than 0.5 mm (about half the width of a grain of rice) and the cancer cells are found only in the top layer of cells of the stomach lining. This is also known as carcinoma in situ or severe dysplasia.

**T1**: The tumor has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa. The tumor is 1 cm (less than half of an inch) or less.
T2: Either:

- The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm.
- **OR**

- The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the stomach (called the *muscularis propria*).

**T3:** The tumor has grown through the muscularis propria and into the subserosa.

**T4:** The tumor has grown into the serosa (the outer layer of tissue covering the stomach, also called the visceral peritoneum) or into nearby organs or structures.

**T categories for carcinoid tumors of the small intestine**

T categories of small intestine cancer describe the extent of spread through the layers that form its wall.

The layers of the intestine (from innermost to outermost) are:

- **Mucosa:** This is the innermost layer of the intestine. It has 3 parts: the top layer of cells (called the epithelium), a thin layer of connective tissue (called the *lamina propria*), and a thin layer of muscle.
- **Submucosa:** This is the fibrous tissue that lies beneath the mucosa.
• **Thick muscle layers (muscularis propria):** This layer of muscle contracts to force the contents of the intestines along the tract.

• **Subserosa and serosa:** These are the thin outermost layers of connective tissue that cover the small intestine. The serosa is also known as the visceral peritoneum.

**TX:** Primary (main) tumor cannot be assessed.

**T0:** The primary tumor cannot be found.

**T1:** The tumor has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa. The tumor is 1 cm (less than half of an inch) or less.

**T2:** Either:

• The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm.

• **OR**

• The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the colon (called the muscularis propria).

**T3:** The tumor has grown through the muscularis propria and into the subserosa, the pancreas, and/or the retroperitoneum (the area in back of the abdomen).

**T4:** The tumor has grown into the serosa (the outer layer of tissue covering the intestine, also called the visceral peritoneum) or into nearby organs.

**T categories for carcinoid tumors of the colon or rectum**

*T* categories for carcinoid tumors of the colon and rectum cancer describe the extent of spread through the layers that form its wall. These layers are similar to those found in the wall of the small intestine (see above). From innermost to outermost, they are:

• **Mucosa:** This is the innermost layer of the intestine. It has 3 parts: the top layer of cells (called the epithelium), a thin layer of connective tissue (called the lamina propria), and a thin layer of muscle.

• **Submucosa:** This is the fibrous tissue beneath the mucosa.

• **Thick muscle layers (muscularis propria):** This layer of muscle contracts to force the contents of the intestines along the tract.

• **Subserosa and serosa:** These are the thin outermost layers of connective tissue that cover the large intestine. The serosa is also known as the visceral peritoneum.
TX: Primary (main) tumor cannot be assessed due to incomplete information.

T0: The primary tumor cannot be found.

T1: The tumor has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa. The tumor is 2cm (about 4/5 of an inch) or less.

- **T1a:** The tumor is less than 1 cm across (1 cm is less than half an inch).

- **T1b:** The tumor is 1 to 2 cm across.

T2: Either:

- The tumor has grown into the lamina propria or submucosa (or both) and is greater than 2 cm.
- **OR**

- The tumor has grown through the lamina propria and submucosa and into the main muscle layer of the colon (called the *muscularis propria*).

T3: The tumor has grown through the muscularis propria and into the subserosa or other tissue around the colon or rectum.

T4: The tumor has grown through the wall of the colon (or rectum) and into the serosa (also called peritoneum) and/or into nearby organs.

**T categories for carcinoid tumors of the appendix**

TX: Primary (main) tumor cannot be assessed.

T0: No signs of a primary tumor.

T1: The tumor is no more than 2 cm (about 4/5 of an inch) across.

- **T1a:** The tumor is no more than 1 cm across (a little less than half an inch).

- **T1b:** The tumor is larger than 1 cm but not larger than 2 cm across.

T2: Either:

- The tumor is larger than 2 cm across but not larger than 4 cm.
- **OR**

- The tumor has grown into the cecum (the first part of the large intestine).
T3: Either:

- The tumor is larger than 4 cm across.
- OR

- The tumor has grown into the ileum (the last part of the small intestine).

T4: The tumor has grown into nearby organs or tissues (such as the abdominal wall).

N categories for GI carcinoid tumors

NX: Nearby (regional) lymph nodes cannot be assessed.

N0: The cancer has not spread to nearby lymph nodes.

N1: The cancer has spread to nearby lymph nodes.

M categories for GI carcinoid tumors

M0: The cancer has not spread (metastasized) to distant organs or structures.

M1: The cancer has spread (metastasized) to distant organs or structures (such as the liver, lungs, bones, etc.).

Stage grouping

Once the T, N, and M categories for a tumor are known, the information is combined to determine the overall stage. This process is known as *stage grouping*.

