
EASY READING

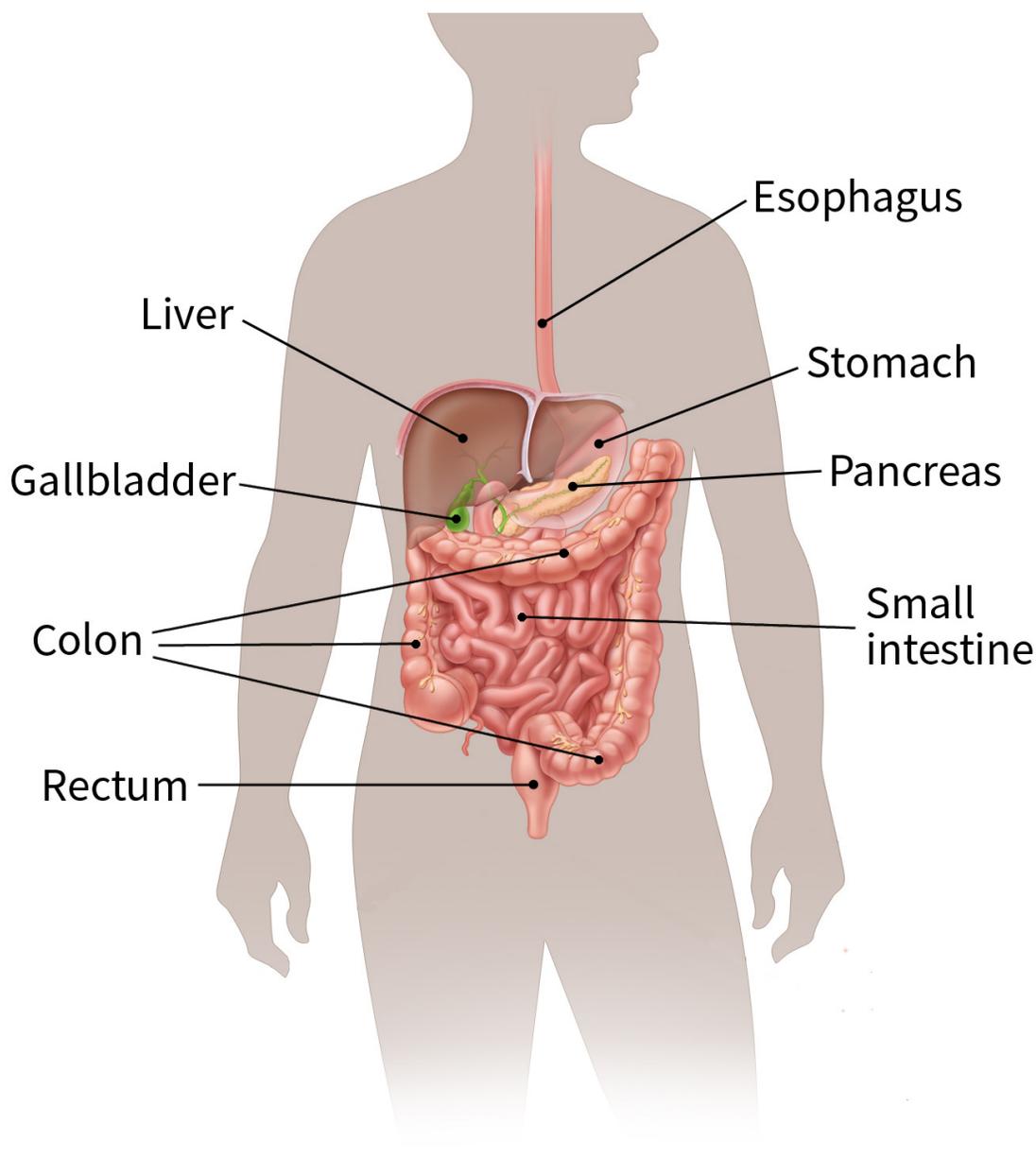
If You Have a Gastrointestinal Stromal Tumor (GIST)

Jump to a topic

- [What are GISTs?](#)
- [How does the doctor know I have a GIST?](#)
- [Tests to find GISTs](#)
- [How serious is my cancer?](#)
- [What kind of treatment will I need?](#)
- [What will happen after treatment?](#)

What are GISTs?

Cancer can start any place in the body. A GIST (pronounced “jist”) is an uncommon type of cancer that starts in the digestive tract, also known as the gastrointestinal (GI) tract. This is the path inside our body that food passes through. Most GISTs start in the stomach or small intestine, but they can also start in the esophagus (the tube that connects the throat to the stomach), colon, rectum, or other places.



GISTs are not the same as more common types of cancer that start in the GI tract, such as colon cancer and stomach cancer. GISTs are not treated the same way as these cancers.

GISTs start when certain cells that help move food through the GI tract begin to grow out of control. They can crowd out normal cells, which makes it hard for the body to work the way it should.

