

Making Informed and Shared Decisions: Tips for Productive Conversations

When patients and caregivers participate in making healthcare decisions, they are more likely to report better overall quality of life, satisfaction with treatment, and fewer regrets about treatment choice. Here are some tips on how to have productive conversations – and what to do if you run into obstacles.

What's happening?

What might you say or do?

Your healthcare provider makes a recommendation without engaging in shared decision-making.

Acknowledge the provider's expertise while asserting your need for more information.

For example, "I appreciate your opinion. It would help me feel better about our next steps if I had a better understanding of all of the options first before moving forward."

You're not sure whether you want to say, "yes" or "no," and you feel pressured to decide.

Give yourself the space and time to consider your options. Even if the situation is urgent, you can ask questions or request a break to talk to someone you trust. This will give you more time to formulate your response.

For example, you might say, "Could you help me understand the thinking behind your recommendation?"

Or "I'd like to take some time to think about it (or talk with my spouse, child, or other key person)?" Keep in mind that you have the right to say "no" and to request additional information to help you make the best decision possible.

You are hesitant to proceed and are afraid of making a wrong decision.

As rare disease patients and caregivers, we often must make really tough decisions with little scientific evidence to guide us.

Take your time to think through the range of possible outcomes of a given decision, how likely each outcome is to occur, and how you would feel if each of these outcomes came to be.

Once you've reached a decision, give yourself grace. You may regret decisions down the road, but try to remember that hindsight is always clearer, and you can only make the best decision you can with the information you have at the time.

You consistently find communicating with your healthcare provider challenging.

Unfortunately, this is not uncommon. Many rare disease patients and caregivers will encounter at least one provider who is a poor communicator in their journey.

Be polite but persistent in the pursuit of the information you need to make the decisions that are right for you or your family member. However, if the communication is chronically poor, you may need to consider finding a new provider.