Stage groupings for carcinoid of the stomach

Stage 0: Tis, N0, M0: Carcinoma in situ: the tumor is less than 0.5 mm (and the cancer cells are found only in the top layer of cells of the stomach lining (Tis). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage I: T1, N0, M0: The tumor is 1 cm or less in size and has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIA: T2, N0, M0: Either the tumor has grown into the lamina propria or
submucosa (or both) and is greater than 1 cm in size; OR the tumor has grown into the main muscle layer of the stomach (called the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIb: T3, N0, M0:** The tumor has grown through the muscularis propria and into the subserosa (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIIa: T4, N0, M0:** The tumor has grown into the outer layer of tissue covering the stomach (the serosa or visceral peritoneum) or into nearby organs or structures. The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIib: any T, N1, M0:** The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

**Stage IV: any T, any N, M1:** The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

### Stage groupings for carcinoid of the small intestine

**Stage I: T1, N0, M0:** The tumor is 1 cm or less and has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIa: T2, N0, M0:** Either the tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm; OR the tumor has grown into the main muscle layer of the intestine (called the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIb: T3, N0, M0:** The tumor has grown through the muscularis propria and into the subserosa (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIIa: T4, N0, M0:** The tumor has grown into the outer layer of tissue covering the intestine (the serosa or visceral peritoneum) or into nearby organs or structures. The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

**Stage IIIb: any T, N1, M0:** The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to
Stage IV: any T, any N, M1: The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

Stage groupings for carcinoid of the colon and rectum

Stage I: T1, N0, M0: The tumor is 2 cm (about 4/5 of an inch) or less and has grown into the lamina propria and may have grown into the submucosa (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIA: T2, N0, M0: Either the tumor has grown into the lamina propria or submucosa (or both) and is greater than 2 cm; OR the tumor has grown into the main muscle layer of the colon (called the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIB: T3, N0, M0: The tumor has grown through the muscularis propria and into the subserosa or other tissue around the colon or rectum (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIA: T4, N0, M0: The tumor has grown through the wall of the colon (or rectum) and into the serosa (also called peritoneum) and/or into nearby organs (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage IIIB: any T, N1, M0: The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

Stage IV: any T, any N, M1: The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

Stage groupings for carcinoid tumors of the appendix

Stage I: T1, N0, M0: The tumor is no more than 2 cm across (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

Stage II: T2 or T3, N0, M0: The tumor is either larger than 2 cm across or has grown into the cecum (T2), or it is larger than 4 cm across or has grown into the ileum (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage III: Either:

T4, N0, M0: The tumor has grown into nearby organs or tissues, such as the abdominal wall (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0).

OR

Any T, N1, M0: The tumor can be any size and may or may not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant sites (M0).

Stage IV: Any T, any N, M1: The tumor can be any size and may or may not have grown into nearby structures (any T). It may or may not have spread to nearby lymph nodes (any N). The cancer has spread to distant sites (most often the liver) (M1).

- References
  See all references for Gastrointestinal Carcinoid Tumor

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Survival Rates for Gastrointestinal Carcinoid Tumors

Survival rates are often used by doctors as a standard way of discussing a person's prognosis (outlook). Some people with cancer may want to know the survival statistics for people in similar situations, while others may not find the numbers helpful, or may even not want to know them. Stop reading here and go to another section if you decide that you do not want to know them.

The 5-year survival rate refers to the percentage of patients who live at least 5 years after their cancer is diagnosed. Of course, many people live much longer than 5 years (and many are cured). Also, people who have this cancer can die from something else. These survival rates, called observed survival rates, do not take this into account.
To get 5-year survival rates, doctors have to look at people who were treated at least 5
years ago. Improvements in treatment since then may result in a better outlook for
people now being diagnosed with carcinoid tumors.

Survival rates are often based on previous outcomes of large numbers of people who
had the disease, but they can’t predict what will happen in any particular person’s case.
Many other factors can affect a person’s outlook, such as treatment received, the grade
of the tumor and its growth rate, and the patient’s age and health. Your doctor can tell
you how the numbers below may apply to you, as he or she is familiar with your
situation.

Most GI carcinoid tumors are found while they are still localized, but this varies based
on the organ they start in. Tumors of the stomach, duodenum (the first part of the small
intestine), appendix, and rectum are likely to be found before they have spread. In
contrast, many tumors of other parts of the small intestine (the jejunum/ileum) and the
colon (including the cecum) have already spread to nearby tissues or lymph nodes or to
distant sites when they are first diagnosed.

The following 5-year survival rates are based on people diagnosed with carcinoid (well
and moderately-differentiated neuroendocrine tumors) between 1988 and 2004:

<table>
<thead>
<tr>
<th>Site</th>
<th>Localized</th>
<th>Regional</th>
<th>Distant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stomach</td>
<td>73%</td>
<td>65%</td>
<td>25%</td>
</tr>
<tr>
<td>Duodenum</td>
<td>68%</td>
<td>55%</td>
<td>46%</td>
</tr>
<tr>
<td>Jejunum/ileum</td>
<td>65%</td>
<td>71%*</td>
<td>54%</td>
</tr>
<tr>
<td>Cecum</td>
<td>68%</td>
<td>71%*</td>
<td>54%</td>
</tr>
<tr>
<td>Appendix</td>
<td>88%</td>
<td>78%</td>
<td>25%</td>
</tr>
<tr>
<td>Colon</td>
<td>85%</td>
<td>46%</td>
<td>14%</td>
</tr>
<tr>
<td>Rectum</td>
<td>90%</td>
<td>62%</td>
<td>24%</td>
</tr>
</tbody>
</table>

*The 5-year survival for these tumors at the regional stage is slightly better than for the
localized stage, although the reason for this is not exactly clear.

