National Comprehensive Cancer Network®

2026

NCCN Guidelines for Patients®

Cancer care recommendations from leading experts at the National Comprehensive Cancer Network® (NCCN®)

Gastrointestinal Stromal Tumors



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NCCN Guidelines for Patients®

The essential guide for people facing cancer.

Based on care recommendations from leading cancer experts.

Explains high-quality cancer care provided at state-of-the-art cancer centers.

Reviewed and revised every year.

Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network® (NCCN®).

Because cancer care is always evolving, NCCN develops and frequently updates evidence-based cancer care recommendations used by health care providers worldwide. These recommendations are known as the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®).

The NCCN Guidelines for Patients plainly explain these expert recommendations, so you can talk with your care team about the best care for you.

These NCCN Guidelines for Patients are based on the NCCN Guidelines® for Gastrointestinal Stromal Tumors, Version 1.2026 — January 13, 2026.

View the NCCN Guidelines for Patients free online: NCCN.org/patientguidelines

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The way forward starts here.

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NCCN Foundation seeks to support the millions of patients and their families affected by a cancer diagnosis by funding and distributing NCCN Guidelines for Patients. NCCN Foundation is also committed to advancing cancer treatment by funding the nation's promising doctors at the center of innovation in cancer research. For more details and the full library of patient and caregiver resources, visit NCCN.org/patients.

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1
About GISTs

5 What are GISTs?

6 How are GISTs treated?

6 How can I get the best care?

Gastrointestinal stromal tumors (GISTs) are a type of soft tissue sarcoma. GISTs usually appear in the wall of the stomach or small intestine. Together, you and your cancer care team will decide on a treatment plan.

What are GISTs?

A gastrointestinal stromal tumor (GIST) is a type of soft tissue sarcoma. GISTs are commonly found in the wall of the stomach or small intestine.

While all GISTs are cancer, their behavior can vary widely from case to case.

Some GISTs are small, slow-growing, and unlikely to spread. Others may be large and grow quickly, regrow after treatment, and spread to the liver or within the abdominal cavity.

Where do GISTs form?

GISTs can form anywhere within the walls of the gastrointestinal (GI) tract. But they are usually found in the stomach, followed by the small intestine.

Less commonly, GISTs form in the rectum, colon, or esophagus. GISTs that form outside the stomach tend to be more aggressive, but those within the stomach can also grow quickly.

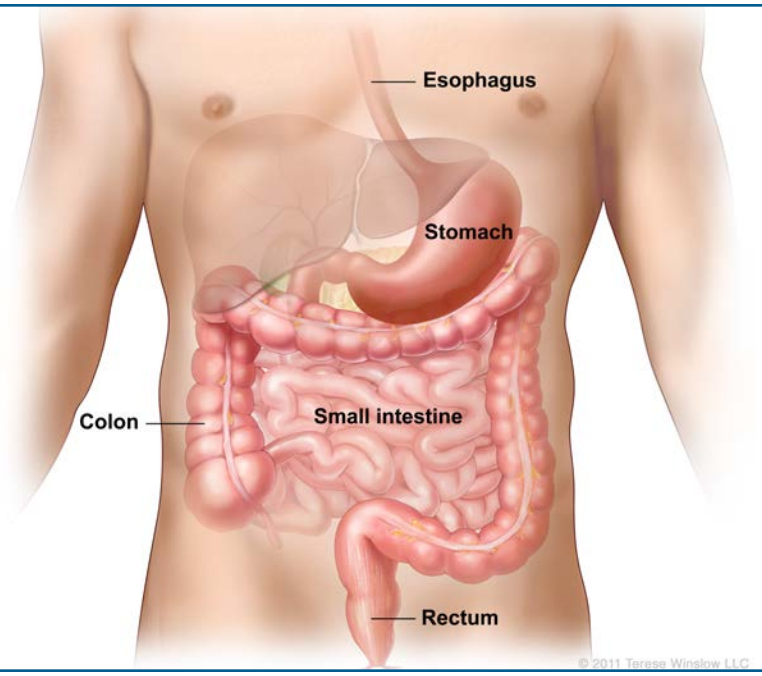
Symptoms

A GIST may cause health changes you can feel or notice. Symptoms include:

- Feeling full quickly when eating
- Abdominal pain, swelling, or bloating
- Feeling sick to your stomach
- Blood in stool and/or vomit
- Fatigue

Where GISTs form

GISTs are usually found in the stomach or small intestine but can occur anywhere in the GI tract.



How are GISTs treated?

When possible, surgery is the recommended treatment for GISTs. If there is a high risk of complications from surgery or the need to remove multiple organs, drug therapy may be given first.

Some very small stomach GISTs do not need treatment.

How can I get the best care?

Advocate for yourself. You have an important role to play in your care. Many people feel more satisfied when they actively take part in planning their cancer care.

The *NCCN Guidelines for Patients* will help you play a larger role in your care. Discuss the recommendations in this guide with your care team. Ask questions about your options and share your goals and concerns.

Don't know what to ask? You're not alone. That's why we include suggested questions to ask at the end of chapters.

Keep reading to find the best care for you.

How this guide can help you

Making decisions about cancer care is stressful. There's a lot to learn, and you don't know what the future holds.

Use this guide to get the information and support you need.

Patients, doctors, and other health care professionals trust the *NCCN Guidelines for Patients.* This guide uses clear, everyday language to explain current cancer care recommendations made by respected experts in the field. Their recommendations are based on the latest research and practices at leading cancer centers.

