



GIST Sarcoma Life Raft Group Canada
Ensuring that no one has to face GIST alone

GASTROINTESTINAL STROMAL TUMOUR (GIST) PATIENT HANDBOOK

A GUIDE TO NAVIGATING YOUR CARE



2019 Second Edition
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WHAT IS GASTROINTESTINAL STROMAL TUMOUR?

Gastrointestinal stromal tumour (GIST) is a rare soft-tissue sarcoma, which is a type of cancer that arises out of connective tissue. It can occur anywhere along the GI tract. GISTs are completely different from the more common gastrointestinal tumours (such as stomach cancer and colon cancers) because of the type of tissue in which they start. GISTs can develop at any age but usually occur in people over 50 years of age. GISTs are rare and almost all GISTs occur sporadically without a clear reason why they develop.

A new GIST diagnosis can be challenging and overwhelming. You should not have to go through this journey alone. Successful GIST management is a collaboration between the patient, caregiver and healthcare team.

This handbook is designed to help you:

1. Navigate treatment
2. Acquire important information from your healthcare team
3. Advocate for the best care within the Canadian healthcare system

You should speak openly with your healthcare team. They can provide you with the most appropriate and individualized information pertaining to your diagnosis and treatment. In this handbook, sample questions are provided that you can ask your healthcare providers. Answers to these questions can help you better understand your treatment and important considerations for overall management. Additionally, a set of resources and references are provided to complement information received from your healthcare team.

HOW TO USE THE HANDBOOK

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



important task



additional information



related online reading

A glossary is provided for definition and explanation of some of the terms used throughout the handbook.

A worksheet is included at the end of the handbook to help you compile your own “Personal GIST Record”. Because treatment options and recommendations depend on several factors (type and stage of tumour, possible side effects, patient preferences, and overall health), 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.

Note: This handbook 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.

HOW IS GIST DIAGNOSED?

GISTs could grow without producing any obvious symptoms. Sometimes, symptoms such as abdominal pain, anaemia, fatigue, or nausea do occur. However, these may be similar to the symptoms of other problems, such as chronic anaemia, abdominal pain, or gastrointestinal bleeding. This makes GISTs difficult to diagnose. Sometimes, GIST is discovered by chance (“incidentally”), when a person has imaging done for an unrelated condition.

Once you are diagnosed with GIST, the next steps for care are based on the risks associated with your tumour. A typical pathway to GIST care is shown in Tables 1-5. The care pathway is adapted from the National Comprehensive Cancer Network (NCCN) Soft Tissue Sarcoma Guidelines for Patients. Please note each GIST case is unique. This care pathway does not replace medical advice from a healthcare professional.

To help navigate the care pathway:

- Typical tests used for GIST diagnosis are outlined in Table 1
- Typical treatment strategies for small stomach GISTs (<2 cm) are described in Table 2
- Typical treatment strategies for other GISTs are described in Table 3
- A typical follow-up process after surgery is described in Table 4
- Typical treatment strategies for progressed GISTs are outlined in Table 5

Table 1: Tests used to diagnose (confirm) GIST

| Needed for Most Patients | May be Needed for Some Patients |
|-----------------------------------|---|
| Medical history and physical exam | Imaging of chest |
| Biopsy | Endoscopic Ultrasound-guided Fine-Needle Aspiration (EUS-FNA) |
| CT ± MRI of abdomen and pelvis | Testing for gene mutations |
| | Genotyping for treatment planning |

Table 2: Treatment for small stomach GISTs (<2cm)

| EUS-FNA Test Results (risk features) | Primary Treatment | Tests (following surgery when applicable) |
|--------------------------------------|-------------------|---|
| High-risk features | Surgery | <ul style="list-style-type: none"> • Medical history and physical exam • Consider CT of abdomen and pelvis every 3–6 months for 3–5 years, then repeat every year |
| No high-risk features | Not needed | <ul style="list-style-type: none"> • Consider regular endoscopic or imaging tests |