- References

See all references for Gastrointestinal Carcinoid Tumor

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What Should You Ask Your Doctor About Gastrointestinal Carcinoid Tumors?

It is important to have honest, open discussions with your cancer care team. They want to answer all of your questions, no matter how trivial you might think they are. For instance, consider these questions:

- What kind of carcinoid tumor do I have?
- What is the stage of my carcinoid tumor and what does that mean to me?
- What are my treatment choices?
- What do you recommend and why?
- Based on what you've learned about my tumor, what is my prognosis (outlook)?
- What risks or side effects are there to the treatments you suggest?
- How will treatment affect my daily activities?
- What are the chances my tumor will recur with these treatments?
- What should I do to be ready for treatment?

In addition to these sample questions, you might write down some of your own. For instance, you might want more information about recovery times so you can plan your work schedule. Or you might want to ask about second opinions or if you qualify for any clinical trials.

- References

See all references for Gastrointestinal Carcinoid Tumor

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Treating Gastrointestinal Carcinoid Tumors

General approach to treatment

Once a gastrointestinal (GI) carcinoid tumor is found and staged, the cancer care team will discuss your treatment options with you. Depending on your situation, you may have different types of doctors on your treatment team. These doctors may include:

- A surgeon: a doctor who treats diseases with surgery.
- A radiation oncologist: a doctor who treats cancer with radiation therapy.
- A medical oncologist: a doctor who treats cancer with medicines such as chemotherapy.
- A gastroenterologist: a doctor who specializes in diagnosing and treating diseases of the digestive system.
- An endocrinologist: a doctor who specializes in the diagnosis and treatment of diseases related to hormones

Many other specialists may be involved in your care as well, including nurse practitioners, nurses, nutrition specialists, social workers, and other health professionals.

The main types of treatment for GI carcinoid tumors are:

- Surgery
- Chemotherapy and other drugs
- Radiation

In some cases, doctors may recommend combining more than one of these treatments (see the most common approaches used based on the stage and primary site).

It’s important to discuss all of your treatment options, including their goals and possible
side effects, with your doctors to help make the decision that best fits your needs. Some of the factors that might influence your treatment options are:

- The tumor size and location
- Whether it has spread to lymph nodes, liver, bones, or other organs
- Whether you have any other serious medical conditions
- Whether the tumor is causing bothersome symptoms

Take your time and think about all of your options when you make this important decision. If time allows, it’s often a good idea to get a second opinion. A second opinion may give you more information and help you feel more confident about the treatment plan you choose.

It’s also very important to ask questions if you’re not sure about something. You can find some good questions to ask in What should you ask your doctor about gastrointestinal carcinoid tumors?

**Thinking about taking part in a clinical trial**

Clinical trials are carefully controlled research studies that are done to get a closer look at promising new treatments or procedures. Clinical trials are one way to get state-of-the-art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the best way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. You can also call our clinical trials matching service at 1-800-303-5691 for a list of studies that meet your medical needs, or see the Clinical Trials section to learn more.

**Considering complementary and alternative methods**

You may hear about alternative or complementary methods that your doctor hasn’t mentioned to treat your cancer or relieve symptoms. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

Complementary methods refer to treatments that are used along with your regular medical care. Alternative treatments are used instead of a doctor’s medical treatment. Although some of these methods might be helpful in relieving symptoms or helping you feel better, many have not been proven to work. Some might even be dangerous.
Be sure to talk to your cancer care team about any method you are thinking about using. They can help you learn what is known (or not known) about the method, which can help you make an informed decision. See the Complementary and Alternative Medicine section to learn more.

Help getting through cancer treatment

Your cancer care team will be your first source of information and support, but there are other resources for help when you need it. Hospital- or clinic-based support services are an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help.

The American Cancer Society also has programs and services – including rides to treatment, lodging, support groups, and more – to help you get through treatment. Call our National Cancer Information Center at 1-800-227-2345 and speak with one of our trained specialists on call 24 hours a day, every day.

The treatment information given here is not official policy of the American Cancer Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor. Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don’t hesitate to ask him or her questions about your treatment options.

Surgery for Gastrointestinal Carcinoid Tumors

Most gastrointestinal (GI) carcinoid tumors can be cured by surgery alone. The type of operation will depend on a number of factors, including the size and location of the tumor, whether the person has any other serious diseases, and whether the tumor is causing the carcinoid syndrome.

Surgeons often try to cure localized carcinoid tumors by removing them completely, which is usually successful.

The options for GI carcinoid tumors that have spread locally or to distant parts of the body are more complex. Because most carcinoid tumors grow very slowly and some do not cause any symptoms, completely removing all metastatic carcinoid tumors may not always be needed. But in some patients, surgery to remove all visible cancer is the best
option. This is particularly true if removing most of the cancer will reduce the level of hormone-like substances causing symptoms.

Several types of operations can be used to treat GI carcinoid tumors. Some of these remove the primary tumor (where the cancer started), while others remove or destroy cancer that has spread (metastasized) to other organs.

