FOREWORD BY KEN TADA
Husband of Joni Eareckson Tada

# Hope for the Caregiver

## Encouraging Words to Strengthen Your Spirit

PETER ROSENBERGER
Radio Host and 30-year Caregiver

With tenacity, tenderness and humor Peter Rosenberger brings hope to those who find themselves in the overwhelming and sometimes lonely role of caregiver.

Amy Grant

As caregivers, we often feel isolated, but for me, reading and listening to Peter feels like a one-on-one encounter. It could be as intensely personal to you, too!

Graham Kerr, former Galloping Gourmet

Written by one who has "been there and done that," Peter Rosenberger offers caregivers practical advice for everyday living, perspective on their role and relationships, and hope grounded in Christian faith and fellowship. This book is an important resource for caregivers—and for those who care for the caregivers.

Kenneth L. Farmer, Jr., MD
Major General, US Army (Retired),
Former Commanding General, Walter Reed Army Medical Center
and North Atlantic Regional Medical Command

None of us ever plan to be in a position like Peter, but it happens. This book provides help and sign posts for the caregiver! When I was helping to care for a stroke-ridden father for many years, I wish I had had this book to lean upon!

Joe Bonsall, The Oak Ridge Boys

Not only is this a great tool for providing care for another, its spiritual principles are applicable to any situation that challenges us in life. I LOVE the solution of GPS (Grace, Purpose, Stewardship) for navigating the FOG (Fear, Obligation, Guilt) that caregivers experience.

Elizabeth Moss, LPN
CEO, Caregivers By Wholecare

Peter Rosenberger is absolutely amazing. A true leader by example. Hear what he has to say and you will understand why he is the most qualified person to teach you how to thrive as a caregiver.

David Asarnow, CEO Business Oxygen, Inc.

In a world hung up on trying to make sense out of hard times, Peter drives the point home that "We don't have to understand—God understands, and that's enough. He is enough—He is always enough." Peter leads readers through such painful situations with humor and practical help—and in the process, our faith is strengthened. This is THE book for caregivers, written by one with scars and immense credibility.

Jeff Foxworthy

Peter has "walked the walk" as a caregiver and with humility has birthed, I believe, a divinely inspired perspective for a new generation of caregivers. As a caregiver myself, I have experienced the isolation component that Peter addresses in this book. As you read ahead, you will meet an "understanding friend" who will introduce you to ways that can help you rise above your circumstances.

Marianne Clarke, EdD, Caregiver

Peter is authentic in his understanding and awareness when he writes about caregiving—he knows the journey intimately. He is also theologically wise in the midst . . . when he says "we are stewards not owners."

Keith G. Meador, MD, ThM, MPH
Professor of Psychiatry and Health Policy Director,
Center for Biomedical Ethics and Society Associate Dean,
Student Health and Wellness Vanderbilt University

# Hope for the Caregiver

## Encouraging Words to Strengthen Your Spirit

### Peter Rosenberger

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HELPING PEOPLE EXPERIENCE THE HEART OF GOD

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*Solus Christus*

The ultimate caregiver of a wounded bride.

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# FOREWORD

## by Ken Tada

Millions of caregivers are out there plodding through mundane routines with hardly the strength to look up, let alone read a book. So why read this one? Especially a book that reminds them of their never-altering, daily responsibilities?

Count me in that group. For more than thirty-two years of marriage, I have been helping my wife who is a quadriplegic. Sure, several of Joni's friends help, but the main job falls on me, her husband. So of all the books I might read in my free time, why read this one?

Because I need to. I was convinced of that after reading only the first chapter. *Hope for the Caregiver* is not a fancy title, but it delivers on its promise. You and I need hope that we can make it, hope that we won't throw in the towel or walk away from our wedding vows. We need to know why we do this crazy 24/7 routine, why we take thirty minutes to order four different kinds of pills over the phone, making sure the pharmacist gets it right. We need to know how much that counts in the long run. Finally, we need to know that a greater source of strength is waiting to pour Himself into our weary minds, hearts, and bodies.

My wife and I are involved in Joni and Friends, a worldwide ministry that serves special-needs families in the love of Jesus. We meet so many couples who tell us they simply couldn't make it without their faith in God. But often, in the middle of the night when you get up to turn your spouse, it can feel like He's not there. Well, He is. And sometimes we need to be reminded that God *is* the source of our strength.

