

Gastrointestinal Stromal Tumors ^[1]

About gastrointestinal stromal tumors

Gastrointestinal stromal tumors, or GIST, are an uncommon type of cancer that occurs in the gastrointestinal (GI) tract, also known as the digestive system. GIST belongs to a class of diseases called sarcomas, cancers that begin in the connective tissues, which include fat, muscle, blood vessels, deep skin tissues, nerves, bones and cartilage.

Although GIST can start anywhere in the GI tract, they occur most often in the stomach (60%) or the small intestine (30%). The rest are found in the colon and other parts of the GI tract.

Recently, an expert panel concluded that all GISTs, regardless of their size or location, may be malignant (have the ability to spread). Even after a GIST is removed, it may come back in the same area or may metastasize (spread) outside of the GI tract.

To date, very little is known about the risk factors that have specifically been identified as increasing a patient's risk for GIST. The cancer cells of most patients with GIST have a change in an enzyme called KIT, which is found on the surface of normal cells. In healthy individuals, the role of KIT is to signal cells to grow and divide. However, in most patients with GIST, a malfunctioning KIT signals the cells to constantly grow and divide out of control, and they become cancerous.

GIST is often difficult to diagnose and treat because it may not cause any physical symptoms. Recent research has shown people with rare cancers are two times more likely than those with common cancers to receive multiple diagnoses before physicians are able to accurately identify their disease.

GIST may be detected by endoscopy, colonoscopy, CT scan, MRI or pathology evaluation.

Treatment of gastrointestinal stromal tumors

Surgery is the standard treatment for a gastrointestinal stromal tumor (GIST) that has not spread. However, by two years after complete removal of their tumor, half of patients who underwent surgical treatment have relapsed.

Some targeted drug treatments, in addition to surgery, have shown to be very helpful in treating GIST.

GIST patients should work with their physicians to form a multidisciplinary team, including a surgeon, oncologist and pathologist, and should attend regular follow-up visits with them to

monitor for signs of recurrence and to ensure their treatment plan is working.

Questions to ask your doctor

If you are diagnosed with gastrointestinal stromal tumors (GIST), you may want to ask your doctor questions like the ones below about your diagnosis and your treatment plan.

If you are newly diagnosed with GIST:

- Where is the tumor located?
- Has the tumor spread?
- How should I take my medication?
- How can I remember to take my medication?
- When do I start treatment?
- What is the goal of my treatment?
- Will the medication cure me? What can I expect?
- Why is it important to continue treatment?
- What side effects should be expected from treatment?
- What can be done to help me deal with side effects?
- How will treatment affect my daily routine?
- What changes can I expect?

If you have had surgery and are also taking medication:

- How should I take my medication?
- How should I store it?
- How can I remember to take my medication?
- What is the goal of my treatment?
- How long do I need to take medication?
- How do I know if I am experiencing side effects or effects from the surgery?
- What can be done to help me deal with side effects?
- What will happen if I stop my medication due to side effects?
- I am feeling good. Why is it important to continue treatment?
- What should I expect right after surgery versus later, if therapy was added on?

If you have metastatic disease and have been taking medication for several years or just initiated your treatment:

- How is my medication helping me?
- What tests will I be taking?
- How do I know if I'm still responding to treatment?
- How can I remember to take my medication?
- What can be done to help me deal with side effects?
- What can happen if I stop my medication due to side effects?
- How long do I need to take medication?
- If results vary over time, should I be concerned? If so, why?
- I'm feeling good. Why is it important to continue treatment?

If you stopped taking your medication or are not reaching your treatment goals:

- I have been taking my medication. Why am I not seeing results?
- What if my treatment is not working?

- I am feeling good. Why is it important to continue treatment?
- How can I remember to take my medication?
- What can be done to help me deal with side effects?
- What can happen if I stop my medication due to side effects?
- How can I get back on track and take control?

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