**Fulguration (electrofulguration)**

This treatment destroys a tumor by heating it with electric current. It is sometimes used for small rectal carcinoid tumors, which can be reached fairly easily.

**Endoscopic mucosal resection**

In this procedure, the cancer is removed through an endoscope. This is most often used to treat small carcinoid tumors of the stomach and duodenum (the first part of the small intestine) and it can be used to remove small carcinoid tumors of the rectum.

**Local excision**

This operation removes the primary tumor and some normal tissue around it. The edges of the defect are then sewn together. This usually doesn’t cause any prolonged problem with eating or bowel movements. This operation may be done for small carcinoid tumors (no larger than 2 cm, or a little less than an inch).

Carcinoid tumors are sometimes removed during an operation for some other reason. This often occurs with carcinoid tumors of the appendix. When the appendix is removed (for some other reason), it is examined after surgery, and sometimes a carcinoid tumor is found. Most doctors believe that if the tumor is small — 2 cm or less — removing the appendix (appendectomy) is curative and no other surgery is needed. If the tumor is larger than 2 cm, more surgery may be needed.

Rectal carcinoid tumors may be excised (taken out) through the anus, without cutting the skin. Other GI carcinoid tumors can sometimes be locally excised through an endoscope but usually it is done through an incision (cut) in the skin.

**More extensive surgeries**

For larger tumors, a larger incision (cut) is needed to remove the tumor along with nearby tissues. This also gives the surgeon the chance to see whether the tumor has
grown into other tissues in the abdomen (belly). If it has, the surgeon may be able to remove the areas of cancer spread.

**Partial gastrectomy:** In this operation, part of the stomach is removed. If the upper part is removed, sometimes part of the esophagus is removed as well. If the lower part of the stomach is removed, sometimes the first part of the small intestine (the duodenum) is also taken. Nearby lymph nodes are also removed. This operation is also known as a *subtotal gastrectomy*.

**Small bowel (intestine) resection:** This is an operation to remove a piece of the small intestine (also called the *small bowel*). When it is used to treat a small bowel carcinoid, this surgery includes removing the tumor and some of the small bowel around it (called a *wide margin resection*), plus removing nearby (regional) lymph nodes and the supporting connective tissue (called the *mesentery*) that contains lymph nodes and vessels that carry blood to and from the intestine. Tumors in the terminal ileum (the last part of the small bowel) may require removing the right side of the colon (hemicolectomy).

**Pancreaticoduodenectomy (Whipple procedure):** This operation is most often used to treat pancreatic cancer, but it is also used to treat cancers of the duodenum. It removes the duodenum, part of the pancreas, nearby lymph nodes and part of the stomach. The gallbladder and part of the common bile duct are removed and the remaining bile duct is attached to the small intestine so that bile from the liver can continue to enter the small intestine. This is a complex operation that requires a lot of skill and experience. It carries a relatively high risk of complications that could even be fatal.

**Segmental colon resection or hemicolecotomy:** This operation removes between and ½ of the colon, as well as the nearby mesentery (the layers of tissue that hold and connect the intestines), which includes blood vessels and lymph nodes.

**Low anterior resection:** This operation can be used for some tumors in the upper part of the rectum. It removes some of the rectum and the remaining ends are sewn together. This does not have much effect on digestive function.

**Abdominoperineal (AP) resection:** This surgery is done for large or very invasive cancers in the lower part of the rectum. It removes the anus, rectum, and lower part of the colon. After this operation, the end of the colon is connected to an opening on the skin on the abdomen (called a *colostomy*). A bag attached over this opening collects stool (feces) as it leaves the body. (For more information, see [Colostomy: A Guide](#)).

For more information on surgery for treating cancer, see [A Guide to Cancer Surgery](#).
Surgery for carcinoid tumors that have spread to the liver

The liver is a common site of spread for GI carcinoid tumors. Treating cancer that has spread to the liver can help with symptoms and can even help some people live longer.

Liver resection

In this operation, one or more pieces of the liver that contain areas of cancer are removed. If it isn’t possible to remove all areas of cancer, surgery may still be done to remove as much tumor as is possible to help reduce symptoms of carcinoid syndrome. This is sometimes called cytoreductive surgery. Removing liver metastases may help some people with carcinoid tumors live longer, but most people who have this surgery will eventually develop new liver metastases.

Liver transplant

This operation removes the patient’s liver and puts a liver (or a piece of a liver) from someone else in its place. It can be used to treat some neuroendocrine cancers that have only spread to the liver, after the primary tumor has been removed. A liver transplant is generally only an option for people who are young and otherwise healthy. Although this is a very difficult treatment to go through, it can be curative. For more information on liver transplants see Liver Cancer.

References

See all references for Gastrointestinal Carcinoid Tumor

Chemotherapy and Other Drugs for Gastrointestinal Carcinoid Tumors

Chemotherapy (chemo) uses anti-cancer drugs that are injected into a vein or a muscle or taken by mouth to kill cancer cells. These drugs enter the bloodstream and reach all areas of the body, making this treatment useful for some types of cancers that have
spread to other organs.

