National Multiple Sclerosis Society

Self Advocacy for Medical Care and Long Term Care

Introduction

This guide is intended to help people with multiple sclerosis engage in self advocacy to better understand and guide their medical care, and, as necessary, manage their long-term care. It offers an overview of Web sites, resources and information related to these topics for the self-advocate's research purposes. The question-and-answer format was designed to help you navigate through these difficult topics. You will also see some general self advocacy questions without answers that are intended to help you start thinking about your current situation.

The National MS Society's Self Advocacy Worksheet (available at http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/download.aspx?id=8130) complements this guide. It is intended to assist you in planning your course of action. Refer to it to assess your circumstances, concerns or needs, and identify your aims or goals regarding self advocacy. You can also review sample case studies applied to this worksheet. The example for medical is available at http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-for-medica-care-and-LTC/download.aspx?id=8149. The example for long-term care can be accessed at http://www.nationalmssociety.org/living-with-multiple-sclerosis/advocate-for-yourself/self-advocacy-for-medica-care-and-LTC/download.aspx?id=8148.

To discuss any questions about this material or to request a printed copy of any of the National MS Society Web pages or publications referred to in this guide, call an MS Navigator® at 1-800-344-4867.

Medical Care

Whether you are in the pre-diagnosis stage or have advanced MS, you may have questions that need to be answered in order to feel comfortable talking about symptoms or new complications in your disease course with your treating medical professional or family members. Please review the information below to help you get ready to advocate for your own medical care.

Pre-diagnosis

If you suspect that you may have MS, or are experiencing symptoms that you have questions about, please read the following answers to some basic questions about MS.

- What is MS?

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS), which is made up of the brain, spinal cord and optic nerves. The

progress, severity and specific symptoms of MS are unpredictable and vary from one person to another.

- What causes MS?

While the cause (etiology) of MS is still not known, scientists believe that a combination of several factors may be involved. Studies are ongoing in the areas of immunology (the science of the body's immune system), epidemiology (looking at patterns of disease in the population), and genetics in an effort to answer this important question.

- Who gets MS?

In the United States today, there are approximately 400,000 people with MS – with 200 more diagnosed every week. Worldwide, MS is thought to affect more than 2.1 million people. While the disease is not contagious or directly inherited, epidemiologists – scientists who study patterns of disease – have identified factors in the distribution of MS around the world that may eventually help determine what causes the disease. These factors include gender, genetics, age, geography and ethnic background.

- What are the symptoms?

Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision.

- How is MS diagnosed?

There are several tests, strategies and exams that are done in combination to diagnose MS. One test alone is not enough to diagnose MS. The main diagnostic tools are MRI, spinal tap, visual evoked potential, blood tests to rule out other diseases, and an extensive medical history and exam.

Pre-Diagnosis resources:

What is MS? National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/what-is-ms/index.aspx

What Causes MS? National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/what-causes-ms/index.aspx

Who Gets MS? National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/who-gets-ms/index.aspx

Symptoms: National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/index.aspx

Diagnosing MS: National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/diagnosing-ms/index.aspx

Frequently Asked Questions About Multiple Sclerosis: National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/FAQs-about-MS/index.aspx

Do I have MS? National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/do-i-have-ms/index.aspx

Clinically Isolated Syndrome (CIS): National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/diagnosing-ms/cis/index.aspx

MS diagnosis
This section is intended to assist you once you have a confirmed MS diagnosis. It includes information about health care teams for MS, how to choose health care professionals, treatment for MS, alternative therapy and clinical trials. You will also notice lists of questions to ask yourself regarding your health care. These questions are intended to help you self-advocate to ensure that the care that you are receiving for your MS is the best care possible. The questions are also intended to help you evaluate if a change needs to be made in your current health care team or if you need to speak with your treating physicians regarding your care.

- Who should be on my health care team?

The health professionals who are likely to be involved with your care at some point over the course of the disease may include a family physician, neurologist, neuropsychologist, nurse, occupational therapist, orthotist, physiatrist, physical therapist, speech/language pathologist, and urologist.

- How well do you work with your doctors and other members of your MS health care team?

- Do you understand the role that each member of your health care team plays in your MS care?

- Do you feel respected and that you are being listened to? Would your caregiver agree?

