

MANAGING CHANGES IN SYMPTOMS, ABILITIES, AND KEY ROLES

EMOTIONAL RESILIENCE
TIPS AND RESOURCES



SECTION 1



CONVERSATION STARTERS

IDENTIFYING KEY TRANSITIONS



The most common life transitions that people with MS and their families experience include:

- INITIAL SYMPTOMS AND DIAGNOSIS
- MAJOR EXACERBATIONS
- WORSENING SYMPTOMS THAT INTERFERE WITH LIFE ROLES
- EMPLOYMENT CHANGES
- INCREASING DISABILITY

Conversation Starters

INITIAL SYMPTOMS AND DIAGNOSIS



"I've been having some really strange symptoms lately that are making me very anxious. Would you go to the doctor with me so I can try to find out what's going on?"

"Well now we know I have MS – which I guess means we both have to figure out how to deal with this. I think we should go to the next visit with my neurologist together so we can learn as much as we can about our next steps."

"I know you're the one who just got diagnosed, but I'm feeling as anxious as you are. I really need to know what MS is all about and what I can do to help us both deal with this. I'd like to come to your next neurology visit with you – and maybe we should call the National MS Society to see if we can get some resources to help us."

Conversation Starters

MAJOR EXACERBATIONS



“This relapse is a real doozy. Let’s talk about how to manage until I’m back on my feet – maybe a few of our friends could help out so that all the errands and chores don’t fall on you.”

“You seem to have some new symptoms with this relapse – I’m sure you’re just as scared about them as I am. I think we should read up about them (or watch some webinars) together to learn how best to manage these symptoms in case they don’t go away any time soon.”

Conversation Starters

WORSENING SYMPTOMS THAT INTERFERE WITH LIFE ROLES



"I feel like I'm not holding up my end of the bargain. I appreciate your taking on all the chores around here, but I'd like to talk about some strategies or tools I could use to make it easier for me to do at least some of cooking and cleaning. I'd like to get a referral to an occupational therapist who could come in and give us some guidance."

"If my fatigue and cognitive issues keep getting worse, we won't be able to count on my job or my income. I feel like I'm letting you down and wrecking all our plans. I really want our partnership to feel good for both of us. Maybe we could talk with a counselor about ways we could keep our partnership strong and balanced."

"You've seemed really down and depressed lately. I know things are hard but it feels like you're giving up. I read that depression is a common symptom of MS so I think we should talk with the neurologist about how your mood has changed in the last couple of months."

"I never feel like doing anything anymore. I have no motivation. Would you be willing to help me make a plan to start getting more active?"

"I've noticed you have been really down lately and haven't felt like doing much. Let's try to figure something really fun to do together."

"I know that I've been really irritable and difficult to live with. Would you come with me to talk to the doctor about it?"

Conversation Starters

EMPLOYMENT AND FINANCES



"I really enjoy my construction job but it's hard to tell how long before my balance problems will make working on ladders dangerous. Maybe I should look at taking some computer/design courses and then I can apply for other positions in the company."

"I have received a lot of accommodations from the company to help me keep doing my job. But my productivity is way down and I'm not contributing much at this point. I think we need to talk about how we'll manage if I need to leave my job."

"I don't have anything left at the end of the work day. I don't feel like I can do my job and I don't feel safe driving given how tired I am. Maybe we should schedule an appointment with the doctor to discuss my disability application."

"I'm getting really worried about our finances. I think we should get some financial advice to help us plan for the future. I know the National MS Society offers free consultations with financial services professionals so I'm going to give them a call."

"I know that we really wanted you to stay home with the kids, but I may not be able to keep working – which would mean the end of our health insurance. Maybe we should talk about what it would mean for you to go back to work?"

Conversation Starters

INCREASING DISABILITY



"I'm having a lot of trouble getting into the bathtub by myself. Maybe we should think about making some modifications that would help me feel safer and more independent."

"It's getting harder for me to help you with transfers and I'm concerned about your safety and my own. Let's ask your neurologist for a physical or occupational therapy consultation to learn safe strategies and get recommendations for making our house more accessible."

"I've lost a lot of the feeling in my feet – so driving doesn't feel safe. I'm going to look into getting hand controls installed in our car so that I can continue to be independent and safe."

"Staying in this house may not be possible if my symptoms get much worse. It's hard to think about, but I'd like us to talk about what our other living options might be. We don't ever want to have to make a big decision in a crisis."

MAJOR TRANSITIONS CAN SAP A PERSON'S CONFIDENCE AND MOTIVATION IN MANY DIFFERENT WAYS

Conversation Starters

FEAR OF FAILURE

"I have not been out on a date since my diagnosis 2 years ago. Who is going to want to date a person like me with MS? You don't seem to have any trouble finding dates and you have MS too – so what's your secret?"

