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## Neuropalliative Care: A Practical Guide for the Neurologist

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### Abstract

Neuropalliative care is a new and growing field within neurology that focuses on improving the quality of life of patients with serious neurologic illnesses. While specialty-level palliative care training is available to interested neurologists, all neurologists can strive to provide primary palliative care for their patients. In this review, we will describe the scope of neuropalliative care, define patient populations who may benefit from palliative care, and explore the communication and symptom management skills essential to palliative care delivery.

### Keywords

palliative care; neuropalliative care; quality of life; communication skills

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One billion people worldwide suffer from neurologic disease and more than 1 in 10 deaths are related to neurologic illness.<sup>1</sup> Many neurologic diseases have no cure, and lead to significant disability, emotional distress, and chronic, debilitating symptoms. Recognizing the burden of neurologic disorders, increasing attention is being given to helping patients live well with neurologic disease using the principles of palliative care.<sup>2–4</sup> In this review, we will provide an overview of the field of neuropalliative care and discuss the essential palliative care skills needed for clinicians caring for patients with neurologic disease.

### Defining Palliative Care

Palliative care is an approach to care for patients with serious illness aimed at improving the quality of life of patients and families.<sup>5</sup> Palliative care is appropriate for patients at any stage of their illness, including at the time of diagnosis, and can evolve to fit the patient's needs as their disease progresses.<sup>6</sup> The palliative care approach emphasizes relief of physical, emotional, and spiritual distress. Additionally, communication about care preferences is a critical component of palliative care, and expertise in handling difficult conversations, responding to emotion, and discussing patients' wishes is necessary.

There are several different tiers of palliative care delivery.<sup>7</sup> The first of these tiers is palliative care provided by the patients' primary providers. Neurologists can incorporate essential palliative care skills, such as exploration of patients' goals and wishes for care and provision of symptom relief, into their routine practice to provide primary palliative care. Patients with many neurologic diseases view their neurologist as a primary care provider. This longitudinal relationship between patient and provider offers a trusting foundation for discussion about care preferences. For patients who require more intensive symptom management or additional support, specialty-level palliative care may be appropriate. Specialty palliative medicine is typically delivered by a multidisciplinary team of palliative care specialists, including, but not limited to, physicians, nurses, nurse practitioners, social workers, and chaplains. Specialty palliative care, including neuropalliative care, includes both consultative and direct palliative care services and can be delivered in the outpatient, inpatient, and home settings.

### **Trajectories of Illness in Neuropalliative Care**

There is a wide array of neurology patients who might benefit from palliative care. It has been proposed that these patients fall into four categories:<sup>8</sup> patients with rapid decline, patients with episodic decline, patients with prolonged decline, and patients presenting with acute crisis and uncertain recovery. Examples of patients in each category are shown in ► Table 1. The palliative care needs of these patients and their families vary between categories. For example, patients with more rapid, but predictable, decline may have quickly changing symptoms requiring frequent visits and adjustments to management; patients with a more prolonged decline may have high levels of caregiver burnout; a sudden acute decline may be followed by substantial, yet uncertain, recovery, requiring preference-sensitive decision making. Anticipatory conversations or serious illness conversations require different skillsets depending on the trajectory of illness and are usually most effective if done early and iteratively. Understanding the disease trajectory can assist with timely identification of patient and family needs and facilitate informed decision making.

### **Unique Aspects of Neuropalliative Care**

Much of the palliative care literature to date has focused on nonneurologic palliative care. While the core principles of palliative care apply to neurologic patients, this population also has unique palliative care needs due to communication, prognostic, and psychosocial challenges.<sup>2</sup>

In contrast to oncology, for example, patients with serious neurologic illness may lose their ability to communicate early in their disease course. Patients with motor neuron disease or stroke may experience motor impairments limiting their ability to converse. Similarly, patients with rapidly progressive dementia may initially retain the motor skills of speech but be unable to participate in decision making due to cognitive impairment. Surrogate decision makers are thus commonly required to serve as the voice of patients. These communication challenges demonstrate the importance of early initiation of palliative care.

