



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.

- [References](#)

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Last Medical Review: May 17, 2017 Last Revised: May 17, 2017

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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.

- [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.

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.

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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](#), 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](#) 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](#) 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](#), 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](#) (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](#) or while you get other treatments such as [targeted therapy](#).

- [References](#)

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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](#) 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 Staging](#).

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.
IB	T3 N0 M0	Low	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 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 T2 N0	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.

	M0		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	Stage grouping	Mitotic rate	Stage description*
I	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.

II	T3 N0 M0	Low	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 low.
	OR		
IIIA	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.
	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.
IIIB	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		
	T3 N0 M0	High	The cancer is larger than 5 cm (2 inches) but not more than 10cm (T3). It has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	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.
	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](#).

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](#) may be used first to try to shrink the tumor enough to make it resectable.

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Last Medical Review: December 20, 2017 Last Revised: December 20, 2017

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Survival Rates for Gastrointestinal Stromal Tumors

Survival rates tell you what portion 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 about how likely it is that your treatment will be successful. Some people will want to know the survival rates for their cancer, and some people won't. If you don't want to know, you don't have to.

What is a 5-year survival rate?

Statistics on the outlook for a certain type and stage of cancer are often given as 5-year survival rates. The 5-year survival rate is the percentage of people who live at least 5 years after being diagnosed with cancer. For example, a 5-year survival rate of 70% means that an estimated 70 out of 100 people who have that cancer are still alive 5 years after being diagnosed. Keep in mind, however, that many of these people live much longer than 5 years after diagnosis.

Relative survival rates are a more accurate way to estimate the effect of cancer on survival. These rates compare people with cancer to people in the overall population. For example, if the 5-year relative survival rate for a specific stage of gastrointestinal stromal tumor (GIST) is 80%, it would mean that people who have that stage of cancer are, on average, about 80% as likely as people who don't have that cancer to live for at least 5 years after being diagnosed.

But remember, the 5-year relative survival rates are estimates – your outlook can vary based on a number of factors specific to you.

Cancer survival rates don't tell the whole story

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they can't predict what will happen in any particular person's case. There are a number of limitations to remember:

- The numbers below are among the most current available. But to get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago.

As treatments are improving over time, people who are now being diagnosed with GISTs may have a better outlook than these statistics show.

- These statistics are based on the stage of the cancer when it was first diagnosed. They do not apply to cancers that later come back or spread, for example.
- The outlook for people with GISTs varies by the stage (extent) of the cancer – in general, the survival rates are higher for people with earlier stage cancers. But many other factors can affect a person's outlook, such as age and overall health, where the cancer is in the body, and how well the cancer responds to treatment. The outlook for each person is specific to their circumstances.

Your doctor can tell you how these numbers may apply to you, as he or she is familiar with your particular situation.

Survival rates for GISTs

It is very hard to get accurate numbers on survival rates for GISTs. Part of this is because these tumors are not common. In the past, they were often classified as other types of cancers, which made the numbers available for study even smaller. Treatment has also changed dramatically in recent years now that newer, [targeted therapy drugs](#) are being used. The survival rates below are based on people treated many years ago, largely before these newer treatments were used, so people being treated for GISTs today are likely to have a better outlook.

Based on people diagnosed between 2003 and 2009 the overall relative 5-year survival rate of people diagnosed with a malignant GIST was estimated to be about 76%.

- If the tumor was still just in the organ where it started, the 5-year relative survival was 91%.
- If it had grown into nearby structures (or spread to nearby lymph nodes) when it was first diagnosed, the 5-year relative survival was around 74%.
- If it had spread to distant parts of the body when it was first diagnosed, the 5-year relative survival was 48%.

Remember, these survival rates are only estimates – they can't predict what will happen to any individual person. We understand that these statistics can be confusing and may lead you to have more questions. Talk to your doctor to better understand your specific situation.

Last Medical Review: May 17, 2017 Last Revised: May 17, 2017

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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](#)?
- What do you recommend? Why?
- What's the goal of the treatment?
- Should I get a [second opinion](#)? 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](#) 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](#) 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](#) 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](#).

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