

Thinking Outside the Box: Incorporating Nationwide Programs into Group Meetings

November, 2009

Programs and Services Department National Multiple Sclerosis Society

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TELETRAINING TOPIC

Thinking Outside the Box: Incorporating Nationwide Programs into Group Meetings

From hosting a North American Education Program, to teaching self-advocacy skills, to facilitating discussions on critical advocacy issues, self-help groups (SHGs) can be the perfect setting to engage people living with MS in educational and self-empowerment opportunities. Areas of interest to be discussed during the call include:

- An overview and discussion on the Society's nationwide programs
- An overview and discussion on the Effective Communication and Self Advocacy tool kit
- Strategies for implementing these programs in the self-help group setting
- Q&A

SCHEDULE AND CALL-IN INFORMATION

Call One

- Thursday, November 12, 2009
- 1-2 pm ET (12 pm CT, 11 am MT, 10 am PT)
- Participant Dial-In Number: 800-247-9979
- Conference ID: 3616 1649

Call Two

- Thursday, November 12, 2009
- 7-8 pm ET (6 pm CT, 5 pm MT, 4 pm PT)
- Participant Dial-In Number: 800-247-9979
- Conference ID: 3616 2489

When asked after dialing in, please provide your First and Last Name, and City and State. This information is required for purposes of tracking attendance.

PRESENTERS

The presenters for this teletraining are Kimberly Koch and Renee Vandlik.

Ms. Koch is the Associate Vice President, Family & Support Programs in the Society's Programs and Services Department. Her current responsibilities include connection programs, the Children and Teens with MS: A Network for Families, children's publications, family caregiver initiatives, and *Relationship Matters: A Program for Couples Living with MS*.

Ms. Vandlik is the Senior Manager of State Government Relations in the Society's Advocacy Department. In this role, she assists chapter staff in identifying and resolving state and local public policy issues and engaging volunteers in MS activism. Prior to joining the Public Policy Office, she worked for nearly six years as the Advocacy

Manager for the Wisconsin Chapter and gained experience in constructing a statewide advocacy program while cultivating and mobilizing a grassroots base of activists.

Please contact your chapter liaison to request copies of the materials referenced in this handout, and to discuss ways to deliver any of these programs in the self-help group setting.

Nationwide Programs

Living Well with MS

Living Well with MS is a series of workbooks that contain exercises and reflection pieces that challenge individuals to problem solve and think creatively about living with MS. Topics include:

- Coping with Change
- MS and Wellness
- Considering Adaptive Devices

Sam	ple	Exercise:	MS	and	Wellness

EXERCISE A WHAT IS THE ROLE OF WELLNESS IN YOUR LIFE? As a way to begin exploring your attitudes about MS and wellness, ask yourself the following questions: 1. Do you consider yourself a healthy person? Yes No
Please explain:
Do you consider yourself a well person? Yes No Please explain:
3. What role, if any, does MS play in your assessment of your own "health" and "wellness?"
4. If you do not consider yourself healthy and well, what would have to change in order for you to alter that opinion?
5. Do you believe you have control over your level of wellness? Yes No Please explain:
6. Are you willing to think about your health and wellness in broader terms than having MS? Yes No Please explain:

DISCUSSION

You may be asking yourself how it is possible to be healthy and well in spite of a chronic illness like MS. There are four main strategies to follow:

- Work with your healthcare provider(s) to manage your MS symptoms, slow disease progression, and prevent unnecessary complications.
- Attend to your non-MS healthcare needs via regular medical check-ups and appropriate health screening measures, as well as adequate management of any problems that may arise independent of MS.
- Engage in the same health maintenance and disease prevention behaviors that are recommended for everyone—whether or not they have MS—including good sleep habits, adequate nutrition, proper exercise, and attention to your emotional and spiritual needs.

• Be an educated consumer; stay informed about MS management strategies as well as general health maintenance guidelines for a person in your age group. The remainder of this workbook will examine these strategies in greater depth.

CogniFitness: Keeping the Mind Moving Activity Kit

Consider *CogniFitness* a mental exercise program in a box. This fun and educational activity kit was designed to help keep the mind moving and develop new techniques to strengthen cognitive skills.

