

## Guest Editorial

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# Palliative rehabilitation and Amyotrophic Lateral Sclerosis: A perfect match

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The World Health Association defines palliative care as a medical discipline that aims to improve the quality of life of the patient and caregiver/family faced with an incurable and potentially life-threatening illness. Palliative care relieves pain and other distressing symptoms, affirms life while regarding death as a normal and life fulfilling process; neither hastens nor postpones death; integrates psychological and spiritual aspects of care; offers support to maximize the level of activity until death; offers a support system to help family and caregivers to cope before and after death; uses a team approach to meet the needs of the patient and the family/caregivers; and strives to enhance quality of life while positively influencing the course of the illness [6, 18]. Palliative care provides comfort while attempting to maintain the highest possible quality of life. Although physical, emotional and spiritual preparation for death is embraced, palliative care emphasizes the compassionate care of those who are still living. Palliative care is well suited to an interdisciplinary team model that provides support for the whole person. Palliative care and rehabilitation share common goals and therapeutic approaches. Both disciplines have a multidisciplinary model of care that aims to improve the patient's levels of function while maximizing comfort. At present there is no evidence based reason to support this approach and research on best practices is needed. However, clinical experience suggests that the application of the fundamental principles of palliative and rehabilitation medicine is likely to improve care of ALS patients [1–5, 7–11, 13–16].

Once the diagnosis of ALS has been made and imparted to the patient and family, the clinician is charged with designing a patient specific treatment regimen. This presents a significant challenge because the symptoms both at time of diagnosis and throughout the clinical course are relentlessly progressive, markedly variable, and dependent upon the segment (cranial, cervical, thoracic, lumbosacral) of onset, the degree of upper and or lower motor neuron clinical dysfunction, the pattern of segment to segment spread and the rate of evolution. In ALS symptoms result predominantly from weakness, largely the result of lower motor neuron loss, and or incoordination, largely the result of upper motor neuron loss, of voluntary musculature that may include loss of hand and arm strength and dexterity, axial weakness of the neck and back, leg weakness or incoordination, weakness or incoordination of speech and swallowing, and progressive weakness of respiratory musculature. Coexisting frontotemporal lobar degeneration may produce progressive cognitive dysfunction that can precede or follow the onset of motor symptoms [12]. The palliative rehabilitation model, emphasizing a coordinated, multidisciplinary approach to management of all symptoms, whether physical, spiritual or emotional, is perfectly suited to the care of these patients. The focus is to prolong independence, avoid complications and strive to maximize quality of life.

While the maintenance of physical independence in ALS should not be de-emphasized, it is essential to an understanding of the palliative rehabilitation mod-

el that the quality of life of patients with ALS is not solely determined by their motor capabilities. A survey tool designed to assess quality of life (QOL) in ALS patients failed to find a correlation of QOL with a decline in strength and physical function. Rather, as physical capacity waned psychological, religious and existential factors appeared to maintain and even improve the patient's QOL [17]. Clinicians caring for ALS patients should take heed. A traditional rehabilitative program aimed at restoration and maintenance of function should not be abandoned but it is most well suited to those in the early days of this progressive disease. Rather, ALS calls out for a holistic, palliative rehabilitation approach.

In this issue of *NeuroRehabilitation* the contributors review ALS including making the diagnosis and clinical course, association with frontotemporal lobar degeneration, respiratory symptoms and management, common physical issues and treatment, nutritional issues and management, dysphagia evaluation and management, dysarthria evaluation and management and the ethical issues that present themselves from time of diagnosis to the end of life.

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