

**“THIS IS A MAJOR CONTRIBUTION
AND AN IMMENSELY WISE BOOK.”**

Larry Dossey, MD, author of *HealingWords*

HOW TO BE SICK



A BUDDHIST-INSPIRED GUIDE
FOR THE CHRONICALLY ILL
AND THEIR CAREGIVERS

TONI BERNHARD

foreword by SYLVIA BOORSTEIN,
author of *Happiness Is an Inside Job*

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more advance praise for
How to Be Sick

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—**SYLVIA BOORSTEIN,**
author of *Happiness Is an Inside Job*

“An immensely wise book. Health psychology has been poisoned by the view that the best way to approach illness is through a muscular, militant resistance. Toni Bernhard reveals how letting go, surrendering, and putting the ego aside yield insights and fulfillment even in the presence of illness. A major contribution.”

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“Everyone should read this book—anyone who is sick, anyone who loves someone who is sick, and anyone who has ever experienced things being other than they’d hoped they would be. Toni Bernhard open-heartedly shares the deep pain and equally deep joy of her experience in a way that allows us to validate the pain of our own circumstances, and still find joy and contentment within any context. She offers simple, deeply wise practices that reduce the suffering associated with grasping for things to be other than they are by allowing us to accept and enjoy things exactly as they are, including our own desire for something else. Her willingness to step fully into her life after it’s been dramatically narrowed by illness, and to share this process with us, inspires us each to live our own lives more fully, accepting the challenges that arise, and finding the joys inherent in each moment. Toni’s writing feels like a good friend, helping us cultivate compassion for ourselves and those around us, as we make our way through whatever life presents to us. Her honesty in sharing her struggles and setbacks helps us be kinder to ourselves as we experience our own. I plan to buy a copy for everyone I love.”

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continued...

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—**TARA BRACH, author of *Radical Acceptance***

“Told with relentless honesty and clarity.”

—**STEPHEN BATCHELOR,
author of *Confession of a Buddhist Atheist***

“An encouraging book that treats sickness as something to welcome because, when you are sick, that is the obstacle that has to be your gate. This book is full of compassion about how to sit sweetly with your difficulties—which means not making yourself wrong for *having* difficulties.”

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“Toni Bernhard offers a lifeline to those whose lives have been devastated by illness, and shows us all how to transform suffering into peace and even joy.”

—**LYNN ROYSTER, director of the Chronic Illness Initiative at DePaul University**

“A roadmap to finding grace and balance amid affliction.”

—**CHRISTINA FELDMAN, author of *Woman Awake***

“Practical, wise, and full of heart.”

—**JAMES BARAZ, author of *Awakening Joy***

“This warm and engaging book can help with even the most difficult situation.”

—**THOMAS BIEN, PhD, author of *Mindful Therapy***

“*How To Be Sick* is a good friend to keep close by so that illness doesn’t become the enemy.”

—**ED & DEB SHAPIRO, authors of *Be the Change***

“Don’t pass up this book—and don’t be misled by the title. This book isn’t about being sick as much as it is about living right now. This practical yet exceedingly graceful book is a love story—about life, the endurance of the human spirit, and the power of a sustaining relationship.”

—**ALIDA BRILL, author of *Dancing at the River’s Edge***

“Living a life of peace and contentment is not difficult when life is cooperating—but what happens when the reality of our lives is suddenly turned upside down and shaken by hardship or affliction? This book is an inspiring and instructive guide for coping with a chronic condition or life-threatening illness but it is much more than that. Each chapter is about unpacking the highest truth in the lowest places of our lives.

The book is called *How To Be Sick* but it’s really about how to live.”

—**JIM PALMER, author of *Divine Nobodies***

“An intimate, gripping, profound, and eminently useful book about being joyfully and wisely alive no matter what happens to you.”

—**RICK HANSON, PHD, author of *Buddha’s Brain***

“Who would have thought that there is a ‘how to’ for being sick? But now there is! Deeply moving and impressive. I highly recommend her book as a must-read for anyone who is ill or caring for someone ill. Her gifts will transform you.”

—**LEWIS RICHMOND, author of *Healing Lazarus***

continued...