Your health is unique to you, so your cancer care should be, too. As you read this guide, you'll learn which treatments are likely to provide the best results for you. And you'll be better prepared to talk with your care team.

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Testing for GISTs

8 Imaging tests

10 Biopsy

10 Biomarker testing

12 Key points

12 Questions to ask

Imaging and a biopsy are needed to diagnose gastrointestinal stromal tumor (GISTs). Your test results and treatment options should be reviewed by a team of experts with experience in treating this rare type of cancer.

If a gastrointestinal stromal tumor (GIST) is suspected, imaging of the belly (abdomen) and hips (pelvis) is needed.

Imaging tests

Imaging tests take pictures of the inside of your body. After you have imaging, a radiologist, an expert in interpreting imaging tests, will write a report and send it to your health care provider.

The report may be sent to you through your patient portal or access system.

You should discuss these results with your care team.

Contrast material

Contrast material is used to improve imaging pictures. Contrast materials are not dyes. They're substances that help enhance and improve the images of organs and structures in the body.

The contrast isn't permanent and will leave the body in your pee within 24 hours after the test. The types of contrast vary and are different for CT and MRI.

Contrast might not be used if you have a serious allergy or if your kidneys aren't working well. Tell your care team if you've had allergic reactions to contrast in the past. You might be given medicine to decrease the likelihood of an allergic reaction.

CT scan

A CT scan is a more detailed type of x-ray. It's painless and noninvasive. CT makes many images from different angles. A computer combines the images to make 3D pictures.



CT scan

A CT scan uses x-rays and computer technology to take pictures of the inside of the body. It takes many x-rays of the same body part from different angles. All the images are combined to make a series of detailed cross-sectional images of the body.

Some people refer to this test as a CAT scan. Either name is correct.

MRI scan

An MRI scan uses radio waves and powerful magnets to take pictures of the inside of the body. It doesn't use x-rays or radiation.

Because the MRI machine uses very strong magnets, tell the technologist if you have any metal in your body. You'll probably need to undress completely and wear a robe in the scanning room.

During the test, you'll likely be asked to hold your breath for 10 to 20 seconds as the technician collects the images. Contrast is often used. A scan taken with and without contrast is called a dynamic MRI.

The most common type of MRI machine, a closed MRI, has a capsule-like design where the magnet surrounds you. There are open MRIs, which have a magnetic top and bottom and an opening on each end.

Closed MRIs are more common than open MRIs, so if you're afraid of enclosed or tight spaces (claustrophobia), be sure to talk to your care team about it. A mild relaxant/sedative can be given to some patients with claustrophobia to help them tolerate the MRI scan.

MRIs are also loud. Ask the scanning team for earplugs or headphones to help with the noise. Sometimes they might play music inside the machine. You can ask for a blanket or cushions to make yourself more comfortable during the scan.

The MRI technicians can talk to you through an intercom inside the machine. You'll also be able to signal to the scanning team with a button if you need help.

PET scan

A PET scan uses a harmless radioactive substance called a tracer. The tracer is injected into a vein to show where cancer spots might be in the body. It harmlessly comes out of the body in your pee within 24 hours.

The tracer can cause bright spots on PET scans. Not all tumors appear on a PET scan, and not all bright spots are cancer. It's typical for the brain, heart, kidneys, and bladder to be bright on a PET scan.

Inflammation or infection can also show up as a bright spot.

When a PET scan is combined with CT, it's called a PET/CT scan.

Biopsy

Your doctor may want to remove a small sample of the tumor for testing (a biopsy). If needed, an endoscopic ultrasound (EUS)-guided biopsy is recommended.

A thin tube (endoscope) is inserted through the mouth. It's guided down the esophagus into the stomach.

The endoscope has an ultrasound probe and a needle for removing a sample of the GIST. The ultrasound probe sends images to a monitor. This allows your doctor to see where to position the biopsy needle.

If a thin, hollow needle is used, it's called an EUS fine-needle aspiration biopsy (EUS-FNAB). This type of biopsy removes a small amount of fluid and tumor tissue.

Use of a slightly larger needle to remove a circular-shaped piece of tissue is called an EUS core needle biopsy (EUS-CNB). A pathologist examines the removed tissue under a microscope to determine whether the tumor is a GIST.

Biomarker testing

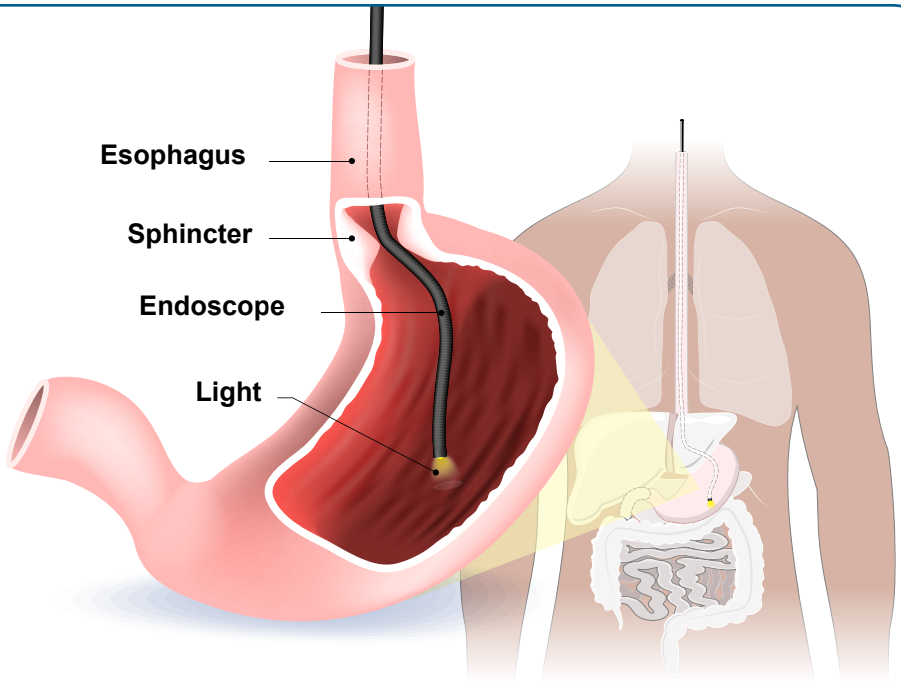
Knowing whether the tumor has certain features, called biomarkers, can help guide your treatment. Biomarkers are often genetic changes (mutations).

