



# Talking With Your Doctor About Multiple Myeloma: A guide to making the most of your healthcare visits

There's a lot to think about and many important decisions to make when you or someone you care for has multiple myeloma. It's important to have an ongoing conversation with your healthcare team throughout your care that is based on openness, honesty, and trust.

We've created this guide to help you prepare for visits with your healthcare team. The guide includes a list of questions you may want to ask at different points along your treatment journey, plus tips to help prepare you for your doctor's visits. Feel free to print out this guide and bring it with you to each visit.

## QUESTIONS FOR YOUR DOCTOR

### UNDERSTANDING TESTING

There are several tests used to diagnose and monitor multiple myeloma and its treatment. Here are some questions you may want to ask about testing:

- What types of tests will I undergo, and how often?
- What will I need to do to prepare for these tests?
- Where will I go for these tests?
- What should I expect when I go for testing?
- Do any of the tests have possible side effects?
- When and how will I get the results of my tests?
- Can you explain what the different laboratory values used for diagnosing and monitoring multiple myeloma mean?
- Will I have the opportunity to discuss the results with you after each test?
- How can I get copies of my results and imaging records?

### UNDERSTANDING YOUR DIAGNOSIS

Like any serious medical diagnosis, it's important to understand as much as you can about multiple myeloma and about how the disease is affecting you. Here are some questions you may want to ask about your condition:

- What is multiple myeloma?
- How is multiple myeloma different from other cancers, like breast or lung cancer?
- How would you describe my risk level?
- What is my prognosis (outlook)?
- What doctors and other healthcare professionals will be involved in my care?
- Will there be one healthcare professional coordinating my care?
- Are there any local support groups you can recommend?
- Are there any websites you can recommend for more information about multiple myeloma?



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## TREATING AND MONITORING MULTIPLE MYELOMA

The treatment decisions you and your doctor make are very important. Here are some questions you may want to start with:

### UNDERSTANDING YOUR TREATMENT OPTIONS

- What types of treatments are available for multiple myeloma?
- What are the benefits and risks of each treatment?
- What treatment do you recommend, and why?
- What other options do I have?
- Will I be able to continue my normal work schedule with this treatment?
- Do I need chemotherapy as part of my multiple myeloma treatment?
- Could a stem cell transplant be an option for me?
- Could a clinical trial be an option for me?
- What are your thoughts on getting a second opinion?

### PAYING FOR TREATMENT

- Can I get help paying for treatment and related expenses?
- Is this treatment covered by my insurance?
- Are there patient assistance programs?
- Is there a financial counselor or someone in the office I can speak with about affording treatment?

### UNDERSTANDING YOUR TREATMENT

- What are the goals of this treatment?
- What percentage of people respond to this treatment?
- What are the side effects I may experience on this treatment?
- Will you be prescribing any other medications with this treatment, and if so, what are the side effects associated with these medications?
- Are there ways to help manage these side effects?
- What are the signs of a possibly serious side effect, and what should I do if I experience these signs?
- Could this treatment interact with any other medications I am taking?
- How will I take this treatment (by mouth or injection; at home or at a treatment center)?
- How often will I take this treatment?
- How long will I need to stay on treatment?
- How should I expect to feel while taking this treatment?
- Will I need to restrict my work or activities while undergoing treatment?
- Are there other complementary therapies (such as acupuncture or massage) that you recommend to help me feel better or manage stress?
- What else do you recommend I do?



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## MONITORING TREATMENT RESULTS

- How will I know if the treatment is working?
- How often will you monitor my treatment results?
- What does it mean if my multiple myeloma is in remission?
- What do the different response levels to treatment mean (like partial response, complete response, and overall response)?
- What symptoms or test results would indicate that my multiple myeloma is getting better or worse?
- What are the signs I should be looking for that may indicate I have a problem, like anemia or an infection?
- If the first treatment we try does not work, what are my options?

## MANAGING RELAPSED MULTIPLE MYELOMA

If your multiple myeloma gets worse after you've been on one kind of treatment, you will need to talk with your doctor about what to do next. Here are some questions you may want to start with:

- What are my treatment options now?
- How do these drugs work differently than my last treatment?
- How long will I be on this treatment?
- What are the benefits and risks of each treatment option?
- Could a clinical trial be an option for me now?

## QUESTIONS FOR CAREGIVERS

Being diagnosed with multiple myeloma can be overwhelming, for both the person living with the disease and the people who care for and about them. And if you are taking on the role of caregiver, you may be looking for guidance on how you can best help support the person with multiple myeloma. Here are some questions you can ask the healthcare team to help get the support you need:

- What type of care will the person with multiple myeloma need?
- What can I do to help support the person with multiple myeloma?
- What are common symptoms and side effects associated with multiple myeloma and its treatment?
- Is there someone on your team who can help me with financial issues related to the treatment of multiple myeloma?
- Is there someone on your team who can help me find out more about accessing and paying for additional supportive care?
- What can I do to take care of myself, to make sure I can continue to be the best caregiver possible?
- Can you recommend organizations or resources for more support?





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## TIPS FOR PREPARING FOR YOUR DOCTOR'S VISIT

These tips may help you prepare ahead of time, so you can make the most of each visit with your healthcare team:

- **Print out this list of questions, circle your top 5 questions, and use the “Notes & Questions” space to list any additional questions you may have.** Time can be limited in doctor's appointments, so it's important to make sure your biggest concerns are addressed at each visit.
- **Bring a notepad and pen, or a tape recorder or smartphone with recording capabilities.** It can be hard to remember all of the information your doctor gives you during an appointment. By recording the conversation, you can listen again later to anything you may have missed. Just be sure to first ask your doctor if he or she is comfortable with being recorded.
- **Consider bringing a friend or family member for support.** It can be helpful to have someone you trust at the visit who can also listen, ask questions, and go over the information with you again afterwards.
- **Bring a list of important information your doctor needs to know to inform your treatment.** This includes your other medical conditions, any new symptoms you may be experiencing, and any medications you are taking (including prescription and over-the-counter medications, plus vitamins, supplements, and herbal remedies).
- **Think about some of the questions your doctor may ask you during the visit, so you are prepared to answer.** This can include questions about how well you're staying on track with taking your treatment, any symptoms you may be experiencing, and questions about changes in your appetite and bodily functions.

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