

MIND, BODY, SPIRIT

Everyone knows that ALS is a complicated disease involving mind, body and spirit. Bernie Siegel was the first to suggest we have the ability to heal ourselves holistically in his acclaimed book titled, "Peace, Love and Healing". While this has become something of a catch phrase, it certainly rings true for the ALS patient community. A positive attitude, love from and for someone in your life, friends, family, and a sense of optimism for today and the future – all of these and more make a huge difference in disease progression, quality of life, symptom management.

While we can't think our way towards healing, our mind can focus on negativity or positivity and helps to foster the quality of our days. If the messages that linger in our brains tell us we are valuable, that we have a life worth living and enjoying, the effect is one of strength. In our son Ben's film, at one point he says, "My body is 15 percent dead, but I'm 85 percent alive." Focusing on the 85 percent made a world of difference for him, imbued him with energy to create his film "*Indestructible*" and to enjoy his young son John.

A sense of spirituality transcends religion and provides an appreciation for the wonder and meaning of life. Sometimes those with ALS, family members and friends ask, why has this happened to me, to my friend, to my son? But that's the wrong question because there is no answer. No one is immune to tragedy, sadness, illness or despair. It's what a person does with the negative events in their life that matters, that brings forth the sense of spirituality that provides comfort, direction and peace.

Defining these qualities concretely can be challenging. Age has very little to do with outcome. We've met some patients who are in the 80's, determined to enjoy every minute, engaging with family and friends. Others in the 40's hide in their bedrooms and refuse to see friends or family. Some have a virulent form of the disease that overtakes their respiration within months. Others live 15, 20 even 30 years. Do they have issues? Of course. Sometimes their speech is so diminished that few can understand them. But that doesn't stop them from traveling or using speech apps and eye gaze computers to communicate. The message here is to surround yourself with those who you care about and who care about you. By developing and maintaining support, by enjoying life even within limitation, the quality of life improves and living longer and better becomes a realistic expectation.