MOTOR NEURONE DISEASE – THE FAST FACTS

MND is a progressive, terminal neurological disease

- Sufferers progressively lose the ability to walk, talk, feed themselves, swallow, and ultimately breathe
- MND can affect anyone
- The estimated life time risk of being diagnosed with MND is **1 in 350** for men and **1 in 400** for women – this is about the same as one person in an average to large sized movie theatre (**Source: Kiernan MC et al. Lancet 2011; 377: 942-55**)
- About 10% of MND is familial – meaning that the disease is passed down from generation to generation within the same family.
- The remaining 90% of people diagnosed with MND are classified as having sporadic disease meaning their is no family history of MND at the time of diagnosis.
- Every day at least 2 people are diagnosed with MND in Australia
- Every day at least 2 Australians die as a result of the disease
- There is currently no truly effective treatment and no known cure
- Cognitive dysfunction can occur and is seen in approximately 20-50% of patients, with a strong association between some cases of MND and a form of dementia known as Frontotemporal Dementia (FTD). (**Source: Ng SL et al. Ann N Y Acad Sci 2015; 1338(1):71-93**)
- **MND is aggressive and relentlessly progressive** – 50% of patients die within the first 30 months of symptom onset and only about 20% of patients survive longer than 5 years. (**Source: Kiernan MC et al. Lancet 2011; 377: 942-55**)
- There is no single diagnostic test for MND – clinicians must rely on a combination of clinical signs found on examination of patient, evidence of progression and worsening of symptoms over time, and specialised neurophysiological testing such as nerve conduction studies and electromyography. In addition, the clinician works to "rule out" out potential diagnoses that may present in a similar way to MND. (**Source: Kiernan MC et al. Lancet 2011; 377: 942-55**)

When patients present to neurologists, the main clinical presentations of MND seen at diagnosis include:

- ***Limb-onset ALS*****:** with a combination of upper and lower motor neuron signs in the limbs (approximately 70% of MND patients present with limb onset disease)

- ***Bulbar-onset ALS***: presenting with speech and swallowing difficulties with limb features developing later in the course of the disease (approximately 25% of MND patients initially present with bulbar disease)
- The less common ***primary lateral sclerosis (PLS)*** form with pure upper motor neuron involvement only
- ***Progressive muscular atrophy (PMA)*** with pure lower motor neuron involvement at presentation