Unfortunately, gastrointestinal (GI) carcinoid tumors often do not respond well to chemo. Because of this, chemo generally is used only for tumors that have spread to other organs, are causing severe symptoms, and have not responded to other medicines.

Some of the chemo drugs used to treat GI carcinoid tumors include:

- Capecitabine (Xeloda)
- 5-fluorouracil (5-FU)
- Doxorubicin (Adriamycin)
- Etoposide (VP-16)
- Dacarbazine (DTIC)
- Streptozocin
- Temozolomide
- Cisplatin
- Cyclophosphamide (Cytoxan)

Some tumors, especially high-grade tumors, may be treated with more than one drug. For these, combinations of etoposide plus carboplatin or temozolomide plus capecitabine may be used.

Chemo drugs kill cancer cells but also damage some normal cells, which can cause some side effects. Side effects depend on the type of drugs, the amount taken, and the length of treatment. Short-term side effects might include:

- Nausea and vomiting
- Loss of appetite
- Hair loss
- Mouth sores
- Low blood counts

Because chemo can damage the blood-making cells of the bone marrow, you may have low blood cell counts. This can result in:

- Increased risk of infection (from too few white blood cells)
- Bleeding or bruising after minor cuts or injuries (from a shortage of blood platelets)
- Fatigue or shortness of breath (from too few red blood cells)

Most side effects go away a short time after treatment. Often medicines can help prevent or minimize many of the side effects. For example, your doctor can prescribe drugs to help prevent or reduce nausea and vomiting.
Intra-arterial therapy and chemoembolization

Normally, chemo drugs enter the bloodstream and can travel throughout the body. When carcinoid cancer has spread to the liver, it is sometimes treated by directly injecting the chemo drug into the hepatic artery, which supplies blood to parts of the liver. This exposes the liver tumors to high doses of the drug but limits exposing the rest of the body. This lets patients avoid some side effects. Sometimes the chemo drug is injected together with a material that plugs up the artery (an approach called chemoembolization). When the arteries leading to them are blocked, the tumors become starved for nutrients and oxygen and many die off.

For more information on chemo, see Chemotherapy.

Other drugs for treating carcinoid tumors

Somatostatin analogs are man-made drugs chemically related to the natural hormone, somatostatin. These drugs can help control the symptoms caused by the hormones released from carcinoid tumors, including carcinoid syndrome. They can also help slow or stop tumor growth for a time in patients with metastatic neuroendocrine cancers.

The main somatostatin analogs used to treat carcinoid tumors are:

- Octreotide (Sandostatin)
- Lanreotide (Somatuline Depot)

These drugs can help treat flushing, diarrhea, and wheezing from carcinoid syndrome. They can also help slow or stop the growth of carcinoid tumors that have spread, which might help prolong life. Octreotide is also sometimes given to prevent and treat problems caused by the release of serotonin or other hormones when patients with carcinoid tumors have surgery.

The main side effects of these drugs are pain at the site of the injection and rarely stomach cramps, nausea, vomiting, headaches, dizziness, and fatigue. In patients that don’t have carcinoid syndrome, they can also cause diarrhea. These drugs can also cause sludging (thickening or crystallizing) of bile in the gallbladder, which can lead to gallstones. They can also raise blood sugar levels and make pre-existing diabetes more difficult to control.

Octreotide comes in a short-acting version that is given 2 to 4 times a day. It is also available as a long-acting injection (Sandostatin LAR) given only once a month, which may help patients more than the short-acting version.
Lanreotide only comes as a monthly injection.

A newer somatostatin analog, pasireotide (Signifor), is more often used to treat the symptoms of Cushing syndrome.

**Interferons** are natural substances that normally activate the body's immune system. They also slow the growth of tumor cells. Interferon-alfa is sometimes helpful in shrinking or slowing the growth of metastatic neuroendocrine cancers and improving symptoms of carcinoid syndrome. Its usefulness is sometimes limited by its flu-like side effects, which may be severe. The drug is given by injection.

**Cyproheptadine** is an antihistamine that can help relieve some of the symptoms of carcinoid syndrome.

Other medicines are also available to control specific symptoms. For example, **telotristat (Xermelo)** can be used along with a somatostatin analog to help control carcinoid syndrome diarrhea.

Be sure to describe your symptoms to your doctor and ask about medicines to control them.

- References

  See all references for Gastrointestinal Carcinoid Tumor

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# Radiation Therapy for Gastrointestinal Carcinoid Tumors

**External beam radiation therapy (EBRT)**

In this form of radiation therapy, a machine aims a beam of high-energy rays (or particles) to kill cancer cells. It is like having a regular x-ray except it takes longer and uses much higher amounts of radiation. Patients typically have treatments 5 days a
week for several weeks.

This is the type of radiation used most often to treat cancer. Unfortunately, EBRT is not very effective against most gastrointestinal (GI) carcinoid tumors. It is used mainly to treat pain from cancers that have spread to the bones or other parts of the body. Although surgery is the first option for most carcinoid tumors, those who can't have surgery might choose radiation therapy.