The presence (or lack) of specific mutations or other biomarkers can affect how the GIST responds to certain targeted therapies.

If treatment with drug therapy is planned, the biopsy sample will be used for biomarker testing.

Upper endoscopy

Upper endoscopy allows your doctor to see the inner wall of your stomach and esophagus. If ultrasound is used, your doctor will be able to see the deeper wall layers and nearby organs.



Testing for many genetic biomarkers at one time is called multi-gene sequencing. This test can find gene mutations for which targeted treatments may be available. The results help your treatment team choose the best drug therapy for your GIST.

Other names for biomarker testing include molecular testing, tumor profiling, genomic testing, tumor gene testing, somatic genomic testing, and mutation testing.

KIT and *PDGFRA* gene mutations

Mutations in the *KIT* gene are the most common genetic changes found in GISTs.

The next most common mutations are those in the *PDGFRA* gene. *PDGFRA* mutations often occur in GISTs of the lower half of the stomach. A sample of the tumor is needed for testing since these mutations aren't found in every cell.

SDH deficiency

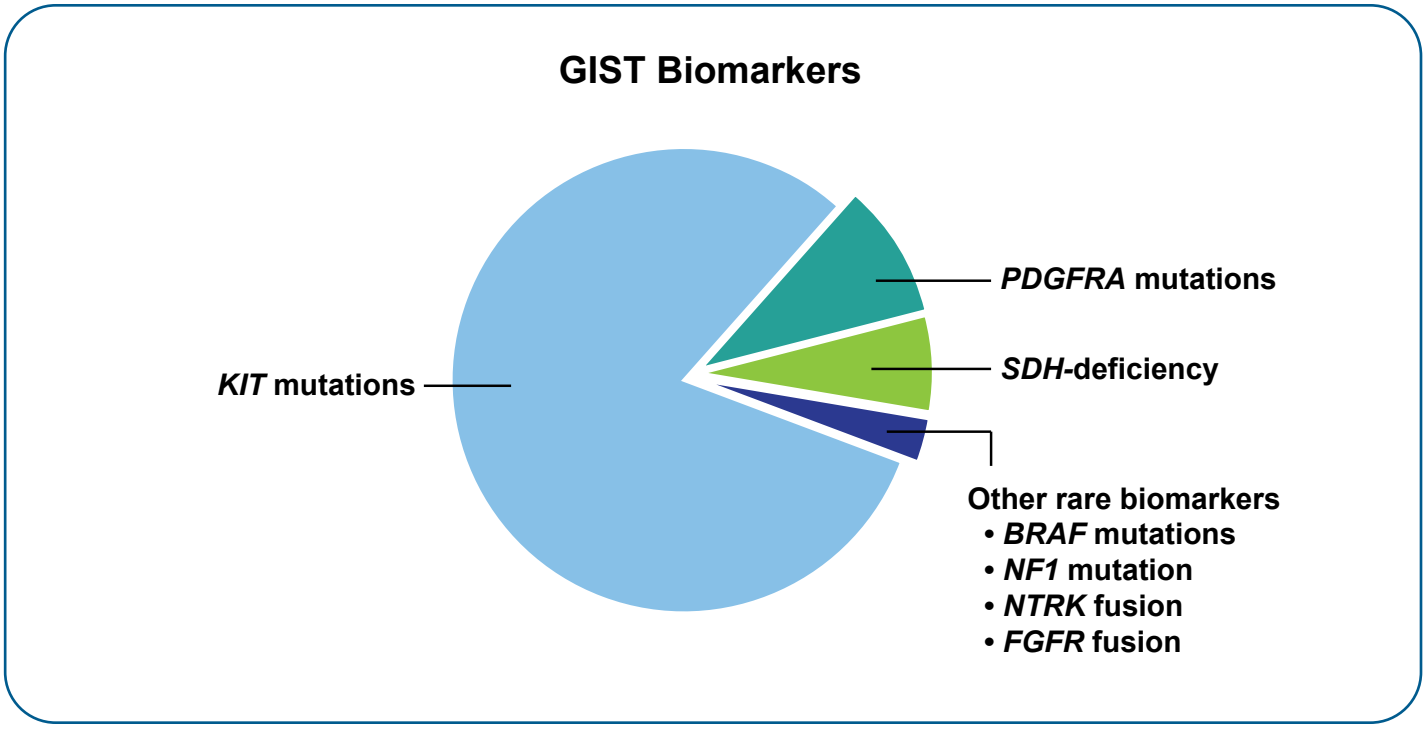
For GISTs without a *KIT* or *PDGFRA* mutation, testing to look for an *SDH* mutation is recommended. Many GISTs without a *KIT* or *PDGFRA* mutation have *SDH* deficiency. This means that a part of the *SDH* gene is inactive.