Some neurologic diseases are associated with behavioral challenges. Impulsivity, loss of empathy, and apathy are frequently seen in patients with behavioral-variant frontotemporal

dementia.<sup>9</sup> Similarly, patients with Huntington's disease may show apathy, depression, or obsessive-compulsive behaviors.<sup>10</sup> Coupled with the communication challenges detailed earlier, these aspects of neurologic illness place additional burden on caregivers and families. Management of these symptoms often requires a multidisciplinary approach and attention to both the patient and the caregiver.

Perhaps in no field as much as neurology, prognostication remains a formidable challenge. There is a high degree of uncertainty and variability in neurologic illness. Estimations of the duration of disease, the impact of disease on a patient's function, and the possibility of relapse/recurrence of disease may be difficult to predict.<sup>11</sup> Our prognostication tools have limitations, and there is variability in how these tools are implemented and interpreted.<sup>12</sup> Additionally, patients' views of acceptable quality of life may change over time so care must evolve to meet their needs. Providers must take care not to insert their own biases in prognostication, as these may not reflect the patient experience.<sup>13</sup>

Neurologic illnesses can have a tremendous impact on patients' sense of self. Boersma and colleagues have suggested that "neurology patients experience their disease as something intrinsic to their person, which clearly differs from patients with cancer who see 'the cancer' as something outside of themselves."<sup>2</sup> The psychological and existential distress that results from a neurologic disease can be profound. Studies of patients with motor neuron disease found significantly higher scores for demoralization, hopelessness, and suicidal ideation when compared with patients with cancer.<sup>14</sup> Symptoms of significant depression are estimated to be present in 35% of patients with Parkinson's disease.<sup>15</sup> Post-stroke depression occurs in one-third of stroke survivors.<sup>16</sup> The psychological stress of a neurologic illness may be worsened by the uncertainty inherent in many types of neurologic disease. In studies of patients with multiple sclerosis and Parkinson's disease, uncertainty was associated with higher rates of depression.<sup>17-19</sup> The psychological effects of neurologic illness have a significant impact on patients' quality of life and may require intensive intervention frequently.

### **Unmet Needs in Neuropalliative Care**

Despite the widespread recognition of the importance of palliative care skills, there are significant gaps in care delivery. At all levels of training, there is room for improvement in knowledge of palliative care fundamentals. One survey of neuro-oncologists found that only 51% of providers felt comfortable dealing with end-of-life conversations and symptom management.<sup>20</sup> While palliative care competency is listed as a core competency for neurologists by the Accreditation Council for Graduate Medical Education (ACGME),<sup>21</sup> a survey of neurology residency program directors found that less than 52% of programs had formal lectures in palliative care topics.<sup>22</sup> The lack of training in palliative care is reflected in the results of a 2009 brief nationwide questionnaire demonstrating low knowledge of core palliative care topics among neurology residents nationwide.<sup>23</sup> Equally troubling, practicing physicians may overestimate their knowledge about the medical and ethical care of dying patients.<sup>24</sup>

These gaps in training can translate into missed opportunities for improved patient care. Advanced care planning, defined as upstream conversations about patients' care preferences,

is not consistently incorporated into neurology patients' routine care. For example, patients with advanced dementia in nursing homes are less likely to have advance directives and more likely to be rehospitalized, undergo laboratory tests, and have tube feeding at the end of life than their oncology counterparts.<sup>25</sup> In a study of neuro-oncology patients, 22% of patients were enrolled in hospice in the last 7 days before death, too late, in many cases, to receive optimal benefit from multidisciplinary care.<sup>26</sup> In another study of patients with acute stroke, only 39% of those who died during their initial hospitalization had their treatment preferences documented.<sup>27</sup> Survivors of severe stroke report poor quality of life and a variety of unmet needs in all palliative care dimensions, including high caregiver stress, and both patients and families grieve "the loss of their previous life, identity and roles."<sup>28</sup>

The need for a palliative care approach is recognized by patients with neurologic diseases and their families. Surveys of patients and caregivers of patients with Parkinson's disease reveal eagerness for more involvement by neurology clinicians in advance care planning.<sup>29,30</sup> Stroke survivors and their families also showed a desire to discuss the potential for death and to prepare for disability.<sup>28</sup> Questionnaires completed by patients with advanced multiple sclerosis revealed that the majority wished that discussions about disease progression and dying were initiated by their physician. Physicians who addressed these issues were considered more empathetic.<sup>31</sup>

## Key Palliative Care Skills for the Neurologist

To meet the needs of the growing number of patients with chronic and progressive neurologic diseases, all neurologists need to master the core competencies required for effective symptom management, communication, and advance care planning. These skills can be learned,<sup>32</sup> and ideally should become a part of routine practice. In the following section, we will describe important core skills that all neurologists should master to practice high-quality primary palliative care.

