

# **Amyotrophic Lateral Sclerosis**

For Prelims: Amyotrophic Lateral Sclerosis, <u>Neurodegenerative Disease</u>, <u>National Policy for Rare Diseases</u> (NPRD), World Health Organization.

For Mains: Amyotrophic Lateral Sclerosis and Challenges with it.

#### **Source: TH**

# Why in News?

Amyotrophic Lateral Sclerosis (ALS), a debilitating **Neurodegenerative Disease**, presents a range of challenges for both patients and caregivers in India.

 Despite its rare occurrence, ALS profoundly impacts the lives of those affected due to its progressive nature and lack of effective treatment.

# What is Amyotrophic Lateral Sclerosis (ALS)?

#### About:

- ALS is a rare and **fatal type of motor neuron** disease. It is characterized by **progressive degeneration** of nerve cells in the spinal cord and brain.
  - It's often called Lou Gehrig's disease, after a famous baseball player who died from the disease.
- ALS is one of the most **devastating of the disorders** that affects the function of nerves and muscles.
- As motor neurons degenerate and die, they stop sending messages to the muscles, which causes the muscles to weaken, start to twitch (fasciculations), and waste away (atrophy).
- Eventually, the brain loses its ability to initiate and control Voluntary Movements.
  - The movements that are under our control are called voluntary actions, such as walking, running, sitting etc.
  - On the other hand, the movements that are not under our control are called involuntary movements.

#### Causes:

- Causes are not yet, in a few cases, genetics is involved.
- ALS research is looking into possible environmental causes of ALS.

### Symptoms:

 With ALS, there may be weakness in a limb that develops over a matter of days or, more commonly, a few weeks. Then, several weeks to months later, weakness develops in another limb. Sometimes the initial problem can be one of slurred speech or trouble swallowing.

#### Treatment:

• There is no cure and proven treatment for ALS.

## What are the Initiatives to Tackle ALS?

- The Government's <u>National Policy for Rare Diseases (NPRD)</u>, 2021, introduced a significant provision offering financial aid of up to Rs. 50 lakh to patients afflicted by <u>Rare Diseases</u> and receiving treatment at designated Centers of Excellence.
  - The **World Health Organisation (WHO)** characterizes rare diseases as debilitating conditions with a prevalence of 1 or less per 1000 population.
- This policy initiative aims to support individuals, including those with conditions like ALS, by providing substantial financial assistance for their treatment.

