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## **What is Motor Neuron Disease or ALS?**

MND or ALS (amyotrophic lateral sclerosis), is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord.

Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in MND eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose the ability to speak, eat, move and breathe. The motor nerves that are affected when you have MND are the motor neurons that provide voluntary movements and muscle control. Examples of voluntary movements are daily activities like bathing, brushing teeth, walking, talking and jaw movements.

When daily activities are impacted, quality of life and life expectancy for MND patient is severely compromised. Most of the patients become fully dependent on their family for their daily routines. The role of caregiver becomes highly demanding.

MND/ALS is fatal. Almost 65% people die within 3 years, 20% survive up to 5 years and only 10% survive for a decade and very few survive beyond 10 years.

## **MND and Awareness**

MND is a rare disease. So awareness about the symptoms of the disease needs to be spread. We need awareness campaign about the early symptoms and devastating effects of the disease.

Early Symptoms in MND:

Muscle weakness, fatigue, difficulty swallowing, difficulty in speech, saliva drooling, loss of function in any limb, loss of grip, loss of balance, fasciculation

Variants in MND:

* Amyotrophic lateral sclerosis (ALS) – Impacts both upper and lower limbs, muscle wasting
* [Primary Lateral Sclerosis (PLS)](https://www.webmd.com/brain/what-are-motor-neuron-diseases#2-4) – Starts with upper limbs, slurred speech
* [Progressive Bulbar Palsy (PBP)](https://www.webmd.com/brain/what-are-motor-neuron-diseases#2-5) – Impacts swallowing and speech
* [Pseudobulbar Palsy](https://www.webmd.com/brain/what-are-motor-neuron-diseases#2-6) – Impacts swallowing, speech and loss of control while crying and laughing
* [Progressive Muscular Atrophy](https://www.webmd.com/brain/what-are-motor-neuron-diseases#2-7) - weakness in the upper legs and arms, and in the trunk.
* [Spinal Muscular Atrophy](https://www.webmd.com/brain/what-are-motor-neuron-diseases#3-8) -
* [Kennedy's Disease](https://www.webmd.com/brain/what-are-motor-neuron-diseases#3-9) – Tremor, cramps, twitches

Mega awareness campaign should be launched about early symptoms to watch.

Please refer <https://www.als.org/understanding-als> for further understanding of ALS

## **MND/ALS treatment**

Consulting a neurologist in early phase is advised. Physiotherapy, Speech and swallowing therapy, nutrition and diet, Yoga along with FDA approved drugs like Riluzole, Edaravone may sustain quality of life. However there is no effective treatment to stop or reverse the progression of the disease.

Today there is no cure for MND/ALS and new treatment options are in trial. So the situation is hopeless for this disease.

## **MND drugs in Pipeline**

1. Stem cell therapy
2. *Masitinib -* The oral tyrosine kinase inhibitor masitinib targets microglia, macrophage, and mast cell activity in the central and peripheral nervous systems to provide a neuroprotective effect.
3. Nuedexta – Treatment for bulbar symptoms
4. Tofersen - Tofersen is an antisense oligonucleotide being investigated for treatment of ALS caused by mutations in the SOD1 gene, which occurs in up to 2% of ALS cases.
5. AMX0035 - The treatment includes sodium phenylbutrate, which is a medication for urea cycle disorders, and the supplement taurursodiol—a combo that would maintain functioning of the mitochondria and endoplasmic reticulum to protect against neuronal damage

There is lot of enthusiasm in MND patients to get any treatment that may be effective in slowing or reversing the damage. Since results of clinical trials and availability of drugs takes decades, it is better to have realistic goal to improvise quality of life of the patient.

## **MND/ALS warriors and Inspirational survivors**

Stephen Hawking, renowned theoretical physicist was the longest survivor of ALS. He battled the disease for 53 years defying projected life expectancy of 3 to 5 years. So case of Stephen Hawking means a lot to those who are battling with this disease.

Probably intervention by combination of slow progression, excellent care, assistive technology, multi-disciplinary treatment, family support and his own strength helped Stephen Hawking to fight against this disastrous disease.

Please refer to link below that lists notable people who survived ALS

<https://en.wikipedia.org/wiki/List_of_people_with_amyotrophic_lateral_sclerosis>

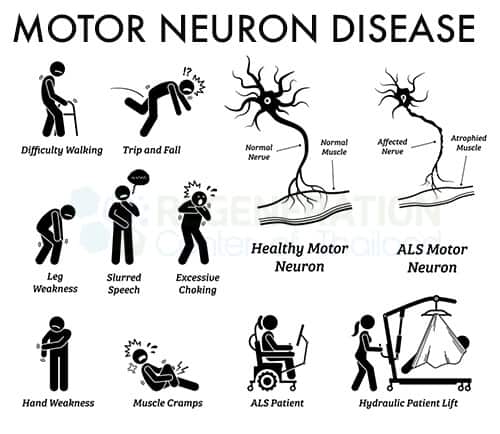
There are many unknown people who are fighting this disease and have a heroic story to tell.

As a respect to ALS patients we are aiming to provide intervention to patients using assistive technology especially in communicative devices so that their brain remains active. It is not just the longevity but the focus is to improve the quality of life for those suffering from ALS.

## **ALS/MND and Assistive technology**

Since ALS/MND is a progressive life threatening disease, here we are aiming to provide comfortable life to the patient and caregiver.

The need of ALS patient is dynamic as the course of the disease changes.



ALS patient and caregiver have challenges at different stages of disease. Most of the time PALS/CALS are not aware of the impending difficult situation. So with the help of assistive technology and ALS care package we can at least aim to provide some comfort to both PALS/CALS

Some of the areas where technology and business acumen may bring welcome change are

1. Communication Devices – Speech Generation, Text to speech apps, Voice Banking, Eye gaze control are some of the software defined tools that assist MND/ALS patient in speech impairment.
2. Sitting to Standing Aid – Due to muscle weakness, standing from sitting position is arduous task and needs assistance of attendants. Electric or hydraulic lifts for home use can be a welcome addition in ALS toolkit.
3. Customized Bed – Auto Reclining bed and chair with soft touch and eye to prevent bed sores
4. Customized Utensils for Dysphagia (difficulty in swallowing and drinking)
5. Dining Assistance – Robotic feeder like Obi can assist in independent eating.
6. Hand Pedal/Foot Pedal / Motorized wheel chair – Since MND/ALS patients are prone to muscle weakness, pedal wheel chair may be a good option to strengthen muscles. Please refer to cogy wheelchair
7. For patients in advanced stages, respiratory support is required
8. Bathroom aids

Need of MND/ALS patient are much more than what listed above. It will be a good idea to provide ALS toolkit package at an affordable cost in a prompt manner. Challenge here is that patient and caregiver both are not sure of how to deal with the impending issues. So if the procedure of care is standardized and promptly provided to the patient easily, it will make life easy.

So if there are programs like “MND/ALS Care” that provide complete MND/ALS solution for 3 to 5 year, it may bring a huge relief to patients.