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## LIFE'S LAST



Giving and
Receiving Peace When
a Loved One is Dying

## Introduction

It's easy to lose your bearings when someone you care about is dying. Even if you've been extremely close, a great divide opens with you on one side, in the kingdom of the well, and your loved one on the other, in the kingdom of the sick—the night side of life.

Roles begin to blur as a friend or parent or lover becomes sicker and disappears into the startling and unfamiliar identity of "the dying one." Days fill with physical care and decisions that can't, ultimately, save this precious life. And we, who are well, look for any kind of guidance about what to say and how best to help. We're scared, anxious, and grieving, and we're desperate to offer support. But very often, we retreat emotionally—even in the midst of busily working for a "good death"—because it's so hard to stay present through the pain. We often know what to *do*—what tasks we need to perform—but we no longer know how to *be*.

I've watched this happen repeatedly in the four decades I've worked with dying people and their families, and I experienced it myself when caring for my father, mother, and best friend after they were diagnosed with terminal conditions. No matter how prepared we believe we are, I think most of us feel blindsided by what's asked of us as we try to comfort our loved ones and struggle to find the skill and grace that will help us reduce their pain.

This book will show you how to sustain emotional closeness when death enters the picture and help you nourish your relationship with the other person in ways that will allow your connection to deepen until the very end. In doing that, you'll find that you can bear the pain of your losses together and experience peace—even fulfillment—that you never could have had without each other.

In the chapters to come, I'll ask you to make a series of simple commitments about how you'll choose to be when you're with your loved one. These promises need never be spoken, but you can feel, understand, and act on them in ways that will help you stay focused and present. Each one will help you orient yourself, stay grounded, and keep offering meaningful support and compassion, even when you feel upset, confused, or lost.

I've used these essential guidelines to accompany hundreds of people through their dying time and to train many thousands of volunteers to do the same. They've helped countless people find a path

to peace in the midst of turmoil. I began developing these guidelines in the 1970s as a psychologist at the Cancer Research Institute (CRI), which is part of the University of California Medical Center in San Francisco. There, in the days before there was a hospice movement in the United States, I was the sole staff member assigned to focus on the non-physical needs of patients dying of cancer—their emotions, their spirits. I was particularly struck by the loneliness that was so much a part of life on the cancer ward. As people got sicker, their friends and families often stopped visiting, sometimes scared off by the symptoms or their own sadness, sometimes seeming to think that there was nothing they could do—so why visit at all. The few who came were likely to dance around the issue of death and would leave without ever really asking the person in the bed what he or she was thinking or feeling.

So much comes up emotionally and spiritually for people as their time runs short. They review their lives, forgive and ask forgiveness, and cycle through a wide spectrum of feelings, in which they confront anger, sadness, fear, regret, joy, love, and the unanswerable question of what comes next. I realized that more than anything I could do as a professional, simply accompanying someone through that challenging emotional and spiritual vortex—human to human—had the most profound impact. So, I sat at bedsides, listening, talking, and witnessing the struggles, hopes, and stories of people who were about to die. In my years of doing that, I learned what helped them, what actions and attitudes made the biggest difference. Because the need was so great, and I was just one person, I founded an organization called Shanti to train volunteers to be with the dying, as I was doing. It later became San Francisco's first community-based agency supporting people with HIV/AIDS, and it has served as a model for volunteer service groups in hundreds of communities around the world.

Shanti is a Sanskrit word that translates roughly as "the peace that surpasses understanding" or, more succinctly, "inner peace." Helping bring inner peace to the dying and those who care for them was—and is—a goal of Shanti volunteers. And, it's the goal of everything you'll find in this book.

## **Healing without Cures**

I want you to know that even in the thick of everything you're both facing, you can support your dying loved one in ways that create opportunities for greater independence and heartfelt connection as the hours and days count down. I've worked at close range with family members, lovers, and friends of the dying and consulted with thousands of health professionals and volunteers in hospitals, hospices, clinics, nursing homes, and the community. All of them discovered that greater peace at the end of life is a

collective process. As my best friend Rico Jones put it shortly before he died, "It's all about relationships."

Being with your loved one now, and allowing yourself to have an honest, vulnerable relationship with him or her, requires skills that may be quite different from your usual ways of being around each other. You'll want to stay as present as possible in the time that's left, instead of checking out or holding onto expectations of how things should be. You may need to let go of old habits, such as fixing or giving advice or hiding your true feelings. The stories in this book, drawn from my own experiences and those of Shanti volunteers, will show you what works best as you support the other person now.

Family members, lovers, and friends—and people who were dying—have spoken to me candidly about the toughest parts of their experience, the choices and situations that had no obvious solutions, and the feelings of hopeless inadequacy. But, these same situations often became turning points for them as they learned to take heart-centered action and witnessed their care making a positive difference. They were able to find healing, even though it wasn't necessarily physical healing, and it happened not only for their dying loved ones but for them as well. You'll hear their voices, and have their wisdom and support, throughout this book.

I want you to know that if you're fighting to hold things together for yourself and your loved one, you are not alone. The people you'll meet in this book are with you. I'm with you. All of us have learned that some of the circumstances that befall us are outrageously painful and unfair, but they can trigger quantum leaps in our understanding of the meaning of our life and death. If we let it, the pain we face can open us to both giving and receiving greater expressions of caring and compassion. At a time of so much sadness and loss, we can find ourselves—and those we care about so much—filled with love.

## This book is for you

if one of your loved ones has been diagnosed with a life-threatening illness;
if you've just heard the bad news about a friend or acquaintance and don't
know what to do or say;

if you're contending with the ups and downs of someone's cancer, heart disease, AIDs, or other potentially terminal condition;

if the prognosis is bleak, and you don't know how to balance hope with the reality that time is short;

whether your heart is overflowing with love for the other person right now, or you're caring for someone who sets you on edge.

My hope and belief is that the insights and stories you'll read in the pages to come will help you find your center when your world is spinning and let you be the person you most want to be as you accompany someone through his or her last months and days.

My additional hope is that health professionals and volunteers who work with the dying, and, at times, constitute a kind of extended family, find encouragement to focus on caring, as well as curing—being tough on problems yet tender with people.

There is one promise that dying people need to hear, more than any other, from those who love and care about them: I choose to be with you in a healing partnership, though I know you're dying. I will stand with you in the midst of despair.

I'd like to help you make this brave and comforting choice. It can be life's last gift.