The kit is comprised of 7 modules, each covering a different topic area of cognition:

- 1. Attention
- 2. Memory
- 3. Executive skills
- 4. Reasoning
- 5. Communication
- 6. Math
- 7. Creativity

CogniFitness is intended to be used in a stepwise manner, building on basic skills before moving on to more complex exercises over a period of weeks or months. The activity kit was designed to be conducted in a group setting and can be easily facilitated by a peer, activity coordinator or any health professional.

MS Learn on Line

MS Learn Online is the National MS Society's online educational webcast series. New webcasts are debuted bi-monthly, but past webcasts can be viewed and downloaded at any time from the Society's website (www.nationalMSsociety.org and go to Multi-Media Library/Webcasts & Podcasts).

Sample MS Learn Online Series

MS: The Basic Facts

- Starting with the Basics
- Newly Diagnosed with MS

Treatments

- Understanding Your Treatment Options
- Tysabri: What You Need to Know
- Complementary and Alternative Options in Treating MS

Symptom Management/Staying Well

- Managing Your Symptoms
- C.A.L.M. Down and Manage Your Stress
- Healthy Living with MS

Progressive MS

- Progressive MS
- Tips for Making Life Easier

Family Life and Relationships

- Positive Relationships
- Together in the MS Journey

Life Planning and Independence

- Career Crossroads
- Improving Independence
- Health Insurance and Medicare
- Emergency & Disaster Preparedness for People with Chronic Illness and Disabilities

Spanish

- El Cuidado Clinico de la Esclerosis Multiple
- Problemas Visuales en la Esclerosis Multiple

North American Education Program

The North American Education Program (NAEP) is an educational program that focuses on topics related to symptom management and research.

Current and Previous NAEP Programs

• Clinical Trials: Solving One Piece of the MS Puzzle
This program profiles exciting developments in the research pipeline, with
interviews of top researchers, medial professionals, and clinical trial participants.
The DVD is a two-part program (40 minutes total run time).

Part One: What You Need to Know about Clinical Trials, outlines the clinical trials process, lists the challenges to current clinical trials, and profiles participants of past trials.

Part Two: *Therapeutic Strategies in Clinical trials*, explores scientific medical treatments and their strategies to slow, stop and repair the effects of MS.

The companion book offers in-depth information about these strategies as well as therapies that are currently in clinical trials.

- The Clues of Epidemiology
 Have you ever wondered if age, race, gender, or geographic location affects who has multiple sclerosis? This program includes discussions with top scientists and researching in epidemiology, the study of disease patterns and factors such as geography, genetics and demographics.
- Hold that Thought! Cognition and MS
 This program focuses on informing people of the various conditions and effects that MS has on cognition and how to better cope with, and handle the numerous effects.

Materials available:

- Participant book
- DVD or VHS

Please note: not all NAEP materials may be available.

Career Crossroads

This program focuses on the legal employment rights of employees with MS, and examines the various ways to mitigate the physical effects of MS from affecting work performance. It also provides information on ways to disclose MS to an employer, and discusses legal protections and rights.

Materials available:

- Participant workbook
- DVD

Fatigue: Take Control

This program focuses on the fatigue and mobility issues associated with MS. Participants can learn about various ways to cope with dealing with fatigue during daily routines and how to mitigate the effects of fatigue on everyday life.

Materials available:

- Participant workbook
- DVD

Knowledge is Power

The Knowledge Is Power (KIP) program is designed as an at-home educational series for people newly diagnosed with MS and their families, but could be adapted for use in the group setting. Knowledge Is Power provides information about dealing with one of the greatest challenges presented by MS—the unpredictability and uncertainty of the future.

