



## Service Priorities and Programmes Electronic Presentations

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**Submitting author:** Dr Benjamin CHENG

**Post title:** Associate Consultant, TMH, NTWC

### **The development of neurology palliative care service for motor neuron disease (MND) patients facing End-of-Life Needs**

*Cheng HWB(1), Chu CKA(1), Lee S(1), Lee JS(1), Hong YF(1), Chung YK(1)  
Department of Medicine & Geriatrics, Tuen Mun Hospital, New Territories, Hong Kong*

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#### **Introduction**

Motor neuron disease (MND) is a neurodegenerative disease characterized by loss of motor neurons in the spinal cord, brainstem and motor cortex. Clinically it is manifested as progressive decline in physical, respiratory, swallowing and communication function and ultimately death. Traditional model of care was fragmented and did not match with patients and carers multi-facet needs.

#### **Objectives**

Traditional model of care for MND patients was fragmented and did not match with multifacet needs of patients and carers. Furthermore, there could be lack of integrated care at end of life for patients with MND in most lower- and middle-income countries or in places with inadequate palliative care (PC) coverage. Early PC specialist involvement and multidisciplinary team care would enhance symptoms control, advance care planning (ACP), home care provision and bereavement support for MND patients.

#### **Methodology**

A special workgroup for MND patients that includes neurologist, respiratory physician, rehabilitation specialist and palliative care (PC) physician was formed in Hong Kong since year 2013. In various disease phase, each specialty team play a leading role in coordinated care of MND patients.

#### **Result**

From Apr 2013 to Mar 2015, 41 patients newly diagnosed with MND were cared in our model. 96.4% agreed to participate in the ACP discussion. Seventy-five percent of them opted for do-not-attempt cardiopulmonary resuscitation (DNACPR) and no intubation/mechanical ventilation. There were 16 (51.6%) of patients passed away within the review period. All of them succumbed with no CPR performed which was honoring their wish. The average duration under PC was 118 days. Strategies toward standardizing care delivery for MND patients and carers may help to address the

physical, psychosocial and spiritual needs of MND patients. The experience shared from this article conceptualizes the roles of various multi-disciplinary team members, with emphasis paid on PC team position in taking care of advanced MND patients.