

# Find the Right Doctor

Doctors are good, bad, and above all—human and they, like the rest of us, are not perfect. A good doctor will combine test results with clinical signs and history. It is important that you find the best doctor to help you throughout your care. Some important questions to ask when selecting a doctor are:

- How many GIST cases have you seen and treated?
- Are you aware of the treatment and clinical trial options for GIST?
- How regularly do you review medical literature about GIST?
- Do you ever consult with other doctors to get second opinions?

## GIST Specialist vs. Local Oncologist

It is best to go to a doctor who has experience with treating this disease. Finding a doctor with such experience may be difficult since GIST is a rare cancer. Visiting a hospital that routinely sees many sarcoma and GIST patients increases the chances of seeing a doctor who has experience and expertise in GIST. It may be difficult to find a sarcoma center near your area. A patient's options include:

Have your local oncologist work collaboratively with a GIST specialist so that your doctor is guided by an expert opinion on how to best treat your cancer. This may involve discussing CT/PET scan schedules, dose considerations, etc.

A patient can travel to a GIST specialist and use him/her as a primary physician to treat GIST. To find a GIST specialist, search the directory at [www.liferaftgroup.org/gist\\_directory.php](http://www.liferaftgroup.org/gist_directory.php)



## The Life Raft Group

The LRG is an international patient support organization for people with GIST and their family members. The mission of the Life Raft Group is to ensure the survival of GIST patients while maintaining the quality of their lives. To accomplish this mission the Life Raft Group devotes its efforts to: Information & Support, Treatment Surveillance, Research, Patient Consultation & Assistance, and Advocacy.

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# Managing Your GIST Care

# Understand Your Cancer

Being diagnosed with cancer, especially a rare one like Gastrointestinal Stromal Tumor (GIST) can be overwhelming. This pamphlet is designed to help you take your first steps to managing your own care.

## Why Manage Your Own Care?

There are a number of reasons why a patient should take an active and managing role in their own care. Medical care is quite complex and mistakes do happen. Furthermore, oncology is a broad field and GIST is a rare disease. You must realize that it is *your* body and ultimately *your* decisions to make.

## Stay Informed and Educated

This is key to becoming a long-term survivor of this rare disease. It is important for you to learn about treatment efficacy and side-effects, new clinical trials and cutting-edge information being developed by leading GIST researchers. By staying up-to-date and informed, you are more prepared to be a participating member of your medical team. Ways to find this information include:



### Research Online.

PubMed, Medline and others are ideal for reading articles that were written and reviewed by experts in the field. Additionally, the Life Raft Group's website provides a comprehensive overview various treatments and side-effects, clinical trial lists and much more.

### Join the Life Raft Group.

You will have access to an internet community of patients and caregivers, as well as monthly newsletters and webcasts that keep the public up-to-date with the latest information about GIST. You can also join local, face-to-face groups through the LRG.

## Research Your Treatment Options

Surgery is often the first form of treatment for GIST patients. However, there are many instances when patients are encouraged to take Gleevec prior to or after surgery. Careful research should be done to see if this the right choice for you.

Gleevec (Glivec) was the first drug approved to treat GIST. In initial trials, 85% of participants experienced shrinkage or stability. However, increasing drug resistance is a concern, research should be made into the many new drugs in development with applications for GIST.

Sutent is currently the recommended choice after Gleevec-failure, and is now FDA-approved for second-line GIST treatment. In addition to these FDA-approved drugs, you may wish to discuss other treatments with your doctor.



## Record Keeping is Essential

It is important that you keep a record of pathology reports and information that you may not be able to remember, such as prior treatment side-effects or trials. This not only helps you keep track of your medical history, but it also helps the various doctors on your healthcare team. Keep this information in a binder or notebook that can serve as a portable reference.

## Ask Questions

You will most likely have many questions along this journey. We encourage you to write these down and consult your doctor. You can even record them in your binder. Talking to your doctor can often be intimidating; remember that this is your care and your life. If you are not being treated in a respectful manner, you may want to consider finding a medical professional that will respect your role in your treatment.



# Manage Your Cancer

## Don't Go It Alone!

No matter how smart, how thorough or how capable you are, it's very difficult to do this alone. Every patient needs a partner to help with certain important functions, such as **Listener, Case Manager and Support.**



**Listener.** The demands cancer makes on a person's mind and life are far more intense than one might imagine. It is imperative that you find a loved one to act as a Listener, whether it be to act as a "sounding board" or a shoulder to lean on.

**Case Manager.** The amount of information you will need to absorb on your journey with GIST can be overwhelming. In addition to learning about treatment options and side-effects, you must deal emotionally with this information. It is worthwhile to find a friend or family member who can help manage your GIST care by taking notes at doctors appointments and advocating on your behalf.

**Support.** Remember this, your friends want to help you. If you need to spend some time in the hospital, ask your friend to walk your dog or water your plants. If your treatment has made you too tired to cook dinner, ask a friend to make or bring something to you. Designate people in your mind to assist you with these routine tasks so you won't burden yourself with excessive worry when the occasion arises.

The theme here is simple: you have begun an arduous journey; allow others to offer what help they can along the way.

## Take Your Medicine

If you are on a drug treatment, take careful note: your doctor has not prescribed your dosage for his own personal amusement. **Take the medication as it is prescribed by your doctor.** If you have experienced problems with side-effects or other factors that affect your ability to take all of your medication, speak to your doctor about a possible change.