### Identification of Patients Needing Palliative Care Intervention

The first step in the management of palliative care needs is to recognize the need for intervention and a serious illness conversation in a timely manner. A serious illness conversation is a discussion between a provider and a patient about the patient's understanding of their illness, hopes and worries, decision-making preferences, prognosis, and medical goals/trade-offs.<sup>33</sup> On the part of the clinician, this requires (1) an understanding of the trajectory of the patient's illness and related comorbidities and (2) effective communication skills including eliciting individual communication and treatment preferences, listening, and adapting information about prognosis and treatment options to the patient. Many models have been recommended for identifying patients in need of a serious illness conversation. The "surprise" question ("would you be surprised if this patient died within the next year?") has been used effectively to identify patients in nephrology, emergency medicine, and oncology populations who would benefit from palliative care,<sup>34–36</sup> but has not been validated for neurologic patients. This tool may be less applicable in neurologic conditions given the often fluctuating and unpredictable course of illness. Alternatives to the surprise questions include needs- or trigger-based approaches. For

example, one study in the neurology intensive care unit (ICU) identified palliative care needs by incorporating a list of questions into daily rounds that nudged clinicians to identify and address palliative care needs in a timely manner.<sup>37</sup> Trigger-based approaches have also been used in the oncology ICU to identify patients with palliative care needs.<sup>38,39</sup> Retrospective research in the neurology ICU has similarly used these triggers to define the prevalence of palliative care needs for critically ill neurologic patients.<sup>40</sup> Identification of patient-specific triggers for serious illness conversations may help facilitate initiation of goals of care conversations by providers.

### **Serious Illness Conversation Triggers**

At present, there is no consensus on which patient-level characteristics are best utilized as serious illness conversation triggers. However, several experts in the field have recommended that frequent hospitalizations and serious comorbidities, or a major decrease in functional capacity, are possible triggers for a wide variety of neurologic conditions.<sup>41</sup> The need for serious illness conversations can also be assessed on a routine basis for patients who are seen longitudinally in clinic. A summary of potential triggers applicable to a wide variety of neurologic diseases is listed in ►Table 2. These event-based triggers can be used as a starting point for initiating a broader conversation about patients' understanding, goals, and preferences.

### **Serious Illness Conversations**

Serious illness conversations may take place over multiple visits and can be initiated by the patient or the clinician. While neurology-specific tools have not yet been developed, general guidelines exist and are available in print and online to help providers structure these discussions.<sup>33,42,43</sup> Serious illness conversations cultivate patients' prognostic awareness and allow for the transfer of important information about goals and values to inform medical decision making.<sup>44</sup> Research in oncology and geriatrics has shown that discussing preferences is associated with better quality of life, less aggressive medical care near death, goal-concordant care, and better bereavement for families.<sup>45–47</sup> Clinicians are often hesitant to discuss difficult or emotion-laden topics due to lack of training, lack of comfort, prognostic uncertainty, and concern that serious illness conversations will adversely affect patients.<sup>33</sup> However, research has shown that these conversations do not increase patient anxiety, depression, or hopelessness. Effective delivery requires physician empathy and skilled communication skills.<sup>31,48</sup>

## **Components of Serious Illness Conversations**

### **Assessment of Illness Understanding**

Prior to discussing medical decision making, it is important to ascertain patients' understanding of their illness. This involves asking patients about what their understanding and perception of their illness. Questions such as “What have you heard about your illness?” or “What is your sense of what is happening?” can open the conversation and provide a framework for further discussion.<sup>41,49</sup>

## Understanding Goals/Values

As part of discussing a patient's illness understanding, it is important to explore the patient's hopes and worries about the future. Statements like "as you think about the future, what things are you hopeful for?" and "What are your biggest worries about the future?" allow patients to convey important concerns and wishes. It is important to note that in serious illness, there is a natural oscillation between hopefulness and the realization that hopes are unlikely to be realized. Hope is an important coping mechanism, and often is not a reflection of denial.<sup>42</sup> Patients and family members of patients with neurologic illness, particularly in the setting of prognostic uncertainty, appreciate clinician acknowledgment of the need for hope.<sup>50</sup>

## Assessment of Information Sharing Preferences

Not all patients necessarily want prognostic information, and for those who do, the type of information desired may vary. One study interviewing older adults suggests that up to 25% of patients prefer not to discuss prognosis.<sup>51</sup> For those who are interested in prognostic information, Holloway et al recommended assessing whether the patient is looking for information about "how long" or "how well" they might live.<sup>11</sup> Additionally, some patients may like to know clinical details, while others are more interested in "big picture" concepts. Patients may also desire to have difficult information discussed in the presence of a family member or caregiver.

