

Shared Decision Making in Multiple Sclerosis

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Introduction

One of the many challenges with managing your health and wellness is that MS affects you in unique and personal ways. Combine this with an overwhelming amount of information and tips from your doctors, friends, family, and the internet, and you may find yourself in "analysis paralysis" – making a decision becomes a daunting task.

Shared decision making (SDM) can help you and your healthcare team make informed decisions. SDM is a **collaborative approach that actively involves** people with MS, their families, and the MS team in the decision-making process. It is a **team-based process** with you and your support partner at the center, and takes into account your shared **preferences**, **values**, **and goals**.

This approach can be utilized not only when it comes to managing your health (e.g., making treatment decisions), but also when it's time to make difficult choices about relationships, work, or finances. Basically, SMD can help improve every aspect of your health and wellness.

Now, you may be wondering, how do I go about trying this out? Follow these steps to guide you through the SDM process.

1. **Identify your teammates** – Remember that you're not in this alone. Write down the names of people in your support network. You may be involving your medical team, support partner, therapist, social worker, financial planner, etc. If you need help finding healthcare team members, the <u>National MS</u>
<u>Society</u> Navigators can help you find professionals in near you.



- 2. **Define the problem**. Identify and write down the specific problem you are having. Are you having trouble going up the steps at home? Are you experiencing fatigue so severe it is keeping you from getting chores or work done? What is the thing that you would like to find a solution for?
- 3. **Communicate your needs.** This can be tough! Many of us have trouble articulating (and even identifying) our needs and even more trouble asking for and receiving help. Consider writing down your needs, so you have clearly articulated them for yourself. Then, begin communicating with your support network. Talking with your support network is an important aspect of staying positive and building resilience. None of us can do everything alone (MS or not!).
- 4. **Brainstorm your options.** This is a good time to reach out to members of your healthcare team. If you are having trouble with mobility and accessibility at home, you can refer to your list of team members and see who may be a beneficial partner on your healthcare team someone like an occupational

therapist (OT). Reaching out to your OT would be a good first step because they can provide professional recommendations tailored just for you.

- 5. **Evaluate your options.** Once you have discussed your problem with various members of your support team, evaluate the pros and cons of each option. Notice if the options align with your values and goals, and discuss questions with your team.
- 6. **Make a decision** With your assessment in hand, you are ready to go forth and implement an action plan! The best part? You know that you have your entire team behind you every step of the way.
- 7. **Evaluate outcomes.** This is an important step to SDM. If your plan of action did not give you the results you were looking for, go back to steps 4-6 and continue to rely on the support of your team.

Using the Shared Decision Making model can help you come to **informed decisions that align with your values.** Use these tips to make the most of your SDM process:

- **Practice the 3 C's with your healthcare team**: Communication, collaboration, and coordination.
- **Vet your sources of information:** Make sure the information you gather is trusted, up-to-date, and considers your values and preferences. MS Path 2 Care can help you navigate resources.
- **Recognize barriers**: As you get to know the people in your support network, understand that some individuals may not be as effective in helping you with shared decision making. You may face barriers, such as:
 - Low level of education or health literacy
 - Misunderstanding of the MS disease course and its implications
 - Low confidence level or low self-efficacy
 - Cultural and religious values and customs
 - Language barriers
- **Use Decision Aids:** A decision aid can help you articulate and communicate throughout the SDM process. Here are some decision aid-style prompts:
 - O What is the decision to be made?
 - o What is the evidence that supports each option?
 - O What are the benefits of each option?
 - O What are the risks of each option?
 - O What are your values?
 - O What are your preferences?

Decision Aids can help you feel better informed and improve the quality of decisions. They are designed to complement, rather than replace, counseling from a health practitioner. There are many decision aids available on the internet, including this from the Multiple Sclerosis Trust.

• Attend MS educational programs, and bring your support partner -- By increasing your knowledge about MS, you and your support partner can be better informed and have a clearer understanding of your own values and preferences.

<u>Can Do MS</u> offers a wide variety of programs and resources, including practical tips on communication, emotional resilience, and symptom management. We also created <u>MS Path 2 Care</u> to help guide you through shared decision making.