Table 3: Treatment for other GISTs

| Possible Surgery | Treatment Options | Treatment Results | Next Treatment |
|--------------------------------------|---|--|--|
| Surgery is an option | <ul style="list-style-type: none"> • Surgery • GIST medication, then surgery (if high risk of issues after surgery) | All cancer removed | <ul style="list-style-type: none"> • GIST medication: <ul style="list-style-type: none"> ○ If medium/high risk of recurrence (and had none before) ○ If taken before surgery • Observe if low risk of recurrence • See Table 4 |
| | | Not all cancer removed | <ul style="list-style-type: none"> • GIST medication and consider second surgery • See Table 4 |
| | | Metastasis | <ul style="list-style-type: none"> • GIST medication • See Table |
| Surgery is not the best first option | <ul style="list-style-type: none"> • GIST medication | <p>Response or stable disease</p> <p>Progression</p> | <ul style="list-style-type: none"> • Continue GIST medication and consider surgery • See Table 5 |

Table 4: Follow-up care after surgery

| Surgery Results | Follow-up Care |
|---|---|
| All cancer removed | <ul style="list-style-type: none">• Medical history and physical exam every 3–6 months for 5 years, then repeat every year• Imaging of abdomen and pelvis every 3–6 months for 3–5 years, then repeat every year |
| Not all cancer removed (persistent or metastatic disease) | <ul style="list-style-type: none">• Medical history, physical exam, and imaging of abdomen and pelvis every 3–6 months |

Table 5: Treatment for disease progression

| Cancer Growth | Treatment Options |
|----------------------|---|
| Limited growth | <ul style="list-style-type: none">• Continue GIST medication and consider:<ul style="list-style-type: none">○ Surgery if possible○ Ablation, embolization, or chemoembolization○ Palliative radiation therapy if cancer spread to the bones• Increase dose or change GIST medication and do imaging tests to assess treatment response |
| Widespread growth | <ul style="list-style-type: none">• For certain patients:<ul style="list-style-type: none">○ Increase dose or change medication and do imaging tests to assess treatment response |

For GISTs that continue to progress despite treatment with medication, the following options are available:

1. Switch to the next GIST medication in line.
See your doctor regarding available options
2. Participate in a clinical trial
3. Consider using other cancer medications.
See your doctor regarding different options
4. Best supportive care

YOUR GIST CARE TEAM

As you go through your GIST care journey, it is important to get to know and understand the roles of the different healthcare professionals involved. Below are some of the specialized healthcare professionals who participate from diagnosis to treatment, to providing additional support for your GIST care.

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, and side effects management). They will also be your primary point of contact for any concerns relating to your diagnosis.



If your medical oncologist does not specialize in GIST or sarcomas, ask to be referred to a medical oncologist who does. As GIST is a rare type of cancer, it is important to be under the care of a physician who is familiar with the latest treatment guidelines.

SURGEON/SURGICAL ONCOLOGIST

Surgery may be performed as first treatment to remove a GIST which hasn't grown or spread far. If it is recommended that your tumour be resected (removed), a general surgeon or a surgical oncologist will be responsible for the procedure. They are responsible for obtaining a pathology specimen for biopsies, 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.

PATHOLOGIST

A doctor who analyzes 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).

NURSING TEAM

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

MENTAL HEALTH TEAM

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

DIETITIAN

Both the illness and the treatments may have effects on your digestive system. A dietitian 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.



Multidisciplinary cancer centres that specialize or are experienced in treating GIST can provide care for you. Find out if there is one near 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.

GENERAL QUESTIONS

What is my diagnosis?



The pathologist will make a diagnosis of GIST by looking at the shape and appearance of tumour cells, by performing tests for various markers on the tumour specimen, and by finding the mitotic count (a measure of actively dividing cells). An example of a diagnostic test is “immunohistochemical staining” (IHC) where antibodies are used to test for certain antigens (markers) in a sample of tumour tissue. The antibodies are usually linked to an enzyme or dye so the marker can be seen under a microscope when the antibody binds the antigen. Different types of human cells are distinguished by the specific types of proteins that they produce (“protein expression”). Most GISTs produce large amounts of proteins called “CD117” (also known as “KIT”). The second most common mutation in GISTs is in the platelet-derived growth factor receptor alpha (PDGFRA) gene.

