

FIVE KEY PRACTICE ASPECTS**Neuropalliative care****Gamini Pathirana¹**

¹Consultant Neurologist,
National Hospital of Sri Lanka,
Colombo, Sri Lanka

Correspondence

Gamini Pathirana
National Hospital of Sri Lanka,
Colombo, Sri Lanka

E-mail: drpathirana@gmail.com

Abstract

“Five Key Practice Aspects” is a thoughtfully curated series of articles authored by expert neurologists to distill and highlight the most critical facets of everyday clinical practice within various neurology subspecialties. Each article in this series identifies and elaborates on the five most essential considerations in the diagnosis and management of neurological conditions, combining robust evidence-based insights with the seasoned clinical experience of specialists in the field.

The goal of this series is to serve as a concise yet comprehensive reference that caters to both the trainee seeking foundational knowledge and the seasoned neurologist looking for a practical refresher. By focusing on the aspects that are most relevant and actionable in real-world practice, this series offers a streamlined guide that supports informed decision-making across diverse clinical scenarios.

Designed for ease of access and utility, “Five Key Practice Aspects” is a portable resource for busy clinicians who need reliable information on the go. Whether navigating complex cases or honing subspecialty skills, this series aspires to become an indispensable companion in the pursuit of excellence in neurological care.

Neuropalliative care is an essential and evolving subspecialty that integrates palliative care principles into managing patients with advanced neurological diseases. Conditions like Parkinson disease, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), and dementia lead to symptoms that profoundly affect quality of life for patients and caregivers alike.¹ Neuropalliative care aims to enhance quality of life through holistic, patient-centred approaches, addressing physical, psychological, social, and spiritual needs.²

Outlined here are five key practice areas in neuropalliative care: symptom management, communication and goals of care, psychological and caregiver support, ethical decision-making and advance care planning, and a multidisciplinary approach. These components establish an effective neuropalliative care model.

1. Symptom management

Symptom management is foundational to neuropalliative care. Patients with neurodegenerative diseases experience various symptoms, including pain, fatigue, dyspnoea, dysphagia, cognitive decline, mood disorders, and sleep disturbances.³ Each disease presents its unique spectrum of symptoms, necessitating a tailored approach. For instance, ALS patients may face muscle weakness, respiratory issues, and communication difficulties, while Parkinson disease patients contend with tremors, rigidity, and autonomic symptoms. Clinicians often employ both pharmacological and non-pharmacological approaches, with support from multidisciplinary teams.¹

Pain management: Neuropathic pain is common, particularly in conditions like multiple sclerosis and advanced Parkinson



This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

disease. Antiepileptics or antidepressants may be effective, while opioids might be necessary for some patients.⁴

Spasticity and mobility: Spasticity in ALS, MS, or post-stroke conditions can be managed with medications such as baclofen or tizanidine, alongside physical therapy to improve mobility.

Cognitive symptoms: Cognitive impairment in conditions such as Alzheimer disease and frontotemporal dementia is managed with cholinesterase inhibitors and memantine, though supportive care plays a significant role.²

2. Communication and goals of care discussions

Effective communication is essential in neuropalliative care, especially as progressive conditions such as MS involve prolonged disease courses. Goals of care discussions help align treatment with patients' values, focusing on quality of life rather than extending suffering.¹ These conversations should start early and evolve with disease progression, covering prognosis, interventions (e.g., feeding tubes, tracheostomy), and patient preferences.

These discussions prepare patients and families for transitions from curative to palliative or hospice care, offering guidance and support during challenging times.⁴

3. Psychological and caregiver support

Psychological support is crucial for managing the emotional strain on both patients and caregivers. Neurodegenerative diseases often bring about depression, anxiety, and grief due to functional decline and loss of independence. Counselling, cognitive-behavioural therapy, and pharmacological treatments are important components of neuropalliative care.²

Caregivers, often family members, bear significant responsibilities and may experience burnout. Recognizing the caregiver's role, neuropalliative teams provide education, emotional support, and respite care to ensure caregivers can sustain their health and caregiving capacity.⁴

4. Ethical decision-making and advance care planning

Patients with progressive neurological diseases often encounter complex ethical decisions, especially surrounding life-sustaining interventions such as mechanical ventilation and artificial nutrition. Ethical

principles, including autonomy, beneficence, non-maleficence, and justice, guide these decisions. Advance care planning (ACP) is essential, particularly for patients who may lose the ability to communicate their wishes as the disease advances.¹

For example, ALS patients may need to decide early about tracheostomy and long-term ventilation, while those with dementia might consider nutrition and hydration options as dysphagia progresses.³

5. The multidisciplinary approach

The complexity of neurological diseases demands a multidisciplinary approach. Neuropalliative care teams generally include neurologists, palliative care specialists, physical and occupational therapists, speech and language pathologists, social workers, psychologists, and spiritual care providers. This collaborative approach addresses physical, emotional, social, and spiritual needs through coordinated expertise.³

For instance, physical therapists manage mobility and spasticity, speech pathologists address dysphagia, and spiritual care providers support patients and families with existential concerns.⁴

Neuropalliative care prioritises quality of life by managing symptoms and providing patient-centred care. Focusing on these five key practice points: symptom management, communication, psychological support, ethical decision-making, and a multidisciplinary approach helps healthcare providers support patients and families through the challenges of neurodegenerative diseases.

REFERENCES

1. Boersma I, Miyasaki J, Kutner J, et al. Palliative care and neurology: time for a paradigm shift. *Neurology*. 2014; 83(6):561-7. doi: 10.1212/WNL.0000000000000674.
2. Chang RS-K, Poon WS. "Triggers" for referral to neurology palliative care service. *Ann Palliat Med*. 2018;7(3):289-95. doi: 10.21037/apm.2017.08.02.
3. Kluger BM, Bernat JL. Palliative care and inpatient neurology: Where to next? *Neurology*. 2019;92(17):784-5. doi: 10.1212/WNL.00000000000007354.
4. Oliver D, de Visser M, Voltz R. Palliative care in neurology. *Lancet Neurol*. 2017;16(11):868. doi: 10.1016/S1474-4422(17)30320-4.