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Clinical Bulletin

Information for Health Professionals

Opening Doors: The Palliative Care Continuum in Multiple Sclerosis

*David Gruenewald, MD, FACP, Marion Brodkey, MA, RN, BSN,
Nancy Clayton Reitman, MA, BSN, RN, MSCN,
and Maura Del Bene, APRN, PMHNP-BC, ANP, ACHPN*

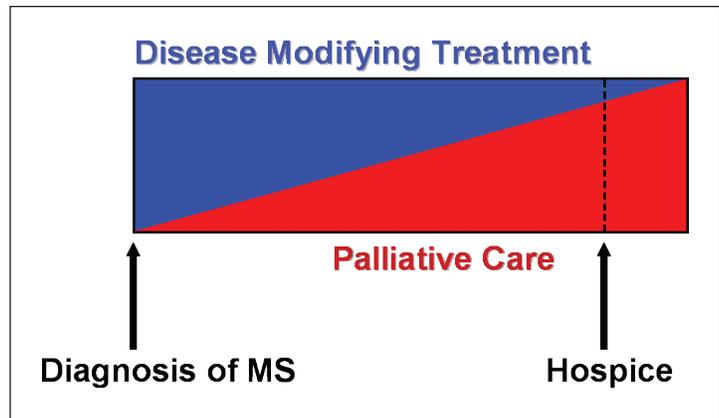
INTRODUCTION: WHAT IS PALLIATIVE CARE?

Palliative care is both a *philosophy* of care and an organized, highly-structured *system* for delivering care. In palliative care, a team of providers work together to develop a plan of care that addresses problems in multiple domains affecting the physical, psychological, social, and spiritual well-being of the affected person and his or her family. While it has some features in common with comprehensive multiple sclerosis (MS) care, palliative care can be differentiated from traditional MS care by its multi-faceted approach, which includes not only traditional disease-model medical care but also the goals of improving quality of life for patient and family; managing distressing symptoms; facilitating communication, decision-making and advance care planning; and providing opportunities for personal growth throughout the entire disease course. Furthermore, palliative care can be provided in all care settings (home, outpatient clinic, long-term-care facility, hospital, or intensive care unit).

The American Academy of Hospice and Palliative Medicine (AAHPM) states “The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies.”¹ Palliative care should not be confused with end-of-life and hospice care, which is just one end of the palliative care continuum. Palliative care may be delivered for many years prior to death, whereas hospice care is generally received in the last few months of life. Current palliative care practice guidelines recommend the early introduction of palliative care for people with serious illness, ideally at the time of diagnosis.^{2,3} With serious chronic illnesses such as MS, palliative care can begin immediately post-diagnosis with advance care planning, and continue through intensive disease treatment and timely symptom management, culminating with hospice services for terminal care and bereavement

for the family. Thus, palliative management of symptoms and psychosocial needs can occur alongside life-prolonging or disease modifying treatments. The graphic at the right depicts how palliative care can be initiated concurrently with disease-modifying treatment in MS.

The long disease course and the unpredictability and variability of MS make it challenging to fit the illness into a typical end-of-life care model. However, MS remains an incurable disease that is often associated with increasing symptoms, disability, and losses of physical, psychological and social role functioning over time. For this reason, people with MS share experiences in common with people affected by diseases with a shorter and clearer terminal phase. Therefore it is appropriate to offer a palliative care approach to people with MS and their families whenever their physical, psychosocial, and spiritual needs warrant such support.⁴



Source: Adapted from CAPC (www.capc.org).

Current clinical practice in MS includes the provision of disease-modifying treatment, management of MS-related symptoms, and interdisciplinary rehabilitation interventions. In some cases, however, medical and psychosocial complexities may signal the need for palliative care, which may uncover issues such as depression, chronic pain, caregiver burnout, existential suffering, and changing patient goals that may be overlooked or incompletely managed in usual MS care. See Box 1 on the following page for a summary of palliative care issues for people with MS.