SDH-deficient GISTs typically form in the stomach in younger people but can also be seen later in life. Most grow slowly, but some can be more aggressive. These are likely to spread in the body through lymph nodes or blood, or within the abdominal cavity.

Referral to a genetic counselor for inherited (germline) testing is recommended for everyone with *SDH*-deficient GISTs.

Other biomarkers

In addition to *SDH* deficiency, GISTs without a *KIT* or *PDGFRA* mutation should be tested for other biomarkers. These include *BRAF*



mutations, *NF1* mutation, *NTRK* fusions, and *FGFR* fusions. Referral to a genetic counselor for inherited (germline) testing is recommended for people with GISTs that have an *NF1* mutation.

Key points

- Imaging of the abdomen and pelvis is needed for a suspected gastrointestinal stromal tumor (GIST). Expect to have a CT, an MRI, or both. Contrast should be used.
- For a GIST that is 2 centimeters or larger, a chest x-ray or chest CT may be recommended to look for cancer spread.
- If needed, the type of biopsy generally recommended for GISTs is an endoscopic ultrasound (EUS)-guided needle biopsy.
- Biomarkers are often genetic changes (mutations) in the tumor.
- The most common biomarkers in GISTs are *KIT* gene mutations, followed by *PDGFRA* gene mutations.
- For a GIST without a *KIT* or *PDGFRA* mutation, testing to look for *SDH* deficiency and other rare biomarkers is recommended.

Questions to ask

- What tests will I have?
- Do the tests have any risks?
- Will my insurance pay for all the tests you're recommending?
- Do I need to do anything to prepare for testing?
- Should I bring someone with me to the appointments?

What's next?

After testing confirms what type of GIST you have and if there's any other cancer in your body, treatment begins. Read on to learn more.

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Types of treatment

14 What is the recommended treatment for GISTs?

18 Surveillance after surgery

18 Progression

20 Destroying tumor cells directly

21 Clinical trials

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23 Key points

23 Questions to ask

Your test results and treatment options should be reviewed by a team of experts from different fields of surgery and medicine who have experience in treating gastrointestinal stromal tumors (GISTs). This is called multidisciplinary cancer care.

What is the recommended treatment for GISTs?

When possible, surgery is the recommended treatment for most gastrointestinal stromal tumors (GISTs). If there is a high risk of complications from surgery, drug therapy may be given first. Some very small stomach GISTs do not need treatment.

When preparing for surgery, seek the opinion of an experienced surgeon. Hospitals that perform many surgeries often have better long-term results. You can ask for a referral to a hospital or cancer center that has experience in treating GISTs.

Surgery, or tumor resection, is based on the safest and best way to remove the cancer. Cancer removal through surgery can be done in different ways, depending on the specific circumstances. Tumors in hard-to-reach locations, particularly large tumors, or those that have spread (metastasized) to other organs might not be removable by surgery.

You might have more than one surgery. You might also have a temporary wound drain to prevent fluid from collecting in the body after surgery.

Goal of surgery

The goal of surgery is to remove all the visible cancer. To do so, the tumor is removed along with a rim of normal-looking tissue around its edge, called the surgical margin.

The surgical margin may look normal during surgery, but cancer cells may be found when viewed under a microscope by a pathologist after testing. In both cases, it's called a positive margin. You may need another surgery to try to remove the remaining tumor cells.

A clear, or negative, margin is when no cancer cells are visible in the tissue around the edge of the tumor, and no cancer cells are found after testing.

Very small stomach GISTs

Very small stomach GISTs (smaller than 2 centimeters, or roughly the width of an adult's finger) are unlikely to spread.

Using biopsy results (if available) and imaging scans, your doctor will look for features that suggest the tumor will grow quickly, called high-risk features. If high-risk features are found, an operation to remove the GIST is recommended. See "Treatment after surgery" on page 17 for next steps.

For very small stomach GISTs without high-risk features, no treatment is needed. Instead, the tumor may be monitored with a non-invasive imaging test or endoscopy. This option has risks. Talk with your doctor about whether this is the best option for you.

All other GISTs

Surgery to remove the GIST may be your first treatment. It will only be done if your care team determines it's safe for you. Surgery to remove a GIST requires a great deal of skill.

Depending on the size and location of the tumor, surgery can be difficult. GISTs are fragile and easily rupture. In addition, nearby organs and tissues may be affected. Blood vessels might have to be removed, or pieces of them cut out and sewn back together. Parts of your stomach or other organs might have to be removed and reattached.

The best possible surgical outcome is called negative margins without the tumor breaking apart or rupturing. A negative margin means that no tumor cells remain in the spot from which the tumor was removed. All the tumors must be removed to have a negative margin.

