

The current state of neuro-palliative care

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The July 2018 issue of *Annals of Palliative Medicine* is a focused issue guest edited by Kwok Ying Chan, FHKCP, of the Palliative Medical Unit at Grantham Hospital in Hong Kong. The issue is dedicated to neuro-palliative care, a relatively new subspecialty of neurology and palliative medicine. Neurologists commonly encounter life expectancy-limiting conditions such as dementia, multiple sclerosis, Parkinson's disease, motor neuron disease, and stroke, each of which have unique quality-of-life limiting symptoms and unique treatment and management approaches for these symptoms. While *Annals of Palliative Medicine* featured a focused issue on palliative care for dementia in 2017 (1,2), neuro-palliative care transcends a single diagnosis and focuses more globally on alleviating physical, social, psychological, and spiritual suffering.

Neuro-palliative care principals call for a better understanding of the profile of symptoms encounters by patients with neurological disorders, which can inform management strategies and help to alleviate suffering (3). In the Preface to the focused issue, Kwok Ying Chan champions early discussions on goals of care with families and patients who have advanced or incurable neurological disorders and endorses increased research efforts to improve the understanding of these diseases.

The focused issue features five interesting review articles on diverse topics pertaining to neuro-palliative care. First, Chang and Poon discuss triggers for referrals to neurology palliative care services. Next, Jeffrey Sheung Ching Ng details advanced Parkinson's disease and discusses holistic approaches to symptom control and palliative care management for patients afflicted with this progressive neurological condition. Sreenivasan and Nobleza next provide an interesting report on the complexities, challenges, and ethical issues faced when caring for patients with advanced neurological diseases. The authors highlight shared challenges across a diverse group

of neurological conditions, including acute neurologic conditions like cerebrovascular disorders and vegetative state, as well as progressive conditions of varying rapidity like Creutzfeldt-Jakob disease, amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's disease, Alzheimer's disease, other dementias, and central nervous system malignancies. Cheng and colleagues next review the current literature on supportive and palliative interventions in motor neuron disease. The final review, authored by Tsz Kin Kwok, focuses on palliative care needs for patients with neurological conditions who are on mechanical ventilator support.

The focus issue next features three original research investigations. In the first, Chang and Wong report on prognostic indicators of neuromuscular disorders, finding that age at diagnosis, early-onsets dyspnea, dysphagia, constipation, and impaired mobility correlated with early death. Kluger *et al.* then describe their development of an interdisciplinary outpatient clinic for patients and families affected by neurologic disorders and share lessons learned and ongoing challenges for their clinic. Cheung and colleagues then investigate advanced care planning practices and report on the first such study assessing end-of-life care preferences, documentation, and communication in patients with advanced neurology diseases.

The neuro-palliative care focused issue of *Annals of Palliative Medicine* is concluded with two thought-provoking perspective reports and a letter to the editor. Chan and Chan describe how enhanced psychosocial support can serve as an important component of a neuro-palliative care service, with psychological therapies having the potential to improve well-being in end-of-life patients. Luk and Chan similarly detail end-of-life care for advanced dementia patients in residential care homes. Lastly, Li *et al.* discuss a collaborative model between hospital-based and

community-based palliative care teams for patients with moderate to severe developmental intellectual disabilities.

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Footnote

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