
Gastrointestinal Carcinoid Tumor Early Detection, Diagnosis, and Staging

Know the signs and symptoms of gastrointestinal carcinoid tumors. Find out how these carcinoid tumors are tested for, diagnosed, and staged.

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](#)
- [Tests for Gastrointestinal Carcinoid Tumors](#)

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.

- [Gastrointestinal Carcinoid Tumor Stages](#)
- [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.

- [Questions to Ask About Gastrointestinal Carcinoid Tumors](#)

Can Gastrointestinal Carcinoid Tumors Be Found Early?

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

Carcinoid tumors often are found by accident. These tumors aren't causing any symptoms but are found when tests are done for other reasons or diseases. They may also be found when parts of the gastrointestinal system are removed to treat other diseases. When patients have parts of their stomach or small intestine removed to treat other diseases, taking a close look in the microscope often shows small groups of neuroendocrine cells that look like tiny carcinoid tumors. Researchers still do not know why some tumors stay small, but others grow large enough to cause symptoms.

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 might notice a small bump in the stomach wall that turns out to be a carcinoid tumor.

Sometimes during [colorectal cancer](#)¹ 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 tumor is found at the tip. This happens in about 1 of every 300 people who have appendix surgery. Most of these carcinoids were too small to have caused any symptoms.

Hyperlinks

1. www.cancer.org/cancer/types/colon-rectal-cancer.html
2. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

Norton JA and Kunz PL. Carcinoid) Tumors and the Carcinoid Syndrome. In: DeVita VT, Hellman S, Rosenberg SA, eds. *Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015:1218–1226.

Schneider DF, Mazeh H, Lubner SJ, Jaume JC, Chen H. Cancer of the Endocrine System. In: Niederhuber JE, Armitage JO, Doroshow JH, Kastan MB, Tepper JE, eds. *Abeloff's Clinical Oncology*. 5th ed. Philadelphia, Pa: Elsevier; 2014:1112-1142.

Strosberg JR. Clinical characteristics of well-differentiated neuroendocrine (carcinoid) tumors arising in the tubular digestive tract, lung, and genitourinary tract. UpToDate website. UpToDate Updated Oct. 20, 2017. Accessed Aug. 2, 2018.

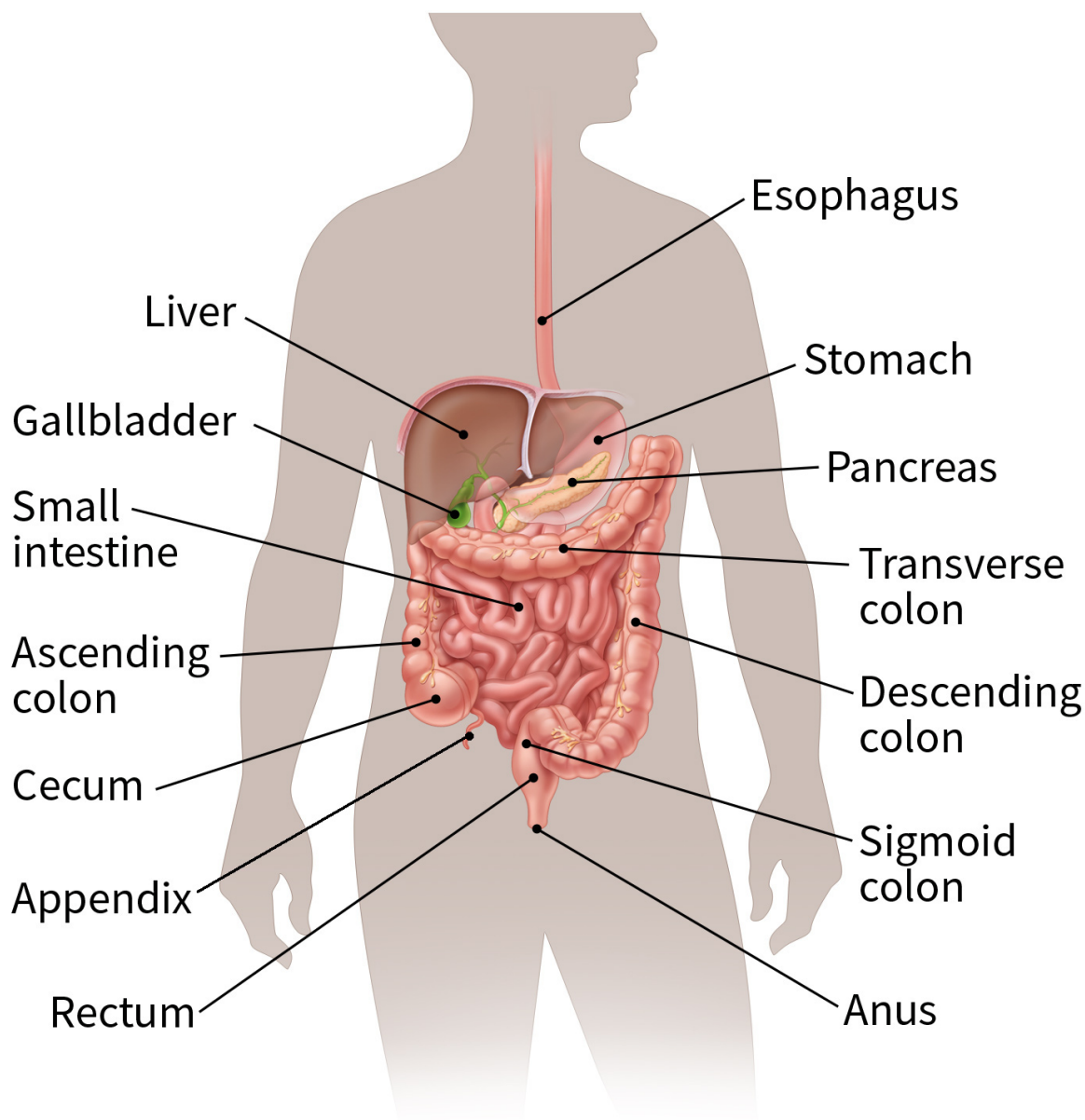
[See all references for Gastrointestinal Carcinoid Tumor](#)

