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About Gastrointestinal Stromal Tumor

Overview and Types

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

- [What Are Gastrointestinal Stromal Tumors?](#)

Research and Statistics

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

- [Key Statistics for Gastrointestinal Stromal Tumors](#)
 - [What's New in Gastrointestinal Stromal Tumor Research?](#)
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What Are Gastrointestinal Stromal Tumors?

Cancer starts when cells in the body begin to grow out of control. Cells in nearly any part of the body can become cancer, and can spread to other areas of the body. To learn more about how cancers start and spread, see [What Is Cancer?](#)¹

Gastrointestinal stromal tumors (GISTs) start in special cells in the wall of the

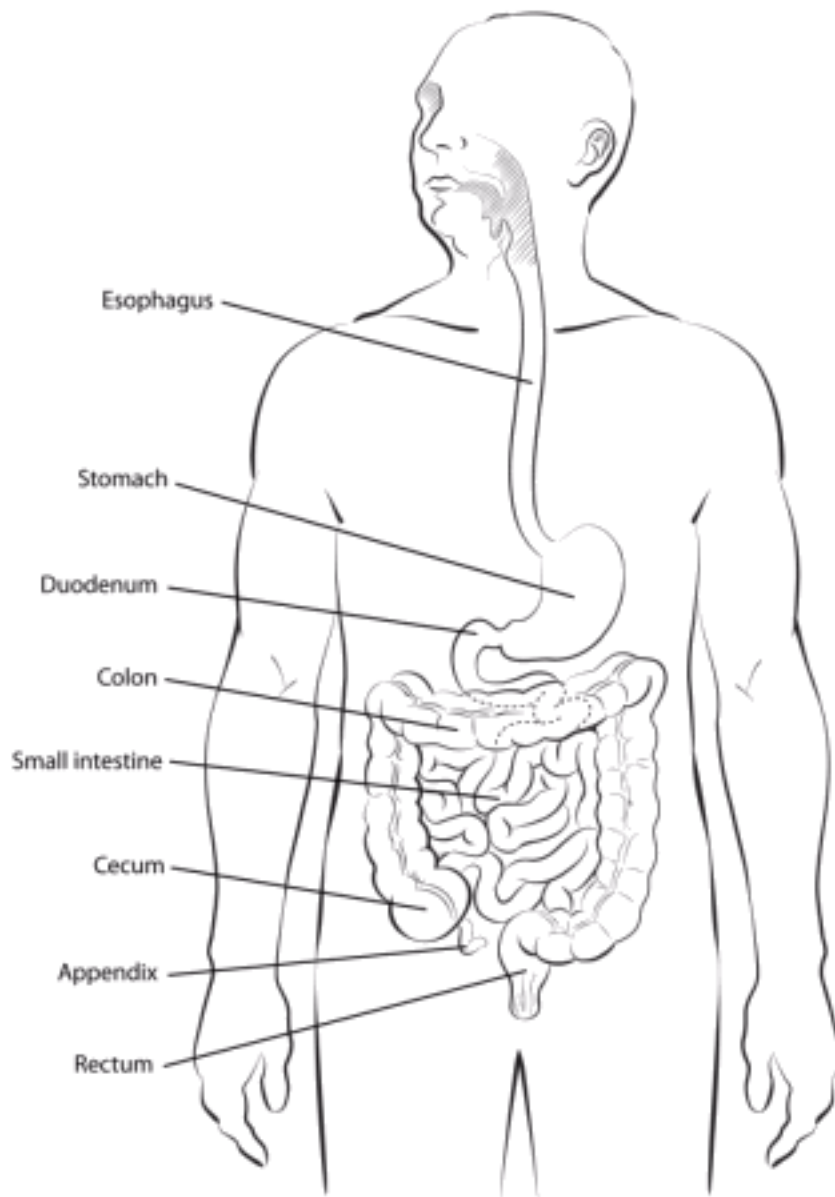
gastrointestinal (GI) tract, also known as the digestive tract. To understand GISTs, it helps to know something about the structure and function of the GI tract.

How the gastrointestinal tract works

The gastrointestinal (GI) tract processes food for energy and rids the body of solid waste. After food is chewed and swallowed, it enters the esophagus, a tube that carries food through the neck and chest to the stomach. The esophagus joins the stomach just beneath the diaphragm (the thin band of muscle below the lungs).

The stomach is a sac-like organ that helps the digestive process by mixing the food with gastric juices. The food and gastric juices are then emptied into the small intestine. The small intestine, which is about 20 feet long, continues breaking down the food and absorbs most of the nutrients into the bloodstream.

The small intestine joins the large intestine, the first part of which is the colon, a muscular tube about 5 feet long. The colon absorbs water and mineral nutrients from the remaining food matter. The waste left after this process goes into the rectum as stool (feces), where it is stored until it passes out of the body through the anus.



Gastrointestinal stromal tumors

Gastrointestinal stromal tumors (GISTs) are uncommon tumors of the GI tract. These tumors start in very early forms of special cells in the wall of the GI tract called the **interstitial cells of Cajal (ICCs)**. ICCs are cells of the autonomic nervous system, the

part of the nervous system that regulates body processes such as digesting food. ICCs are sometimes called the “pacemakers” of the GI tract because they signal the muscles in the GI tract to contract to move food and liquid along.

More than half of GISTs start in the stomach. Most of the others start in the small intestine, but GISTs can start anywhere along the GI tract. A small number of GISTs start outside the GI tract in nearby areas such as the omentum (an apron-like layer of fatty tissue that hangs over the organs in the abdomen) or the peritoneum (the layer of tissue that lines the organs and walls of the abdomen).

Some GISTs seem to be much more likely to grow into other areas or spread to other parts of the body than others. Doctors look at certain factors to help tell whether a GIST is likely to grow and spread quickly, such as how large the tumor is, where it's located in the GI tract, and how fast the tumor cells are dividing (its mitotic rate, described in [Tests for Gastrointestinal Stromal Tumors²](#)).

Other GI tract cancers

It's important to understand that GISTs are not the same as other, more common types of GI tract cancers that develop from other types of cells.

Cancers can occur anywhere in the GI tract from the esophagus to the anus. Most GI tract cancers, including those of the esophagus, stomach, colon, and rectum, start in the gland cells that line almost all of the GI tract. The cancers that develop in these cells are called **adenocarcinomas**.

Cancers can also start in squamous cells, which are flat cells that line some parts of the GI tract, like the upper part of the esophagus and the end of the anus. Cancers starting in these cells are called **squamous cell carcinomas**.

The GI tract also has neuroendocrine cells. These cells have some features in common with nerve cells but other features in common with hormone-producing (endocrine) cells. Cancers that develop from these cells are called **neuroendocrine tumors (NETs)**. These cancers are rare in the GI tract. [Carcinoid tumors³](#) are an example of a neuroendocrine tumor found in the GI tract.

Other rare types of cancer in the GI tract include different types of [soft tissue sarcomas⁴](#), such as:

- Leiomyosarcomas: cancers of smooth muscle cells
- Angiosarcomas: cancers of blood vessel cells

- Malignant peripheral nerve sheath tumors (MPNSTs): cancers of cells that support and protect nerves

GISTs are different from these other GI tract cancers. They start in different types of cells, need different types of treatment, and have a different prognosis (outlook). This is why doctors need to figure out whether a person with a tumor in the GI tract has a GIST, some other type of cancer, or a non-cancerous condition.

Hyperlinks

1. www.cancer.org/cancer/cancer-basics/what-is-cancer.html
2. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/how-diagnosed.html
3. www.cancer.org/cancer/gastrointestinal-carcinoid-tumor.html
4. www.cancer.org/cancer/soft-tissue-sarcoma.html

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Key Statistics for Gastrointestinal Stromal Tumors

Gastrointestinal stromal tumors (GISTs) are not common, and the exact number of people diagnosed with these tumors each year is not known. Until the late 1990s, not much was known about these tumors (and doctors didn't have good ways of identifying them with lab tests), so many of them ended up being classified as other kinds of GI cancers.

Current estimates for the total number of GIST cases each year in the United States range from about 4,000 to about 6,000.

These tumors can start anywhere in the GI tract, but they occur most often in the stomach (about 60%) or the small intestine (about 35%). Most of the rest are found in the esophagus, colon, and rectum. A small number develop in the abdomen outside the GI tract.

GISTs are most commonly found in people in their 60s. These tumors are rare in people younger than 40, but they can occur in people at any age.

