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Gastrointestinal Stromal Tumor Early Detection, Diagnosis, and Staging

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

Detection and Diagnosis

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

- [Can Gastrointestinal Stromal Tumors Be Found Early? Signs and Symptoms](#)

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/cancer/diagnosis-staging/tests/endoscopy/colonoscopy.html

References

Casali PG, Dei Tos AP, Gronchi A. Chapter 60: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 11th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2019.

Signs and Symptoms of Gastrointestinal Stromal Tumors

- 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

1. www.cancer.org/cancer/managing-cancer/side-effects/low-blood-counts/anemia.html

References

Casali PG, Dei Tos AP, Gronchi A. Chapter 60: Gastrointestinal Stromal Tumor. In: DeVita VT, Lawrence TS, Rosenberg SA, eds. *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. 11th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2019.

Morgan J, Raut CP, Duensing A, Keedy VL. Epidemiology, classification, clinical presentation, prognostic features, and diagnostic work-up of gastrointestinal stromal tumors (GIST). UpToDate. 2019. Accessed at <https://www.uptodate.com/contents/epidemiology-classification-clinical-presentation-prognostic-features-and-diagnostic-work-up-of-gastrointestinal-stromal-tumors-gist> on October 14, 2019.

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Tests for Gastrointestinal Stromal Tumors

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

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](#)¹, 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](#)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 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 (i1an1sn). (See

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 esophagogastroduodenoscopy).

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 doctor's off3 0 0 1 72

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 of bleeding.

occurs, doctors can sometimes inject drugs into the tumor through an endoscope to constrict blood vessels and stop the bleeding.

Needle biopsy

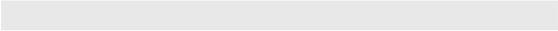
A biopsy can also be done using a thin, hollow needle to remove small samples of the area. The most common way to do this is during an endoscopic ultrasound (described

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](#)⁹ 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



- [cancer.html](#)
3. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/mri-for-cancer.html
 4. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html
 5. www.cancer.org/cancer/diagnosis-staging/tests/imaging-tests/nuclear-medicine-scans-for-cancer.html
 6. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy.html
 7. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy/upper-endoscopy.html
 8. www.cancer.org/cancer/diagnosis-staging/tests/endoscopy/colonoscopy.html
 9. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/targeted-therapy.html
 10. www.cancer.org/cancer/diagnosis-staging/tests/understanding-your-lab-test-results.html
 11. www.cancer.org/cancer/managing-cancer/side-effects/low-blood-counts/anemia.html
 12. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/surgery.html
 13. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/targeted-therapy.html

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Gastrointestinal Stromal Tumor Stages and Other Prognostic Factors

- 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.

			The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
IB	T3	Low	The tumor is larger than 5 cm but not more than 10 cm across (T3).
	N0 M0		The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
II	T1	High	The tumor is no more than 2 cm across (T1).
	N0 M0		The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	OR		
	T2	High	The tumor is larger than 2 cm, but not more than 5 cm across (T2).
	N0 M0		The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
OR			
	T4	Low	The tumor is larger than 10 cm across (T4).
	N0 M0		The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
IIIA	T3	High	The tumor is larger than 5 cm but not more than 10 cm across (T3).
	N0 M0		The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.

	M0		rate can be low or high.
	OR		
	Any T		

	OR		
	T4		The tumor is larger than 10 cm across (T4).
	N0	Low	The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is low.
	M0		
	T2		The tumor is larger than 2 cm but not more than 5 cm across (T2).
	N0	High	The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	M0		
IIIB	OR		
	T3		The tumor is larger than 5 cm but not more than 10 cm across (T3).
	N0	High	The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	M0		
OR			
	T4		The tumor is larger than 10 cm across (T4).
	N0	High	The cancer has not spread to nearby lymph nodes (N0) or to distant sites (M0). The mitotic rate is high.
	M0		
IV	Any T		The tumor is any size (Any T) AND it has spread to nearby lymph nodes (N1).
	N1	Any rate	The cancer has not spread to distant sites (M0). The mitotic rate can be low or high.
	M0		
	OR		
	Any T		The tumor is any size (Any T) AND it might or might not have spread to nearby lymph nodes (Any N).
	Any N	Any rate	The cancer has spread to distant parts of the body (M1). The mitotic rate can be low or high.
	M1		

*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.

- 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

1. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating.html
2. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/causes-risks-prevention/risk-factors.html
3. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/surgery.html
4. www.cancer.org/cancer/managing-cancer/treatment-types/targeted-therapy.html
5. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/causes-risks-prevention/what-causes.html
6. www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/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. Ask your doctor how these numbers might apply to you.

What is a 5-year relative survival rate?

A **relative survival rate** compares people with the same type and stage of gastrointestinal 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.

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.

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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

- Should I get a [second opinion](#)²? 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](#)³?
- 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](#)⁴ 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](#)⁵ 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](#)⁶ for which you may

medical writing.

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