Besides, I like listening to Peter Rosenberger. Joni and I have known Peter and his wife Gracie for many years. I won't go into the details about her disability (or I should say, disabilities), but we don't hold a candle to the challenges the Rosenbergers face. Yes, caring for my quadriplegic wife has its difficulties—especially adding her chronic pain to the mix—but our circumstances have never seemed as grim as Peter's and Gracie's. But that's for him to tell in this book.

Plus, *Hope for the Caregiver* is easy to read. The chapters are short, and you can, with no trouble, read a few pages and then come back to it after running to the drugstore. Peter has taken great pains to make everything practical. Are your medical bills piling up? Is your insurance not covering everything it should? Are you wondering if you should switch doctors? Peter's got helpful advice for you—stuff you can really do something about.

I felt like Peter was speaking to me in this book. Sometimes it helps knowing that you're not alone, that others have charted the confusing labyrinth of medical and family issues. It helps to know that you're not the only one who would really rather go out to the backyard and enjoy a cigar than spend the evening ferreting through EOBs.

This book is worth your time because three decades of caregiving has earned Peter a certain degree of authority. I mean, the guy has been through hell, yet he tells his caregiver story with humor, inspiration, and down-to-earth wisdom. Most of all, it's worth your time because (how can I say this as a husband, as a man) *we all need help*. I don't like asking for help, but that doesn't mean I don't need it. And you need it, too.

Gracie Rosenberger and my wife Joni are true treasures. They are unique and gifted women who have contributed much to Peter's life and mine, and we love them. They are our wives, and we expect to stand by their sides "until death do us part." I suspect that you truly love your spouse, your child, your parent(s), your brother, your sister, your friend. You wouldn't be hanging in there and holding onto these pages if you did not value your relationship with the special person in your life who lives with challenges.

So when it comes to books on caregiving, is there really anything new under the sun? I think there is, and you're holding it in your hands. I hope I've convinced you that this short but powerful collection of essays from my friend Peter contains fresh insights for you. So try it out. Take it to your loved one's next medical appointment and peruse it in the waiting room. Who knows? By the time the appointment is over, your heart may sense something it hasn't felt in a long time: a new resolve to keep caring and giving, not so much out of duty but out of a fresh wind of love.

*Ken Tada*

*Joni and Friends International Disability Center*

*Fall 2014*

* * *

*The teaching of the wise is a fountain of life.*

*Proverbs 13:14*

# INTRODUCTION

Each Wednesday morning, I attend a men's Bible study at my church. With the usual half-dozen men meeting over coffee, we work through Scripture, as well as various theological books. We share burdens, successes, funny stories, and even tragic losses. One morning, I opened a discussion about prayer and admitted that I don't often know how to pray for Gracie or myself.

"What do I even ask for?" I blurted out while holding my hands up helplessly. "If she's in a lot of pain, do I ask God for pain relief, or should I go 'all-in' and ask Him for a total body healing—including legs?"

I mean, we are praying to the King of kings, Lord of lords, Alpha and Omega, the Great I AM. Why do we dance around the subject of prayer? Sometimes it seems that many try to wash God's hands and "clean up the mess." It's unsettling to realize that God is not as freaked out about our suffering as we are. Going further, He deliberately allows.

Some folks may take issue with that statement, and want to put it back on the afflicted. "There must be some sin blocking God's provision," is a common statement. If, as in my family's case, amputated limbs are a sign of God's displeasure at sin(s), then there would be a whole lot more amputees in this world, and in pulpits.

God's use of suffering in our lives—without an expiration date on this earth—doesn't sell well. Imagine going to a crusade to hear big-time evangelists preach that message! That's why you hear words like *victory*, *breakthrough*, and *blessings* instead of *perseverance*, *endurance*, and *resolve*. People want to be bailed out of their misery, and, to be blunt, who can blame them?

That plays for a while, but eventually one has to stop praying for a bailout and start living a life of faith and trust—and our prayers change.

As I pondered on how to pray, and what to pray specifically as a caregiver, I wrote the Caregiver's Prayer. My hope is that it will serve as a helpful road map to a more meaningful prayer life for my fellow caregivers.

# THE CAREGIVER'S PRAYER

Heavenly Father, I love _______.
I have committed my life to caring for him/her,
Yet I know the task is greater than my abilities.

As I seek to help another,
I ask for strength to shoulder the burdens before me.
Yet I also ask for the wisdom to know what is mine to carry.

