

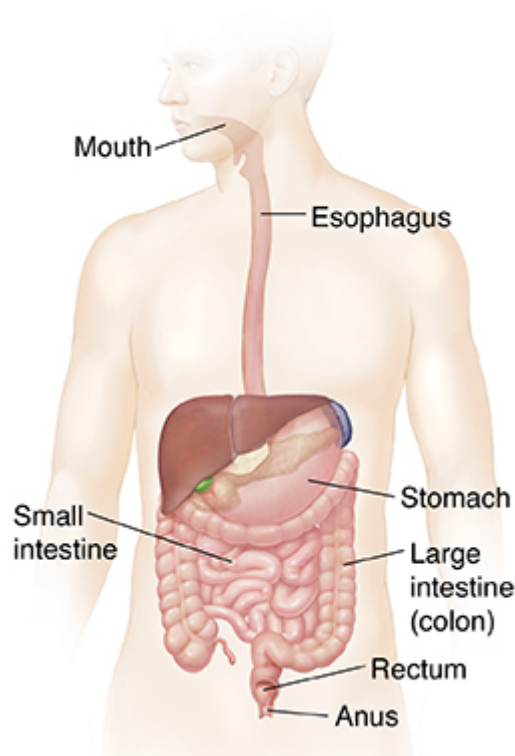
# Gastrointestinal Stromal Tumor (GIST)



## What is a GIST?

A gastrointestinal stromal tumor (GIST) is a rare type of soft tissue cancer. It may also be called a soft tissue sarcoma. It occurs in the GI (gastrointestinal) or digestive tract. A tumor can happen anywhere in your GI tract, from the esophagus to the anus. But they are found most often in the stomach. And in the small intestine (small bowel). In rare cases, a GIST tumor occurs outside the GI tract and in the belly (abdomen).

GIST starts in cells that are part of the nervous system. They send signals to the muscles of your GI tract. This helps your GI tract move food and liquid through it.



## Who is at risk for GIST?

Researchers are still learning what causes GIST. In most cases, a gene change (mutation) causes the cells to grow out of control. This causes a tumor to grow.

A risk factor is anything that may increase your chance of having a disease. The exact cause of someone's cancer may not be known. But risk factors can make it more likely for a person to have cancer. Some risk factors may not be in your control. But others may be things you can change.

Anyone can get GIST. But certain genetic syndromes have been linked to a higher risk. These include:

- Neurofibromatosis type 1 (NF1)
- Carney-Stratakis dyad
- Carney triad

## What are the symptoms of GIST?

Many people with GIST have vague symptoms. Symptoms often depend on where the tumor is in the GI tract, its size, and how fast it is growing. As the tumor grows, symptoms may include:

- Swelling pain in the stomach or belly
- Vomiting
- Blood in stools or vomit
- Feeling very tired (from low levels of red blood cells, a condition called anemia)
- Feeling full after eating only a small amount
- Trouble or pain when swallowing
- Loss of appetite
- Weight loss

Many of these may be caused by other health problems. It's important to see a healthcare provider if you have these symptoms. Only a healthcare provider can diagnose cancer.

## How is GIST diagnosed?

Your healthcare provider will ask about your health history, your symptoms, and your family history. A physical exam will be done. You may also have some tests, such as:

- **Blood tests.** These help your provider get an idea of your overall health and how well certain organs are working.
- **Endoscopy.** This is a procedure that uses a thin, flexible tube that is put down your throat. The tool used (endoscope) has a small light and video camera on the end. This lets your provider closely check the lining of your esophagus, stomach, and upper small intestine.
- **CT scan.** This test uses a series of X-rays and a computer to make detailed images of the inside of the body. A substance called contrast dye may be given before the scan. This helps make the images clearer. Contrast can be given into your vein. Or in a liquid that you drink.
- **MRI.** This test uses large magnets, radio waves, and a computer to make images of the inside of the body. Contrast dye may be given before the scan. This helps make the images clearer. This test uses no X-rays.
- **Biopsy.** Tiny pieces of tissue (called a sample) are taken from the tumor. They're sent to a lab and checked under a microscope to diagnose cancer. A biopsy may be done during an endoscopy. Or the sample may be removed during surgery.

