

TALKING WITH YOUR PATIENTS ABOUT **LIFE PLANNING AND MS**

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**National
Multiple Sclerosis
Society**

The National MS Society's Professional Resource Center provides:

- Easy access to comprehensive information about MS management in a variety of formats;
- Dynamic, engaging tools and resources for clinicians and their patients;
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nationalMSSociety.org/PRC

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Introduction

Use this resource to help facilitate conversations with your patients about planning for the future. The unpredictable course of MS is a source of considerable distress for most people. Having a frank discussion about the status of their disease and what may happen in the future is important, and will likely address questions your patients may be too afraid or uncomfortable asking. Helping people to “hope for the best, while planning for the worst” may help them anticipate possible future needs and engage in appropriate planning to meet those needs. While most individuals with MS do not become severely disabled, we can’t predict with any certainty what the outcome may be for any given individual. Rather than seeing life planning as a fatalistic or negative activity, encourage your patients to see it as taking ownership of the future, reducing medical and financial risk, and doing everything that can be done to assure security, autonomy, and quality of life.

Why should I discuss life planning with my patients?

- Lack of planning can seriously impact a family’s financial security and access to healthcare and long-term care services.
- Multiple sclerosis is an expensive disease, often involving significant out-of-pocket expenditures for medical and equipment needs. In 2014, the annual direct healthcare costs for people with MS were reported to be \$24,327 higher than for the general population. In addition, people with MS had a significant higher risk of being unemployed (Campbell et al., 2014).
- MS often strikes in the early adult years when careers are not fully established and many people have growing families that require their care and support. Generally, there has not been sufficient time to accrue assets for the future. People may not be able to count on home ownership as a resource in the same way that older adults often can, and mortgage payments may still be a major financial burden.
- The opportunity to purchase long-term care insurance or disability insurance is usually lost once the diagnosis is made, so other protections must be sought.

What is life planning?

- Life planning is a process of anticipating needs that might arise in the future and planning for them. It focuses on physical health, finances, family resources, and potential long-term care needs.
- Life planning includes:
 - Managing income, assets, expenses, and investments
 - Maximizing health insurance coverage
 - Anticipating changes in employment and income
 - Understanding rights, benefits, and protections relative to employment, disability rights, and insurance
 - Maximizing government assistance and other resources

- Planning with the family for possible future long-term care needs
- Successfully planning an estate

What can I say to a patient who feels that anticipating possible needs in the future is being pessimistic and giving in to the disease?

- Emphasize that planning for future care needs is not just for those dealing with chronic illnesses. The subject is receiving increasing public attention within our society at large. Long-term care insurance is being highly promoted, and while it may not be available for someone who has already been diagnosed with MS, it is certainly a viable option for the healthy spouse.
- Normalize life planning by pointing out that we all buy home insurance and car insurance as a matter of course; we know and hope the coverage will never be needed, but if it is, we are prepared. It is in this same spirit that people with MS need to engage in the life planning process.
- Point out that although families have traditionally provided the safety net of care for their members, today's fragmented and mobile population means that family members are often not available to assume this role. In addition, it is now the reality for most families that households depend on the employment of all adult family members in order to meet expenses.
- Emphasize that this type of planning helps them proactively exert some control over their future, rather than being caught off-guard and unprepared, or making difficult decisions in the midst of a crisis.

Should I discuss the subject of life planning with someone who is newly diagnosed?

- When a person is newly diagnosed, the priority is to provide support and encouragement, and not to focus on a discussion of worst case scenarios. However, health insurance is one important topic to address very early on.
- Encourage your patients to explore and understand protections that exist for someone who has a pre-existing condition and may want or need to change employment. It is no longer necessary to feel 'locked' into a job to maintain health insurance. Once someone has had group coverage for a year, he or she has usually met any 'pre-existing' requirement and can switch into another group plan without a penalty or waiting period.
- It is also advisable to encourage patients to take a financial inventory early in the course of their disease, taking into consideration their assets and debts, and any expenses that might need to be added to their budget (e.g., medications, physical therapy).

Beyond financial planning, what can I advise my patients with MS to do to plan for future needs?

- Encourage them to maintain open lines of communication within their families, thinking together about what would happen if MS imposed changes in the future—What if they require assistance with personal care in the future? How available are family members? What other life demands are competing with the needs of the family member with MS? Is the home accessible?
- Encourage them to look at options for assistance, i.e., community services, benefits, and entitlements that could help address their needs in the future. The best time to be an ‘educated consumer’ is not when one is in crisis, but when one can take the time to learn about options and gather information for future reference.

If a patient is considering hiring help at home, how can I support the process?

- Be sure your patient is clear about what kind of help is required—companionship, chore services, or personal hands-on care. The level of skill required for each of these services varies, as does the cost. Therefore, if a person only needs someone to run errands and vacuum the house, there is no need to pay for a certified nurse’s aide.
 - Suggest that the patient and family spend time clarifying exactly how much help they need, and whether they will get services through a community agency or hire help on their own. Who will interview and train the applicants (if they plan on hiring privately), and who will be responsible for the scheduling and payment of a privately-hired assistant?
 - Suggest they talk to their insurance company about any third party coverage of home services.
 - Encourage them to call the National MS Society, or their local department of social services, to see if they qualify for services that could be paid for on their behalf or for which they might only have to pay on a sliding scale, and for referrals to agencies in their community.
- They may need a physician’s order for some home care services, so be prepared to complete paperwork or justification for the services.

