



Importance Of Shared Decision Making

Shared decision making is a process in which the patient and healthcare team work together to make decisions about the patient's care. This resource can help you understand more about how shared decision making works and why it is an important part of your care.

KEY POINTS

1. Shared decision making means that you and your healthcare team work together to make decisions about your care
2. Shared decision making is important because it helps you understand all of your options and choose the care approach that's right for you
3. You can decide how much you want to share in decisions with your healthcare team

WHAT IS SHARED DECISION MAKING?

Shared decision making is a process of making decisions about a patient's medical care. It means that you and your healthcare team will **share** the responsibility for making decisions about your care plan.

You may remember a time when doctors made all the decisions. This practice has changed as more and more care options have become available, and as healthcare providers have realized how important patients' preferences and values are in choosing the right approach to managing multiple myeloma. Today, you have the power to be an equal partner in your care.

There are 4 key parts to shared decision making. These require that both you and your healthcare provider:

- Participate in discussions about your treatment decisions
- Share information with each other
- Take steps to build agreement around a preferred approach to care
- Agree on an approach

WHY IS SHARED DECISION MAKING IMPORTANT IN MULTIPLE MYELOMA?

Shared decision making can help you and your healthcare team decide—together—which options are the right ones for you at different points throughout your care. When you have multiple myeloma, shared decision making is important for several reasons:

Multiple myeloma is a long-lasting and progressive (worsening over time) disease. When you are living with multiple myeloma, you will likely have many ups and downs. Each time the disease relapses (comes back), you and your loved ones will face new challenges. Understanding and being involved in your care plan can help you to prepare for these challenges.

There are more options to choose from than ever before. Care for multiple myeloma has changed a lot over the past 20 years. Many options are available today, including those available through clinical trials. There are also new tests to monitor the condition, as well as supportive care for people living with multiple myeloma. Working closely with your healthcare team lets you explore all your options to find what works best for you.

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Each option comes with benefits and risks. Thanks to all of these advances in care, people are living longer with multiple myeloma than ever before. With all of the available options, it's important that you understand both the benefits and the risks of each. You can learn more about risks and benefits by reading materials provided to you by your healthcare team, or by researching from other trusted information sources.

As part of shared decision making, you and your healthcare provider will also talk about the benefits and risks of each option, including:

- How well each option has been shown to work
- The likelihood of any possible side effects and how they may impact you
- The time commitment involved in each option or clinical trial
- The cost of different options

Both you and your healthcare provider are experts. Your healthcare provider is the expert on the medical data and the choices for care available. And **you** are the expert on you, your values, and your preferences.

By taking an active part in decision making, you can make sure that the care approaches that you and your healthcare provider choose take into account:

- Your goals for your care
- How much time and effort you are willing and able to put into your medical care
- Your family situation, and how much support you have at home
- Your culture and faith
- Any related issues you may be experiencing, such as anxiety, pain, or insomnia

Being part of decision making can help you feel better about your care—and may even influence the outcome. Research shows that when decisions are made together after thoughtful discussion, patients may feel:

- More confident in their decisions
- More satisfied with their care
- Greater trust in their healthcare team
- Less stressed, anxious, or regretful about their decisions

In addition, research shows that patients who share in decisions about their care may be more likely to:

- Stick to their care plan
- Have better health outcomes



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HOW DOES SHARED DECISION MAKING WORK?

If your healthcare provider is following shared decision making, these are the steps you may experience:

1. **Invitation:** Your provider tells you about all available options for your care—including clinical trials—and invites you to discuss these options. If your healthcare provider does not invite you to discuss your options, you should feel free to start the conversation yourself.
2. **Options:** Your provider gives you information about each of the available options. You may also want to gather information from other sources, such as other healthcare providers, patient organizations, trusted websites, support groups, or family and friends.
3. **Benefits and risks:** You and your provider talk about the pros and cons of each option. Your provider shares the medical data on how well each option has been shown to work, as well as the likelihood of side effects.
4. **Goals and concerns:** Your provider asks you about your goals for your care and about what values are most important to you. You and your provider also discuss your personal preferences, issues, and concerns about each option.
5. **Time to consider:** You are given time to think about your choices and to ask more questions if needed.
6. **Action:** You and your provider decide on an approach to your care and work through any challenges to starting on your care plan.

Keep in mind that these steps will not occur all in one visit. It may take 2, 3, or more visits for you and your healthcare provider to come to a decision about your care plan. If you do require care right away, you and your healthcare provider may need to make some decisions more quickly. Remember, you should always feel free to start the conversation about your care with your healthcare provider.

WHAT IS MY NURSE'S ROLE IN SHARED DECISION MAKING?

There are many professionals on your healthcare team who can work with you to understand and make decisions about your treatment, including your oncology nurse. Your nurse can:

- Gather information for you and go through it with you step by step
- Help you learn more about your options for care
- Put you in touch with the right professionals to answer your questions
- Connect you with resources such as support groups
- Help your loved ones understand how to help care for you



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WHAT ARE THE CHALLENGES OF SHARED DECISION MAKING?

Making decisions together is important, but the process is not without its challenges. For example, you and your healthcare provider, or your loved ones, may not agree on the goals of care.

Shared decision making takes more effort from you and from everyone on your healthcare team. After all, it takes work to explain information, listen to others, and come to an agreement.

It also takes time—which is often limited during doctor visits. You can help with this part by using our doctor discussion guide to help prepare for your visits. Download *Talking With Your Doctor About Multiple Myeloma: A Guide to Making the Most of Your Healthcare Visits*.

WHAT IF I'M NOT SURE HOW MUCH I WANT TO BE INVOLVED IN DECISIONS ABOUT MY CARE?

Every patient feels differently about how much input they want to have in their care plan. Some people want to listen to their healthcare provider's opinion, but have the final say in which options they choose. Others want to come to an agreement with their healthcare provider. And some want their healthcare providers to make the decisions they think are best.

Talk with your healthcare team about how you see your role in making decisions about your care.

FOR MORE INFORMATION ON SHARED DECISION MAKING, VISIT:

Informed Medical Decisions Foundation at www.informedmedicaldecisions.org

Talking With Your Doctor: A Guide for Older People, a guide from the National Institute on Aging

Information about these independent organizations is provided as an additional resource for obtaining information related to multiple myeloma. It does not indicate endorsement by Celgene Corporation of an organization or its communications.

Your healthcare team is your best source of information.

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