

I Will Be Paralyzed and Happy

By Bob Brintz

ALS [amyotrophic lateral sclerosis also known as Lou Gehrig's disease] is typically described as an incurable, untreatable, progressive, terminal disease that gradually causes total paralysis before it kills you within two to five years of onset. My experience with ALS began in early 2007 with an initial reaction of panic, fear, astonishment and disbelief; and a promise to my children that I would do everything in my power to survive.

Now, I'm almost totally paralyzed. My arms, legs and hands are useless. I can no longer speak or swallow. I take water and liquid food through a tube in my stomach and require a ventilator connected to a tube in my throat in order to breathe. I require the assistance of caregivers 24/7 (24 hours a day, seven days a week). I am typing this article with my eyes, using a computer that can also speak what I type.

For six years, ALS has been my constant teacher. It has taught me that the human spirit is capable of embracing the full measure of life's joy despite the presence of a profoundly disabling disease. I have also come to recognize that the mental anguish that most people with the disease experience is far more life-threatening than its relentless progression.

End-stage ALS occurs when the muscles of the diaphragm become too weak to support breathing, resulting in respiratory failure and death by suffocation. A person with ALS (PALS) can extend his or her life theoretically indefinitely by electing to have a tracheotomy (a breathing tube inserted in the neck) and a small portable ventilator (vent) that pumps air into the lungs.

The decision whether to use a vent or not is controversial among PALS. Most PALS are confronted with this decision after they have already experienced profound loss of motor functioning and are dependent on caregivers and assistive technology in almost every aspect of daily living. They will have experienced unspeakable helplessness, frustration, fear and discomfort and have been rendered more vulnerable to potentially life-ending illnesses and mishaps. They will have seen the suffering of family members who are forced to watch them deteriorate. Each significant progression of the disease

poses additional physical insults and limitations to adjust to and more losses of prior joys. Life on a vent will be more of the same and may also entail a crushing cost for 24/7 care. This decision-point provides a "convenient" and socially acceptable opportunity for PALS to say, "Enough. I don't want to continue to live this way. I'm ready to die." Many PALS commit suicide even before reaching this decision.

Personally, I am dismayed that only about 10 percent of PALS choose to live, while a disheartening 90 percent elect to die. I believe the decision to die is a tragic and avoidable waste of human potential.

Why do so many PALS opt to die? I think it's because of our self-cherishing egos. We form a self-image having capabilities, qualities, and a degree of independence, and experiencing so many pleasures, which paralysis simply does not allow. We spend a lifetime developing and reinforcing our self-image, becoming so attached to this creation of our mind, this self-delusion, that we become devastated when our reality rises up to smash it to bits.

Thankfully, there are powerful antidotes to such thinking. I don't know of any body of knowledge that presents a more compelling solution than the Dharma. Here are eight lessons of Dharma and ALS that have helped me to live:

1. The second noble truth – the truth of the causes of suffering – tells us that all suffering is a mental phenomenon caused by the karmic fruits of ignorance and attachment, especially self-cherishing. If we can overcome these mental afflictions, we can be happy, regardless of our external circumstances.

2. The first noble truth – the truth of suffering – tells us that human existence is rife with loss and suffering. No one is spared. ALS certainly heightens one's awareness of this truth. Dharma teaches us that the only reasonable solution is universal kindness and compassion. (Imagine a world in which everyone shared this view.)

3. The third of the six perfections is patience. I try to practice patience with those who unwittingly cause me physical pain or



Bob Brintz rests in the Grand Canyon, United States, a year after being diagnosed with ALS (Lou Gehrig's disease). Photo courtesy of Bob Brintz.

discomfort; patience with my own limitations as well as those of others; patience waiting for a cure; patience as the perfect antidote to frustration and anger; patience at all times as a potent calming and pacifying agent. ALS is my perfect teacher of patience.

4. From meditation on impermanence and death we learn that this life is as fleeting as a small flame in a strong wind. We also learn how rare this human existence is. ALS demonstrates the truths of impermanence and death. I now savor every moment as a precious gift and opportunity to project love and kindness into the world.

5. My rudimentary understanding of emptiness suggests that no disease can take away anyone's independence. Independence is a delusion based on ignorance. We are all inextricably bound together in a web of interdependence.

6. Self-cherishing is the most afflictive of all thoughts. Cherishing others sets one free.

7. The Dharma and ALS have taught me the true meaning of hope. Hope isn't about a desired outcome or about the future; it is a constant mindset that embraces the positive potential of this very moment.

8. The Dharma also teaches us the transformational mechanics of cultivating positive thinking. Visualization, introspective awareness, mindfulness, ruthless selectivity in the kinds of thoughts I will allow, equanimity, contemplation and analytical meditation are the tools I have borrowed to root out negativity.

Early on, I began to visualize myself in a wheelchair, paralyzed and happy. My mantra was: "I will be paralyzed and happy.

but to rejoice in what I could still do. When I lost the use of my right hand, I rejoiced that I still had the use of my left hand. I was grateful for the many years of good service my right hand had given me.

Today, I can still see and hear and think and love and be loved. Assistive technology enables me to eat, breath and communicate. I play an active role in the life of my family. I keep abreast of local, national and world news. I'm busy and productive every day. I have met and embraced the Dharma. My life is full of joy.

Those who are able to cultivate the ability to focus on the positives, to develop an unwavering sense of hope, and to remain calm and equanimous in the face of adversity, will have the capacity to live vibrantly with ALS. Sadly, so many have been unable to find their true path to survival. I am determined to change this. I pray that the most precious Guru-Buddha bless me to be able to do this.

Sixty-four-year-old former attorney Bob Brintz, a student of Lama Zopa Rinpoche from Texas, United States, lives with ALS (Lou Gehrig's disease) and is almost completely paralyzed. Through his writings on the website patientslikeme.com, borrowing heavily from Buddhist teachings, he tries to encourage other ALS patients that they too can transform their way of thinking to one that allows joyful living with ALS. His posts on patientslikeme.com include "A Path to Survival," "A Path to Survival II: The Roadmap" and "The Darkness." You can also find links to Bob's writing with *Mandala's* online content for this issue, mandalamagazine.org.