“A warm and compassionate guide for navigating illness on a personal and practical level, a level physicians rarely see or discuss with their patients. The greatest compliment I could give this book is that I will be recommending it to all of my chronically ill patients as a guide for remaining happy even in the absence of good health.”

—**DR. ALEX LICKERMAN, former director of primary care at the University of Chicago**

“A unique and creative adaptation of spiritual practice to the challenges of chronic illness. *How to Be Sick* is a wise, compassionate book that will help all of us live well.”

—**DOROTHY WALL,**
author of *Encounters with the Invisible*

“Each of us finds our way to live with the challenges and uncertainty of illness. Toni Bernhard found a path that led to balance, wisdom, and love. She caringly points us to the possibility of finding happiness even in the midst of difficult conditions. That is a true gift.”

—**FRANK OSTASESKI, founder of the Metta Institute**

How to Be Sick

*A Buddhist-Inspired Guide
for the Chronically Ill
and their Caregivers*



Toni Bernhard



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For Tony

*In sickness and in health,
to love and to cherish,
till death do us part.*

Table of Contents

Foreword by Sylvia Boorstein	ix
Preface	xiii

How Everything Changed

1. Getting Sick: A Romantic Trip to Paris	I
2. Staying Sick: This Can't Be Happening to Me	9

Accepting Pain

3. The Buddha Tells It Like It Is	21
4. The Universal Law of Impermanence	27
5. Who Is Sick?	37

Finding Joy and Love

6. Finding Joy in the Life You Can No Longer Lead	45
7. Soothing the Body, Mind, and Heart	51
8. Using Compassion to Alleviate Your Suffering	57
9. Facing the Ups and Downs of Chronic Illness with Equanimity	73

Turnarounds and Transformations

10. Getting Off the Wheel of Suffering	89
11. Tonglen: Spinning Straw into Gold	97
12. With Our Thoughts We Make the World	103
13. Healing the Mind by Living in the Present Moment	111
14. What to Do When (It Seems) You Can't Do Anything	121
15. Zen Helps	127

From Isolation to Solitude

16. Communicating with Care	139
17. The Struggle to Find Community in Isolation	145
18. And in the End . . .	159

A Guide to Using the Practices to Help with Specific Challenges	165
With Gratitude	179
Bibliography	183
Index	185
About the Author	193

Foreword

“**YOU ARE GOING TO BE OKAY!**” Words of reassurance are the first therapy offered to people who awaken after a surgery, or are revived after an accident, or just before the disclosure of a fearful diagnosis. “You are going to be okay” often goes along with the summary of what now needs to happen to make things better. “You’ll need to stay a few more days in the hospital and then you can go home and finish recuperating there.” Or, “We’re on the way to the hospital and the doctors there are ready for you.” Or, “We’ll do chemo and then radiation and it might be a hard year but the chances are good that you’ll be your old self again afterward.” “You are going to be okay,” in these circumstances, means “Things are uncomfortable now, but you will get well. You will be better.” But it doesn’t always happen that way.

This is a book for people who will not be their old self again and for all those for whom, at least now, getting better *isn’t* possible. This is a book that most reassuringly says even to those people, “You, too, are going to be okay—even if you never recover your health!”

Toni Bernhard is the perfect person to write this book. In the middle of a vibrant, complex, gratifying family and professional

life—literally from one day to the next—she took ill with a hard-to-diagnose and basically incurable, painfully fatiguing illness that waxes and wanes in its intensity, that sometimes seems to respond to a new treatment and then doesn't after all, that doesn't get worse but also never gets better. Nine years after the onset of her illness, she is still sick. She knows the cycle of hoping and feeling disappointed from the inside out as well as the cycles of deciding to give up hope in order to avoid the pain of disappointment and the sadness, and then the relief, of surrender.