I ask for the courage to admit my failures and make amends.
I thank You for Your grace and mercy,
and ask that You help me daily apply it to myself
and extend it to others.

As I walk through this long valley of the shadow of death,
I ask for a deeper awareness of Your presence to calm my fears.
As I glance backwards, may I only see Your provision.
As I look forward, may my eyes see Your guidance.

May I reflect You as I minister to this one whom I love.
I pray all this in the name of Your Son, Jesus Christ,
Who laid down His own life . . . for me.

# PART I

# HEAD

*Happy is the man who finds wisdom,*
*and the man who gains understanding.*

*Proverbs 3:13 NKJV*

Tomorrow hopes we learned
something from yesterday.

*John Wayne*

I do believe I’m feelin’ stronger every day.

*Chicago, Peter Cetera/James Pankow*

I’ll never be your beast of burden
My back is broad but it’s a hurting.

*The Rolling Stones, Mick Jagger/Keith Richards*

I can’t carry it for you . . . but I can carry you!

*Samwise to Frodo, Lord of the Rings*

# Chapter 1

# SHOCK AND AWE

*When I am afraid, I will trust in You.*

*Psalm 56:3 HCSB*

As caregivers, we sometimes experience “flash-bulb moments” so shocking that the memory is seared into our brains for a lifetime. One of mine came at St. Thomas Hospital more than twenty-five years ago—at 3:00 a.m.

Memories intensify with the engagement of all five senses, and that night, each of mine felt slammed. The bitter taste of old coffee filled my mouth as I hunched over a stack of medical records, while I fought against gagging from the nauseating stench of my wife’s fresh vomit still on my clothes. Caffeine and stress fought against me as I tried in vain to steady my shaking hands and calm my heart down after watching her endure a seizure. Ignoring the looks of nurses and staff, as well as the beeps of countless machines and various announcements over the hospital's intercom system, I sat halfway down the dimly lit ward with my back against the wall and scanned over charts, lab reports, and doctors' notes in the massive folder that bore my wife's name.

Despite three years of marriage, that night served as my first opportunity to review the file that had steadily grown since Gracie's car accident at age seventeen, on November 18, 1983.

After her wreck and lengthy recovery, Gracie returned to Nashville's Belmont University where I first met her. Mutual friends felt us a perfect match, and, from the moment I first saw her, I agreed.

"Peter, she's wonderful, but you need to know that she had a serious car accident that left her permanently hurt," one of Gracie's friends warned.

Several others, including her family, repeated the admonition as our relationship grew, but with no frame of reference as to what the caution meant, I plunged ahead.

Nodding my head with an understanding I lacked, I assumed that no matter what her injuries, I still wanted to meet her. My limited understanding led me to think, *How bad could the car wreck have been? After all, she's back at school, and others were trying to set us up.*

As she walked toward me, I swear to you that the sun followed her every step. Although noticing the limp, it didn't detract. This girl was beautiful in ways that I could not express. A nearby friend offered a squeegee to help with the drool flowing from my open mouth as I watched her head my way. Surprising me with her forthrightness, she walked right up to me, stuck out her hand, smiled, and said, "Hi Peter, I'm Gracie Parker. I need to sit down. May I put my feet in your lap?"

Plopping her misshapen feet into my lap, we sat with a group of friends in the courtyard by the student center. Noticing the scars extending above the ankles and disappearing under her cropped jeans, I "smoothly" blurted out, "Good Lord, girl, what happened to you?!"

With a direct look, her frank but understated remark was only, "I had a bad car accident."

* * *

A whirlwind courtship and three years of marriage later, I sat outside a hospital room in the middle of the night, following my wife's grand mal seizure. This time, I directed the same question to the pile of medical documents in front of me.

*"Good Lord, girl, what* ***happened*** *to you?"*

Not even her family had read what I now studied. Poring through doctors' notes, I realized Gracie's accident was unlike anything I imagined. This was no fender-bender resulting in a broken limb that would simply serve as a weather indicator for life. Turning the pages, one word just kept flooding my mind: *devastation*.

Tears hit a few of the pages, as I hung my head in grief and hopelessness. For the first time in my life, I felt a despair that would hover over me for the next dozen years—and one that still requires my vigilance to guard against.

Reading until dawn, I closed the massive folder and sadly noted that the cover stated, "Volume 4 of 4." Before converting most of her records electronically years ago, the volumes grew to seven—for just one of the twelve hospitals where she's received treatment.

