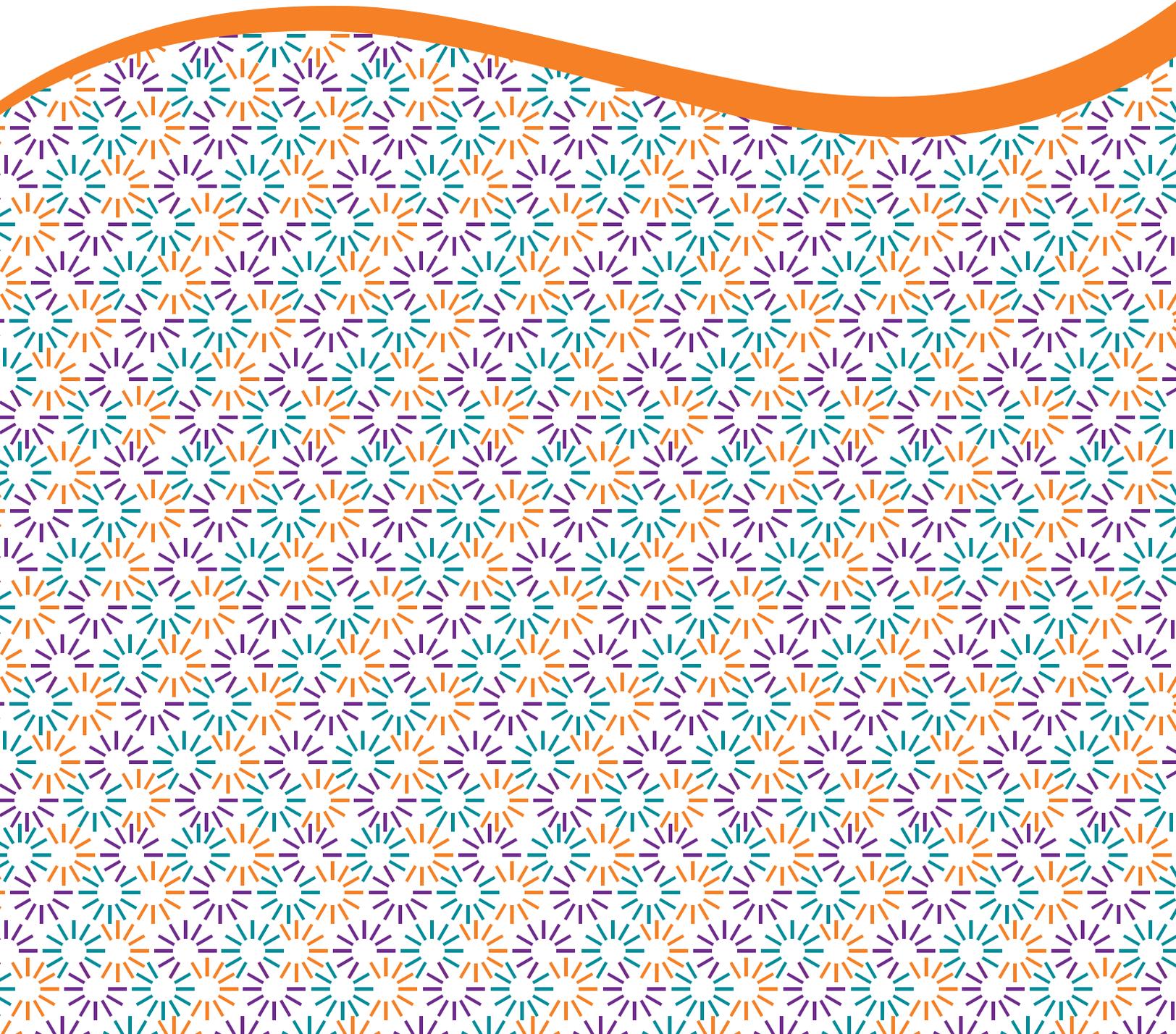




Live Fully, Live Well

A Wellness Program for People with MS & Their Support Partners

MEETING-IN-A-BOX TOOL KIT: DISCUSSION GUIDE



*This program is made possible by MS ActiveSource,
which is sponsored by Biogen Idec and Elan Pharmaceuticals, Inc.*



Live Fully, Live Well is a comprehensive wellness program from the National MS Society and Can Do MS, designed for people living with MS and their support partners. *Live Fully, Live Well* covers topics affecting the whole family living with MS in order to strengthen relationships, increase understanding and promote improved health and quality of life.