Decades ago, a friend of mine, a man with a family and friends and flourishing career, said of his unexpected, debilitating illness, “This isn't what I wanted—but it's what I got.” He said it matter-of-factly, without bitterness, as if he understood that it was the only reasonable response. I knew that he was telling me something important. It is a fundamental human truth, transcending cultures and traditions, that the wisest response to situations that are beyond our control, circumstances that we cannot change, is noncontention. In this book, Toni shows how her longtime study and meditation practice in the Buddhist tradition help her accommodate her situation with gentle acceptance and compassion. The techniques that Toni presents for working with one's mind in the distressed states it finds itself when facing an uncomfortable and unchangeable truth are basic Buddhist insights and meditation practices, but they are non-parochial. They will work for anyone.

This book is written for people who are ill and aren't going to get better, and also for their caregivers, people who love them and suffer along with them in wishing that things were different. It speaks most specifically about physical illness. In the largest sense, though, I feel that this book is for all of us. Sooner or later, we all are all going to not “get better.” Speaking as an older person who has had the good fortune of health, I know that the core challenge

in my life, and, I believe, in all of our lives, from beginning to end, is accommodating to realities that we wish were other, and doing it with grace.

Toni has given us a gift by sharing her life and her wisdom and I am grateful for it.

—Sylvia Boorstein

Preface

*One, seven, three, five—
Nothing to rely on in this or any world;
Nighttime falls and the water is flooded with moonlight.
Here in the Dragon's jaws:
Many exquisite jewels.*

—SETCHO JUKEN

IN MAY OF 2001, I GOT SICK AND NEVER RECOVERED. The summer of 2008 marked my seventh year of living with chronic illness. One night that summer, at about 10:00 P.M., my husband came into our bedroom and joined me on the bed that has become my home. My husband's parents named him Tony; my parents named me Toni. We met when we were dating each other's roommates in college. On the morning of November 22, 1963, he knocked on my apartment door with the news that President Kennedy had been shot. Tony and I have been inseparable ever since. By this time of night, I'm in what we call "stun-gun" state—as if I'd been hit with a Taser—meaning it's often hard for me to move my body and do anything other than stare blankly into space.

I greeted him with, "I wish I weren't sick."

Tony replied, “I wish you weren’t sick.”

There was a slight pause, then we both started laughing.

“Okay. That got said.”

It was a breakthrough moment for the two of us.

We’d had this exchange dozens of times since the summer of 2001, but it took seven long years for the exchange to bring us to laughter instead of to sorrow and, often, to tears. This book tells the story of how Tony and I moved from tears to laughter. Not always laughter, of course, but laughter enough.

I’ve written *How to Be Sick* to help and inspire the chronically ill and their caregivers as they meet the challenges posed by any chronic illness or condition, including:

- ▶ coping with symptoms that just won’t go away
- ▶ coming to terms with a more isolated life
- ▶ weathering fear about the future
- ▶ facing the misunderstanding of others
- ▶ dealing with the health care system; and
- ▶ for spouses, partners, or other caregivers, adapting to so many unexpected and sometimes sudden life changes.

In chapters 1 and 2, I talk about how I got sick and, to Tony’s and my own bewilderment, stayed sick. Starting in chapter 3, I describe how, drawing on the teachings of the Buddha (often called the Dharma), I learned the spiritual practice of “how to be sick,” meaning how to live a life of equanimity and joy despite my physical and energetic limitations. I offer simple practices, ranging from those that are traditionally Buddhist to others I devised after becoming chronically ill. I also include a chapter on Byron Katie’s work, which I have found particularly helpful.

You need not be a Buddhist to benefit from the practices in this book. If a suggested practice resonates with you, truly “practice”

it. Work with it over and over until it enters your heart, mind, and body and becomes a natural response to the difficulties you face as the result of being chronically ill or being the caregiver of a chronically ill person.

At the end of the book, I've provided a quick reference guide that matches specific challenges faced by the chronically ill and their caregivers to practices described in the book.

I put this book together slowly and with great difficulty. I wrote it lying on my bed, laptop on my stomach, notes strewn about on the blanket, printer within arm's reach. Some days I would get so involved in a chapter that I'd work too long. The result would be an exacerbation of my symptoms that would leave me unable to write at all for several days or even for weeks.

There were also periods when I was simply too sick to even think of putting a book together. Then the project would be left untouched for months on end. Being so physically sick would sometimes have such a strong effect on my mental state that, during the darkest moments, I considered tossing out all the work I'd done, despairing of ever being able to complete it.

