

PAMPHLET 87

THE POWER OF PURPOSE

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By

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We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. When we are no longer able to change a situation...we are challenged to change ourselves.

Victor Frankl in Man's Search for Meaning

Steven and Jennifer Bishop had the good life: Steven had a good job, they had a new home in Colorado, and money in the bank. After four years of infertility treatments, Jennifer fulfilled part of her purpose in life and stayed home to raise her beautiful new son Christopher.

They personified the American dream at its best. Steven, a somewhat rudderless young man without direction, grew under Jennifer's influence and showed promise to be a good—if typical materialistic and conforming—American man.

Everything changed in that one visit to the doctor that many of us dread: Will this be the time they find something wrong with me? Will my life change dramatically in the course of a brief meeting with a relative stranger? For Steven Bishop the change in life course happened on March 15, 2001.

Steven was diagnosed with amyotrophic lateral sclerosis (ALS). ALS is a degenerative disease of the neuromuscular system that most often strikes adults. Typically ALS progresses until the person loses fine motor control, the ability to walk, talk, and swallow often ending in complete paralysis. Life expectancy after an ALS diagnosis is typically two to five years.

Old dreams died painfully. New dreams formed excitedly. As they adapted their lives to their new circumstances Steven had to sell his beloved Mercedes. The man who bought the car asked why Steven wanted to sell it. After Jennifer explained, the man asked her anxiously if Steven's disease was contagious. A light went off in

Jennifer's mind. She knew she and Steven would dedicate whatever time they had to raise awareness about ALS.

Steven had a choice to make: he could be mad at God and the world for allowing this disease to happen to him or he could embrace the opportunity to experience a whole new set of emotions revolving around the preciousness of life. Steven chose a spiritual life of service, gratitude, and compassion. Instead of waiting to die from ALS the Bishops would learn to live with ALS.

"I never asked, 'Why me?'" Steven said. "Instead I decided to ask, 'What's the most meaningful way we can spend whatever time I have left?'"

Their mission:

1. To raise public awareness of what ALS is and what its effects are,
2. To raise funds for research,
3. To provide help and hope to those affected by ALS, and
4. To encourage people to plan responsibly for the future.

The Bishop's joyful mantras for living with ALS:

1. Everyday is a Saturday at the Bishop's,
2. Live for today but plan for tomorrow, and
3. Life is too short to drink cheap wine

Steven and Jennifer put action to their new sense of purpose: they appeared on the local Muscular Dystrophy Association (MDA) telethon in 2001 and then the Jerry Lewis National Labor Day telethon in 2002 and 2003. They were appointed national Co-chairpersons of MDA's ALS Division and served in those roles through 2003 and made many public appearances, speaking engagements, and public service announcements. They appeared on the cover of *Parade* magazine in August of 2003 and were the cover story for winter 2003 in *Special Living* magazine. Today they write many articles and give speeches throughout the nation for various organizations. Most recently they work on their web site www.alsliving.com

Fellow ALS sufferer Philip Simmons wrote in his book *Learning to Fall* that we can learn to go through loss to a wholeness, richness, and depth we had never before envisioned. A more conscious awareness of our own mortality can become our best guide to

being more fully alive. The awareness of death calls us to our highest human duties.

Simmons wrote that learning to live richly in the face of loss is “learning to fall.” Each of us will one day lose everything. Therefore what makes Steven and Jennifer Bishop special isn’t their losses. What makes them models for the rest of us is that they live rich lives as they fall. They choose to live. We have a say in the style of our falling and our way of falling expresses our essential humanity.

My friend and colleague Bob Terry: tall, white-haired with a full white beard, and robust personality looked like Santa Claus. A brilliant writer (*For Whites Only, Authentic Leadership, and Seven Zones for Leadership*), thinker, and charismatic speaker he was the original “Mr. Authenticity.”

Bob was diagnosed with ALS six months after Steven Bishop. Bob lived out his life in his special style: he laughed, he provoked, he challenged, he continued to learn, he loved his family and friends, he reveled in the attention he received, he explored his authenticity and spirituality, and he continued to contribute to his already great legacy. And when he was ready, he died quietly in his sleep (September 20, 2002).

Victor Frankl wrote of the men in concentration camps who walked through the huts comforting others, giving away their last piece of bread. They were few in number, but they offer proof that everything can be taken from a person but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way.

Steven Bishop has no regrets since being diagnosed with ALS. He is happier than he has ever been. He knows his time is limited and he addresses what needs addressing and makes his apologies while he can. He surrounds himself with people he loves and cares about and makes no excuses for things that are no longer positive in his life. He lives the Serenity Prayer and changes what he can and accepts what he cannot.

