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Risky Business: Understanding and Attenuating Risk Associated with Disease-Modifying Therapy in Relapsing-Remitting Multiple Sclerosis

POTENTIAL BARRIERS AND SOLUTIONS TO THE USE OF SHARE DECISION MAKING IN MS

Potential barrier: I just found out that I have MS and now I'm expected to make these difficult decisions. I feel like I was hit by a ton of bricks. I'm pretty angry right now.

Potential solution: First know that your response and your feelings are perfectly normal. Most people who receive a life-changing diagnosis respond the same way. You may feel stressed, angry, sad, or afraid. Talk with your MS team. Let your doctor know that you are too overwhelmed right now to make a decision. Perhaps a social worker or someone else on the team can help you process your emotions, allowing you to reach a point that you can work with your doctor and all the members of the care team to come up with a treatment plan that works for you.

Potential barrier: I can barely get out of bed, let alone deal with all of these decisions. My mind is spinning, my hands are shaking, I don't feel as if I can catch my breath, and my heart feels as if it is pounding out of my chest.

Potential Solution: Many people with MS have depression and anxiety. Again, rest assured that these emotions are pretty common. If you are depressed or anxious, you may find making decisions to be too much for you to handle. This can interfere with your ability to fully participate in your care, whether in making treatment decisions or in following through with the treatments. Talk with your doctor to refer you to a member of your care team who has the expertise help you or with whom you feel the most comfortable. Simply talking with someone—whether a professional, a friend, a family member, or people who take part in face-to-face or online support groups—and knowing that you are not alone, can help to relieve some of your depression and anxiety. Tell your doctor if your depression, anxiety, or other emotions do not resolve. It is important to discuss strategies for addressing your symptoms to allow you have the quality of life you want. Know that treatments are available.

Potential barrier: I don't understand complicated information that my doctor has told me about MS or my treatment.

Potential Solution: Don't feel bad; MS is a very complicated topic with many treatment choices. Ask questions, and more questions, until you truly understand what your doctor is telling you. Take the time to tell the doctor what you thought you heard. Don't be surprised if you misunderstood something—this is very common. You may want to keep a notebook of questions to discuss with your care team or bring a family member to take notes. If you need extra help when you are making a decision about your treatment, ask your doctor if they could recommend a decision aid. Decision aids are tools to help you understand the side effects, risks, and benefits of each treatment option for your situation and the tradeoffs of each option. You and your doctor can review the decision aid together and then take that information and merge it with your ability, values, and preferences to come to the right treatment for you.

Potential barrier: Speaking of time, my doctor always seems to be in such a hurry. What can I do to make sure that we have enough time to use shared decision making?

Potential solution: Not having enough time is often one of the biggest barriers to using shared decision making. You can help to make the most of your time together by preparing in advance for your appointment. Be organized. Bring a list of questions and concerns. Ask a friend or family member to come along and take notes or ask your doctor if she minds if you record your conversation so that you can replay it at home. Also, remember there are other members of the care team that can help you with your care and you should feel comfortable talking with them.

Potential barrier: My doctor and I disagree about which treatment is best for me. I want to wait a few years and see how I do without any treatment. I feel as if he is pressuring me to start treatment right away.

Potential solution: When you use shared decision making in MS, you and your care team become partners. Sometimes partners disagree, but making sure that you fully understand each other is crucial. Your doctor is an expert on MS, and you are the expert on you. Your physician's role is to share with you all of the risks and benefits of each available treatment, including no treatment. You bring your values, abilities, and preferences. Ask your doctor to explain why he feels that treating your MS is important and to explain what the risks are of not treating MS. It is also important to learn about your diagnosis from reputable sources so you also recognize the consequences of not initiating treatment.