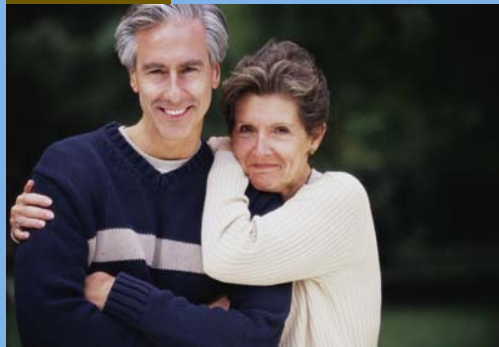




The Life Raft Group

Ensuring that no one has to face GIST alone

Living Well with Side Effects: A Guide to Side Effect Management for GIST Patients



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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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Introduction



Gleevec and Sutent are powerful anti-cancer drugs that are building bridges to finding a cure for GIST. While both have beneficial and negative effects, for most people, the benefits far outweigh the negative effects.

However, side effects can have a negative impact on every day life. Some people react differently to the same drug, some people have no side effects, some people have all of them, and most people fall somewhere in between.

Learning how to manage side effects or in some cases, how to live with them, not only improves quality of life, but it also allows patients to be able to take these drugs at the proper dose and schedule, which is key to successful treatment.

Side Effect Management

There are many suggestions on how to treat side effects from GIST treatment. This pamphlet touches on a few of the most common ones.



GIST patient Marcel Szyszkowski

For more information on side effect management, visit: www.liferaftgroup.org/side_effects.html

Taking Your Medication:

For many people, the side effects can be so intolerable that patients choose to discontinue their medication or, at least, not take it as prescribed.

Even if you experience minor side effects, it is still important that you take your medication. GIST tumors can grow quickly and not taking your medicine can greatly affect your health. It is important to take the appropriate dose that is prescribed by your doctor.

If the medication is still not tolerated well, then talk with your doctor about changing the time of day that you take it, splitting the dose across the day, or other helpful suggestions to minimize discomfort.

Here are some tips to remind you to take your medication:

- Take the drug at the same time every day. Try to link it with another regular activity like brushing your teeth.
- Put a written reminder by the refrigerator or phone.
- Keep a chart or calendar as a reminder.
- Use alarms.
- Try using a pill box to organize the pills.



Caution: It is important for patients to report side effects and discuss their management with their doctor. The material presented here is for information purposes only; it is not a substitute for your physician's guidance and care.



Side Effect Management

Common Gleevec Side Effects

- Fatigue
- Nausea/vomiting
- Rash
- Edema
- Muscle cramps
- Diarrhea
- Abdominal pain



Common Sutent Side Effects

- Fatigue
- Nausea, Vomiting, Diarrhea, Altered Taste
- Rash/dermatitis and discoloration of skin
- Arthralgias, Edema
- Hypertension, Headache
- Dyspepsia, Stomatitis
- Anemia, Neutropenia, Thrombocytopenia
- Hypothyroidism



Fatigue:

Tiredness and exhaustion are major side effects from GIST treatment.

- Gleevec may cause anemia, which, in turn, causes weakness and exhaustion. There are medications that treat anemia.
- Plan your day so that you have time to rest.
- Stay physically active.
- Save your energy for the most important things or reduce nonessential tasks.



Nausea:

Nausea is one of the more common side effects. It may also be accompanied by an urge to vomit and by loss of appetite. Nausea may be caused by a local irritant effect of the drug in the stomach.



- Take Gleevec with food and plenty of water.
- Take certain foods that help quell the nausea, such as chocolate or sweet potatoes.
- Spread out Gleevec during the meal if you take multiple capsules or tablets.
- Anti-nausea medications may help.

Rash:

Gleevec-induced rashes vary from mild to severe. Rashes occur more frequently in females and at higher doses with gender appearing to be the more important factor.

- *Mild Rash*—Treat with antihistamines or topical steroids.
- *Moderate Rash*—May respond to oral steroids, such as prednisone.
- *Severe Rash*—May require discontinuation of Gleevec and systemic steroids. After the rash resolves, Gleevec is often restarted with prednisone. The prednisone is then tapered off over the course of several weeks.

Edema:

Symptoms include: eye puffiness, swelling of lower legs, increase in abdominal girth, shortness of breath, or weight gain.

- Weigh yourself regularly; report significant or rapid weight gain to your health care provider.
- Be alert for any changes to your body.
- Limit the amount of salt you consume with your food.

Muscle Cramps (Myalgias):

Muscle cramps may occur in the hands, feet, and/or legs. They are occasional in nature and may increase with prolonged therapy.

- Increase oral fluid intake on a regular basis.
- Take chelated magnesium and/or calcium supplements such as Tums®.
- Exercise regularly.
- Tonic water which contains quinine may help.



Diarrhea:

In clinical trials, diarrhea was reported in about 70 percent of GIST patients. Although common, it tends to be mild and easily treatable.

- Eat small, frequent meals.
- Eat “plain” foods high in protein and potassium.
- Keep activity to a minimum, especially immediately after a meal.
- Consider anti-diarrhea medication.

Dumping Syndrome/Post-Gastrectomy:

This condition occurs when food moves too quickly from the stomach to the small intestines. This typically occurs after a portion of the stomach is removed.



- Eat small, frequent high protein meals and snacks.
- All food/drink should be moderate in temperature.
- Limit milk intake at first after a gastrectomy.
- Lie down/recline immediately after eating to slow down the time it takes your stomach to empty.
- Avoid sugar and simple carbohydrates.

Side Effect Summary:

- Gleevec and Sutent are generally well tolerated.
- Majority of patients (90-100%) experience adverse effects at some time, most being mild to moderate grade.
- Severe toxicity are seen in only one out of five patients.
- Sutent and Gleevec side effects are mostly reversible upon discontinuation of the therapy.

Side Effect Monitoring:


- Notify your health care professional of any side effects you may be experiencing.
- Keep a diary or log.



Drug-Drug Interactions:

- GIST drugs are metabolized by the liver; therefore, other drugs that are metabolized by the liver may affect the amount of drug in the body.
- Discuss with your physician, pharmacist or other health care professionals any medications or herbal products before beginning to take them.
- Limit acetaminophen (Tylenol®) to 1300 mg/day.

Drug-Food Interactions:

-  Grapefruit and other foods may alter drug metabolism.
- Do not eat grapefruit or drink grapefruit juice while taking this class of drugs.
- Avoid caffeinated beverages for one hour around Gleevec ingestion.
- Avoid star fruit and seville oranges.