But mental states come and go—and in the end, I pressed on, determined to finish the book in the hope it would help others. The Buddha's teachings have inspired and comforted me during this illness. The Buddha and the schools that his teachings gave rise to offer many simple and helpful practices that guide both the healthy and the sick through life's ups and downs.

The inspiration to write this book came from a person I knew for such a short time and in such limited circumstances that I don't even know how to spell her name. In 1999, I was on a ten-day silent meditation retreat at Spirit Rock Meditation Center. As always on retreat, each of us had what's called "work meditation,"

meaning we are responsible for performing a task each day to help the retreat run smoothly. Some people cut vegetables, some wash dishes, others clean the bathrooms. As much as possible, we maintain silence even if we work alongside others.

My work meditation was to clear the trays from the serving tables in the dining hall after lunch and put the leftovers in containers. I shared this job with a woman who introduced herself as Marianne and was about my age. She looked a bit frail to me, but we shared the work equally, only speaking in a whisper now and then: “Is this container big enough to hold the extra salad?” In the meditation hall, I noticed that she seemed to be with a young man who might be her son. I remember thinking how nice it was that they were here together. She had a kind face and a gentle smile and I looked forward to seeing her every day after lunch.

In addition to working in the dining hall, we followed a path to a small building where the teachers ate and then we brought their serving trays back to the kitchen. On the seventh day of the retreat, to my surprise, another woman accompanied my partner. The three of us cleared the serving tables in the dining hall and then the new woman followed me outside as I began to walk down to the teachers’ dining room. She asked, “Do you know about Marianne?”

When I shook my head, she told me, “She’s very sick. She only has a couple of weeks to live.” Then, she turned around and went back into the dining hall.

I continued to the teachers’ dining room, shaken by this unexpected discovery. The room was empty, but the *San Francisco Chronicle* was on the table where the teachers ate. (I was on retreat, but the teachers weren’t and so newspapers were always scattered about on the table. I’d learned to avert my eyes.) But the *Chronicle* that day had a headline in letters too bold to ignore:

JFK JR.'S BODY FOUND

Having no idea what the backstory was, I quickly left the room in shock, my heart pounding, my mind spinning. There, on the path, was one of the teachers. In my distress, I broke the silence. She briefly told me what had happened to JFK Jr. (and also commented that they shouldn't leave newspapers lying around). I asked her if she knew about Marianne. She told me Marianne was here with her son. Then she told me something she probably shouldn't have (which is why I'm not using her name). She said that on the information sheet we fill out when we get to the retreat, under the question that asks if there's anything the teachers should know about us, Marianne had written, "I have just two weeks to live but it won't affect my practice."

The next day Marianne's spot and her son's spot in the meditation hall were empty.

In memory of Marianne, I vow to do my best not to let my illness affect my practice. I also vow to let my practice continue to teach me how to be sick—and to enable me to help others who are chronically ill.

How Everything Changed



Getting Sick: A Romantic Trip to Paris

Paris ain't much of a town.

—BABE RUTH

AT THE END OF AUGUST 2001, I was to begin my twentieth year as a law professor at the University of California at Davis. To celebrate and to treat ourselves, Tony and I decided to go on a special vacation. Surfing the Internet, I found a studio apartment to rent in Paris at a reasonable rate. We were not world travelers: a trip to Paris was a big deal for us. For three weeks, we'd immerse ourselves in the life and culture of the City of Lights. We were going to have a great time.

At the airport things got off to an inauspicious start. As we sat in our seats on the United Airlines commuter flight from Sacramento to Los Angeles, where we would change to a direct flight to Charles de Gaulle, we noticed the plane wasn't backing away from the gate. Soon came the announcement of an equipment problem delaying our takeoff. Tony and I realized we weren't going to make the Los Angeles flight to Paris if we continued to sit there.

While others onboard chatted about what was going on, we quickly got up, grabbed our carry-ons (all we ever take), and

headed for the United Airlines check-in counter. Because we'd acted so swiftly, the agent was able to get us on a TWA flight just about to depart for St. Louis. From there, we could change to a non-stop TWA flight to Charles de Gaulle, arriving about the same time as we'd originally planned. Like characters on a TV commercial, we ran down the concourse to the TWA boarding gate, our carry-ons in tow. The flight had already boarded but they let us on.

