

CONSORTIUM OF MS CENTERS

# Comprehensive Palliative Care in MS:

CMSC Consensus  
Statement and  
Proposed Guidelines

Summary of Recommendations and Guidelines Prepared by:



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## Purpose

Several organizations have expressed interest and published guidelines or consensus statements emphasizing the need for palliative care for neurologic diseases. In addition, the need for palliative care in neurology has been identified by the European Academy of Neurology in their guideline on palliative care for patients with chronic and progressive neurological disease<sup>1</sup> and in numerous journal articles.<sup>2–13</sup> The recommendations focus on a multidisciplinary approach to care, initiating palliative care early in the disease, incorporating patients' and families' goals of care, providing expert assessment and management of symptoms, making certain advance directives are discussed, and emphasizing support for caregivers.

A consensus meeting was organized by the Consortium of Multiple Sclerosis Centers (CMSC) to review these issues and develop a consensus statement regarding the incorporation of palliative care into the care of patients with multiple sclerosis (MS). The proposed consensus statement/guideline provides information that health care practitioners can access immediately in the comprehensive care of their patients with MS. These guidelines will benefit families and caregivers of people with MS, as well.

## Methods

Sponsored by the CMSC, a consensus meeting was convened in Newark, NJ on November 9, 2018 and included an expert group of healthcare providers from the US and Canada, specializing in neurology, family medicine, psychology, nursing and MS care, rehabilitation therapy, and hospice and palliative medicine (HPM). The focus of the meeting was to initiate discussions about incorporating palliative medicine into the multidisciplinary, comprehensive care of patients with MS, their families and their caregivers. The meeting included the healthcare practitioners' personal experiences with the palliative care approach and discussions of current publications on palliative care for patients with neurological disease, and incorporated

articles detailing a national strategy for palliative care,<sup>14</sup> the World Health Organization's global perspective<sup>15</sup> and The National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care, 4th edition.<sup>16</sup>

## Summary

Multiple sclerosis (MS) is a chronic, frequently disabling neurological disease that has an unpredictable and variable impact on a person's physical and cognitive abilities, emotions, and quality of life. The CMSC has long promoted a multidisciplinary, comprehensive, patient-centered approach to MS care. Multidisciplinary, coordinated care is the recommended strategy for effective quality care in MS, and this approach dovetails nicely with inclusion of palliative care into the MS model of care.

The guidelines on the following charts and tables provide the definitions of palliative care, and a description of the palliative care system's four domains of assessment – physical, psychological, social and spiritual. By incorporating these four domains into the care of patients, the palliative care system can be viewed as a whole-person approach to the care and management of patients with MS. When to initiate palliative care for patients with MS was also discussed and early integration of palliative care is recommended. It is important to identify opportunities when we can assess the four domains of care and support patients early in the trajectory of the disease. Also included is a list describing the primary palliative care skills that MS clinicians can provide and when specialty palliative care skills are recommended. MS care providers can practice primary palliative care and palliative care specialists can support the team in complex cases, as needed.<sup>17</sup> The differing perspectives and responsibilities of the multiple disciplines involved in the care of patients with MS are presented, and resources and tools regarding palliative care are included.

Education is needed to help close the gap in understanding about the importance of palliative care in MS and current practices in the care of people with MS. This consensus statement/recommendation is an effort by the CMSC to address this important gap in knowledge and enlighten healthcare providers about the benefits of incorporating a palliative care system into the management and care of people with MS and their families.

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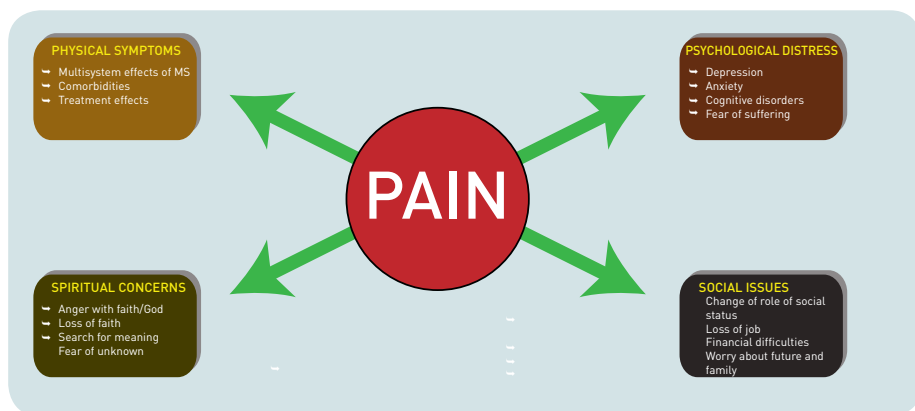
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## SECTION 2