Given the multiple factors affecting information delivery, one strategy is to utilize the "Ask, Tell, Ask" method, which is a helpful way to share a difficult diagnosis or address prognostic considerations.<sup>52,53</sup> The first "Ask" is typically an invitation for the patient to explain his or her understanding of his or her condition. For example, the clinician can ask "Tell me what you have heard about this condition" or "What have you heard about the prognosis for this disease?" This allows patients to tell their story and helps clinicians avoid repeating results the patient already knows. The first Ask can also be used to ask for permission to discuss a certain topic. For example, "Would it be okay if I tell you about the prognosis for this condition?" or "What information would be helpful to you?" Patients may respond with readiness or may express ambivalence about receiving further information. Clinicians should only start sharing information, tailored toward the patient's understanding, situation, and willingness, once they have assessed the patient's perspective. The final Ask is to help clinicians know whether and how their explanation was understood and received.

## Sharing Prognostic Information

Prior to sharing prognostic information, neurologists must conceptualize their own understanding of the patient's disease. This can be a challenging task, given the uncertainty in neurologic disease and the limitations of our prognostication tools. Frameworks that utilize a systematic approach for formulating a prediction have been described. One such model recommends (1) anticipating the types of prognostic information needed in the encounter, such as questions that may arise about survival, functionality, and quality of life; (2) anchoring to available data by considering the overall trajectory of the patient's illness; (3) tailoring the best available evidence to patient-specific factors; and (4) de-biasing to avoid the clinician's overly optimistic or pessimistic predication.<sup>11</sup>

In many situations, prognostic information may come as surprise to patients or be emotionally difficult to internalize. Using techniques developed to deliver bad news, such as the six-step “SPIKES” mnemonic (setting up the interview, assessing the patient’s perception, obtaining the patient’s invitation, giving knowledge and information to the patient, addressing the patient’s emotions with empathic responses, formulating a strategy and summary) can help to optimize delivery of serious information.<sup>54</sup>

In sharing prognostic information, it is important to try to align with patients’ hopes. “I wish” statements can be effective tools in the setting of loss, unrealistic hopes, grief, and bad news.<sup>55</sup> As opposed to “I’m sorry” statements, “I wish” allows the focus to remain on the patient, acknowledges the patient’s emotions, and prepares the patient for shifting their hope.

### **Trust-Building Strategies**

Throughout serious illness conversations, expressions of empathy and curiosity can cultivate rapport and build trust. Borrowing from the oncology literature, the “NURSES” mnemonic provides strategies for responding to patient emotion.<sup>52</sup> These include **N**aming the emotion, **C**hecking to make sure one is **U**nderstanding correctly what the patient is communicating, **D**emonstrating verbal and nonverbal **R**espect, providing expression of **S**upport, and **E**xploring the patient’s emotions.

While neurologic diseases carry significant uncertainty and a wide degree of variability, knowledge that the provider will be supporting the patient longitudinally can be valuable. In interviews of patients with Parkinson’s disease, patients expressed feelings of abandonment and confusion at the time of diagnosis.<sup>29</sup> Similarly, patients with multiple sclerosis reported higher satisfaction with diagnosis disclosure when emotional support was communicated.<sup>56</sup> Particularly after delivery of bad news, close follow-up with patients can affirm clinicians’ commitment to nonabandonment and ongoing emotional support.

### **Symptom Management**

In addition to core communication skills, knowledge of fundamental nonneurologic symptom management is a key component of neuropalliative care. Symptoms fall into three main categories: neurologic physical symptoms, non-neurologic physical symptoms, and psychological/spiritual symptoms. While a detailed analysis of symptom management is outside the scope of this review, ►Table 3 provides an overview of nonneurologic symptoms that are an important part of the palliative care assessment. High-quality care requires attention to all aspects of the patient experience, including nonneurologic physical symptoms and emotional and spiritual suffering.

