

Volume 14, 8 December 2014

Publisher: Igitur publishing

URL: <http://www.ijic.org>

Cite this as: Int J Integr Care 2014; WCIC Conf Suppl; [URN:NBN:NL:UI:10-1-116648](https://nbn-resolving.org/urn:nbn:nl:ui:10-1-116648)

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Poster

## Nurse-led care management motor neuron disease

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### Abstract

Neurology Nurse-led integrated care management of patients with Motor Neurone Disease in small populations mustapa.m, staff nurse and Pengirn tengah, DSN, consultant neurologist

**Background:** Integrated care pathways for motor neurone disease are well established in healthcare systems of developed countries like the United Kingdom and Canada e.g. the Champlain Care Plan developed in Ontario. Motor neurone disease (MND) is a neurodegenerative disease affecting nerves in the spine and brain causing progressive loss of function and subsequent rapidly progressive weakness, difficulty in speaking (dysarthria) and swallowing (dysphagia), and breathing (dyspnoea). This disease has a poor prognosis and is relatively rare with worldwide incidence of 1-2 persons/ 100,000 people and estimated prevalence of 7 in 100,000. In Brunei Darussalam no incidence or prevalence data is available but based on a population of approximately estimated at 348,200, we should see approximately 4-8 new cases per year. In comparison to larger countries with bigger populations, integrated care pathways are even more challenging due to relatively few healthcare professionals with high enough levels of expertise to draw upon to support them

**Aims:** The aims of this study are to describe nurse-led integrated care management for MND patients and to outline the scope of this role particularly in the context of MND as a rare disease in a small population.

**Methods:** We retrospectively reviewed case notes of MND patients seen at the MND Clinic, RIPAS Hospital who were case-managed by the Neurology Nursing team with one focal person from 1st July 2010 to 30th June 2014 and also reviewed the literature on MND.

**Results:** Ten patients were seen during this time. Death rates were 2 in 2011, 1 in 2012, 3 in 2013 and 2 in 2014 thus far. At present, two patients are still living. Out of eight patients, six patients died in hospital, while two patients died at their own home. 70% died because of progressive disease and 30% of the patients died due to acute problems such as lung infections. A variety of other professional and non-professional care providers were required during the course of the illness.

**Discussion and Conclusions:** Integration of MND care can be hospital nurse-led successfully in small populations with limited resources. The nursing role here is to integrate care not only in the hospital settings but also at home. A designated mobile phone is available for nurses to liaise closely with patient and family members while at home so problems can be communicated directly either by texting, instant messaging or calling to the phone service. Involvement of Allied Health Professionals is essential but this may become inco-ordinated, hence the usefulness of the nurse

care-manager in our service. In comparison to other studies where MND patients state a preference for dying at home, 6 out of 8 of our patients died in hospital. Some of our patients preferred dying in hospital because they felt safe and comfortable, and relatives and friends were able to visit daily. In conclusion, given the short life expectancy of MND patients and the complexity of care, the Neurology Nurse as care manager can be successfully implemented not only for nursing care but also identify and co-ordinate other needs of the patients both in and out of hospital.

## **Keywords**

**integrated care for motor neuron disease patient**

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## **PowerPoint presentation**

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