Survival statistics for GIST are discussed in [Survival Rates for Gastrointestinal Stromal Tumors](#)¹.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/survival-rates.html

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American Joint Committee on Cancer. Gastrointestinal stromal tumors. In: *AJCC Cancer Staging Manual*. 7th ed. New York, NY: Springer; 2010:175-180.

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What's New in Gastrointestinal Stromal Tumor Research?

Important research on gastrointestinal stromal tumors (GISTs) is going on in many university hospitals, medical centers, and other institutions around the world. Scientists are learning more about what causes the disease and how best to treat it. There has been a great deal of progress in recent years, especially in treating GISTs.

Targeted therapy drugs

As researchers have come to understand the genetic changes that cause these tumors, they've been able to use newer treatments to target these changes.

Doctors know [targeted treatments](#)¹ like imatinib (Gleevec), sunitinib (Sutent), and regorafenib (Stivarga) often work, but they still aren't sure exactly how and when to give them to make them most effective. For example, should these types of drugs be given after [surgery](#)² to all patients, even those with very small tumors? How long should drug treatment be continued? These and other questions are now being studied in [clinical trials](#)³.

Other drugs that target the KIT or PDGFRA proteins are also being studied for use against GISTs. Some of these, such as sorafenib (Nexavar), nilotinib (Tasigna), dasatinib (Sprycel), pazopanib (Votrient), and ponatinib (Iclusig), have helped some patients in early studies. Other, newer drugs that target these proteins, such as crenolanib and BLU-285, are also being studied.

Many other drugs that target different proteins involved in tumor cell growth are now being tested as well.

Immunotherapy

Immunotherapy is the use of medicines to boost the body's own immune response to help fight the cancer.

For example, immune system cells normally have proteins that act as checkpoints to keep them from attacking other healthy cells in the body. Cancer cells sometimes take advantage of these checkpoints to avoid being attacked by the immune system.

Newer drugs called **immune checkpoint inhibitors** work by blocking these checkpoint proteins, which can boost the immune response against cancer cells in the body. These drugs have been shown to be helpful against many types of cancer in recent years. Some of these drugs, such as such as nivolumab (Opdivo) and ipilimumab (Yervoy), are now being studied for use against GISTs.

Other types of immunotherapy are now being explored as well.

People with GISTs who are no longer responding to standard treatments may want to ask their doctor about [clinical trials](#)⁴ of these newer types of treatments.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy.html
2. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/surgery.html
3. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
4. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html

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Gastrointestinal Stromal Tumor 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 stromal tumors.

- [Gastrointestinal Stromal Tumor Risk Factors](#)
- [What Causes Gastrointestinal Stromal Tumors?](#)

Prevention

The only known risk factors for gastrointestinal stromal tumors (GISTs) age and certain rare, genetic syndromes – cannot be changed. At this time we do not know of any way to protect against these cancers.

Gastrointestinal Stromal Tumor Risk Factors

A risk factor is anything that affects a person's chance of getting a disease like cancer. Different cancers have different risk factors. Some risk factors, like smoking, can be changed. Others, like a person's age or family history, can't be changed.

But having a risk factor, or even several, does not mean that a person will get the

disease. And many people who get the disease may have few or no known risk factors.

Currently, there are very few known risk factors for gastrointestinal stromal tumors (GISTs).

Being older

These tumors can occur in people of any age, but they are rare in people younger than 40 and are most common in people aged 50 to 80.

Genetic syndromes

Most GISTs are sporadic (not inherited) and have no clear cause. In rare cases, though, GISTs have been found in several members of the same family. These family members have inherited a gene mutation (change) that can lead to GISTs.

Primary familial GIST syndrome: This is a rare, inherited condition that leads to an increased risk of developing GISTs. People with this condition tend to develop GISTs at a younger age than when they usually occur. They are also more likely to have more than one GIST.

Most often, this syndrome is caused by an abnormal *KIT* gene passed from parent to child. This is the same gene that is mutated (changed) in most sporadic GISTs. (See [What Causes Gastrointestinal Stromal Tumors?](#)) People who inherited this abnormal gene from a parent have it in all their cells, while people with sporadic GISTs only have it in the cancer cells.

Less often, a change in the *PDGFRA* gene causes this genetic syndrome. Defects in the *PDGFRA* gene are found in about 5% to 10% of sporadic GISTs.

Sometimes people with familial GIST syndrome also have skin spots like those seen in patients with neurofibromatosis (discussed below). Before tests for the *KIT* and *PDGFRA* genes became available, some of these people were mistakenly thought to have neurofibromatosis.

Neurofibromatosis type 1 (von Recklinghausen disease): This disease is caused by a defect in the *NF1* gene. This gene change may be inherited from a parent, but in some cases it occurs before birth, without being inherited.

People affected by this syndrome often have many benign (non-cancerous) tumors that form in nerves, called *neurofibromas*, starting at an early age. These tumors form under

the skin and in other parts of the body. These people also typically have tan or brown spots on the skin (called *café au lait spots*).

People with this condition have a higher risk of GISTs, as well as some other types of cancer.

Carney-Stratakis syndrome: People with this rare inherited condition have an increased risk of GISTs (most often in the stomach), as well as nerve tumors called *paragangliomas*. GISTs often develop when these people are in their teens or 20s. They are also more likely to have more than one GIST.

This syndrome is caused by a change in one of the succinate dehydrogenase (*SDH*) genes, which is passed from parent to child.

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What Causes Gastrointestinal Stromal Tumors?

We do not know exactly what causes most gastrointestinal stromal tumors (GISTs). But in recent years, scientists have made great progress in learning how certain changes in DNA can cause normal cells to become cancerous. DNA is the chemical in each of our cells that makes up our *genes*, which control how our cells function. We usually look like

our parents because they are the source of our DNA. But DNA affects more than just how we look.

Some genes control when cells grow and divide into new cells:

- Certain genes that help cells grow and divide are called *oncogenes*.
- Genes that help 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.

Gene changes that can lead to GISTs

The gene changes that lead to most GISTs are now understood, but it's still not clear why these changes occur. There are no known lifestyle-related or environmental causes of GIST. Some might have causes that haven't been found yet, but many of these changes may just be random events that sometimes happen inside cells that unfortunately lead to cancer.

A few families have gastrointestinal stromal tumors (GISTs) caused by a gene mutation passed down from parent to child. (See [Gastrointestinal Stromal Tumor Risk Factors](#).) But most gene mutations related to GISTs are not inherited. These changes occur for no apparent reason, and are called *acquired* or *sporadic*.

Changes in KIT or PDGFRA genes

The cancer cells of most patients with GISTs have a change in an oncogene called *KIT*. This gene directs cells to make a protein called KIT, which causes the cells to grow and divide. Usually the *KIT* gene is inactive in interstitial cells of Cajal (ICCs), which are the cells from which GISTs develop. The *KIT* gene is only active if there is a need for more ICCs. But in most GISTs the *KIT* gene is mutated and is always active, so the cells are always growing and dividing.

In about 5% to 10% of GISTs, the cancer cells have mutation in a different gene called *PDGFRA*, which causes the cells to make too much of a different protein (also called PDGFRA). This has the same effect on the cells as does KIT.

Most GISTs have changes in either the *KIT* or the *PDGFRA* gene, but not both.

Other gene changes

A small number of GISTs, especially those in children, do not have changes in either of these genes. Many of these tumors have changes in one of the *SDH* genes. Researchers are still trying to determine what other gene changes can lead to these cancers.

As doctors have learned more about the gene and protein changes in GIST cells, they have been able to use this information to help diagnose and treat these cancers. (See [Targeted Therapy for Gastrointestinal Stromal Tumors¹](#).)

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/targeted-therapy.html

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Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015.

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Can Gastrointestinal Stromal Tumors Be Prevented?

The risk of many types of cancer can be reduced with certain lifestyle changes (such as maintaining a healthy weight or quitting smoking), but the only known [risk factors for](#)

[gastrointestinal stromal tumors \(GISTs\)](#) age and certain rare, genetic syndromes – cannot be changed. At this time we do not know of any way to protect against these cancers.

References

Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015.

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Gastrointestinal Stromal Tumor 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 Stromal Tumors Be Found Early?](#)
- [Signs and Symptoms of Gastrointestinal Stromal Tumors](#)
- [Tests for Gastrointestinal Stromal 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 Stromal Tumor Stages](#)
- [Survival Rates for Gastrointestinal Stromal Tumors](#)

Questions to Ask About Gastrointestinal Stromal 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 Your Doctor About Gastrointestinal Stromal Tumors](#)

Can Gastrointestinal Stromal Tumors Be Found Early?

