

EVERYDAY NEEDS SUPPORT TOOLKIT

STEPS FOR OPTIMIZING EMOTIONAL SUPPORT, PHYSICAL CAREGIVING, AND ASSISTANCE WITH EVERYDAY NEEDS



STEPS YOU CAN DO TO ADDRESS ASSISTANCE WITH EVERYDAY NEEDS

Support Partner

STEPS YOU CAN DO TO ADDRESS BALANCING PHYSICAL CAREGIVING WITH SELF-CARE



STEP 1

Recognize and acknowledge the impact of your everyday needs on your partner's emotional and physical wellbeing.

When the demands on your partner's time and energy seem to feel overwhelming

When your partner seems to have too much to do related to work and home responsibilities and to little time for him or herself

When you worry that it all may become too much for your support partner to handle

When you sense that your support partner is irritable, short-tempered or depressed, or perhaps using alcohol or substances to deal with feelings

When your partner seems worried about finances or job security

When you feel as though your shared world is getting smaller and smaller because of worsening MS

Support Partner STEP 1

Recognize and acknowledge the impact of your partner's caregiving needs on your physical health.

If you experience pain or physical discomfort related to your caregiving activities

If you're reluctant to help with transfers or other activities because they result in significant neck, back, leg or other types of pain for you

When you feel exhausted because of disrupted or inadequate sleep

If you find yourself using alcohol or other substances to deal with stress

When you find yourself neglecting your own physical health and preventive care because of your partner's needs

When you feel that your partner would be capable of doing more activities safely and independently – alone or with you – with the use of appropriate assistive devices

When you feel limited or trapped because you're afraid to leave your partner alone due to safety concerns

STEP 2

The next step is to allow yourself to share those feelings and begin to problem-solve with your partner.

Choose a relaxed time (not during an argument) and place for these important conversations with your partner.

Plan a conversation starter that you think will resonate with your partner.

"Lately we spend so much time taking care of me and what I need that there's not enough time for us to be a couple. Could we talk about how to get some of our couple time back?"

"I'd like to talk about how to have more time for fun stuff. Could we talk about getting someone in to help us with the household chores so that you don't have so much on your plate?"

"While I feel that we could use some extra help, I worry about bringing a stranger into our home and I'm scared to have someone other than you helping me."

"Lately it's like you have two full-time jobs – which makes me feel incredibly guilty. Perhaps an occupational therapist could suggest some tools and strategies to help me do more of the household tasks."

"I'm starting to feel a little trapped in my own house. Could we talk about ways to make the house more accessible for me or possibly consider a different house altogether?"

Support Partner STEP 2

The next step is to allow yourself to share those feelings and begin to problem-solve with your partner.

Choose a relaxed time (not during an argument) and place for these important conversations with your partner

Plan a conversation starter that you think will resonate with your partner. The goal is not to arouse guilt but to initiate shared problem-solving around these concerns.

"I'm sorry that I'm less able to assist you these days. I really need to speak with a physical therapist to learn safer ways to assist you that don't cause me so much physical discomfort. I hope the PT can teach us how to do these activities in a way that is safer for both of us."

"I realize I've been a little cranky lately – I really think it's because my sleep and yours have been so disrupted these days by MS symptoms. Perhaps we could talk with the neurologist about ways to manage your bladder and spasticity so we both get more sleep."

"I think we sometimes get so focused on your MS care and doctors' appointments that we forget that my health is pretty important of us. I need your help to carve out some time for my preventive care and wellness activities."

"I know you're frustrated that you can't do more on your own and you're having to wait for me to help you. I wonder whether we could talk with a physical therapist to learn about strategies or tools to help you be more independent?"

"It's very scary for me to leave you alone because of the falls you've been taking. Could we come to some agreement about what it's safe for you to do when I'm not there? And perhaps talk with a physical therapist about ways to minimize your risk of falling?"

STEP 3

Talk with your partner about strategies the two of you could use to get the assistance you need with daily activities.

Identify strategies that feel best for you individually and for your relationship.

- Explore options for getting help in the home and experiment with one or two of them.
- Talk with an occupational therapist about options for making your living space safer and more accessible.
- Visit other types of living situations that would offer more services and accessibility.

Try out your strategies for a period of time.

Check in with each other on a regular basis to evaluate the success of the strategies you are using.

Support Partner STEP 3

Talk with your partner about strategies the two of you could use to optimize physical caregiving activities and personal health and wellness.

Identify strategies that feel best for you individually and for your relationship.

- Prioritizing and schedule time for each person's exercise, physical activity, and other wellness activities, including healthcare appointments.
- Schedule appointments for the recommended screenings that are recommended for your age and gender.
- physical stress for the support partner.

Try out your strategies for a period of time.

Check in with each other on a regular basis to evaluate the success of the strategies you are using.

• Be sure to let the healthcare team know about the symptoms that are disrupting sleep and resulting in exhaustion for both of you.

• Work with a physical therapist to identify mobility aids and adaptive equipment that optimize independence and safety while reducing



Person with MS + Support Partner STEP 4

If the strategies don't appear to be working or your communication seems to falter, a counselor or therapist can help you find solutions.

Helpful Websites:

- Can Do Multiple Sclerosis (cando-ms.org) find opportunities, library articles, and a wide array of virtual wellness program options.
- National MS Society (1-800-344-4867) speak to a National MS Society MS Navigator for support, information, referrals.
- Findempathie.com find a mental health professional who specializes in MS.
- HelpPro.com find a mental health professional.

multidisciplinary webinars, podcasts, online learning



A STEP TOOLKIT

CANDO-MS.ORG