How do I respond to a patient who is convinced he/she is going to ‘end up in a nursing home’?

- Anticipating the ‘worst case scenario’ is the way some people emotionally prepare themselves for a possible eventuality. It allows them to adjust to an idea over a period of time and lower expectations so that they will not feel too “let down” or disappointed. However, premature worry about uncertainties significantly reduces one’s present quality of life. Remind your patient—particularly if he or she has been on disease-modifying

medication and doing well that most people with MS do not become severely disabled. Do not, however, offer false hope or dismiss realistic concerns.

- Remind your patients that even those with a progressive course of MS can usually continue to live in their own home with home-based services. While there are those whose complex medical needs require 24-hour skilled nursing care, most people are able to manage with home care services, adult day care, visiting nurses, home-based personal assistant services, and help from family and friends.

How can I respond to family members who have different ideas about what will be best for their loved one with MS regarding the future?

- Family members have different strengths, abilities, needs, and priorities. They are at different places in their lives in terms of age, experience, responsibilities, life plans, needs, and emotional make-up. Therefore, families need to be reassured that it is not surprising for tensions to arise when difficult decisions must be made, e.g., hiring help at home, or considering nursing home placement.
- Often families are able to come to some consensus. However, if conversations are too stressful, or they are not able to even initiate conversation, they might consider a family counselor to help facilitate the discussion. The National MS Society can refer families to counselors who are familiar with MS and planning issues.

If MS is progressing for my patient, what types of resources might they need to explore?

- Physical rehabilitation
- Vocational rehabilitation
- Counseling
- Durable medical equipment
- Assistive technology
- Home modifications
- Car modifications
- Home-based nursing and personal assistance services
- Delivered meals
- Adult day programs
- Assisted living options
- Nursing home facilities

What professionals can help my patients with accessing these services and with the life planning process?

- **Social workers and discharge planners** assist individuals with referrals to community resources and with understanding insurance coverage.

- **Financial planners** assist individuals to set long-term financial goals and formulate strategies to achieve them. These strategies include investments, tax planning, asset protection, risk management, retirement planning, and estate planning. Financial planners should have CFP certification by the Certified Financial Planner Board of Standards, Inc.
- **Elder law attorneys** specialize in legal issues affecting the elderly and people with disabilities. These issues include public benefits (Medicaid, Medicare, Social Security), probate and estate planning, wills and trusts, guardianships/conservatorships, and health and longterm care planning. Elder law attorneys receive certification from the Board of Certification of the National Elder Law Foundation (NELF).
- **Care managers**—sometimes referred to as geriatric care managers—are experts in health and social service systems; their role is to link people to services through a process of assessment, planning, and coordination. Care managers usually hold advanced degrees in social work, psychology, nursing, or a related health and human services field. CMC and CCM are designations of a ‘certified care manager’.

What other resources are available on this topic?

- The National Multiple Sclerosis Society can provide your patients with names of professionals in the community who are experienced with life planning for those with chronic illness. The Society also offer educational programs, support groups, and other resources to support patients’ coping efforts and help them deal with MS-related changes.
- The National MS Society has created educational materials on a wide range of topics. Your patients can obtain these and other materials free of charge by calling (1-800-344-4867) or in the Library section of the website at nationalMSSociety.org/Brochures
 - A Guide for Caregivers
 - At Home with MS: Adapting Your Environment
 - Hiring Help at Home: The Basic Facts
 - Managing Progressive MS
 - PLAINTALK: A Booklet about MS for Families
 - So You Have Progressive MS?
 - Specific life planning resources are available at: nationalMSSociety.org/Planning
- Recommended reading:
 - National Endowment for Financial Education (2003). Adapting: Financial Planning for a Life with Multiple Sclerosis.
 - Paralyzed Veterans of America and the National Multiple Sclerosis Society (available by calling 1-800-344-4867 or at nationalMSSociety.org/pdf/financeguide/MS_PVA_Adapting.pdf)
 - Kalb R (ed.). (2006). Multiple Sclerosis: A Guide for Families (3rd ed.). New York: Demos Medical Publishing.
 - Kalb R (ed.). (2008). Multiple Sclerosis: The Questions You Have, The Answers You Need (4th ed.). New York: Demos Medical Publishing.

About the author

Dorothy Northrop, MSW, ACSW, retired from the National Multiple Sclerosis Society in 2013 after 18 years and now works part-time as a social worker at the MS Comprehensive Care Center at Holy Name Hospital in Teaneck, New Jersey. At the time of her retirement, Ms. Northrop was serving as Vice President of Clinical and Continuum of Care Initiatives, focused on expanding long-term care options and health care access for people with MS. She served on various advisory and professional boards related to long-term care during her tenure, including the Policy Panel of 'Long Term Services and Supports' of the National Association of Social Workers, the Accreditation Commission of the National Association of Home Care & Hospice, and the Leadership Council of Advanced Person-Centered Living. Ms. Northrop received her Masters degree in social work from Columbia University.

Other resources for
Talking with Your MS Patients include:

Cognitive Dysfunction
Diagnosis of Multiple Sclerosis
Progressive Disease
Elimination Problems
Sexual Dysfunction
Depression and Other Emotional Changes
Initiating and Adhering to Treatment with Injectable Disease Modifying Agents
Family Issues
Reproductive Issues
The Role of Rehabilitation
Life Planning
Primary Progressive MS (PPMS)
Palliative Care, Hospice and Dying
Wheeled Mobility



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