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 and Other Prognostic Factors
- 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 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, there are no effective screening tests 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 a colonoscopy\(^1\) to look for colorectal cancer. Rarely, a GIST may be seen on an imaging test, like a computed tomography (CT) scan, that is done for another reason. Some GISTs may also be found incidentally (unexpectedly) during abdominal surgery for another problem.

Hyperlinks

1. [www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/colonoscopy.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/colonoscopy.html)

References


Signs and Symptoms of Gastrointestinal Stromal Tumors

Most gastrointestinal stromal tumors (GISTs) develop within the wall of 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 can be found accidentally when the doctor is checking out 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 might 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\(^1\)), which can 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 and vomiting
- Feeling full after eating only a small amount of food
- Loss of appetite
- Weight loss
- Problems swallowing (for tumors in the esophagus)

Some tumors grow 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.

Hyperlinks


References


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 to have further tests to confirm what it is.

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 physically examine you 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 do imaging tests or endoscopy exams to help find out if it is cancer or something else. If you’re seeing your primary care doctor, you might be referred to a specialist, such as a gastroenterologist (a doctor who treats diseases of the digestive system).

If a GIST is found, you will likely have further tests 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 are 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 thought to have a GI tumor will get one or more of these tests.

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 to other parts of the body.

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.

Barium x-rays

Barium x-rays are not used as much as they were in the past. They have largely been replaced by CT/MRI and by endoscopy (where the doctor actually looks inside your
esophagus, stomach, and intestines with a narrow fiberoptic 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 your 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 had 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:** 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 (colon and rectum). 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. Often, air is blown in through the tube as well to help push the barium toward the wall of the colon and better coat the inner surface. This is called an **air-contrast barium enema** or **double-contrast barium enema.** You may be asked to change positions to help spread the barium, as well as to get different views of the colon. Then one or more sets of x-rays are taken.

**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 cancer spread in all areas of the body at once.

Many centers now have machines that 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 where cancer might have 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 done several weeks after starting the drug. 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 an **endoscopy**[6], the doctor puts an endoscope (a flexible lighted tube 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 will 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 has broken through the inner lining of the GI tract and is easy to see on endoscopy, there is a greater chance that the GIST might spread to other parts of the body.

**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\(^7\) 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 likely 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 esophagogastrroduodenoscopy).

**Colonoscopy (lower endoscopy)**

For colonoscopy\(^8\), 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 might also 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 likely be given intravenous (IV) medicine to make you feel relaxed and sleepy during the procedure. Less often, you might be given general anesthesia to put you into a deep sleep. 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 likely need someone you know to drive you home (not just a cab or rideshare service).

**Capsule endoscopy**

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 still 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 likely 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 (or beyond it and into a nearby organ). The test can also help show if the tumor has spread to nearby lymph nodes. It can also be used to help guide a needle biopsy (see below). You are typically given medicine before this procedure to make you sleepy. (Less often, you might be given general anesthesia to put you into a deep sleep.) Because of this, you will probably 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 can’t tell for sure if the abnormal area is a GIST, some other type of tumor (benign or cancer), 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 is a GIST, a biopsy is usually done only if it 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
A biopsy can also be done using a thin, hollow needle to remove small samples 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. This is known as an **endoscopic ultrasound-guided fine needle aspiration (EUS-FNA)**.

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. This is known as a **percutaneous biopsy**.

**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, the 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 might be able to tell that a tumor is most likely a GIST just by looking at the cells with a microscope. But sometimes further lab tests might be needed to be sure.

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

If GIST is suspected, some of the proteins most often tested for 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 CD34, might be tested for as well.

**Molecular genetic testing:** Testing might also be done to look for mutations in the KIT or PDGFRA genes, as most GIST cells have mutations in one or the other. Testing for mutations in these genes can also help tell if certain targeted therapy drugs are likely to
be helpful in treating the cancer.

Less often, tests might be done to look for changes in other genes, such as the *SDH* genes.

**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 (or mitotic index).** 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 determining 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**\(^1\) (**CBC**) can show if you have a low red blood cell count (that is, if you are anemic). Some people with GISTs may become **anemic\(^1\)** 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\(^1\)** or while you get other treatments such as **targeted therapy.**

**Hyperlinks**

3. [www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html)
4. [www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy.html)
5. [www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/nuclear-medicine-scans-for-cancer.html)
6. [www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy.html)
7. [www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/upper-
endoscopy.html
8. www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/colonoscopy.html
10. www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-lab-test-results.html

References


Gastrointestinal Stromal Tumor Stages and Other Prognostic Factors

After someone is diagnosed with cancer, doctors will try to figure out if it has spread, and if so, how far. This process, called staging, is based on the results of physical exams and other tests, which are described in Tests for Gastrointestinal Stromal Tumors.

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 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.

The AJCC TNM staging system

The staging system most often used for GIST tumors is the American Joint Committee on Cancer (AJCC) TNM system; the most recent version is effective as of 2018. This staging system is based on 4 key pieces of information:

- The extent of the main (primary) tumor (T): How large is the cancer?
- The spread to nearby lymph nodes (N): Has the cancer spread to nearby lymph nodes? (This is uncommon in GISTs.)
- The spread (metastasis) to distant sites (M): Has the cancer spread to distant parts of the body? (The most common sites of spread are the liver, bones, lungs, and the tissue layers lining the inside of the abdomen.)
- The mitotic rate: This 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. Although the T, N, and M categories are the same for all GISTs, there are 2 different stage grouping schemes, depending on where the cancer starts:

- The stomach or the omentum (an apron-like layer of fatty tissue that hangs over the organs in the abdomen)
- The small intestine, esophagus, colon, rectum, or peritoneum (a layer of tissue that lines the organs and walls of the abdomen.)