Where is the tumour located? How big is it?

What is the role of genetic testing in GIST? What is the genetic mutation type of my tumour?



Most GIST tumours arise from cells that have undergone a mutation. That is, the DNA sequence of a gene (such as the KIT or PDGFRA genes) has changed. This may have occurred by random chance, sometime during a patient's life. These "somatic" mutations do not affect germ cells (egg or sperm cells), and they cannot be passed on to a patient's children. Using modern molecular technology, these GIST mutations can be identified in a pathology laboratory.

Many different mutations have been found in GISTs, and knowing the exact mutation type may help your doctor match you with appropriate treatment whenever possible. Your doctor may suggest tests for gene mutations.

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)?

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?

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



Surgeons attempt to achieve negative surgical margins (i.e. they try to remove the lesion so it contains a small amount of normal-looking tissue around the edge of the tumour).

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

Was there evidence of metastasis?



Evidence of tumour spread (metastasis) may include gross (visible) tumour outside of the primary (original) site. You may be at high risk if your primary tumour ruptured during removal. Differentiating between primary and metastatic disease is important for treatment decisions. By routinely monitoring following surgery and throughout treatment, your oncologist will advise you about signs of metastatic disease.

Will I experience any side effects as a result of the surgery?

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

TREATMENT

The treatment for GIST usually includes oral medication and/or surgery, depending on the features of your tumour and your health status. Treatments, such as tumour ablation, may be considered in patients with progressive disease showing limited growth and who take GIST medication. 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?



According to NCCN guidelines, GIST treatment is determined by the size and location of the tumour, surgery outcome, and whether or not the disease is localized or metastatic. Tumours that can first be treated with surgery are those that have not grown or spread far. After any type of surgery, you may receive GIST medication. If all the cancer appears to be removed, you could start GIST medication if there's a high or medium risk for the cancer returning. Medication is also given to patients who cannot have their GIST surgically removed, may have serious complications from surgery or have metastatic disease. Surgery may be possible for tumours which have responded to or remained stable after GIST medication. National Comprehensive Cancer Network guidelines state imatinib is often the first-line treatment for large, recurrent or metastatic GIST. When tumours do not respond to imatinib or the side effects are too intense, sunitinib may be given. A third-line treatment option, regorafenib, can be recommended when GIST keeps growing while taking imatinib or sunitinib. Speak to your medical oncologist about the right course of treatment for you.



What are the latest clinical practice guidelines?

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.

How long should I take the medication? At what dose?

Please explain the details of what was done during my surgery?

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

What is needed or recommended to best manage side effects of surgery or medication?

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?

Would you recommend that I participate in any clinical trials?

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, or continue treatment for a defined period of time. If your oncologist finds that your treatment is not effective, they may recommend trying another treatment. Your oncologist will continuously monitor for signs of local recurrence or distant metastasis.



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 they believe that doing so may actually harm you.

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



ADDITIONAL RESOURCES

MEDICATION FUNDING SUPPORT

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

- Provincial and/or federal government funding

Private

- Contact your patient support program for available funding sources
- 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 centre to find out if there is a medication reimbursement specialist near you.

