

Writing Your Own Script & The Dignity Of Risk

Bob & Ellen Wilson, SDBIF Members

Do not fear death so much, but rather the inadequate life. Bertolt Brecht

For Ellen Wilson the phone call she received at 4:00 p.m. on Saturday, July 1, 1995, will always be a distinct dividing line in her life. Before the phone call her husband, Bob, owned a yacht brokerage in San Diego. Ellen had recently quit her job and begun training in a physical therapy program at California State University. Bob's business was successful and he had recently started helping others by working as an inspector for the Federal Emergency Management Agency (FEMA). Then came the phone call.

The phone call was from a detective in New Orleans reporting that Bob had been brutally beaten. His frontal lobe was caved in, the vision in his left eye was gone, the hearing in his left ear was gone, and his hands and fingers were broken. Bob refused to die despite multiple stab wounds and severe traumatic injury to every lobe of his brain. The police asked Ellen to come identify him because his face was swollen beyond recognition. She was able to identify Bob only by his feet. After six hours in reconstructive surgery Bob began the journey to regain independence and self-direction after brain injury. He spent one month in acute care in New Orleans, four months hospital rehabilitation in New York, and seven months outpatient rehabilitation in San Diego. Ellen would learn that the human spirit is limitless and that each step of recovery requires risk. In the process they would lose their business, their home and be forced to move in with Ellen's newly married daughter and her husband. The journey would not be easy.

Make voyages! Attempt them! There's nothing else!
Tennessee Williams

That first year they heard from a formidable group of rehabilitation doctors and counselors that the majority of Bob's recovery had taken place. The message was clear, "Bob would forever be limited." He could not be expected to drive again, work again, or even be able to plan and carry through on simple projects. Few professional voices said otherwise. Harlan Alcorn, clinical psychologist, disagreed. He urged Bob and Ellen to believe that the human spirit cannot be measured by a neurological test. A person's determination and perseverance can fuel hope and expectancy. Dr. Alcorn helped them leave the door open so that their spirits could stay intact.

All growth is a leap in the dark, a spontaneous, unpremeditated act without the benefit of experience. Henry Miller

Two critical philosophies guided Bob and Ellen throughout recovery. The first, "write your own script," and the second, "the dignity of risk," most accurately describes how they have reshaped their lives.

Dr. Alcorn urged Ellen to allow Bob to "write his own script." He explained how important it is to treat the "person" and not the "diagnosis." He insisted that once focus is on the diagnosis, the person is lost. It is far better to have expectancy, to encourage the survivor to take a journey, rather than to say "you should be going to x, y, x for the remainder of your life." Better to say, "I don't know the destination", leaving the door open to hope. According to Dr. Alcorn, "when you kill hope, you kill effort, fulfilling the prophecy that was made." Bob and Ellen heard plenty of doom and gloom proclamations along the path from emergency to rehabilitation. It was not easy to find open doors of hope amidst all the "you'll nevers" thrown at them by well-meaning medical personnel. They decided that hope was the only way.

Dare to be yourself. Andre Gide

Ellen watched Bob in a coma, barely alive, unable to talk, gradually relearn how to speak, stand, walk, brush his teeth and tie his shoes. He progressed through all the stages of development, from infancy to toddler to teen, to finally, almost six years later, to an adult with purpose participating in life. Somewhere along the way, the phrase, "the dignity of risk", popped out at Ellen from a textbook. She felt a strong tendency from a caregiver's perspective to be overly protective. This is understandable since so much had been taken

from Bob and since they both felt so vulnerable. Yet each new step for Bob required her to step back in order to allow him to take risks. Like a flash, she realized that Bob deserved to have the dignity that risk brings. To live otherwise, simply isn't living.

Risk! Risk anything! Care no more for the opinions of others, for those voices. Do the hardest thing on earth for you. Act yourself. Face the truth. Katherine Mansfield

Ellen knows that we all have a basic need to direct our own life. As hard as it was to say "yes" each and every time Bob wanted to stretch his limits, she said "yes." She chose to stand beside her husband and say to him, "go for it." After Bob passed the driver's safety interview he declared he intended to fly to New York alone and drive his truck home. The man who was told he would never read a map found his way safely from New York to San Diego. The man who had his hands and fingers crushed by an assailant using the claw end of a hammer is using that same tool to remodel a fixer-upper for Ellen. In the first few months, Ellen questioned why they took on such a project, but, as always, she is astounded by what Bob can do. The more risk he takes, the fuller life he lives and the more he progresses. Bob is making his own path, he is determining himself what his limits are instead of other people dictating to him his capabilities. His hands and fingers were crushed, not his spirit.

The guy who takes a chance, who walks the line between the known and unknown, who is unafraid of failure, will succeed. Gordon Parks

A footnote: Bob and Ellen not only had to deal with recovery and the emotions of loss, grief, depression and despair, they also had to fight FEMA, a big bureaucracy. FEMA helps those who face natural disasters like floods and earthquakes, but would not accept responsibility for Bob who was injured while on assignment. When Bob and Ellen attempted to file suit against FEMA they had trouble finding an attorney because of their unusual claim. Yet, they knew they were right. Bob would not give up. As usual, his tenacity overcame the odds. FEMA finally awarded the Wilsons a financial settlement.

Don't give up! Bob Wilson