Last Revised: September 24, 2018

Signs and Symptoms of Gastrointestinal Carcinoid Tumors

- [Symptoms by tumor location](#)
- [Signs and symptoms from hormones made by 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 tumor location

The symptoms a person can have from a GI carcinoid tumor often depend on where it is growing.

The appendix

People with tumors in their appendix often don't have symptoms. If the tumor is discovered, it is usually when the appendix is removed 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 fever, 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. These symptoms can sometimes go on for years before the carcinoid tumor is found. A tumor usually has to grow fairly large before it completely blocks (obstructs) the intestine and causes severe belly pain, nausea and vomiting, and a potentially life-threatening situation.

Sometimes a carcinoid tumor can block the opening of the [ampulla of Vater](#)¹, 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.

A carcinoid tumor sometimes can cause intestinal bleeding. This can lead to [anemia](#)² (too few red blood cells) with [fatigue](#)³ 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 when the stomach is examined by an [endoscopy](#)⁴ looking for other things. 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 cause different symptoms 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 carcinoid syndrome symptoms. 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 carcinoid tumors cause the carcinoid syndrome. For example, those in the rectum 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. Carcinoid tumors in the midgut (appendix, small intestine, cecum and ascending colon) that spread to the liver are most likely to cause carcinoid syndrome.

Cushing syndrome

Some carcinoid tumors produce ACTH (adrenocorticotrophic hormone), a substance that causes the adrenal glands to make too much cortisol (a steroid). 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
- A bulge of fat on the back of the 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](#)⁵ (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 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.

Hyperlinks

1. www.cancer.org/cancer/types/pancreatic-cancer/about/what-is-pancreatic-cancer.html
2. www.cancer.org/cancer/managing-cancer/side-effects/low-blood-counts/anemia.html
3. www.cancer.org/cancer/managing-cancer/side-effects/fatigue-weakness-sleep.html
4. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html
5. www.cancer.org/cancer/managing-cancer/side-effects/low-blood-counts/anemia.html
6. www.cancer.gov/types/gi-carcinoid-tumors/hp/gi-carcinoid-treatment-pdq#section/21
7. www.ncbi.nlm.nih.gov/books/NBK448096/
8. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

National Cancer Institute Physician Data Query (PDQ). Gastrointestinal Carcinoid Tumors Treatment (PDQ®)—Health Professional Version. 2018. Accessed at

<https://www.cancer.gov/types/gi-carcinoid-tumors/hp/gi-carcinoid-treatment-pdq#section/21>⁶ on August 3, 2018.

Norton JA and Kunz PL. Carcinoid) Tumors and the Carcinoid Syndrome. In: DeVita VT, Hellman S, Rosenberg SA, eds. *Cancer: Principles and Practice of Oncology*. 10th ed.

Philadelphia, Pa: Lippincott Williams & Wilkins; 2015:1218-1226.

Pandit S, Bhusal K. Carcinoid Syndrome. [Updated 2017 Oct 9]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2018 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK448096/> Accessed August 3, 2018.

