

STRENGTHENING YOUR SOCIAL RELATIONSHIPS AND SUPPORTS

EMOTIONAL RESILIENCE
TIPS AND RESOURCES



SECTION 1



CONVERSATION STARTERS

Conversation Starters

DILEMMA:

“I hate to make plans because sometimes I have to cancel at the last minute. People think I’m blowing them off and they’re losing patience with me.”

Conversation Starter

- “I would totally love to go out to dinner with you on Saturday. But I’d also like to have a back-up plan in case my fatigue kicks in or my walking is off. Could we plan on ordering take-out and eating it at my house if going out isn’t going to work for me?”

DILEMMA:

“I don’t like it when people give me that sad look and feel sorry for me! I don’t want pity!”

Conversation Starter

- “Please don’t look so sad – I’m doing fine and getting very good care. Why don’t you tell me what’s going on with you?”

Conversation Starters

DILEMMA:

“A lot of my symptoms are invisible to other people – so no one understands how I’m feeling or why some days are so much harder than others!”

Conversation Starter

- “I know my MS is confusing – it’s confusing for me too! It changes all the time and I never know what to expect. If you’d like, I can fill you in on the symptoms you can’t see and how they affect me.”

DILEMMA:

“I hate asking other people for help!”

Conversation Starters

- “You’re such a tech guru – would you mind helping me figure out how to Zoom?”
- “Would it be possible for you to pick up a couple things for me at the drugstore when you go to do your errands?”
- “I finally got an appointment to see my doctor. It’s next Tuesday at 3pm. Do you think you could give me a lift?”

Conversation Starters

DILEMMA:



“We can’t do the things we used to do with other people, because my partner’s MS symptoms are so unpredictable. Why is that so hard for others to understand?”

Conversation Starter

- “My partner and I love getting together with you guys, but sometimes her MS makes it impossible. I know she’s looks fine on the outside, but she feels really crummy some of the time. Please know that spending time with you is very important to us. Can we come up with a backup plan in case her symptoms flair up?”

Conversation Starters

DILEMMA:

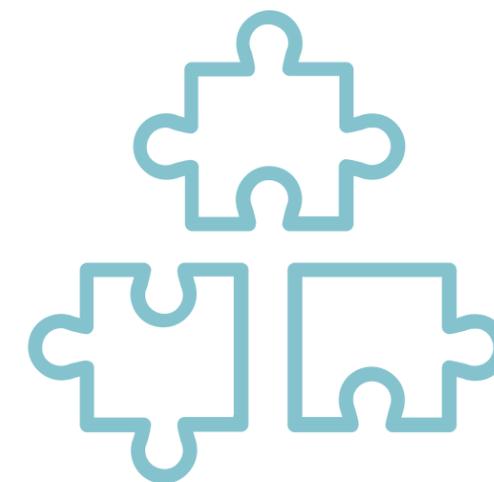


“I don’t get invited places much anymore. Sometimes they’re not accessible but sometimes I think people may be uncomfortable around me. I miss hanging out with other people!”

Conversation Starter

- “Thanks so much for the invitation! That restaurant is really hard for me to get into. Would you mind if we met at this other restaurant that has an easy entrance and an accessible bathroom?”

SECTION 2



STEPS FOR
PROACTIVE
PROBLEM-SOLVING

Steps for Proactive Problem Solving

PEOPLE FEELING SORRY FOR YOU



- Set the tone for your interactions. If you talk only about MS, that's what others will focus on.
- If someone asks how you are, decide whether this is a 'fine – thanks, how are you' situation, or a situation in which the person really wants to know the full story. Consider the other person's strengths - share difficult details with people who have the skills to support you in the way you need.
- Make sure to spend as much time talking about the other person as you do about yourself. Ask questions.
- Talk about your interests, activities, good books you've read, or movies you've seen – because that's the best way to convey that you are more than your MS.
- If you are having difficulty with coming up with topics or questions, search for "conversation starters" on the web to get started. This could even be a fun game through text or over dinner.

[SEE EXAMPLE LIST HERE](#)

- If you are a support partner, focus on the ways your partnership has stayed the same, or been strengthened, by MS. Or focus on what you and your partner Can Do, or how you have overcome challenges as a team.

Steps for Proactive Problem Solving

EXPLAINING INVISIBLE SYMPTOMS



- Explain that the symptoms they see – like walking difficulties – are just one aspect of MS - the tip of the iceberg.
- Use metaphors to describe your symptoms. For example, *"MS fatigue feels like slogging through mud with weights on your feet."* Or *"My vision is like looking through a dark screen with black patches on it."* Or *"My bladder requires that I know where every single bathroom is in every place I am."*
- Explain MS Fatigue using the image of an energy bank. Let your friends know that you have a limited number of energy dollars in your bank and you have to spend them wisely. Please understand if i run out and have to change plans.