- How do you locate doctors with MS expertise?

If you need a referral to an MS clinic or a neurologist with experience with MS, please call an MS Navigator® at the phone number above or refer to the Web site below.

MS diagnosis resources:

Team of Professionals: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/team-of-ms-professionals/index.aspx

The Family's Relationship with the Physician and Health Care Team: **MS: A Guide for Families** by Dr. Rosalind C. Kalb, PhD: Information available at
http://www.nationalmssociety.org/multimedia-library/books/a-guide-for-families/index.aspx

Primary Care in MS: National MS Society Web site
http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=3689

Making the Most of Your Doctor Visits: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/doctors-visit/index.aspx

Resources for MS Physicians:
Treatment Locations by State: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/treatment-locations/index.aspx

Choosing the Right Health Care Providers: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=25

How is MS treated?
Although there is still no cure for MS, effective strategies are available to modify the disease course, treat exacerbations (also called attacks, relapses or flare-ups), manage symptoms, improve function and safety, and provide emotional support. In combination, these treatments enhance the quality of life for people living with MS.

- Are you following all of your doctor's advice?
- Is there anything about your MS treatment that displeases you? Are you sharing that with your treating physician? Are you discussing treatment goals?
- Emotional concerns?
- Complementary and Alternative Therapies?

- Do you know why your doctor has prescribed certain medications — including disease-modifying and symptom management drugs?

Disease-modifying therapies can reduce disease activity and disease progression for many individuals with relapsing forms of MS, including those with secondary-progressive disease who continue to have relapses.

Treatment resources:

MS and Your Emotions: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=151

Complementary and Alternative Medicine: National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/complementary--alternative-medicine/index.aspx

Treatments: National MS Society Web site
http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/index.aspx

The Disease-Modifying Drugs: National MS Society Web site
http://www.nationalmssociety.org/aboutmultiplesclerosis/treatments/download.aspx?id=45

Advanced MS
Multiple sclerosis is a progressive disease for which no cure has yet been found. Although we have treatments to manage the disease course, they are only partially effective, which means that some people's MS will worsen in spite of everything they and their doctors do to try and prevent it.

Many people ask themselves: Why did this happen? Did I choose the wrong doctor or the wrong medication? Did I follow the wrong diet or the wrong exercise program? Did I get too stressed out at my job? But the fact is, MS progresses because that is the natural course of the disease.

While researchers are working to identify new and better strategies to stop that progression, people whose MS has become more disabling — and their family members and friends — need information about how to manage the challenges they face.

Advanced MS Resources:

Living with Advanced MS: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/living-with-advanced-ms/index.aspx

Caring for Loved Ones with Advanced MS: A Guide for Families: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/living-with-advanced-ms/download.aspx?id=789

Managing Progressive MS: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=314

So You Have Progressive MS: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=316

My MS, My Way: National MS Society Web site
http://www.mymsmyway.com/

Living Wills: Protecting Your Medical Choices: National MS Society Web site
http://www.nationalmssociety.org/multimedialibrary/momentummagazine/momentum-summer-08/download.aspx?id=1064

Long-Term Care

The progress, severity and specific symptoms of multiple sclerosis in any one person cannot yet be predicted. Nearly a quarter of individuals living with MS will require long-term care support and services at some point during the course of the disease. The National Multiple Sclerosis Society is dedicated to helping people living with MS and their families secure those critical services.

- What is long-term care?

The phrase “long-term care” refers to all the services that people with an illness or disability might need to help them in performing activities of daily life, such as dressing, showering, preparing meals, managing their home and so forth. Long-term care encompasses a wide range of services, including housekeeping, personal assistance, adult day health care, respite care, support for caregivers, community housing options and nursing home care.

- Do I need long-term care?

This decision needs to be made by you, your family and your health care team.

- How do I pay for long-term care?

Shopping around for private long-term care insurance after a diagnosis is your best bet in finding an insurer. Please note that relatively few long-term care insurers will sell to people with MS. Those that do may not widely advertise and may accept people on a case by case basis.

- Do you have personal insurance that will pay for long-term care?

You need to check with your private insurance company to see if they cover the expense for long-term care. Please check any and all policies that you

hold including all long term-care policies — private and through your employer.