### DEFINITIONS: PALLIATIVE CARE IN MS

**Palliative care** - is an approach or system of supportive care that can be started early in the trajectory of MS. “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>1</sup> Aspects of the varied dimensions of pain are illustrated in *Figure 1 entitled “Concept of Total Pain.”*

The National Consensus Project for Quality Palliative Care defines palliative



**Figure 1 Concept of Total Pain**

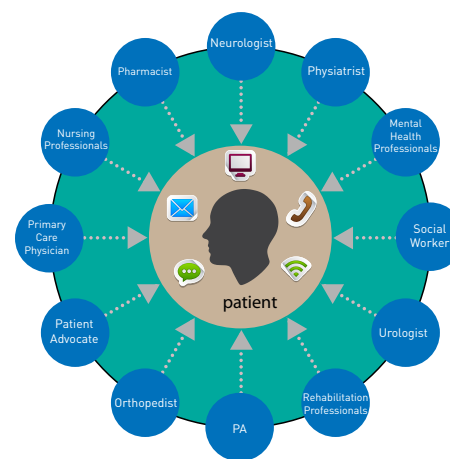
Ref: Cicely Saunders, 1978; International Association for the Study of Pain, 2009.

care as: “Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.”<sup>2</sup> It is important to emphasize the patient and the family as the unit

of care in the palliative care approach. Caregiver burden is likely to be a big issue in MS and it is an area that is addressed in the palliative care approach and often not elsewhere.<sup>3</sup>

There are often misconceptions about palliative care that equate it with hospice and end-of-life care. It is important to clarify the definition of palliative care so that patients, caregivers, and providers understand that palliative care refers to a type of supportive care that may be initiated early in the disease process and be offered intermittently or continuously for years depending on the needs of the patient and family. In palliative care, you do not have to give up treatment that might cure or mitigate a serious illness.<sup>4</sup> As an example for patients with MS, palliative care can be offered alongside disease-modifying therapies focused on symptom control, improving function or preventing relapses/progression. Palliative care can be helpful at any stage of illness,<sup>4</sup> and it may be considered from the point of diagnosis depending upon the patient, his or her symptoms, and concerns of the family and caregivers. Patients and clinicians may be more open to receiving “supportive care” rather than “palliative care,” even if they are identical terms.<sup>5</sup> These definitions and clarifications may help in the understanding and acceptance of palliative care in MS.

**Primary palliative care** – is a type of comfort care provided by health care professionals who are not palliative care specialists. For patients with MS, this may include any member of the MS Care team such as primary care clinicians, neurologists, physiatrists, nurses, mental health professionals, social workers, pharmacists, chaplains and others who care for the MS population but are not board certified in the specialty of hospice and palliative care medicine. Members of the MS Care team are shown in *Figure 2.*<sup>6</sup> The skill set needed for primary palliative care may include basic management of pain, symptoms, depression and anxiety. Other skills include communication with the patient and




**Figure 2 Members of the MS Care Team**

family regarding prognosis, treatment goals, alleviating suffering, advance directives and end-of-life care.<sup>2,7</sup>

**Specialty palliative care** – is a type of comfort care provided by health care professionals who are board certified in the specialty of hospice and palliative care medicine. This may include palliative care-certified physicians, nurses, social workers, pharmacists and chaplains. Specialty palliative care may involve management of refractory pain or other symptoms; management of more complex cases of depression, anxiety, grief or existential distress; and assistance with conflict resolution related to treatment and/or goals within families, between staff and families and among members of the treatment team.<sup>2,7</sup> “Analogous to the management of hypertension and heart disease by primary care clinicians who may turn to cardiology specialists and clinical practice guidelines for consultation or management of more complex cases, specialist level palliative care is available for consultation, teaching, research and care of the most complex patients living with a serious illness. Specialist level palliative care is delivered through an interdisciplinary team with the professional qualifications, training, and support needed to deliver optimal patient- and family- centered care.”<sup>2</sup>

**Hospice care** – focuses on compassionate, end-of-life care for severely ill patients. Hospice teams provide patients and their families with expert medical care, pain management, emotional and spiritual support and access to quality comfort care for individuals at the end of life. Hospice care is differentiated from palliative care as it focuses on individuals with a life expectancy of months, not years.<sup>2</sup> For information regarding hospice criteria for neurological conditions, please refer to: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4142002/table/T1/?report=objectonly>.

