

# Quality of Life: Who Can Make the Judgment?\*

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To the Editor:

Sixteen years ago I recruited “Lance” for our medical internship program at the University of Florida in Jacksonville. Before his training program was completed he was diagnosed with amyotrophic lateral sclerosis (ALS). He knew that he had an incurable and progressive disease and that he would deteriorate considerably before losing his life.

His condition worsened, his motor strength waned, and he was confined to a wheelchair. He became unable to verbalize clearly, unable to handle secretions, unable to sustain nutrition, and was threatened by all the complications of severe respiratory muscle dysfunction. A near-fatal respiratory failure occurred and although reluctant, Lance accepted intubation because of his fear of suffocation.

Eight years later I visited Lance and barely recognized him because of the marked atrophy from the neck down. He was propped up in a wheelchair with his arms strapped to the sides and a ventilator behind him supplying oxygen via tracheotomy. There was an ostomy site in the side of his neck and that fed him via syringe. He was unable to hold his head up and his responses were mumbled and uninterpretable.

I was surprised to learn that Lance’s life was rich and that he worked actively as an emergency room physician with the assistance of nurse practitioners. Although he had lost the use of his muscles, his brain functioned perfectly well. Eventually, he and his wife opened a clinic to provide medical care to and improve the coping skills of ALS patients and families. He also made a number of important findings on ALS by studying himself, which caused an

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\* This letter is a modified version of my article, which appeared in the *American Journal of Medicine* 100 (1996): 365-366.

improvement in his own condition and which he confirmed on some of his own ALS patients.

Lance's story has an unfortunate ending. An attendant cleaned and changed the tubing on his ventilator in an improper manner and Lance suffocated and died.

This letter is not written to support the use of life sustaining measures in all patients with progressive neurologic disease. Lance's case is most unusual and will likely never happen again. It is written because it showed me an exceptional quality of life despite medical infirmities. Today, patients and families are empowered to decide whether to use respirators.

Quality of life is difficult to judge or forecast not only for yourself, but especially for another individual. Viktor Frankl's *Man's Search for Meaning* portrayed concentration camp victims who knew that death was near but still sought to improve quality of life, albeit with modified goals and objectives, so that their unfortunate, futile existence could provide some degree of satisfaction and meaning.

Similarly, in my area of medicine these types of decisions are often made by cancer patients; despite the fact that life will be shortened, interpersonal relationships and the experiencing of lifecycle events can become highly significant to a patient, family and friends.

Lance created a quality of life beyond all expectations. Had I been the one responsible for the respirator and ICU decision to extend his life, especially given the serious debilitation that he had already suffered, I would not have been able to envision the fullness, richness and creativity that he was able to express.

Source: ASSIA – Jewish Medical Ethics,

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