## How is GIST treated?

GIST can be treated in many ways. It grows differently in each person. The type of treatment that's best for you depends on where the tumor is, how big it is, and if cells from the tumor have spread to other parts of your body. If the cancer has spread it is called metastasis. When GIST spreads, it often goes to the liver and the stomach lining.

GIST may be treated with:

- **Surgery.** If the cancer has not spread, surgery can be done to remove the tumor and a healthy edge of tissue around it.
- **Targeted therapy.** These medicines target certain parts of cancer cells that make them unlike normal cells. They're very helpful in treating GIST. Targeted therapy doesn't work the same as chemotherapy (chemo). It causes different side effects. The type of targeted therapy often used to treat GIST is known as tyrosine kinase inhibitors (TKIs).

The medicines most often used to treat GIST are taken by mouth as a pill at home. They include:

- **Imatinib.** This is often the first medicine used for GIST with mutations that respond to it. It can be given before surgery to try to shrink the tumor so it's easier to remove. It can also be used after surgery to help lower the chance of the cancer coming back. It may not cure advanced GIST. But it can help people live longer and feel better.
- **Sunitinib.** This TKI medicine targets a few receptors. It is often used when imatinib doesn't work. Or if imatinib side effects become a problem. It can often shrink tumors or stop them from growing for a time. It may help people with GIST live longer.
- **Regorafenib.** This medicine is often used for advanced GIST that can't be surgically removed. Or if other medicines are no longer working or are causing bad side effects. It can often shrink tumors or slow their growth for a time.
- **Ripretinib.** This medicine might be used for advanced GIST if other targeted therapies stop working. It can help slow tumor growth and even shrink tumors for a time.
- **Avapritinib.** This medicine targets a specific gene change called PDGFRA exon 18 mutation. It might be used if tests show that your cancer cells have this mutation. GISTs with this mutation don't often respond well to imatinib and other targeted therapy medicines.

Other treatments, like radiation therapy and chemo, are often not effective. They are not often used to treat GIST.

Talk with your healthcare providers about your treatment choices. Make a list of questions. Think about the benefits and possible side effects of each choice. Talk about your concerns with your healthcare provider before making a decision.

## What are treatment side effects?

Surgery can cause side effects like pain, bleeding, and infection. Your healthcare providers will talk with you about these before you have surgery. Side effects depend on the type of surgery done and where the tumor is.

Targeted therapy medicines also cause side effects. These depend on which medicine is used. They can include:

- Nausea
- Diarrhea
- Loss of appetite
- Fluid retention and swelling
- Muscle cramps
- Bleeding from the GIST tumor
- Feeling very tired (fatigue)
- Skin rash
- Changes in skin and hair color
- Redness and pain in the palms of the hands and soles of the feet
- Hair loss
- Blood pressure changes
- Mouth irritation

In most cases, side effects are mild to moderate. And there are often ways to manage them. More serious side effects can include high blood pressure, increased risk of bleeding, swelling, and heart, lung, or liver problems.

## **When to call the healthcare provider**

It's important to know which medicines you're taking. Write down the names of your medicines. Ask your healthcare team how they work, how to take them, and what side effects they might have.

Talk with your healthcare providers about what side effects to look for and when to call them. For instance, imatinib can cause itchy skin rashes that can lead to infections. Make sure you know what number to call with questions. Is there a different number for evenings, weekends, and holidays?

It may be helpful to keep a diary of your side effects. Write down the physical, thinking, and emotional changes. A written list will make it easier for you to remember your questions when you go to your appointments. It will also make it easier for you to work with your healthcare team to make a plan to manage your side effects.

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