National ALS/MND Day

Motor Neurone Disease (MND) is an all-embracing term used to cover a number of illnesses of the motor neurone. Amyotrophic Lateral Sclerosis (ALS), Progressive Muscular Atrophy (PMA), Progressive Bulbar Palsy (PBP), and Primary Lateral Sclerosis (PLS) are all subtypes of motor neurone disease. MND is the generic term, used more in Europe, while ALS is sometimes used more generically in the USA. These diseases are also sometimes known as Maladie de Charcot, and are often referred to in America as **Lou Gehrig's Disease**, after the famous baseball player who died of the disease.

By any of its names, ALS/MND is characterized by progressive degeneration of the motor cells in the brain and spinal cord. The motor cells (neurones) control the muscles that enable us to move around, speak, breathe, and swallow. With no nerves to activate them, muscles gradually weaken and waste. Symptoms may include muscle weakness and paralysis, as well as impaired speaking, swallowing, and breathing. In most cases, it does not affect intellect, memory, or the senses.

Progress is relentless and generally rapid, with a life expectancy of between 2 and 5 years from the onset of symptoms.

Though it can affect anyone, ALS/MND is more often found in the 40 to 70 year age group. Once thought rare, it is in fact quite common. There are nearly 120,000 cases diagnosed worldwide each year. That is 328 new cases every day!

The impact on the community of ALS/MND is usually measured by the **incidence** and **prevalence** of the disease. **Incidence** is the number of new cases added in a defined period, usually a year. **Prevalence** is the number of cases existing at any point in time. The incidence of ALS/MND is 2 per 100,000 of total population, while prevalence is 6 per 100,000 of total population. Research has found that the incidence is higher in people aged over 50 years. Only 10% of cases are familial (inherited) with the remaining 90% sporadic.

The disease affects each individual differently and can have a devastating impact on family, carers, and friends. The rapidly progressive nature of the disease requires constant adaptation to increasing and changing levels of disability which, in turn, require increased levels of support.