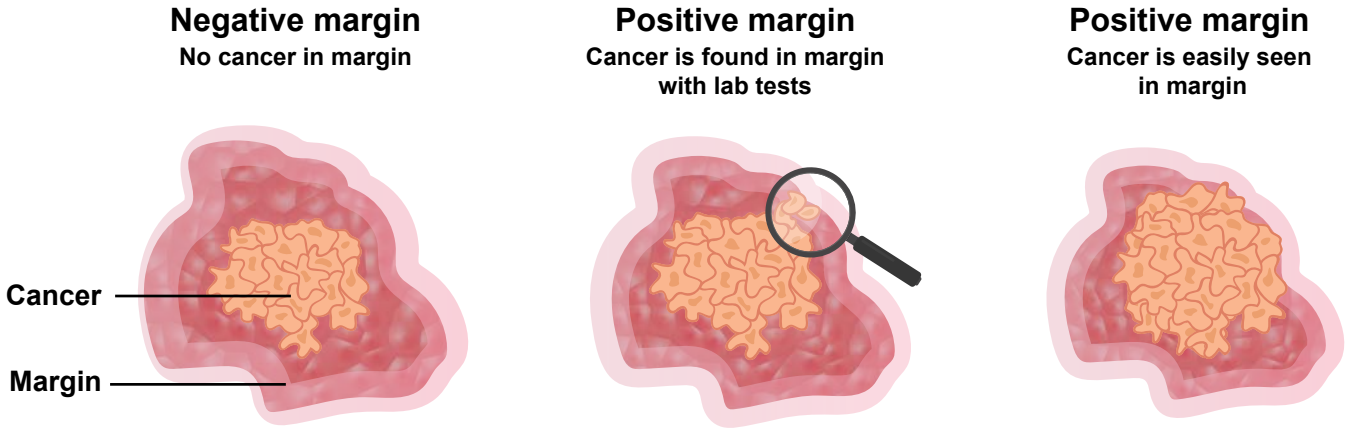
If there is a high risk of serious problems from surgery, you may have drug therapy first. It can shrink the tumor and make surgery less risky or less extensive.

If drug therapy is planned, the tumor will be biopsied. This serves two main purposes. The biopsy sample is tested to confirm that the tumor is a GIST. The sample is also used for biomarker testing.

Biomarker testing is needed because some drug therapies work best in cancers with certain gene mutations or other biomarkers.

Surgical margin

The tumor will be removed, along with some normal-looking tissue around its rim. The normal-looking tissue is called the surgical margin. The surgical margin will be tested for cancer. Postoperative therapy will be based on if there is cancer in the margins.



For recommended drug therapy according to biomarker, see **Guide 1**. If the GIST does not have any of the biomarkers listed in **Guide 1**, drug therapy before surgery is not recommended.

It's important to take your drug therapy, known as a tyrosine kinase inhibitor (TKI), as directed. GISTs may worsen if you stop taking your medicine or if you miss doses.

Before starting drug therapy, you will have a CT and/or MRI scan of your abdomen and pelvis. Your doctor might also order a PET/CT. During drug therapy, imaging will be used to check how treatment is working.

Either a CT or MRI is recommended every 2 to 3 months. The results of these scans will be compared to your original (baseline) scans.

If the tumor has **shrunk** or stopped growing, drug therapy will be continued until your doctor feels it has provided all the benefit it can. This may take 6 to 9 months, or more. At that time, your doctor and surgeon will decide if and when surgery is appropriate.

After surgery, more treatment may be needed.

If the GIST has **grown** during drug therapy and surgery does not become possible, see "Progression" starting on page 18.

Guide 1
Drug therapy before surgery for high-risk candidates

Biomarker	Recommended drug therapy
KIT or *PDGFRA* mutations	Imatinib (Gleevec)
PDGFRA mutations that don't respond to imatinib, including D842V	Avapritinib (Ayvakit)
SDH deficiency	Clinical trial, Regorafenib (Stivarga), Sunitinib (Sutent)
NTRK fusions	Entrectinib (Rozlytrek), Larotrectinib (Vitrakvi), Repotrectinib (Augtyro)
BRAF V600E mutation	Dabrafenib (Tafinlar) + Trametinib (Mekinist)

Treatment after surgery

If the results of surgery are very good, it's called complete resection. In this case, you might start (or continue) taking imatinib. This depends on:

- The risk of recurrence based on features of the tumor, and
- Whether you had drug therapy before surgery (and if so, the type)

If you were **not** on any type of drug therapy before surgery and the risk of recurrence is **low**, observation is recommended. Observation is also recommended for GISTs with mutations that don't respond to imatinib.

If you were **not** on any type of drug therapy before surgery and the risk of recurrence is **high**, starting imatinib is recommended for GISTs with mutations that respond to it.

If you were taking imatinib before surgery and the risk of recurrence is **high**, continuing imatinib is recommended.

If you were taking any of the drug therapies listed below before surgery for a single tumor, no further treatment is needed.

- Avapritinib
- Sunitinib
- Dabrafenib plus trametinib
- Entrectinib
- Larotrectinib
- Repotrectinib

If you start (or continue) imatinib after surgery, talk to your doctor about how long you can expect to take it. There isn't a one-size-fits-all recommendation. The optimal length of drug therapy after surgery is unknown. For high-risk disease, it may be given for at least 3 years after surgery.

"I take each day at a time. Sometimes the fatigue is greater than other days. You must persevere."

Surveillance after surgery

Testing is used to find signs of cancer returning as early as possible. This is called surveillance. Surveillance after **complete removal** of a GIST includes physical exams and imaging scans of your stomach and hip area.

These are recommended every 3 to 6 months for 5 years after surgery. For those at high risk of recurrence, testing every 3 months is recommended. After 5 years, most people have imaging and a physical exam once per year.

Some people may need less frequent surveillance. Those with low-risk or very small tumors may have imaging less often than described above. And those with high-risk tumors who stop TKI therapy may have imaging more often. Talk to your doctor about how often is right for you.

