



# After a Gastrointestinal Stromal Tumor Diagnosis



A gastrointestinal stromal tumor (GIST) is a rare type of cancer that starts in the digestive tract or nearby parts of the body. Most GISTs grow in the wall of the stomach or the small intestine. If you have been told you have a GIST, you've probably already had blood tests, scans, an endoscopy, and a biopsy (a test that takes some tissue to check for cancer). Other tests might have been done on the cancer cells to check for certain proteins and gene changes called biomarkers. You might also have other procedures to find out if the cancer has spread. These tests help your doctor know what type of GIST you have, what stage it is, and what treatment might help.

## Treatment for a GIST

Your treatment will depend on the location and stage of the GIST. Your treatment options will also depend on test results on the cancer cells, your health, and your personal preferences.

Not all GISTs need to be treated right away. But if treatment is needed, the main types used are surgery and targeted therapy. Surgery is used if the GIST can be completely removed. Targeted therapy may be used to help shrink the tumor before surgery.

Other treatments for GISTs can include radiation, chemotherapy (chemo), ablation, and embolization. In many cases, more than one type of treatment is needed. Your doctor will help you decide which treatments are best for you.

## Be sure to ask:

- Where is the tumor located? How big is it?
- How likely is the tumor to grow or spread quickly?
- What stage is the GIST, and what does that mean?
- Will I need more tests?
- What treatment do you think is best for me?
- What is the goal of treatment?
- Will treatment include surgery? Can all of the cancer be removed?
- Will I need other types of treatment, too?
- What are the chances that the tumor will come back?
- What will we do if the treatment doesn't work or if the cancer recurs?

## What to expect before and during treatment

Your cancer care team will explain your treatment plan to you. This team may include different doctors, nurses, and other health care workers, depending on the type of treatment you need. For example, if you need surgery, you will work with a surgeon. They will tell you what to expect before, during, and after treatment. If you need other types of treatment, your cancer care team will explain how it is given, help you get ready for it, keep track of how you're doing, and help you with any side effects. You might also get blood tests, scans, or other tests at certain times to see how well your treatment is working.

Not everyone going through treatment for a GIST will have the same side effects. For example, the side effects of surgery are different from the side effects of targeted therapy, radiation, and chemo. And people getting the same treatment might have different side effects.

## Be sure to ask:

- What side effects might I have, and what can I do about them?
- How will we know if the treatment is working?
- How often will I get treatment? How long will it last?
- Where will I go to get treatment? Can I drive myself?
- How will treatment affect my daily life?
- Do I need to change what I eat during treatment?
- Are there any clinical trials that might be right for me?

## What to expect after treatment

After treatment, ask your cancer doctor for a treatment summary and follow-up plan. This is called a survivorship care plan. Your cancer doctor will work with your family or primary care doctor to help manage side effects from treatment and check your general health. You will have regular tests to check if your cancer has come back or if a new cancer has started in a different part of your body.

You might be faced with changes to your body after treatment. Be sure to ask the doctor what to expect, and let them know if you have any problems.

People who have had a GIST are at risk of having it again or getting certain other types of cancer. Even if you feel fine after finishing treatment, it's important to ask your cancer care team about a regular schedule for follow-up tests to check if the GIST has come back.

For some people, the cancer might not go away completely. They might continue to get treatment, and tests will still be needed to see how well it's working.

### Be sure to ask:

- Where do I get a copy of my treatment summary and follow-up plan?
- How often do I need to see my cancer care team?
- When and how should I contact them?
- Will I need tests to see if my cancer has come back, or to check for problems from my treatment?
- Do I need any screening tests, like a mammogram or colonoscopy, to find other cancers early?
- Do I need a special diet after treatment?
- Are there late or long-term side effects from treatment that I should watch for?
- Where can I find my medical records after treatment?



For more information and support, visit the American Cancer Society website at [cancer.org/gist](https://cancer.org/gist) or call us at **1-800-227-2345**. We're here when you need us.

## Staying healthy

Be sure to tell your doctor or cancer care team if any treatment side effects don't go away or if you have any new symptoms.

There are things you can do to keep yourself healthy during and after treatment. Getting to and staying at a healthy weight, eating well, being active, not smoking, and avoiding alcohol can help you stay healthy and may help lower your risk of getting a new cancer.

## Dealing with your feelings

Having a GIST might make you feel scared, sad, or nervous. It's normal to have these feelings, and there are ways to help you cope with them.

- Don't try to deal with your feelings by yourself. Talk about them, no matter what they are.
- It's OK to feel sad or down once in a while, but let your cancer care team know if you have these feelings for more than a few days.
- If your doctor says it's OK, continue doing things you enjoy like spending time outdoors, going to a movie or sporting event, or going out to dinner.
- Get help with tasks like cooking and cleaning.

You might want to reach out to friends, family, or religious leaders or groups. Counseling can also help. Some people find it helpful to talk with others who've been through the same things. A support group can offer that. Tell your cancer care team how you're feeling. They can help you find the right support.