PERMITTING VAD FOR ADVANCED INCURABLE ILLNESS (non-terminal condition)

The case for allowing the <u>option</u> of VAD for people who suffer unbearably from incurable disease but are not terminal, is based on the principles of autonomy, dignity and compassion.

MD Muscular dystrophies are a group of related and inherited disorders that contribute to muscle loss and weakness over time. Each type of MD can affect children and adults. There is no cure for these diseases, making their debilitating effects even more upsetting. The effects can target all muscles or just a group of muscles in the body, causing severe decreases in mobility, lung failure, scoliosis, cardiac fibrosis and tightening of muscles around main joints.

Chronic Obstructive Pulminary Disease (COPD) is a condition which makes it increasingly difficult to breathe due to permanent damage of the lungs and constricting airways, and is often a result of smoking. Coughing and breathing difficulties usually get worse as this disease progresses, and many who suffer from COPD also have chronic bronchitis and/or emphysema. Over time, those with COPD have trouble breathing, and the irreversible damage to the lungs weakens one of the most important systems in the body. There is no cure.

Scleroderma this connective tissue disorder and autoimmune disease causes changes in the skin, blood vessels, internal organsand muscles, and can occur solely on the skin level or internally throughout the entire body. Once diagnosed, symptoms usually progress slowly over time and most often lead to skin darkening, thickening and hardening, causing a tight, mask-like appearance, especially on the face. When this disease spreads to the internal organs like the heart, kidney, lungs and GI tract, the organs begin to fail, leading to complications like lung problems, cancer and heart failure. The cause of this disease is unknown and there are also no methods of prevention.

Parkinsons disease is a progressive neurological disorder that affects movement, speech, concentration. While treatment canhelp management of symptoms, there is no cure.

Huntington's disease is a progressive neurodegenerative disease, characterised by constant and uncontrollable jerking motions along with behavioural changes and cognitive decline. It is incurable and death typically occurs around 15 to 25 years after the first symptoms.

CRPS Chronic pain conditions such as fibromyalgia and neuropathic pain can cause debilitating pain that persists for months or years.

Neurological damage such as profound stroke and severe quadriplegic spinal injury, causing permanent paralysis, immobility, incontinence, needing tube feeding and support to breathe, requiring dependence on carers for every action.