



Wellbeing and support needs

There is no cure for MND and no effective treatment... maintaining quality of life and independent living is a priority for people living with motor neurone disease (MND Australia 2009).

Victorian Government Department of Human Services 2008

After diagnosis, people with MND may find themselves negotiating an often inflexible, occasionally expensive and sometimes disjointed healthcare system, while coping with the trauma of a recent diagnosis. They must simultaneously come to terms with the prospect of reduced life expectancy, reduced income as their ability to work diminishes, confusion about help and support mechanisms, the disappointment associated with their lost future and fear for their family.

Gallagher and Monroe 2006

Psychosocial care plays a particularly important role in determining how patients and families respond to the impact of illness. It can help them cope with experiences of loss and change and expand their sense of what is possible.

McLeod and Clarke 2007

The physical aspects of MND clearly receive the majority of attention, both from a research and a health care point of view. Perhaps the great physical impairment associated with MND may lead to the assumption that alleviation of the physical burden will also relieve the emotional burden and thus restore Quality of Life (QoL). However the available research shows that the relationship is not this simple.

QoL has been reported to be correlated to suffering, social support, sense of burden and hopelessness; however it is not significantly correlated to physical functioning. Clarke et al. recently reported that determinants of QoL in MND patients were more likely to be related to psychosocial aspects of life rather than physical aspects.