NEUROPALLIATIVE CARE CURRICULUM
FOR NEUROLOGY RESIDENTS

This curriculum, developed in collaboration with the Graduate Education Subcommittee, provides a comprehensive outline of the relevant neuropalliative care educational goals for future generations of neurologists-in-training. The clinical scope of this curriculum encompasses evaluating palliative needs, conducting serious illness and goals-of-care conversations, assessing and communicating prognosis, and undertaking symptom management for selected common and uncommon neurologic conditions. This outline serves to aid in the development of neuropalliative learning objectives and educational material, and thus is aimed primarily at neurology residency directors and educators who seek to provide a framework for primary neuropalliative skills for neurology trainees. These objectives can serve as the basis for a dedicated neuropalliative rotation, or can be applied throughout residency when addressing topics pertinent to serious neurological conditions. Additionally, a list of resources to aid in teaching communication skills, symptom assessment, and other neuropalliative topics are provided in the index.

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Part I. General Clinical Approach

Clinical evaluation:

History
Efficiently obtains a complete, relevant, and organized neurologic history and comprehensive review of systems pertinent to neurologic disorders.
Establishes initial code status on admission
Obtains a patient/family’s baseline understanding of disease and prognosis, including previously imparted medical information
Identifies patient/family’s communication preferences for information sharing
Obtains efficient and relevant family, spiritual/cultural, and social histories, and attends to potential psychosocial influences on care (e.g., insurance status, financial and caregiving resources, support structure, medical/health literacy, medical mistrust, gender-related competency, cultural humility, etc.).
Identifies medical power of attorney (MPOA), or, in the absence of an advance directive, surrogate decision maker as determined by legal standards in the local region of practice.
Obtains a general caregiver assessment, with emphasis on identifying caregiver burnout.
Obtains a loss history, and knowledge of prior experience with hospice or palliative care services.

Neurological, general, and palliative exams
Efficiently performs a relevant general physical exam accurately incorporating all additional appropriate maneuvers
Performs focused neurologic exam appropriate to the clinical context, focusing on aspects relevant to comfort and function and avoiding necessary noxious maneuvers. This may include:
• Assessing for pain, dyspnea, and anxiety in nonverbal patients
• Assessing for mood, affect, and pseudobulbar symptoms
• Assessing need for formal assessment of capacity, including impact of CNS-altering medications
• Assessing for agitation
• Recognizing respiratory distress
• Performing a wound/skin assessment
• Recognizing common end-of-life findings

Clinical scales
Demonstrates awareness that clinical scales exist in different domains (function, caregiver strain, symptom burden, mood) and can be applied with expert input where clinically relevant (see appendix for domain-specific scale examples).

Diagnostic evaluation:
Integrates and understands the influence of potential factors in evaluating palliative needs and assessing prognosis, including:
• Clinical assessment
• Psychosocial assessment
• Spiritual assessment
• [See appendix for specific clinical, psychosocial and spiritual assessments]

Integrates special clinical considerations into evaluating palliative needs and prognosis, including:
• Neuropsychiatry testing
• Respiratory parameters
• Rehabilitation evaluations
• Special neurological tests

Integrates social work, chaplain, and other psychosocial evaluations into evaluating palliative needs and prognosis
Is aware of the benefits and limitations of population-level prognostication and prognostication scores, algorithms, and biomarkers.

Treatment strategies and side effects:

Symptom management
Appropriately recognizes acute need for symptomatic treatment for:
• Existential distress
• Pain
• Spasticity
• Nausea/vomiting
• Constipation/diarrhea
• Depression/anxiety/insomnia
• Dyspnea and respiratory distress, including at end of life
• Sialorrhea, including at end of life
• Seizure at end of life
• Agitation/psychosis/delirium
• Pseudobulbar affect

Appropriately recognizes the need for symptom management in chronic progressive neurologic conditions.