GIST cells can sometimes spread to other parts of the body. For instance, GIST cells in

the stomach might travel to the liver and grow there. When cancer cells do this, it's called **metastasis**. To doctors, the cancer cells in the new place look just like the ones from the stomach.

Cancer is always named based on the place where it starts. So when a GIST spreads to the liver (or any other place), it's still called a GIST. It's not called liver cancer unless it starts from cells in the liver.

Are there different kinds of GISTs?

Not all GISTs are the same. Some are likely to grow and spread slowly. Others are more likely to grow and spread quickly. Your doctor has ways to help tell what's most likely to happen with your tumor.

Questions to ask the doctor

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer you think I might have?
- Where is the cancer?
- What will happen next?

How does the doctor know I have a GIST?

Many GISTs don't cause symptoms right away. Sometimes they are found when a person has an exam or test done for another problem.

If a GIST does cause [symptoms](#)¹, they might include throwing up blood, or having bloody or dark colored stools. They might also cause belly pain, loss of appetite, or weight loss. Some people with GISTs feel tired because they've lost blood from the tumor into their stool. Your doctor will ask questions about your symptoms and do a physical exam.

Tests to find GISTs

If your doctor thinks you might have a GIST (or some other type of GI tumor), more [tests will be done](#)². Here are some of the tests you might need:

CT or CAT scan: This test uses x-rays to make detailed pictures of the inside of your

body. CT scans can often show the size, shape, and place of tumors in the GI tract. This test may also be done to see if cancer has spread.

MRI scan: MRIs use radio waves and strong magnets instead of x-rays to make very detailed pictures of the inside of your body. MRIs can make it easier to see the size and shape of the tumor.

Barium x-ray tests: Different types of x-ray tests can be used to look at the inside of your GI tract. For these tests, you either swallow a chalky liquid, or it is put in through your rectum. The barium in the liquid outlines the inner lining of the GI tract on x-rays. These types of tests aren't used as much as they were in the past.

PET scan: In this test, you are given a special type of sugar that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as "hot spots" where the cancer is found. This test can help show where a GIST has spread.

Endoscopy: For these tests, the doctor puts a flexible lighted tube with a tiny video camera on the end into the body to see the inner lining of the GI tract. Depending on where the tumor is thought to be, the tube can be put down the throat (for an [upper endoscopy](#)³) or put into the rectum (for a [colonoscopy](#)⁴). If abnormal areas are seen, small samples can be taken out for a biopsy (see below).

Endoscopy can also be used to do a kind of ultrasound test called **endoscopic ultrasound (EUS)**. Ultrasound uses sound waves to make pictures of the inside of the body. For EUS, a small ultrasound probe is on the end of the scope, which allows it to get very close to a tumor. This test can show how far a tumor has grown into the wall of the GI tract. It can also help show if the tumor has reached nearby lymph nodes.

Biopsy

In a biopsy, the doctor takes out small pieces of an abnormal area to check for cancer cells. If cancer is found, lab tests will also be done to find out what type of cancer it is. But not everyone who has a tumor that might be a GIST needs to have a biopsy before treatment.

There are different ways to do a biopsy. It can be done during endoscopy or surgery, or sometimes using a thin, hollow needle to get biopsy samples. The type used will depend on the size of the tumor and where it is in your body. Ask your doctor what kind you will need.

If a GIST is found, tests can be done on the biopsy samples to help tell how quickly the tumor is likely to grow and spread. This might affect your treatment.

Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

How serious is my cancer?

If you have a GIST, the doctor will want to find out if it has spread and if so, how far it has spread. This is called [staging the cancer](#)⁵. Your doctor will want to find out the stage to help decide what type of treatment is best for you.

The stage is based on how much the cancer has grown in the place where it started or spread to other parts of your body. It's also based on where the tumor is in the GI tract, and how quickly it's likely to grow and spread (based on lab tests of biopsy samples).

Your cancer can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread from where it first started. Ask the doctor about the cancer stage and what it means for you.

When trying to decide on treatment, doctors often use a simpler system that divides GISTs into 2 main groups:

- **Resectable tumors:** those that can be removed safely with surgery
- **Unresectable tumors:** those that can't be removed safely

Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?
- Would you explain to me what my cancer's stage means?
- How does the stage of the cancer affect my treatment options?
- What will happen next?

What kind of treatment will I need?

Not all GISTs need to be treated right away. Some small tumors that are likely to grow slowly can just be watched carefully. But if treatment is needed, **surgery** is usually the main treatment, if it can be done. **Targeted drugs** are more likely to be used if the tumor has spread. Other types of treatment are used less often.

The treatment plan that's best for you will depend on:

- The stage of the tumor and where it is
- If the tumor can be removed safely with surgery
- The chances of the tumor coming back after treatment
- Your age and overall health
- Your feelings about the treatment and the side effects that can come with it

Surgery

Surgery is used to take out the tumor and a margin or edge of the healthy tissue around it. This is the main treatment for GISTs, if it can be done. The [type of surgery](#)⁶ depends on where the tumor is. Ask your doctor what kind of surgery you will need and what to expect.