Once off the ground, we praised ourselves. We'd been so much smarter than the other passengers. By the time we left the United Airlines counter with our TWA tickets in hand, those who'd been on the commuter flight had formed a long line behind us. Ah, pride. "Caution, caution," the Buddha would have said, but at that moment we were so pleased with ourselves for deftly averting a disastrous beginning to our special vacation. Several doctors have told us the odds are high that on one of these two TWA flights I picked up the virus from which I have never recovered.

We arrived at our studio apartment on the tiny *Rue du Vieux Colombier* in the sixth arrondissement on the Left Bank. The apartment was much smaller than it had looked in the online pictures. It consisted of a bathroom and a kitchen, each of which could be comfortably occupied by only one person at a time, and a living room. It was furnished with a tiny table and two chairs, a loveseat (a romantic euphemism for a couch that's too small to lie down on), and a double bed in the corner. On the wall opposite the bed sat a bookshelf with a cabinet at the bottom. We found a tiny television set inside, but we had no intention of spending our time in Paris watching TV.

We wandered around that first day, waiting for nightfall so we could sleep and adjust to the new time zone. The next day, I felt awful but assumed it was only jet lag. The day after that, I still felt bad but, refusing to believe it could be anything other than lin-

gering jet lag, suggested we go to a movie. We picked an American film, *Anniversary Party*. Frankly, I just wanted to sit in the dark and try to assess what was going on in my body. While watching the movie I began to realize that I was indeed sick.

Soon thereafter, I developed typical flu symptoms and couldn't get out of bed. After three days, Tony and I reached the same hopeful conclusion: "This is no big deal. We still have eighteen days left in Paris."

After a week, it became: "No big deal, we still have two weeks left in Paris."

"...we still have ten days left in Paris."

The "days left" dwindled and dwindled.

We developed a routine. In the morning, Tony would go to a *brasserie* and then walk the streets of Paris, returning around noon, always hoping for a change in my condition. Then he'd go out in the afternoon for more walking. Maybe he would take in a museum. He was not enjoying these solo excursions.

During the second week of our stay, I so badly wanted to keep Tony company that I decided one day to tough it out. I insisted we go to see the famous Impressionist collection at the Musée d'Orsay, which was converted from a train station and is known for its soaring interior spaces. The line to get in went around the block. Right then and there, we would have returned to the apartment had I not done my research and known to buy museum passes in the Métro. Under the assumption we'd be museum-hopping together, Tony had bought two passes on our second day in Paris. We were allowed inside immediately.

As soon as I entered the Impressionist gallery, the adrenaline I'd used to get myself there wore off—this excursion had been a mistake. I collapsed into one of the lovely wicker chairs that sit in rows in the middle of the bigger galleries and told Tony to go ahead and enjoy the paintings. He would periodically come back

and check on me, asking if we should leave, but I kept telling him to go off and look for a while longer.

As I sat, my eyes lit on a large painting by Claude Monet, *Essai de figure en plein-air: Femme a l'ombrelle tournée vers la droite*. A woman stands in a field, her face shaded by her umbrella. It's painted with a soft, muted palette, yet is somehow wonderfully luminous. I was vaguely aware of musical wicker chairs going on around me—people would sit for a few minutes, get up and be quickly replaced by someone who had been waiting to take the first free chair. I just sat, bathed in the colors and the composition on Monet's canvas. I felt as if he'd painted this young woman in a field to watch over me so I could let Tony experience the museum. But my attempt at keeping him company had failed.

Except to see a doctor, that was the end of going out. My days were spent in bed. Too sick to read, I thought I'd try the little television after all. I was shocked at the poor quality of French programming: every channel had the worst kind of quiz show, featuring contestants who'd been coached to scream on cue, loud-mouthed obnoxious hosts, and the gaudiest of sets. In my naïveté, I was expecting high French culture to emanate from the tube. I gave up in frustration, but as the hours wore on, and I was still bored and restless, I tried TV again. I heard familiar theme music, actors were running around pushing a gurney, and on the screen the word “*Emerges*” appeared. Even with my poor French, I knew this was “ER.” I settled in for some televised comfort food, only to find it was dubbed into French. Even movies were dubbed instead of subtitled. So much for that.