Procedures
Regarding family conferences and serious illness conversations:
• Demonstrates an awareness of resources for navigating challenging serious illness communication scenarios (see
appendix for resources)

- Demonstrates an awareness of techniques to communicate about prognosis, including strategies to address prognostic uncertainty (e.g., best case/worst case, offering time-limited trials)
- Demonstrates ability to recognize and appropriately respond to strong emotions and navigate family conflict
- Facilitates medical decision-making to reflect a patient’s values and goals of care, as well as an awareness when senior or expert guidance is required
- Demonstrates awareness of the importance of cultural competency and the impact of cultural beliefs in communication and shared decision-making

Regarding advance care planning:
- Demonstrates ability to discuss basics of advance care planning and code status with patients and their families
- Assesses the existence of advance directives for health care at initial encounter and reviews content when available
- Encourages advance directive completion for patients with serious neurological conditions
- Readdresses code status appropriately upon changes in clinical status and/or trajectory of care
- Recognizes local and institutional requirements for code status documentation
- Recognizes local and institutional requirements for associated durable documentation, such as Medical Orders for Life-Sustaining Treatment (MOLST) and Physician Orders for Life-Sustaining Treatment (POLST)

Regarding prognostication:
- Uses prognostic communication as a key element for shared decision-making
- Recognizes and mitigates cognitive biases, including self-fulfilling prophecy and disability paradox
- Understands the difference between palliative care and hospice

Understands the principle of double effect and its significance in end-of-life care for neurologic patients

Appropriately refers patients with advanced palliative needs for consultation with specialty palliative care, ethics, bereavement services, spiritual support, child life services, neuropsychiatry, and other ancillary services

Recognizes the availability of disease-specific societies and support groups, and refers if appropriate.

Demonstrates a basic understanding of special considerations with pediatric palliative care, including family dynamics and psychosocial considerations.

**Part II. Syndromes and Specific Disorders**

Can identify role of primary palliative care support, advance are planning, and major symptom-management challenges for specific neurologic conditions, including:

<table>
<thead>
<tr>
<th>Acute</th>
<th>Chronic/progressive</th>
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<tbody>
<tr>
<td>Severe acute traumatic brain injury</td>
<td>Movement disorders, with a focus on Parkinson’s disease and Huntington’s disease</td>
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<tr>
<td>Acute disorders of consciousness</td>
<td>Chronic disorders of consciousness</td>
</tr>
<tr>
<td>Acute neurovascular injury</td>
<td>Dementia, with a focus on Alzheimer’s disease</td>
</tr>
<tr>
<td>New-onset refractory status epilepticus</td>
<td>Autoimmune neurological disease, with a focus on multiple sclerosis</td>
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<tr>
<td>New-onset autoimmune neurologic disease</td>
<td>Neuromuscular disorders, including amyotrophic lateral sclerosis and muscular dystrophies</td>
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<tr>
<td>Death by neurologic criteria</td>
<td>Malignant brain tumors</td>
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<tr>
<td>Refractory status epilepticus</td>
<td>Refractory epilepsy and severe epilepsy syndromes</td>
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<td>Congenital and pediatric progressive neurologic disease</td>
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Part III. Appendix

Communication skills training


The Neuropalliative Open-Access Curriculum


Supplemental reading


Serious illness communication strategies

- Best Case/Worst Case: https://patientpreferences.org/best-case-worst-case/

Domain-specific scales

- Functional ability
  Palliative Performance Scale (PPS)
  Karnofsky Performance Scale (KPS)

- Caregiver burnout
  Zarit caregiver burden scale (Zarit)
  Caregiver burden inventory (CBI)

- Palliative symptom assessment
  Edmonton Symptom Assessment System (ESAS; ESAS-PD for Parkinson disease)
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- Dementia
  - Mini-Mental State Exam (MMSE)
  - Montreal Cognitive Assessment (MoCA)
  - Functional Assessment Staging Tool (FAST)

- Delirium
  - Confusion Assessment Method for the ICU (CAM-ICU)

- Depression
  - Patient Health Questionnaire (either PHQ-2 or the full PHQ-9)
  - Edinburgh Postnatal Depression Scale (EPDS)

- Anxiety
  - General Anxiety Disorder (GAD-7)

- Spiritual
  - Spiritual Distress Assessment Tool (SDAT)
  - Professional Chaplains (PC-7)