

The Unexpected Caregiver.®

How to keep
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I was surprised to lose a formerly easy give and take with my dad when dementia crept into the equation ... What I wouldn't have done to have had Kari Berit in my corner during that time! Kari's long experience working with the elderly, her creativity and her ability to find the keys to connection with elders are inspiring. Fortunately she has written a book stuffed full of good ideas for bringing caregivers and aging parents together in meaningful shared activities.

Kari helps us see through our own confusion and pain to the possibility of authentic interactions on this path of discovery.

Carol Leavenworth,
Licensed Professional Counselor and Jungian psychotherapist

Kari Berit describes a kind of quest for a positive caregiving relationship that involves active communicating and attempting to forge new connections that create a positive experience for both aging adult and caregiver. Certainly this represents an aspect to caregiving, social well being, that isn't often the focus of such monographs.

Dr. Susan E. Ramlo

The Unexpected Caregiver lives up to its title, as it is packed cover to cover with invaluable information for any adult finding themselves in the role of caregiver to aging loved ones.

Midwest Book Review

An unexpectedly activist view of caregiving for people who too often are consigned to inactivity. If you're a Boomer providing care to your folks, Kari Berit will challenge your stereotypes, not to mention you and your parents. Walking, talking, writing, dancing, surfing the Net and questing for timeless spiritual value — you may never before have considered these parts of caregiving. But you will.

Dennis Streeter, host, *Healthy Aging*

Just in time to serve the huge number of middle-aged children with aging parents. Whether you already are the family caregiver in charge, or might have that responsibility in the future, *The Unexpected Caregiver* offers information that is practical, sensible, and wise.

Connie Goldman, author,
The Gifts of Caregiving — Stories of Hardship, Hope and Healing

Kari Berit's concise but engaging style delivers the kind of information that I need as I care for my aging parents, but in a way that is lively and heartfelt.

Paul Krause, CEO, Story Circles International, Inc.

Kari's book offers a wealth of information and ideas for assuring that not only my own family, but those I work with every day, can provide the best solutions for their parents.

Kyle R. Nordine, President and CEO,
Northfield (MN) Retirement Community

Kari Berit has written a comprehensive and useful guide to caregiving for the many boomers who will bear the difficult and yet noble role of caring for their aging parent(s). I highly recommend this book.

Paul D. Nussbaum, Ph.D., Clinical Neuropsychologist and Adjunct
Associate Professor, Department of Neurological Surgery University
of Pittsburgh School of Medicine

A splendid treasure chest of practical ideas that will help ease the stress of caring across generations.

Pat Samples, author, *Daily Comforts for Caregivers*

I am delighted with your message to an important group of people (the adult children of elders) who have incredible influence on their parents.

You have a wonderful way of coming across to people with an honest, realistic message and in a conversational tone. Good for you.

Bruce Roberts, co-author,
I Remember When: Activities to Help People Reminisce

Kari Berit has spent her career searching for better ways to enrich the lives of the elderly. Kari's advice for those of us who care for elderly loved ones is priceless.

Mike Eden, President, The Eden Group, Wilson, WY

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PREFACE

Your Caregiving Journey Needs Compassionate Guidance

Robert V. Taylor, Activator and Speaker
Author, *A New Way to Be Human*

Caregiving is a journey into the heart of the unexpected and the unknown. At its very worst it creates resentful caregivers or angry martyrs. At its finest it is an invitation into the depths of what it means to be human and shines a light on life that we could never have imagined.

It's uncharted territory for most people including those who work in the caring professions of mental, physical, social and spiritual health. Uncharted because we unexpectedly find ourselves caring for and making decisions about a person — a lover, spouse, child or parent — that turn our life and emotions topsy turvy.

Over the last several years I became an unexpected caregiver for my mother and then my spouse. Theirs were two very dissimilar circumstances. My mother was of an age in which her lack of self-care suddenly spiraled into one complication after another. My spouse was a loving, engaged and supportive partner in caregiving and my mom got her wish to die at home in our house. Two years later my healthy, younger spouse succumbed to a virus which brought him very close to death and then the long road to full recovery. Caregiving is an invitation that is as unexpected as it is surprising!