I spent most of each day and many a night when I was too sick to sleep listening to the BBC on a short-wave radio Tony bought for me when it was clear I'd be in bed for a while. The BBC had a wonderful array of programs, including clever and funny quiz shows. It became my introduction to our own National Public

Radio (NPR), which I began listening to every day soon after returning to Davis and finding myself bed-bound. When I'm listening to NPR's broadcast of the BBC News and I hear the plummy tones of the very same British voice that came over the short wave radio in our Paris apartment announcing, "You're listening to the BBC World Service," a tinge of sadness passes over me. I'm briefly transported back to that bed on the Left Bank where it all began.

A few days after the trip to the Musée d'Orsay, we decided I should see a doctor. I looked in the yellow pages and found an entry for "the American Hospital." Even though the name suggested home and a refuge for me, the person who answered the phone was just plain rude. When I described my symptoms, she gruffly said, "Well, what do you want *us* to do about it?" It was a harbinger of things to come.

I tried "the British Hospital." The woman who answered the phone only spoke French, but I heard concern and kindness in her voice. She put me on hold while she found a nurse who spoke English. She told me to come right in.

I still shake my head in disbelief when I think of the unnecessary stress we subjected ourselves to getting from our apartment on the Left Bank to the British Hospital in a northern suburb of Paris, and thereafter to a pharmacy in central Paris, and then finally back to the Left Bank. Whew! Typical Californians, we never considered taking a cab. We weren't being cheap; it just didn't cross our minds. We think of cabs as something New Yorkers use. Foolishly, we walked from our apartment to the nearest Métro stop. Two transfers and several staircases later, we found ourselves above ground in an altogether different sort of Paris—the suburbs. Walking along with our map at hand, we made agonizingly slow progress. Even this small excursion was wearing me out.

The doctor thought I simply had the flu. She wrote down my diagnosis as *grippe*—a word that's always made me think of the

rhyme for “post-nasal drip” in Adelaide’s song from *Guys and Dolls*. She wanted to be sure it didn’t turn into a bacterial infection that would ruin our whole vacation, so she gave me a prescription for antibiotics. We trekked back to the Métro and, after another transfer and more stairs, surfaced above ground at the only open pharmacy between the northern suburb and our Left Bank apartment, since it was one of those European days off intriguingly called a bank holiday.

The hospital and pharmacy ordeal is a haze in my mind, although a few vivid memories remain. I recall the hospital staff continually apologizing because, since it was a bank holiday, they had to charge us for the appointment—a whopping \$15.00 when converted from francs to dollars. I recall surfacing from the Métro to go to the pharmacy and finding myself face to face with a postcard-picture view of the Arc de Triomphe, the tiniest flash of the Paris we’d hoped for. I also remember the agony I felt as I leaned against the wall in the Métro stairwells, using both hands on the banister to pull my body up step after step. Tony told me, years later, that when he saw me dragging my body up the stairs, he realized how sick I was. That’s *his* vivid memory of that day.

Our last week in Paris, I discovered that the French Open was on TV all day long. Tennis was something where language didn’t matter. Even I could figure out that “*égalité*” meant “deuce.” I made a bed for myself on the floor, close enough to the TV to be able to see the ball being hit over the net, and a love affair was born. I still watch a lot of tennis. I can recite the names of players from all over the world. I love how international tennis is. I love the aesthetics of the game—complexity within seeming simplicity. All a player has to do is get the ball over the net, inside the lines. But within that seeming simplicity lies an array of strategies—physical and mental—that has the feel of a chess game: aces, lobs, volleys, luring your opponent into the net so as execute a passing

shot. As I lay there learning to love watching tennis, it seemed I might be getting better. I was deeply disappointed that our vacation had been ruined, but I was hopeful.

The day before we were scheduled to fly home, I felt I was on the road to recovery.