Schneider DF, Mazeh H, Lubner SJ, Jaume JC, Chen H. Cancer of the Endocrine System. In: Niederhuber JE, Armitage JO, Doroshow JH, Kastan MB, Tepper JE, eds. *Abeloff's Clinical Oncology*. 5th ed. Philadelphia, Pa: Elsevier; 2014:1112-1142.

[See all references for Gastrointestinal Carcinoid Tumor](#)

Last Revised: September 24, 2018

Tests for Gastrointestinal Carcinoid Tumors

- [Medical history and physical exam](#)
- [Imaging tests](#)
- [Endoscopy](#)
- [Biopsy](#)
- [Blood and urine tests](#)

Certain signs and symptoms might suggest that a person could have a gastrointestinal (GI) carcinoid tumor, but tests are needed to confirm the diagnosis.

Medical history and physical exam

You will be asked questions about your general health, lifestyle habits, symptoms, and risk factors. The doctor also will probably ask about symptoms that could be caused by carcinoid syndrome, as well as those that might be caused by a mass (tumor) in the stomach, intestines, or rectum.

Some patients with carcinoid 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 carcinoid 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. These might include imaging tests, lab tests, and other procedures.

Imaging tests

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. Barium studies can be used to examine the upper or lower parts of the digestive system. This type of study is often useful in diagnosing some GI carcinoid tumors, but is least effective in finding those in the small intestine.

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 with small bowel follow-through: This [test](#)¹ is used to examine the lining of the stomach and the first part of the small intestine.

Enteroclysis: This is another way to look at the small intestine. A thin tube is passed through 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 is used to look at the inner surface of the colon and rectum.

[Barium x-rays](#)² are used less these days than in the past. In many cases, they are being replaced by [endoscopy](#)³, where the doctor looks into the esophagus, stomach, or colon with a narrow fiber optic scope.

Computed tomography (CT) scan

A [CT scan](#)⁴ is most often used to look at the chest and/or belly (abdomen) to see if GI neuroendocrine (carcinoid) tumors have spread to nearby lymph nodes or other organs such as the liver. It can also be used to guide a biopsy needle into an area of concern..

Magnetic resonance imaging (MRI) scan

[MRI scans](#)⁵ sometimes can see cancer spread to the liver better than a CT scan.

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](#)⁶ and special cameras can be helpful in looking for GI carcinoid tumors. They can help find tumors or look for areas of cancer spread if doctors aren't sure where it is in the body.

Positron emission tomography (PET) scan: For most types of cancer, PET scans use a form of radioactive glucose (sugar) to find tumors. This type of PET scan is useful in finding high-grade (grade 3) carcinoid tumors, but a newer type of PET scan, called a Gallium-68 PET/CT Dotatate scan is being used for low (grade 1) or intermediate-grade (grade 2) GI carcinoid tumors. It uses the radioactive agent gallium-68 dotatate which attaches to the somatostatin protein on carcinoid cells.

A special camera can detect the radioactivity. The gallium-68 PET/CT scan is slowly becoming more widely available since it was approved by the FDA in 2016 and is able to find carcinoid tumors better than an Octreoscan (described below).

Another radioactive agent, copper Cu-64 dotatate, also attaches to the somatostatin protein, and was approved in 2020 for use with a PET scan in people with a GI carcinoid tumor.

Octreoscan (somatostatin receptor scintigraphy): This test uses a drug called octreotide joined to a radioactive drug. Octreotide is a hormone-like substance that attaches to GI carcinoid cells. A small amount is injected into a vein and it travels through the blood where it attaches to GI carcinoid tumors. A few 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. Along with showing where tumors are located, this test can help tell whether treatment with certain drugs such as octreotide and lanreotide is likely to be helpful. This test is most helpful for grade 1 and 2 GI carcinoid tumors.

I-131 MIBG scan: This test is used much less often to find GI carcinoid tumors. It uses a chemical called MIBG that is attached to radioactive iodine (I-131). 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 GI carcinoid tumors, but other kinds of neuroendocrine tumors can also pick up this chemical.

Endoscopy

[Endoscopy tests](#)⁷ 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 in the lab 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 medicine in a vein to make them feel relaxed and sleepy. If you are sedated for the procedure, you will need someone to take you home.

Colonoscopy

A [colonoscopy](#)⁸ is also called lower endoscopy. It uses a special endoscope known as a colonoscope which is inserted through the anus 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 before and the morning of the exam.

You will be given intravenous medicine to make you feel relaxed and sleepy during the procedure. 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.