**Palliative Care vs. Hospice Care** – Both palliative care and hospice care are both considered comfort care. The objective of both types of care is to reduce stress and to offer complex symptom relief associated with serious illness. Both involve assessing and providing physical and psychosocial relief. Palliative care may be considered at the time of diagnosis, concurrently during treatment and follow-up or at the end of life. Alternatively, hospice care is a type of comfort care that is specifically for those with a terminal illness who are not seeking curative treatment and have a prognosis of six months or less. *Figure 3*, “Palliative Care vs. Hospice Care,” presents a side-by-side comparison of palliative medicine and hospice in the US.

	Palliative care	Hospice
Model of care	Interdisciplinary team  Primary goal: Quality of life and relief of suffering	Interdisciplinary team  Primary goal: Quality of life and relief of suffering
Eligibility	Patients of all ages and with any diagnosis and any prognosis  Concurrent curative treatments	Patients of all ages who have a prognosis of <6 months if the disease follows its usual course  Symptom relief
Place	Hospital, Outpatient Clinics, Nursing homes, Home	Hospital, Home, Nursing home, Residential hospice facilities
Payment	Medicare Part B  Some private insurances	Medicare hospice benefit  Medicaid  Hospice benefit under private insurances
 Albert Einstein College of Medicine		

**Figure 3 Palliative Care vs. Hospice Care**  
Courtesy of Priya Pinto, MD, reproduced with permission.

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## SECTION 3

### FOUR DOMAINS OF PALLIATIVE CARE

Palliative Care is specialized medical care for patients with chronic and potentially life threatening illness, such as MS, that provides an extra dimension of support for patients and families. Palliative care is often delivered by a team and focuses on the relief of (1) physical, (2) psychological, (3) social, and (4) spiritual suffering.<sup>1</sup> These four aspects of care or four domains of care comprise the cornerstone of the palliative care approach to assessing and caring for patients suffering from significant illness. Palliative care is appropriate at any stage of serious illness and helps patients live well.

Care delivery can be organized around addressing patient needs in the four domains of palliative care:

**Physical** – the care team must be able to provide impeccable assessment and treatment of symptoms such as pain, spasticity, functional ability, bowel and bladder function, strength and fatigue. For more information about the varied symptoms of MS, please refer to Newsome et al, 2017.<sup>2</sup>

**Psychological** – Depression, anxiety and cognitive changes are common and resources must be available to assess and manage them. Other aspects of the psychological domain may include evaluating suicide ideation, leisure time activities, pain distress, hopelessness and apathy. Additional information about mental health issues is available in Newsome et al, 2017.<sup>2</sup>

**Social** – Loss of function in MS can be associated with social isolation, unemployment and financial stress, role changes and caregiver burden. A team member should be designated to address these concerns. Caregiver burden is an often overlooked significant issue for families of patients with chronic serious illness.<sup>3</sup>

**Spiritual** – Patients with serious illness often experience illness embedded in their spiritual or religious framework. Exploring hope, suffering and the meaning of illness can be an important aspect of relieving suffering.<sup>1</sup>



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1. National Consensus Project for Quality Palliative Care and National Coalition for Hospice and Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018:166. [https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf). Accessed January 7, 2019.
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## SECTION 4

### DEVELOPMENT OF A PALLIATIVE CARE MANAGEMENT PLAN

For MS care teams that want to pursue the development of a palliative care management plan, here are some suggested guidelines and recommendations to consider:

#### Practice Point One:

A palliative care plan should be developed by a comprehensive, multidisciplinary team in collaboration with the patient and family to address the four domains of care: the physical, psychological, social and spiritual needs of the patient.<sup>1,2</sup> When an MS care team decides to incorporate the palliative care approach into its everyday operations, the team members could ask each other the following questions:

- Are there opportunities where you can add to your current assessments to include the four domains?
- Has your team had a discussion regarding the team's 'approach to care'?
- Is there willingness/resistance to embracing a palliative care approach?
- What changes would be needed in the short term?
- Is there a team member with particular interest in building and supporting this system change within the team?

