

GIST Patient Handbook

A Guide to Navigating Your Care



*Ensuring that no one has to
face GIST alone*

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GIST Sarcoma
Life Raft Group Canada
www.liferaftgroup.ca
info@liferaftgroup.ca

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Introduction

A new diagnosis of Gastrointestinal Stromal Tumour (GIST) can be challenging and overwhelming. This booklet is intended as a guide to help you (the patient) navigate treatment, acquire important information from your healthcare team, and advocate for the best care within the Canadian healthcare system.

GIST Sarcoma Life Raft Group Canada (LRGC) encourages you to speak openly with your healthcare team. Only they can provide you with the most appropriate and individualized information pertaining to your diagnosis and treatment. In this booklet, we have provided sample questions that you can ask your healthcare providers. These questions will help you better understand your treatment and ensure that your healthcare team is addressing important considerations that will lead to the best outcome. Additionally, a set of resources and references are provided to complement information received from your healthcare team.

Throughout this document, you will find relevant side notes that are labeled with the symbols below:

- ☑ important task
- ◇ additional information
- 📖 related online reading

A separate worksheet is included to help you compile your own Personal GIST Record. Since GIST management can be complex, completing this record (with the help of your care team) will help you and your team keep track of your care. Feel free to modify the worksheet as necessary for your personal use. Please don't hesitate to contact LRGCC if you have any questions or suggestions while filling out the worksheet.

This booklet is not a comprehensive source of information about GIST and does not replace professional medical advice from your care team. Any medical concerns should be directed to your healthcare provider.

What is GIST?

GIST stands for GastroIntestinal Stromal Tumour. GIST is a rare sarcoma that can occur anywhere along the GI tract. GIST is completely different from the far more common carcinomas (such as stomach cancer and colon cancer), in terms of both biology and treatment. We estimate that about 500 Canadians are diagnosed with GIST every year. Most cases occur in older people, but cases in young adults and even children have been seen. GIST is rare and strikes randomly; there are no known risk factors and no ways to prevent it.

Navigating Your Care

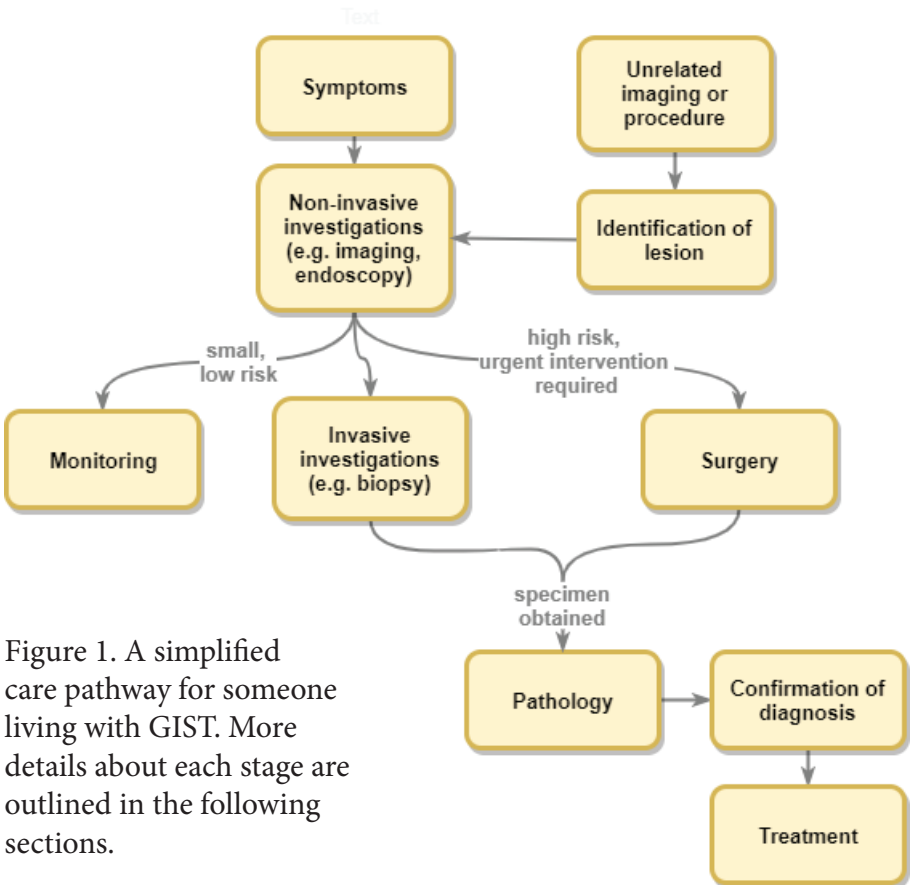


Figure 1. A simplified care pathway for someone living with GIST. More details about each stage are outlined in the following sections.

