# HEALING THROUGH ILLNESS, LIVING THROUGH DYING



# Guidance and Rituals for Patients, Families, and Friends

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### Contents

Foreword	ix
Introduction	xi
Part One:	Getting Your Bearings
Chapter 1: Li	<ul> <li>ving Fully with a Serious Illness</li></ul>
Chapter 2: W	Then the World Shifts
Chapter 3: U	<ul> <li>nderstanding Ritual</li></ul>
Part Two:	A Map of Patients' Choices
Chapter 4: Re	<ul> <li>Regaining Balance</li> <li>Counterbalance</li> <li>Discovering a New Compass</li> <li>Discerning the Right Path</li> <li>Your Personal Orientation Program</li> </ul>
Chapter 5: Fi	<ul><li>ght? Or Let Go?</li></ul>
Chapter 6: G	athering with Friends and Family
Chapter 7: O	<ul><li>utlets for Anger and Grief</li></ul>

<ul><li>Take a Bre</li><li>Setting Bo</li></ul>	
Chapter 9: Relaxation Riti  Bathroom  Bedtime M  Anytime M	Meditation (1997)
• Ritual for	Talking About Death  Questions Difficult to Ask
Chapter 11: Nurturing On  Nature  Music and Meditation Soul Frien Affection	n and Prayer
<ul><li>Prevent Pa</li><li>Sorting Th</li><li>Writing or</li><li>Medical D</li></ul>	se Ends: Offerings of Love
<ul><li>Life Review</li><li>Writing ar</li><li>Planning A</li></ul>	n Ethical Will Aspects of One's Funeral ng an Unfinished Project
<ul><li>Story Tim</li><li>Make a W</li><li>Laughter</li></ul>	ences
-	Recovery

Part Three: A Map for Family and Friends
Chapter 16: Suggestions for Using Part Three
Chapter 17: Aftermath of Diagnosis
Chapter 18: When Bedfast for Brief or Extended Times
Chapter 19: Holding Vigil in the Final Days
Chapter 20: Near the Time of Passing
Chapter 21: Just After Passing

<ul> <li>Chapter 22: The Days Between Death and the Funeral or Memorial177</li> <li>Remembering Together</li> <li>Adding Personal Touches to the Funeral</li> <li>Holding a Place for Love</li> </ul>
Part Four: Specific Circumstances
Chapter 23: General Guidelines for Children
Chapter 24: Alzheimer's and Dementia Patients
Chapter 25: Unexpected Sudden Death
Chapter 26: Removing Artificial Life Support
Chapter 27: Home-Centered After-Death Care
Chapter 28: Creating a Personalized Funeral or Memorial Ceremony 207 • Structure of a Ceremony
<ul> <li>Chapter 29: Sample Ceremonies</li></ul>
Chapter 30: A Few Notes on Grief
Afterword
Acknowledgments
Resources
List of Rituals
Index
About the Author

Part One
Getting Your Bearings

#### CHAPTER I

## Living Fully with a Serious Illness

Diagnosis of a serious illness pushes the world sideways, turns stomachs upside down, and radically rearranges priorities. There is suddenly much to learn about the disease, the various options for treatment, and the problematic side effects of drugs. Overwhelmed with fighting for more life and negotiating for better quality of that life, it is easy to lose sight of the fact that in the midst of all this—there is still a life to be lived.

The rituals in *Healing Through Illness*, *Living Through Dying* will prompt you to remember what it is that feeds and heals your greater self. You will find suggestions, exercises, and rituals offering perspective, along with a broader sense of the options open to you at any given time. This book is not a to-do list, but a map of places you may want or need to visit.

For some patients, the journey will take them into recovery for many years, while for others the chances of remission are slim. No one ever knows for certain what the future will bring, but an alarming prognosis brings a face-to-face confrontation with great uncertainty. Whether the doctor's prognosis is somber or encouraging, a life-threatening diagnosis causes people to suddenly realize that we—all of us—really are mortal, and death may come sooner than expected.

The threat of death can hang over us like a shadow, but shining a light on it can help release some of the dread and anxiety. If we know what to expect, we may fear it less. If we put our affairs in order, we will release certain burdens. If we see our true priorities, we can more gracefully enter into the fullness of the time that's left us, however long or short it may be.

#### Lessons Learned from Being Present

I was thirty-five the first time I was a part of someone's death. My Uncle Ray was dying, and I didn't know what to expect, or what was expected of me. I had lost two cousins, two other uncles, and all of my grandparents, but I had not been present with any of them in their dying, and I was glad I hadn't been. Death had seemed so awful until I witnessed it.

