



## INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

26 March 2020

The International Alliance of ALS/MND Associations would like to ensure that people with Amyotrophic Lateral Sclerosis or Motor Neurone Disease (ALS/MND) have been included in any governmental list or programs for extremely vulnerable persons in their guidance on shielding and protecting vulnerable persons from COVID-19. The Alliance is a global network of ALS/MND associations informed by people living with ALS and their caregivers, that builds capability for its members and connects to external stakeholders.

Motor Neurone Disease (MND) is the name given to a group of diseases in which the nerve cells (neurones) that control muscles undergo degeneration and die. Amyotrophic Lateral Sclerosis (ALS), Progressive Muscular Atrophy (PMA), Progressive Bulbar Palsy (PBP) and Primary Lateral Sclerosis (PLS) are all subtypes of motor neurone disease. Although MND is the widely used generic term in the United Kingdom, Australia and parts of Europe, ALS is used more generically in the United States, Canada and South America. These diseases are also sometimes known as *Maladie de Charcot* and are often referred to in the United States as Lou Gehrig's Disease, after the famous baseball player who died of the disease.

By any name, ALS/MND is characterised by progressive degeneration of the motor nerve 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 failing to activate them, muscles gradually weaken and shrink. Progress is generally rapid, with an average life expectancy of between 2 and 5 years from the onset of symptoms. People living with Amyotrophic Lateral Sclerosis or Motor Neurone Disease often have a harder time with breathing and lung function and therefore are at risk from Covid-19, regardless of age.

According to the World Health Organization (WHO) "people with pre-existing medical conditions appear to be more vulnerable to becoming severely ill with the virus." We believe that this pandemic has important implications for people with ALS/MND and we are calling on the Governments worldwide to define people with ALS/MND as being extremely vulnerable as a matter of urgency.

Sincerely,

Calaneet Balas, Chair  
International Alliance of ALS MND Associations

**United In The Worldwide Fight Against ALS/MND**

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