Your GIST Care Team

Below are some of the specialized healthcare professionals that you may meet:

Medical oncologist

Your medical oncologist is usually the leader of your GIST care team. They are responsible for coordinating the diagnosis, management and follow-up care (e.g. recurring lab tests, imaging, side effect management). They will also be your primary point of contact for any concerns relating to your diagnosis.

Surgical oncologist

If it is recommended that your tumour be surgically resected (removed), a surgical oncologist will be responsible for the procedure. They are responsible for obtaining a pathological specimen for diagnosis, resecting the tumour, and following up on surgical concerns (e.g. wound healing, side effect management).

Family physician

Your family physician will not be managing your GIST treatment directly, but it is important to follow up with them regularly for ongoing health maintenance and management of symptoms related to GIST. Your family physician acts as manager of all your health records (since all specialist consult notes are forwarded to them) and can connect you to helpful resources in the community including healthcare providers and support groups.

◇ You may be seen by a physician trainee (e.g. resident or fellow) under the supervision of a staff physician. These physician trainees often have more time to answer questions. However, you may ask to see the staff physician if you have any concerns that they are unable to address.

☑ If your medical oncologist does not specialize in GIST or sarcomas (soft tissue cancer), ask to be referred to a medical oncologist who does. GIST is rare and not all physicians are familiar with the latest treatment guidelines.

Pathologist

You might not meet this physician in person, but they analyze the specimen obtained by your surgeon or gastroenterologist to make a diagnosis.

Radiologist

A diagnostic radiologist reads and interprets your imaging investigations (e.g. MRI, CT scan, ultrasound). An interventional radiologist conducts minimally-invasive image-guided procedures.

Nursing team

Nurses will play a key role throughout your medical care. Your nurses can help address any questions or concerns you may have or relay them to your physician.

Mental health team

This team can support you through the emotional stresses of living with GIST. It may consist of psychiatrists, psychologist, social workers, or other counselors.

Dietician

Both the illness and the treatments may have effects on your digestive system. A dietician can help to manage your nutritional needs specific to GIST.

Drug Reimbursement Specialist

These professionals can help coordinate financial assistance for funding prescription medications.

Other

You may find services from other professionals to be beneficial for you. Speak with your healthcare team about services that may fit your needs.

☑ A multidisciplinary cancer center that specializes or is experienced in treating GIST will provide the best care for you. If you are not currently under the care of one, contact LRGC to find out if one is nearby you.

New Diagnosis

A new diagnosis of GIST is often accompanied by multiple test results, reports, and appointments. To help you manage all this new information, this section contains questions that may be useful to review with your healthcare team.

As you review your diagnosis with your healthcare team, be sure to obtain a copy of all reports and investigations for your records. You can use the included Personal GIST Record to help organize these documents.

Remember, you have the right to access your personal health information. This means that your care team must provide you with a copy of any reports upon request. However, some clinics may charge a small administrative fee for this. Should you have difficulties obtaining your records, please contact LRGCC.

General Questions

What is my diagnosis?

Where is the tumour? How big is it?

What is the mutational type of my tumour?

Imaging Report Questions

Can you review the imaging with me? How can I obtain a copy of the imaging for my records?

Is there evidence of tumour metastasis (spread)?

◇ The confirmatory test for GIST is done through a test called immunohistochemical staining of the tumour specimen. Almost all GIST diagnoses are based on positive staining of the CD117 (KIT) or DOG1 proteins.

◇ Most commonly, GISTs carry a mutation in exon 11 of the KIT gene. Knowing the mutation can help with prognostication (predicting the course of the disease) and treatment selection. Some cancer centres do not automatically send the specimen for genetic analysis, but we strongly recommend that you request that this test be done. Please contact LRGCC if you have any difficulties obtaining these test results.

Pathology Report Questions

Was my case reviewed by a pathologist that specializes in sarcomas?

Can you review the pathology report with me and provide me with a copy?

Were there adequate surgical margins? If not, what does this mean for me?

What was the mitotic rate (an indication of tumour cell growth rate)?

What is the risk of recurrence for my tumour?

Surgical Report Questions

Can you review the surgery report with me and provide me with a copy?

Were any organs or parts of organs removed along with the tumour?

Was there evidence of metastasis?