You can never do it alone. At least not if you cherish and value your own life as much as the life of the one you are caring for. Caregiving will often upend your life as you know it. Experts like

Kari Berit — through this remarkably practical book and her radio show — are guides and companions on your journey. Her wisdom will immeasurably enrich your own caregiving and life along with the life of the one you care for because it is wisdom forged in the crucible of experience.

As you read and return to this book do so with kindness, compassion and love — to yourself. It is all too easy to succumb to the persistent needs or demands of the one you are caring for. They are real but you are not a machine. Unless you treat and care for yourself with kindness, compassion and love, you will burn out or become unwell or resentful. Treating yourself with these qualities is a reminder of the importance of your well-being.

The quality of your caregiving — beyond the mechanics and the practical acts you do — will be authentically kind, loving and compassionate when you treat yourself with love, compassion and kindness. You are both too valuable for anything less!

These qualities will ground you in the daily grind and frustrations that are typically felt by both the caregiver and the one being cared for. With this grounding it becomes possible for each to receive unexpected or surprising gifts from one another. Gifts such as new insights into your relationship, the healing of old wounds, the taming of fear, the intimacy of tears and laughter or the great silence of simply being together because words are unnecessary.

As you walk this path you will discover new ways of being human and of courageous love that take you beyond unexamined limitations. Caregiving is not a passing chore; it will transform you, your heart and spirit and how you view the world.

This remarkable book gives you a toolbox of practical hope to work with.

INTRODUCTION

To Love Yourself Too

Kari Berit

I love what I do. Whether I'm in front of an audience speaking or conducting a family meeting, I have experienced great joy in my work and have learned tons. This book is a result of my 25+ years of experience in the areas of eldercare, senior housing, family dynamics, radio show hosting, adult education, as well as several years spent as a court-appointed guardian for an at-risk elderly man. I've also been a family caregiver to my mother, grandfather and sister, not to mention a support to my family and friends around caregiving issues.

My expertise lies in aging and managing the relationship between adult children and their aging parents. I have found that taking care of older adults and their families requires dedication, compassion, energy and, as I have personally discovered, physical and emotional resilience. This book will help you develop these traits and provide many of the key tools, skills and resources you need to tackle the challenges of caring for yourself while also giving care to a loved one. I am certain that all caregivers will find support from my knowledge and stories. More and more frequently, we are giving care to a multitude of generations under one roof. Our families are both precious and challenging.

As a young girl at family gatherings, I worried that my mom would drink too much. I fretted that my sister would say something that would cause mom to cry. I brooded over the fact that, even though it was my birthday on December 25th, the day was not about me. Instead of birthday presents I received Merry Birthday combination gifts, and they were somehow never more special than what everyone else received.

Those feelings and memories seem so trivial when I consider what I have been given. But to a young girl, those concerns created the limiting belief: “Everything will be all right if I don’t make a fuss or say what I want.” My job was to monitor how others were feeling and to consider what, if anything, I needed to do for them, and put my feelings aside. In other words, to fix the situation at the cost of ignoring my needs. I always figured I would deal with what I wanted or needed later.

Later rarely comes when you’re taking care of other people’s feelings before your own.

These are the lessons that come from being the child of an alcoholic mother. I learned to enter a room cautiously and to look for potential danger (generally disguised as a thermal glass that smelled of pine needles). I could then choose to either tiptoe past the room or engage in cheerful conversation about mindless things. Alternatively, I could cut myself down in an attempt to raise her self-esteem. As if that was possible.

After doing this for over 50 years, that way of life felt normal. If I put myself first, I was “selfish.” That is the message I received years ago and sadly, this is still the case today. If I share that I’m caring for myself by getting a massage or spending a day reading, I oftentimes receive a sarcastic response such as, “Well, it must be nice to be you.”

As caregivers we face a significant challenge: in order to care deeply for someone else, we must first love ourselves. Many of us have come to adulthood carrying a suitcase full of wounds from our past that are reopened when we’re called upon to give care to family. With the emotional scars we carry and the minimal amount of time we devote to repairing our past hurts, giving care to a loved one can become an illusion that we’re mending the relationship. For others who have solid family systems, caregiving can focus more on love, which is the goal of all caregiving journeys.