The main side effects of GI radiation therapy are:

- Tiredness (fatigue)
- Nausea and vomiting
- Diarrhea (if the belly or pelvis is treated)
- Skin changes, which can range from mild redness to blistering and peeling
- Hair loss in the area being treated

Radioembolization

This technique combines embolization with radiation therapy and is used to treat liver metastases. Embolization reduces blood flow to a tumor by injecting materials that plug up the artery feeding the area of the liver containing the tumor. This artery that is blocked is a branch of the hepatic artery, the artery that feeds the liver. Most of the healthy liver cells will not be affected because they get their blood supply from another blood vessel (the portal vein).

In this procedure a catheter is put into an artery in the inner thigh and threaded up into the liver. A dye is usually injected into the bloodstream at the same time to allow the doctor to monitor the path of the catheter via angiography, a special type of x-ray. Once the catheter is in place, small particles called microspheres are injected into the artery to plug it up.

In radioembolization, microspheres that are attached to a radioactive element called yttrium-90 (or 90Y) are used (some brand names for these beads include TheraSphere® and SIR-Spheres®). After they are injected, the beads travel in the liver blood vessels until they get stuck in small blood vessels near the tumor. There they give off radioactivity for a short while, killing tumor cells. The radiation travels a very short distance, so its effects are limited mainly to the tumor.

Radiopharmaceuticals
In this form of radiation therapy, a drug is linked to a radioactive element. The drug travels throughout the body, attaches to the cancer cells, and gives off radiation to kill them. This type of treatment has been used for a long time to treat some cancers, but is now also being used to treat carcinoid tumors. One option is to use I-131 MIBG in higher doses than are normally used to image carcinoid tumors (see “Imaging tests” in the section “How are gastrointestinal carcinoid tumors diagnosed?” Treatment using I-131 MIBG is available in Europe, but is not available in the United States.

Another being studied is a drug like octreotide called edotreotide linked with a radioactive form of the element yttrium. This is discussed in more detail in “What's new in gastrointestinal carcinoid tumor research and treatment?”

For more information on radiation therapy, see the Radiation Therapy section of our website, or read Understanding Radiation Therapy: A Guide for Patients and Families.

- References

See all references for Gastrointestinal Carcinoid Tumor

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**Treatment of Gastrointestinal Carcinoid Tumors by Stage**

**Localized disease**

A tumor is localized when it is found only in the organ where it started. Treatment of localized carcinoid tumors is based mostly on their size. Experts sometimes disagree on the exact size for making treatment decisions, and there are some sizes where it has not been determined exactly what treatment is best.

**Stomach**

Carcinoid tumors of the stomach are grouped by the level of a hormone called gastrin.
and the amount of acid in the stomach (measured before surgery). Certain conditions linked to high gastrin levels are also linked to getting many carcinoid tumors of the stomach. Patients with these conditions who have stomach carcinoid tumors are treated differently from patients without these conditions.

**Type 1:** Patients with high gastrin levels but low levels of stomach acid are said to have type 1 tumors. These carcinoid tumors tend to be small, but there may be many of them. The tumors don’t tend to grow into the deeper layers of the stomach or spread to other organs or tissues, and are often treated by removing them completely through an endoscope. The other option is to watch the tumors closely (by endoscopy), and only removing them if they start growing.

**Type 2:** Patients who have high gastrin levels and high stomach acid levels are said to have type 2 tumors. Like type 1 tumors they are often small and there may be more than one at a time. Type 2 tumors also don’t tend to grow into deeper layers of the stomach or spread to other organs. Small tumors can be watched closely without treatment, removed with endoscopy, or treated with a medicine like octreotide (Sandostatin) or lanreotide (Somatuline) that will lower both gastrin and stomach acid. For tumors larger than 2 cm (slightly less than an inch), just watching the tumor closely isn't usually an option. These tumors need to be removed, either through an endoscope or in a regular operation through an incision in the abdomen that removes the tumor and some surrounding stomach tissue.

**Type 3:** Patients who don’t have high gastrin levels (and have normal levels of stomach acid) are said to have type 3 tumors. There is usually only one tumor, and the tumor tends to grow into deeper layers of the stomach or even spread to nearby lymph nodes or other organs (like the liver). If the tumor is small, endoscopic surgery may still be an option. More, often, though, more extensive surgery is needed: A piece of the stomach is removed (a partial gastrectomy) along with nearby lymph nodes.

**Small intestine**

Some small tumors in the duodenum (the first part of the small intestine) can often be removed through the endoscope (endoscopic resection). Depending on the size of the tumor and whether it is growing into nearby tissues, other options include surgery to remove the tumor (local excision), removing all or part of the duodenum with nearby lymph nodes, and removing the duodenum and part of the pancreas (a pancreatoduodenectomy).

For tumors in other parts of the small intestine, treatment is either local excision for small tumors or small bowel resection (removal of a piece of intestine as well as some
surrounding blood vessels and lymph nodes) for larger tumors.

**Large intestine (other than appendix and rectum)**

The usual treatment is hemicolecctomy (removal of a section of colon along with nearby lymph nodes and blood vessels). Because many patients have more than one carcinoid tumor, the surgeon will often check the rest of the colon for other tumors during surgery. For very small tumors, sometimes the tumor can be removed without surgery using a colonoscope.