Flexible sigmoidoscopy

[Flexible sigmoidoscopy](#)⁹ is similar to a colonoscopy and can be used to look for a rectal tumor and some tumors in the lower part of the colon. This test uses a shorter, flexible, hollow tube, with a light on the end of it that is also inserted through the anus up into the colon.

Capsule endoscopy

Unfortunately, neither an upper nor lower endoscopy can reach all areas of the small intestine, where many NETs begin. A device known as a 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 they go 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 very long (20 feet [6 meters]) 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 (30 centimeters) at a time.

This procedure is done after the patient is given drugs to make them 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.

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 a 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.

Biopsy

In many cases, the only way to know for sure if a person has some type of GI carcinoid tumor is to remove cells from the tumor and look at them in the lab. 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 (tweezers 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](#)¹⁰.

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, an endoscopic biopsy or a CT-guided needle biopsy will not 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 [Biopsy and Cytology Tests](#)¹¹.

Blood and urine tests

[Blood and urine tests](#)¹² can be very helpful in diagnosing carcinoid syndrome in patients who have symptoms that might be caused by it.

Many GI 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. 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.

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 carcinoid syndrome.

Other common tests to look for carcinoids include blood tests for chromogranin A (CgA) 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](#)¹³ is working, since the levels of these substances tend to go down as tumors shrink.

Hyperlinks

1. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/x-rays-and-other-radiographic-tests.html
2. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/nuclear-medicine-scans-for-cancer.html
3. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html
4. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html
5. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/mri-for-cancer.html
6. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/nuclear-medicine-scans-for-cancer.html
7. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html
8. www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-

- [staging/screening-tests-used.html](#)
9. www.cancer.org/cancer/types/colon-rectal-cancer/detection-diagnosis-staging/screening-tests-used.html
 10. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/ct-scan-for-cancer.html
 11. www.cancer.org/cancer/diagnosis-staging/tests/biopsy-and-cytology-tests.html
 12. www.cancer.org/cancer/diagnosis-staging/tests/understanding-your-lab-test-results.html
 13. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/treating.html
 14. www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm504524.htm
 15. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Neuroendocrine and Adrenal Tumors. V.2.2018. Accessed at https://www.nccn.org/professionals/physician_gls/pdf/neuroendocrine.pdf on August 4, 2018.

Norton JA and Kunz PL. Carcinoid) Tumors and the Carcinoid Syndrome. In: DeVita VT, Hellman S, Rosenberg SA, eds. *Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015:1218–1226.

Schneider DF, Mazeh H, Lubner SJ, Jaume JC, Chen H. Cancer of the Endocrine System. In: Niederhuber JE, Armitage JO, Doroshow JH, Kastan MB, Tepper JE, eds. *Abeloff's Clinical Oncology*. 5th ed. Philadelphia, Pa: Elsevier; 2014:1112-1142.

U.S. Food and Drug Administration website.
<https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm504524.htm>¹⁴.
Published June 1, 2016. Accessed July 11, 2018.

[See all references for Gastrointestinal Carcinoid Tumor](#)

Last Revised: September 16, 2020

Gastrointestinal Carcinoid Tumor Stages

- [How is the stage determined?](#)
- [Localized, regional, and distant stages](#)
- [The AJCC TNM staging system](#)

