

Motor neurone disease

Motor neurone disease (MND) which is known as amyotrophic lateral sclerosis (ALS) in many other parts of the world, and as Lou Gehrig's disease in the USA, is a progressive neurological disease. There is a "...persistent underutilisation of therapies that improve survival and quality of life..." (Miller and others 2009a) for people with MND.

MND Australia 2008

Motor neurone disease (MND) is an uncommon degenerative disorder of motor neurones which leads to progressive paralysis of cranial and skeletal muscles. MND onset is insidious. Initial symptoms can include:

- stumbling
- weakened grip
- hoarse voice
- cramp
- muscle wasting.

The condition is incurable and leads to death within a few years of diagnosis, generally one to five years. Death is most commonly due to respiratory muscle weakness and ventilatory failure.

Incidence (number of new cases of MND each year): Incidence of MND in Australia is estimated as being the same as the MND death rate. The death rate in 2007 was approximately 1 in 38,000 or 2.65 in 100,000 people.

Prevalence (number of people with a diagnosis of MND): Prevalence (average duration x incidence) is estimated as approximately 1 in 15,000 people. This estimate would give a prevalence of 6/7:100 000 or approximately 1,400 people living in Australia with MND (population 21,072,452 in 2007).

Male/female ratio: More males than females, approx ratio 3:2

Distribution: Worldwide

Average age of onset: Most commonly - middle years and onwards

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.

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

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.

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.