

# Majority of ALS patients are not depressed

July 12, 2005 - ST. Paul, Minn. - Contrary to what you might think, most people with amyotrophic lateral sclerosis (ALS) are not depressed. They are also not more likely to get depressed as the end of life approaches, and they are not more likely to be depressed if they want to die or hasten their own death. Two new studies, published in the July 12 issue of *Neurology*, the scientific journal of the American Academy of Neurology, provide the evidence to contradict these assumptions.

The two studies involved the same group of 80 people with advanced ALS. To enter the study, participants had to have breathing difficulties with a forced vital capacity, or breathing power, of less than 50 percent of normal, which is related to a high likelihood of hospice admission and death or the need for mechanical ventilation within six months. The participants were assessed every month until death; 53 of the participants died during the study period.

The first study found that 57 percent of the participants were never depressed during the study period, and only eight percent were depressed at all visits. The researchers also found that people were not more likely to become depressed as death approached.

"It's remarkable that a majority of ALS patients have a more positive attitude toward life even as the inevitability of death is imminent," Catherine Lomen-Hoerth, MD, PhD, wrote with her colleague and mentor Richard K. Olney, MD, in an accompanying editorial. Olney was founder and director of the ALS Treatment and Research Center at the University of California-San Francisco before he was diagnosed with ALS in 2004 and turned over the reins to Lomen-Hoerth, his former student. The AAN presented Olney with a special Public Education Award for his efforts to raise awareness of the disease and money for research by sharing his story as a researcher/doctor turned patient with the national media.

"The resiliency of people with ALS is inspiring for all working in the field of ALS and helps remind us daily of our own mortality and the importance of living each day fully," Lomen-Hoerth wrote.

The researchers also looked at factors that could possibly increase or reduce the risk of depression, such as the patient's spiritual beliefs, whether a spouse was serving as the caregiver, and the patient's financial status. None of these factors made a person more or less likely to be depressed.

The second study examined whether patients expressed a wish to die, and whether people who were depressed were more likely to wish to die. Of the 53 patients, 23 thought about ending their life, 10 expressed that wish to others, and three people hastened their death. In these cases, caregivers reported that the patients asked for relief from suffering and continued to ask even after they were told by the hospice team that additional relief would have the secondary effect of reducing the strength of their breathing muscles and hastening their death.

Those who hastened their death were not different from those who did not hasten their death demographically or in their level of disability or access to services. They were not more likely to be more or less educated, live alone, older, or have more unmet needs or use fewer services than other patients. The two groups also did not differ in how burdened they thought their families were in providing care.

Those who expressed the wish to die or to hasten their death were not more likely to be depressed, if their answers to questions about feeling they "would be better off dead" were excluded. "These findings suggest that the desire to die in end-stage disease may not simply be due to depression," said study author Steven M. Albert, PhD, MSc, of Columbia University in New York, NY. "It may be due to a more general loss of meaning and purpose."

The study found that those who expressed the wish to die were less optimistic, took less comfort in religion, and felt more hopeless.

Compared to those who were unable to act on their wish to die, those who hastened their death reported less suffering and an increased perception of control over the disease in their final weeks of life.

Timothy E. Quill, MD, director of the Center for Palliative Care and Clinical Ethics at the University of Rochester Medical Center in Rochester, NY, and a national spokesman on end-of-life issues, wrote in an accompanying commentary, "In discussing feeding tubes and mechanical ventilation as end-of-life options, we have found that having a willingness to discuss stopping them once started allows some patients who fear chronic dependence to try these treatments in a way that keeps them in control of the process. Sometimes knowledge that there could be an escape allows some patients to keep going in circumstances they would otherwise feel trapped."

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