Steps for Proactive Problem Solving

CANCELLING PLANS AT THE LAST MINUTE



- Make sure to tell people how much you enjoy their company and want to spend time with them.
- When you make a plan, always propose a backup plan and explain why so that neither of you will be disappointed.
- Think about activities that can still be connecting but allows your partner to get the rest they need. For example:
 - Hosting a virtual watch party (e.g., Netflix Party, Hulu Watch Party, Disney+ GroupWach, or Amazon Prime Video Watch Party). These allow you to watch movies and shows with your friends, react and interact, without having to leave home.
 - Online, Zoom, or digital board games (see resources section for some online group board games)

Steps for Proactive Problem Solving

HELPING PEOPLE UNDERSTAND WHY SOCIAL OUTINGS CAN BE SO DIFFICULT



- Make sure to tell people how much you enjoy going places with them.
- Explain how MS symptoms can make some outings very challenging and suggest a solution. For example,
 - *“After a full day of work, I barely have energy left to eat dinner. Could we plan our outing for the weekend?”*
 - *“Large parties are hard for me because I have trouble following conversations when there are a lot of distractions. Could we plan a small get-together in a quiet place?”*
 - *“I’d love to go out for dinner with you, but could we pick a restaurant that’s quieter and less crowded so I can maneuver my scooter more easily?”*

Steps for Proactive Problem Solving

ASKING PEOPLE FOR ASSISTANCE



- Pick the right person for the right task.
- Be specific with your requests (time, place, what you need) so that people can figure out if the timing works for them.
- Be prepared for when people ask how they can help. Have a list of the kinds of things that are helpful for you and let them choose what works for them.
- It takes a lot of courage to ask for help. Try not to get discouraged if people aren't able to help, or if their assistance turns out to be unhelpful (e.g., you wanted comfort and they tried to problem-solve). Ask for what you need, "It would be great if you could just comfort me right now", or as stated above know their strengths. If they are a problem solver, go to them to help you solve problems. Find another person who is good at what you need: comforting, cooking, driving, or entertaining.

Steps for Proactive Problem Solving

NOT GETTING INVITATIONS TO DO THINGS WITH OTHER PEOPLE



- If friends seem to have backed away, reach out and start a conversation about it.
- Remember that people may shy away for many different reasons – they don't know what to say, they don't understand MS and find it scary, they worry you won't be able to do the things they want to do, or they just feel uncomfortable.
- You can put people at ease by explaining MS and the ways it affects you. You can explain that it's not contagious and describe the things you can and cannot do. If you feel comfortable answering their questions, let them know. But most of all, let them know that you miss them and would love to find ways to get together with them.

Steps for Proactive Problem Solving

FEELING NERVOUS OR WORRIED ABOUT A SOCIAL EVENT



- Store your energy, rest a bit more than normal before the event.
- Prepare a bag of essentials and comfort items such as a bottle of water, cooling cloth or face spritzer, pads, undergarments, a change of clothes, or cell phone charger.
- Try to stay in the moment. If you are feeling overwhelmed by a group conversation try to pull one friend aside for a one-on-one conversation that is easier to manage.
- Celebrate any successes. Even if you need to leave early, you still went.

Steps for Proactive Problem Solving

SUPPORT PARTNERS: FEELING DISCONNECTED



- Think about activities that provide connection while also allowing your partner to rest.
- Talk to your partner about having dedicated time for socializing with personal friends or family.
- If your partner is worried about being alone, or if you are worried about leaving your partner alone, solve this problem together. Think about other family or friends who can support your partner while you spend time with your friend(s).

SECTION 3



WORKSHEET FOR
IDENTIFYING AND
OVERCOMING
BARRIERS TO
YOUR SOCIAL LIFE

THE PROBLEM

1. The Problem:

2. Identify the barriers that are getting in the way of your social life:

- Accessibility
- Fatigue, bladder problems, or other MS symptoms
- Communication or cognition challenges
- Depression or other mood changes
- Fears about how I will be perceived
- People with feel sorry for me
- COVID-19
- Changes in function that interfere with shared activities
- Other _____

3. Share your barriers with your partner or a friend for emotional support (pick the right person)!

4. Individually or together, write down all of the solutions that come to mind – without judgement or criticism:

5. Write down what happened:

If necessary, tweak your solution and try again.
Think about any emotions or MS symptoms that got in your way.
Try another solution.
Talk it over with your partner or a friend to share and problem-solve.
Take time to enjoy your successes (even small wins!) and keep the momentum going.