### **Caregiver Assessment**

Palliative care emphasizes treatment of not only the patient but also the family and caregivers. Caregiver distress is high in neurologic disease, with depression reported in 40 to 60% of caregivers of patients with a variety of neurologic conditions.<sup>57,58</sup> Caregivers are at higher risk for poor health and mortality compared with age-matched controls.<sup>59</sup> Possible risk factors for caregiver burnout include female gender, residing with the patient, financial



strain, isolation, low educational attainment, and obligation as a carer.<sup>60</sup> Caregivers' self-efficacy, their ability to find meaning, and their preparedness can protect their emotional well-being.<sup>61,62</sup> It is therefore important to assess caregiver coping and acknowledge their commitment and dedication to the care recipient. Interventions to reduce caregiver burnout may help improve quality of life for patients and allow patients to stay at home longer.

### End-of-Life Care

As patients progress through the stages of neurologic disease, the neurologist may want to refocus the goals of treatment at certain time intervals. This includes conversations about focusing on comfort rather than cure, or minimizing potentially harmful intervention. When prognosis seems to be closer to months than years, patients can be eligible for additional support from hospice organizations. While palliative care spans from the time of diagnosis to bereavement, hospice is comfort-focused care for patients with a life-expectancy of 6 months or less. Patients in hospice are no longer seeking curative treatment. Hospice is a philosophy of care which can be delivered in the patient's home, in a nursing facility, or in a hospice care facility. Care plans are developed based on a patient's needs and the availability of services. Hospice is an interdisciplinary team, and if a patient enters hospice, their neurologist can choose to take a more or less involved role.<sup>63</sup>

### The Future of Neuropalliative Care

Neuropalliative care remains a new field of study, and there are exciting opportunities for growth of the field.<sup>64</sup> Given the vast number of patients with neurologic conditions requiring palliative care interventions, neurologists are tasked with providing primary palliative care. Training aimed at equipping residents, attendings, and supportive clinical staff with key communication and symptom management skills is necessary to meet the needs of this growing patient population. Standardizing core palliative care competencies across residencies and emphasizing them on neurology boards certification will provide more structure to this training. For clinicians wishing to gain specialty-level expertise in this area, board-certified neurologists can apply for ACGME accredited fellowships in hospice and palliative medicine. Opportunities for neurology-specific palliative care training programs are emerging to help cultivate leaders in this field.

Given the distinct needs of patients with neurologic diseases and their families, research is needed to define the scope of palliative care needs and the best ways to meet the needs of this population. This work includes defining palliative care outcomes that can be used to assess the success of interventions. Few randomized controlled trials exist in palliative care, and fewer still in neuropalliative care. Research to critically examine the benefit of palliative care interventions will help inform the growth of neuropalliative care and encourage evidence-based practice. With the continued progress in diagnosis and treatment of neurologic disease, neurology clinicians, educators, and researchers are called upon to identify the optimal palliative care approach to neurology care and to define the field of neuropalliative care.



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**Table 1**

Neurologic conditions and trajectory of illness

<b>Neurologic condition</b>	<b>Trajectory of illness</b>
Amyotrophic lateral sclerosis	Rapid or prolonged decline
Brain tumors	Rapid or prolonged decline
Stroke	Acute decline followed by uncertain recovery
Multiple sclerosis and neuroinflammatory conditions	Episodic decline and recovery or prolonged decline
Dementia	Rapid or prolonged decline
Parkinson's disease	Prolonged decline
Traumatic brain/spine injury	Acute decline followed by uncertain recovery
Other neurodegenerative conditions	Varies

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**Table 2**

Potential triggers for serious illness conversations

<b>Event-based trigger</b>
Hospitalization(s)
Unintentional weight loss
Cognitive changes
Frequent falls
Development of a serious comorbidity
Change in functional status

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**Table 3**

Common physical and psychosocial symptoms in neuropalliative care

Physical symptoms	Emotional/Spiritual symptoms
Pain	Grief
Dry mouth/Increased saliva	Depression
Constipation	Anxiety
Loss of appetite	Spiritual suffering
Fatigue	Loss of dignity
Insomnia	Depersonalization

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