

OPENING DOORS: THE PALLIATIVE CARE CONTINUUM IN MULTIPLE SCLEROSIS

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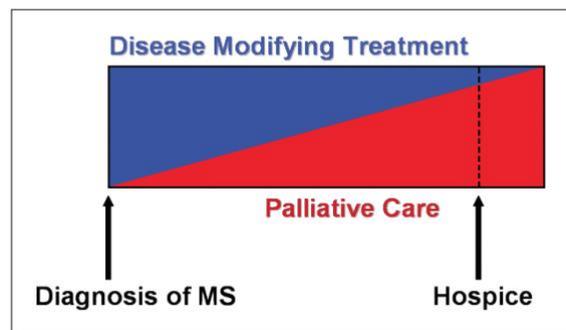
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Introduction: What Is Palliative Care?

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 Center to Advance Palliative Care (CAPC) states “palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family...It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.”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. Palliative care practice guidelines recommend the early introduction of palliative care for people with serious illness, ideally at the time of diagnosis.² With serious chronic illnesses, such as MS, palliative care can begin immediately post-diagnosis with person-centered 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



Source: Adapted from Center to Advance Palliative Care (www.capc.org).

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 loss of physical, psychological and social role functioning over time. Studies of people who feel severely affected by MS, regardless of the degree of physical disability, have identified unmet needs in multiple domains of concern including physical, psychosocial, practical, and spiritual. Non-physical needs were often cited as their main concerns. These included changes in role functioning and loss of identity, difficulties in accessing health care services, including care coordination, dissatisfaction with interactions with physicians, challenges in managing everyday life, including assistance with basic activities of daily living, and changes in the social support network, often resulting in social isolation.^{3,4} For these reasons, 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.¹

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. A palliative care consultation 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](#) 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 may improve the management of complex symptoms, reduce caregiver burden, and decrease the cost of care by minimizing the 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 yet been determined.

An increasing number of models of MS palliative care have been described, but no model has been universally accepted or implemented. In the UK, fewer centers had formal links between palliative care and MS care than for other neurodegenerative disorders, such as Parkinson's disease and motor neuron disease, suggesting less integration of palliative care into MS care.⁶ Higginson and colleagues developed and evaluated a palliative care consultation service for people with MS and their families and caregivers. This service was integrated with an existing service for people severely affected by MS run by neurologists and MS nurses. Palliative care consultation within the MS service was shown to improve symptoms of pain, nausea, vomiting, mouth problems and sleep problems as well as improve care partner wellbeing.^{7, 8}

In Italy, the Palliative Network for Severely Affected Adults with MS (PeNSAMI) developed a program of palliative home care for people with neurodegenerative diseases, including MS, and their care partners. A randomized controlled trial of the program reported that home palliative care improved patients' health-related quality of life and symptoms of pain, breathlessness, sleep, and bowel problems.⁹

In Germany, a regional telephone hotline was implemented in 2012 to provide information about palliative care to people severely affected by MS, their care partners, and healthcare professionals.¹⁰ Preliminary evaluation found that the hotline was well accepted by patients, their care partners and formal caregivers, and appeared to be a valuable source of information about palliative care and how to access services. The hotline was made available nationwide in Germany in 2014. Also, in Germany, specialized palliative home care is available for patients with neurodegenerative diseases who have reduced life expectancy and extensive care needs. The service includes a multidisciplinary team to provide symptom management, counselling and support for psychosocial crises and decision-making.¹¹ Of note, people with MS are seldom referred to this service. The perception that palliative care services are not needed in MS, even for patients severely affected, as well as a lack of training in neurological diseases for palliative care specialists are barriers to referrals to this program.¹⁰

Although it is still 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 it is appropriate to consider including palliative care specialists as part of comprehensive MS care whenever someone's quality of life is affected by 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
- 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

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 and managing psychosocial and spiritual distress
- Incorporating care partners 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 multiple 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

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. On the contrary, we believe that introducing palliative care to address quality of life at any point in the trajectory of a serious illness is a sign of respect, loyalty, and compassion, as well as hopefulness that relief is possible. See [Box 2](#) for examples of language to use to introduce the idea of palliative care to your patients.

