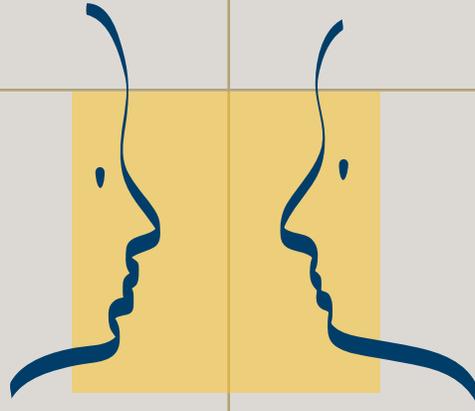




National
Multiple Sclerosis
Society

*Talking with Your
MS Patients about
Difficult Topics*



Talking about Palliative Care, Hospice, and Dying

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Professional Resource Center

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The National MS Society's Professional Resource Center (PRC) has long been a resource for health professionals providing care to people with multiple sclerosis. The PRC, which houses a comprehensive library of MS information, provides continuing education opportunities and offers multidisciplinary expertise on MS disease process and management questions, health insurance issues, long-term care options, and the development of MS specialty clinics. The goal of these services is to enhance quality of care and increase access to care for people with multiple sclerosis.

Physicians are invited to consult via email with MS specialist colleagues who serve on our National Clinical Advisory Board

MD_info@nmss.org

Allied health professionals are invited to consult via email with MS specialist colleagues

HealthProf_info@nmss.org

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Professional Resource Center

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Introduction

This booklet is designed to facilitate conversations with your patients about the need for palliative care or hospice care, and about what dying with MS may be like. Typically these discussions are left for very late in the disease course, if they occur at all. Often clinicians may feel that they are reducing feelings of hope by talking about end-of-life concerns or by recommending palliative care or hospice services. But questions about what might happen to a person living with a serious, chronic illness are natural: “Will I die from MS?” is not an unusual question from one faced with this frightening diagnosis.

In fact, many patients and their loved ones feel a sense of relief that the clinician is willing to answer their questions about “late stage” MS and particularly about dying, even if the questions are asked early in the diagnosis. Too often we let these concerns become the “elephant in the room.” As clinicians, we may feel that once medications are no longer effective, we have “nothing left to offer.” Often an honest discussion about progression and end-of-

life choices, along with timely referrals to and collaboration with comprehensive palliative care or hospice services, can return to the patient a sense of hope for whatever amount of time is remaining, be it months or many more years.

At whatever point during the disease course you find yourself caring for a person with MS, either on your own or with a multi-disciplinary team, you have an opportunity to focus on that person’s unique quality-of-life needs and the relief of suffering. You can also facilitate advance planning at any time. Once you have a clear understanding of the different services available to people with advancing disease, and obtain a comfort level with the topic of disease progression and dying, you can be effective in facilitating these difficult conversations with your patients and making referrals whenever they demonstrate readiness or you determine the need. Even though you are not providing primary care to your patients with MS, we feel certain that they will benefit from the opening of this door to discussion at some point in their illness.

1. How is palliative care similar to and different from end-of-life or hospice care?

Sometimes these two services are confused or the terms are used interchangeably because palliative care services, education, and certification grew out of the hospice movement. Palliative medicine and hospice exist along a continuum of care that addresses the ongoing need to set care goals reflective of the values and wishes of the person living and eventually dying with a chronic, progressive illness. More specifically:

- Palliative medicine clinicians specialize in intensive symptom management—

including pain and other kinds of suffering—and the ongoing discussion of goals of care, with a focus on enhancement of patient quality of life and caregiver well-being. Hospice clinicians have a similar focus, but have additional expertise in helping the patient and family “finish” their relationship business, address financial concerns relating to the time after the loved one has died, creating “legacy” wish lists, and other specific end-of-life matters.