Recurrence or spread

Recurrent describes cancer that returns after treatment. Metastatic describes cancer that has spread to areas of the body far from where it started.

Recurrent or metastatic GISTs are treated with drug therapy. It's usually needed lifelong.

Imatinib is the preferred first-line therapy for GISTs with mutations that respond to it, including most *PDGFRA* exon 18 mutations. Avapritinib is preferred for GISTs with *PDGFRA* exon 18 mutations, including D842V, that do not respond to imatinib.

If you're not a candidate for imatinib or avapritinib, you may have other options. This depends on the mutations found during biomarker testing. Options for less common biomarkers are:

- ***NRTK* gene fusion-positive GISTs:** Larotrectinib or entrectinib
- ***SDH*-deficient GISTs:** Sunitinib, regorafenib, or a clinical trial
- ***BRAF* V600E-mutated GISTs:** Dabrafenib plus trametinib

Progression

The tumor may grow or spread during treatment with imatinib or avapritinib. If the new growth is limited, it may be possible to remove or control the cancer using local treatments. These include:

- Resection (surgery)
- Ablation, embolization, or chemoembolization (see the next page for more information)
- Palliative radiation therapy to relieve symptoms

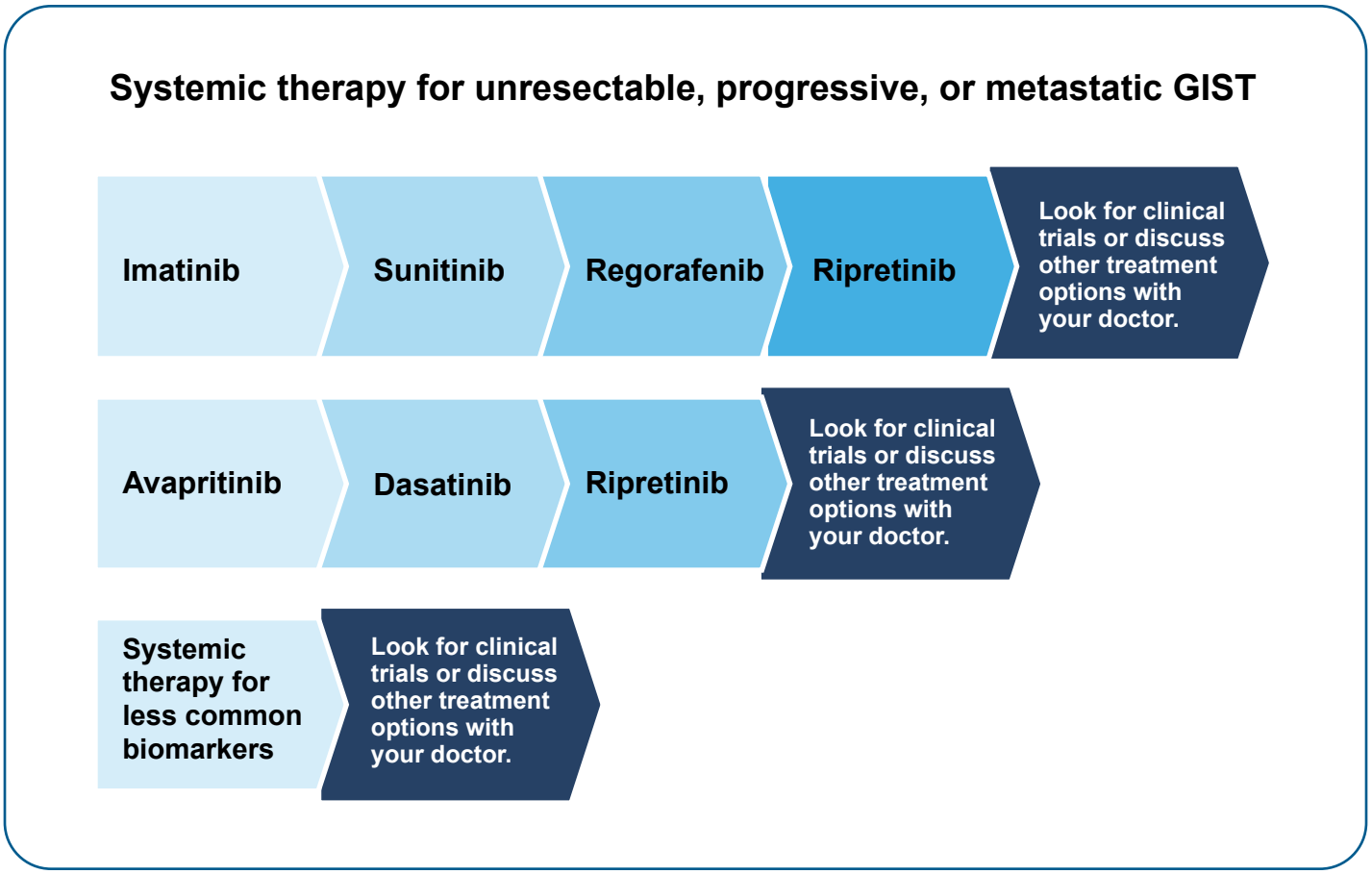
Another recommended option for progression is to switch to a different drug. See the illustration on the next page for the medicines typically given after imatinib or avapritinib, and beyond. An alternative recommended option may be increasing your imatinib dose if you're taking standard-dose imatinib. This may work best in people with *KIT* exon 9 mutations.