Screening is testing for diseases like cancer in people who do not have any symptoms. Screening tests can find some types of cancer early, when treatment is most likely to be effective. But at this time, no effective screening tests have been found for gastrointestinal stromal tumors (GISTs), so routine testing of people without any symptoms is not recommended.

Many GISTs are found because of [symptoms](#) a person is having, but some GISTs may be found early by chance. Sometimes they are seen on an exam for another problem, like during colonoscopy to look for colon cancer. Rarely, a GIST may be seen when an imaging test, like a computed tomography (CT) scan or barium study, is done for another reason. Some GISTs may also be found incidentally (unexpectedly) during abdominal surgery for another problem.

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Signs and Symptoms of Gastrointestinal Stromal Tumors

Most gastrointestinal stromal tumors (GISTs) occur in the stomach or small intestine. These tumors often grow into the empty space inside the gastrointestinal (GI) tract, so they might not cause symptoms right away unless they are in a certain location or reach a certain size.

Small tumors might not cause any symptoms and may be found accidentally when the doctor is looking for some other problem. These small tumors often grow slowly.

Symptoms related to blood loss

GISTs tend to be fragile tumors that can bleed easily. In fact, they are often found because they cause bleeding into the GI tract. Signs and symptoms of this bleeding depend on how fast it occurs and where the tumor is located.

- Brisk bleeding into the esophagus or stomach can cause the person to **throw up blood**. When the blood is thrown up it may be partially digested, so it might look like coffee grounds.
- Brisk bleeding into the stomach or small intestine can make **bowel movements (stools) black and tarry**.
- Brisk bleeding into the large intestine is likely to **turn the stool red with visible blood**.
- If the bleeding is slow, it often doesn't cause the person to throw up blood or have a change in their stool. Over time, though, slow bleeding can lead to a low red blood cell count (anemia), and make a person feel **tired and weak**.

Bleeding from the GI tract can be very serious. If you have any of these signs or symptoms, see a doctor right away.

Other possible symptoms of GISTs

Other symptoms of GISTs can include:

- Abdominal (belly) pain
- A mass or swelling in the abdomen
- Nausea, vomiting
- Feeling full after eating only a small amount of food
- Loss of appetite
- Weight loss

- Problems swallowing (for tumors in the esophagus)

Sometimes the tumor grows large enough to block the passage of food through the stomach or intestine. This is called an *obstruction*, and it can cause severe abdominal pain and vomiting. Because GISTs are often fragile, they can sometimes rupture, which can lead to a hole (*perforation*) in the wall of the GI tract. This can also result in severe abdominal pain. Emergency surgery might be needed in these situations.

Although many of the possible symptoms of GISTs (like belly pain and nausea) can be caused by things other than cancer, if you have these symptoms, especially if they last for more than a few days, it's important to see a doctor.

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Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015.

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Tests for Gastrointestinal Stromal Tumors

Gastrointestinal stromal tumors (GISTs) are often found because a person is having [signs or symptoms](#). Others are found during exams or tests for other problems. But these symptoms or initial tests aren't usually enough to know for sure if a person has a GIST or another type of gastrointestinal (GI) tumor. If a GI tumor is suspected, you will need further tests to confirm the diagnosis.

Medical history and physical exam

The doctor will ask you questions about your medical history, including your symptoms, [possible risk factors](#)¹, family history, and other medical conditions.

Your doctor will give you a thorough physical exam to get more information about the possible signs of a GI tumor, like a mass in the abdomen, or other health problems.

If there is a reason to suspect that you may have a GIST (or other type of GI tumor), the doctor will use imaging tests or endoscopy exams to help find out if it is cancer or something else. If it is a GIST, further tests will be done to help determine the [stage](#) (extent) of the cancer.

Imaging tests

Imaging tests use x-rays, magnetic fields, or radioactive substances to create pictures of the inside of the body. Imaging tests may be done for a number of reasons, including:

- To help find out if a suspicious area might be cancer
- To learn how far cancer has spread
- To help determine if treatment has been effective
- To look for signs that the cancer has come back

Most people who have or might have a GI tumor will have one or more of these tests.

Barium x-rays

Barium x-rays are not used as much today as in the past. In many cases they are being replaced by endoscopy – where the doctor actually looks into your colon or stomach with a narrow fiber-optic scope (see below).

For these types of x-rays, a chalky liquid containing barium is used to coat the inner lining of the esophagus, stomach, and intestines. This makes abnormal areas of the lining easier to see on x-ray. These tests are sometimes used to diagnose GI tumors, but they can miss some small intestine tumors.

You will probably have to fast starting the night before the test. If the colon is being examined, you might need to take laxatives and/or enemas to clean out the bowel the night before or the morning of the exam.

Barium swallow: This is often the first test done if someone is having a problem swallowing. For this test, you drink a liquid containing barium to coat the inner lining of the esophagus. A series of x-rays is then taken over the next few minutes.

Upper GI series: This test is similar to the barium swallow, except that x-rays are taken after the barium has time to coat the stomach and the first part of the small intestine. To look for problems in the rest of the small intestine, more x-rays can be taken over the next few hours as the barium passes through. This is called a *small bowel follow through*.

Enteroclysis: This test is another way to look at the small intestine. A thin tube is passed through your mouth or nose, down your esophagus, and through your stomach into the start of the small intestine. Barium is sent through the tube, along with a substance that creates more air in the intestines, causing them to expand. Then x-rays are taken of the intestines. This test can give better images of the small intestine than a small bowel follow through, but it is also more uncomfortable.

Barium enema: This test (also known as a *lower GI series*) is used to look at the inner surface of the large intestine. For this test, the barium solution is given through a small, flexible tube inserted in the anus while you are lying on the x-ray table. When the colon is about half full of barium, you roll over so the barium spreads throughout the colon. For a regular barium enema, x-rays are then taken. After the barium is put in the colon, air may be blown in to help push the barium toward the wall of the colon and better coat the inner surface. Then x-rays are taken. This is called an *air-contrast barium enema* or *double-contrast barium enema*.

Computed tomography (CT) scan

A [CT scan](#)² uses x-rays to make detailed, cross-sectional images of your body. Unlike a regular x-ray, a CT scan creates detailed images of the soft tissues in the body.

CT scans can be useful in patients who have (or might have) GISTs to find the location and size of a tumor, as well as to see if it has spread into the abdomen or the liver.

In some cases, CT scans can also be used to guide a biopsy needle precisely into a suspected cancer. However, this can be risky if the tumor might be a GIST (because of the risk of bleeding and a possible increased risk of tumor spread), so these types of biopsies are usually done only if the result might affect the decision on treatment. (See the biopsy information below.)

Magnetic resonance imaging (MRI) scan

Like CT scans, [MRI scans](#)³ show detailed images of soft tissues in the body. But MRI scans use radio waves and strong magnets instead of x-rays.

MRI scans can sometimes be useful in people with GISTs to help find the extent of the cancer in the abdomen, but usually CT scans are enough. MRIs can also be used to look for cancer that might have come back (recurred) or spread (metastasized) to distant organs, particularly in the brain or spine.

Positron emission tomography (PET) scan

For a [PET scan](#)⁴, you are injected with a slightly radioactive form of sugar, which collects mainly in cancer cells. A special camera is then used to create a picture of areas of radioactivity in the body. The picture is not detailed like a CT or MRI scan, but a PET scan can look for possible areas of cancer spread in all areas of the body at once.

Some newer machines can do both a PET and CT scan at the same time (PET/CT scan). This lets the doctor see areas that “light up” on the PET scan in more detail.

PET scans can be useful for looking at GISTs, especially if the results of CT or MRI scans aren't clear. This test can also be used to look for possible areas of cancer spread to help determine if surgery is an option.

PET scans can also be helpful in finding out if a drug treatment is working, as they can often give an answer quicker than CT or MRI scans. The scan is usually obtained about 4 weeks after starting the medicine. If the drug is working, the tumor will stop taking up the radioactive sugar. If the tumor still takes up the sugar, your doctor may decide to change your drug treatment.

Endoscopy

For these tests, the doctor puts a flexible lighted tube (endoscope) with a tiny video camera on the end into the body to see the inner lining of the gastrointestinal (GI) tract. If abnormal areas are found, small pieces can be biopsied (removed) through the endoscope. The biopsy samples can be looked at under the microscope to find out if they contain cancer and if so, what kind of cancer it is.