PROVINCIAL FORMULARY RESOURCES ARE OUTLINED BELOW

PROVINCE/TERRITORY FORMULARY/RESOURCE

Alberta

Alberta Health Services Outpatient Cancer Drug Benefit

<https://www.albertahealthservices.ca/services/Page2328.aspx>

British Columbia

British Columbia Cancer Benefit Drug List

<http://www.bccancer.bc.ca/systemic-therapy-site/documents/policy%20and%20forms/benefit%20drug%20list.pdf>

Manitoba

Manitoba Pharmacare

<https://www.gov.mb.ca/health/pharmacare/>

New Brunswick

New Brunswick Drug Plans Formulary

<https://www2.gnb.ca/content/dam/gnb/Departments/h-s/pdf/en/NBDrugPlan/NewBrunswickDrugPlansFormulary.pdf>

Newfoundland and Labrador

Newfoundland and Labrador Prescription Drug Program

http://www.health.gov.nl.ca/health/prescription/special_auth_drug_products.pdf

PROVINCE/TERRITORY FORMULARY/RESOURCE

Northwest Territories

Northwest Territories Extended Health Benefits for Specified Disease Conditions Program

<https://www.hss.gov.nt.ca/en/services/supplementary-health-benefits/extended-health-benefits-specified-disease-conditions>

Nova Scotia

Appendix III – Criteria for Coverage of Exception Status Drugs

<https://novascotia.ca/dhw/pharmacare/documents/Criteria-for-Exception-Status-Coverage.pdf>

Nunavut

Extended Health Benefits (EHB) Eligible Specified Conditions

<https://gov.nu.ca/health/information/specified-disease-conditions>

Ontario

Ontario Drug Benefit Formulary/Comparative Drug Index

<https://www.formulary.health.gov.on.ca/formulary/>

Quebec

Régie de l'Assurance Maladie du Québec*

http://www.ramq.gouv.qc.ca/SiteCollectionDocuments/liste_med/Liste_med_2018_11_15_en.pdf

**Official Mark of the Régie de l'assurance maladie du Québec*

PROVINCE/TERRITORY

FORMULARY/RESOURCE

Prince Edward Island

Health PEI - PEI Pharmacare Formulary

https://www.princeedwardisland.ca/sites/default/files/publications/pei_pharmacare_formulary.pdf

Saskatchewan

Saskatchewan Cancer Agency Drug Formulary

<http://www.saskcancer.ca/Formulary%2015-11-2018>

Yukon

Yukon Drug Formulary

<http://apps.gov.yk.ca/drugs/f?p=161:9000:3578563698801045>





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 selected resources that may also be of interest to you.

GIST SUPPORT



GIST Sarcoma Life Raft Group Canada, <https://liferaftgroup.ca/> is a registered Canadian charity that provides support to GIST patients and their caregivers. Life Raft Group Canada provides a “virtual home” for GIST patients to find emotional support from their peers and to learn more about how to live with GIST. They sponsor the annual GIST Day of Learning conference, host local gatherings of GIST patients, advocate for access to medical treatment for GIST patients, financially support GIST research in Canada, and work to increase awareness of GIST among the general public and healthcare professionals in Canada.

GIST SUPPORT INTERNATIONAL

GIST Support International (GSI), <http://www.gistsupport.org> 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.

American Cancer Society

If You Have a GIST:

<https://www.cancer.org/>

National Comprehensive Cancer Network

Treatment Guide for GIST:

<https://www.nccn.org/>

GENERAL CANCER SUPPORT



Canadian Cancer Society

Canadian Cancer Society, <http://www.cancer.ca> 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.

Wellspring

Wellspring, <https://wellspring.ca> 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.

Cancer Chat Canada at De Souza Institute

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

Please check your provincial cancer agency for additional resources.



GLOSSARY

Biopsy

An examination of removed tissue specimen for the determination of cause or extent of a disease.

Carcinoma

Cancers that start from the linings of organs and often grow on outer surfaces of the body or the outside of internal organs.

Clinical trial

An organized process of testing the safety and therapeutic benefit of a newly developed drug on a large number of human subjects. The success of clinical trials determines whether or not a drug will be launched in market.

Computerized Tomography (CT) scan

A sophisticated computerized analysis technique that combines multiple X-ray images, taken at different angles, to produce a three-dimensional image that allows the doctor to see bones, blood vessels, soft tissues, tumours, etc. in much greater detail than is possible with standard X-rays. Standard X-ray pictures produce a two-dimensional “flat” image, which may be sufficient to indicate, for example, a broken bone.