Uncle Ray was at home with family in attendance. I don't think any of us had previously been present with someone during the last hours and at the moment of passing. Our instincts guided us fairly well even though we felt helpless and unsure. We did what we could to help Uncle Ray be comfortable, and we told him how much we cared about him.

My Uncle Ray taught me many things about life when I was still new to this world, and it seems most fitting that he taught me, and my family, valuable lessons about death as he was leaving this life. Most importantly, we learned that death doesn't have to be frightening and awful; the act of dying can be simple, profound, and even beautiful. When I later read Elisabeth Kubler-Ross's words, "Being present at a peaceful death is like witnessing a shooting star," I knew exactly what she meant.

When my father died seven years after Uncle Ray, my family was more deeply impacted, but we were less unsure, more

comfortable, able to be more present, and so, better able to offer him support.

I mourned the deaths of my favorite uncle and my dad, yet I was most grateful for the lessons learned in their dying when I had to support my husband, Tony, on his journey through the end of life.

Tony's diagnosis demanded much of both of us. It sometimes frightened us, always challenged us, yet it also provoked certain things within us to blossom in some completely unexpected ways. Together, we learned that alongside the uncertainty and sadness there can be growth and healing, humor, and the strength of love.

#### Notes on Using This Book

This book does not need to be read in any particular order. Part One provides a foundation, then feel free to turn to whichever chapter addresses your immediate needs, or piques your curiosity.

Part Two, "A Map of Patients' Choices," contains rituals to help the patient and caregiver reorient following diagnosis, or at other junctures in their journey. The rituals in Part Two help patients create space for reflection, and invite expression of thoughts and feelings. The chapters on taking care of business and taking care of one's self encourage a clearer understanding of priorities, and offer support in following through. Part Two also includes rituals that can bring deeper meaning, growth, healing, and greater joy into the journey for both patient and caregiver.

Part Three, "A Map for Family and Friends," provides rituals that family and friends can call upon in offering support to the patient following diagnosis, through treatment, and during the final passages of life. The rituals also support family and friends,

encouraging them to more gracefully act on their natural impulses. (Some patients might want to look through Part Three and indicate their preferences.) There are also rituals to support family and friends as they move through the first few days following their loss.

Part Four, "Specific Circumstances," addresses particular areas that may be important for certain readers. For example, the chapter on children includes helpful information whether the child is the patient, a family member, or simply visiting. Sometimes, patients near the end of life will have symptoms of dementia, even if that wasn't an issue previously. A familiarity with what is included may prove helpful for you should you want or need the information at some point along your journey.

All online resources listed in this book are also provided on my website, www.healingthroughillness.com.

These rituals are suggestions and ideas. Choose what holds meaning or value for you. As suggested previously, approach it like a map—some places you may want to visit, others you'll drive right past, and one or two might be worth extra effort even if that requires going out of your way, or getting off the beaten path.



Ritual can be public and formal like a wedding or the inauguration of a president. It can also be simple and ordinary like shaking hands when introduced to someone. In these, and many other situations, ritual offers a template that helps us know what to do.

When we meet someone new we generally follow the established pattern of exchanging: "How do you do?" "It's nice to meet you." This tiny ritual gives us the half-minute we need to get a sense of the person and to figure out what we want to say next. It provides a structure that supports us as we make that very small transition.

Death is a huge transition, the greatest one since birth. The months or years between diagnosis and death involve many transitions, and so we need many different rituals to help us as we move from the disruption of diagnosis through various ups and downs until we come to the end of life. That time may be only a few months as it was with my dad, or almost two years as it was with my husband, or in some cases, even decades of treatment-free living. Whatever the time frame may be, ritual can support and enrich you throughout your journey.

One way that ritual supports us is through the use of symbols or symbolic action, such as the exchange of rings in a wedding ceremony. When we shake hands, we make a literal and figurative connection with the other person. We regularly use a wide variety of such symbols in our lives without always being aware of them, yet the inherent symbolism usually resonates within us.

Taking off our work clothes and slipping into something more comfortable at the end of the day helps us to feel looser and more relaxed—in part because of the comfy sweats or shorts, but also because we have shed symbols of our work day. It is part practical and part symbolic, as many rituals are. Taking several deep breaths and letting go of work-related problems as we exhale can enhance this small ritual and help us shed even more of the job and its pressures when we change clothes.

Throughout this book there are a number of simple rituals such as this that can easily slip into everyday routines, as well as special occasion rituals that require planning.