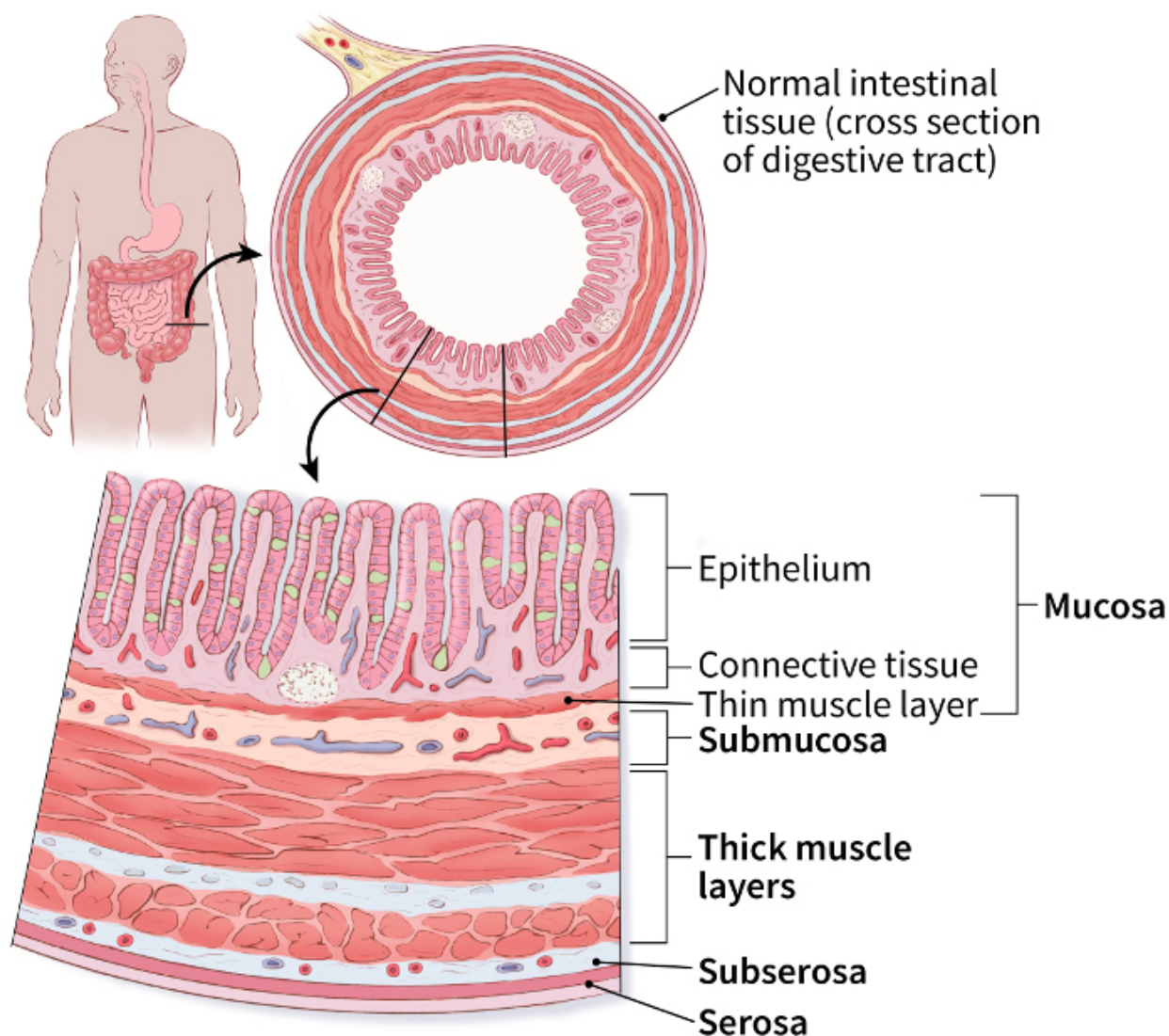
After someone is diagnosed with a gastrointestinal (GI) carcinoid tumor, doctors will try to figure out if it has spread, and if so, how far. This process is called **staging**. The stage of cancer describes how much cancer is in the body. It helps determine how serious the cancer is and how best to [treat](#)¹ it. Doctors also use a cancer's stage when talking about survival statistics.

How is the stage determined?

GI carcinoid tumors are typically given a **clinical stage** based on the results of any exams, biopsies, and imaging tests that might have been done (as described in Tests for Gastrointestinal Carcinoid Tumors). If surgery has been done, the **pathologic stage** (also called the **surgical stage**) can also be determined.

GI carcinoid tumors typically start in the inner lining of the wall of the GI tract. As they grow, they can spread into deeper layers of the GI tract. For most of the GI tract, these layers include:

- **Mucosa:** This is the innermost layer. It has 3 parts: the top layer of cells (the epithelium), a thin layer of connective tissue (the lamina propria), and a thin layer of muscle (the muscularis mucosa).
- **Submucosa:** This is the fibrous tissue that lies beneath the mucosa.
- **Thick muscle layer (muscularis propria):** This layer of muscle contracts to force the food along the GI tract.
- **Subserosa and serosa:** These are the thin outermost layers of connective tissue that cover the GI tract. The serosa is also known as the visceral peritoneum.



Localized, regional, and distant stages

Until recently there was no standard staging system for describing the spread of GI carcinoid tumors. Many doctors simply staged GI carcinoid tumors as localized, regional spread, and distant spread. This approach was fairly easy to understand and could be useful when determining treatment options.

- **Localized:** The cancer has not spread beyond the wall of the organ it started in (for example, the stomach, small 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 and 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 staging system

The staging system most often used for GI carcinoid tumors is the American Joint Committee on Cancer (AJCC) **TNM** system, which is based on 3 key pieces of information:

- The size and extent of the main **tumor (T)**: Where is the tumor? How far has it grown into the wall of the GI tract and nearby structures?
- The spread to nearby lymph **nodes (N)**: Has the cancer spread to nearby lymph nodes?
- The spread (**metastasis**) to distant sites (**M**): Has the cancer spread to distant parts of the body? (The most common sites of spread are lymph nodes far away from the tumor, the liver, the lungs, and the bones.)

