

Questions to Ask Your Doctor About Systemic Mastocytosis (SM) ^[1]

Systemic mastocytosis (SM) can be a mysterious disease. Since doctors don't see the disease very often, it can take 2 to 10 years to receive a proper diagnosis after onset of symptoms¹. Pursuing a diagnosis, or understanding what it means and how SM can impact your life, can be confusing and stressful. It is important to have an informed conversation with your doctor so you can better understand what your diagnosis means, what you can expect, and the best choices for you in managing your treatment.

These conversations are easier to have when you are prepared. Here are some questions that can help start a conversation with your doctor about SM diagnosis, treatment, and ongoing support. Not all of these questions will apply to you, and you might have others you can write in using the additional space at the bottom of the document.

Print this sheet out, and bring it with you to your appointment. Also, consider bringing a notebook or a voice recorder so you can easily review the answers your doctor provided once you are home. As it can sometimes be overwhelming to have these discussions with your doctor, it might help to ask a caregiver or loved one to accompany you to assist in capturing the information.

[Download the questions to ask \(PDF 0.6 MB\)](#) ^[2]

Seeking Diagnosis:

- Can you tell me more about SM? Do you think this could be what is causing my symptoms? What leads you to believe this is my diagnosis?
- Are there other specific tests I should have to confirm my diagnosis?
- What type of SM do I have? Can you explain my test results to me?
- What does this diagnosis mean? What is my prognosis?
- How much experience do you have in treating SM?
- Can you discuss the ways to manage each of my symptoms of the disease?
- Will I need other tests before we can decide on a treatment?
- Will I be able to continue to work to support myself and my family?
- Are there any lifestyle changes I will have to make now that I have this disease?

My Treatment and Ongoing Support:

- What are my treatment options, and what treatment plan do you recommend? Why?
- What can I expect once I start treatment?

- What are the possible side effects of the treatment, and are they manageable?
- What do you think are important things for my family to know about my treatment options and/or treatment plan?
- What type of follow-up will I need after treatment?
- Do you have any materials about the disease that you can provide me?
- Is there a specific person I should contact if I have questions or issues?

Support and Maintaining My Mental Health:

- Are there any local support groups that you can recommend?
- Can you recommend any online patient resources?

For more information and resources, visit *No Disease Too **Small*** (www.nodiseasetoosmall.com ^[3]).

The Mastocytosis Society* may be another source of information for you: www.tmsforacure.org ^[4]

Footnotes:

*The Mastocytosis Society is a not-for-profit group, independent from Novartis. Novartis has no financial interest in this organization, but may provide occasional funding support. Novartis is not responsible for the organization's information content or actions.

1. Sev'er A, et al. *Women's Health & Urban Life*. 2009; 8(2):84-112.

Source URL: <https://www.novartis.com/our-focus/cancer/supporting-people-affected-systemic-mastocytosis/questions-ask-your-doctor-about-systemic-mastocytosis>

Links

[1] <https://www.novartis.com/our-focus/cancer/supporting-people-affected-systemic-mastocytosis/questions-ask-your-doctor-about-systemic-mastocytosis>

[2] <https://www.novartis.com/sites/www.novartis.com/files/no-disease-too-small-questions-to-ask-to-your-doctor.pdf>

[3] <http://www.nodiseasetoosmall.com>

[4] <https://www.tmsforacure.org/>