

My Disease by Timothy Johnson

In considering my plight, a well-known phrase from "The Rime of the Ancient Mariner" comes to mind: "Water, water, everywhere / Nor any drop to drink," the last line of which often gets quoted as "But not a drop to drink." Samuel Taylor Coleridge utilizes this phrase to describe the irony of the mariner's hopeless situation, for he finds himself surrounded by water but dying of thirst because the salinity renders the ocean water undrinkable. For me, the phrase morphs into, "People, people, everywhere / Nor any less lonely." Although surrounded by people to the point of suffocating due to the vast numbers and proximity, I feel utterly alone, like no one knows my pain. In order to understand my pain, you need to know I have a debilitating, progressive disease.

Since the official label of the disease is a certain misnomer, and a few simple letters cannot capture the all-encompassing meaning, a meaningful explanation of the disease emerges through a description of the causes, symptoms, prognosis, effect on quality of life, and present treatment options.

I must be transparent: my lifestyle choices caused the disease. Like a smoker with emphysema, I bear the burden of causation. Rather than decreasing the psychological toll, this burden increases the pain, because this flood of guilt exacerbates the mental and physical symptoms. The guilt stems not only from the personal impact of my shameful choices but even more from the impact on the people who ache and suffer every day because of my choices. Sharing the suffering magnifies the weight of loneliness, hopelessness, and pain. Direct your sympathy to the others who suffer because of this self-caused disease.

The symptoms progress toward incapacitation. At the onset, I staggered and stumbled repeatedly. Walking and breathing, activities I had always performed without thinking, became labored. My feet bogged down in quicksand; my respiratory system strained from the boulder on my chest. My speech slurred; my grip on objects and essentials weakened. A consuming state of weariness took root. The world around me became hazy. My body became both imprisoned and a prison.

The short-term prognosis offers progression, and the long-term prognosis promises fatality. The disease assails my body in a brutal, relentless campaign. In vain I try to resist, to fight away the inevitable. Every person lives with certainty of death, but the disease converts this certainty from an eventual to an immediate concern, bringing death's shadow close enough to seem tangible. Although some days are better than others, the disease persists its steady march to dominate, to decay my neurological and psychological faculties. Day-by-day, month-by-month, the disease decomposes the traits of my humanity.

Quality of life encounters total degradation. The deterioration ended my ability and desire to dance. The continuing normalcy of the rest of the world shocked me to the point of paralysis. How could everything still be the same when everything had changed? Shouldn't the world stop? How could people continue with life as usual? My friends graduated from college, got jobs, married, had children. I knew nothing but taking one tiny step at a time in the swirling blizzard of the disease. Like an inner Russian nesting doll left outside in a Siberian winter, I was trapped inside multiple sheets of ice and entombed by frozen figures. My own flesh was an iceberg; my environment was the arctic circle.

The few treatments prove futile. In fact, the few treatments currently available do nothing to relieve the illness or the mental health effects and do not even attempt to stabilize or reverse the morbidity process. The treatments offer minimal relief and temporary comfort measures.

Although the symptoms are progressive, prognosis is fatal, quality of life is thwarted, and treatments are few, reasons for hope emerge. Ironically, the looming shadow of death generates an awakening, which illuminates the true essentials of life and refocuses the mirage-like significances of life. These lessons depend upon a choice: *Do I mindlessly shrivel up and await death, or do I determine to make the best of my plight and the most of the life that remains to me?* Choosing to no longer mechanically exist, but instead to exert every effort to live to the fullest under the present constraints starts the flow of life lessons.

Dying understandably produces sadness, but dying does not represent the saddest state of existence. What's worse than dying? Living without meaning, purpose, hope, joy, love, and humor. When the mixing pot of life is void of these ingredients, life remains bitter. With these essential ingredients, a dying person can concoct the incomparable recipe of a life infused with satisfaction.