If the new growth is widespread, switching medicines or increasing the dose of imatinib is typically only considered for people who

are otherwise fairly healthy. Doctors call this performance status. It's a rating of your ability to do daily tasks independently.

If a GIST spreads or continues to grow despite treatment with the TKIs shown in the illustration, there are others that may be given. Your doctor may suggest another biopsy. The goal is to look for uncommon mutations that may have a corresponding targeted therapy. Consider enrolling in a clinical trial for treatment. Your care team can help you find open trials for which you may be eligible. See the page 21 for more information.

Best supportive care is always an option for progressive GISTs. It can be used alone or with other treatments to improve quality of life. This care might include reintroducing TKI therapy to help manage symptoms.



Destroying tumor cells directly

Ablation

Ablation (uh·BLAY·shun) is a type of treatment that uses extreme heat or extreme cold to destroy cancer cells.

You may already have had a mole or wart frozen off by your dermatologist or at home with an over-the-counter freezing solution. The principle is the same.

Ablation can destroy small tumors (3 centimeters or smaller, the size of a grape) with little harm to nearby tissue. Tumors must be in an area that can be reached by ablation and not near other major organs, blood vessels, or bile ducts.

Types of ablation include:

- **Thermal** – Uses heat generated by radio waves or microwaves to kill cancer cells. This type of ablation may not be appropriate for some tumors.
- **Cryoablation** – Freezes cancer cells with a very cold substance.

Ablation can be done through the skin, through small cuts (laparoscopic), or through a large incision like in surgery (open approach).

All types of ablation use a special needle, called a probe, which is inserted into the tumor. The probe is guided into place with a CT scan, ultrasound, or other type of imaging. It's removed after the procedure.

Direct therapy

Direct therapy (also called arterially directed therapy) treats tumors by injecting particles, chemotherapy, or radioactive beads directly into the blood vessels that supply the tumor(s).

A small catheter is inserted into an artery and is guided to the tumor. Once in place, the particles, chemotherapy, or beads are injected. These treatments take a few days but act directly on the tumor's blood supply and can be effective in reducing the size of the tumor.

Common types of arterially directed therapy include:

- **Blocking blood flow** (transarterial embolization) involves injecting tiny particles into the blood vessels feeding the tumor(s). Stopping the blood flow cuts off the oxygen supply to the tumor and causes cancer cells to die.
- **Chemotherapy and blocking blood flow** (transarterial chemoembolization) involve injecting a chemotherapy mixture into the tumor to block the blood vessels connected to the tumor(s).
- **Chemotherapy beads** (drug-eluting bead transarterial chemoembolization) are tiny particles loaded with chemotherapy injected into the blood vessels feeding the tumor(s). The particles give off small amounts of chemotherapy to the tumor over several days.
- **Radioactive beads** (radioembolization) are tiny beads made of glass or resin filled with a radioactive substance and injected directly into the tumor(s). This procedure is often referred to as Y-90.

The type of direct therapy recommended depends on the size, number, and location of tumors, as well as your previous medical history and the expertise of your treating physicians.

Clinical trials

A clinical trial is a type of medical research study. After being developed and tested in a lab, potential new ways of fighting cancer need to be studied in people.

If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. FDA.

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment and are done in phases.

- **Phase 1 trials** study the safety and side effects of an investigational drug or treatment approach.
- **Phase 2 trials** study how well the drug or approach works against a specific type of cancer.
- **Phase 3 trials** test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase 4 trials** study the safety and benefit of an FDA-approved treatment.

Who can enroll?

It depends on the clinical trial's rules, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or general health. They ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.



Finding a clinical trial

In the United States

NCCN Cancer Centers
NCCN.org/cancercenters

The National Cancer Institute (NCI)
cancer.gov/about-cancer/treatment/clinical-trials/search

Worldwide

The U.S. National Library of Medicine (NLM)
clinicaltrials.gov

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)
1.800.4.CANCER (1.800.422.6237)
cancer.gov/contact

Informed consent

Clinical trials are managed by a research team. This group of experts will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss it with people you trust. Keep in mind

that you can leave and seek treatment outside of the clinical trial at any time.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. But you may need to pay for other services, like transportation or childcare, due to extra appointments. During the trial, you will continue to receive standard cancer care. This care is often covered by insurance.

Supportive care

Supportive care is an important part of cancer care. The goal is to improve your quality of life during and after cancer treatment. Supportive care is for everyone with cancer and their families, not just for those at the end of life. It's also known as palliative care.

Supportive care includes a wide range of services. Supportive care prevents or manages the symptoms of cancer and the side effects of cancer treatment, like pain and cancer-related fatigue. It also addresses the mental, social, emotional, and spiritual concerns faced by people with cancer.

Supportive care provides help with additional needs, such as:

- Making treatment decisions
- Coordinating your care
- Paying for care
- Planning for advance care and end of life

Read more about the types of support you may receive in *NCCN Guidelines for Patients: Palliative Care,* available at NCCN.org/patientguidelines and on the NCCN Patient Guides for Cancer app.



Key points

- No treatment is needed for very small, low-risk gastrointestinal stromal tumors (GISTs). You may have testing to monitor the size of the tumor. But surveillance instead of surgery has risks. Talk with your doctor about whether it's the best option for you.
- When possible, surgery is recommended for all other GISTs. If surgery is too risky, you may have drug therapy first to shrink the tumor.
- If drug therapy is planned before surgery, a biopsy is needed to confirm that the tumor is a GIST.
- After complete resection, a physical exam and CT scan are recommended every 3 to 6 months for 5 years after surgery.
- If needed, the best drug treatment for you depends on the mutations and other features found during biomarker testing.
- Most GISTs have either *KIT* or *PDGFRA* mutations. Imatinib is often the best choice for these tumors.
- Avapritinib is recommended for GISTs with certain *PDGFRA* mutations, like D842V, that don't respond to imatinib.
- For GISTs that progress through all recommended drug therapies, enrolling in a clinical trial for treatment should be considered.

