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Learning Objectives

• Recognize the stresses associated with being a member of the “sandwich generation”
• Acknowledge how MS adds to the stress of caring for oneself while caring for others
• Learn strategies to prioritize needs, establish boundaries and identify and utilize resources
• Understand the importance of clear and open communication and effective teamwork
Polling Question #1

How many people do you take care of in addition to yourself?

- 1
- 2-4
- 5-7
- More than 7
What do we know about the “sandwich generation?”

- Over 2.2 million Americans care for children and aging parents/in-laws in addition to themselves.
- People with MS and support partners are often members of the sandwich generation.
- Providing support for others affects people in multiple ways:
  - Feelings of accomplishment, pride, satisfaction, closeness
  - Increased stress, fatigue and other physical symptoms, relationship challenges and higher rates of depression, sleep problems, absenteeism
As if that weren’t complicated enough...

• MS is:
  • A chronic, unpredictable illness
  • Often invisible to others
  • Expensive
  • Time- and energy-consuming

• MS makes everyday activities more challenging
• People with MS may question their capacity due to problems with mobility, energy, cognition and/or mood
• Support partners may feel overwhelmed by multiple roles at home and work
• Assistance – whether asking for it, offering it, or receiving it – is complicated
Polling Question #2

What is your greatest challenge as a member of the sandwich generation?

• Not enough time and/or energy
• Too many people need me
• Feeling stressed and overwhelmed
• Difficulty saying “no”
• Helping people from a distance
Kelly

Kelly is married with three children, aging parents with increasing health issues, and a husband who travels for work

- MS for 12 years, with increasing mobility problems, fatigue and depression
- Retired on disability
- House in chaos, lots of fast food, missing kids’ activities and struggling to keep up with everyone’s needs
- Parents living an hour away
- Kelly feels alone, guilt-ridden and overwhelmed.
Charlie

A 49-year-old engineer whose wife has secondary progressive MS and uses a wheelchair for mobility

• Two teenage children and two sets of aging parents
• Increasing responsibilities at home, at work and with both sets of parents
• No time for self-care, relaxation or time with friends
• Stressed out, resentful, lonely, short-fused
• High blood pressure, recent weight gain
• Financial concerns now and for the future
First Steps for Kelly and Charlie

- Write down your schedule for the past week
  - Think about who/what filled your time
  - Think about what/who didn’t get enough time
- How many hours of your day were committed to other people? To yourself?
- How many activities were “have to’s” vs. “want to’s”?
- How many activities supported your priorities? The priorities of others?
- Did you allot adequate time to your wellness needs?
Attending to Your Own Needs

• Are your wellness needs being met?

Self-care isn’t selfish; Self-care is self-sustaining
Recommendations for Kelly and Charlie

- Make time for self-care – physical, emotional, social and recreational
  - See a primary care provider for overall health management
  - Consult a mental health professional to help with mood, concerns, priority-setting
  - Consult a physical therapist for exercise plan and mobility concerns
  - Consult an occupational therapist for organizational tips
  - Consider meeting with a financial planner
  - Have some fun
Recommendations, cont’d

• Communicate needs and feelings
  • Talk with your partner
  • Schedule a family meeting

• Acknowledge your limits and communicate them to others
  • Recognize that you can’t be all things to all people
  • Decide what you’re willing and able to do for others (boundary-setting)
  • Practice saying “no”
  • Investigate other resources
Recommendations, cont’d

• Investigate family and community resources
  • Talk with extended family
  • Consider your children a resource
  • Consider faith-based organizations
  • Call the National MS Society – 1-800-344-4867

• Think about which needs and priorities you can realistically address on your own and which require help from others
Why is asking for help so difficult?

• Do you feel that:
  • “it’s all on you”
  • asking for help is a sign of weakness
  • others won’t be willing to help
  • others won’t do as good a job as you do or the way you want it done
  • no one can care for your loved ones as well as you can
  • asking for help is a slippery slope to losing control
Polling Question #3

In the past month, how many times have you asked for help?

• 0
• 1-2
• More that 3
Tips for Asking for Help

• Decide what you want and need help with.
• Be specific with your requests.
• Plan ahead and give people notice.
• Remember something done differently is better than not done.
• People want to help but need direction.
• Give people useful feedback.
As a member of the sandwich generation...

• Remember to
  • Take time for the things that give your life meaning and joy and contribute to your feelings of self-worth
  • Keep your oxygen tank filled and your mask ready
  • Be as open to receiving as you are to giving
  • Acknowledge and address your feelings before they spiral out of control
  • Ask for help when you need it
Resources to Consider

- Can Do MS **Webinars and Articles**
  - Communication
  - Healthcare team
  - Mood
  - Cognition

- National Multiple Sclerosis Society
  - **Wellness Discussion Guide for People with MS and Their Healthcare Providers** ([www.nationalmssociety.org/wellnessguide](http://www.nationalmssociety.org/wellnessguide))
  - **Hiring Help at Home: The Basic Facts**
  - **Taming Stress in Multiple Sclerosis**
  - **MS Navigator Service** (1-800-344-4867; ContactUsNMSS.org)
    - Information, referrals, support
    - Free financial planning consultation
Questions/Comments

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Can Do MS Resources

Find these resources at www.MSCanDo.org.
National MS Society Resources

Taming Stress in Multiple Sclerosis

Hiring Help At Home
THE BASIC FACTS
MULTIPLE SCLEROSIS

Rona Poli, diagnosed in 1986

Wellness Discussion Guide for People with MS and Their Healthcare Providers
Integrating Lifestyle and Complementary Strategies into MS Care

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Cognition Research and Strategies

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