Will I experience any ongoing side effects as a result of the surgery? (e.g. change in appetite, digestive function, pain, etc.)

Do I need to make any changes to my diet or lifestyle?

🔑 For an approachable guide to pathology reports, read Understanding Your GIST Pathology Report: <http://www.gistsupport.org/about-gist/for-new-gist-pages/understanding-your-pathology-report-for-gist/>

☑ It is important that the tumour biopsy is reviewed by a pathologist who is experienced with sarcomas to avoid misdiagnosis and misclassification.

◇ Surgeons attempt to achieve negative surgical margins (i.e. they try to remove the lesions surrounded by a border of normal tissue, ensuring that no tumour tissue is left behind).

◇ Evidence of tumour spread (metastasis) may include gross (visible) tumour outside of the primary (original) site. Microscopic spread may also be suspected if your primary tumor ruptured, was bleeding, or if there was procedure-related contamination. Differentiating between primary and metastatic disease is important for treatment decisions.

🔑 More information on nutrition for GIST: <https://liferaftgroup.org/proper-nutrition-for-gist-cancer/>

Treatment

The treatment for GIST usually includes oral medication (e.g. Gleevec® (imatinib) or Sutent® (sunitinib) or Stivarga® (regorafenib) and/or surgery, depending on the features of your tumour and your health status. Other treatments, such as tumour ablation, may be used in special circumstances. Your healthcare team will assess these factors and recommend treatment options for you.

When reviewing treatment options with your healthcare team, here are some questions to ask:

Questions for Your Oncologist

What are the risks and benefits of medication alone, medication and surgery, or surgery alone?

What treatment do you recommend and why?

What are the latest clinical practice guidelines?

How long will I need to stay on the medication? At what dose?

What changes to my GI tract were made during surgery? Do I need vitamin B-12 injections after gastrectomy?

What are the side effects of the medication? What is the likelihood that I will experience them?

🔗 For a comprehensive review of current treatments for GIST, see Life Raft Group US: Treatments for GIST: <https://liferaftgroup.org/treatments-for-gist/> or GIST Support International: Treatments for GIST: <http://www.gistsupport.org/treatments/>

◇ Clinical practice guidelines are documents that outline the best standard of care based on current evidence and expert consensus. They are written for a clinician audience, so it is best to review these with your physician. See the reference section for links to the latest guidelines.

Questions for Your Surgeon

Do I need additional baseline imaging studies prior to surgery?

What types of surgery are available? What type do you recommend and why?

Should I take Gleevec pre-surgery to reduce scope of resection?

Would you recommend that I participate in any clinical trials?

🔗 Review LRG's Clinical Trial FAQ: <http://liferaftgroup.ca/en/clinical-trial-faq/>

Medication Funding

Medications for GIST can be costly. However, there are both public and private funding sources that you may be able to access to help cover the cost of your medications. Your eligibility for financial assistance varies depending on several factors including your personal circumstances, the medication that you require, and the province that you live in.

Potential sources of medication funding:

Public	Private
<ul style="list-style-type: none"> Provincial and/or federal government funding 	<ul style="list-style-type: none"> Novartis-Alliance Patient Support Program for Gleevec (includes both funding and nursing support team) Private health insurance

The best way to determine your eligibility and apply for funding is to speak with a medication reimbursement specialist/navigator as well as your oncologist. Contact your regional cancer center to find out if there is a medication reimbursement specialist near you. LRG can also help direct you to relevant resources.

For your reference, coverage for imatinib, the first line drug for most types of GIST, is outlined in Table 1. Online links to the funding programs are available on [our website](#) and in the [electronic PDF format of this booklet](#).

Table 1. Imatinib funding coverage by province

Province/ Territory	Coverage
Alberta	Covered under the Alberta Health Services Outpatient Cancer Drug Benefit .
British Columbia	Covered under the British Columbia Cancer Agency Drug Benefit List .
Quebec	Covered under Régie de l'Assurance Maladie du Québec .
Manitoba	Requires approval by Manitoba Pharmacare's Exception Drug Status mechanism.
New Brunswick	Covered under the New Brunswick Drug Plan Formulary .
Newfoundland and Labrador	Requires approval by Special Authorization Drug Products mechanism.
Northwest Territories	Requires approval by the Northwest Territories Extended Health Benefits Exception Drug (Prior Approval) mechanism.
Nova Scotia	Requires approval by the Nova Scotia Pharmacare Exception Drug Status mechanism.
Nunavut	Requires approval by the Extended Health Benefits mechanism.
Ontario	Covered as a General Benefit of the Ontario Drug Benefit / Trillium Drug Program or with approval by the Exceptional Access Program .

