

WEB EXCLUSIVES

What I've Learned About Living Well with Illness

BY ERIC KINGSON

You may be among the 1.4 million Americans newly diagnosed with cancer this year, or maybe you're one of the roughly 10 million Americans who have been diagnosed at some point in their lives. Whoever you are—patient, survivor, family, friend, or medical professional—your life has probably been or will be rocked by this disease. Mine and my late wife's, Joan, certainly were.

Joan was diagnosed with cancer in October 1998, beginning a 32-month journey I have since written about in *Lessons from Joan: Living and Loving with Cancer – A Husband's Story*. Joan didn't live as long as we had hoped, but most who find cancer unexpectedly in their midst will live many years. No matter how long you live, it's important to live good and kind lives.

Cancer and other life-threatening illnesses, those uninvited teachers, leave a new understanding of what's important. Here's some of what Joan and I learned about living well with cancer.

Self-help is good, but don't blame yourself. The self-help literature is replete with suggestions for preventing, warding off, and learning to live with many illnesses. Joan and I read some of the books on dealing with cancer. They were often helpful. However, some self-help approaches imply that not only can you cure your illness but that it is somehow “your fault” if you do not. Joan greatly resented and rejected this message. As she might say, “Look, you can live well, exercise, eat lots of broccoli, and have a good outlook and still die from cancer!” She was similarly clear when told she “failed chemo.” “No,” she would say, “chemo failed me.”

You can control the little things, and they matter. The truth is, many of the big things in life are out of your control. You may not be able to prevent your company from closing or cancer from striking, but you can control your responses to such events. And there are many little things in life you can control: taking time with your loved ones, looking up to enjoy passing clouds on a warm summer day, or going to a baseball game, play, or concert.

Learn to accept care from those you love. It's a gift to you and to them. Learning to give, to care for others, is an important part of our development as human beings. As infants, we depend entirely on others. By adulthood, most of us give more than we receive—as parents, as members of our community. Some people, like Joan, excel at giving to others but have difficulty accepting the care of others. Over the course of her illness—and without loss of strength, dignity, or humanity—Joan learned to accept, even at times enjoy, the care of health care providers, family, and friends. Her comfort and grace in accepting care with appreciation was a gift that brought her closer to her caregivers.

Take care of yourself and your family. Being confronted with a life-threatening illness is (no surprise) extraordinarily stressful. Whether you are diagnosed with cancer or giving care to someone with cancer, find ways to care for yourself and those you love. Embrace small pleasures, pace yourself, develop good relationships with health care providers, and “don't sweat the small stuff.” Find humor wherever you can. You and those around you need it more than ever. Accept and acknowledge the concern of family and friends. And consider seeking professional support for yourself and your family from chaplains, therapists, and other counselors.

Kindness matters. Simple kindness gives expression to and reinforces the human spirit. The nurse who kissed Joan's forehead in advance of a feared procedure or the physician who gave Joan his tie as she neared death touched us in special ways. Joan's capacity to get outside her pain, to move beyond her anxiety and engage with interest the concerns of the nursing students, aides, and others giving her care—even as she approached death—touched others deeply. Life-threatening illness challenges the understanding and rhythm of our lives. Kindness, given and received, provides the opportunity to transcend human suffering and find meaning in the capacity of the human spirit to endure.

Leave a videotape, letter, or other message for those you love. As someone who lost his father at 13, I have often hoped, even as an adult, to find a note from him: some advice about life, some stories of importance to him. In contrast, I have deeply appreciated my mother's forethought in leaving a long letter for her sons. And Joan's eloquent video good-bye is part of her treasured legacy to our family. Consider leaving a message for those you love. By the way, you don't have to be ill or proximate to death to do this.

Do not underestimate the effects of a parent's illness on children. As I look back on this time and think about how threatening and ultimately devastating the loss of a parent is, I wish we had better prepared Aaron and Johanna for the depth of the loss they would experience. We, especially Joan, tried. But we were also invested in maintaining some normality to their high school years, maybe too invested. And, while not keeping any information from them, we did not want to rob them or ourselves of the hope that we might have many years in front of us. No suggestions for others here, just the observation that no matter which route is chosen, the pain and sadness that children must bear when a parent dies runs very deep.

Recognize special “opportunities” that are a by-product of cancer. No, I am not suggesting cancer and other life-threatening illnesses are gifts, just that they provide opportunities and insights you would not normally have. There are potential advantages to having blinders for every day life—the fantasy that keeps

awareness of our impermanence at bay, ripped away by a cancer diagnosis. Everyone born goes down life's path to death. Some arrive there sooner than others. Some live better because they recognize the limitations that life brings. Cancer can provide people with the opportunity to reflect on the meaning of their lives, to renew their commitments, to grow in ways never expected, to have time to repair relationships, to say full good-byes to those they love. Growth and learning and teaching do not stop with a cancer diagnosis, not even with death's approach. Joan learned much in her 32 months of cancer, especially about how loved and worthy of love she was. She taught much to our family and others about dying, living, and courage, about the endurance of the human spirit.

Living in hope trumps fear. Fear is not an unreasonable response to a cancer diagnosis, especially advanced cancer. Mark Twain observed that he spent much of his life worrying about things that never happened. Similarly, living in too much fear, even when based in reality, can ruin the time you have, time that may stretch out to decades.

In the course of Joan's cancer, we learned to live in hope. Living in hope is not synonymous with blind denial or sticking one's head in the sand. Hope evolved over the course of the illness, from hope for a cure to hope for remission to hope for a "good" death. Joan's appreciation for our children, her friends, her walks, and books were expressions and outgrowths of the hope. My pleasure in her smile, humor, and courage were part of the hope. And hope drove our faith in good lives for our children and the permanence of our union. There was still much fear, but we learned that living in hope gave us much life, more than we could ever have expected.

Laugh and love a lot. No point in living, no matter how long, if you can't find laughter and joy in every day with those you love.

Eric Kingson, a professor of social work and public administration at Syracuse University, wrote *Lessons From Joan: Living and Loving With Cancer – A Husband's Story* about his family's journey after his wife, Joan, was diagnosed with cancer. It can be ordered online from [Syracuse University Press](#) or through local bookstores.