GISTs are often below the surface (mucosa) of the inner lining of the GI tract. This can make them harder to see with endoscopy than more common GI tract tumors, which typically start in the mucosa. The doctor may see only a bulge under the normally smooth surface if a GIST is present. GISTs that are below the mucosa are also harder

to biopsy through the endoscope. This is one reason that many GISTs are not diagnosed before surgery.

If the tumor breaks through the inner lining of the GI tract and is easy to see on endoscopy, there is a greater chance that the GIST is cancerous (malignant).

Upper endoscopy

For this procedure, an endoscope is passed through the mouth and down the throat to look at the inner lining of the esophagus, stomach, and first part of the small intestine. Biopsy samples may be taken from any abnormal areas.

Upper endoscopy can be done in a hospital, in an outpatient surgery center, or in a doctor's office. You are typically given medicine through an intravenous (IV) line to make you sleepy before the exam. The exam itself usually takes 10 to 20 minutes, but it might take longer if a tumor is seen or if biopsy samples are taken. If medicine is given to make you sleepy, you will need someone you know to drive you home (not just a cab or rideshare service).

This test is also known as an EGD (short for esophagogastroduodenoscopy).

Colonoscopy (lower endoscopy)

For this test, a type of endoscope known as a *colonoscope* is inserted through the anus and up into the colon. This lets the doctor look at the inner lining of the rectum and colon and to take biopsy samples from any abnormal areas.

To get a good look at the inside of the colon, it must be cleaned out before the test. Your doctor will give you specific instructions. You might need to follow a special diet for a day or more before the test. You will also likely have to drink a large amount of a liquid laxative the evening before, which means you will spend a lot of time in the bathroom.

A colonoscopy can be done in a hospital, in an outpatient surgery center, or in a doctor's office. You will be given intravenous (IV) medicine to make you feel relaxed and sleepy during the procedure. The exam typically takes 15 to 30 minutes, but it can take longer if a tumor is seen and/or a biopsy taken. Because medicine is given to make you sleepy, you will need someone you know to drive you home (not just a cab or rideshare service).

Capsule endoscopy

Unfortunately, neither upper endoscopy nor colonoscopy can reach all areas of the small intestine. Capsule endoscopy is one way to look at the small intestine.

This procedure does not actually use an endoscope. Instead, you swallow a capsule (about the size of a large vitamin pill) that contains a light source and a very small camera. Like any other pill, the capsule goes through the stomach and into the small intestine. As it travels through the intestine (usually over about 8 hours), it takes thousands of pictures. These images are transmitted electronically to a device worn around your waist. The pictures can then be downloaded onto a computer, where the doctor can view them as a video. The capsule passes out of the body during a normal bowel movement and is discarded.

This test requires no sedation – you can just continue normal daily activities as the capsule travels through the GI tract. This technique is fairly new, and the best ways to use it are still being studied. One disadvantage is that any abnormal areas seen can't be biopsied during the test.

Double balloon enteroscopy (endoscopy)

This is another way to look at the small intestine. The small intestine is too long and has too many curves to be examined well with regular endoscopy. But this method gets around these problems by using a special endoscope that is made of 2 tubes, one inside the other.

You are given intravenous (IV) medicine to help you relax, or even general anesthesia (so that you are asleep). The endoscope is then inserted either through the mouth or the anus, depending on if there is a specific part of the small intestine to be examined.

Once inside the small intestine, the inner tube, which has the camera on the end, is advanced forward about a foot as the doctor looks at the lining of the intestine. Then a balloon on the end of the endoscope is inflated to anchor it. The outer tube is then pushed forward to near the end of the inner tube and is anchored in place with a second balloon. The first balloon is deflated and the endoscope is advanced again. This process is repeated over and over, letting the doctor see the intestine a foot at a time. The test can take hours to complete.

This test may be done along with capsule endoscopy. The main advantage of this test over capsule endoscopy is that the doctor can take a biopsy if something abnormal is seen. Like other forms of endoscopy, because you are given medicine to make you sleepy for the procedure, someone you know will need to drive you home (not just a cab or rideshare service).

Endoscopic ultrasound (EUS)

This is a type of imaging test that uses an endoscope. Ultrasound uses sound waves to take pictures of parts of the body. For most ultrasound exams, a wand-like probe (called a *transducer*) is placed on the skin. The probe gives off sound waves and detects the pattern of echoes that come back.

For an EUS, the ultrasound probe is on the tip of an endoscope. This allows the probe to be placed very close to (or on top of) a tumor in the wall of the GI tract. Like a regular ultrasound, the probe gives off sound waves and then detects the echoes that bounce back. A computer then translates the echoes into an image of the area being looked at.

EUS can be used to find the precise location of the GIST and to determine its size. It is useful in finding out how deeply a tumor has grown into the wall of the GI tract. The test can also help show if the tumor has spread to nearby lymph nodes or has started growing into other tissues nearby. In some cases it may be used to help guide a biopsy (see below).

You are typically given medicine before this procedure to make you sleepy. Because of this, you need to have someone you know drive you home (not just a cab or rideshare service).

Biopsy

Even if something abnormal is seen on an imaging test such as a barium x-ray or CT scan, these tests often cannot tell if the abnormal area is a GIST, some other type of tumor (benign or cancerous), or some other condition (like an infection). The only way to know what it is for sure is to remove cells from the area. This procedure is called a *biopsy*. The cells are then sent to a lab, where a doctor called a *pathologist* looks at them under a microscope and might do other tests on them.

Not everyone who has a tumor that might be a GIST needs a biopsy before treatment. If the doctor suspects a tumor may be a GIST, biopsies are usually done only if they will help determine treatment options. GISTs are often fragile tumors that tend to break apart and bleed easily. Any biopsy must be done very carefully, because of the risk that the biopsy might cause bleeding or possibly increase the risk of cancer spreading.

There are several ways to biopsy a GI tract tumor.

Endoscopic biopsy

Biopsy samples can be obtained through an endoscope. When a tumor is found, the doctor can insert biopsy forceps (pincers or tongs) through the tube to take a small sample of the tumor.

Even though the sample will be very small, doctors can often make an accurate diagnosis. However, with GISTs, sometimes the biopsy forceps can't go deep enough to reach the tumor because it's underneath the inner lining of the stomach or intestine.

Bleeding from a GIST after a biopsy is rare, but it can be a serious problem. If this occurs, doctors can sometimes inject drugs into the tumor through an endoscope to constrict blood vessels and stop the bleeding.

Needle biopsy

Sometimes, a biopsy is done using a thin, hollow needle to remove pieces of the area. The most common way to do this is during an endoscopic ultrasound (described above). The doctor uses the ultrasound image to guide a needle on the tip of the endoscope into the tumor.

Less often, the doctor may place a needle through the skin and into the tumor while guided by an imaging test such as a CT scan.

Surgical biopsy

If a sample can't be obtained from an endoscopic or needle biopsy, or if the result of a biopsy wouldn't affect treatment options, your doctor might recommend waiting until surgery to remove the tumor to get a sample of it.

If the surgery is done through a large cut (incision) in the abdomen, it is called a *laparotomy*. Sometimes the tumor can be sampled (or small tumors can be removed) using a thin, lighted tube called a *laparoscope*, which lets the surgeon see inside the belly through a small incision. The surgeon can then sample (or remove) the tumor using long, thin surgical tools that are passed through other small incisions in the abdomen. This is known as *laparoscopic* or *keyhole surgery*.

Lab tests of biopsy samples

Once tumor samples are obtained, a pathologist looks at them under a microscope. The pathologist might be able to tell that a tumor is most likely a GIST just by looking at the cells. But sometimes further lab tests might be needed to be sure.

Immunohistochemistry: For this lab test, a part of the sample is treated with man-made antibodies that will attach only to a certain protein. The antibodies cause color changes if the protein is present, which can be seen under a microscope.

Some of the proteins most often tested for if GIST is suspected are KIT (also known as CD117) and DOG1. Most GIST cells have these proteins, but cells of most other types of cancer do not, so tests for these proteins can help tell whether a GI tumor is a GIST or not. Other proteins, such as PDGFRA, might be tested for as well.

Molecular genetic testing: If the doctor is still unsure if the tumor is a GIST, testing might be done to look for mutations in the *KIT* or *PDGFRA* genes themselves, as most GIST cells have mutations in one or the other. Less often, tests might be done to look for changes in other genes, such as *SDH*.

