

Palliative approach

A palliative approach is required following a diagnosis of MND to ensure that early discussions around future care management decisions and advance care planning are held and optimal symptom management for the person with MND and their family is achieved.

- the aim is to assist people with MND to maintain quality of life and also to support MND carers to maintain their own health and well being through a coordinated inter/multidisciplinary team approach
- this palliative approach is conducted within a neuro-rehabilitative framework in order to achieve holistic care and support based on the needs and wishes of the person with MND and their family (MND Australia 2014)

MND Australia 2014

MND is a life limiting disease characterised by a series of losses with the accompanying issues of grief and bereavement which affect the patient, the carers and the family from diagnosis.

- establishing links with palliative care at an early stage can provide the primary health care team with a useful source of advice and support
- it is important that people living with MND are clear about the role of palliative care services and the benefits that they can provide

Palliative Care Services

Palliative care services provide their own program of services to the patient and their family, in the home, hospice, residential care facility or hospital.

Services may include:

- counselling
- dietary advice
- loan of equipment
- medical consultancy to the patient's GP
- music therapy
- nursing
- occupational therapy
- opportunities for monitoring and review of symptom management
- physiotherapy
- social worker services
- speech pathology
- respite
- support- pastoral, spiritual, bereavement
- support from trained volunteers

Miller and others 2009b

Palliative care is the holistic management of symptoms in patients with terminal illness. Palliative care does not preclude active treatment or life-prolonging interventions. Hospice is a major provider of care in the final stages of ALS. Palliative care addresses advance directives and psychosocial and spiritual issues.

Mitsumoto and others 2005

ALS is a unique disease because loss of function relentlessly progresses, and subsequent death occurs mostly in a predictable manner. In ALS, death is at the end of a continuum of care. Therefore, the end-of-life care is heavily influenced by the type and quality of care provided from the earliest stages of ALS.

According to the World Health Organization, palliative care is defined as follows:

'The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families'.

The Workgroup agreed that palliative care begins at the time of diagnosis for patients with ALS. However, initiating end-of-life discussion is difficult for many physicians and health care providers (in the following text, 'physicians' may be extended to include other health care providers) depending on their own experience and philosophy. The timing of when to introduce end-of-life discussions with patients and their families also is uncertain.

The Workgroup developed six triggers for identifying when end-of-life discussions should be introduced (Table I). These triggers were created with a consensus from the Workgroup, and based on their years of clinical experience in caring for patients with ALS and their family members. Important factors that determine when the patient and family are ready to discuss end-of-life issues include coping skills, depression and anxiety, cultural issues, use of functional assistive devices, and physiologic status, among others.

BLE I. Six triggers for initiating discussion about end-of-life issues

1. The patient or family asks – or 'opens the door' – for end-of-life information and/or interventions (elicited or spontaneous, verbal or non-verbal)
2. Severe psychological and/or social or spiritual distress or suffering
3. Pain requiring high dosages of analgesic medications
4. Dysphagia requiring feeding tube
5. Dyspnea or symptoms of hypoventilation, a forced vital capacity of 50% or less
6. Loss of function in two body regions (regions include bulbar, arms, and legs)

Physicians' perception of own mortality - to engage in end-of-life discussions, physicians need to come to terms with the limitations of medical therapies and to develop an attitude of unconditional acceptance and support for the patient. This requires that physicians address their personal attitudes toward death and dying, come to terms with their own mortality, and take the necessary steps to work through their personal issues surrounding death and dying.