Palliative care specialists are often termed “good stewards of resources,” specifically because of the time they spend identifying various systems, products, and venues of care. They promote communication between the various care providers on behalf of the patient and family. Short-term, interdisciplinary palliative care consultation may improve the management of important symptoms such as pain, reduce caregiver burden, and be cost-effective by reducing use of primary care and hospital services.⁵ However, the best model for providing palliative care services to people with MS and their families has not been determined. It is unclear whether MS palliative care services should be provided by palliative care specialists, by neurology and rehabilitation staff with training in palliative care, or by collaboration between traditional MS care providers and palliative care specialists.⁶ Nevertheless, it is appropriate to consider including palliative care specialists as part of comprehensive MS care whenever there is suffering as a consequence of living with MS.

The palliative care team may include physicians, nurses, home health aides, nurse practitioners, social workers, chaplains and spiritual counselors, psychiatrists and psychologists, pharmacists, nutritionists, and physical, occupational, speech, massage, recreation, and respiratory therapists. Palliative care services may take the form of:

- ◆ Palliative care consultations during a hospital in-patient stay
- ◆ In-patient care on a palliative care unit

BOX 1: Palliative Care Issues for People with MS

Healthcare providers should consider the following palliative care issues for people with MS:

- ◆ Managing pain and other complex symptoms
- ◆ Evaluating for, and managing, psychosocial and spiritual distress
- ◆ Incorporating family and hired caregivers into the unit of care, which involves assessing the impact of illness on family and significant others, and including them in the care planning process as appropriate
- ◆ Establishing clear communication between patient, family/significant others, and the care provider team
- ◆ Using a team approach to develop a coordinated plan of care that addresses the unique needs of the individual with MS and his or her family and significant others, drawing upon the expertise of care providers from different disciplines
- ◆ Advocating for the information and resource needs of people with MS and their families
- ◆ Understanding what quality of life means to each patient—which could include the person's ability to make personal decisions regarding location of care, pain and symptom management strategies, disease modifying treatment, social and family interactions and roles, etc.
- ◆ Setting goals based on the values of the patient and what is possible to achieve
- ◆ Determining the individual's decision-making capacity, and identifying appropriate surrogate decision-makers in the event the patient becomes unable to make care decisions
- ◆ Determining what medical interventions the patient may or may not want, including resuscitation, intubation, dialysis, antibiotics, and artificial nutrition and hydration
- ◆ Being aware of any religious, cultural, or personal beliefs that affect the person's ongoing care
- ◆ Remaining involved regardless of the stage of illness or care venue

- ◆ Home-based care in coordination with a certified home health agency
- ◆ Community-based care in an out-patient palliative care clinic or during in-home visits by a physician or nurse practitioner
- ◆ Hospice care in a home, in-patient hospice unit, nursing home, or adult family home

This bulletin is intended for use by healthcare professionals who are already experienced in the clinical care of people with MS. For essential information about the etiology, diagnosis, and management of MS, the reader is referred to www.nationalmssociety.org/PRCPublications.

In the following sections, we use a vignette adapted from real-life clinical experience to provide information on decision-making and advance care planning, while also addressing communication issues and the management of psychosocial and spiritual issues. We offer some tools for recognizing the palliative care needs of patients with MS, and for implementing some aspects of palliative care, whether one is a solo practitioner or part of a comprehensive MS team.

Sometimes patients, family members, and even clinicians feel that introducing palliative care and/or end-of-life issues is disrespectful of the “compelling drive” to continue treatment or “continue to fight,” even in patients with advanced disease.⁷ On the contrary, we believe that introducing palliative care to address suffering at any point in the trajectory of a serious illness is a sign of respect, loyalty, and compassion, as well as hopefulness that suffering can be relieved. See Box 2 for examples of language to introduce the palliative care team to patients.