Self-care is the crux of the new edition you now hold in your hands. The book is laid out in five sections, with four chapters in each section. The sections are as follows:

1. The challenges caregivers face in connecting — and in many cases, re-connecting — with their parents under the stress and pressure of caregiving.
2. Addressing the obvious challenges involved in the upkeep of their parents' mental, physical, and emotional health.
3. Creating and encouraging “parent-directed” activities that preserve independence and personal dignity as mental and physical abilities inevitably decline.
4. Developing stimulating activities that are both suitable for those later in life and can help to deepen the ties between adult children and their parents.
5. Facing up to the inevitable end-of-life issues that many cultures work so hard to delay and deny.

Within each of these five sections, four concise chapters combine to bracket the subject in different, but complementary ways: the first chapter in each section lays out the issue itself from an objective point of view to provide basic information and context; the second chapter provides interpersonal insights focused on the needs of caregivers as they work with their parents; the third chapter lays out practical and relevant activities which caregivers can use to engage with their parents within a caregiving relationship; and the fourth chapter is targeted specifically to the care of the caregiver, providing both pragmatic and supportive ideas to maintain your emotional health while giving care.

We are entering a time in history when there will be more people over 65 years of age than there will be teenagers. The 85+ crowd will outnumber the little ones under five. Meanwhile, the pool of professional caregivers can't keep up with demand and we will more and more frequently have to rely on family to answer the call to care. Of course, we expect them to do this on top of their already full lives and without any additional pay.

In my book, I provide creative ways to interact with your parents, facts about aging and caregiving to help you become a smarter

caregiver and suggestions for how to care for yourself. I discuss the brain in Chapter 3 and submit that by engaging it in your new role, you will be a more involved and innovative caregiver. When you feel stuck or frustrated, sing loudly in the shower, work a Sudoku, or dance to the music you love. Get outside of yourself. Laugh, cry and look at your situation from another side. In particular, take advantage of the mental fitness resources I've listed in the resource directory. Although not directly linked to the act of caregiving, they can help you become a more flexible thinker and flexibility is crucial in effective caregiving.

Caring for yourself is critical to your journey. You must put yourself first, and I don't write these words lightly. I've been a family caregiver and I've made promises I could not keep. I've stretched myself too thin, but I've also taken the difficult step of walking away. As a professional caregiver I've been chastised by family members, slapped across the face by residents afflicted by Alzheimer's disease, and escaped to stairwells to cry when I lost my professionalism and yelled at overtired staff. I have been at the end of my caregiving tether and I understand at the deepest level the importance of taking care of myself while giving care to others. You do no service to anyone by exhausting yourself to the point that someone else has to become a caregiver to you.

You don't need to read this book straight through. Grab a cup of coffee or glass of wine and choose a chapter that speaks to you. With my title, I set four goals for this book:

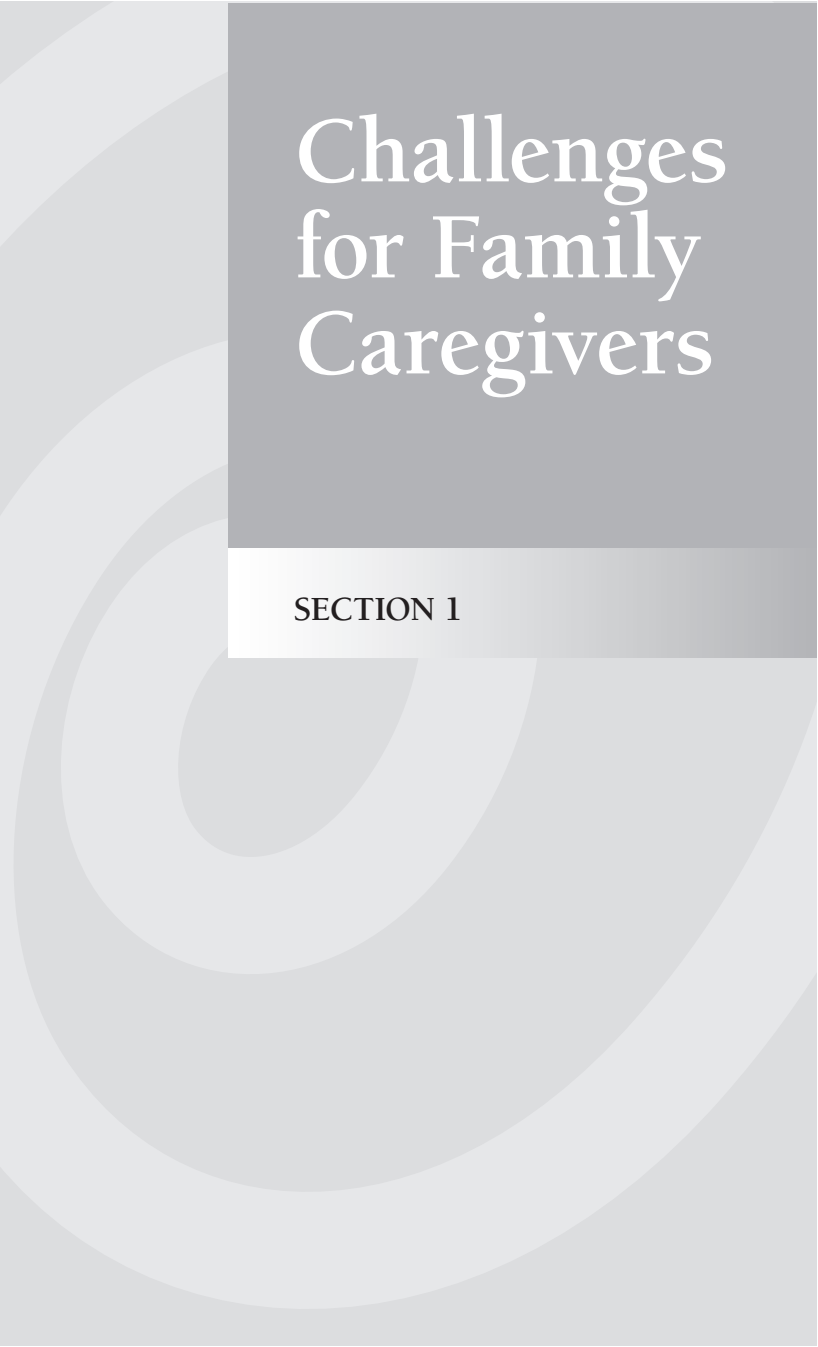
1. To help you keep your parents active. I put emphasis on being engaged in life, whatever that might mean for them.
2. To help you keep your parents safe. Not just making smart choices, but also feeling secure enough to be willing to try new things.
3. To help you keep your parents independent. Of course your parents want to be in charge, but part of the journey in aging is to better understand how we rely on each other and the benefits of being inter-dependent.

4. To help keep yourself S.A.N.E. — Supported, Appreciated, Not guilty and Energized. Just because you're giving care to someone else, that doesn't mean you should neglect yourself, play the martyr card, feel guilty about how much you're not doing, or lose your own zest for life. The first four caregiver chapters will unpack the S.A.N.E. acronym. The final caregiver chapter, Chapter 20, will deal with the caregiver's loss and grief.

I invite you to think anew and with an open mind while reading through the ideas put forth in my book. Instead of thinking, "Oh, this won't work," try approaching your caregiving situation with a positive mindset: "I wonder how I could make this work." If you need further inspiration, I have over 200 archived shows available for download at KariBerit.net/radio.

My overall goal with this book is to help you provide care with as much creativity and compassion as possible. I also want you to take care of yourself. When you are good to yourself, you will be more loving and gentle in your caregiving.

Using the creative ideas and caregiving approaches in this updated version of *The Unexpected Caregiver*, you will emerge from this journey with your heart intact and that will make all the difference.

The cover features a background of concentric, overlapping circles in various shades of grey. A dark grey rectangular box is positioned in the upper right quadrant, containing the title text. Below this box, a white horizontal bar contains the text 'SECTION 1'.

Challenges for Family Caregivers

SECTION 1

Caregiving absolutely requires communicating. No matter how early or advanced their need, how strong or weak your past relationship, you and your loved one must find common ground on which to openly communicate, exchange information, share emotions and move forward in the face of new challenges.

It's not about being right or wrong. Or taking charge. Or maintaining control. It's about getting past all the deep fears and fragile feelings, the things not said, the bright memories and the bittersweet ones, and coming to terms with the months and years that lie ahead.

They may be tough years. Trying years. Perhaps ultimately painful and tragic years. But they also can be years that call to something deep inside, resonating with chords only parents and their children can hear. Years that can leave you with a richness, a rightness and a depth of love and satisfaction that lives on long after your parents are gone.