#### Practice Point Two:

Consider and include the patient voice and caregiver voice in the plan of care. Align care with the person's and family's goals and values. Emphasize shared decision-making that promotes patient autonomy and an individualized plan of care.

- Focus on person-centered care, incorporating goals and values of the patient

- Provide support to patients and caregivers:
  - » Caregivers often experience physical and psychological stress during caregiving. The needs of caregivers should be assessed routinely.<sup>2</sup>
  - » Support should be available to counsel patients and caregivers through difficult role changes and to strategize with patients and families to reduce social isolation and financial stress
- Consider adding a peer/partner navigator to help patient and family, provide an additional layer of support, and improve outreach to healthcare professionals

### Practice Point Three:

The management plan should be individualized for each patient and should include a focus on positive aspects. It is important to look for opportunities to include joy, love, and meaning in the patient's life.

- Dignity therapy with patients and families is important.<sup>3,4</sup> Consider asking: When did you feel most alive? How do you want to be remembered?

### Practice Point Four:

Devote a visit to palliative care: palliative medicine concerns require a separate 20-30 minute visit for follow ups and at least an hour for initial consultation. For example, if the neurologist is going to have appointment with patient about DMTs, a separate visit needs to take place for discussion of palliative care strategies.

- The patient and the multiple disciplines involved need to learn about the focus of palliative care to address and treat the patient's physical, psychological, social and spiritual needs (the four domains of care)
- Education and training in palliative care principles is recommended for all MS care team members.<sup>5</sup>

### Practice Point Five:

If access to a palliative care specialist is difficult or impossible, consider appointing one person on the team, perhaps a psychologist, social worker

or chaplain to handle palliative care concerns. This individual can be the one voice on the team who can coordinate the palliative care efforts of the team in assessing the four domains of care. This individual can introduce the benefits of palliative care to patients and their families.

An excellent example of building a team committed to the palliative care approach in neurology is described in Kluger et al, 2018.<sup>5</sup> Their team consisted of a neurologist, nurse, chaplain, social worker, psychologist and acupuncturist. All members of the team were interested in palliative care for a population of patients with neurologic diseases. They held bi-monthly meetings to review literature, study palliative care principles from palliative care specialists, plan for clinic operations and create rules of shared leadership between team members. This article provides well-organized recommendations for creating and maintaining a palliative care clinic. For specific information, please refer to Kluger et al, 2018<sup>5</sup> and the following attachments:

- University of Colorado Hospital Outpatient Palliative and Supportive Care Clinic Satisfaction Survey (<http://apm.amegroups.com/article/viewFile/17473/20135/122962>)
- Neurology Supportive & Palliative Care Evaluation Request (<http://apm.amegroups.com/article/viewFile/17473/20135/122962>)
- Guidelines for Palliative Care Clinic (<http://apm.amegroups.com/article/viewFile/17473/20135/122963>)
- Brief Needs Assessment Tool (<http://apm.amegroups.com/article/viewFile/17473/20135/122964>)

### Practice Point Six:

When creating a palliative care management plan, consider exploring with an existing palliative care clinic how to best serve those with MS.

- Creating a dedicated clinic day when a team member from all specialties can see patients together can be incredibly impactful.
- Maintaining open communication and bidirectional feedback around triggers for specialist palliative care referral, expectations of each service and coordination of the care plan are essential.



## Practice Point Seven:

It is important to recognize that the one individual who is managing the palliative care needs of the patient must report back to the team so that there is ONE plan that lists all of the patient's goals. It is important to promote coordinated care as opposed to working independently with a single discipline on specific goals. To assist in collaboration within the multidisciplinary team, each team member should inquire about the four domains and the information learned should be shared during team meetings. The plan should include the patient's priority concerns and who specifically on the team (or referral) will address those needs.