Province/ Territory	Coverage
Prince Edward Island	Covered by the Cancer Treatment Centre Formulary and PEI pharmacare , but patients must apply for coverage under the High-Cost Drug Program. A prescription that is written by an oncologist waives the requirement for the Pharmacare Special Authorization form.
Saskatchewan	Covered under the Saskatchewan Cancer Agency Drug Formulary .
Yukon	Covered under Pharmacare PHRM (seniors plan) and the Chronic Disease Program .

Follow-Up and Monitoring

After starting treatment, your oncologist will continue to monitor changes with appointments, imaging, and lab work. Depending on your situation, they may recommend that you discontinue medical treatment, continue treatment for a defined period of time, or continue treatment indefinitely. If your oncologist finds that your treatment is not effective, they may recommend trying another treatment.

During the monitoring period, continue to keep a comprehensive record of all of your imaging and investigations results. The included Personal GIST Record can help with this. Consider asking your physician the following questions:

What investigations (e.g. imaging or lab work) will be monitored? How often?

What symptoms of recurrence or other complications should I look out for?

Common Questions and Concerns

Can I get a second opinion? How do I approach this?

There may be times when you are unsure about care decisions that your physician has made. If this is the case, voice your concern to your physician and ask for further clarification on the matter. If you still feel unsure, reiterate your concerns and ask your physician for a referral. Remember, your physician's goal is to manage your care in a way that best suits your interests. This means that your physician will likely support your request unless he or she believes that doing so may actually harm you.

If you have concerns about your care and are unable to obtain a physician referral, please contact LRGC and we may be able to assist you.

What clinical trials are available? Can I enroll in them?

For more information, read Life Raft Group Canada's Clinical Trial FAQ online: <https://liferaftgroup.ca/en/clinical-trial-faq/>

Additional Reading

Clinical Practice Guidelines

Gastrointestinal stromal tumours: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up.

<http://www.esmo.org/Guidelines/Sarcoma-and-GIST/Gastrointestinal-Stromal-Tumours>

Alberta Health Services GIST Guidelines.

<http://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-guide-sar002-gist.pdf>

NCCN Clinical Practice Guidelines in Oncology: Soft Tissue Sarcoma

<https://www.nccn.org/patients/guidelines/sarcoma/index.html>

Additional Support

Life Raft Group Canada is here to support you. Please contact us if you require any GIST-related support or if you want more information.

Below are select resources that may also be of interest to you.

General Cancer Support

Canadian Cancer Society

Canadian Cancer Society offers support and information for people with cancer and their family, friends and caregivers. Programs offered include the Cancer Information Service, Peer Support Service, and Community Services Locator. <http://www.cancer.ca/>

Wellspring

Wellspring is a network of community-based support centres offering programs and services that meet the emotional, social, practical and restorative needs of people living with cancer and those who care for them. <https://wellspring.ca>

Cancer Chat Canada at De Souza Institute

Cancer Chat Canada provides free and professional-led online support groups for Canadians affected by cancer, including patients, survivors and family members. <https://cancerchat.desouzainstitute.com/>

Please check your provincial cancer agency for additional resources

GIST Support

GIST Support International

GIST Support International (GSI) is an all-volunteer, non-profit organization that reaches out to GIST patients and their families and friends to provide education and support. GSI runs a website that includes a wealth of educational materials about GIST (primarily in the U.S. context), runs an active mailing list, and hosts regular meetings in the U.S. <http://www.gistsupport.org>

The Life Raft Group (U.S.A)

The Life Raft Group is a charitable non-profit organization providing support through information, education, and innovative research to patients with GIST. In addition to educational resources, The Life Raft Group runs events in the U.S.A., a tissue bank for research, a newsletter and webcasts that are accessible from Canada.

<https://liferaftgroup.org>

Contact

Need GIST support? Have a question, comment, or concern? LRG is here to help. Please contact LRG by:

Phone

1-855-LRG-GIST (1-855-574-4478)

Email

info@lifteraftgroup.ca

Mailing Address

GIST Sarcoma Life Raft Group Canada
330 King Street West
Cobourg, Ontario K9A 2N5

Website

<https://lifteraftgroup.ca/>

Contributors

We would like to thank the following individuals for their hard work in the initial creation and on-going content review of this handbook.

Board Members

David Josephy
Jason Larkin
Laetitia Tam
Fred Nagy
Hazel McLeod

Staff

Malcolm Sutherland

Volunteers

Susan Turner

