

Motor neurone disease

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease characterized by loss of motor neurons in the spinal cord, brainstem, and motor cortex. The cause of the disease is still not known. ALS is not curable, but a number of important therapies are available (Miller and others 2009a).

There is a "...persistent underutilisation of therapies that improve survival and quality of life..." (Miller and others 2009a) for people with MND. This website aims to assist practitioners in the provision of optimal care for people living with MND by providing easily accessible evidence based information about these therapies.

MND Australia 2014

MND onset is insidious. Initial symptoms can include:

- stumbling
- weakened grip
- distorted speech
- cramp
- muscle wasting
- swallowing difficulties
- shortness of breath

Average age of onset is most commonly the middle years and onwards.

- Incidence: approximately 2.65 in 100,000 people
- Prevalence: 6/7:100 000
- Male/female ratio: 3:2
- Distribution: Worldwide

Death is most commonly due to respiratory muscle weakness and ventilatory failure.

Orrell 2010

Amyotrophic lateral sclerosis (ALS), or motor neuron disease (MND), remains one of the most devastating, and incurable, neurological diseases. Although appearing to be relatively rare, as most individuals survive from diagnosis to death by only 2 or 3 years, the incidence is around 2–3 per 100 000, and around 1 in 500 individuals will die of the condition. The underlying causes remain uncertain, but appear to be multifactorial, including genetic and environmental causes.

Miller and others 2009a

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Chio and others 2009

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disorder characterized by a progressive degeneration of upper and lower motor neurons leading to limb paralysis, dysphagia, dysarthria, and respiratory failure.

The cause of the disease is unknown and there is no effective cure.

Although it is generally reported that the mean survival of patients from symptom onset is 3–5 years, ALS has a considerable variability in outcome and its prognostic factors are not satisfactorily defined.

The median survival from onset to death in ALS is reported to vary from 20 to 48 months with ALS referral centres reporting longer survival times. This wide range narrows when considering population-based studies, which are more likely to reflect the experience of the general ALS population (20–36 months). All studies report that 5 to 10% of ALS patients survive for more than 10 years.

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.