

End of Life Issues: Palliative and At-Home Care for the Patient With Advanced MS

Reitman, NC. Care at home of the patient with advanced multiple sclerosis: part 1 of 2. *Home Healthc Nurse*. 2010;28(4):243-52.

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*. 2010;16(5):627-636.

Life expectancy for the majority of MS patients is nearly the same as the life expectancy of the general population. About one third of MS patients will have a progressive form of the disease that will lead to severe disability and will no longer respond to disease-modifying therapy. According to Reitman, these advanced MS patients are the ones who are most likely to “fall off of the clinician’s radar screen” when, in fact, they are most in need of attention and referrals. Advanced MS patients commonly experience pain, spasticity, fatigue, depression, bedsores, and incontinence; management of their conditions should not abruptly end, but should shift to palliative care. Palliative care is a promising option for advanced MS patients, as it is interdisciplinary and can help patients cope with their disease more comfortably and improve quality of life.

It is important to note that MS does not need to reach a terminal stage for the patient to receive palliative care. Indeed, palliative care is not the same as hospice and end-of-life care. Though part of the palliative care continuum, hospice and end-of-life care are usually delivered for less than 6 months to patients with a life-limited prognosis. Palliative care, on the other hand, can be provided over a period

Table. Triggers for Nurses to Initiate Palliative Care
• The patient acknowledges the loss of his or her ability to physically or cognitively practice independent self-care
• Noticeable changes in the patient’s support network
• Expressed or observed emotional, social, or spiritual stress that does not go away
• Unrelieved pain associated with chronic or progressive disease
• The patient or his/her family mentions the dying process
• The development of symptoms such as unrelenting fatigue, weakness, dysphagia, loss of skin integrity, and dyspnea
• Repeated urinary tract infections, aspiration pneumonia, or other infections that lead to hospitalization
• Bowel incontinence
• Depression and/or talking about suicide

of several years prior to death. According to the American Academy of Hospice and Palliative Medicine, 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.”

The care needs of the advanced MS patient can be unique compared to patients with other advanced diseases, in part because the MS patient is generally younger and more likely to have a family. Therefore, MS patients may have unmet needs if cared for in traditional nursing homes, which tend to serve older adults. Aspects of palliative care should be planned for before contact with a patient is lost, and clinicians, particularly home healthcare nurses, are in a prime position to monitor disease progression and initiate palliative care strategies.

Recognizing when to begin palliative care involves several factors and can come from different sources. Healthcare colleagues, members of the patient’s family, and even the patient himself or herself can provide information on the patient’s health status. Actions and comments from the patient—for example, comments about becoming a burden to

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CLINICAL INSIGHT

- ✦ Because progressively ill MS patients may not be regularly seen in the clinic, they may miss receiving many services that would make life more comfortable for them and their caregivers.
- ✦ Interventions for issues such as pain and symptom control, complex psychosocial issues, hydration, and nutrition help progressive MS sufferers to continue to participate in the world around them.
- ✦ Prompt interventions provide a greater benefit to advanced MS patients.
- ✦ The cognitive function and the ages of people afflicted with MS may produce additional needs: relationship needs, either parental or sexual; the desire for meaningful work; and the desire for a social network of peers.



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family or knowing that a condition will not improve—may prompt a discussion about palliative care options. Nonverbal cues may also signal a need for palliative care; examples are listed in the Table. Several scales that assess functional ability and status, including the Karnofsky Scale and the Palliative Performance Scale, and failure to thrive measures like the Adult Failure to Thrive Guideline can be used and modified to determine the

need for palliative care in the advanced MS patient.

The Effects of Prompt Palliative Care in Advanced MS Patients

In a delayed intervention study conducted in the United Kingdom by Edmonds et al, patients who received immediate palliative interventions showed improvement in a clinical score encompassing 5 key symptoms (pain, nausea, vomiting, mouth problems, and sleeping); meanwhile, those who received palliative intervention 3 months after a referral (the standard best practice) showed a deterioration of the same clinical score. There was also a reduction in caregiver burden

in the caregivers of patients in the group that received immediate intervention; there was no reduction in those of the delayed group. Although the data support additional follow-up, only 6 patients out of the 52 included were found to require ongoing care, implying that already-established specialist palliative care services are unlikely to become overwhelmed with complex patients. Taken together, providing timely palliative care to those severely affected by MS offers comfort to patients who need it most. ■

***This summary was reviewed by
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