Numbers or letters after T, N, and M provide more details about each of these factors. Higher numbers mean the cancer is more advanced.

Once the T, N, and M categories of the cancer have been determined, this information is combined in a process called **stage grouping** to assign an overall stage. For more information, see [Cancer Staging²](#).

The main stages of GI carcinoid tumors in the TNM system range from I (1) through IV (4). Some stages might be divided further with letters (A, B, etc.). As a rule, the lower the number, the less the cancer has spread. A higher number, such as stage IV, means cancer has spread more. And within a stage, an earlier letter means a lower stage. Although each person's cancer experience is unique, cancers with similar stages tend to have a similar outlook and are often treated in much the same way.

The system described below is the most recent AJCC system, effective January 2018. It includes lower-grade carcinoid tumors that start in the GI tract, but not other types of cancers that can start there. (For example, it doesn't include high-grade neuroendocrine carcinomas, or the more common types of [stomach cancer³](#) or [colorectal cancer⁴](#), which have their own staging systems.)

The stages of GI carcinoid tumors are slightly different, based on which part of the GI

tract the cancer starts in:

- The **stomach**
- The **small intestine (jejunum or ileum)***
- The **appendix**
- The **colon or rectum**

*Carcinoid tumors starting in the duodenum or ampulla of Vater are uncommon and have their own staging system, which is not included here.

GI carcinoid tumor staging with the TNM system can be complex. If you have any questions about your cancer's stage or what it means, ask your doctor to explain it to you in a way you understand.

Stages of carcinoid tumors of the stomach

AJCC stage	Stage grouping	Stage description*
I	T1 N0 M0	The tumor is no more than 1 centimeter (cm) across 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 parts of the body (M0).
II	T2 N0 M0	The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm across; OR the tumor has grown into the main muscle layer of the stomach (the muscularis propria) (T2).
		The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
	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 parts of the body (M0).
	T4 N0 M0	The tumor has grown into the outer layer of tissue covering the

III		<p>stomach (the serosa or visceral peritoneum) or into nearby organs or structures (T4).</p> <p>The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).</p>
	OR	
	Any T N1 M0	<p>The tumor can be any size and might or might not have grown into nearby structures (any T).</p> <p>It has spread to nearby lymph nodes (N1), but not to distant parts of the body (M0).</p>
IV	Any T Any N M1	<p>The tumor can be any size and might or might not have grown into nearby structures (any T).</p> <p>It might or might not have spread to nearby lymph nodes (any N).</p> <p>The cancer has spread to distant parts of the body (M1).</p>

*The following additional categories are not listed in the table above:

Stages of carcinoid tumors of the small intestine (jejunum or ileum)

AJCC stage	Stage grouping	Stage description*
I	T1 N0 M0	<p>The tumor is no more than 1 centimeter (cm) across and has grown from the top layer of cells and into deeper layers, such as the lamina propria or the submucosa (T1).</p> <p>The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).</p>
II	T2 N0 M0	<p>The tumor has grown into the lamina propria or submucosa (or both) and is greater than 1 cm across; OR the tumor has grown into the main muscle layer of the intestine (the muscularis propria) (T2).</p> <p>The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).</p>

	OR	
	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 parts of the body (M0).
III	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 (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
	Any T N1 or N2 M0	The tumor can be any size and might or might not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1 or N2), but not to distant parts of the body (M0).
IV	Any T Any N M1	The tumor can be any size and might or might not have grown into nearby structures (any T). It might or might not have spread to nearby lymph nodes (any N). The cancer has spread to distant parts of the body (M1).

*The following additional categories are not listed in the table above:

Stages of carcinoid tumors of the appendix

AJCC stage	Stage grouping	Stage description*
I	T1 N0 M0	The tumor is no more than 2 centimeters (cm) across (T1). The cancer has not spread to nearby lymph nodes (N0) or to

		distant parts of the body (M0).
II	T2 N0 M0	The tumor is more than 2 cm but no more than 4 cm across (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
III	T3 N0 M0	The tumor is more than 4 cm across, OR it has grown into the subserosa or the mesoappendix (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
III	T4 N0 M0	The tumor has grown into the outer layer of tissue covering the appendix (the peritoneum) or into nearby organs or structures (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
IV	Any T N1 M0	The tumor can be any size and might or might not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant parts of the body (M0).
	Any T Any N M1	The tumor can be any size and might or might not have grown into nearby structures (any T). It might or might not have spread to nearby lymph nodes (any N). The cancer has spread to distant parts of the body (M1).