6. Focus on what matters to you and aligns with your values

Some relationships are worth fighting for and some aren't.

Some people's opinions matter and some people's don't.

If interactions with a person never end up feeling good, stop beating your head against the wall.

Be open to doing things differently or using different tools if a shared activity is important to you (e.g., traveling, going out for a walk, playing a sport).

7. Learn from the experiences and wisdom of others

Talk to your support group.

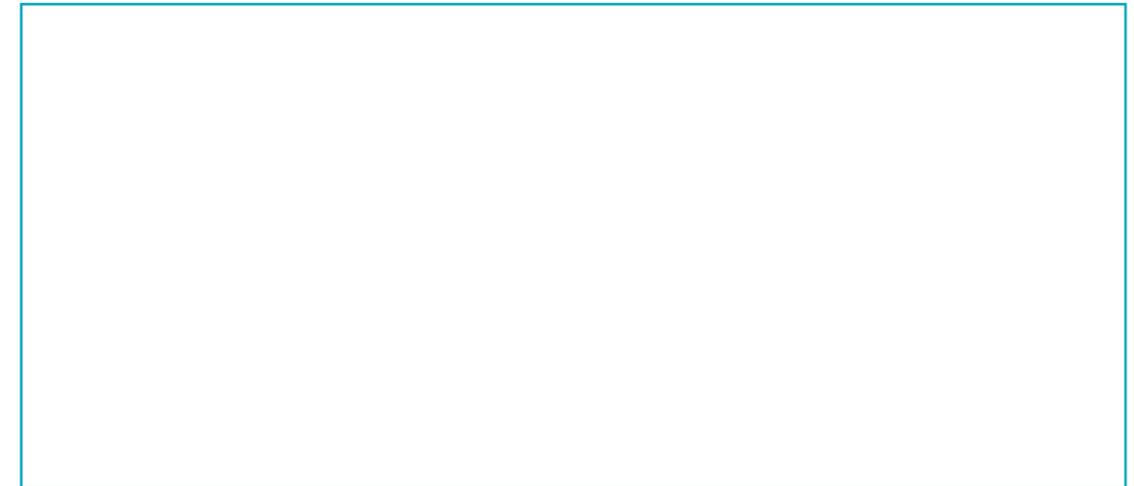
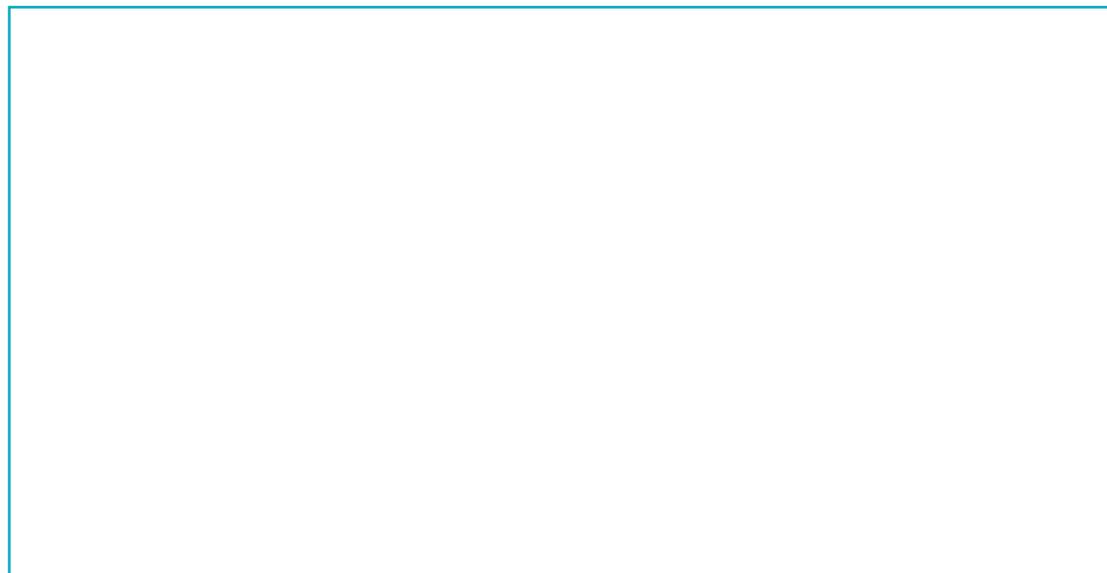
Join a Facebook or LinkedIn group.

Check out MS bloggers.