It starts with just communicating, however easy or awkward that may be. In this section, I'll help you focus on the underlying inter-generational issues that spawn so many elephants in so many living rooms. I'll examine some communication skills that can make this unexpected caregiver relationship more comfortable and more productive — for everyone involved. I'll show you how simple books written for children have the power to open up resilient lines of communication that help the family come to terms with what's happening with mom and dad. And finally, I'll address how you, in your new role as caregiver, can find the support you need.

Forging Connections: Bridging Generations and Time

My expertise is in the dynamics of caregiving between adult children and their aging parents. In the first edition of my book, I addressed the differences between Baby Boomers and their two generations of parents. Since then, there are fewer people from the WWI Generation receiving care, and Generation X and the Millennials are increasingly moving into caregiver roles. In summary, we've all gotten older since my first book.

Aging has always been something I've found fascinating. When I first began my work in this field, issues of aging were confined to the back pages of newspapers and magazines. In the early 90s I led a workshop at the American Society on Aging Annual Meeting entitled, "Let's Talk About the 'A' Word." At that time, very few people were talking about aging, let alone embracing any part of it. My workshop was covered by *The New York Times* and what caught the reporter's attention were the comments about coffee and the nursing home: "I'm not going to one of these nursing homes ... unless they have lattes." Now that the Baby Boom Generation is moving into, dare I say, "older age," aging issues are popping up all over the place. By most accounts the number of Boomers in the United States turning 65 hovers around 10,000 every day! This trend started in 2011 and will continue through 2030. The greying of America (and many other countries) is upon us, and we still don't like to talk about the "A" word...but that is exactly where I'll begin.

Aging Is Not Something to Fix

“Granny hands, granny hands, you’ve got granny hands!” That’s what the kids at Burnside Elementary told me. We were playing a game in which everyone willing to play was required to hold out their hands and close their eyes. When my turn came around, the game came to a sudden halt. My playmates squealed, “You’ve got granny hands. Your hands are ugly.” I was only eight, and the message my classmates shared with me was that my hands looked old and “old” is ugly.

When we think about aging, we tend to grab hold of the myths: Will I lose control of myself when I’m old? Will I get Alzheimer’s disease? Will I be dependent upon my children? Will I have enough money? The profundity of these questions, for which we have no answers, leaves us fearful of becoming an insult to society or a burden to our loved ones. When we fear anything, we allow it to have power over us. When we face that fear, we wrest our power back.

Instead of adopting the attitude of “I’m not going to think about getting older until I’m there,” let’s imagine what being older could be like. In 1989, I encountered my first group of older adult learners taking part in an educational program. These aging seniors were rebels. They were vibrant, engaged, responsive and goal-driven. They thoroughly enjoyed life as older adults, rather than resenting the loss of their youth. They laughed off the bumps and bruises of their aging journey and embraced the here and now.

You may not be giving care to one of those active agers. You may have a parent riddled with physical issues or struggling to remember your name. To you, aging may very well be ugly. I remember people telling me that I looked like my mother. My reaction was quick and to the point: I actually look more like my dad, or a combination of them both. My mom had Huntington’s disease later in life. That is what aging looked like to me and I wanted none of it. It was only after I met more active older adults that I saw how positive aging can be.

Aging in and of itself is not a disease. We don’t need to fix it and anti-wrinkle cream won’t reverse it. We become more susceptible to diseases as we age and certainly our family histories can influence

how we age, but we also have a fair bit of control. Most of the control lies in our attitudes towards the changes we see in our loved ones who are aging now. Those positive or negative attitudes will influence how you age; in fact, the latest studies confirm this.

Researchers at the National Institute of Health have used both MRI scans and autopsies to study brains of participants in one of the longest-running scientific studies of human aging. The National Institute of Health's "Baltimore Longitudinal Study of Aging" started in 1958 to answer critical questions about what happens as we get older. Current brain research has shown that internalizing society's negative beliefs about aging affects brain structure ("Karma bites back: Hating on the elderly may put you at risk of Alzheimer's," 2015: *Los Angeles Times*). Think about it. If aging is something we fear, yet also understand that at a deeper level is unavoidable, then it causes us stress. According to the research, negative perceptions of aging play a key role in bringing about diseases that cause dementia. This should be more than enough reason to adjust our attitudes about aging!

