

I sit here amongst my thoughts...

Behind these prison walls I contemplate. Are the years in this place worthy enough to be written about? Has my lust for life overwhelmed me – propelling me to choose a life of adversity, anguish, and misfortune? Is my life interesting enough to be told? Will I be able to maintain the momentum and the strength to complete this most difficult of tasks? This is a story of my fight to survive.

Many years ago almost to this day I made a crucial decision – to continue my life after disease robbed me of the energy I once relied upon to sustain strength, courage, and pride. It was Palm Sunday, 1996, my 36th birthday, when I started the third stage of my life. A life or death choice was made that night.

After I made this choice I would continue to write about the first two stages of my life through Morse code. I slowly tapped out my story on my computer, an account of my life, *Still Here—Avoiding Death with Every Breath*. Through the worst of my times that book became my focus and my personal achievement, something my daughters can remember me by after I'm gone. The trials and tribulations of a healthy boy – then a young man's drastic life change – and the desolation caused by one of the most devastating diseases man has ever known.



*Working on my
book (1999)*

Struggling with an incurable disease for nearly 13 years, ALS (Amyotrophic Lateral Sclerosis), better known as Lou Gehrig's Disease, was quickly becoming a losing battle. The day I turned 36 I lay on a stretcher thinking, "Is this it? I can't possibly die now. Not on this day." As I am rushed into a waiting ambulance I feel the relief of oxygen burst into my nearly powerless lungs. The intensity is horrific as I realize how serious my situation is. I slowly feel myself losing consciousness. I pray, "Lord don't let me die." In anger and confusion my weakened and frail body falls into a deep sleep.

A dream perhaps? I wish I could say this was my subconscious playing out the reality of my existence in time. I ask myself, "Is this actually my birthday?" If it is, I have defied all odds in making it to this point in my life. A sequence of frightening events begins. I am a bystander. Each passing hour I feel my strength diminishing, as though my destiny is not to see beyond this day. A struggle for every breath is a testament to my very existence. I will let nothing stop me from seeing this day through.

Jim, my older brother, and I had rented a high rise apartment on the 14th floor. We called it "the ultimate bachelor pad." Jim became my savior that night.

After a restless and disturbing sleep, I find myself in a state of unfamiliar chaos. Jim and I usually celebrate our birthdays together because they are only nine days apart. I am concentrating, focusing on proving my disease isn't going to get the better of me. Despite the terribly dramatic way the day has begun, I determine to muster my strength for anything dealt my way. Is my endurance being tested? Is my existence going to end today? I can't seem to escape these thoughts. Over the years I have proven just how precious my life is. In the next few hours will my will be broken? Can the overwhelming



Amanda, "a perfect fit, tiny at age four"

odds I've surpassed for so many years be sustained for just a little longer? "Dear God" I pray, "Don't let this life fade."

The pride of my life is on her way, my eleven-year-old daughter Amanda. There is no fooling her today; Amanda and I are as close as a father and daughter could be. She knows things aren't the same the moment she walks through the door. Amanda lives with her mother (we've been separated for several years and have recently divorced). My daughter frequently visits me and I treasure every moment of our time together.

Happy birthday to me...

Well, the anticipation is over. It's party time! The tunes are cranked, my other two brothers and my sister are over with their kids.

Amanda rarely spends time with her cousins, so this is a special day for her also. The kids are going wild. It's great to see them all together again. I sit back without any idea of what the outcome of this day will be, but to my brother Jim, I just don't look right. His words, along with my reply, will prove to be our trademark, "Breathe man. *Breathe!*" – "Hey man, I'm *trying.*"

Although short of breath, I have actually been having a great time. The anxiety of wanting everything to turn out perfect is coupled with the concern that Amanda might think I am not quite myself. I do a fairly decent job of convincing everyone I am doing fine. So, I am now a surprising 36 years old. I feel as though I am 20. I have aged very well despite what I've had to deal with over the years. Originally, the so-called experts told me my life expectancy was three years. Those idiots. I told them back then they were full of shit. I was right.

My will to survive is boundless. The confidence I carry with me throughout my sometimes dreadful predicaments never deters me from my mission, continuing my life. Over the years, I've written a series of poems.

A L S – A Killer In Time

An eternal flame burning deep inside,
A silent killer crashes through an open mind,
Tears of rage, an incoming tide “unable to hide”
Destruction of life’s future – Destruction of life’s past,
Is the mind strong enough to compete with this task,
To battle an inferno you can’t possibly win,
Fight to find the inner strength from deep within.
A body is rejected by its coming changes,
A winding road of confusion, denial,
Time’s relentless search for survival,
A test of courage, A test of patience,
A test of tolerance to frustration.
A love for life – A temptation for time,
The never ending feelings,
Roaming through this inspiring mind.

Expressing my situation through poetry is gratifying. In this way I keep my mind occupied with the anticipation of what the next day will bring. Always with the question, “Can my strength last another day?” While writing my story, I have attempted to express my thoughts in sequence with the times the poems were written.