Life lacked meaning because I strived for the wrong goals—materialistic things. Trek after trek, I journeyed toward aspirations that vanished like a desert mirage upon reaching the destination. Materialistic

ambitions promised the cool refreshment of a mountain spring but delivered tepid, muddy water. Replacement of the mirages with tangible destinations came from the unveiling of what truly matters: people matter, relationships matter. By devoting myself to loving others, to building relationships, I found meaning in life, meaning in my dying.

Purpose inundates life with vitality. "Dying" does not have to be synonymous with "useless." In fact, dying can open a floodgate of usefulness. Walking the high-wire from life to death provided a view of life with unprecedented clarity, a view that revealed the existence of the dam and how to release the flow of purpose. Serving as a conduit for the message that meaning is found in people and relationships flooded the plains of my life and produced an oasis of purpose.

In "The Shawshank Redemption," Andy wrote to his friend, "Remember, Red, hope is a good thing, maybe the best of things, and no good thing ever dies." Hope transcends physical reality. When I let the disease strip away my hope, I lost an entity worth more than health or life. Absence of hope left me feeling completely alone and almost convinced me to give up. A single ember of hope encouraged me to hold on. As I persisted, the tiniest crack formed in the prison of ice, allowing in the minutest ray of light, causing the ember of hope to ignite and spread. Hope became a fire and then an inferno.

People search for happiness, but joy surpasses happiness. Happiness depends on immediate circumstances; joy itself forms a foundational element of life. Happiness requires a full cup; joy fills the cup to overflowing. When I lost the right to care for myself, to live alone, to manage my own affairs, I saw only the forfeitures, a myopic focus that demolished every fragment of joy. The igniting of hope formed a bedrock of joy, helping me see past the losses to the many blessings still in my life: the rare citadels of purpose and meaning, family who loved and supported me through all of the mess, a mind that now functioned lucidly. When joy transformed my countenance, the smile led others to ask how I could be happy. I explained that my smile rose not from happiness but from the overflow of joy.

People wonder whether they deserve love, but love does not center around merit. In fact, love means the most when least deserved. At first, I felt entirely unlovable and the darkness enclosed me. I blindly stumbled along, reaching out for something solid in strange surroundings. Recognizing the love pouring in lit my entire world in a brilliant array of colors. Without the love of my family and friends, I would never have found my way. The darkness would have engulfed me forever. As a result of their gracious love, light pervaded my life and my world.

Life without humor likens to a cancerous state of existence. My mother's voice echoes: "Laughter is the medicine of the soul." The ability to laugh with cheer and kindness fosters the healing the soul needs because of the pains and pitfalls of life. Formerly, I wondered if I would ever truly laugh again. Oh, I still laughed, but merely for two reasons: to cover up the decay of my soul at moments when laughter was expected and as a cynical response of frustration at my condition and situation. The return of hope, joy, and love brought back authentic laughter. The return of laughter facilitated much needed healing for my ailing soul.

Returning to the question, "What is my disease?" My disease is commonly called "Life Without Parole," but this label fails to capture the true meaning. An accurate label for the condition is "Death In Prison," which communicates the inevitable result. Although the descriptions of causes, symptoms, prognosis, effect on quality of life, and treatment options do not entirely exist in a literal sense, the figurative sense barely examines the observable tip of the iceberg. Like the Ancient Mariner, an albatross weighs upon my neck, the albatross of guaranteed death in prison. I am no longer the person I was when I received this sentence. The looming shadow of death spawned my awakening, my transformation.

Nearly fifty thousand people in this country struggle under this disease, but I still feel alone. Maybe each person with this disease feels alone, even in a setting swamped with people. Frozen in my own flesh, on a crumbled foundation, surrounded by interminable darkness, I considered giving up. Now, I am thankful that did not happen. Awakened and transformed, I can be a productive member of society, contributing in a variety of positive ways, evidenced by my current mode of living. Every day, I choose to concoct a life with the essential ingredients of meaning, purpose, joy, love, and humor, the savor of which makes me actually thankful for my disease.