"I just keep thinking that nothing is ever going to be the same. I'm scared to try new things because if I'm not successful, it'll be too scary to keep trying. Could you please be my cheerleader – I really need someone in my corner right now."

"I know you think no one will want to hire you because of your MS – but you have lots of skills and talents to contribute. How about if we look at some job postings together and see if anything looks appealing to you?"

Conversation Starters

LACK OF CONFIDENCE AND MOTIVATION



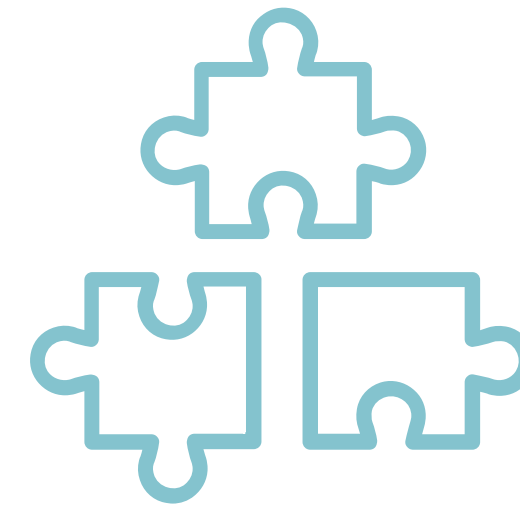
"I feel as though I have to do everything differently than I did it before – like I'm a beginner at everything! I hope you can be patient with me while I get to know my new self."

"I've always prided myself on being the "fixer" in our family. MS can't be fixed and it's making me feel out of control. Can we figure out the things we can fix or control and work on those?"

"I don't feel like going out to dinner anymore because I'm afraid that I'll have an accident. I can't seem to go 5 minutes without having to go to the bathroom. I wonder if it would be helpful to talk with someone else who has MS and see what he/she has done to manage this."

"I don't think I'll ever feel safe driving again. I think I need to get a driver evaluation but I'm really scared about it. Will you go with me?"

SECTION 2



PROACTIVE PROBLEM
SOLVING FOR
REDUCING ANXIETY
AND COPING MORE
EFFECTIVELY WITH
EMOTIONAL
SYMPTOMS

Steps for Proactive Problem Solving

EXTERNAL FACTORS

- **Managing Your Environment**
 - Accessibility assessment of your living space
 - Bathroom location (first floor?)
 - Laundry facilities
 - Access in and out of the house
 - Assessment of your transportation options
 - Vehicle accessibility and comfort
 - Use of hand controls
 - Trunk space for mobility equipment
 - Public transportation
- **Financial Planning**
 - Long-term care needs and costs for person with MS
 - Long term care insurance for support partner
 - Proactive financial planning for the unpredictable future
- **Employment Planning**
 - Disclosure decisions and accommodations requests
 - Alternate employment options and/or job retraining
 - Accommodations to enhance job accessibility and performance
 - Social Security Disability benefits

Steps for Proactive Problem Solving

HEALTH MAINTENANCE AND OPTIMAL WELLNESS FOR THE PERSON WITH MS AND THE SUPPORT PARTNER

- **Regular Physical Activity/Exercise**
- **Healthy, Balanced Diet**
- **Relaxation Training**
 - 20-30 minutes daily of diaphragmatic breathing, meditation, tai chi, or other similar activity (based on deep breathing)
- **Maintaining Regular Medical Appointments**
 - PCP for managing health and/or other co-morbid conditions as well as ongoing health screenings.
 - Neurology – MS related treatments
 - Dental care
 - Vision screening and eye health
 - Others?
- **Mental Health**
 - Maintaining social connections and friendships
 - Virtually with FaceTime, Zoom or other options
 - In person with appropriate COVID precautions
 - Professional help with a therapist
 - Managing psychological/emotional well being
 - Coping with MS changes