**Appendix**

Most often, an appendectomy (surgical removal of the appendix) is the only treatment needed for carcinoid tumors that are 2 cm (a little less than an inch) across or smaller. Still, other factors, such as the way the tumor cells look under the microscope, the patient's age, general health, and the patient's degree of worry about the possibility of the cancer coming back, might also be used to determine whether more treatment is needed.

Tumors larger than 2 cm are more likely to have already spread to nearby tissues and lymph nodes, so more extensive surgery is usually recommended for these tumors. This means removal of about a third of the colon next to the appendix (a hemicolecctomy), along with nearby blood vessels and lymph nodes. This procedure might not be recommended for people who are older or have other serious health problems (especially if these problems make surgery more risky), because the benefit might not outweigh the risks.

**Rectum**

Doctors check how deep the cancer is growing into the wall of the rectum before surgery by using endoscopic ultrasound (discussed in the section about diagnosis). Most rectal carcinoid tumors that are smaller than 2 cm (slightly less than an inch) can be removed through an endoscope or local excision through the anus.

The best approach for rectal carcinoid tumors between 1 and 2 cm, depends on how deeply the tumor has grown into the wall of the rectum, as well as other details of each patient's medical situation. If the tumor has grown into the thick muscle layer of the rectum (the muscularis propria) or deeper, it needs to be treated the same as a larger tumor.
Carcinoid tumors larger than 2 cm (and those that have grown deep into the wall of the rectum) have a higher risk of growing and spreading, so they are removed by the same operations used for adenocarcinomas (the usual type of rectal cancer). This operation is a low anterior resection if the carcinoid is in the upper part of the rectum. If the lower part is involved, abdominoperineal (AP) resection and colostomy are used.

**Regional spread**

Regional spread means that the cancer has either spread to nearby lymph nodes or it has grown through the wall of the organ where it started and has invaded nearby tissues such as fat, ligaments, and muscle.

If possible, the primary (main) tumor and any areas of cancer spread should all be removed by surgery. Nearby lymph nodes should be removed and checked for signs of cancer spread. This provides the best chance of cure. If this can't be done, surgery should remove as much cancer as possible without causing severe side effects. Surgery should also be done to relieve symptoms such as intestinal blockage caused by the local growth of the tumor.

**Distant spread**

At this stage, a cure is not usually possible, although treatment is not always needed right away, depending on how quickly the tumors are growing. The goal of surgery in this situation is usually to relieve symptoms and slow the course of the disease. For example, removing or bypassing areas blocked by cancer growth can relieve some symptoms. If distant metastases are not causing symptoms, treatment may not be needed, although chemotherapy or interferon-alfa may help delay symptoms in some patients. If the cancer has spread to the liver, even when it isn’t causing symptoms, some doctors recommend treatment with octreotide or lanreotide because it may slow tumor growth.

If carcinoid syndrome is causing bothersome symptoms, treatment options include chemotherapy, immunotherapy, treatment with octreotide or lanreotide, or surgery to remove the metastatic tumors. If metastatic tumors in the liver cannot be removed by surgery without causing severe side effects, ablation or embolization can be used to destroy as much of the tumors as possible. Patients should also be advised to avoid alcoholic drinks, stress, strenuous exercise, spicy foods, and certain medicines that can make the symptoms of carcinoid syndrome worse.
Recurrent carcinoid tumors

When cancer come backs after treatment it is called a *recurrence*. Recurrence can be local (in or near the same place it started) or distant (spread to organs such as the lungs or bone). Patients with recurrent carcinoid tumors are treated with surgery to remove all signs of tumor whenever possible. This provides the best chance for a good long-term outcome. If surgery is not possible, the treatments used for distant spread may be helpful.

Carcinoid heart disease

The substances released into the blood by some carcinoid tumors can damage the heart. Early symptoms are fatigue and shortness of breath. Eventually, patients get fluid in their legs and even their abdomen. The major cause is damage to the valves of the heart. Doctors can usually make the diagnosis by listening to the heart and by an ultrasound exam of the heart called an *echocardiogram*.

The main treatment is with a somatostatin analog like octreotide or lanreotide to block the cancer’s secretion of the toxic substances. Drugs (diuretics) to strengthen the heartbeat and to get rid of fluid can also help. In some instances, heart surgery may be needed to replace the damaged valves.

- References

  See all references for Gastrointestinal Carcinoid Tumor

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After Treatment

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- What Happens After Treatment for Gastrointestinal Carcinoid Tumors?
- Lifestyle Changes After Treatment of Gastrointestinal Carcinoid Tumors
- How Might Treatment for a Gastrointestinal Carcinoid Tumor Affect Your Emotional Health?

Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- If Treatment of Gastrointestinal Carcinoid Tumor Stops Working

What Happens After Treatment for Gastrointestinal Carcinoid Tumors?

For some people with gastrointestinal (GI) carcinoid tumor, treatment may remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. (When cancer comes back after treatment, it is called a recurrence.) This is a very common concern in people who have had cancer.

It may take a while before your fears lessen. But it may help to know that many cancer survivors have learned to accept this uncertainty and are living full lives. Living With Uncertainty: The Fear of Cancer Recurrence gives more detailed...
information on this.