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## SECTION 5

### MEMBERS OF THE MS CARE TEAM

A multidisciplinary team approach is essential to managing the complex multi-systems care required for the optimal treatment of patients with MS. Team members may include some or all of the following: neurologists, MS nurse practitioners and other nursing professionals, physicians' assistants, rehabilitation therapists, palliative care specialists, pain specialists, pharmacists, mental healthcare professionals, chaplains, social workers, primary care physician, physiatrists, urologists, gastroenterologists, orthopedist, family member or patient advocate. Each member of the team brings a different focus, knowledge, and skills to the care of the patient with MS. It is important to stress partnership and collaboration among all members of the multidisciplinary team.

Below is a description of the roles that some key members of the team play within the framework of the multidisciplinary MS care team that has incorporated a palliative approach to care.

### Neurologist

- Perform comprehensive assessments and create a plan to address multiple symptoms (mobility dysfunction, spasticity, pain, fatigue, loss of vision, emotional/psychosocial disorders, cognitive impairment, balance, bowel and bladder dysfunction, dysarthria and dysphagia, sexual dysfunction).
- Refer and promote communication within the multidisciplinary, patient-centered team for optimal care<sup>1</sup>
- Support a palliative approach to care, to include solicitation of the patient's goals and referral to the team's palliative care 'point person'
- Know when to refer patients for specialist palliative care. Understand when and how to refer for hospice care and how to communicate this recommendation to the patient and family.

## Nursing and Rehabilitation Therapist (includes nursing professionals, registered nurses, occupational therapists, physical therapists, speech and language therapists)

- Discover opportunities to assist patient in achieving goals of care (participate in activities they enjoy; make life worth living; prevent suffering)
- Understand the functional and psychological impact/limitation occurring as a result of changes in physical abilities.
- Provide interventions for symptom management including fatigue, spasticity, pain, which may be causing social-isolation and caregiver burn-out.
- Explore goal and address barrier to achieving functional abilities:
  - » explore non-pharmacologic solutions – including use of devices (Assistive Technology), Personal Assistance and referrals to health and wellness programming.
  - » discuss risks, provide resources.
- Provide care coordination to ensure that care plan interventions have been implemented and to report back on progress (or barriers) to the goals being met

## Mental Health Professionals and Social Workers

- Identify and treat mood disorders (major depression, anxiety, suicide ideation) Note: depression is under-diagnosed and undertreated<sup>2,3</sup>
- Identify and treat cognitive dysfunction
- Assess for and treat suicidality
- Assess and treat demoralization, and symptoms of hopelessness and apathy<sup>4,5</sup>
- Enhance professional and caregiver psychosocial support
- Decrease social isolation/maintain purpose and meaning of life
- Increase awareness of caregiver burnout/caregiver respite/support
- Enhance communication between patient, family, and multidisciplinary care team

- Maximize mental health quality of life in people with MS and caregivers
- Initiate shared decision-making and discussion of end-of-life care, as needed.

For additional information about the roles of the neurology palliative care team members, please refer to Kluger et al, 2018, table 1 (<http://apm.amegroups.com/article/viewFile/17473/20135/122965>).<sup>6</sup>

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## SECTION 6

### ESSENTIAL SKILLS NEEDED FOR THE PALLIATIVE CARE APPROACH

For all MS clinicians, these are recommendations of primary palliative care skills and considerations needed to incorporate the palliative care approach into the multidisciplinary care model for the management of people with MS.

#### Communication is key.

Communication with the patient and family about the diagnosis, prognosis and goal setting should be transparent. It should include setting of goals and various options for the treatment of symptoms and management of disease. Team meetings should include the patient and caregiver. Goal-setting discussions\* should be shared with the whole team to insure the patient's goals remain central to the care plan being developed by each discipline. Communication about and consideration of the four domains of care – physical, psychological, social and spiritual – should be incorporated into patient visits and assessments.<sup>1,2</sup>

**\*Note:** A helpful reference of the six-step approach to setting goals of care can be found at: Quill TE, et al. *Primer of Palliative Care*. 5th ed. Glenview, IL: American Academy of Hospice and Palliative Medicine;; 2010. Goal setting, prognosticating, and self-care; pp. 109–138.

