Medical Xpress

New guidelines identify best treatments to help ALS patients live longer, easier

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New guidelines from the American Academy of Neurology identify the most effective treatments for amyotrophic lateral sclerosis (ALS), often called Lou Gehrig's disease. The guidelines are published in the October 13, 2009, issue of *Neurology,* the medical journal of the American Academy of Neurology.

"While we are waiting for a cure, people need to know that a lot can be done to make life easier and longer for people with ALS," said lead guidelines author Robert G. Miller, MD, with the Department of Neurology at California Pacific Medical Center in San Francisco and Fellow of the American Academy of Neurology.

ALS is a rapidly progressive and fatal neurologic disease that attacks the nerve cells that control voluntary muscles. Eventually people with ALS are not able to stand or walk, or use their hands and arms, and they have difficulty breathing and swallowing. Most people with ALS die within three to five years from the onset of symptoms. However, about 10 percent survive for 10 or more years.

According to the guidelines, the drug riluzole should be offered to people with ALS to slow the rate at which the disease progresses. Riluzole is the only drug approved by the U.S. Food and Drug Administration to treat ALS and has a modest effect on prolonging survival.

The guidelines also state that life expectancy will likely increase and

quality of life may increase for people with ALS who use an assisted-breathing device. Longer life expectancy is also likely for people with ALS who use a feeding tube known as a PEG tube, since nutrition plays a critical role in prolonging survival. The guidelines also recommend doctors consider offering their patients botulinum toxin B to treat sialorrhea, also known as drooling, if oral medications do not help. Moreover, doctors should consider screening their patients for behavioral or thinking problems because studies show many people with ALS have these problems. Such problems might affect some patients' willingness to accept suggested treatments.

"Important treatments available for people with ALS are often not suggested by doctors and not used by patients," said Miller. "It's important that people with ALS know that more treatments are now available to ease the burden of the disease and that they should see neurologists who are aware of these new guidelines and follow them."

In addition, the guidelines recommend people with ALS enroll early in a specialized multidisciplinary ALS clinic to optimize care. "Attending a multidisciplinary clinic will likely increase survival and access to treatments, and may improve quality of life," said Miller.

The cause of ALS is not known, and it's not yet known why ALS strikes some people and not others.

Source: American Academy of Neurology (news : web)