

INTRODUCTION

There's an old saying that what happens to us in life is not as important as how we handle it. At some point, each of us will come to the pivotal crossroads where we either receive a serious diagnosis or know that we are living the last chapter of our lives. Some spiritual traditions suggest that this last chapter—leading up to and including the moment of death—is the most important one of all.

That may strike us as a pretty heavy prospect, but if we shift the lens of understanding just a little, we can entertain the possibility that this most poignant phase of life also has its opportunities, surprises, moments of grace, and hidden blessings. This is one of the premises of *Ten Thousand Joys & Ten Thousand Sorrows*.

My husband, known by his nickname “Hob,” was diagnosed with Alzheimer's when he was in his early seventies. With the help of his nature, his life's work, and, above all, his lightheartedness and sense of humor, he negotiated the difficult passages of this illness with insight and inspiring perspectives. Given the tremendous challenges of Alzheimer's, he naturally had his share of difficult times—of frustration, discouragement, and fear. Yet one day, referring to the challenge of it all, he declared emphatically:

“This is the best education I've ever had!”

To be honest, there was an expletive before the word *education*. As Hob never swore, this was a dramatic statement. What could he possibly mean? How could a heartbreaking illness be an education, especially one like Alzheimer's—or any other form of dementia—that gradually steals away the mind? In this cryptic statement, loaded with irony and feeling, he was referring to *how* one handles life, especially when confronted with relentless loss and increasing disability.

The compelling question is: How do we accept the process of aging, diminishment, and loss? In the case of dementia, how do we find meaning amidst what appears to be a ruthless and meaningless process? Is it possible to find something redeeming while living with a heartbreaking illness? Hob and I lived tenderly with these questions. *Ten Thousand Joys & Ten Thousand Sorrows* shares some of the ways we found peace with them.

I had to write about this experience. Writing felt like a calling—one so strong there was no way I could have ignored it. Both Hob and I had been trained extensively in psychology and meditation. We had worked and taught in these fields for many years. I knew that the wisdom gained from our experience would shed light on the darkest moments. From the beginning, I sensed that there would be insight, learning, and wisdom that we could share with others.

I began to write, albeit irregularly. I jotted down Hob's observations. I reflected on the careening, unpredictable journey we were on. Periodically I would remind Hob that I was writing and that his voice would be part of a book.

Shortly before his death, I was sitting beside his bed late one evening, as I did every evening. Although he could no longer speak, I had a sure sense that we were deeply in touch, connected at a level beyond words. Sometimes he would stir slightly or squeeze my hand. These felt like return messages. Usually this was a time for silence or maybe quiet singing, but that night, certain that he could hear me, I said, “Hob, I want to make a promise. I'm going to complete this writing. Your voice will be part of it because I've written down things you've said and about how you've handled it. It will become a book—hopefully, something helpful to others.”

These words assumed the force of a contract between us. At the same time, I began to feel our connection with everyone who was dealing with mental loss. You, the reader, somehow became a fellow traveler on this most challenging of journeys.

Hob was a gifted and much-loved teacher. When mental loss took away his facility with words, he sometimes descended into discouragement or fear. At those times, I'd remind him that even though he could no longer teach using language, he was still a teacher by virtue of *how* he was living with Alzheimer's. Friends and family validated that. They were inspired and heartened by how he was handling the illness.

This can be true for any of us. Think of friends who have met a difficult illness with courage, who have grown through adversity, who have inspired others. Here is where hope lies. When adversity comes, we can support and inspire each other in countless ways. Sometimes the most valuable gifts we can give—the quality of our presence, for example—are invisible. The truth is that each of us, when faced with a life-threatening illness, is called to the most heroic chapter of our lives.

Without question, Alzheimer's is one of the most difficult of illnesses. It is daunting, tedious, exhausting, financially draining, and heartbreaking: the full catastrophe, as Zorba the Greek referred to life at its most trying. Nor does this disease happen solely to the person who has it; it affects family and friends, which translates into an estimated twenty nine million Americans who have a family member with the disease. I'm convinced that nearly everyone has been touched—however remotely—by this illness, not only because it is epidemic but because losing one's mind is such a frightening prospect. Currently, estimates claim that there are nearly five million cases of Alzheimer's nationwide; projections declare that by 2050 as many as thirteen to sixteen million people in this country could be suffering with this mythic disease.

Ten Thousand Joys & Ten Thousand Sorrows is a collection of vignettes, reflections, and teachings that intimately reveal how Alzheimer's affects the patient, family, and friends. For the first few years of a six-year journey, Hob was able to offer penetrating and revealing observations about his mental decline. He treated his unraveling mind with playfulness and humor. He even faced death with openness and honesty—another theme in the book that is especially important because ours is a death-denying culture.

To highlight the important insights and learnings of our story, I've added self-help sections at the end of each chapter to encourage you, the reader, to reflect on what may be most helpful. In addition to highlighting main points, each section includes reflections, suggestions, and seed thoughts—simple, prayer-like statements. The seed thoughts are easy to remember and can be used like mantras to refocus and uplift the mind in challenging moments.

The self-help sections include approaches that helped us along the way. Hob and I discovered perspectives and attitudes that lightened the burdens of illness. Determined to live the experience consciously and lovingly, we regarded this—the final challenge of our relationship—as an opportunity for opening to the unknown, for learning, and, above all, for deepening in love.

There were many really hard times, yet looking back on the experience, it is clear to me that something precious was forged in the fires of our adversity. This is one of the great mysteries of life: like the metaphors from alchemy where fire transforms one element into another, life's greatest challenges change us forever. When life catapults us into crisis, we touch the archetypal themes of what it really means to be human. This is where the personal and the universal meet.

Our story is everyone's story. Often as I wrote, I felt your presence. It is my deepest hope that you will discover some of the comforting and inspiring themes that sustained us through the most challenging, and richest, chapter of our lives.