BOX 2: Introducing the Palliative Care Team to Your Patients

- Would you be comfortable talking about your quality of life and future with MS?
- The palliative care team 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.
- The palliative care team can work with us to come up with the best plan to manage your symptoms.
- The palliative care team can help us to develop a treatment plan that’s based on what is important to you and your family.
- Why do you need the palliative care team? Well, we both need them. Your illness is complicated and serious, and we don’t want to let it get ahead of us. This team will help us make a plan that will help you 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. She was stable on interferon beta for several years following her diagnosis. She had an exacerbation about 2 years ago, which was primarily sensory. At that time, interferon beta was stopped, and she was started on dimethyl fumarate. She has never before experienced an exacerbation that affected her mobility. 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. 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-care as observed or acknowledged by the patient
2. Change in the patient’s role, family structure or potential care network (e.g. childbirth, divorce, employment status change 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 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 or causing 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. Referrals to private home health agencies;
2. Continuation of the treatments at home but adding 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 person living with a chronic illness will likely experience a medical crisis at some point. 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 struggling?" or to say, "I'm wondering if you're feeling [overwhelmed/sad/angry/scared] by what's going on." Even the process of asking questions and listening carefully to the answers can be therapeutic.¹² 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 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. Asking permission to discuss care goals is important; if patients and families are reluctant to proceed, they may need for you to refocus the conversation on unresolved worries and concerns before discussing 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. [Table 1](#) shows a structured approach to communication that prepares patients and families to discuss palliative care, conveys information in a sensitive but straightforward way and allows for the expression of emotions before a care plan is developed.

TABLE 1
Structuring a Palliative Care Conversation Including Discussing Serious News
 (condensed and adapted from references 13-16)

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	<p>“Is this a good time to meet to talk about the results of your scan?”</p> <p>“Should we ask your husband to participate?”</p>
2. Establish what patient and family know	Assess what the person knows about his or her medical situation by using open-ended questions	<p>“What do you understand about your condition?”</p>
3. Determine how information 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	<p>“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?”</p> <p>“If you were unable to make your own medical decisions, who would you want to make them for you?”</p>
4. Deliver the information	Convey serious 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	<p>“I’m sorry to have to tell you this, but the scan shows some new spots in your brain.”</p>
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	<p>“This must be hard to accept.”</p> <p>“I can’t even imagine how upsetting this must be for you.”</p> <p>“Would you like to tell me how you’re feeling?”</p>
6. Establish care goals and treatment priorities	Ask permission to talk about next steps. A separate meeting may be required after giving serious 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	<p>“Would it be OK if we talked about where to go from here?”</p> <p>“What are you hoping for now?”</p> <p>“What is most important to you now?”</p> <p>“Let’s hope for the best, but plan for the worst.”</p>
7. Establish a plan	Develop the overall care plan and follow up	<p>“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. What do you think?”</p>

Death in MS

A survey study by Marrie et al. of people with MS participating in the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry found that in various hypothetical situations many people with MS would give strong consideration to physician-assisted dying (PAD).¹⁷ Over one-third of study participants said they would definitely or probably consider PAD in all 5 hypothetical situations (extreme pain, extreme emotional distress, financial burden to caregivers and inability to do things that make them happy or make life worth living). Nearly two-thirds of study participants would consider PAD for unbearable pain. Although people with MS would not necessarily request PAD if they developed the condition described in these scenarios, these findings indicate that attention to the broad range of physical, psychosocial, financial and spiritual concerns of people with MS is imperative.

Compared to people without MS, people with MS are more likely to experience a prolonged course of progressive dwindling prior to death, with accumulation of frailty, disability and functional dependence.¹⁸ The high prevalence of progressive dwindling makes it challenging to identify a terminal phase of MS in many cases, even when a person has essentially been confined to bed for a long time. Some questions regarding mortality in MS remain unanswered due to methodological challenges and variations in geographic location. However, the following statistics and research findings give us a clearer picture of MS mortality:

- Although some studies show that survival in MS has improved in the past several decades, MS is estimated to shorten the lifespan by 7-14 years.¹⁹⁻²³ Disease-modifying drugs appear to improve survival in MS.^{24, 25} However, the effect of newer disease-modifying therapies on mortality in MS is still unclear.
- Common comorbid illnesses increase the risk of death in people with MS as in those without MS, including diabetes mellitus and chronic heart and lung diseases.²⁰ Complications of MS, such as infection, also play an important role. Respiratory infections, aspiration, urinary tract infections and sepsis are common causes of the excess death rate in people with MS.^{22, 23, 26, 27}
- Epidemiological studies have found that the standardized mortality ratio for suicide in people with MS is approximately two-fold higher than in the general population. Younger men in the first few years after diagnosis appear to be at the highest risk.^{28, 29} However, some recent

- studies suggest that suicide risk may be similar in people with and without MS, at least until 20 years or more from clinical onset. [30](#), [31](#)
- Greater disability is associated with increased mortality risk in people with MS.[32](#) Deterioration of 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.[33](#)

Approximately 15% 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 from disease onset to death.[19](#),[34](#)
- Two-thirds of people with PPMS die as a direct result of complications of MS.[35](#)
- The leading cause of morbidity and mortality in PPMS is pulmonary dysfunction secondary to MS.[36](#)

Quality of life for people with MS near the end of life may be poor.[3](#), [4](#), [37](#)

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 Goals of Care Conversations Including End-of-Life Discussions

Clinicians need to recognize and acknowledge their comfort level with discussing quality of life, 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—empathic, active 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 goals of care and end-of-life concerns.