#### How Ritual Serves Us

Serious illness can cause us to feel isolated from the "regular" world, other people, and cut off even from ourselves at times. Ritual can provide us with a sense of connection on a number of levels. Gathering in a circle creates a sense of social connection. Spiritual connections are made through rituals like communion. At its best, ritual brings us into connection with our deepest and truest self.

Ritual offers a way into doing what we instinctively want to do, but may not know if we should, or how to go about it.

Ritual shows us how to gracefully transition into, through, and then out of, new or uncomfortable situations.

Ritual can create a safe space for raw expression of thoughts and feelings. Reflecting upon those thoughts and feelings can help us discern what will create a greater sense of wholeness.

Ritual can help us combat feelings of helplessness through understanding what our options are.

Ritual can help us discover a way of resolving something that troubles us; repairing relationships, finding forgiveness, even reaching into the future.

The following story of a father diagnosed with cancer illustrates a few of the many different needs that can be met through ritual.

In a ritual to express and release anger at the prospect of dying too soon, John chanted and shouted his thoughts and feelings while beating on a drum. Through this he realized that his greatest anger was fueled by grief at not getting to watch his children grow up, and not being able to guide and help them along their path.

In talking about this, John came to see he could still be a part of their development after his death. He wrote letters to each child to be opened at different junctures in their lives; when they turned sixteen and twenty-one years old, when they were choosing a career, when they got married, and when they had their first child. Through this, he was able to fulfill a certain part of parenting he didn't want to lose. John discovered that by envisioning each child at those ages, in some way he did get to "see" them growing up.

The first ritual of simply being able to vent his anger was helpful for John. The second ritual of writing the letters was deeply meaningful in so many ways. Opening those letters will become a ritual for his children, and through this, they will be able to connect with their father over the years and feel his presence at key times in their lives.

#### Working with Ritual

No ritual is right for everyone, so I offer a range of rituals to suit different needs, different styles. Choose what holds meaning or value for you.

You may find many of the rituals appealing, or only a few. Some may work for you exactly as they are, but with others you may need to reshape the general idea so it feels more comfortable, or better addresses your needs.

If only a small piece of a particular ritual holds meaning for you, take that piece and make it your own. Ritual is most meaningful when it addresses the specific needs of an individual, and in a manner consistent with her or his style and values. Give yourself the creative latitude to do what feels right in altering the rituals so they are a better fit for you.

There is, though, a structure to ritual that needs to be respected. The exact wording of "nice to meet you" can be changed, but the general format is followed: exchanging a few friendly words, making contact, then an open period of conversation followed by something like, "Nice to have met you," or "I hope to see you again" to provide a closing.

The most important part of ritual is what happens in the "empty" spaces—conversations and connections that happen in between. Ritual creates a container for the connections to happen.

Chapter 6, "Gathering with Friends and Family," offers a primer on taking a basic idea and bending it different ways to suit different people.

All of the rituals in this book can be done on your own, though in some cases it may be beneficial to enlist someone to lead, such as a friend, therapist, or clergyperson. If you don't know someone who would serve well, check with a local support group or hospice agency to see if they can offer a recommendation.

The rituals don't need to be done in any particular order, and it may be that a ritual from the first part of the book might be done much later. Rituals can also be repeated at different times.

#### Ritual Created Through Intent

Almost anything can be made into a ritual through focus of intent, even something as simple and ordinary as breathing.

"I breathe in cleansing and healing energy. As I breathe out, I let go of tensions and toxins."

Inhaling and exhaling not only take on symbolic meaning, but there is also a physical response. The body begins to relax, and mental tensions are reduced. While we cannot as readily perceive the impact of other intents in the ritual, it is likely that these also happen on some level.

#### Rituals of Gratitude

There are a number of rituals in this book that suggest focusing on gratitude. Expressing gratitude is healing for us, like putting salve on a wound. It invites us to not just count our blessings, but to feel our blessings.

Focusing on gratitude opens the heart and enables connections with our selves and with others. I find it interesting that many traditional prayers begin and end with expressing gratitude to a higher power.

Expressing gratitude is a way of connecting to The Holy, however it is perceived. Gratitude connects us with our own holiness, and it helps us connect with a sense of wholeness. (The word "holy" derives from the word "whole.") In the wake of something painful or difficult, it is healing to connect with a sense of wholeness. Gratitude is a wonderful means to that end.

This book is not an exhaustive listing of rituals that could be done, but I hope you find rituals here that help you. And I hope these ideas provide you with inspiration to create other rituals.