

How to Talk to Your Oncologist About Multiple Myeloma

Written by Clinical Care Options and Smart Patients

Doctors and researchers are constantly discovering new information about multiple myeloma, which leads to an increasing number of treatment options. Having more choices is beneficial because it helps people with multiple myeloma live longer. However, the growing number of treatment options also makes decisions about treating multiple myeloma more complicated. Both patients and doctors face the challenge of keeping up with the influx of new information.

Consultation Checklist

To help you with this, we have developed a **PDF** to print and fill out. The first part of the form is for you to answer. The second part will be done with your hematologist/oncologist to gather the medical information you need for multiple myeloma treatment decisions.



The consultation form will help you and your doctor apply reliable, up-to-date information to your treatment. The form also helps you consider and share your concerns with your treatment team. All of this helps you be a partner in developing your treatment plan instead of a bystander while others make plans for you.

Seek Accurate Information and Evaluate Information Sources

Most patients are deeply curious about their diagnosis and treatment—and what it all means for themselves, their lives, and their loved ones. You should have as much information as possible when you go to appointments with your multiple myeloma specialist.

It's important that what you learn is accurate and reliable. Make sure you aren't being misled in your search for information.

- Pay close attention to the source of any information you find, particularly on the Internet.
- Look for the patient version of reliable academic or scientific sources.
- Seek out well-trained experts or very knowledgeable patients and caregivers connected with reputable organizations.

Spot Misleading Claims

Think about the qualifications and motivation of the person or company providing information to you. Be cautious of people trying to sell you something or who steer you away from professional cancer care. Look for credible scientific or academic sources. Check anything you find using reliable reference sources. In general, the more evidence you find from credible scientific or academic sources, the more reliable the finding. If something seems too good to be true, it almost certainly is.

Build a Good Relationship With Your Healthcare Team

How can you build a good relationship with your hematologist/oncologist and healthcare team? There is so much ground to cover, and your specialist usually doesn't know your level of knowledge and interest. You can help your doctors by actively engaging in the conversation and letting them know what is essential to you.

By taking a collaborative approach, you and your healthcare team work together as partners to make important decisions about your treatment. Instead of simply being told what to do, you are actively involved in the decision-making process, ensuring that your preferences, values, and goals are considered.

Your healthcare professional will provide all the necessary information about your diagnosis, treatment options, and potential risks and benefits. They'll discuss these options in a way you can easily understand, using clear language and visual aids if needed. Your doctor also will discuss potential outcomes and any uncertainties associated with each option.

Communicating Your Goals and Concerns

As a patient, it's important for you to have an active role in these discussions. You should feel empowered to ask questions, express your concerns, and share your preferences and priorities. Most doctors are receptive to patients who are eager to learn and understand. Even a single comment or response from you can elevate the discussion to a deeper level.

- Ask to understand the numbers on your reports. Which ones are most important for you to follow? Why?
- Ask about treatment options you're interested in. Give background information on what causes you to ask. Share what you have learned and the reliable source where you learned it.
- Be open to hearing why your specialist thinks something might or might not be right for you. Look at what new possibilities this might create.
- Between appointments, make notes for questions you want answered. Carry the list to your appointments. (If your specialist has online access, such as a patient portal, you can send the list before your appointment. Be sure to carry a copy with you to the appointment anyway.)
- Take notes on what you and your doctor discuss. You can ask if the specialist will allow you to record the appointment. Most smartphones can do an excellent job with this.
- Bring a loved one or informed friend with you to your appointments to help you take notes and remember what was said. A second pair of eyes and ears can help, and your companion might think of questions that escape you.
- Share your goals, fears, and concerns with your hematologist/oncologist. Don't be afraid to talk about what you want out of your treatment or to ask for any information about your care.
- If you don't understand something, ask the doctor to pause to explain it and spell it so you can find more information later. Don't be shy!

This sort of active interest on your part usually reveals a hematologist/oncologist who will be happy to build a decision-making partnership with you.

Remember, as a patient, you have every right to seek a different specialist if the communication and relationship with your current doctor do not meet your needs or expectations. Only you know the balance of factors acceptable to you.

List of Reliable Sources of Information in the US Related to Multiple Myeloma

International Myeloma Foundation: **myeloma.org**

Multiple Myeloma Research Foundation: **themmrf.org**

Leukemia and Lymphoma Society: **lls.org**

HealthTree Foundation—Home of The Myeloma Crowd: **healthtree.org**

The National Cancer Institute at NIH: **cancer.gov/types/myeloma**

National Comprehensive Cancer Network's Patient Guidelines for Multiple Myeloma: **nccn.org/patients/guidelines/content/PDF/myeloma-patient.pdf**

American Cancer Society: **cancer.org/cancer/types/multiple-myeloma.html**

Patient arm of the American Society of Clinical Oncologists: **cancer.net**

Clinical trials: **clinicaltrials.gov**

SparkCures (lots of help and info on multiple myeloma clinical trials): **sparkcures.com**

Smart Patients community: **smartpatients.com/communities/multiple-myeloma**