This meeting-in-a-box tool kit is for you to use to facilitate conversations in the self-help group setting around a variety of wellness issues.

TOPICS COVERED IN THE LIVE FULLY, LIVE WELL PROGRAM INCLUDE:

- Attending to Your Whole Self
- Maximize Mobility, Achieve Independence
- Tips for Managing Fatigue
- Travel and Recreation for People Living with MS
- Planning for Your Future (Finances and Careers)
- Exercise Can Be a Part of Your Life with MS
- Eating Well, Eating Easy

INCLUDED IN THE KIT ARE:

- (1) Facilitator's Guide*
- (15) Participant folders*
- (1) Program DVD*
- (1) CD (Webinars, Calls to Action and Resource Materials)*

** Additional copies available upon request. Please contact your chapter liaison.*

*The DVD and Discussion Guide are tools to help jumpstart the discussion in your group. You can incorporate the **Live Fully, Live Well** DVD into the meeting as a lead-in to the discussion questions, or use the suggested questions in this guide on their own to help generate conversation.*

Use each of the seven topics in the tool kit as part of seven separate meetings, or have a general discussion on wellness, using select suggested questions presented throughout the guide and have a high-level meeting on wellness in general.

AS YOUR GROUP'S LEADER, YOU MAY CHOOSE TO FACILITATE THE PROGRAM OR PERHAPS INVITE A GUEST SPEAKER. SUGGESTED SPEAKERS COULD INCLUDE:

- MS Nurse
- PT/OT
- Recreational Therapist
- Financial Planner
- Career and/or Life Coach
- Nutritionist
- Exercise Physiologist

THE ENCLOSED FOLDERS ARE FOR GROUP MEMBERS TO TAKE HOME AND USE AS PART OF THEIR PERSONAL WELLNESS PLAN. EACH PARTICIPANT FOLDER INCLUDES:

- (1) **Live Fully, Live Well** DVD and CD
- (8) Personal Call to Action Plans
- (1) Resource Guide
- Can Do MS brochure
- Active Source materials

*To enhance the learning and sharing experience, you may want to ask group members to listen to the **Live Fully, Live Well** one-hour webinar presentations prior to your meeting — one or all seven, depending on the focus of your meeting.*

THE PROGRAMS ARE AVAILABLE ON THE ENCLOSED CD
OR USE LINK FROM PAGE 9 OF RESOURCE GUIDE

nationalMSsociety.org/living-with-multiple-sclerosis/live-fully-live-well/index.aspx

- **Attending to Your Health** with Patricia Kennedy, RN, CNP, MSCN
- **Maximize Mobility, Achieve Independence** with Mandy Rohrig, PT, DPT
- **Fatigue Related Challenges** with Juliann Hanson-Zlatev, OTR, DPT
- **Recreational Activities and Travel** with Linda Walls, OTR
- **Planning for Your Future** with Silvia Stazio, CFP and Steve Nissen, MS, CRC
- **How Does Exercise Fit Into Your Life with MS?** with Susan Kushner, MS, PT
- **Eating Healthy, Eating Easy** with Denise Nowack, RD

Unless notes otherwise, please contact an MS Navigator™ at 1-800-344-4867 (1-800-FIGHT MS) to request copies of any of the publications or DVDs listed in this guide.

Discussion Guide

Attending to Your Whole Self

SUGGESTED DISCUSSION QUESTIONS:

- What is your definition of wellness?
- What do you think people with MS can do to be healthy and well?
- How do you take care of yourself? As a support partner, how do you take care of yourself?
- What are the biggest challenges you face when trying to take care of your health and wellness?
- How do you and your support partner stay connected?
 - What activities do you enjoy?
 - Have you had to modify your activities or find new ones because of MS?
 - Is there a new or different activity you would like to try? What is keeping you from trying it?
- What strategies do you use to keep MS in its place — so life doesn't become all about MS.
- What is your MS-Free Zone — that part of you that MS can't touch (examples might be your sense of humor, religious faith, love of music) and that gives you time and space from MS?
- What is your support system? Has it changed since the diagnosis?
- Is change difficult? What gets in the way?
- Does making changes feel like you are giving in to the disease or taking charge of it?