Gross tumour

The visible portion of the tumour removed by surgery.

Imatinib (brand name Gleevec®)

A drug that helps slow down or stop the growth of cancer cells in your body. It is used in a subtype of GIST where: 1. Tumours cannot be removed by surgery; and/or 2. The cancer has spread to other parts of the body. Imatinib is also used in a subtype of GIST where treatment after surgery is needed (adjuvant treatment) when the risk of tumours coming back is increased.

KIT

A “receptor” tyrosine kinase protein produced by a few specific cell types and “displayed” on their surfaces. Significance of KIT in GIST:

1. Most GISTs have a mutation in the KIT gene which causes the body to make too much of the KIT protein.
2. KIT belongs to a large family of related proteins called “tyrosine kinases”.
3. Mutations in KIT are commonly tested when planning GIST treatment.

Magnetic Resonance Imaging (MRI)

An imaging technology that uses powerful magnetic fields, radio waves, and a computer to show detailed pictures inside the body. These pictures show the difference between normal and diseased tissue. For GIST diagnosis it is used to provide additional information after CT scan.

Metastasis

The spread of a tumour to a different location in the body from where it originally developed (primary tumour).

Primary tumour

The first mass of cancer cells. Once removed, a cancer can grow back in the same location (local recurrence) or spread to another location in the body (metastasis).

Regorafenib (brand name Stivarga®)

A drug used to treat GISTs that have spread to other parts of the body or are not treatable with surgery in patients who have already received imatinib and sunitinib treatment. It works by slowing down the growth and spread of cancer cells and cutting off the blood supply that keeps cancer cells growing.

Sarcoma

Cancer that occurs in tissue that connects, supports or surrounds other structures and organs in the body (e.g. blood vessels, fat cells, or nerves).

Sunitinib (brand name Sutent®)

A drug used for treating GIST. It specifically targets the activity of certain enzymes called tyrosine kinases that play a major role in transmitting the chemical signals required for critical cellular processes. It prevents the growth of blood vessels from surrounding tissue to a solid tumour, and prevents the proliferation of cancer cells.

Surgical margin

A portion of tissue containing healthy cells that is sometimes removed with tumour tissue in surgery. Surgeons usually try to achieve negative surgical margins by removing some of the healthy tissue surrounding the tumour to ensure the entire tumour was removed in the procedure.

Tumour ablation

A procedure in which a body part or tissue or its function is removed or destroyed. This procedure is sometimes considered when GIST has progressed with limited growth.

Ultrasound

Technology based on sound waves used to examine live images inside the body. Used to confirm presence of small GIST tumours found by endoscopy.



CONTACT

Need GIST support? Have a question, comment, or concern?
Life Raft Group Canada (LRGC) is here to help. Please contact LRGc by:

Phone

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

Email

info@liferaftgroup.ca

Mailing Address

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Cobourg, Ontario K9A 4K2

Website

<https://liferaftgroup.ca>

PERSONAL GIST RECORD

Use this form to maintain a record of your GIST care. Remember to attach copies of all diagnostic, pathology, imaging, and surgical reports.

| General information | |
|---|-----------------|
| Patient name: | Date of birth: |
| Phone: | Email: |
| Health care providers (names, institution, phone) | |
| Family physician: | |
| Surgeon: | |
| Medical oncologist: | |
| Other providers: | |
| Diagnosis | |
| Cancer type: | Diagnosis date: |
| Location: | Risk category: |
| Tumor size: | |
| Metastasis: | Mitotic rate: |
| Mutation testing results: | |

Treatment history

Surgery:
 Yes No

Date/procedure/location/findings:

Other procedures:
 Yes No

Date/procedure/location/findings:

Systemic therapy (medications, chemotherapy, hormonal therapy, other): Yes No

Agent name

Start and end date

Treatment side effects: Yes No (description/treatments/results)



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