BOX 2: Introducing the Palliative Care Team to Your Patients

- ◆ The Palliative Care Team works with me to better manage your pain, shortness of breath, and other symptoms.
- ◆ They can help us to develop a treatment plan that’s based on what is important to you and your family.
- ◆ They can answer some of the questions you may have about what to expect in the future while living with MS and the treatments we are pursuing.
- ◆ Why do you need this? Well, we both need this. Your illness is complicated and serious, and we don’t want to let it get ahead of us. This team will help us to make a plan for now and in the future—even if that includes hospitalization.

TRIGGERS TO INITIATING PALLIATIVE CARE IN MULTIPLE SCLEROSIS

Marcie, a 37-year-old woman diagnosed with MS 11 years ago, lives with her fiancé and works full time in her own business. Thursday morning Marcie tries to get out of bed, but is unable to coordinate her lower extremities and falls to the floor. She is frightened and confused by this experience. Her last MS exacerbation was 3 years ago and was primarily sensory; she has never experienced an exacerbation that affected her mobility. Fortunately, Marcie’s fiancé is home and is able to accompany her that day to her neurologist’s office at an MS specialty care center. Marcie is able to walk, with full assistance, only 10 to 15 feet. After a complete work-up ruling out the presence of infection, Marcie is prescribed a 5-day course of IV methylprednisolone to treat the exacerbation. The treatment is to be done by a visiting nurse, as a second trip to the MS center would be too challenging given Marcie’s physical limitations.

On Sunday, Marcie pages the on-call MS nurse practitioner (NP). Her emotional state is fragile, including extreme anxiety. Marcie tells the NP she’s worried that after 3 doses of methylprednisolone she’s actually feeling worse: she can’t walk or execute basic activities of daily living without assistance, and is overcome with fear. She tells the NP, “I’m afraid I’ll never recover this time.”

Starting Point

Triggers are actions or words that initiate the “circuit paths” for a series of reactions or responses. Triggers to start the process of palliative care in MS will be unique for each individual living with the disease. The timing and manner in which palliative care is implemented will be as varied as the clinical course for each individual with MS. For example, an exacerbation like Marcie’s could present an opportunity to talk about both the present medical situation as well as future decision making. Professionals have an especially challenging task: they must balance the hope and optimism of currently available treatments in a disease with a predominantly relapsing and remitting course with the knowledge that many of their patients will eventually progress and possibly incur concurrent diseases along the way.

Some “triggers” that may open dialogue about palliative care include:

1. The patient’s mild or moderate, intermittent or permanent loss of cognitive or physical ability for independent self-care⁷ as observed or acknowledged by the patient
2. Change in the patient’s role, family structure, or potential care network (e.g., childbirth, divorce, or death)
3. Unrelieved psychological, social, or spiritual distress (expressed or observed)
4. The patient or family asking about the dying process in MS
5. Stressors related to lack of financial planning for the future
6. Pain associated with chronic or progressive disease process that is unrelieved after 48 hours
7. Management of advanced symptoms such as fatigue, nausea, loss of appetite, loss of skin integrity, dysarthria, increasing upper extremity weakness, decrease in sexual function
8. Repeated urinary tract infections, aspiration pneumonia, or other infections leading to repeated hospitalization
9. Bowel incontinence
10. Dysphagia warranting a feeding tube; weight loss, cachexia, and/or anemia
11. Dyspnea or symptoms of hypoventilation requiring non-invasive or invasive ventilation
12. Depression and/or suicidal ideation
13. Verbal or non-verbal cues to unspoken concerns, e.g., “I’m coping with it the best I can,” or the patient begins to cry during the interview

Marcie articulates her situation as “being trapped.” The NP acknowledges Marcie’s anxiety and gently introduces the topic of preparation and planning for future situations. For the current crisis the NP offers a choice of the following:

1. *Information for contacting private home health agencies;*

2. Continuation of the treatments at home, physical/occupational therapy (PT/OT) home evaluation for safety, and a home health aide a few days a week through visiting nurse service; or
3. Admission to the in-patient neuro-rehabilitation unit.

