

# THE PROACTIVE

## A MONTHLY NEWSLETTER

Volume 3

Amyotrophic Lateral Sclerosis

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### Breaking ALS Down:

#### Amyotrophic

"A" means no or negative +  
"MYO" refers to muscle +  
"TROPIC" means nourishment =  
"no muscle nourishment"

#### Lateral

The area in the spine where the brain tells the muscles what to do.

#### Sclerosis

Hardening: as the disease progresses, the lateral areas harden and the signals stop.

### Treatment:

There is no cure for ALS, so treatment aims to alleviate symptoms, prevent unnecessary complications, and slow the rate of disease progression.

ALS can cause a range of physical, mental, and social changes, so a team of specialists will often help patients manage their symptoms and care, improve their quality of life, and prolong survival.

#### Medication

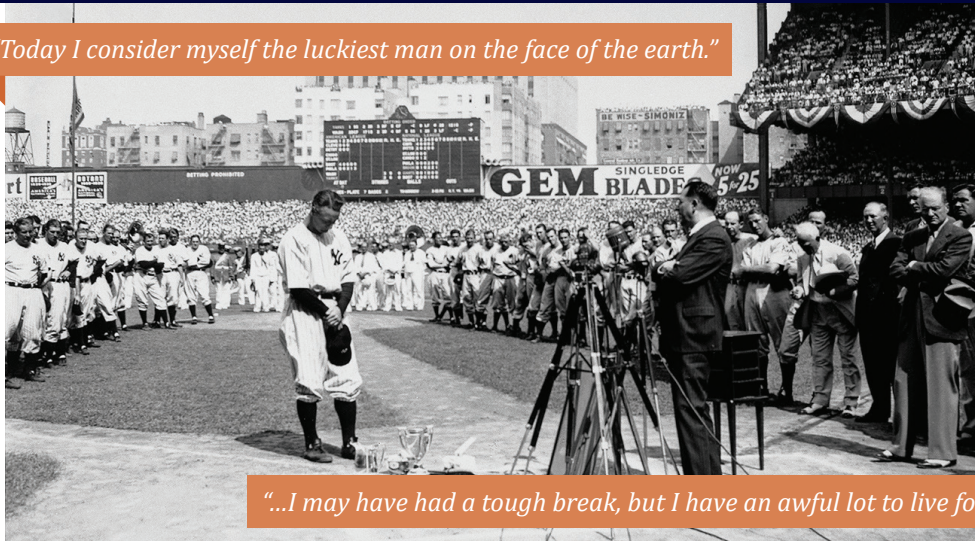
Riluzole (Rilutek) appears to slow the progression of the disease. It may work by reducing the body's levels of glutamate, an excitotoxin that has been linked to neuronal damage.

In May 2017, Radicava (Edaravone) was approved to treat ALS. It may slow the decline in physical function by one third.

#### Therapy

- Physical therapy can help people with ALS manage pain and address mobility issues.
- Occupational therapy can help a patient maintain their independence for longer.
- Breathing therapy may be needed in time, as the respiratory muscles get weaker.
- Speech therapy is useful when ALS begins to make it harder to talk.
- Nutritional support is important, as difficulty with swallowing can make it hard to get enough nutrients.

"Today I consider myself the luckiest man on the face of the earth."



"...I may have had a tough break, but I have an awful lot to live for."

On a hot and muggy summer day in 1939, baseball player Lou Gehrig addressed the crowd at Yankee Stadium. He had been diagnosed with ALS, and would be forced to retire from baseball.

## What is ALS?

Amyotrophic Lateral Sclerosis is the most common type of motor neuron disease (MND). It is sometimes called Lou Gehrig's Disease, after the famous baseball player who had the condition.

ALS attacks the nerve cells that are used in voluntary muscle actions, known as motor neurons. These are actions that we can control, such as those in the arms, face, and legs.

Motor neurons are found in the brain and spinal cord. As ALS progresses, these cells degenerate and die. They stop sending messages to muscles. The brain can no longer control voluntary movement, and the muscles weaken and waste away. The person can no longer control their arms, face, and legs. In time, the inability to breathe unsupported can lead to respiratory failure.

### Statistics:

Sporadic ALS makes up 95 percent of people with the disease. There is no clear cause. Familial ALS is passed down through genes and makes up about 5-10 percent of people with the disease. The child of a person with ALS will have a 50 percent chance of developing the condition.

Half of all people with ALS will live for 3 years or more after diagnosis, but some live for longer. Around 20 percent of people will live 5 years or more after diagnosis, 10 percent will live for 10 years or more, and 5 percent will live for 20 years.

The Centers for Disease Control and Prevention (CDC) estimate that between 14,500 and 15,000 people in the United States had ALS in 2016, with around 5,000 people receiving a diagnosis annually.

Source: Medical News Today, James McIntosh, 14 December 2017