For other people, the cancer may never go away completely. These people may stay on drug therapy or get regular treatments with chemotherapy, radiation therapy, or other therapies to try to help keep the cancer in check. Learning to live with cancer that does not go away can be difficult and very stressful. It has its own type of uncertainty. Read When Cancer Doesn't Go Away for more about this.

**Follow-up care**

When treatment ends, your doctors will still want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will probably ask questions about any problems you may have and examine you and order lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have.

Doctors often advise most people who have had their GI carcinoid tumors completely removed to return after several months for a complete physical exam and imaging tests to look for any signs of recurrence. Blood and or urine tests may be helpful for some patients. Further visits may be recommended every several months after that. For small rectal tumors, proctoscopy is often recommended 6 and 12 months after treatment. Small tumors of the appendix, when adequately treated, usually don't require close follow-up, as they are very unlikely to recur. Repeat upper endoscopy once or twice a year is usually recommended for patients with stomach carcinoids who have high gastrin levels. Your doctor may follow one of these schedules, but he or she might have reasons to recommend a different schedule as well.

It is very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think about their cancer coming back, this could happen.

Should your cancer come back, When Your Cancer Comes Back: Cancer Recurrence can give you information on how to manage and cope with this phase of your treatment.
Seeing a new doctor

At some point after your treatment, you might see a new doctor who doesn’t know anything about your medical history. It’s important to be able to give your new doctor the details of your diagnosis and treatment. Gathering these details during and soon after treatment may be easier than trying to get them at some point in the future. Make sure you have the following information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report(s)
- If you stayed in the hospital, a copy of the discharge summary that the doctor wrote when you were sent home
- If you were treated with radiation (including radiopharmaceuticals), a copy of your treatment summary
- Since some drugs can have long-term side effects, a list of your drugs, drug doses, and when you took them
- Copies of your imaging tests (which can often be stored digitally on a DVD, etc.)
- Contact information of the doctors who have treated your cancer

The doctor may want copies of this information for his records, but always keep copies for yourself.

- References
  See all references for Gastrointestinal Carcinoid Tumor

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Lifestyle Changes After Treatment of Gastrointestinal Carcinoid Tumors

You can’t change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and
feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

**Making healthier choices**

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control might help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society at 1-800-227-2345.

**Eating better**

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small meals every 2 to 3 hours until you feel better. You might also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is to start healthy eating habits. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

You can get more information in *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*. 
Rest, fatigue, and exercise

Extreme tiredness, called fatigue, is very common in people treated for cancer. This is not a normal tiredness, but a bone-weary exhaustion that often doesn’t get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it’s normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. If you haven’t exercised in a few years, you will have to start slowly, maybe just by taking short walks.

Talk with your cancer care team before starting anything. Then, try to find an exercise buddy so you’re not doing it alone. Having family or friends involved when starting a new physical activity program can give you that extra boost of support to keep you going when the push just isn’t there.

If you are very tired, you will need to balance activity with rest. Sometimes it’s really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. (For more information on dealing with fatigue and other treatment side effects, see the “Physical Side Effects” section of our website.)

Keep in mind exercise can improve your physical and emotional health.

- It improves your heart fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

Getting regular physical activity also plays a role in helping to lower the risk of some cancers, as well as having other health benefits. For more on this, see American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention.
How Might Treatment for a Gastrointestinal Carcinoid Tumor Affect Your Emotional Health?

When treatment ends, you may find yourself overcome with many different emotions. This happens to a lot of people.

You may find yourself thinking about death and dying. Or maybe you’re more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationships with those around you. Unexpected issues may also cause concern. For instance, you might be stressed by financial concerns resulting from your treatment. You might also see your cancer care team less often after treatment and have more time on your hands. These changes can make some people anxious.

Almost everyone who is going through or has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, religious or spiritual groups, online support communities, or one-on-one counselors. What’s best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It’s not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel
may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You can also read *Distress in People With Cancer* or see the “Emotional Side Effects” section of our website for more information.

- **References**
  
  See all references for Gastrointestinal Carcinoid Tumor

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**If Treatment of Gastrointestinal Carcinoid Tumor Stops Working**

If cancer keeps growing or comes back after one kind of treatment, it’s possible that another treatment plan might still cure the cancer, or at least shrink it enough to help you live longer and feel better. Clinical trials also might offer chances to try newer treatments that could be helpful. But when a person has tried many different treatments and the cancer is still growing, even newer treatments might no longer be helpful. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides, including treatment side effects. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer, when you have been through many treatments and nothing’s working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. Your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more treatment might have about a 1 in 100 chance of working. Some people are still tempted to try this. But it is important to have realistic expectations if you do choose this plan.
Palliative care

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is that the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation or chemotherapy might be used to help relieve pain caused by a large tumor. But this is not the same as treatment to try to cure the cancer.

Hospice care

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more by reading Hospice Care.

Staying hopeful is important, too. Your hope for a cure may not be as bright, but there is still hope for good times filled with happiness and meaning with family and friends. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

You can learn more about the changes that occur when treatment stops working, and about planning ahead for yourself and your family, in Nearing the End of Life and Advance Directives.

- References