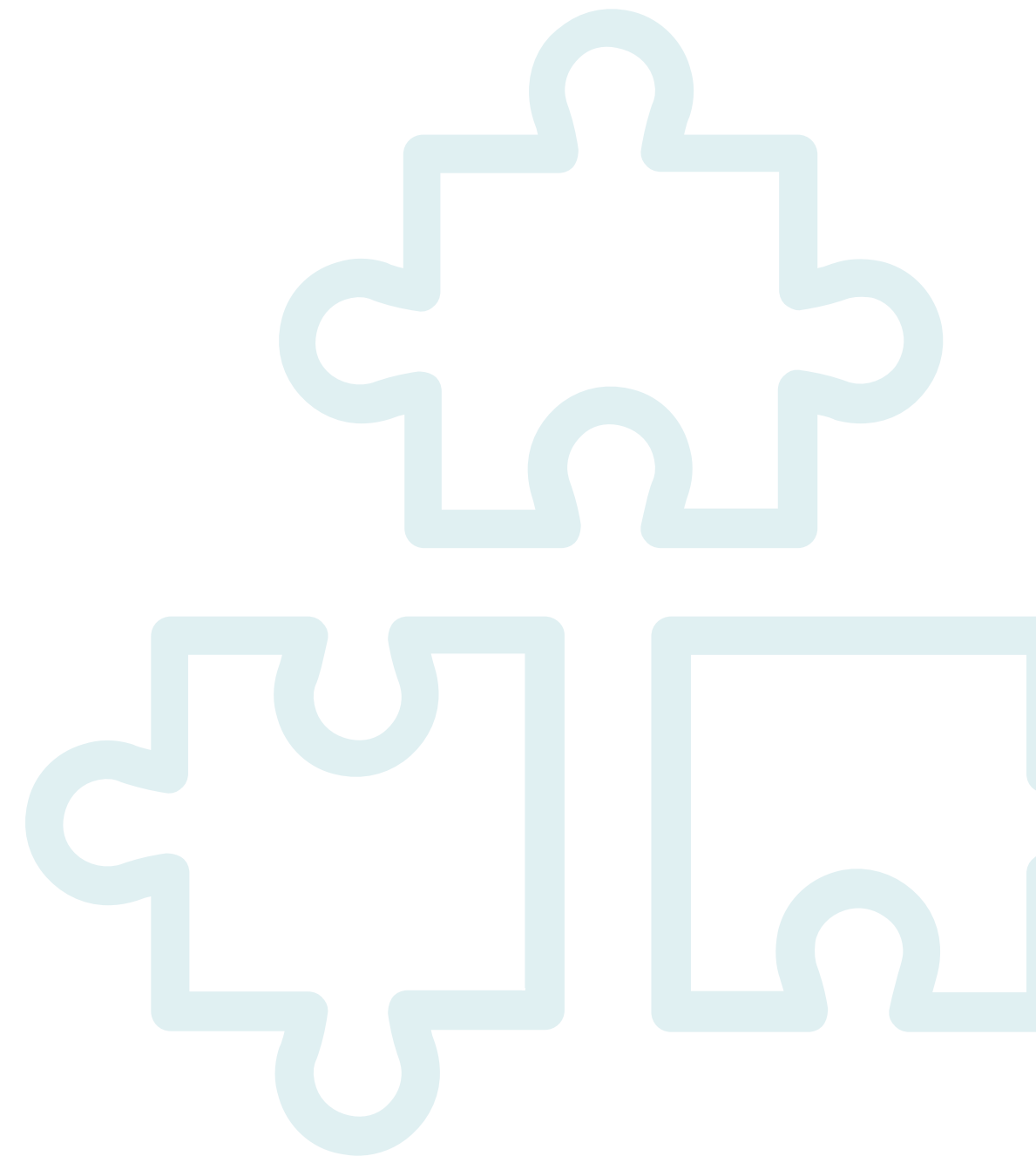
EMERGENCY PLANNING

- **Emergency Contacts**
 - Care for children
 - Care of pets
 - Care for house
 - Others?
- **Transitions: Intermediate Care and Support**
 - Day-to-day care/support for
 - Self
 - Children
 - Pets
 - Housework
 - Shopping
 - Others?
- **Getting To And From Medical/Rehab Appointments**

LONG TERM PLANNING

- **Healthcare access and costs**
- **Advance care directives**
- **Assistance in the home**
- **Alternative living options**

CONNECTIONS WITH YOUR SOCIAL AND PROFESSIONAL SUPPORT COMMUNITIES





SECTION 3

HELPFUL RESOURCES

Knowledge is Power - For Individuals Who Are Newly-Diagnosed

[VIEW NOW](#)

Multiple Sclerosis Relapses (Webinar)

[WATCH NOW](#)

Symptom Management - Motor Components (Webinar)

[WATCH NOW](#)

Symptom Management - Sensory Components (Webinar)

[WATCH NOW](#)

Treating Mood Issues -- the Process of Therapy/Counseling (Article)

[READ NOW](#)

Striving for Cognitive Wellness (Webinar)

[WATCH NOW](#)

How to Choose the Mobility Device That's Right for You (Brochure)

[READ NOW](#)

Applying for Social Security Benefits (Brochure)

[READ NOW](#)

Driving with Multiple Sclerosis (Brochure)

[READ NOW](#)

At Home with MS -- Adapting Your Environment (Brochure)

[READ NOW](#)

Financial Planning for a Life with MS (Brochure)

[READ NOW](#)

Managing Complex Care Needs Whenever They Arise (Article)

[READ NOW](#)

**Wellness Discussion Guide for People with MS
and their Healthcare Providers (Brochure)**

[READ NOW](#)

Understanding Your Healthcare Team (Handout)

[READ NOW](#)

National MS Society MS Navigator®

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*Information, support, referrals,
employment (1-800-344-4867)*





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