Maximize Mobility, Achieve Independence

SUGGESTED DISCUSSION QUESTIONS:

- What does independence mean to you? Has this changed since the diagnosis?
- What are the biggest challenges to your independence?
- What, if any, have been your mobility challenges?

- Do you use a mobility device?
- What was it like for you to make the transition to using the device?
- How do others (friends, family members, colleagues, strangers) react to your mobility device?
- What can people do to educate others about mobility aids — and help them understand that mobility aids don't define those who use them?
- What advice would you give others who are considering a mobility device?
- Have you made any modifications to your home environment? If yes, what are they?

FACILITATOR'S TIP:

If anyone is struggling with finding a modification, have the group brainstorm potential solutions.

Fatigue Related Challenges

SUGGESTED DISCUSSION QUESTIONS:

- Ask group members to choose one of their environments (home, work, or community) and identify two situations in that environment that contribute to their fatigue and may need modification. As a group, brainstorm solutions.
- What strategies do you use to manage your energy?
- What strategies do you use to combat fatigue?
- How does heat affect your fatigue level and your MS symptoms? How do you manage it?
- How does your diet, weight and fitness affect your fatigue level?
- How do others react to your fatigue and how do you explain it to them?
- Are there environmental changes that might reduce your energy expenditures?
- What other MS symptoms seem to contribute to your fatigue (e.g., sleep disturbed by trips to the bathroom, stiffness or spasms), and what could you do to address them?
- How can mobility aids help people to conserve energy?

FACILITATOR'S TIPS:

- If anyone is struggling with finding a modification, have the group brainstorm potential solutions.
- Small changes can make a big difference in energy conservation. Changes in your home and workplace can save valuable energy for activities that are important to you.

Recreational Activities & Travel

SUGGESTED DISCUSSION QUESTIONS:

- How has MS affected your ability to participate in the activities you enjoy?
- Have you found ways to adapt those activities so that you can still participate or have you found new activities to enjoy?
- Ask group members to volunteer to share ways they have adapted leisure activities to accommodate their MS.
- Ask group members to talk about their travel experiences. If the first stories they tell are about unsuccessful or frustrating travel experiences, ask if others have found travel more enjoyable and what strategies they used. Or ask for a volunteer to tell one travel horror story and one travel success story.
- Ask for volunteers to talk about how they and their partners have handled shared leisure activities that have been affected by MS: Do they both stop doing them? Do they enjoy separate activities? Do they find new ones to share together? How has it worked out for them?
- Ask group members if any of them have discovered new hobbies that they would never have tried before they got MS.

Planning for Your Future (Finances & Careers)

SUGGESTED DISCUSSION QUESTIONS:

- Ask for volunteers to share strategies they have used to safeguard their financial future. If no one has any to share, ask the group what seems to get in the way (e.g., Anxiety? Not sure how to do it? Can't get their partner to participate? etc.)
- Ask for volunteers to share strategies they have used to safeguard their employment.
- Ask the group what kinds of accommodations they have requested from their employer, recently or in the past. What was the experience like? What kind of response did they get?
- Ask for volunteers to share any career changes they have made as a result of MS, and how they went about making the change(s).
- If there are group members who are no longer employed, ask for volunteers to talk about how they made the decision to retire/leave the workforce. What recommendations would they have for others in the group?

How Does Exercise Fit Into Your Life with MS?

SUGGESTED DISCUSSION QUESTIONS:

- What kinds of exercise are people getting (e.g., individual, group, housework, gardening)?
- What benefits are people getting from the exercise they do?
- What obstacles do people face when trying to exercise?
- Ask for volunteers to describe ways in which they have been able to incorporate exercise in spite of their disability.
- Have people utilized rehabilitation specialists — PTs or OTs — to help them design an exercise program? And if so, how well did that work for them?
- Have people had to give up forms of exercise that they loved? And if so, how did that feel and what have they found to replace those activities?
- How can you exercise in spite of your fatigue?

Eating Well, Eating Easy

SUGGESTED DISCUSSION QUESTIONS:

- What are the biggest obstacles to healthy eating?
- What strategies have you found to simplify shopping?
- What strategies have you found to simplify meal preparation?
- Ask for menu ideas that allow group members to eat well, eat easy.
- What are your triggers for overeating?