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, dismissiveness)
- Absence of dialogue (passive dismissiveness)

Increasingly, resources are available for non-palliative care clinicians to learn communication skills necessary for effective goals of care conversations (e.g., reference 16). If uncomfortable with developing and using these skills, 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.[38](#), [39](#)

Initiating End-of-Life/Hospice Care

Currently, there are no disease-specific hospice criteria for MS. 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 with 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 often 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 a relatively early stage 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. Whether provided by palliative care specialists or by neurology and rehabilitation staff trained in palliative care, palliative care should be available alongside standard MS care and should be offered any time an individual with MS has complex needs. Furthermore, palliative care should be accessible in all care settings (home, out-patient MS clinic, hospital unit, or long-term care facility).

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 incorporate 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 the transition to hospice services.

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

References

1. Center to Advance Palliative Care. <https://www.capc.org/about/palliative-care/>. Accessed July 2018.
2. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, Third ed. 2013.
3. Galushko M, Golla H, Strupp J, et al. Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: A qualitative study. *J Palliat Med* 17: 274–281, 2014.
4. Borreani C, Bianchi E, Pietrolongo E, et al. Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention. *PLoS One* 9: e109679, 2014.
5. Higginson IJ, McCrone P, Hart SR, et al. Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *J Pain Symptom Manage* 38: 816–826, 2009.
6. van Vliet LM, Gao W, DiFrancesco D, et al. How integrated are neurology and palliative care services? Results of a multicentre mapping exercise. *BMC Neurology* 16: 63, 2016.
7. Higginson IJ, Vivat B, Silber E, et al. Study protocol: delayed intervention randomised controlled trial within Medical Research Council (MRC) Framework to assess the effectiveness of a new palliative care service. *BMC Palliat Care* 5: 7, 2006.
8. Edmonds P, Hart S, Gao W, et al. Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service. *Mult Scler* 16: 627–636, 2010.
9. Borreani C, Bianchi E, Pietrolongo E, et al. Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention. *PLoS One* 9: e109679, 2014.
10. Knies AK, Golla H, Strupp J, et al. A palliative care hotline for multiple sclerosis: A pilot feasibility study. *Palliat Support Care* 13: 1071–1078, 2015.

11. Strupp J, Voltz R, Golla H. Opening locked doors: Integrating a palliative care approach into the management of patients with severe multiple sclerosis. *Mult Scler J* 22: 13-18, 2016.
12. Cassell EJ. Diagnosing suffering: A perspective. *Ann Intern Med* 131: 531–534, 1999.
13. von Gunten CF, Ferris FD, Emanuel LI. Ensuring competency in end-of-life care: Communication and relational skills. *JAMA* 284: 3051–3057, 2000.
14. Back A, Arnold R, Tulsky J. Mastering communication with seriously ill patients: balancing honesty with empathy and hope. New York, NY: Cambridge University Press; 2009.
15. Tulsky JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA* 294: 359-365, 2005.
16. VITALtalk. <http://vitaltalk.org/>. Accessed July 2018.
17. Marrie RA, Salter A, Tyry T, et al. High hypothetical interest in physician-assisted death in multiple sclerosis. *Neurology* 88: 1528–1534, 2017.
18. Martin JE, Raffel J, Nicholas R. Progressive dwindling in multiple sclerosis: An opportunity to improve care. *PLoS One* 11: e0159210, 2016.
19. Scalfari A, Knappertz V, Cutter G, et al. Mortality in patients with multiple sclerosis. *Neurology* 81: 184-192, 2013.
20. Marrie RA, Elliott L, Marriott J, et al. Effect of comorbidity on mortality in multiple sclerosis. *Neurology* 85: 240-247, 2015.
21. Bronnum-Hansen H, Koch-Henriksen N, Stenager E. Trends in survival and cause of death in Danish patients with multiple sclerosis. *Brain* 127: 844–850, 2004.
22. Sadovnik A, Eisen R, Ebers G, Paty D. Cause of death in patients attending multiple sclerosis clinics. *Neurology* 41: 1193–1196, 1991.
23. Hirst C, Swingler R, Compston DAS, et al. Survival and cause of death in multiple sclerosis: A prospective population-based study. *J Neurol Neurosurg Psychiatry* 79: 1016– 1021, 2008.