- Palliative care can be accessed earlier than hospice care and can be appropriate at any point in an illness. Palliative care's goal is to relieve suffering, be it physical, emotional, or spiritual in nature.
- Palliative care can be utilized as a complement to MS comprehensive care; ideally both can be provided in an integrated way to enhance the care that each can offer the person with refractory symptoms and other care complexities.
- Palliative care can be initiated while curative or disease modifying treatments are still being utilized, whereas hospice care is accessed when it is determined that the person's remaining lifespan is likely to be 6 months or less and potentially curative treatments are no longer in the picture.
- Palliative care can be provided either as a consultation in a hospital setting or as a home visiting medical service; palliative medicine concepts can be utilized—and often are—as a part of the MS clinical team's approach to patient care. Hospice can be accessed at home, in special residences in some locations, or in assisted living or nursing home facilities. Both palliative care and hospice are appropriate for people of any age.
- Palliative medicine and hospice care are typically provided by teams that include specially trained doctors, nurses, and social workers, working in partnership with the ill person's primary care physician. Hospice teams generally provide additional services, including spiritual counseling, volunteer visitors, massage and music therapy, nutritionist, and home health aides.

2. How do I know if a patient is ready to talk about palliative care?

- Patients often give us verbal “triggers” that they are ready for a discussion about how MS is affecting their quality of life. Sometimes it's also clear that they are not able to understand the goals of the symptom management and referrals we've initiated for them. We need to listen carefully for the cues. Some of these include:
 - Comments about the burden that they feel they are causing their family members.
 - Unrealistic statements about being cured; for example, someone who has lost use of lower extremities who says, “When I am walking again . . .” or who refers to planning to use a “miracle” cure read about on the Internet.
 - Reports of distress—physical, emotional, or spiritual.
 - Comments about how the treatments no longer seem to be working and “I'm getting worse.”
 - Subtly expressed suicidal thoughts, such as “I'd be better off dead” or expressions of hopelessness, such as “What's the point of living?” The person may not actually be suicidal, but just feeling despair about the burden he or she may be causing others. But of course, these statements must be explored and an appropriate referral made if the intention is sincere.
 - Comments about having reached the limit of what can be handled or tolerated.

- The conversation can begin with your stated wish to clarify the feelings being expressed by the patient or family member. You can probe further with comments such as, “I think I am hearing that you feel . . . Is that correct?” or “What I think you are saying is . . . Am I on track?” By acknowledging the frustration, hopelessness, or other emotions behind the comments or statements, you will open the way to more direct dialogue about feelings and concerns.
- Asking directly if the person is suffering is also effective. Suffering can include physical symptoms or emotional and spiritual distress.
- Next you can let the patient and/or family member know that there are options for care at this point in the illness, even if disease modifying medications are no longer in the picture.

3. How do I know a patient is ready to be referred to a palliative medicine service?

The Center to Advance Palliative Care sponsors Get Palliative Care (www.getpalliativecare.org), which provides a listing by state of palliative care services. Their site also lists the following clinical and psychosocial “benchmarks” to use as a guide for palliative care readiness:

- In the presence of a serious, chronic illness:
 - Declining ability to complete activities of daily living
 - Weight loss
 - Multiple hospitalizations
 - Difficulty controlling physical or emotional symptoms related to serious medical illness
 - Patient, family or physician uncertainty regarding prognosis
 - Patient, family or physician uncertainty regarding goals of care
 - Patient or family requests for futile care
 - Do not resuscitate (DNR) order conflicts
 - Use of tube feeding or total parenteral hyperalimentation (TPN) in cognitively impaired or seriously ill patients
 - Limited social support and a serious illness (e.g., homeless, chronic mental illness)
 - Patient, family or physician request for information regarding hospice appropriateness
 - Patient or family psychological or spiritual distress
- To this list, and specific to MS, we would add:
- Cognitive changes that indicate decline in the person’s decision-making abilities and abilities to carry out activities of daily living (ADLs) independently
 - Referrals to palliative care can be made by the person’s primary care physician, or by his or her MS neurologist, nurse practitioner, or nurse. Call your local hospital or the patient’s home-based program to find out the best way to make a referral.
 - When a patient and family are referred for palliative care, it is important that you reassure them that you will stay involved in their care.
 - Ask permission to contact the palliative care primary nurse or physician once the case is open.