Mitotic rate: If a GIST is diagnosed, the doctor will also look at the cancer cells in the sample to see how many of them are actively dividing into new cells. This is known as the *mitotic rate*. A low mitotic rate means the cancer cells are growing and dividing slowly, while a high rate means they are growing quickly. The mitotic rate is an important part of the stage of the cancer. (See [Gastrointestinal Stromal Tumor Stages](#).)

Blood tests

Your doctor may order some blood tests if he or she thinks you may have a GIST.

There are no blood tests that can tell for sure if a person has a GIST. But blood tests can sometimes point to a possible tumor (or to its spread). For example, a [complete blood count](#)⁵ (CBC) can tell if you have a low red blood cell count (that is, if you are anemic). Some people with GIST may become anemic because of bleeding from the tumor. Abnormal liver function tests may mean that the GIST has spread to your liver.

Blood tests are also done to check your overall health before you have [surgery](#)⁶ or while you get other treatments such as [targeted therapy](#)⁷.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/causes-risks-prevention/risk-factors.html
2. www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html
3. www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html

4. www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html
5. www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-lab-test-results.html
6. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/surgery.html
7. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/targeted-therapy.html

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Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015.

National Cancer Institute. Physician Data Query (PDQ). Gastrointestinal Stromal Tumors Treatment. 2017. Accessed at www.cancer.gov/types/soft-tissue-sarcoma/hp/gist-treatment-pdq on April 17, 2017.

National Comprehensive Cancer Network (NCCN). NCCN Clinical Practice Guidelines in Oncology: Soft Tissue Sarcoma. V.2.2017. Accessed at www.nccn.org/professionals/physician_gls/pdf/sarcoma.pdf on April 17, 2017.

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Gastrointestinal Stromal Tumor Stages

After someone is diagnosed with cancer, doctors will try to figure out if it has spread, and if so, how far. This process is called **staging**. The stage of a 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.

The stages for gastrointestinal stromal tumors (GIST) range from stages I (1) through IV (4). 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.

How is the stage determined?

The staging system most often used for GIST tumors is the American Joint Committee on Cancer (AJCC) **TNM** system, which is based on 4 key pieces of information:

- The extent of the **tumor (T)**: How large is the cancer?
- 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 organs such as the liver?
- The **mitotic rate** is a [lab test](#) measurement of how fast the cancer cells are growing and dividing. It is described as either low or high. A low mitotic rate predicts a better outcome.

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 a person's T, N, and M categories have been determined, this information is combined in a process called **stage grouping** to assign an overall stage. The stage grouping for GIST tumors depends on where the tumor starts:

- The stomach or the omentum (The omentum is an apron-like layer of fatty tissue that hangs over the organs in the abdomen.) **OR**
- The small intestine, esophagus, colon, rectum, or peritoneum. (The peritoneum is a layer of tissue that lines the organs and walls of the abdomen. Tumors in these locations are more likely to grow quickly compared to GISTs that start in the stomach or omentum.)

For more information see [Cancer Staging²](#).

The staging system in the table below uses the **pathologic stage** (also called the **surgical stage**). It is determined by examining tissue removed during an operation. Sometimes, if surgery is not possible right away or at all, the cancer will be given a **clinical stage** instead. This is based on the results of a physical exam, biopsy, and imaging tests. The clinical stage will be used to help plan treatment. Sometimes, though, the cancer has spread further than the clinical stage estimates, and might not

predict the patient's outlook as accurately as a pathologic stage.

The system described below is the most recent AJCC system, effective January 2018. Cancer staging can be complex, so ask your doctor to explain it to you in a way you understand.

GIST that starts in the stomach or the omentum

AJCC stage	Stage grouping	Mitotic rate	Stage description*
IA	T1 or T2 N0 M0	Low	The cancer is: <ul style="list-style-type: none"> • 2 cm (4/5 of an inch) or less (T1) OR • Larger than 2 cm but not more than 5 cm (2 inches) (T2). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
	T3 N0 M0		Low
II	T1 N0 M0	High	The cancer is 2 cm or smaller (T1). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	OR		
II	T2 N0 M0	High	The cancer is larger than 2 cm but not more than 5 cm (T2). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	OR		

	T4 N0 M0	Low	The cancer is larger than 10 cm (T4). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
IIIA	T3 N0 M0	High	The cancer is larger than 5 cm (2 inches) but not more than 10 cm(T3). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
IIIB	T4 N0 M0	High	The cancer is larger than 10 cm (T4). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
IV	Any T N1 M0	Any rate	The cancer is any size (Any T) AND it has spread to nearby lymph nodes (N1). It has not spread to distant sites (M0). The cancer can have any mitotic rate.
	OR		
	Any T Any N M1	Any rate	The cancer is any size (Any T) AND it might or might not have spread to nearby lymph nodes (Any N). It has spread to distant sites such as the liver(M1). The cancer can have any mitotic rate.

*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 primary tumor.
- **NX:** Regional lymph nodes cannot be assessed due to lack of information.

GIST of the small intestine, esophagus, colon, rectum, or peritoneum

AJCC	Stage	Mitotic	Stage description*
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stage	grouping	rate	
I	T1 or T2 N0 M0	Low	<p>The cancer is:</p> <ul style="list-style-type: none"> • 2 cm (4/5 of an inch) or less (T1) OR • Larger than 2 cm but not more than 5 cm (2 inches) (T2). <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.</p>
	T3 N0 M0	Low	<p>The cancer is larger than 5 cm (2 inches) but not more than 10 cm(T3).</p> <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.</p>
IIIA	T1 N0 M0	High	<p>The cancer is 2 cm or smaller (T1).</p> <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.</p>
	OR		
IIIB	T4 N0 M0	Low	<p>The cancer is larger than 10 cm (T4).</p> <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.</p>
	OR		
IIIB	T2 N0 M0	High	<p>The cancer is larger than 2 cm but not more than 5 cm (T2).</p> <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.</p>
	OR		
IIIB	T3 N0 M0	High	<p>The cancer is larger than 5 cm (2 inches) but not more than 10cm (T3).</p> <p>It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.</p>
	OR		

	T4 N0 M0	High	The cancer is larger than 10 cm (T4). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
IV	Any T N1 M0	Any rate	The cancer is any size (Any T) AND it has spread to nearby lymph nodes (N1). It has not spread to distant sites (M0). The cancer can have any mitotic rate.
	OR		
	Any T Any N M1	Any rate	The cancer is any size (Any T) AND it might or might not have spread to nearby lymph nodes (Any N). It has spread to distant sites such as the liver(M1). The cancer can have any mitotic rate.

*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 primary tumor.
- **NX:** Regional lymph nodes cannot be assessed due to lack of information.

Resectable versus unresectable tumors

The AJCC staging system gives a detailed summary of how far a GIST has spread. But for treatment purposes, doctors are often more concerned about whether the tumor can be removed (resected) completely with [surgery](#)³.

Whether or not a tumor is resectable depends on its size and location, if it has spread to other parts of the body, and if a person is healthy enough for surgery:

- Tumors that can clearly be removed without causing major health problems are defined as **resectable**.
- Tumors that can't be removed completely (because they have spread or for other reasons) are described as **unresectable**.
- In some cases, doctors may describe a tumor as **marginally resectable** or **borderline resectable** if it's not clear if it can be removed completely.

If a tumor is considered unresectable or marginally resectable when it is first found, treatments such as [targeted therapy](#)⁴ may be used first to try to shrink the tumor enough to make it resectable.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating.html
2. www.cancer.org/treatment/understanding-your-diagnosis/staging.html
3. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/surgery.html
4. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy.html

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Survival Rates for Gastrointestinal

Stromal Tumors

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. Talk with your doctor about how these numbers may apply to you, as he or she is familiar with your situation.

What is a 5-year relative survival rate?

A **relative survival rate** compares people with the same type and stage of gastrointestinal stromal tumor (GIST) to people in the overall population. For example, if the **5-year relative survival rate** for a specific stage of GIST 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 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 GIST 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 is limited to the organ where it started.
- **Regional:** The cancer has grown into nearby structures or spread to nearby lymph nodes.
- **Distant:** The cancers has spread to distant parts of the body such as the liver.

5-year relative survival rates for GIST

(Based on people diagnosed with GIST between 2008 and 2014.)

SEER Stage	5-Year Relative Survival Rate
Localized	94%
Regional	83%
Distant	52%
All SEER stages combined	83%

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, overall health, [cancer resectability](#)¹, how well the cancer responds to treatment, and other factors can also affect your outlook.
- **People now being diagnosed with GIST 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.