*The following additional categories are not listed in the table above:

- TX: Main tumor cannot be assessed due to lack of information.
- T0: No evidence of a main tumor.
- NX: Nearby lymph nodes cannot be assessed due to lack of information.

Stages of carcinoid tumors of the colon or rectum

AJCC stage	Stage grouping	Stage description*
I	T1 N0 M0	The tumor is no more than 2 centimeters (cm) across 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 parts of the body (M0).
IIA	T2 N0 M0	The tumor has grown into the lamina propria or submucosa (or both) and is greater than 2 cm across; OR the tumor has grown into the main muscle layer (the muscularis propria) (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
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 parts of the body (M0).
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 (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
IIIB	Any T N1 M0	The tumor can be any size and might or might not have grown into nearby structures (any T). It has spread to nearby lymph nodes (N1), but not to distant parts of the body (M0).
IV	Any T Any N M1	The tumor can be any size and might or might not have grown into nearby structures (any T). It might or might not have spread to nearby lymph nodes (any N). The cancer has spread to distant parts of the body (M1).

*The following additional categories are not listed in the table above:

Hyperlinks

1. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/treating.html
2. www.cancer.org/cancer/diagnosis-staging/staging.html
3. www.cancer.org/cancer/types/stomach-cancer.html
4. www.cancer.org/cancer/types/colon-rectal-cancer.html

References

American Joint Committee on Cancer. Neuroendocrine Tumors of the Appendix. In: *AJCC Cancer Staging Manual*. 8th ed. New York, NY: Springer; 2017: 389-394.

American Joint Committee on Cancer. Neuroendocrine Tumors of the Colon and Rectum. In: *AJCC Cancer Staging Manual*. 8th ed. New York, NY: Springer; 2017: 395-406.

American Joint Committee on Cancer. Neuroendocrine Tumors of the Jejunum and Ileum. In: *AJCC Cancer Staging Manual*. 8th ed. New York, NY: Springer; 2017: 375-487.

American Joint Committee on Cancer. Neuroendocrine Tumors of the Stomach. In: *AJCC Cancer Staging Manual*. 8th ed. New York, NY: Springer; 2017: 351-359.

Last Revised: September 24, 2018

Survival Rates for Gastrointestinal Carcinoid Tumors

- [Understanding the numbers](#)

Survival rates can give you an idea of what percentage of people with the same type and stage of cancer are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can't tell you how long you will live, but they may help give you a better understanding of how likely it is that your treatment will be successful.

Keep in mind that survival rates are estimates and are often based on previous outcomes of large numbers of people who had a specific cancer, but they can't predict what will happen in any particular person's case. These statistics can be confusing and may lead you to have more questions. Ask your doctor how these numbers might apply to you.

What is a 5-year relative survival rate?

A **relative survival rate** compares people with the same type and stage of gastrointestinal (GI) carcinoid tumor to people in the overall population. For example, if the **5-year relative survival rate** for a specific stage of GI carcinoid tumor is 90%, it means that people who have that cancer are, on average, about 90% as likely as people who don't have that cancer to live for at least 5 years after being diagnosed.

Where do these numbers come from?

The American Cancer Society relies on information from the Surveillance, Epidemiology, and End Results (SEER) database, maintained by the National Cancer Institute (NCI), to provide survival statistics for different types of cancer.

The SEER database tracks 5-year relative survival rates for GI carcinoid tumors in the United States, based on how far the cancer has spread. The SEER database, however, does not group cancers by [AJCC TNM stages](#) (stage 1, stage 2, stage 3, etc.). Instead, it groups cancers into localized, regional, and distant stages:

- **Localized:** The cancer has not spread beyond the wall of the organ it started in (for example, the stomach, small intestine, or rectum).
- **Regional:** The cancer has either spread to nearby lymph nodes, or it has grown through the wall of the organ where it started and into nearby tissues such as fat, ligaments, and muscle (or both).
- **Distant:** The cancer has spread to distant parts of the body such as the lungs, liver or bones.

5-year relative survival rates for GI carcinoid tumors

(These numbers are based on people diagnosed with grade 1 or 2 GI carcinoid tumors [stomach, small intestine, colon, appendix, cecum and rectum] between 2012 and 2018.)