#### Symptom Management is essential.

Diagnosis and treatment of the varied physical and psychosocial symptoms is essential for all patients with MS. It is also important to oversee the management of pain, other typical MS symptoms, depression and anxiety. Treatment may include pharmacologic and non-pharmacologic interventions and rehabilitation therapy. Basic principles of symptom management should be incorporated into the palliative care approach and the four domain assessments.<sup>1,2</sup>

#### Support for caregivers is important.

The needs of caregivers should be reviewed regularly. Support for caregivers is an essential aspect of palliative care that may improve the patient and caregiver's quality of life, and may be helpful in the bereavement process as well. In addition, it is important to include education and support of healthcare providers involved in the care of these patients to lower the risks of emotional exhaustion and burnout.<sup>1</sup>

#### Palliative care combined with the multidisciplinary care of patients with MS will benefit patients, families and the MS care team.

The multidisciplinary system of care should be applied to all patients under the care of an MS healthcare provider or MS care team. The focus of the MS care team is the patient and he or she will need a team of healthcare providers for 20+ years. The patient may not necessarily be a candidate for aggressive therapy, but they need to stay well, receive care for symptoms, eat a healthy diet, and receive proper equipment to meet their challenges. A multidisciplinary palliative care assessment is the optimal way to reach and care for patients with MS and their families.<sup>1</sup>

#### Advance care planning should be part of every patient's routine care.

It is important to address early advance care planning with patients, especially if deteriorating cognition is of concern.<sup>1</sup> Most patients want to end their life, if necessary, at home; few want to die in the hospital or ICU, but too often people end up there. Similarly, surrogates are more often ill-informed about the choices their loved one would make, feel too confident in their ability to choose, and are more aggressive in care at the end of life.

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## SECTION 7

### WHEN TO START PALLIATIVE CARE

- Initiate palliative care early in the management of patients with MS; evidence shows it can improve symptom management and improve patient and family satisfaction.<sup>1-3</sup>
- Consider integrating the palliative approach by including the four domains of care into each assessment to then identify opportunities for support early in the trajectory of the disease.
- Initiation at the time of diagnosis can be considered in certain cases. Patients and/or family may benefit from the care of a chaplain, social worker or psychologist.<sup>4</sup> One could deliver the diagnosis of MS using a palliative care approach. The SPIKES protocol (see Section 9: Tools and Resources) is particularly helpful. Also, anticipate patients will be in a state of shock at first visit and will need quick follow up but NOT necessarily a referral to palliative medicine.
- As part of a comprehensive review of systems and neurological assessment, clinicians can elicit and discuss whether patients perceive that they are suffering, and then a discussion can take place about how palliative care can assist in relieving their suffering. Consider asking the patient and family: "How are you coping?"
- Consider initiation of primary palliative care strategies when patients exhibit identified triggers including:
  - » High symptom burden (pain, fatigue, mobility decline, social isolation, depression, cognitive decline, fear of or concerns about death and dying)<sup>1</sup>
  - » caregiver burden/support<sup>5</sup>
  - » need for in-depth goals of care discussions<sup>5</sup>
  - » frequent hospitalizations,<sup>6</sup>
  - » cognitive decline or behavioral/psychiatric changes

- » psychosocial support<sup>5</sup>
- » major decrease in functional capacity
- » patients acquiring greater number of comorbidities over time,<sup>6</sup>
- » patient request for advance care planning<sup>5</sup>
- » care transitions<sup>5</sup>
- » spiritual support<sup>5</sup>
- » social/family issues<sup>5</sup>
- » patients with questions about or expressed interest in physician aid in dying.<sup>7</sup>
- Introduce palliative care during periods of transition (stopping or changing DMTs; identifying changes in EDSS or disease progression). As an example, when changing or discontinuing DMTs, the healthcare provider may say, “These medications and/or treatments are no longer working for you; there are symptomatic treatments we can offer; and, we can offer you supportive care, comfort and safety.” The healthcare provider can then consider initiating the palliative care approach, explain the benefits of the approach to the patient and family, and assess the four domains: physical psychological, social, spiritual.
- Consider referral to specialty palliative care for more complex or refractory problems. When specialty skills such as negotiating a difficult family situation, addressing existential distress, or managing refractory symptoms are needed, it can be of value to call on a palliative care specialist. Once the palliative care specialist provides the requested care and assistance, the primary care physician or another member of the MS care team can handle ongoing palliative care needs.<sup>8</sup>

