Questions and Answers about ALS

Q. What is ALS?
Amyotrophic lateral sclerosis (ALS), often referred to as “Lou Gehrig’s disease,” is a progressive neurodegenerative disease that attacks nerve cells in the brain and spinal cord. As a result, the motor neurons reaching from the brain to the spinal cord and from the spinal cord to the muscles progressively degenerate, eventually leading to their inability to function, and death. Another way to think of what happens with ALS is to consider the motor neurons the messengers from the brain and the brain stem to the working, voluntary muscles of the body. When those motor neurons die, the muscle loses its ability to move. There is no current treatment to restore the motor neuron function.

When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. If all the voluntary muscle action is affected, patients in the later stages of the disease become completely paralyzed. Yet, throughout the stages of ALS the senses and intelligence remains, and for the majority the brain remains unaffected.

Q. How many people are living with ALS?
Approximately 5,600 people in the U.S. are diagnosed with ALS each year. It is estimated that as many as 30,000 Americans may have the disease at any one time.

Q. Is ALS contagious?
No, ALS is not contagious.

Q. Is ALS hereditary?
About 5 to 10 percent of ALS cases are hereditary. This is called “familial ALS”. The other ALS cases have no familial link, and they are called “sporadic ALS”.

Q. How is ALS diagnosed?
There is no specific test to definitively diagnose ALS, so it is diagnosed through a process of elimination, which can take several months. Some of the tests to confirm a diagnosis of ALS include:
- EMG (electromyogram) and nerve conduction tests used to measure level of muscle function
- MRI (magnetic resonance imaging) and CT (computerized tomography) which are scans of the brain and spine used to look for other diseases (other than ALS) that have the same early symptoms as ALS.
- In addition, blood tests and a spinal tap may be used to identify diseases that mimic ALS such as myasthenia gravis, polymyositis, multiple sclerosis, stroke syndromes, spinal cord tumors or Lyme disease.
- Muscle or nerve biopsy studies may be used to confirm neurogenic abnormalities in ALS.
Q. Is depression a frequent condition with ALS patients?
Yes, depression is frequently associated with ALS. Proper diagnosis, treatment, and support can help to minimize depression. Studies indicate that primary Caregivers may have higher rates of depression than those with the disease.

Q. What is Rilutek?
Rilutek, the first treatment to alter the course of ALS, was approved by the FDA in 1995. This antiglutamate drug appears to prolong the life of people with ALS by at least a few months. Other medications are available to address symptoms associated with ALS, however they have not been shown to alter the progression of the disease.

Q. Does ALS cause dementia?
A specific type of dementia known as Frontotemporal Dementia, which affects the executive thought process, has been associated with ALS.

Q. How does The ALS Association Chapter help?
The services provided to people with ALS and their families by The ALS Association are free. These services may include:
- Care Consultation
- Equipment Program
- Augmentative/Alternative Communication
- Support Groups
- Book and Video Loans
- Educational Symposiums
- The Care Connection
- Chapter Newsletter