*SEER= Surveillance, Epidemiology, and End Results

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/surgery.html

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Questions to Ask Your Doctor About

Gastrointestinal Stromal Tumors

It's important to have honest, open discussions with your cancer care team. Ask any question, no matter how small it might seem. Some questions to consider:

When you're told you have a gastrointestinal stromal tumor (GIST)

- How sure are you that my tumor is a GIST?
- Where is my tumor located? How big is it?
- How likely is this tumor to grow or spread quickly?
- Has my tumor spread beyond where it started?
- What is the [stage](#) of my cancer, and what does that mean?
- Will I need any other [tests](#) before we can decide on treatment?
- Will I need to see any other doctors?
- If I'm concerned about costs and insurance coverage for my diagnosis and treatment, who can help me?

When deciding on a treatment plan

- How much experience do you have treating these tumors?
- What are my [treatment options](#)¹?
- What do you recommend? Why?
- What's the goal of the treatment?
- Should I get a [second opinion](#)²? How do I do that? Can you recommend someone?
- What are the chances my cancer can be cured?
- 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 I should expect? How long are they likely to last?
- Will treatment affect my daily activities?
- How likely is it that the cancer will come back after treatment? Is there anything I can do to lower this risk?

During treatment

- How will we know if the treatment is working?
- Is there anything I can do to help manage side effects?
- 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?
- Should I exercise? What should I do, and how often?
- Can you suggest a [mental health professional](#)³ I can see if I start to feel overwhelmed, depressed, or distressed?

After treatment

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

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about second opinions or about [clinical trials](#)⁵ for which you may qualify.

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 more about speaking with your health care team, see [The Doctor-Patient Relationship](#)⁶.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating.html
2. www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/seeking-a-second-opinion.html
3. www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/understanding-psychosocial-support-services.html
4. www.cancer.org/cancer/gastrointestinal-stromal-tumor/after-treatment/follow-

[up.html](#)

5. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
6. www.cancer.org/treatment/understanding-your-diagnosis/talking-about-cancer/the-doctor-patient-relationship.html

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Treating Gastrointestinal Stromal Tumors

If you've been diagnosed with a gastrointestinal stromal tumor (GIST), your cancer care team will discuss your treatment options with you. It's important to weigh the benefits of each treatment option against the possible risks and side effects.

Which treatments are used for GISTs?

Types of treatment for GIST include:

- [Surgery for Gastrointestinal Stromal Tumor](#)
- [Targeted Therapy for Gastrointestinal Stromal Tumor](#)
- [Ablation and Embolization to Treat Gastrointestinal Stromal Tumors](#)
- [Chemotherapy for Gastrointestinal Stromal Tumor](#)
- [Radiation Therapy for Gastrointestinal Stromal Tumor](#)

Common treatment approaches

Not all GISTs need to be treated right away. But if treatment is needed, the main types used are surgery and targeted therapy. Other treatments, such as ablation, embolization, chemotherapy, and radiation, are used much less often.

- [Treatment Choices for Gastrointestinal Stromal Tumor Based on Tumor Spread](#)

Who treats GISTs?

Based on your treatment options, you might have different types of doctors on your treatment team, including:

- A **surgical oncologist**: a doctor who treats cancer with surgery
- A **medical oncologist**: a doctor who treats cancer with medicines
- A **gastroenterologist**: a doctor who specializes in treatment of diseases of the gastrointestinal (digestive) system
- A **radiation oncologist**: a doctor who treats cancer with radiation therapy

You might have many other specialists on your treatment team as well, including physician assistants (PAs), nurse practitioners (NPs), nurses, nutrition specialists, social workers, rehabilitation specialists, psychologists, and other health professionals.

- [Health Professionals Associated With Cancer Care¹](#)

Making treatment decisions

It's important to discuss all treatment options, including their goals and possible side effects, with your doctors to help make the decision that best fits your needs. Some important things to consider include:

- Your age and expected life span
- Any other serious health conditions you have
- The location and stage of your tumor
- The likelihood that treatment will cure your tumor (or help in some other way)
- Your feelings about the possible side effects from treatment

You may feel that you need to decide quickly, but it's important to give yourself time to absorb the information you have learned. It's also very important to ask questions if there is anything you're not sure about.

- [Questions to Ask Your Doctor About Gastrointestinal Stromal Tumors²](#)
- [Seeking a Second Opinion³](#)

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're 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.

- [Clinical Trials](#)⁴

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 harmful.

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.

- [Complementary and Alternative Medicine](#)⁵

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, 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.

- [Find Support Programs and Services in Your Area](#)⁶

Choosing to stop treatment or choosing no treatment at all

For some people, when treatments have been tried and are no longer controlling the

cancer, it could be time to weigh the benefits and risks of continuing to try new treatments. Whether or not you continue treatment, there are still things you can do to help maintain or improve your quality of life.

Some people, especially if the cancer is advanced, might not want to be treated at all. There are many reasons you might decide not to get cancer treatment, but it's important to talk to your doctors and you make that decision. Remember that even if you choose not to treat the cancer, you can still get supportive care to help with pain or other symptoms.

- [If Cancer Treatments Stop Working](#)⁷
- [Palliative or Supportive Care](#)⁸

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 Stromal Tumor

Surgery is usually main treatment for gastrointestinal stromal tumors (GISTs) that haven't spread. The goal of the surgery is to remove all of the cancer.

The type of surgery needed depends on the location and size of the tumor.

Surgery for small GISTs

If the tumor is small, it often can be removed along with a small area of normal tissue around it. This is done through a cut (incision) in the skin. Unlike many other cancers, GISTs almost never spread to the lymph nodes, so removing nearby lymph nodes is usually not needed.

For some small cancers, “keyhole” (laparoscopic) surgery is an option. Instead of making a large incision in the skin to remove the tumor, several small ones are used. The surgeon inserts a thin lighted tube with a tiny video camera on the end (a laparoscope) through one of them. This lets him or her see inside the belly. Long, thin surgical tools are then used through the other incisions to remove the tumor. Because the incisions are small, patients usually recover more quickly from this type of surgery than from traditional surgery that requires a longer incision.

Surgery for larger GISTs

If the tumor is large or growing into other organs, the surgeon might still be able to remove it entirely. To do this, parts of organs (such as a section of the intestines) might need to be removed. The surgeon might also remove tumors that have spread elsewhere in the abdomen, such as the liver.

Another option for tumors that are large or have grown into nearby areas might be to have the patient take the [targeted drug](#) imatinib (Gleevec) first. This can often shrink the tumor, which can make it easier to remove with surgery.

Choosing your surgeon

No matter what type of surgery is done, it's very important that it is done by a surgeon experienced in treating GISTs. GISTs are often delicate tumors, and surgeons must be careful not to open the outer lining that surrounds them (known as the *capsule*), because it might increase the risk of spreading the cancer. GISTs also tend to have a lot of blood vessels, so your surgeon has to be careful to control any bleeding from the tumor.

For more information about surgery, see [Cancer Surgery](#)¹.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/surgery.html

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Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's*

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Ablation and Embolization to Treat Gastrointestinal Stromal Tumors

If a gastrointestinal stromal tumor (GIST) has spread to the liver, treatments such as ablation and embolization might be used.

Ablation

Ablation is the destruction of tumors using extreme heat or cold, or using chemicals. It can sometimes be used to destroy GISTs that have spread as no more than a few small tumors in the liver. Because ablation often destroys some of the normal tissue around the tumor, it might not be a good choice for treating tumors near important structures like major blood vessels, the diaphragm (the thin breathing muscle above the liver), or major ducts in the liver.

There are several types of ablation:

- **Radiofrequency ablation (RFA)**, which uses high-energy radio waves to heat the tumor and destroy cancer cells
- **Ethanol (alcohol) ablation**, where concentrated alcohol is injected directly into the tumor to kill cancer cells
- **Microwave thermotherapy**, where microwaves transmitted through a probe placed

in the tumor are used to heat and destroy the cancer cells

- **Cryosurgery (cryotherapy)**, which destroys a tumor by freezing it using a thin metal probe. This method sometimes requires general anesthesia (where you are deeply asleep and not able to feel pain)

What to expect

Usually, you don't need to stay in the hospital for this type of treatment. Ablation can often be done without surgery by inserting a needle or probe into the tumor through the skin. The needle or probe is guided into place with ultrasound or CT scanning. Sometimes, though, to be sure the treatment is aimed at the right place, it is done during surgery.