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## SECTION 8

### TOP TEN FACTS ABOUT MULTIPLE SCLEROSIS (MS) FOR NON-MS PROVIDERS

- Multiple Sclerosis is an immune mediated disease that leads to demyelination in the central nervous system.
- There are different disease trajectories in MS: patients may have a relapsing-remitting course, secondary progressive MS, primary progressive MS. Some patients may also not meet criteria for MS but have a single episode of symptoms called a Clinically Isolated Syndrome.<sup>1,2</sup>
- Symptom management in MS includes management of sensory changes, pain/spasticity, fatigue, urinary retention, cognitive changes, weakness, existential concerns and mood changes.
- Patient-centered, individualized care that incorporates rehabilitation and symptom management is important to incorporate into the management plan for each patient.
- Emotional health in MS is an important aspect of care and depression is often under-diagnosed.
- As of January 2019, there were 17 approved disease-modifying therapies (DMT) agents representing nine distinct mechanisms of action. DMTs may reduce relapses and potentially slow or delay the progression of disability.<sup>3,4</sup>
- Estimates suggest that 30% of people with MS require caregiving due to disability.<sup>5</sup>
- Treatments for MS are rapidly changing and a shared decision-making approach is required for discussion of the benefits/burdens of therapy.
- Standardized magnetic resonance imaging (MRI) is important for diagnosis and follow-up of people with MS. MRI is recommended before starting medication therapy, when switching DMTs, and as part of the ongoing monitoring of disease activity while on a DMT.<sup>6</sup>
- Life expectancy in MS varies and may be normal, but on average is felt to be 7 years shorter than the general population.<sup>7</sup>

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#### 1

The National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care, 4th edition provides an extensive list of tools and resources. Please refer to Appendix II pages 70-84. ([https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf))

#### 2

In the article, Kluger et al, 2018 (Kluger et al, Implementation issues relevant to outpatient neurology palliative care. *Ann Palliat Med*. 2018;7(3):339-348. <http://apm.amegroups.com/article/view/17473/20135>), the authors created three forms that may be helpful to MS care team that want to incorporate palliative care into practice. The consensus group recommends reviewing and modifying the forms for your use in jump-starting the palliative approach in the MS care team. The three forms include:

- Form 1: To address the concern that important issues are discussed during patient meetings, Kluger et al (2018) developed checklists for each provider. <http://apm.amegroups.com/public/system/apm/supp-apm.2017.10.06-4.pdf>.
- Form 2: Kluger et al also created an information packet to increase the patients' and families' understanding of palliative care. <http://apm.amegroups.com/public/system/apm/supp-apm.2017.10.06-5.pdf>
- The chaplain on the team provided a booklet of activities to build resilience and manage grief. <http://apm.amegroups.com/public/system/apm/supp-apm.2017.10.06-6.pdf>

#### 3

There are brief, validated screening tools in MS for:

- Clinically significant depression
  - » PHQ-9 (Patient Health Questionnaire-9)
  - » HADS-D (Hospital Anxiety and Depression Scale – Depression)
  - » BDI-FS (Beck Depression Inventory - Fast Screen)
- Anxiety
  - » HADS-A (Hospital Anxiety and Depression Scale – Anxiety)
- Cognitive impairment
  - » SDMT (Symbol Digit Modalities Test)
  - » aMACFIMS (abbreviated minimal assessment of cognitive function in multiple sclerosis)
  - » BICAMS (Brief International Cognitive Assessment for MS)

#### 4

Team self-care. It is important for healthcare professionals to receive education and support to minimize the risks of emotion exhaustion and burn-out. Recommendations for team self-care can be found in Kluger et al, *Ann Palliat Med* 2018, p342. (<http://apm.amegroups.com/article/view/17473/20135>)

#### 5

Communication guides and tools are available to help providers to structure conversations with the patient.