24. Goodin DS, Reder AT, Ebers GC, et al. Survival in MS: A randomized cohort study 21 years after the start of the pivotal IFN β -1b trial. *Neurology* 78: 1315–1322, 2012.
25. Tsai CP, Lee CT. Impact of disease-modifying therapies on the survival of patients with multiple sclerosis in Taiwan, 1997-2008. *Clin Drug Investig* 33: 647–652, 2013.
26. Smestad C, Sandvik L, Celius EG. Excess mortality and cause of death in a cohort of Norwegian multiple sclerosis patients. *Mult Scler* 15: 1263–1270, 2009.
27. Goodin DS, Corwin M, Kaufman D, et al. Causes of death among commercially insured multiple sclerosis patients in the United States. *PLoS One* 9: e105207, 2014.
28. Feinstein A, Pavisian B. Multiple sclerosis and suicide. *Mult Scler J* 23: 923-927, 2017.
29. Pompili M, Forte A, Palermo M, et al. Suicide risk in multiple sclerosis: A systematic review of current literature. *J Psychosom Res* 73: 411–417, 2012.
30. Kalson-Ray S, Edan G, Leray E. An excessive risk of suicide may no longer be a reality for multiple sclerosis patients. *Mult Scler J* 23: 864–871, 2017.
31. Leray E, Vukusic S, Debouverie M, et al. Excess mortality in patients with multiple sclerosis starts at 20 years from clinical onset: Data from a large-scale French observational study. *PLoS One* 10: e0132033, 2015.
32. Cutter GR, Zimmerman J, Salter AR, et al. Causes of death among persons with multiple sclerosis. *Mult Scler Relat Disord* 4: 484–490, 2015.
33. Minden SL, Frankel D, Hadden LS, et al. Disability in elderly people with multiple sclerosis: An analysis of baseline data from the Sonya Slifka Longitudinal Multiple Sclerosis Study. *NeuroRehabilitation* 19: 55–67, 2004.
34. Grytten Torkildsen N, Lie SA, Aarseth H, et al. Survival and cause of death in multiple sclerosis: Results from a 50-year follow-up in Western Norway. *Mult Scler* 14: 1191–1198, 2008.
35. Cotrell DA, Kremenchutzky M, Rice GPA, et al. The natural history of multiple sclerosis: A geographically based study. 5. The clinical features and natural history of primary progressive multiple sclerosis. *Brain* 122: 625–639, 1999.

36. Lehman L, Picone MA. Pulmonary complications. In: Halper J (ed), *Advanced Concepts in Multiple Sclerosis Nursing Care*. New York: Demos, 137–148, 2001.
37. Wollin JA, Yates PM, Kristjanson LJ. Supportive and palliative care needs identified by multiple sclerosis patients and their families. *Int J Palliat Nurs* 12: 20–26, 2006.
38. Potter ML, Wynne BP. Loss, suffering, bereavement, and grief. In: Matzo ML, Sherman DW (eds), *Palliative Care Nursing: Quality Care to the End of Life*. Fourth ed. New York: Springer, 2015.
39. Quill T, Bower KA, Holloway RG, et al. *Primer of Palliative Care*, Sixth ed. Chicago: American Academy of Hospice and Palliative Medicine, 2014.

Multiple Sclerosis, Palliative Care, and End-of-Life Organizations and Resources

- National Multiple Sclerosis Society: nationalmssociety.org
- The National Hospice and Palliative Care Organization: nhpco.org
- Hospice and Palliative Nurses Association: advancingexpertcare.org
- Multiple Sclerosis Association of America: mymsaa.org
- Share the Care: sharethecare.org
- Get Palliative Care: getpalliativecare.org
- Center to Advance Palliative Care: capc.org
- See reportcard.capc.org for state-by-state information on access to hospital-based palliative care services.
- Brandis M, Stacom R. Long-term care in the home for people with multiple sclerosis. *Care Manag J* 10:128–137, 2009.
- Reitman NC. Care at home of the patient with advanced multiple sclerosis: Part 1. *Home Healthc Nurse* 28:243–252, 2010.
- Reitman NC. Care at home of the patient with advanced multiple sclerosis: Part 2. *Home Healthc Nurse* 28:270–275, 2010.