- Let the palliative care service know that you will be staying involved in the patient's care and would like to collaborate with them and devise a system for sharing information (within HIPAA guidelines).
- Offer to send information about MS (available at www.nationalMSSociety.org/PRCPublications)
- Continue to see the patient and family at regular, agreed-upon intervals to foster ongoing communication and collaboration with the palliative care service.

4. How can I prepare myself to be comfortable talking about end-of-life care with my colleagues and patients?

- One way to become more comfortable with end-of-life issues is to do your own end-of-life planning. If you haven't already done so, start the process of identifying your own end-of-life wishes and decide whom you'd like to ask to be your health care agent in case you are unable to represent yourself at the end of life.
- Some people think that their health care agent needs to be a relative. If married, many people assume that their spouse should be their agent. What is more important than the particular relationship you have is the person's ability to truly represent your dying wishes with the greatest integrity. Someone very close to you, like a spouse or grown child, may find it simply too painful to speak about *your* choices in the midst of facing your loss.
- It is most important to have an honest and thorough conversation about potential "if-then" scenarios with your chosen healthcare agent, rather than assuming that he or she "will just know" what you would have wanted. For example:
 - "If I were to lose all brain function, and the chances of regaining it were very slim, I would not want to remain on life support."
 - "If I were to go into a coma after a diagnosis of a terminal illness, I would not want to be given antibiotics for infections."
 - "If I were to be in a car accident, completely lose the use of my limbs, and sustain severe brain injury, I would not want CPR."
- Read books about death and dying. Since the beginning of the hospice movement in the US some 30 years ago, there has been an increase in the literature for professionals and laypersons alike. We make some recommendations at the end of this booklet.
- Once you feel more prepared to have these discussions about palliative and end-of-life care with your patients, practicing empathic listening is key. Asking open-ended questions and following up on verbal and non-verbal cues with a sense of genuine curiosity will make for positive communication with patients and their family members.
- And of course, practice makes for improvement. The first time that you try to talk about end-of-life concerns or make a palliative care referral may in fact feel awkward. You can begin the discussion by letting the patient and family know that you realize this is a difficult issue but that you want to offer them the best care

possible, and so you are thinking that they may be ready for this type of service or change in focus of the care you are already giving them. It's important to make sure that the patient and family don't feel that you are abandoning them because the issues have gotten too complex or that "there's nothing left to be done."

- In addition, open the door to learning more about palliative care by taking advantage of conversational opportunities when collaborating with palliative care or hospice service providers. Ask for reading materials about palliative and hospice care.

5. How can I know the person with MS is in the "terminal" stages and hospice appropriate?

- It is not easy to determine a "terminal" phase of MS. In fact, Medicare does not yet have any specific guidelines for certifying people with MS for hospice. It is useful, however, to become familiar with the Medicare guidelines that are available for other conditions. You can go to the Center for Medicare and Medicaid Services website at www.medicare.gov or the Medicare Rights Center website at www.medicarights.org to determine if there are some overlapping medical problems that might be appropriate for qualifying a patient for the 6-month hospice benefit (part of Medicare and Medicaid covered services, as is true with many commercial insurances). Examples of these include:
 - Critical nutritional impairment
 - Life-threatening complications and events, such as repeated hospitalizations for infections
 - Refusal of ventilation
 - Rapid disease progression such as changes in speech and swallowing abilities, respiratory function, and ambulation; increased dependence in ADLs; or increased cognitive impairment
- Some of the common core indicators of end-stage disease include the following:

- Physical decline
- Weight loss
- Multiple co-morbidities
- Dependence in most ADLs
- Desire/will to die
- Karnofsky score < 50% (a functional impairment scale in which lower scores indicate lower expectations for survival)

We have heard from home care and hospice nurses about people with MS seeming to be in the terminal stages of illness, perhaps with a repeat respiratory infection or a stage III or IV pressure ulcer, who then recover and go on to live many more months. This does not necessarily mean that these patients are not appropriate for hospice services.

