

Contents

Introduction: Why I was Compelled to Write this Book, and What it Offers You	1
<i>... there is only one person whom one needs for dying. To have such a person is a great good fortune. To be that person, to have been such a person, is a heavy and blessed experience ... Once at least, in each lifetime, we are meant to be a blessing to each other. —Gerda Lerner</i>	
Part I. Where are We?	15
<i>From out of that primal chaos something true can self-organize. —John Briggs and F. David Peat</i>	
Chapter 1. Is this The Call?	17
<i>I am always waiting for The Call, and always dreading it. —Artemis, April 28</i>	
Chapter 2. Will Her Body Outlive Her Mind? Hospitalizations and their Consequences	29
<i>I never thought I would outlive anything like this. —Olwen, May 6</i>	
Chapter 3. Mobilizing to Beat the Odds and Get Mother Home	51
<i>I want to go back to my apartment and live there for a short time. —Olwen, May 9</i>	
Chapter 4. Detour through Rehab: Buying Time and/or Losing Ground?	65
<i>I am going to 102!! —Olwen, May 12</i>	
Chapter 5. Getting Mother Home— But Can We Keep Her There?	81
<i>We'll know in a week or so. —Kate, May 20</i>	
Part II. Creating Space for the Dance to Unfold	93
<i>It's come to the point where it's long enough. We know it can't get great again. —Olwen, May 26</i>	
Chapter 6. Hospice: Shifting the Paradigm	95
<i>You can't do this, dear. It's too much. It's too hard. —Olwen, June 3</i>	

Chapter 7. Building Our own Family of Caregivers and Our Private World 111

We live in a world that is terrified by death and hides its dying. We know the vacuum that forms around the dying. —Marie de Hennezel

Part III. Rhythms of the Dance 125

Always the years between us, always the years. Always the love. Always the hours. —“Virginia Woolf” in “The Hours”

Chapter 8. Peaks and Valleys:

When a Heart can no longer do its Work 127

You die in episodes. Dying is an irregular process full of mountains and valleys. It chews away at your life while consuming hers. —a friend, June 15

Chapter 9. How do You Let Go of Your Life? 143

I don't know what I'm doing, and I don't know if I'll ever finish it . . . It's the last thing I am doing, and I can't do it . . . I want to let go. I'm trying to let go. —Olwen, June 25

Chapter 10. My Life or Hers?

the Dream versus the Nightmare 163

You do what you have to do, and I'll do what I have to do. —Olwen, June 26

Chapter 11. Weaving a Path Through the Shadows 183

I've lived a good life really, but I know I worked at it. I had to do a lot of things, and I was able to do them. —Olwen, October 2001

Chapter 12. Retrieving the Understory 201

When I go way back, I'm glad sometimes I didn't know—not the answer, but what did it mean? —Olwen, June 13

Chapter 13. The Dance of Grace 215

Only when you drink from the river of silence shall you indeed sing . . . And when the earth shall claim your limbs, then shall you truly dance. —Kahlil Gibran

Part IV. Dancing with the Ancestors 233

If you know who you are and you know where you've come from, then you'll know what you must do. —Ancient Celtic Proverb

Chapter 14. Unexpected Gifts	235
<i>Through mourning we let the dead go and take them in. —Judith Viorst</i>	
Chapter 15. The Houses Speak	249
<i>To be rooted is perhaps the most important and least recognized need of the human soul. —Simone Weil</i>	
Chapter 16. Roots and Completion	265
<i>The longing to tell one's story and the process of telling is symbolically a gesture of longing to recover the past in such a way that one experiences both a sense of reunion and a sense of release. —bell hooks</i>	
Part V. Giving Cultural Form and Visibility to the Dance	279
<i>Wisdom, then, is born of the overlapping of lives, the resonance between stories. —Mary Catherine Bateson</i>	
Chapter 17. The Caregiver's Story	281
<i>Family caregivers are the backbone of the long-term care system, they are not doing well, and current public policy does little to support them. —Susan Reinhard</i>	
Chapter 18. The Dance of Death:	
What do we need to Know and Do?	299
<i>[H]ealing and wholeness are always possible . . . Even as people confront death, . . . they can reach out to express love, gratitude, and forgiveness. When they do , they consistently find that they, and everyone involved, are transformed— for the rest of their lives, whether those lives last for decades or just days. —Ira Byock</i>	
Chapter 19. Dancing the Dance of Death	313
<i>. . . [W]ith the help of another presence that allows despair and pain to declare themselves, the dying seize hold of their lives, take possession of them, unlock their truth. They dis- cover the freedom of being true to themselves. It is as if, at the very culmination, everything managed to come free of the jumble of inner pains and illusions that prevent us from belonging to ourselves. —François Mitterand</i>	
Epigraphs	328
Notes	331
Further Reading	335
Acknowledgments	339
About the Author	345
Reader Commentary	346