

# **Senate Inquiry into Aged Care - Younger People in Nursing Homes**

## **Submission from the MND Association of NSW**

**July 2004**

Motor Neurone Disease (MND) presents unique physical and psychosocial challenges. As people with MND face a spiralling process of loss it is important, wherever possible, to maintain quality of life by facilitating on-going care in the person's own home. This requires complex, coordinated care from a variety of health care providers and support for primary carers through respite care, training in management of progressing physical and emotional needs and support in planning ahead and anticipating changing need. The alternative of residential care in an aged care facility is usually a very poor option for people with MND. The complex physical needs of people with MND are inadequately met in residential facilities. As well as negative impact on quality of life, the cost of residential care is high and therefore supporting the provision of care by family carers represents a major social and economic contribution. The impact on the quality of life of younger people with MND, in particular, is negatively effected by inappropriate placement in a nursing home.

People with MND have complex needs and meeting these needs often presents a challenge to nursing home staff. People with MND who are admitted to nursing homes are usually younger than other residents and in the advanced stages of the disease. They may be unable to move their limbs and have severely impaired communication. Their cognition is usually unaffected.

The patient may therefore be extremely anxious and frightened as they are unable to easily communicate their needs and may feel very unsafe residing with people with dementia. They require assistance with complex positioning and comfort needs and are unable to do anything without the assistance of others. The time required to ensure adequate nutritional and fluid intake is often an issue.

For staff, caring for someone with MND involves a lot of time and patience. The nursing homes are not funded to provide on going low-key care such as moving a limb etc and it is therefore hard to match the care the person received at home. Staffing levels are usually insufficient to provide the person with MND with optimal care. High staff turnover is also an issue in some instances as it takes new staff time to understand the particular care needs of a patient with MND. The complex and differing nature of diseases such as MND necessitates ongoing education and staff with the necessary nursing skills.

A summary of the particular issues for people with MND in residential care includes:

- capacity of nursing homes to manage PEG and ventilation

- non invasive positive pressure ventilation is becoming a more common supportive treatment for people with MND and use of this equipment may be poorly understood by nursing home staff.
- risks of mixing severely disabled people with people with dementia
  - it is unusual for people with MND to have dementia, however, they may have severe communication difficulties. This is often mistaken for intellectual impairment which can be very isolating and frustrating especially for younger people with MND
- capacity of NH to invest time in communication issues
  - this issue remains a primary concern for people living with MND, carers, family members and staff. Nursing home staff are often from a NESB which exacerbates the communication difficulties.
- capacity of NH to meet the needs of people with MND
  - Complex and changing care needs require specific understanding and skills.
  - Nursing Homes are not adequately funded for staff hours to provide this level of care
- adequacy of Home and Community Care in addressing needs
  - Most people with MND would prefer to stay at home and are better managed at home but require comprehensive and reliable home and community care services
- services available if you are age 64 versus age 65
  - ongoing changes to eligibility for aged care and disability services and nursing home placement creates confusion for care providers and recipients

The MND Association of NSW recommends an increase in community care services and respite care services provided in a timely in order to minimise the need for people with MND to enter nursing homes. Carer stress and burnout are usually the catalyst for admission to residential care and therefore adequate support and respite for carers throughout the course of the disease is imperative.

The MND Association of NSW recommends that provisions are made in nursing homes for younger people and people without any cognitive impairment in order to maintain their quality of life.