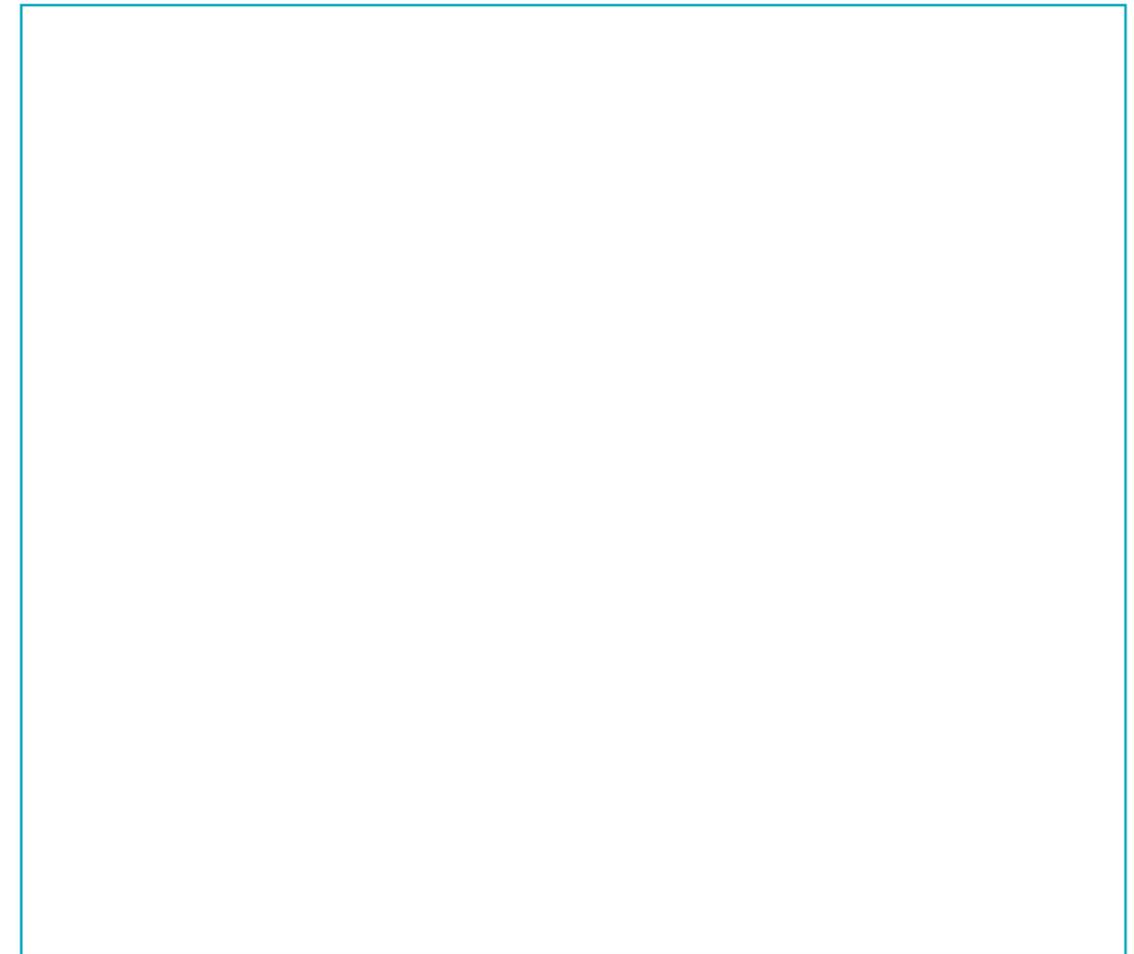
Visit adaptive sports websites.

Use your rehabilitation team – physical and occupational therapists, speech language pathologists for recommendations and tools.

8. Please write out all possible solutions, and evaluate what happened



9. Recognize and celebrate successes!





SECTION 4

HELPFUL RESOURCES

Information for Support Partners

[SEE RESOURCES HERE](#)

Where to Find MS Support Online

[SEE RESOURCES HERE](#)

Secondary Progressive MS: Managing Transitions in Your Partnerships (Webinar)

[WATCH NOW](#)

Managing the Impact of Mood and Cognitive Changes (Webinar)

[WATCH NOW](#)

The Art of Communication (Webinar)

[WATCH NOW](#)

It Takes a Village: When Cognition Shifts Roles (Library Article)

[READ NOW](#)

Understanding Your Healthcare Team (Handout)

[READ NOW](#)

Host a Virtual Game Night

[JACK BOX GAMES](#)

[JIGSAW PUZZLES](#)

[MORE GAMES](#)

Online Movie/Show Watching Options

[NETFLIX PARTY](#)

[HULU WATCH PARTY](#)

[FACEBOOK WATCH PARTY](#)

[AMAZON PRIME WATCH PARTY](#)



AN EMOTIONAL RESILIENCE GUIDE AND RESOURCE

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