

PHYSICAL CAREGIVING SUPPORT TOOLKIT

Multiple Sclerosis

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

STEPS YOU CAN DO TO TAKE
CARE OF YOUR SUPPORT
PARTNER WHO PROVIDES
PHYSICAL CAREGIVING

Support Partner

STEPS YOU CAN DO
TO BALANCE
PHYSICAL CAREGIVING
WITH SELF-CARE



### STEP 1

Recognize and acknowledge the impact of your partner's caregiving activities on his or her physical health.

If your partner experiences pain or physical discomfort related to caregiving activities

If your partner becomes reluctant to help with transfers or other physical activities because they result in significant neck, back, leg or other types of pain

If you hesitate to ask for physical assistance because it may cause your partner discomfort or pain

If you notice that your partner seems exhausted because of disrupted sleep or inadequate sleep

If you think that your partner is using alcohol or other substances to deal with stress or physical pain

If you believe that your partner is neglecting his or her own physical health and preventive care because of your needs

When you begin to feel that your partner is doing so much that it's time to consider using tools, assistive devices, or other helpers to assist you

### 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.

"I realize that the physical tasks you do to help me are becoming more and more challenging and I can tell that you're struggling with some of them. Perhaps we could talk with a physical therapist about different ways for me to transfer and get up after a fall so that you don't get hurt in the process?"

"I want to be able to do more on my own so that you don't have to do so much. Can we talk with a physical therapist about some tools or assistive devices that would help both of us?"

"I'd like us to figure out whether I could safely do some of the tasks that you've been doing for me so that you have more time to do your own thing."

"I know you're always worrying about my health and wellbeing, but I'm equally concerned about yours. How can I help you make your health an equal priority?"

"I'm very scared of falling when you're not home. Perhaps a physical therapist could help me learn ways to be safer when I'm on my own in the house."

#### 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 optimize physical caregiving activities and personal health and wellness.

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

- Prioritize and schedule time for each person's exercise, physical activity, and other wellness activities, including healthcare appointments
- Come to an agreement about the activities that you can do safely and independently as well as those for which your partner's assistance is essential
- Encourage your partner to schedule appointments for the recommended screenings for his or her age and gender
- Be sure to let the healthcare team know about symptoms of yours
   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 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.

#### 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.

- Prioritize 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.
- 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 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.



### 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 multidisciplinary webinars, podcasts, online learning 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.



# A STEP TOOLKIT

CANDO-MS.ORG