



Navigating your GIST journey

A discussion guide for appointments

Understanding and managing **gastrointestinal stromal tumours** (GISTs) can be challenging, but being informed will help you navigate living with GIST.

The best way to keep informed is to talk to your healthcare team.

This guide includes some suggested questions you can ask during appointments to help you understand your GIST and treatment.



The information provided in this guide is intended solely for disease awareness and educational purposes. This guide is meant to support, not replace, discussions with your healthcare professional.

The images in this material are purely illustrative and do not refer to real patients. Any reference to people is to be considered random.

GIST overview

A GIST is a rare type of cancer that occurs in the digestive tract.

GISTs affect each person differently and may change over time. Because of this, treatment plans differ between people or as time goes on. This is why it is important to understand your own GIST and your treatment options.



Glossary

When talking to your doctor, you may hear words and phrases that might be new to you.

Gene mutation: a change in the DNA sequence that can cause a cancer to develop or grow.

Genetic testing: helps your doctors understand what type of mutations your GIST has, which then helps them decide which treatment to use.

Tyrosine kinase inhibitors (TKIs): medicines that are used to treat GIST. TKIs work by blocking certain proteins that help cancer cells to multiply and the tumor to grow.

Don't be afraid to ask your healthcare team if there are other words you don't understand.



Understanding disease progression

GISTs can progress. This means that the cancer cells may multiply or spread, even with treatment.

You might hear the phrase '**advanced GIST**'. This is used to describe a GIST that cannot be treated with surgery alone, or has come back, or has spread to another part of the body.

Progression to advanced GIST can be due to an additional **gene mutation** that stops a treatment from working. This is called '**treatment resistance**'.

If your GIST progresses, your doctor may adapt or change your treatment. You can ask them questions to understand what this might mean for you.



Questions you might want to ask your healthcare team

- What is the difference between GIST and advanced GIST?
- If my GIST progresses, how will my treatment goals change?
- How do gene mutations impact my treatment?
- Why might my treatment stop working?
- How will I know if my treatment is no longer working or if my GIST is progressing?



Understanding treatment options

GISTs can be treated with supportive care, surgery and/or medicines called tyrosine kinase inhibitors (TKIs).

The type of treatment depends on the type and severity of your GIST. In some cases, taking part in a clinical trial may be an option.

Your doctor will discuss your treatment options with you. Aim to understand all the options and what they might mean for you and your GIST.

Questions you might want to ask your healthcare team

- What are the available treatment options for me?
- Are there any treatment options available if my GIST progresses?
- How do you decide which treatment plan may be right for me?
- How can I maximise how well my medicine works?
- Are there any clinical trials that I might be eligible for?



Managing symptoms and side effects

When taking medicines, you might experience side effects. The side effects vary depending on the treatment you receive and may differ from person to person, even among those taking the same medication.

It is important to communicate with your doctor about any side effects you might experience.



Questions you might want to ask your healthcare team

- How can I tell the difference between a symptom of GIST and a side effect of my medication?
- What are the common side effects of my treatment? How severe are they, and how frequently do they occur?
- What should I do if I experience a side effect?
- Is there anything I can do to help reduce or manage side effects?



Preparing for your appointments

Bring this guide: refer to the 'Questions to ask your healthcare team' sections to help guide your conversation.

Take notes: write down any questions you may have.

Using a notes app or notebook can be a useful way to keep all your notes in one place, in case you need to look back at them later.

Bring someone for support: you might receive a lot of information during an appointment. Having someone with you to take notes or just be there to support can help.

Remember that your healthcare team is there for you.

Questions you might want to ask your healthcare team

- Who can I contact if I need help outside of my scheduled appointments?
- In case I would like to get some psychological support, how would I get this?
- Are there any patient advocacy or support groups available to me?

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Notes

Use this page to note down anything you want to remember.

Help yourself by being informed

Dealing with a serious condition like GIST can be overwhelming.

Remember: you are not alone. Your healthcare team is here to support you every step of the way.

Don't hesitate to ask questions or ask for an explanation if any medical terms are confusing. Similarly, if you are unsure about a symptom, a side effect or your treatment, ask your healthcare team.

If you are proactive and informed about your GIST and treatment plan, you can better navigate your GIST journey.



Discover more here:
www.livingwithgist.eu



Abbreviations: DNA=deoxyribonucleic acid; **GIST**=gastrointestinal stromal tumour; **TKI**=tyrosine kinase inhibitor.

References: **1.** The Life Raft Group. Understanding GIST. Available at <https://liferaftgroup.org/understanding-gist/> [accessed June 2025]. **2.** GIST Cancer UK. GIST for beginners. Available at <https://www.gistcancer.org.uk/wp-content/uploads/publication-gist-for-beginners-2024.pdf> [accessed June 2025]. **3.** American Cancer Society. If you have a gastrointestinal stromal tumor (GIST). Available at <https://www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/if-you-have-gastrointestinal-stromal-tumor-gist.html> [accessed June 2025]. **4.** American Cancer Society. Treating gastrointestinal stromal tumors. Available at <https://www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating.html> [accessed June 2025]. **5.** American Cancer Society. What causes gastrointestinal stromal tumors? Available at <https://www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/causes-risks-prevention/what-causes.html> [accessed June 2025]. **6.** The Life Raft Group. Mutational testing and genetics. Available at <https://liferaftgroup.org/2018/08/mutational-testing-and-genetics/> [accessed June 2025]. **7.** American Cancer Society. Targeted drug therapy for gastrointestinal stromal tumors. Available at <https://www.cancer.org/cancer/types/gastrointestinal-stromal-tumor/treating/targeted-therapy.html> [accessed June 2025]. **8.** National Cancer Institute. Gastrointestinal stromal tumors treatment (adult) (PDQ®)—patient version. Available at <https://www.cancer.gov/types/soft-tissue-sarcoma/patient/gist-treatment-pdq> [accessed June 2025]. **9.** The Life Raft Group. Resistant GIST. Available at <https://liferaftgroup.org/resistant-gist/> [accessed June 2025]. **10.** Ford SA and Gronchi A. Eur J Cancer 2016;63:154–167. **11.** American Cancer Society. Targeted therapy side effects. Available at <https://www.cancer.org/cancer/managing-cancer/treatment-types/targeted-therapy/side-effects.html> [accessed June 2025].

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