Possible side effects of ablation

Possible side effects after ablation therapy include abdominal (belly) pain, infection in the liver, and bleeding into the chest cavity or abdomen. Serious complications are uncommon, but they can happen.

Embolization

Embolization is a procedure that injects substances to try to block or reduce the blood flow to cancer cells in the liver.

The liver is unusual in that it has 2 blood supplies. Most normal liver cells are fed by branches of the portal vein, whereas cancer cells in the liver are usually fed by branches of the hepatic artery. Blocking the branch of the hepatic artery feeding the tumor helps kill off the cancer cells, but it leaves most of the healthy liver cells unharmed because they get their blood supply from the portal vein.

Embolization does reduce some of the blood supply to the normal liver tissue, so it may not be a good option for some patients whose liver has already been damaged by diseases such as hepatitis or cirrhosis.

What to expect

The main type of embolization used to treat GISTs that have spread to the liver is arterial embolization (also known as **trans-arterial embolization or TAE**). In this procedure, a catheter (a thin, flexible tube) is put into an artery through a small cut in

the inner thigh and threaded up into the hepatic artery in the liver. A dye is usually injected into the bloodstream at this time to help the doctor see the path of the catheter via angiography, a special type of x-ray. Once the catheter is in place, small particles are injected into the artery to plug it up.

Typically, you won't have to stay in the hospital for this treatment.

Possible side effects of embolization

Possible complications after embolization include abdominal (belly) pain, fever, nausea, infection in the liver, gallbladder inflammation, and blood clots in the main blood vessels of the liver. Because healthy liver tissue can be affected, there is a risk that liver function will get worse after treatment. This risk is higher if a large branch of the hepatic artery is embolized. Serious complications are not common, but they are possible.

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Targeted Therapy for Gastrointestinal Stromal Tumor

Some drugs can target the [gene changes](#)¹ in gastrointestinal stromal tumor (GIST) cells that have been found in recent years. These drugs work differently from standard [chemotherapy](#) (chemo) drugs. Targeted drugs are very helpful in treating GISTs, while standard chemo drugs are usually not helpful.

All of these targeted drugs are pills, taken once a day.

Imatinib (Gleevec)

This drug is used to treat most patients with GISTs at some point. It targets both the KIT and PDGFRA proteins, blocking their ability to make tumor cells grow and divide. In most GISTs, the cells have too much of one of these proteins.

Overall, most tumors shrink by at least half when treated with imatinib. Some other tumors shrink less or at least stop growing for a time. A small number of tumors are not helped by this treatment.

Imatinib can be helpful in different situations:

- If a GIST has been completely removed by [surgery](#), doctors typically recommend taking imatinib for at least a year afterward (unless the risk of the cancer coming back is low). This is known as **adjuvant therapy**. Many doctors now recommend at least 3 years of imatinib after surgery for patients who are at a higher risk of their tumors returning (based on the tumor's size, location, and growth rate).
- For larger tumors that may be hard to remove, imatinib may be used first to try to shrink the tumor and make surgery easier. This is known as **neoadjuvant therapy**. Imatinib is often given again after surgery as well.
- Imatinib is usually the treatment of choice for **advanced GISTs** that have spread too far to be removed by surgery. It doesn't seem to cure these tumors, but it can often shrink or slow their tumors' growth for several years, helping patients live longer and feel better. If the drug stops working and the tumor starts growing again, raising the dose of imatinib may help stop the growth for some time, but higher doses can have more side effects.

Side effects can include mild stomach upset, diarrhea, muscle pain, and skin rashes. The stomach upset is lessened if the drug is taken with food. Imatinib can also make people retain fluid. Often this causes some swelling in the face (around the eyes) or in the ankles. Rarely the drug causes more severe problems, with fluid building up in the lungs or in the abdomen. It can also affect heart function in some people.

One other concern when using this drug to treat large GISTs is that these tumors often have a lot of fragile blood vessels. If imatinib causes the tumor to shrink quickly, it could lead to internal bleeding. For this reason, doctors watch patients carefully when they first start taking this drug.

Sunitinib (Sutent)

This drug can be useful in treating GIST if imatinib is no longer working or if a person can't take imatinib because of its side effects.

Sunitinib targets the KIT and PDGFRA proteins, as well as several other proteins that imatinib does not target.

Sunitinib helps some patients, usually by slowing the growth of the tumor. It can also shrink tumors in a small number of patients. More importantly, patients getting the drug may live longer.

Common side effects of sunitinib include fatigue, diarrhea, mouth irritation, and skin and hair color changes. More serious side effects can include high blood pressure, increased risk of bleeding, swelling, heart problems, and serious liver problems.

Regorafenib (Stivarga)

Regorafenib can be used to treat GIST if imatinib and sunitinib stop working. This drug targets many proteins, including KIT and PDGFRA.

Regorafenib can slow tumor growth and even shrink some tumors. So far, though, it's not clear if it helps people live longer.

Common side effects include diarrhea, fatigue, high blood pressure, mouth irritation, hair loss, loss of appetite, and problems with redness, pain, or even blistering of the palms of the hands and soles of the feet (called *hand-foot syndrome*).

Several other targeted drugs are now being studied for use against GISTs as well.

More information about these types of drugs can be found in [Targeted Cancer Therapy](#)².

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/causes-risks-

[prevention/what-causes.html](#)

2. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy.html

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Demetri GD, Reichardt P, Kang YK, et al. Efficacy and safety of regorafenib for advanced gastrointestinal stromal tumours after failure of imatinib and sunitinib (GRID): an international, multicentre, randomised, placebo-controlled, phase 3 trial. *Lancet*. 2013;381(9863):295-302.

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Chemotherapy for Gastrointestinal Stromal Tumor

Chemotherapy (chemo) is the use of drugs to treat cancer. Often, these drugs are injected into a vein (IV) or given by mouth. They enter the bloodstream and reach throughout the body, making this treatment potentially useful for cancers that have spread beyond the organ they started in.

Any drug used to treat cancer can be considered chemo – even the [targeted therapy drugs](#) like imatinib (Gleevec) that are now commonly used to treat gastrointestinal stromal tumors (GISTs). But the term *chemo* is usually used to describe certain drugs that work by attacking quickly growing cells anywhere in the body, which includes cancer cells.

Before targeted therapy drugs were found to be helpful in treating GISTs, traditional chemo drugs were often tried. But GISTs rarely shrank in response to these drugs, so traditional chemo is rarely used today. Patients considering chemo may want to consider taking part in a [clinical trial](#)¹.

Possible side effects

Chemo drugs can cause [side effects](#)². These depend on the specific drugs used, their doses, and how long treatment lasts. Common side effects of chemo include:

- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Diarrhea
- Hair loss
- An increased chance of infection (from a shortage of white blood cells)
- Problems with bleeding or bruising (from a shortage of blood platelets)
- Fatigue or shortness of breath (from low red blood cell counts)

Along with the risks above, some chemo drugs can cause other side effects.

Ask your health care team about what side effects you can expect based on the specific drugs you will get. Be sure to tell your doctor or nurse if you do have side effects, as there are often ways to help with them. For example, drugs can be given to help prevent or reduce nausea and vomiting.

To learn more, see [Chemotherapy](#)³.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
3. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy.html

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Radiation Therapy for Gastrointestinal Stromal Tumor

Radiation therapy is the use of high-energy x-rays (or particles) to kill cancer cells. Radiation is not very helpful in treating gastrointestinal stromal tumors (GISTs), so it is not used often. But sometimes it can be used to relieve symptoms like bone pain.

Before your treatment starts, the radiation team will take careful measurements to find the correct angles for aiming the radiation beams and the proper dose of radiation. This planning session, called *simulation*, usually includes getting [imaging tests](#)¹ such as CT or MRI scans.

Radiation therapy is much like getting an x-ray, but the radiation is much stronger. The treatment itself is painless. It lasts only a few minutes, although the setup time – getting you into place for treatment – usually takes longer. You might get radiation treatment for several days in a row.

Possible side effects

Depending on where the radiation is aimed, [side effects](#)² may include:

- Skin changes in areas getting radiation, ranging from redness to blistering and peeling
- Nausea and vomiting
- Diarrhea
- Fatigue
- Low blood counts

Most side effects go away a short while after treatment ends, although fatigue and skin changes may last longer. Talk with your doctor about the possible side effects and the ways to reduce or relieve them.

For more information, see [Radiation Therapy](#)³.

Hyperlinks

1. www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
3. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/radiation.html

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Casali PG, Dei Tos AP, Gronchi A. Chapter 55: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 10th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2015.