Marcie and the NP agree that being admitted to the neuro-rehabilitation unit will best address her needs. Marcie is pleased that this option won't impose upon her fiancé, who she fears might rethink his long-term commitment to her. In addition, an in-patient stay will allow for contact with the MS team for support and counseling. It will permit Marcie to file for short-term disability insurance, and jump-start the process of returning to independent functioning through physical and occupational therapy.

Once admitted, Marcie's anxiety decreases markedly. This allows the NP to follow up with counseling sessions focused on advance planning and decision making. Marcie recovers from her exacerbation and is discharged 8 days later walking with a cane. Within the next week she is fully recovered.

In the case of Marcie, triggers 1 and 5 were activated, prompting discussions about:

- ◆ The strengths and weaknesses in Marcie's current care network
- ◆ Marcie's knowledge base regarding the potential clinical course of MS and the possibility of recovery and/or progression
- ◆ Limitations in Marcie's ability to finance home care, and
- ◆ How Marcie can better prepare should she become permanently physically disabled during her lifetime with MS.

Any chronically ill person will likely experience a medical crisis at some time during the course of the illness. However, planning for crises immediately after initial diagnosis of MS may not be well received by the patient or family. The clinician therefore must be able to identify and execute in a timely way the initiation of long-term planning (an essential component of palliative care) when triggers present themselves.

Although advance directives related to interventions such as feeding tubes and mechanical ventilation were not immediately relevant to the discussion between Marcie and the NP at this time, a conversation about the future was begun that will continue to serve as an open door over the coming months and years.

PALLIATIVE CARE CONVERSATIONS: FINDING THE RIGHT WORDS

When a trigger or a verbal or non-verbal cue suggesting emotional distress is recognized, patients and families should be asked directly about their feelings. It's OK to ask, "Are you suffering?" Even the process of asking questions and listening carefully to the answers can be therapeutic.⁸ Open-ended questions and attentive listening are useful to explore problem areas, values, concerns, and readiness to hear bad news. The person must be given time to respond to each question. For the health professional, this means being comfortable with periods of silence. As the professional listens

TABLE
Structuring a Conversation in Palliative Care
(condensed and adapted from references 9, 10)

Step	Description	Examples of facilitating comments or questions
1. Prepare for the discussion	Confirm medical facts, determine who should participate in discussion, set an appropriate time and place.	"Should we ask your husband to participate?"
2. Establish what patient and family know	Assess what the person knows about his or her medical situation by using open-ended questions.	"What do you understand about your condition?"
3. Determine how info is to be handled	Assess the amount of detail the patient wants to know about his or her condition and proposed care; determine who should be involved in care decisions.	"Are you a person that likes to know a lot of details about your care and your condition, or do you want just the big picture?" "If you were unable to make your own medical decisions, who would you want to make them for you?"
4. Deliver the information	Convey bad news and other sensitive information in a compassionate but straightforward way. Give information in small chunks, pausing frequently to ask for clarification or answer questions; avoid medical jargon.	"I'm sorry to have to tell you this, but the scan shows some new spots in your brain."
5. Respond to emotions	Allow time to react, listen quietly and attentively, allow for silence and the expression of strong emotions. Doing so shows respect and support.	"This must be hard to accept." "Would you like to tell me how you're feeling?"
6. Establish care goals and treatment priorities	A separate meeting may be required after giving bad news. Ask more open-ended questions to explore the patient and family's needs and expectations. Offer realistic hope but don't give false hope.	"What are you hoping for now?" "What is most important to you now?" "Let's hope for the best, but plan for the worst."
7. Establish a plan	Develop the overall care plan and follow up.	"Given what you've told me is important to you, I recommend that the tube feedings be discontinued as these won't improve your quality of life."

carefully to each answer, focused follow-up questions should be asked, using the person's own language if possible and asking for clarification when necessary.

- ◆ Professional: "How have things been going since last month?"
- ◆ Person with MS: "It seems like my world is falling apart . . ."
- ◆ Professional: "Falling apart? Tell me more about that."

