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Call for greater attention to Amyotrophic lateral sclerosis

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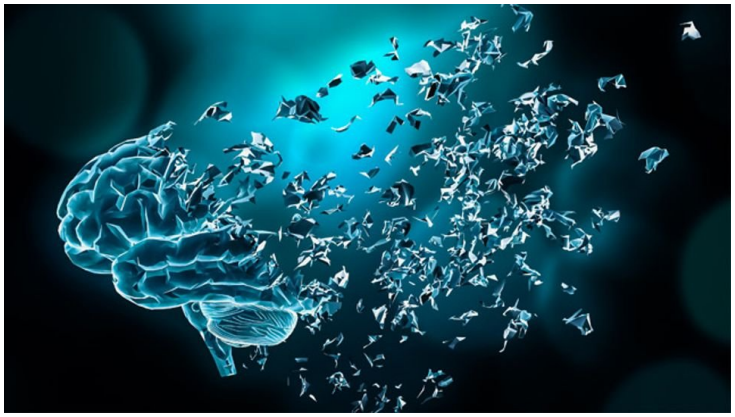
Inclusion of ALS in the national rare disease policy would send a strong message of inclusivity



On Global ALS/MND Awareness Day on 21 June 2023, the ALS Care & Support Foundation has called for greater attention to the special needs of the amyotrophic lateral sclerosis (ALS) community.

A progressive neurodegenerative disease, ALS has no cure or definitive treatment. A motor neurone disease (MND), ALS affects an estimated 450,000 people worldwide, with an average survival rate of just two to five years.

Every 90 minutes someone is diagnosed with ALS and every 90 minutes someone passes away from this disease. In India alone, it is estimated that around 75,000 to 100,000 people live with ALS. The debilitating condition that this disease brings about not only poses immense financial burden but also adversely impacts the physical, emotional and social well-being of the affected individuals and their families.

The inclusion of ALS in the national rare disease policy would send a strong message of inclusivity and support for those living with rare neurodegenerative diseases in the country. In addition, the ALS Care & Support Foundation has identified a few key actions that can make a substantial difference- regular awareness campaigns, financial support, national registry of ALS patients, research and trials in India, multidisciplinary ALS clinics, insurance coverage, and access to global therapies, drugs, supplements and assistive devices.