This is because GISTs that start in the stomach or omentum are typically less likely to grow and spread to other parts of the body than GISTs starting in other locations.

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**

<table>
<thead>
<tr>
<th>AJCC stage</th>
<th>TNM</th>
<th>Mitotic rate</th>
<th>Stage description*</th>
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<tbody>
<tr>
<td>IA</td>
<td>T1 or T2 N0 M0</td>
<td>Low</td>
<td>The tumor is:</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>- No more than 2 cm across (T1) OR</td>
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<tr>
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<td>- Larger than 2 cm but not more than 5 cm across (T2).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.</td>
</tr>
<tr>
<td>IB</td>
<td>T3 N0 M0</td>
<td>Low</td>
<td>The tumor is larger than 5 cm but not more than 10 cm across (T3).</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.</td>
</tr>
<tr>
<td></td>
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<td>High</td>
<td>The tumor is no more than 2 cm across (T1).</td>
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<tr>
<td>Stage</td>
<td>T</td>
<td>N</td>
<td>M</td>
</tr>
<tr>
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</tr>
<tr>
<td>II</td>
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<td>Any T</td>
<td>Any N</td>
<td>M1</td>
</tr>
</tbody>
</table>
*The following additional categories are not listed in the table above:

- **TX:** Main (primary) tumor cannot be assessed due to lack of information.
- **T0:** No evidence of a main (primary) tumor.
- **NX:** Regional lymph nodes cannot be assessed due to lack of information.

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

<table>
<thead>
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<th>AJCC stage</th>
<th>TNM</th>
<th>Mitotic rate</th>
<th>Stage description* (2 cm = almost 1 inch; 5 cm = about 2 inches; 10 cm = about 4 inches)</th>
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<td>T1 or T2 N1 N0 M1</td>
<td>Low</td>
<td>The tumor is:</td>
</tr>
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<td>- No more than 2 cm across (T1) OR</td>
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<tr>
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<td>High</td>
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<tr>
<td>Stage</td>
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<td>N</td>
<td>M</td>
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<td>OR</td>
<td>Any T</td>
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<td>M1</td>
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*The following additional categories are not listed in the table above:

- **TX**: Main (primary) tumor cannot be assessed due to lack of information.
- **T0**: No evidence of a main (primary) tumor.
- **NX**: Regional lymph nodes cannot be assessed due to lack of information.

The TNM staging system is not meant to be used for GISTs in children (pediatric GIST) or GISTS that are the result of inherited genetic syndromes\(^2\).

**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.

**Other ways to determine treatment options and outlook**

Along with the stage and resectability of the cancer, other factors can also affect treatment options and outlook (prognosis).

For example, some GISTs are much more likely to grow and spread than others. Doctors are looking at ways to determine which tumors are potentially more dangerous (and therefore might need more aggressive treatment). **Prediction tools** have been developed to help with this. Doctors and patients can now get a reasonable idea of how likely a GIST is to grow and spread to other parts of the body, or to return (recur) after surgery, based on factors such as:

- Where the tumor starts
- The size of the tumor
- The mitotic rate
- Whether or not the tumor has ruptured

Doctors are also looking at how **mutations in the KIT or PDGFR2A genes**\(^5\), which often drive the growth of GIST cells, might affect how well the cancer responds to treatment with **targeted therapy drugs**\(^6\). **Testing for these mutations** is now becoming more common.
Hyperlinks


References


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 (for example, the small intestine, esophagus, or stomach).
- **Regional**: The cancer has grown into nearby structures or spread to nearby lymph nodes.
- **Distant**: The cancer has spread to distant parts of the body such as the liver.

### 5-year relative survival rates for GIST

These numbers are based on people diagnosed with GIST [small intestine, esophagus, colon, rectum, peritoneum, stomach, omentum] between 2010 and 2016.

<table>
<thead>
<tr>
<th>SEER Stage</th>
<th>5-Year Relative Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localized</td>
<td>93%</td>
</tr>
<tr>
<td>Regional</td>
<td>80%</td>
</tr>
<tr>
<td>Distant</td>
<td>55%</td>
</tr>
<tr>
<td>All SEER stages combined</td>
<td>83%</td>
</tr>
</tbody>
</table>

**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 **other factors**, such as your age and overall health, whether the cancer can be resected (removed), and how well the cancer responds to treatment, can also affect your outlook.
- **People now being diagnosed with GIST may have a better outlook than these numbers show.** Treatments have improved 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*
Questions to Ask About Gastrointestinal Stromal Tumors

It’s important to have honest, open discussions with your cancer care team. You should feel free to 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 my cancer’s stage, 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 opinion²? If so, how do I do that? Can you recommend a doctor or cancer center?
- 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**

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

• How will we know if the treatment is working?
• Is there anything I can do to help manage [side effects](#)?
• What symptoms or side effects should I tell you about right away?
• How can I reach you or someone on your team on nights, holidays, or weekends?
• Do I need to change what I eat or my level of physical activity?
• Are there any limits on what I can do?
• Do you know of any local or online support groups where I can talk to others who have been through this?
• 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?
• Should I be exercising or following a special diet?
• What are the chances of my cancer coming back? Is there anything I can do to help lower my risk?
• What type of [follow-up](#) will I need after treatment?
• 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 [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.

Hyperlinks


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