Resource Guide

Unless noted otherwise, please contact an MS Navigator™ at 1-800-344-4867 (1-800-FIGHT MS) to request copies of the publications and DVDs listed in this guide. Society publications can also be downloaded at nationalMSSociety.org/brochures and click on Brochures by title.

GENERAL

- National MS Society
1-800-344-4867 (1-800-FIGHT MS)
nationalMSSociety.org
- Can Do Multiple Sclerosis
1-800-367-3101
mscando.org

NATIONAL MS SOCIETY: ONLINE

- Live Fully, Live Well: A Program for People with MS and Their Support Partners
nationalMSSociety.org/living-with-multiple-sclerosis/live-fully-live-well/index.aspx
- MS Learn Online
nationalMSSociety.org/mslearnonline
- Multimedia Library: DVDs
nationalMSSociety.org/multimedia-library/videos--dvds/index.aspx
- Multimedia Library: Brochures
nationalMSSociety.org/brochures
- Healthy Living with MS
nationalMSSociety.org/living-with-multiple-sclerosis/healthy-living/index.aspx
- Living with MS
nationalMSSociety.org/living-with-multiple-sclerosis/index.aspx
- You CAN!
nationalMSSociety.org/youcan

CAN DO MULTIPLE SCLEROSIS: ONLINE

○ Can Do Library

msscando.org/living-with-multiple-sclerosis/can-do-library

Attending to Your Whole Self

PUBLICATIONS

- Intimacy and Sexuality in MS
- Multiple Sclerosis and Your Emotions
- Preventive Care Recommendations for Adults with MS
- Taming Stress in Multiple Sclerosis
- A Guide for Caregivers
- PLAINTALK: A Booklet about MS for Families
- Living with MS
- Choosing the Right Healthcare Provider
- Review of Regular Medications and Supplements
- Sleep Disorders and MS: The Basic Facts
- Acupuncture and MS: The Basic Facts
- Clear Thinking about Alternative Therapies

ONLINE

- Dealing with MS in Your Important Relationships
nationalMSSociety.org/living-with-multiple-sclerosis/relationships/index.aspx
- Getting the Care You Need
nationalMSSociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/index.aspx
- My Life, My Decisions, My MS (online course)
nationalMSSociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/my-life-my-ms-my-decisions/index.aspx
- Get Involved
nationalMSSociety.org/get-involved/index.aspx

Maximize Mobility, Achieve Independence

PUBLICATIONS

- Gait or Walking Problems: The Basic Facts
- At Home with MS: Adapting Your Environment
- Minimizing Your Risk of Falls: A Guide for People with MS

ONLINE

- Promoting, Function, Independence and Mobility
nationalMSSociety.org/mobility
- Adaptive Equipment, Emotional Adjustment
nationalMSSociety.org/mobility

DVD COLLECTION

- Free From Falls: A Comprehensive Fall Prevention Program for People with MS
(Also available online at *nationalMSSociety.org/mslearnonline*.)

Tips for Managing Fatigue

PUBLICATIONS

- Fatigue: What You Should Know
- Fatigue: Take Control Workbook
- Sleep Disorders and MS: The Basic Facts
- Urinary Dysfunction and MS
- Hiring Help at Home: The Basic Facts
- At Home with MS: Adapting Your Environment
- Pain: The Basic Facts

ONLINE

- **Symptoms**
nationalMSSociety.org/symptoms
- **Fatigue**
nationalMSSociety.org/fatigue

DVD COLLECTION

- **Fatigue: Take Control**

Travel & Recreation for People Living with MS

ONLINE

- Travel and Recreation
nationalMSSociety.org/travel
- Finding Another Sport You Love
nationalMSSociety.org/travel
- Accessible Nature Trails
nationalMSSociety.org/travel
- A Doctor's Travel Tips
nationalMSSociety.org/travel

Planning for Your Future (Finances & Careers)

PUBLICATIONS

- ADA and People with MS
- Focus on Employment
- Information for Employers — Know Your Rights: A Legal Guide for People Living with MS
- A Place in the Workforce
- Should I Work? Information for Employees
- The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job
- Adapting: Financial Planning for a Life with Multiple Sclerosis

SELF-STUDY PROGRAM

Career Crossroads: Employment and MS was designed by employment and MS experts to help individuals living with MS remain in the workforce. Topics covered over the course of the program include:

- Working with MS
- The Law's on Your Side
- My Little Secret
- Maximize Your Potential
- You're Not Alone
- Taking Charge

Available as a self-study guide with companion DVD by contacting an MS Navigator™ or at nationalMSSociety.org.