- Hospice is intended to be a benefit for patients with a 6-month-or-less life expectancy. Unfortunately many people are referred to the service later in their illness. The average length of hospice service has increased over the past 10 years from 48 to 72 days.
- On the other hand, given the fact that a terminal status in MS seems difficult to determine, the patient referred to hospice may in fact "outlive the benefit," sometimes more than once. Once a person is accepted into a hospice

program, though, and still felt to be in need of, and appropriate for the services, he or she will rarely be de-certified. The 6-month service period is renewable.

- Hospice as a home-based program is intended for people who have an appropriate level of help (generally this means a caregiver living with them). Hospice will generally provide a small

number of a home health aide hours per week, which would most likely be inadequate and potentially unsafe for someone living alone in the last months of an illness.

- For more information about hospice, see the website for the Hospice Foundation of America at <http://www.hospicefoundation.org/hospiceInfo/>

6. What if a health care proxy goes into effect for a person with MS, and other members of the family or loved ones do not agree about carrying out the patient's end-of-life wishes? For example, what if some loved ones want "to do everything possible" and "heroic measures" despite the expressed wishes of the dying person to not prolong the dying process?

This unfortunately is not an unusual situation. Sometimes people execute advance directives without sharing the nature of their wishes with all members of a family or circle of loved ones. This may leave the assigned health care agent (proxy) in a very difficult position—trying to convince the others of their loved one's end-of-life wishes as expressed to him or her at the time the advance directives were executed. It is important at that point to call a family meeting, ideally mediated by an outside party such as a social worker or clergy person known to the ill person and/or family. The purpose of the meeting is twofold: to make clear that it is important to

honor the wishes of the dying person so that she may be allowed to die according to how she lived and in a manner true to her personal values; and to help the dying person's loved ones to begin the process of letting her go. At the family meeting, it is also important to allow for each concerned person to express his or her feelings about what is happening. Having a mediator who is both comfortable with and knowledgeable about the dying process is beneficial. If the person dying with MS is enrolled in a hospice service, the family meeting could be mediated by someone on the hospice staff, as they are well trained to help with these types of conversations.

7. How do people with MS die?

We often talk about dying *with* MS rather than *from* it, as many people with MS live a near-normal lifespan. Some statistics indicate that MS may shorten the lifespan by up to 10 years [Bronnum-Hansen H, Koch-Henriksen N, Stenager E. Trends in survival and cause of death in Danish patients with multiple sclerosis. *Brain* 1994; 127: 844–850]. A better system for tracking MS deaths would be helpful, since MS is

rarely listed as a primary or even secondary cause of death. However:

- People with a more severe course of MS may die from complications of the disease, such as sepsis caused by
 - recurrent or severe acute infections, like urinary tract infections (UTIs) or aspiration pneumonia
 - stage-4 pressure sores

- People with MS are at a higher risk for suicide than the general population. In one large-scale study, the risk was found to be 7.5 times higher in this population [Sadovnick AD, Eisen K, Ebers GC, Paty DW. Cause of death in patients attending multiple sclerosis clinics. *Neurology* 1991; 41: 1193–1196].
- Respiratory insufficiency from weakened diaphragm and accessory muscles that support respiration can also be the cause of death in MS. Decreased nutritional status caused by difficulty swallowing, appetite loss secondary to serious depression, or dementia, can compound a weakened respiratory system.
- Adult failure to thrive (AFTT) has recently been recognized as contributing to a terminal state in many chronic, progressive illnesses.