Side effects of surgery

Any type of surgery can have risks and side effects. Ask the doctor what you can expect. If you have problems, let your doctors and nurses know. They can help you with any problems that come up.

Targeted drugs

[Targeted drugs](#)⁷ attack some of the changes in cancer cells that help them grow. These drugs affect mainly cancer cells and not normal cells in the body. They are often the main treatment for GISTs if surgery is not an option. They can also be used before or after surgery for some tumors.

These drugs are pills that you take at home. They tend to have different side effects from chemo drugs.

Side effects of targeted drugs

Side effects depend on which drug is used. Some of these drugs might cause stomach upset, loose stools, muscle pain, skin changes, and might make a person feel tired. Worse side effects are also possible.

There are ways to treat many of the side effects caused by targeted drugs. If you have side effects, talk to your cancer care team so they can help.

Chemo

[Chemotherapy](#)⁸, or chemo for short, is the use of certain types of drugs to fight cancer. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. The drugs are often given through a needle into a vein. These drugs go into the blood and spread through the body.

Chemo is not often helpful in treating GISTs, so it is not used much.

Side effects of chemo

Chemo can make you feel very tired, sick to your stomach, and can sometimes make your hair fall out. But these problems tend to go away after treatment ends.

There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

Radiation treatments

Radiation uses high-energy rays (like x-rays) to kill cancer cells. Radiation is not very helpful in treating GISTs, so it is not used often. But sometimes it can be used to relieve symptoms like bone pain.

[Radiation for GISTs](#)⁹ is aimed at the tumor from a machine outside the body. This is called external beam radiation.

Side effects of radiation treatments

If your doctor suggests radiation treatment, ask what side effects might happen. Side effects depend on the area being treated. Some common side effects of radiation are:

- Skin changes where the radiation is given

- Feeling tired

Most side effects get better after treatment ends. Ask your cancer care team what you can expect during and after treatment.

Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)¹⁰ to learn more.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. But they might not be for everyone. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

What about other treatments that I hear about?

When you have a GIST, you might hear about other ways to treat it or to treat your symptoms. These may not always be standard medical treatments. These treatments may be [vitamins, herbs, diets, and other things](#)¹¹. You may wonder about these treatments.

Some of these might help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

Questions to ask the doctor

- Will I need to see other doctors?
- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- How will my body look and work after surgery?
- Will I need other types of treatment, too?
- What will these treatments be like?

- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

You'll be glad when treatment is over. But it's hard not to worry about cancer [coming back](#)¹². Even when cancer never comes back, people still worry about it. For years [after treatment ends](#)¹³, you will see your cancer doctor. At first, your visits may be every few months. Then, the longer you're cancer-free, the less often the visits are needed.

Be sure to go to all of your follow-up visits. Your doctors will ask about your symptoms, examine you, and may order tests to see if the cancer has come back.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

For connecting and sharing during a cancer journey

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the [Cancer Survivors Network \(CSN\)](#)¹⁴, a safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)¹⁵, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

1. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/signs-symptoms.html
2. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/how-diagnosed.html
3. www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/upper-endoscopy.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/endoscopy/colonoscopy.html
5. www.cancer.org/cancer/gastrointestinal-stromal-tumor/detection-diagnosis-staging/staging.html
6. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/surgery.html
7. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/targeted-therapy.html
8. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/chemotherapy.html
9. www.cancer.org/cancer/gastrointestinal-stromal-tumor/treating/radiation-therapy.html
10. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
11. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine.html
12. www.cancer.org/treatment/survivorship-during-and-after-treatment/long-term-health-concerns/recurrence.html
13. www.cancer.org/cancer/gastrointestinal-stromal-tumor/after-treatment/follow-up.html
14. csn.cancer.org/
15. www.caringbridge.org/
16. www.cancer.org

Words to know

Biopsy (BY-op-see): Taking out small pieces of an abnormal area to see if there are cancer cells in it.

Endoscopy (end-AH-skuh-pee): A test in which the doctor puts a flexible lighted tube with a tiny video camera on the end into the body to see the inner lining of the GI tract.

Gastroenterologist (GAS-tro-EN-ter-AHL-uh-jist): A doctor who treats diseases of the digestive system. Also called a GI doctor.

Gastrointestinal (GI) tract: The long pathway inside the body through which food passes. It includes hollow organs such as the esophagus, stomach, small intestine, and large intestine (colon and rectum). Also called the digestive tract.

Metastasis (muh-TAS-tuh-sis): The spread of cancer cells from where they started to other places in the body.

Mitotic (my-TAH-tick) **rate:** A lab test done on cancer cells that shows how quickly the cancer is likely to grow and spread. This is an important test for GISTs.

Sarcoma (sar-KO-muh): Cancer that starts in connective tissue, such as cartilage, fat, muscle, nerve, or bone. GISTs are a type of sarcoma.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (www.cancer.org)¹⁶. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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