The volumes offered as part of the KIP program are:

- Taking the First Steps: What is MS? Dealing with Your Diagnosis & Disclosure
- Disease-modifying Treatments for MS
- Maximizing Your Employment Options
- Treating Yourself Well
- Maintaining Healthy Relationships: Family, Friends, and Colleagues
- Working with Your Doctor
- Building and Maintaining Intimate Relationships
- Parenting with MS

Online Education Programs

My Life, My MS, My Decisions

My Life, My MS, My Decisions is program to help people with MS make medical decisions about all aspects of their health. The program includes a DVD and four online courses:

- Teaming Up with Your Healthcare Providers
- Navigating the Medication Maze
- Considering Clinical Trials
- Achieving Optimal Wellness

The DVD follows three people through the medical decision-making process:

- Annie is a woman in her twenties, and was recently diagnosed. Her doctor would like her to begin taking a disease modifying medication, but she is feeling a bit reluctant. She researches the medications, talks with her doctor, and decides to start. During her decision-making process, she explores clinical trials, addresses her depression and overall good health.
- James is in his thirties and has had MS for 10 years. It is affecting his walking
 and his physical relationship with his partner. James talks with his doctor and his
 partner, researches possible medications, talks with his pharmacist about sideeffects of medications, and decides to try an ED medication. James explores
 clinical trails, works on his relationship with his partner, and finds new ways to
 stay healthy.
- Joann is in her forties and uses a wheelchair to get around. She feels that her MS
 is getting worse and her current doctor isn't willing to try some of the newer
 therapies. She decides to change doctors. Her new doctor encourages her to
 explore a clinical trial and she decides to participate.

Self-help groups are an excellent venue for the entire program. The DVD and related worksheets can be used to introduce the topic of medical decision making during a group meeting. Each member can register for the online course and agree to complete the course (or one module of the course) before the next meeting. For that meeting you could facilitate an informal discussion about what group members learned.

You could also pair the DVD with a presentation by a nurse or other medical professional on medical record keeping, working with your doctors, and considering clinical trials.

Resources Available

- Online courses
- DVD
- Worksheets

Additional Online Courses

Adapting: Financial Planning for a Life with MS Together

 MS can be an expensive disease. Learn how to plan for your financial future as a couple through classes in budgeting, debt management, and building your savings.

Intimacy: Enriching Your Relationship

• Learn how to talk about the tough issues that can get in the way of true intimacy. Learn creative ways to address and overcome these issues in your relationship.

Career Decisions: Managing Choices Together

To register for the online courses please email programsonline@nmss.org.

Meeting in a Box Tool Kits

Self-Help Group Meeting Discussion Guide Topic: Long-Term Support and Services Priorities for People Living with MS

TOPIC:

• Long-term support and services priorities for people living with MS, in the context of current health care reform debate.

MEETING OBJECTIVES:

- Provide a forum for meaningful discussions about health care reform
- Gather input from group members on long-term support and services priorities that are important to people living with MS.

TOOL KIT MATERIALS:

Core Items:

- Discussion guide
- Discussion feedback document

Reference Items:

- Handout from April 2009 teletraining for self-help group leaders on advocacy and activism.
- National MS Society Health Care Reform Principles document.
- National MS Society Health Care Reform Principles glossary of terms.
- National MS Society background paper: Long-Term Care Support and Services.

Action Steps:

- Dedicate time during an upcoming meeting to facilitate a discussion on long-term support and services priorities for people living with MS.
- Submit feedback on group's discussion to the Society's point of contact (contact information below).

DISCUSSION GUIDE

Key Messages:

- Reinforce that there is an activist role for everyone regardless of party affiliation
 in our efforts at health care reform.
- Health care reform is a major priority for the Society as we move our public policy agenda forward.
- The very difficult economic situation facing the country is further reason to act now as health care issues are integrally tied to economic issues.
- While 48 million people lack insurance/coverage for their health care, <u>250 million</u> people lack insurance/coverage for long-term services and support. Ten million

Americans daily need long-term services and support with 40 percent of them under the age of 65. Nearly half of all funding for long-term services is provided through Medicaid, which requires individuals to impoverish themselves to receive support.

- Virtually every American will have a family member who requires long-term services and support. Yet the nation lacks a comprehensive national system for financing and delivering long-term services and support to individuals of all ages with disabilities.
- Long-term care support and services include a continuum of preventive, diagnostic, rehabilitative, therapeutic, supportive and maintenance services. They address the long-term health, social and personal needs of individuals with a chronic disability or disease such as MS.
- Current legislative priorities to address these long-term needs are wide ranging and include:
 - Expansion of home and community based services
 - Medicaid waivers that allow for payment for services that permit people to remain in their homes and their communities while still receiving support and services they need, rather than entering a care facility
 - Specialized funding for 18-64 year olds requiring long-term care services
- While there is commitment by some Senators to include long-term support and services in health care reform, there is no guarantee this will happen.
- The current political momentum toward health care reform represents an unprecedented opportunity to engage the first family and administration in the MS movement and provides a new platform under which to move health care reform forward.
- Since members of the administration have personal connections to MS, the Society has a unique opportunity to raise awareness with the general public and influence key policy makers about the challenges of living not only with MS but all chronic disease.