It is important to acknowledge the person's fears, concerns, worries, and hopes before discussing the goals of care. After patients and families feel their concerns have been heard, they are more likely to be able to move on to develop a care plan. The table on page 7 shows a structured approach to communication that prepares patients and families for the discussion, conveys information in a sensitive but straightforward way, and allows for the expression of emotions before a care plan is developed.

DEATH IN MS

Recent studies are providing a clearer picture of the causes of death in MS.¹¹ Death in people with MS is often caused by, or attributed to, other co-morbid conditions, such as heart disease, pulmonary disease, diabetes, or cancer. While it is not always easy to identify a terminal phase of MS, even when a person has essentially been confined to bed for a long period of time, the following statistics and research findings give us a clearer picture of MS mortality:

- ◆ MS can shorten the lifespan by 6–10 years, with the mean age of death being about 61–65 years.^{12–14} However, the effect of newer disease-modifying therapies on mortality in MS is unknown.
- ◆ Respiratory infections contribute to about 29–48% of MS deaths, whereas urinary tract infections (UTI) leading to sepsis are "underlying or contributing causes" of death in about 4–10% of reported MS deaths.^{13–15}
- ◆ Reported rates of suicide in people followed in MS clinics vary from 6.4% to 15%.^{16,17}
- ◆ Decrease in independent mobility due to muscle weakness, spasticity, or a combination of both, can lead to problems with skin integrity, which can quickly result in serious localized infections, sepsis, or even death.¹⁸

Approximately 10% of people who receive a diagnosis of MS are found to have primary progressive MS (PPMS). People with PPMS experience progression of disability from the onset of the disease without the remissions typical of the relapsing-remitting form.

- ◆ Compared to people with RRMS, people with primary progressive MS (PPMS) have a shorter median survival time.¹⁹
- ◆ Two-thirds of people with PPMS die as a direct result of complications.²⁰
- ◆ The leading cause of morbidity and mortality in PPMS is pulmonary dysfunction secondary to MS.²¹

Quality of life for people with MS near the end of life may be poor.²² Unfortunately the MS clinical professional may lack experience in end-of-life care due to limited access to the dying MS patient and the perception that MS is not a terminal illness. Routine integration of palliative care may prepare both the person with MS and the clinical professional for a smooth transition into end-of-life care. Many people with advanced MS live out their lives in their own homes—isolated from MS specialty center-based care—and relying on piecemeal care from community services, or in long-term-care facilities not necessarily set up to accommodate the social and other needs of a younger person with advanced disability. Incorporation of palliative care, including end-of-life planning, is one way to ensure that people with MS receive the necessary attention to their issues in medical, psychosocial, functional, and spiritual domains throughout their entire disease course.

Professional Readiness for End-of-Life Discussions

Clinicians need to recognize and acknowledge their comfort level with loss and death. Being “comfortable” does not mean just having sympathy or empathy. Saying “I’m sorry for your loss” does not adequately demonstrate an ability to be articulate in this arena. As with many difficult topics that require a comfort level for discussion—like sexuality—listening is the healthcare professional’s greatest skill. A patient’s loss of a loved one, colleague, neighbor, or even a healthcare provider, is an opportunity to open the door to discussion of end-of-life concerns.

In order to be able to care effectively for a person facing dying and death, the care provider must come to terms with his or her own mortality and views about death and dying. The following examples are indicators of the *clinician’s* discomfort with the topic of death:

- ◆ “But you’re doing so well!” (reassurance)
- ◆ “Oh, you’ll live to be 100.” (denial)
- ◆ “Let’s talk about something more cheerful!” (changing the subject)
- ◆ “Well, we all have to die sometime.” (fatalism)
- ◆ Absence of dialogue (passive dismissiveness)

If uncomfortable, clinicians must be willing to “pass the baton” to a colleague who can embrace the present situation and engage in a discussion of care goals, values, and other end-of-life concerns. To expand their own self-understanding in relation to dying and death, clinicians may find it useful to reflect on their own experiences with death, and to explore their own beliefs, values, and attitudes regarding death.^{23,24}

Initiating End-of-Life/Hospice Care

Currently, there are no disease-specific hospice criteria for MS. And transitioning from palliative care to end-of-life care or hospice care requires an understanding of MS as well as co-morbid disease processes. Therefore, patient eligibility for hospice can be better facilitated if the following MS Hospice Eligibility criteria, as adapted from core eligibility guidelines, are documented and discussed as appropriate with the hospice organization.