Questions to ask

- What if I am pregnant, or planning to become pregnant?
- Does any option offer a cure or long-term cancer control?
- What are the side effects of the treatments?
- How do I get a second opinion?
- How long do I have to decide about treatment, and is there someone who can help me decide?

4
Other resources

25 What else to know

25 What else to do

25 Where to get help

25 Questions to ask

Want to learn more? Here's how you can get additional help.

What else to know

This guide helps you know your options so you can make informed decisions and improve your cancer care. But it's not the only resource that you have.

Ask for as much information and help as you need. Many people are interested in learning more about:

- The details of their treatment and its side effects
- Being a part of a care team
- Getting financial help
- Finding a cancer care professional who's an expert in their field
- Coping with other health problems

What else to do

Your health care center can help you with next steps. It often has on-site resources to help meet your needs and find answers to your questions. Health care centers can also inform you of resources in your community.

In addition to help from your providers, the resources listed in the next section provide support for many people like yourself.

Where to get help

Look through the list below and visit the provided websites to learn more about these organizations.

Cancer*Care*
Cancercare.org

GI Cancers Alliance
gicancersalliance.org

GIST Support International
gistsupport.org

Imerman Angels
Imermanangels.org

Patient Advocate Foundation
patientadvocate.org

Sarcoma Foundation of America
curesarcoma.org

TargetCancer Foundation
Targetcancer.org

The Life Raft Group
liferaftgroup.org

Triage Cancer
Triagecancer.org

Questions to ask

- Should I consider a clinical trial?
- How do I get a second opinion?
- Does the cancer itself cause any side effects?



Words to know

biomarker
A feature of a tumor or cancer used to guide treatment, often with drug therapy. Tumor gene mutations often serve as biomarkers. Proteins made in response to the cancer can also be biomarkers.

***BRAF* V600E mutations**
A rare gene mutation found in GISTs; serves as a biomarker used to guide treatment with drug therapy.

chemoembolization
Treatment with chemotherapy-coated beads that block blood supply to tumors.

cryoablation
Use of a special probe that destroys tumors by freezing them. Also called cryotherapy.

direct therapy
Treatment that destroys very small tumors with heat, cold, lasers, or chemicals. Also called ablation.

embolization
Treatment that cuts off blood supply to tumors with beads inserted into an artery.

endoscopic ultrasound-guided fine-needle aspiration biopsy (EUS-FNAB)
A procedure that removes fluid with a needle on an imaging device guided through a natural opening.

***KIT* mutation**
The most common gene mutation found in GISTs; serves as a biomarker used to guide treatment with drug therapy.

multigene sequencing
Biomarker testing that looks for a large group (panel) of mutations and other biomarkers at one time.

***NTRK* fusion**
A rare biomarker found in GISTs.

***PDGFRA* mutation**
The second most common gene mutation found in GISTs; serves as a biomarker used to guide treatment with drug therapy.

radiofrequency ablation
Treatment that destroys cancer cells by heating them with high-energy radio waves.

sarcoma
Cancer of bone or soft tissue cells.

***SDH* deficiency**
A gene mutation often found in children and young adults with GISTs; serves as a biomarker used to guide treatment with drug therapy.

tyrosine kinase inhibitor (TKI)
The type of drug most commonly used to treat GISTs.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Gastrointestinal Stromal Tumors, Version 1.2026. It was adapted, reviewed, and published with help from the following people:

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Duke Cancer Institute
Durham, North Carolina

Fox Chase Cancer Center
Philadelphia, Pennsylvania

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska

Fred Hutchinson Cancer Center
Seattle, Washington

Huntsman Cancer Institute at the University of Utah
Salt Lake City, Utah

Indiana University Melvin and Bren Simon
Comprehensive Cancer Center
Indianapolis, Indiana

Johns Hopkins Kimmel Cancer Center
Baltimore, Maryland

Mass General Brigham Cancer Institute
Boston, Massachusetts

Mayo Clinic Comprehensive Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota

Memorial Sloan Kettering Cancer Center
New York, New York

Moffitt Cancer Center
Tampa, Florida

O'Neal Comprehensive Cancer Center at UAB
Birmingham, Alabama

Robert H. Lurie Comprehensive Cancer Center
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Chicago, Illinois

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St. Jude Children's Research Hospital/
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Stanford Cancer Institute
Stanford, California

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The UChicago Medicine Comprehensive Cancer Center
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The University of Texas MD Anderson Cancer Center
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UC Davis Comprehensive Cancer Center
Sacramento, California

UC San Diego Moores Cancer Center
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UCLA Jonsson Comprehensive Cancer Center
Los Angeles, California

UCSF Helen Diller Family Comprehensive Cancer Center
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University of Colorado Cancer Center
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University of Michigan Rogel Cancer Center
Ann Arbor, Michigan

University of Wisconsin Carbone Cancer Center
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UT Southwestern Simmons
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Vanderbilt-Ingram Cancer Center
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Yale Cancer Center/Smilow Cancer Hospital
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Notes



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