- Are there government resources that may help to pay for long-term care?

The Community Living Assistance Services and Supports Program or CLASS Act, part of the Health Care Reform Legislation, is a way for workers to voluntarily have their paycheck reduced and be eligible for long term care services after a 5 year vesting period. This program will be effective come 2011 with further direction from the Department of Health and Human Services in 2012.

- How much care do I need?

This is a question that you need to discuss with your doctor. Your treating physician and your care team can make the correct recommendations as far as your level of care, and write your recommended care plan.

Long-term care resources:

Long-Term Care: Support and Services Background: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=206

MS: The Questions You Have, the Answers You Need by Dr. Rosalind C. Kalb, Chapter 16: Information available at
http://www.nationalmssociety.org/multimedia-library/books/the-questions-you-have/index.aspx

Opening Doors: The Palliative Care Continuum in MS: National MS Society Web site
http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=1027

American Health Care Association
1201 L Street, NW
Washington, DC 20005
1-202-842-4444
http://www.longtermcareliving.com/

The Kaiser Family Foundation
The CLASS Act
1330 G Street, NW
Washington, DC 20005
1-202- 347-5270
http://www.kff.org/healthreform/upload/8069.pdf

Adapting: Financial Planning for a Life with MS: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=11

Talking About Life Planning: National MS Society Web site
http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/download.aspx?id=183

The Long Term Care Needs of People with MS: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=222

Shopping for Life, Disability and Long-Term Care Insurance: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/insurance-and-money-matters/other-insurance/shopping-for-insurance/index.aspx

Plan Smart for the Long Term: Medicaid Changes You Should Know: National MS Society Web site
http://www.nationalmssociety.org/multimedia-library/momentum-magazine/back-issues/insidems-feb-mar-2007/download.aspx?id=119

- What is assisted living?

Please see document below, "Assisted Living for Individuals with MS" or visit
http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=522

- What is the difference between assisted living and skilled nursing facilities?

Assisted living is intended to provide a residential environment and resident-centered services that foster residents' quality of life, privacy, choice, dignity and independence. It is intended to provide quality services, individualized for residents and developed collaboratively with them, to support the resident's decision making to the maximum extent possible.

Skilled Nursing Facilities offer a higher level of care as well as 24 hour skilled nursing services if necessary. Skilled nursing facilities are expected to meet a client's daily needs while trying to maintain the client's independence and physical well being.

- Can I stay in my home with a caregiver?

Please review options for in-home care and caregiver resources below.

Assisted living/Skilled nursing facility/In-home resources:

Assisted Living for Individuals with MS: Guidelines and Recommendations for Quality Care: National MS Society Web site. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867

http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=522

Assisted Living Federation of America
1650 King Street, Suite 602
Alexandria, VA 22314
1-703-894-1805
http://www.alfa.org/i4a/pages/index.cfm?pageid=3278

Nursing Home Care of Individuals with MS: Guidelines and Recommendations for Quality Care: National MS Society Web site. For a copy of this information or to speak with an MS Navigator®, call 1-800-344-4867
http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=523

Centers for Medicare and Medicaid Services: Certification and Compliance, Nursing Homes
1-800-MEDICARE (1-800-633-4227)
http://www.cms.hhs.gov/CertificationandComplianc/12_NHs.asp#TopOfPage
http://www.medicare.gov/Publications/Pubs/pdf/02174.pdf

Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850
1-800-MEDICARE (1-800-633-4227)
http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True

Great Places
http://www.greatplacesinc.com/

A Place for Mom
221 First Ave. West, Suite 350
Seattle, WA 98119-4285
1-206-285-4666
1-877-MOM-DAD9 (1-877-666-3239)
www.aplaceformom.com

Caring for Loved Ones with Advanced MS: A Guide for Families: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=789

The Lifespan Respite Care Act Position: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=208

Serving Individuals with MS in the Home: Guidelines and Recommendations for Home Care Providers and Personal Care Assistants: National MS Society Web site
http://www.nationalmssociety.org/download.aspx?id=1015

A Guide for Caregivers: Managing Major Changes: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=155

MS Basic Fact Series: Hiring Help at Home: National MS Society Web site
http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/download.aspx?id=313