SEER* Stage	5-Year Relative Survival Rate
Localized	97%
Regional	96%
Distant	68%
All SEER stages combined	94%

*SEER= Surveillance, Epidemiology, and End Results

Understanding the numbers

- **These numbers apply only to the stage of the cancer when it is first diagnosed.** They do not apply later on if the cancer grows, spreads, or comes back after treatment.
- **These numbers don't take everything into account.** Survival rates are grouped based on how far the cancer has spread, but your age, [organ the tumor started in](#)¹, overall health, how well the cancer responds to treatment, and other factors can also affect your outlook.
- **People now being diagnosed with a GI carcinoid tumor may have a better outlook than these numbers show.** Treatments improve over time, and these numbers are based on people who were diagnosed and treated at least five years earlier.

Hyperlinks

1. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/about/what-is-gastrointestinal-carcinoid.html
2. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

SEER*Explorer: An interactive website for SEER cancer statistics [Internet]. Surveillance Research Program, National Cancer Institute. Accessed at <https://seer.cancer.gov/explorer/> on February 23, 2023.

[See all references for Gastrointestinal Carcinoid Tumor](#)

Last Revised: March 1, 2023

Questions to Ask About Gastrointestinal Carcinoid Tumors

- [When you're told you have a gastrointestinal carcinoid tumor](#)
- [When deciding on a treatment plan](#)
- [During treatment](#)
- [After treatment](#)

It is important to have honest, open discussions with your cancer care team. They want to answer all of your questions, so that you can make informed treatment and life decisions. For instance, consider these questions:

When you're told you have a gastrointestinal carcinoid tumor

- Where is the cancer located?
- Has the cancer spread beyond where it started?
- What is the cancer's [stage](#) (extent), and what does that mean?
- Will I need other [tests](#) before we can decide on treatment?
- Will I need to see any other doctors or health professionals?
- If I'm concerned about the costs and insurance coverage for my diagnosis and treatment, who can help me?

When deciding on a treatment plan

- What are my [treatment options](#)¹?

- What do you recommend and why?
- How much experience do you have treating this type of cancer?
- Should I get a [second opinion](#)²? How do I do that? Can you recommend someone?
- What would the goal of the treatment be?
- How quickly do we need to decide on treatment?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What risks or side effects are there to the treatments you suggest? Are there things I can do to reduce these side effects?
- How might treatment affect my daily activities? Can I still work full time?
- What are the chances the cancer will recur (come back) with these treatment plans?
- What will we do if the treatment doesn't work or if the cancer recurs?
- What if I have transportation problems getting to and from treatment?

During treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but asking the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything I can do to help manage [side effects](#)³?
- What symptoms or side effects should I tell you about right away?
- How can I reach you on nights, holidays, or weekends?
- Do I need to change what I eat during treatment?
- Are there any limits on what I can do?
- Can I exercise during treatment? If so, what kind should I do, and how often?
- Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?
- What if I need social support during treatment because my family lives far away?

After treatment

- Do I need a special diet after treatment?
- Are there any limits on what I can do?
- What other symptoms should I watch for?

- What kind of exercise should I do now?
- What type of follow-up will I need after treatment?
- How often will I need to have follow-up exams and imaging tests?
- Will I need any blood tests?
- How will we know if the cancer has [come back](#)⁴? What should I watch for?
- What will my options be if the cancer comes back?

Along with these sample questions, you might write down some of your own. For instance, you might want more information about recovery times. Or you might want to ask if you qualify for any [clinical trials](#)⁵.

Keep in mind that doctors aren't the only ones who can give you information. Other health care professionals, such as nurses and social workers, can answer some of your questions. To find out more about speaking with your health care team, see [The Doctor-Patient Relationship](#)⁶.

Hyperlinks

1. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/treating.html
2. www.cancer.org/cancer/managing-cancer/finding-care/seeking-a-second-opinion.html
3. www.cancer.org/cancer/managing-cancer/side-effects.html
4. www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence.html
5. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html
6. www.cancer.org/cancer/managing-cancer/finding-care/the-doctor-patient-relationship.html
7. www.cancer.org/cancer/types/gastrointestinal-carcinoid-tumor/references.html

References

[See all references for Gastrointestinal Carcinoid Tumor](#)

Last Revised: September 24, 2018

Written by

The American Cancer Society medical and editorial content team
(<https://www.cancer.org/cancer/acs-medical-content-and-news-staff.html>)

Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as editors and translators with extensive experience in medical writing.

American Cancer Society medical information is copyrighted material. For reprint requests, please see our Content Usage Policy (www.cancer.org/about-us/policies/content-usage.html).

cancer.org | 1.800.227.2345