In his affliction he became a better father, friend, and husband than he could ever imagine—nothing materialistic or conforming about him today. When he does feel sorry for himself, he then works the hardest to help others. Through his “falling” and his deliberate choice of style, he has risen higher and expresses his essential humanity more than he ever would have expected in his life.

Steven wrote: "I have no blame for this disease. It is what it is and what I make of it. My legacy will be how I handled an insidious attack on my being and then used it to launch a mental assault on the disease."

Steven asks us: "Have you already begun a journey of purpose? If not, make discovering your life purpose the first step in the process. Many of us never even take that step. I certainly had not before my diagnoses. Why must we experience a catastrophic event before we ponder our reason for being? We have a choice to define our purpose and add it to our lives. Choose now to engage in life as it is meant to be."

He continues: "As part of my purpose I intend to encourage others to take care of their families and themselves: financially, emotionally, and with no regrets now before there are life and death decisions to be made. None of us are guaranteed tomorrow. I may outlive many of you. What regrets are you living with? Can you change them? If not, what can you learn from them? Have you told people that you love them? What makes you want to get up in the morning? What can you do to positively affect other people? What will your legacy be?"

Steven again: "I cannot describe the joy I feel when someone tells me their life was changed by something Jennifer and I said about how we are dealing with our life circumstance. Make a positive difference in someone's life. They likely will do the same with someone else. That is the key to our humanity. That is purpose!"

Jennifer wrote to me about her purpose in life:

"My main purpose in life is to be a mother, teacher, listener, and student for my son. We brought him into this world, and I have an amazing need to do everything possible to be a good example, not so much by telling him what to do, but showing him through my actions through my love, respect, and admiration for God.

My purpose is also my husband. When I said 'I do,' I meant it! I have an insatiable need to take care of him. The bible says 'til death do us part' and that's what I intend to do. I care for Steven happily and not out of obligation. I actually thrive on being able to step up to the plate and support my husband, my purpose is to positively support him and enable him to be the best person he can be no matter what the circumstances.

My greater purpose hasn't changed that much from before the diagnosis; it is just more vibrant. Working in the social service field makes me feel alive. Staying home with Christopher was a challenge in the beginning because unlike adults, I couldn't see the internal change I was making/forming in him. But soon after his birth, I knew I was right where I was supposed to be.

I told a friend recently that my job is to cultivate relationships and friendships. It is my life work to be a good friend—a friend that I would want to have. Finally if I can make someone's day by how I handle my life, I'm fulfilling my purpose."

Jennifer wrote: "To my wonderful husband: You are my inspiration and my breath. I love to see you with our son and how motivating you are to others with or without ALS. This is truly your life's calling. I'm forever indebted to you for making me a better person. It will be a privilege and an honor to take care of you until the bitter end or until a treatment or cure is found. I feel this is what God put me on this earth to do."

Steven wrote: "To my incredible wife: You are the cornerstone of who I am today. You make me realize my potential and encourage me to live up to it. Christopher won the "mommy lottery" in you. I am so grateful for what you add to my life and overjoyed at your steadfast grip on what is important. You are a fountain of life to all those around you."

Rollo May wrote of heroes:

Heroes are necessary in order to enable the citizens to find their own ideals, courage and wisdom in the society. The hero carries our hopes, our aspirations, our ideals, our beliefs. In the deepest sense the hero is created by us; he or she is born collectively as our own myth. This is what makes heroism so important: it reflects our own sense of identity and from this our own heroism is molded.

Bob Terry, Philip Simmons, and Steven and Jennifer Bishop chose attitudes that inspire us. Like all leaders they go first and show us the way. They are heroes as are the countless unrecognized everyday people who live extraordinary lives with "style."

Son Christopher will one day miss his dad and he will love his dad. And Christopher will be so deeply proud of his father and so profoundly astounded and inspired by how his dad lived. Steven's

legacy will frame Christopher's own unique life, and Steven will live and continue to change the world through he that is in Christopher. I know this because that is how I feel about my dad, who died recently and courageously, and the model that he was for me and my life (see Pamphlet 85).

Steven Bishop lay next to his son Christopher one summer night and gazed at the stars that shine bright in Colorado. His trust goes beyond the skies. He thought of himself as the lucky one. He imagined the light people see at the time of death as the extension of one's soul into the hearts of those they love. That is how he knows he will live on forever.

Steven and Jennifer Bishop turned their personal tragedy into a human achievement that will endure for the ages. Dostoevski said once, "There is only one thing that I dread: not to be worthy of my sufferings." The Bishops live worthy of their sufferings.

What does life ask of you?

PLEASE VISIT www.alsliving.com AND WRITE STEVEN AND JENNIFER A NOTE.