The events of that night forever altered me, along with the way I view life, hospitals, doctors, other people, my wife, and even God. Although immature, I was devoted. My sincere desire to care for this extraordinary woman led me to begin this journey. I never imagined, however, that the road would contain such suffering, loss, heartache, self-sacrifice, failure, and love.

My love for Gracie committed me to an existence dominated by constant brutal realities that would end with a funeral, but hopefully not mine. While my dying would remove me from the daily burden of caring, my death would also create an even greater hardship for the ones I loved most. So even"driving off a bridge" represented a poor option. That night in the hospital corridor, my heart sunk as I stared at a future full of relentless challenges with no expiration date.

I felt trapped, but also understood the need for me to stay alive and healthy.

A difficult place for a twenty-six-year-old man.

A difficult place for a fifty-two-year-old man.

◆

To date, Gracie's journey includes at least seventy-eight operations (that I can count), multiple amputations (not just both legs, but multiple revisions on both legs), treatment by more than sixty physicians in a dozen hospitals, seven different insurance companies, and medical costs cresting nine million dollars.

As her sole caregiver for nearly thirty years, I often recall that shock-and-awe moment in that lonely hospital when I read her chart for the first time. Somehow pushing the massive despair into an emotional box, I threw myself into the task of fixing that which cannot be fixed, and managing that which cannot be managed.

My wife, my responsibility.

* * *

Someone once asked, “If possible, what would you say to your younger self?”

This book is the answer to that question.

On these pages, I’ve condensed a lifetime of experience into what I hope will be a lifeline of help to my fellow caregivers. These pages contain the things I wish someone had communicated to me.

Through it all, I’ve learned quite a bit about America’s healthcare system. Through marriage to someone with extreme pain, disability, and chronic crises, I’ve learned even more about perseverance, love, and relationships.

It’s not easy caring for a suffering human being—one who lives with a severe disability and intractable pain. I often tell my wife, “You’re easy to love, but you’re hard to love well.”

Armed only with a relentless persistence, a goofy sense of humor, a few "smarts," and a degree in music (composition, *piano principal*), I somehow keep the plates spinning. When it comes to "wanna-be" stand-up comedians who play the piano and take care of a disabled wife for decades, I'm the best there is.

Others may offer opinions about caregivers—seems a lot of folks are talking about this subject. That's okay; everyone is entitled to an opinion. On the subject of "how to help a caregiver," however, my experience trumps opinion.

> Blessed are the flexible
> for they shall not be
> bent out of shape.
>
> *Anonymous*

Whatever burdens my fellow caregivers struggle with, I can help. I'm willing to put it all out there. The question is, are you willing to learn from the insights, wisdom, experience, and even failures—gleaned from watching over someone with a broken body for three decades?

If you're gasping for air, you can't help other people.

*Sandra Rankin*

* * *

I have come to believe that caring for myself is not an act of indulgence. It is an act of survival.

*Audre Lorde*

* * *

*But the Lord is faithful; he will strengthen you*
*and guard you from the evil one.*

*2 Thessalonians 3:3 NLT*

# Chapter 2

# THE DELTA DOCTRINE

It don't take too much I.Q.
To see what you're doin' to me
You better think.

*Aretha Franklin and Ted White*

One day, while flying to Atlanta on Delta Airlines, (**D**uh, **E**verything **L**eaves **T**hrough **A**tlanta), I discovered that flight attendants state the best advice for caregivers—all day long:

> "In the unlikely event of the loss of cabin pressure, oxygen masks will drop from the ceiling. Securely place your mask on first, before helping anyone next to you who may need assistance."

That small directive, which I call the "Delta Doctrine," contains applicable wisdom for so many circumstances—but probably none as poignant as for those of us serving as a caregiver for a chronically ill or disabled loved one.

Compassion and love often mistakenly lead us to hold our own breath while trying to help someone else breathe. But once we make that decision, it is only a matter of time before we find ourselves gasping for air. And, if we are unable to breathe, how can we help anyone else?

Many of America's 65 million caregivers desperately try to assist a vulnerable loved one while growing dangerously close to "blacking out" themselves. Grabbing the mask first is not a sign of selfishness but rather the whisper of wisdom. Unfortunately, that soft voice is hard to hear over the often-deafening cries of someone we love.

Those who "push the wheelchair" serve as the critical team player for a suffering patient. Sadly, too many caregivers don't know how to create a sustainable care-structure for themselves. Simply getting sleep and eating a proper diet is not enough. Caregivers must remain healthy: physically, financially, emotionally, professionally, and spiritually. But staying healthy is impossible if we don't reach for the mask first.