ONLINE

- **Staying in the Game: MS and Employment**
nationalMSSociety.org/employment
- **Insurance and Money Matters**
nationalMSSociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/index.aspx
- **Financial Planning**
nationalMSSociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/financial-planning/index.aspx
- **The National MS Society's Financial Assistance Program**
nationalMSSociety.org/living-with-multiple-sclerosis/society-programs-and-services/financial-assistance-program/index.aspx
- **Health Insurance**
nationalMSSociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/health-insurance/index.aspx

ONLINE COURSES

- **Adapting: Financial Planning for a Life with MS...Together**
nationalMSSociety.org/living-with-multiple-sclerosis/society-programs-and-services/online-classes/index.aspx
- **Career Decisions: Relationship Matters**
nationalMSSociety.org/living-with-multiple-sclerosis/society-programs-and-services/online-classes/index.aspx

DVD COLLECTION

- Career Crossroads: Employment and MS
- MS in the Workplace

Exercise Can Be a Part of Your Life with MS

PUBLICATIONS

- Exercise as Part of Everyday Life
- Stretching for People with MS
- Stretching with a Helper for People with MS

ONLINE

- **Exercise**
nationalMSSociety.org/exercise
- **Finding Another Sport You Love**
nationalMSSociety.org/travel

Eating Well, Eating Easy

PUBLICATIONS

- Food for Thought: MS and Nutrition
- Vitamins, Minerals, and Herbs in MS: An Introduction

ONLINE

- **Nutrition and Diet**
nationalMSSociety.org/living-with-multiple-sclerosis/healthy-living/nutrition-and-diet/index.aspx
- **Take Control of Your Weight**
nationalMSSociety.org/living-with-multiple-sclerosis/healthy-living/nutrition-and-diet/take-control-of-your-weight/index.aspx
- **A Guide to Portion Control**
nationalMSSociety.org/living-with-multiple-sclerosis/healthy-living/nutrition-and-diet/a-guide-to-portion-control/index.aspx

Additional resources you may be interested in...

BOOKS FROM DEMOS MEDICAL PUBLISHING

1-800-532-8663 or online at *demoshealth.com*.

- Bowling AC. *Complementary and Alternative Medicine and Multiple Sclerosis* (2nd ed.) (2007)
- Ettinger AB, Weisbrot DM. *The Essential Patient Handbook* (2004)
- Holland N, Murray TJ, Reingold S. *Multiple Sclerosis: A Guide for the Newly Diagnosed* (3rd ed.) (2007)
- Kalb R (ed.). *Multiple Sclerosis: A Guide for Families* (3rd ed.) (2006)
- Kalb R (ed.). *Multiple Sclerosis: The Questions You Have; The Answers You Need* (5th ed.) (2011)

- Northrop DE, Cooper S. *Health Insurance Resources: A Guide for People with Chronic Disease and Disability* (2nd ed.) (2007)
- Rumrill PD, Hennessey, JL, Nissen SW. *Employment Issues and Multiple Sclerosis* (2nd ed.) (2008)
- Schwarz SP. *300 Tips for Making Life with Multiple Sclerosis Easier* (2nd ed.) (2006)

OTHER

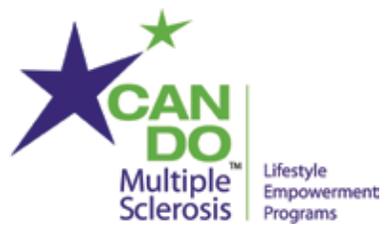
- Kalb R, Holland N, Giesser B. *Multiple Sclerosis for Dummies*. (NJ:Wiley) (2007)

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WEBINAR PROGRAMS

The Webinars can be accessed on the enclosed CD or at nationalMSSociety.org/living-with-multiple-sclerosis/live-fully-live-well/index.aspx or mscando.org/multiple-sclerosis-programs/live-fully-live-well/webinar-series/.

- **Attending to Your Whole Self** with Patricia Kennedy, RN, CNP, MSCN
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