- Many people with MS actually die from concomitant illnesses, such as heart disease, cancer, and renal failure; hence the fact that many people die *with* MS.

We hope that this pamphlet has been helpful to you in thinking about the issues of palliative care and hospice readiness, end of life, and death in MS. These are not easy topics to think about, much less to discuss. And it's not unusual for people on both sides of the healthcare equation to feel, irrational as we know it is, that in *bringing up* death they may be *bringing on* death. However, we feel strongly that we have an obligation to our patients to answer their sometimes "unasked" questions—even about dying.

8. What kinds of resources are available to help my patients and their families with end-of-life issues?

- Chapters of the National Multiple Sclerosis Society (1-800-344-4867) can provide information about local hospice and palliative care programs, names of mental health professionals, support groups, respite programs and educational material. Encourage your patients to make chapter contact.
- The National MS Society has created educational materials on a wide range of topics. Your patients can obtain these and other materials at no charge by calling 1-800-344-4867 or online in the Multimedia Library section of the website at www.nationalMSSociety.org/Brochures:
 - Taming Stress in Multiple Sclerosis
 - MS and the Mind
 - Pain: The Basic Facts
 - Speech and Swallowing: The Basic Facts
- Managing Progressive MS
- A Guide for Caregivers
- Hiring Help At Home: the Basic Facts
- At Home with MS: Adapting Your Environment
- Depression and Multiple Sclerosis
- Urinary Dysfunction and MS
- Cuidando de una persona con Esclerosis Multiple—Una Guia para Cuidadores (A Guide for Caregivers)
- **Palliative Care and Hospice Websites**
 - AARP (end of life, wills, estate planning, etc.): www.aarp.org/families/end_life
 - American Academy of Hospice and Palliative Medicine: www.aahpm.org
 - Palliative care nursing: www.palliativecarenursing.net

- Karnofsky Performance Status Scale Definitions Rating (%) Criteria: www.hospicepatients.org/karnofsky.html
- Promoting Excellence in End-of-Life Care: www.promotingexcellence.org
- Robert Wood Johnson Foundation: www.rwjf.org
- **Recommended Readings**
 - Brandis M, Reitman N, Gruenewald D, Del Bene M. *Opening Doors: The Palliative Care Continuum in Multiple Sclerosis*, 2009. A National MS Society Clinical Bulletin for health professionals available at www.nationalMSSociety.org/ClinicalBulletins.
 - Byock I. *Dying Well: Peace and Possibilities at the End of Life*. New York: Putman, Riverhead, 1997.
 - Callahan M, Kelley P. *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. New York: Bantam, 1992.
 - Casaret DJ, Quill TE. "I'm not ready for hospice": Strategies for timely and effective hospice discussions. *Ann Intern Med* 2007; 146(4): 443–449.
 - DeSpelder LA, Strickland AL. *The Last Dance*. Palo Alto, California: Mayfield Publishing Company, 1983.
 - Nuland S. *How We Die: Reflections on Life's Final Chapter*. New York: Vintage, 1993.
 - Wollin JA, Yates PM, Kristjanson LJ. Supportive and palliative care needs identified by multiple sclerosis patients and their families. *International Journal of Palliative Nursing* 2006; 12(1): 20–26.

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Ms. Brandis has authored several articles and provided numerous academic and public education presentations on the topics of long-term care, palliative care, symptom management, and wellness in multiple sclerosis. Prior to her work at the National MS Society, Ms. Brandis was an ALS nurse clinician at the Eleanor and Lou Gehrig ALS Comprehensive Care Center at Columbia University. Ms. Brandis sits on advisory boards for several organizations that care for people living with disabilities and continues to work with the National MS Society and more recently with The Hospice of Santa Cruz County, the Cabrillo College Stroke and Acquired Disability Center, and the MS Quality of Life Project as a professional education consultant.

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