Help is available, but caregivers must be willing to accept that help while tuning out the fear (and sometimes the panic) that can consume us during highly stressful moments.

On a plane, one must simply reach for the mask that dangles. For caregivers, however, reaching for help is different. Most of the conflicts that caregivers experience involve relationship dynamics. If the patient is bleeding or injured, then it is a medical crisis and that involves a different set of skills and needs, generally referred to as triage.

Caregiving scenarios that strain the bonds of friends, family, and marriage could benefit from “emotional triage.” Since the one who suffers will, by definition, probably not be providing leadership in those areas, it is up to caregivers to ensure their own safety and well-being. Just as paramedics train to care for an agitated (and sometimes even violent) patient, caregivers can learn to protect their own emotional safety and peace of mind.

When the “turbulence of caregiving” hits, I’ve found three simple things that help me make healthy and positive decisions in high-stress moments: Wait, Water, and Walk.

**Wait:** Take a moment before responding. Regardless if the culprit is dementia, drugs, or just your loved one behaving badly, all types of “emotional tug-of-wars” seem to be happening simultaneously while caregiving. If you pick up the rope and involve yourself in a tug-of-war, one of two things will happen: You will win and end up on your rear, or you will lose and end up on your face.

Don’t pick up the rope! Simply wait before responding. Rarely do you have to apologize or make amends for something you didn’t say. Breathe slowly (inhale four seconds; exhale eight seconds), until you feel yourself growing calmer. Stress and anger are toxic for good decisions.

**Water:** Drink some cool water. It will buy you time to think more clearly. Avoid sugary drinks or even coffee, and instead grab a bottle or glass of water. Your body needs water—your brain needs water. From high blood pressure to fatigue, water helps a myriad of issues. A tanked-up brain functions better. Drink to think!

**Walk:** Caregiving creates extreme stress, so when things are bouncing off the walls, take a few moments to put on some comfortable shoes and walk off some of that tension. By doing so, you are truly putting on the mask first, getting better oxygen to your body and brain, and bleeding off anxiety. Walking immediately helps facilitate calmness. Settling yourself down allows you to bring your "A-Game" to the caregiving scenario.

*Wait, Water, Walk* cost little or nothing but can instantly help a caregiver make better decisions, calm down, and feel more at peace. These are the initial steps of the Delta Doctrine. "Put your mask on first" is the most responsible and caring step in your efforts to help others. In doing so, the patient gets a healthier, confident, stronger, and more "self-controlled" caregiver who can provide leadership while offering love.

Face your deficiencies and acknowledge them;
but do not let them master you.
Let them teach you patience, sweetness, insight.
When we do the best we can,
we never know what miracle is wrought in our life,
or in the life of another.

*Helen Keller*

Take rest.
A field that has rested gives a beautiful crop.

*Ovid*

# ABOUT THE AUTHOR

A lifetime of experience. A lifeline for fellow caregivers.

Michael Gomez—Gomezphotography.com

Peter Rosenberger is president of Nashville-based *Standing With Hope,* an outreach whose flagship program provides artificial limbs to people in West Africa. Host of a weekly radio program, he's also an accomplished public speaker, writer, and spokesman for the needs of America's 65 million caregivers.

His is an unparalleled journey. As his wife's sole caregiver for nearly thirty years, he has labored through a medical nightmare that has mushroomed to 78 operations, the amputation of both her legs, and $9 million in medical bills. The experience and wisdom he has gleaned gives Peter a unique and astonishing understanding of health care issues facing millions of people. But more than that, he brings unmatched empathy for the deep heartache that causes even the strongest to falter.

*"…One joke away from being a night club act,"* Peter combines deep compassion with a contagious humor to bring fresh air into the painful places faced by America's caregivers.

This is Rosenberger's third book.

# PETER ROSENBERGER

*Author, Radio Host, and 30-year caregiver*

How do you help someone – who **helps** someone?
**You put 30 years of experience in their hands.**

> ***"If you love someone, you'll be a caregiver.***
> ***If you live long enough, you'll need one."***
> ***– Peter Rosenberger***

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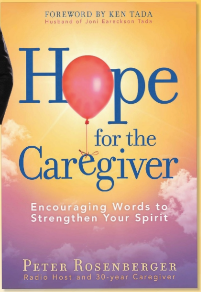

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