Suggested MS Hospice Eligibility Guidelines

1. Critical nutritional impairment evidenced by:

- a. Oral intake of nutrients and fluids insufficient to sustain life and comfort
- b. Continuing weight loss

2. Rapid disease progression in the preceding 12 months evidenced by:

- a. Progression from independent ambulation to being confined to a wheelchair or bed
- b. Progression from normal to barely intelligible or unintelligible speech
- c. Progression from normal to pureed diet or feeding tube
- d. Progression from independence in most or all activities of daily living (ADLs) to the need for major assistance by caretaker in all ADLs

3. Life-threatening complications in the preceding 12 months as evidenced by one or more of the following:

- a. Critically impaired breathing capacity (forced vital capacity less than 30%)
- b. Dyspnea or shallow breathing at rest
- c. BiPAP required for more than 12 hours per day
- d. Patient refusal of artificial ventilation
- e. Recurrent aspiration pneumonia (with or without tube feedings)

4. Other infectious processes (one or more of the following):

- a. Upper urinary tract infection (pyelonephritis)
- b. Recurrent fever after antibiotic therapy
- c. Stage 3 or 4 pressure sores
- d. Sepsis

The following formula identifies potential eligibility for hospice for the given constellation of symptoms:

- ◆ 1a in the absence of a feeding tube
- ◆ 2 + 1
- ◆ 2 + 3
- ◆ 3
- ◆ 4 + 1 and/or 4 + 3

It is important to note that if a person with MS is receiving in-home medical services, the agencies providing this care are generally well-versed in both palliative and end-of-life care. Most often, they will opt to provide end-of-life services when the time comes, rather than transitioning the patient to a hospice agency during the final months.

CONCLUSIONS

Marcie was kind enough to “lend” us her story to demonstrate some of the palliative care opportunities and concerns of people with MS at the beginning of the illness trajectory. MS clinicians have many of the tools to provide aspects of palliative care. The purpose of this bulletin is to promote a comprehensive and proactive approach to the palliative care needs of people with MS and their families for effective symptom management, care coordination, assessment of emotional concerns, and management of psychosocial and spiritual issues. Palliative care should be available alongside standard MS care such as disease-modifying therapy, should be offered any time an individual with MS has complex needs, and should be accessible in all care settings (home, out-patient MS clinic, hospital unit, or nursing home).

Conversations with patients and families, as well as clinical presentation, may serve as triggers to initiate palliative care in MS. It is the responsibility of the MS clinician to respond to these triggers by initiating a dialogue with the person with MS and incorporating the person’s concerns into a palliative plan of care. Palliative care professionals may serve as useful resources to MS care centers for advanced symptom management, long-term-care planning and decision-making, and transition to hospice services.

Finally, a great deal of information and literature is available regarding palliative care, end-of-life care, hospice services, and advance care planning. We encourage you to add to the following resource list any local agencies, medical services, and other organizations that will help you to integrate palliative care into the plan of care for people with MS in your community.

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MULTIPLE SCLEROSIS, PALLIATIVE CARE, AND END-OF-LIFE ORGANIZATIONS AND RESOURCES

- ◆ National Multiple Sclerosis Society: www.nationalmssociety.org. Accessed June 2012.
- ◆ The National Hospice and Palliative Care Organization: www.nhpco.org. Accessed June 2012.
- ◆ Hospice and Palliative Nurses Association: <http://www.hpna.org>. Accessed June 2012.
- ◆ Multiple Sclerosis Association of America: www.msaa.com. Accessed June 2012.
- ◆ Share the Care: www.sharethecare.org. Accessed March 2012.
- ◆ Get Palliative Care: www.getpalliativecare.org. Accessed June 2012.
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