Living as a Gastrointestinal Stromal Tumor Survivor

For some people with a gastrointestinal stromal tumor (GIST), treatment can remove or destroy the cancer. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about cancer coming back. (When cancer comes back after treatment, it’s called a recurrence.) This is a very common concern if you’ve had cancer.

For some people, the GIST may never go away completely. These people may get regular treatments with targeted therapy drugs or other therapies to help keep the cancer in check and to help relieve symptoms. Learning to live with cancer that doesn’t go away can be difficult and very stressful.
Follow-up care

Whether you have completed treatment or are still being treated, your doctors will still want to watch you closely. It’s very important to go to all follow-up appointments, as GISTs can sometimes come back after treatment.

Some treatment side effects might last a long time or might not even show up until years after you have finished treatment. Your doctor visits are a good time to ask questions and talk about any changes or problems you notice or concerns you have.

Exams and tests

During your follow-up visits, your doctors will ask about symptoms, examine you, and may order imaging tests like CT scans. Because of the risk that a GIST may come back after treatment, most doctors recommend follow-up visits and imaging tests every 3 to 6 months for at least several years after treatment. If you’re still being treated with imatinib (or any other targeted drug), you will also need to have CT scans to make sure that the drug is still working.

Ask your doctor for a survivorship care plan

Talk with your doctor about developing a survivorship care plan for you. This plan might include:

- A suggested schedule for follow-up exams and tests
- A schedule for other tests you might need in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- Diet and physical activity suggestions

Keeping health insurance and copies of your medical records

Even after treatment, it’s very important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

At some point after your treatment, you might find yourself seeing a new doctor who
doesn’t know about your medical history. It’s important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in Keeping Copies of Important Medical Records.

Can I lower my risk of the tumor progressing or coming back?

If you have (or have had) a GIST, you probably want to know if there are things you can do that might lower your risk of the tumor growing or coming back, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it’s not yet clear if there are things you can do that will help.

Adopting healthy behaviors such as not smoking, eating well, getting regular physical activity, and staying at a healthy weight might help, but no one knows for sure. However, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of GIST or other cancers.

About dietary supplements

So far, no dietary supplements (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of cancers such as GIST progressing or coming back. This doesn’t mean that no supplements will help, but it’s important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they’re allowed to claim they can do. If you’re thinking about taking any type of nutritional supplement, talk to your health care team. They can help you decide which ones you can use safely while avoiding those that might be harmful.

If the GIST comes back

If cancer does recur, your treatment options will depend on the location of the cancer, and what treatments you’ve had before, and your current health and preferences. For more information on how recurrent cancer is treated, see Treatment Choices for Gastrointestinal Stromal Tumor Based on Tumor Spread. For more general information on dealing with a recurrence, see Coping With Cancer Recurrence.

Getting emotional support

Some amount of feeling depressed, anxious, or worried is normal when cancer is a part
of your life. Some people are affected more than others. But everyone can benefit from help and support from other people, whether friends and family, religious groups, support groups, professional counselors, or others. Learn more in Coping With Cancer\(^{11}\).

**Hyperlinks**


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**Written by**


Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in