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Treatment Choices for Gastrointestinal Stromal Tumor Based on Tumor Spread

Treatment for gastrointestinal stromal tumors (GISTs) depends mainly on the size of the tumor, where it is, how far it has spread, and how quickly it is growing (its [mitotic rate](#)¹).

Localized, smaller (resectable) tumors

Most small GISTs will need to be treated. But for some very small tumors (less than 2 centimeters across) that are not causing any symptoms, one option may be just to watch the tumor carefully with [endoscopy](#)² once or twice a year. If it is not growing, you might not need further treatment.

[Surgery](#) is the main treatment for most small tumors. The need for further treatment depends on the risk of the GIST coming back after surgery.

Tumors that are small and are not growing quickly typically have a low risk of coming back, so often no further treatment is needed.

The risk of a GIST coming back after surgery is higher if the tumor is larger, if it did not start in the stomach, or if the cancer cells are dividing quickly (have a high mitotic rate). If the doctor thinks that the cancer has an intermediate or high risk of coming back based on these factors, adjuvant treatment with the [targeted drug](#) imatinib (Gleevec) is typically recommended for at least a year after surgery. For tumors that are highly likely to come back, many doctors now recommend at least 3 years of imatinib.

Localized, larger (marginally resectable) tumors

Tumors that are larger or in places that make them harder to remove (resect) completely might require more extensive [surgery](#), which could cause health problems later on. Because of this, surgery is not typically the first treatment.

Before starting treatment, it's important to be sure that the tumor is in fact a GIST, so a

biopsy is needed. Once a biopsy is done, treatment with the [targeted drug](#) imatinib is usually started to try to shrink the tumor. It is continued at least until the tumor stops shrinking.

If the tumor shrinks enough, surgery might be done if the doctor thinks he or she can remove it safely. Imatinib will likely be continued after surgery to help lower the chance that the cancer will come back.

If the tumor doesn't shrink enough to make surgery possible, imatinib is often continued for as long as it seems to help. If it's no longer working, sometimes upping the dose can be helpful. If this is no longer helpful, or if the side effects are too severe, the targeted drug sunitinib (Sutent) may be tried instead. If sunitinib is no longer working, regorafenib (Stivarga) may help some patients.

Tumors that are not removable or have spread to distant sites (unresectable tumors)

Treatment options for GISTs that cannot be removed with surgery or have spread (metastasized) depends on why they are unresectable and, if they have spread, how extensive the spread is.

[Surgery](#) is not typically the first treatment for these tumors, so before starting treatment, it's important to confirm that the tumor is in fact a GIST with a biopsy.

Once a biopsy is done, the [targeted drug](#) imatinib is typically the preferred first treatment. It is continued as long as the tumor doesn't grow (and the patient can tolerate the side effects of the drug). If the tumor starts to grow again, it may respond to increasing the dose of imatinib. If the tumor continues to grow or the side effects from imatinib are too severe, a switch to sunitinib may be helpful. If sunitinib is no longer working, regorafenib may help some patients.

If the tumor shrinks enough with targeted therapy, surgery may then be an option for some patients. This might be followed by more targeted therapy if it is still effective.

If the cancer has spread to only 1 or 2 sites in the abdomen (such as the liver), the surgeon may advise removing the main tumor and trying to remove these other tumors as well. If this is the case, be sure to talk with your doctor about what the goals of treatment are (whether it is to try to cure the cancer, to help you live longer, or to prevent or reduce symptoms), as well as its possible benefits and risks. Usually this should be considered only for tumors that are slow growing or those causing complications such as uncontrollable bleeding.

Other options to treat cancers that have spread to the liver include [ablation and embolization](#) to try to destroy these tumors.

Cancers that are no longer responding to the [targeted drugs](#) discussed above can be hard to treat. Some doctors may recommend trying other targeted drugs, such as sorafenib (Nexavar), dasatinib (Sprycel), nilotinib (Tasigna), or pazopanib (Votrient), although it's not yet clear how helpful these drugs are.

Standard [chemotherapy drugs](#) are usually not very effective. Taking part in a [clinical trial](#)³ of a newer treatment may be a good option for some people.

Recurrent tumors

When a cancer comes back after treatment, it is called a *recurrence*. If the cancer comes back (recurs) in or near the place it started, it is called a *local recurrence*. If it recurs at other sites (like the lungs or liver), it is called a *distant recurrence*. Treatment options for recurrent GISTs depend on the location and extent of the recurrence.

For most recurrences, treatment with the [targeted drug](#) imatinib is probably the best way to shrink any tumors, as long as it is still effective and the patient can tolerate taking it. If the starting dose of imatinib doesn't work, the dose can be increased. Another option is to try other targeted drugs, such as sunitinib or regorafenib.

If the cancer comes back as one or more well-defined tumors, [removing](#) or [destroying](#) the tumor may be an option. Doctors are still not certain if removing GISTs that come back after treatment helps people live longer. You should discuss the risks and benefits of this treatment with your doctor and family.

If the targeted drugs mentioned above are no longer helpful, some doctors may recommend trying other targeted drugs, such as sorafenib (Nexavar), dasatinib (Sprycel), nilotinib (Tasigna), or pazopanib (Votrient), although it's not yet clear how helpful these drugs are.

Because these cancers are often hard to treat, you may want to consider taking part in [clinical trials](#)⁴ of newer treatments as well.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/how-diagnosed.html
2. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-

[staging/how-diagnosed.html](#)

3. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
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After Gastrointestinal Stromal Tumor Treatment

Living as a Cancer Survivor

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

- [Living as a Gastrointestinal Stromal Tumor Survivor](#)
-

Living as a Gastrointestinal Stromal Tumor Survivor

For some people with a gastrointestinal stromal tumor (GIST), treatment can 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's called a *recurrence*.) This is a very common concern if you've had cancer.

For some people, the GIST may never go away completely. These people may get regular treatments with [targeted therapy drugs](#)¹ or other therapies to help keep the cancer in check and to help relieve symptoms. Learning to live with [cancer that doesn't go away](#)² can be difficult and very stressful.

Follow-up care

Whether you have completed treatment or are still being treated, your doctors will still want to watch you closely. It's very important to go to all follow-up appointments, as GISTs can sometimes come back after treatment.

Some treatment [side effects](#)³ might last a long time or might not even show up until years after you have finished treatment. Your doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

Exams and tests

During your follow-up visits, your doctors will ask about symptoms, examine you, and may order [imaging tests](#)⁴ like CT scans. Because of the risk that a GIST may come back after treatment, most doctors recommend follow-up visits and imaging tests every 3 to 6 months for at least several years after treatment. If you're still being treated with imatinib (or any other targeted drug), you will also need to have CT scans to make sure that the drug is still working.

Ask your doctor for a survivorship care plan

Talk with your doctor about developing a survivorship care plan for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Diet and physical activity suggestions

Keeping health insurance and copies of your medical records

Even after treatment, it's very important to keep [health insurance](#)⁵. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

At some point after your treatment, you might find yourself seeing a new doctor who

doesn't know about your medical history. It's important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in [Keeping Copies of Important Medical Records](#)⁶.

Can I lower my risk of the tumor progressing or coming back?

If you have (or have had) a GIST, you probably want to know if there are things you can do that might lower your risk of the tumor growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it's not yet clear if there are things you can do that will help.

Adopting healthy behaviors such as not smoking, [eating well, getting regular physical activity, and staying at a healthy weight](#)⁷ might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of GIST or other cancers.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of cancers such as GIST progressing or coming back. This doesn't mean that no supplements will help, but it's important to know that none have been proven to do so.

[Dietary supplements](#)⁸ are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they're allowed to claim they can do. If you're thinking about taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If the GIST comes back

If cancer does recur, your treatment options will depend on the location of the cancer, and what treatments you've had before, and your current health and preferences. For more information on how recurrent cancer is treated, see [Treatment Choices for Gastrointestinal Stromal Tumor Based on Tumor Spread](#)⁹. For more general information on dealing with a recurrence, see [Coping With Cancer Recurrence](#)¹⁰.

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when cancer is a part

of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in [Coping With Cancer](#)¹¹.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/targeted-therapy.html
2. www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html
5. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html
6. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
7. www.cancer.org/treatment/survivorship-during-and-after-treatment/staying-active/nutrition/nutrition-and-physical-activity-during-and-after-cancer-treatment.html
8. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine/dietary-supplements.html
9. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/by-spread.html
10. www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence/coping-with-cancer-recurrence.html
11. www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects.html

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