Discussion:

Long-Term Support and Services Priorities for People Living with MS

- As health care reform legislation takes shape in Washington DC, one element that needs more attention is long-term support and services. You and your group can help ensure that long-term support is included in health care reform legislation by providing your input at this critical time.
- Ask your group members to identify and talk about the long-term support and services they believe are most important to people living with MS. Long-term care support and services include a continuum of preventive, diagnostic, rehabilitative, therapeutic, supportive and maintenance services. They address the long-term health, social and personal needs of individuals with a chronic disability or disease such as MS, and could include:
 - Family caregiver support
 - Respite services
 - Personal assistance and care
 - Homemaker services

- Adult day programs
- Supportive housing, such as assisted living
- Specialized nursing home care

Suggested Discussion Questions:

- Why are long-term support and services important to a person with MS?
- What long-term support and services are currently lacking for people with MS?
- What long-term support and services provisions should the health care reform debate include?
- How do you plan to pay for long-term support if you should need it?
- What is the role of the public sector in providing long-term support and services?

Recommended Meeting Handouts:

- National MS Society Health Care Reform Principles document
- National MS Society Health Care Reform Principles glossary of terms
- National MS Society background paper: Long-Term Care Support and Services

Group members may also request copies of these documents by calling 1-800-344-4867 (1 800 FIGHT MS) or visiting www.nationalMSsociety.org and searching for health care reform principles and/or long-term care support and services.



Report Form for Self-Help Group Meeting Discussion Topic: Long-term Support and Services for People Living with MS (Tool Kit #1) Name of self-help group leader and contact information (email and/or phone number): Chapter: Date of meeting: Number of members in attendance: What were the top three to five long-term services your group identified as most important to people living with MS?: What gaps in long-term services did your group identify as the most important to address for people living with MS?: Please share any additional thoughts or ideas shared at your meeting that your group thinks would have impact as the Society moves health care reform forward under this administration: List any other comments your group members would like to share:

Please return completed forms to your chapter liaison.

Effective Communication and Self Advocacy: Incorporating this Discussion into a Group Meeting

Effective Communication and Self Advocacy

Multiple sclerosis (MS) can complicate life situations and circumstances, but solutions for these dilemmas can be reached with deliberate planning, an informed perspective and effective communication. Use the "Effective Communication and Self Advocacy" materials for small group discussions and to provide references and resources to address a variety of personal dilemmas.

The curriculum focuses upon the necessary research to become an informed self advocate, and relies upon role-playing to practice effective communication techniques. With thoughtful, informed opinions about personal rights and responsibilities, as well as with a honed message to state a need or preference, better outcomes can be achieved for any self advocate. The overview and discussion can be completed in 60-90 minutes.

A sample agenda is:

- 20 to 25 minutes for instructor lead discussion, guided by the power point, or a hardcopy print-out of the power point;
- 10 minutes for individual work and application of a "personal circumstance" or case study applied to the "Self Advocacy Worksheet;"
- 20 minutes for role playing with a partner to present "case study" or personal life circumstances (10 minutes for each partner);
- 15-20 minutes for questions and answers.

The materials for small group discussion include:

- A Self Advocacy and Effective Communications Facilitator Guide;"
- A Self Advocacy and Effective Communications Power Point also available in hardcopy;
- An overview, "What is Self Advocacy:"
- A "Self Advocacy Worksheet," and;
- Case studies of self advocacy in various life settings, including:
 - o In the Family;
 - o In the Community, and;
 - o At Work.

These materials are complemented by resources for self-taught instruction, available at the National MS Society website at www.nationalMSsociety.org, under "Living with MS." Review these to learn more references and resources on self-advocacy related to specific life circumstances and contact your chapter liaison for the discussion materials. Modifications can be made at the presenter's discretion.