It's not a 15-minute fix. Aging is a fluid process. It is crucial to understand the multiple tiny adjustments that are needed in order to maintain a balance of perspective as one ages. We don't all of a sudden get old and cranky. You can't blame your parents' stubbornness on aging. Look at who they were in younger days. Did they roll with life's ups and downs? Were they quick to judge others? Were they always obsessed with doctors appointments?

While you're at it, take a look at how you deal with changes in life. Taking a quick inventory will help you prepare for older age. Adopt the "one day at a time" mantra and drop the worrying. You may not be able to change how your parents think about growing older, but you can always reevaluate your own attitudes towards aging. Understand that aging is an individual journey. Getting sick doesn't mean you've failed, nor is one's health ever totally in one's control. However, it does help make the caregiving journey a whole lot more pleasant when you accept your parents' changes. Don't blame everything that's wrong with your parents on aging, but don't ignore the fact that aging redefines who your parents are and what is important to them.

Generations and Family Dynamics

It almost doesn't matter whether you're a younger Boomer caring for your Silent Generation parent, an older Boomer with Gen X kids or a younger Boomer with Millennial children. At some point, we're all going to be touched by family caregiving. Family dynamics, mixed with common traits across the generations, will play a role in making for a smooth or bumpy caregiving journey. The average family caregiver today belongs to Generation X. Now that I'm aging and moving into a time when I may need care myself, it will be the Millennial generation who will have to step up and help me. Good thing I married a man with two daughters who fit squarely into that age group!

As caregivers across generations, we are being asked to understand very different frames of reference. We will need to find some common ground on which to meet and interact.

As both your parents and you probably remember only too well, that kind of interaction hasn't always been easy. Or peaceful. Or even possible. Whatever your current caregiving situation, it will help to acknowledge that you, your parents and the rest of the family are coming to this new relationship with very different mindsets.

Without going into too many details, I'll provide a quick snapshot of the generational differences and include potential challenges.

- ④ The Greatest Generation (also known as WWII or the GI Generation) (1914-1929) Young during the Depression and had clearly defined family roles. These folks may balk at their daughter driving them to the doctor (men drive; women don't) or get easily frustrated over the speed at which life moves.
- ④ Silent Generation (1928-1945) Learned thriftiness from parents and had no credit cards, artificial hearts or computers. Technology may frustrate them, as much as having their caregiving children wanting to boss them around.
- ④ Baby Boomers (1946-1964) First half danced at Woodstock and protested the Vietnam War, while the younger half put on

tennies with their business suits, rejoined corporate America and became “Yuppies.” I hate to think of the adult children who will have to care for the Boomers, as they will demand individual choices in every aspect of care.

- ④ Generation X (1965-1980) The original latchkey kids, generally unimpressed with authority. Finding the time and energy to give care will be a challenge for this generation spread across or around the globe. Their financial situation and time constraints will be factors in just how much this generation can answer the caregiving call.
- ④ Millennials (1981-2000) Have access to most everything 24/7 and have omnipresent parents. Since many from this generation already live at home with one or two parents, it seems a natural fit that they stay and provide care! I realize that is not ideal, but if this generation can continue working in flexible situations, they may just be available caregivers. I would guess that both Gen X and these folks will need to find ways to be paid family caregivers.

Appreciating the Differences

It’s easy to say that the two halves of the Boomer generation, their Silent Generation parents and their Gen X and Millennial children come at things in uniquely different ways. These differences can easily include divisive issues. Paul Taylor, author of *The Next America: Boomers, Millennials, and the Looming Generational Showdown* (2014: PublicAffairs) said of the Boomers and their Millennial children, “They’re bound together in an intricate web of love, support, anxiety, resentment, and interdependence.” Whichever generation you each belong to, Taylor’s statement pretty much sums up the parent-child relationship.

Take for instance moving or downsizing. When my former husband and I moved in to share a house with my dad, we had some major cleaning to do. I’ll never forget finding a six-year-old piece of turkey in his freezer. We all laughed about the protective value of freezer burn ... and then I went to throw it away. “No,” said my dad. “Don’t throw it. It’s probably still okay.”