- Serious illness communication guide has been utilized in many different patient populations. See: Bernacki R et al. Development of the Serious Illness Care Program: A randomised controlled trial of a palliative care communication intervention. *BMJ Open*. 2015;5(10):1-14. (<https://bmjopen.bmj.com/content/5/10/e009032.long>)

## 5 (continued)

- The Serious Illness conversation guide can be accessed at: <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&%20Tools>.
- SPIKES protocol. SPIKES is an acronym for the six-step approach to delivering bad news about a patient's health status to the patient. The article cited here explains the SPIKES protocol as applied to the patient with cancer. See: Baile et al. SPIKES – A six-step protocol for delivering bad news: Application to the patient with cancer. The Oncologist. 2000;5(4):302-311. <http://theoncologist.alphamedpress.org/content/5/4/302.full>
- Vital Talk. Training to improve communication skills for clinicians to communicate about serious illness with their patients. For more information see: <https://www.vitaltalk.org/>
- Education in Palliative and End-of-life Care (EPEC). Of note, there will be an EPEC neurology adaptation (EPEC-N) by fall of 2019. EPEC-N will cover difficult conversations, caregiver support, goals of care, ACP, pain management... and will also have a specific module on MS. <https://www.nhpco.org/link/education-palliative-and-end-life-care-epec-project>

## 6

Toolkits available from the Center to Advance Palliative Care (CAPC). These toolkits provide the resources and details to for building and strengthening a palliative care program. For more information see: <https://www.capc.org/toolkits/>

## 7

Shared decision-making – is an important communication tool. Patients report improved satisfaction and lower decisional conflict when engaging in shared decision-making. The framework for shared decision-making includes eliciting the patient's values and goals, targeting discussion of clinical options to those values and goals, and partnering with patients to make individualized decisions. Here is a brief list of shared decision-making aids:

- Ontario decision-making: <https://decisionaid.ohri.ca/>
- Shared decision-making aids from AAN on DMTs: [https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-improvement/patient-handouts/15msshareddecisionmakingtool\\_pg.pdf](https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-improvement/patient-handouts/15msshareddecisionmakingtool_pg.pdf)
- Best case/worst case scenario training toolkit: <https://www.hipxchange.org/BCWC>

Patient Guide for shared decision-making – Shared decision-making aids may be helpful in explaining the benefits of palliative care to patients. Here is an example of information about palliative care that healthcare providers can share with cancer patients: Brown et al. Palliative care. 2019;5(1):126. <https://jamanetwork.com/journals/jamaoncology/fullarticle/2713847>

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## 7 (continued)

- Curtis JR, Downey L, Back AL, et al. Effect of a Patient and Clinician Communication-Priming Intervention on Patient-Reported Goals-of-Care Discussions Between Patients With Serious Illness and Clinicians: A Randomized Clinical Trial. JAMA Int Med. 2018 Jul;178(7):930-940.

## 8

Caregiver support – A booklet from the National Multiple Sclerosis Society provides guidance on issues that support partners and caregivers of people with MS may face. See: <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-A-Guide-for-Caregivers.pdf>

Family Caregiver Alliance may also have useful resources. <https://www.caregiver.org/>

## 9

Advance care planning and communication with patients

- The conversation project – focuses on helping people talk about their wishes for end of life care. See: <https://theconversationproject.org/>
- Five Wishes is a resource for advance care planning. Information can be found at: <https://fivewishes.org/five-wishes/health-care-systems>
- <http://www.gowish.org>
- <https://prepareforyourcare.org/welcome>

## 10

Centers and Organizations that can help

- AAHPM – American Academy of Hospice and Palliative Medicine (<http://aaahpm.org>)
- CAPC – Center to Advance Palliative Care (<http://capc.org>)
- CMSC – Consortium of Multiple Sclerosis Centers (<http://mscare.org>)
- HPNA – Hospice & Palliative Nurses Association (<http://advancingexpertcare.org>)
- IOMSN – International Organization of MS Nurses (<http://iomsn.org>)
- National Coalition for Hospice and Palliative Care (<http://nationalcoalitionhpc.org>)
- NHPCO – National Hospice and Palliative Care Organization (<https://www.nhpco.org/>)
- NPCRC – National Palliative Care Research Center (<http://npcrc.org>)
- PAHPM – Physician Assistants in Hospice and Palliative Medicine (<http://pahpm.org>)
- Society of Pain and Palliative Care Pharmacists (<http://palliativepharmacist.org>)
- Social Work Hospice & Palliative Care Network (<http://swhpn.org>)
- The 3rd annual Neuropalliative care Summit will take place this year at the American Academy of Neurology meeting. And, a Neuropalliative Care Society will be launching in 2020.

## SECTION 10

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