



take back your *life*

A Caregiver's Guide to Finding
Freedom in the Midst of Overwhelm

LOREN M. GELBERG-GOFF, LCSW

Copyright © 2018 Loren Gelberg-Goff, LCSW

All Rights Reserved

ISBN 13: 978-0-9994011-0-1 (trade)

Published by Well Within Publishing

All trademarks and registered trademarks are the property
of their respective owners.

Book and Cover Design by CB Messer

10987654321

Dedicated to my amazing children, Cheryl and Elliott, who have taught me the challenges and joys of parenthood and have shown incredible love, devotion, and resilience through our journey together.

*To my husband, Lloyd, who never lost his spirit for life:
TGIA (Thank God I'm Alive).*

To all caregivers who give selflessly of themselves to those they love: You have my admiration, appreciation, and gratitude for all I have learned from you.

THE AUTHOR OF THIS BOOK does not dispense medical advice or prescribe the use of any technique as a form of treatment for physical, emotional, or medical problems without the advice of a physician, either directly or indirectly. The intent of the author is only to offer information of a general nature to help you in your quest for emotional and spiritual well-being. In the event you use any of the information in this book for yourself, which is your constitutional right, the author and publisher assume no responsibility for your actions.

THE IDENTITIES OF CLIENTS DEPICTED or described in stories in this book have been modified to protect their confidentiality.

While most caregivers are women, many men are stepping into this role, and this book is for you too. For consistency, I have used feminine identifiers most of the time, but the strategies and ideas work for men as well. No gender discrimination is intended.

Contents

<i>Introduction</i>	<i>ix</i>
<i>Chapter 1: My Desired Outcome</i>	<i>1</i>
<i>Chapter 2: From Deprivation to Self-Care</i>	<i>13</i>
<i>Chapter 3: Boundaries</i>	<i>30</i>
<i>Chapter 4: Preventing Self-Sabotage</i>	<i>48</i>
<i>Chapter 5: Anger and Resentment</i>	<i>67</i>
<i>Chapter 6: Overcoming Guilt, Shame & Emotional Blackmail</i>	<i>91</i>
<i>Chapter 7: Forgiveness Is Key</i>	<i>103</i>
<i>Chapter 8: Making Changes</i>	<i>121</i>
<i>Chapter 9: Pop Quizzes</i>	<i>133</i>
<i>Chapter 10: Siblings Without Rivalry</i>	<i>144</i>
<i>Chapter 11: And We Breathe</i>	<i>154</i>
<i>Appendix 1: Caregiver's Step-by-Step Guide</i>	<i>167</i>
<i>Appendix 2: Resources and References for Caregivers</i>	<i>179</i>
<i>Acknowledgments</i>	<i>185</i>

Introduction

I BEGAN MY CAREER IN social work more than thirty-five years ago, working with terminally and chronically ill individuals and their families. This work took place in hospitals, clinics, hospices, adult day programs, and ultimately in my private practice. I saw what it took for both patients and their families to find the means to be resilient in the face of the many challenges that came with a serious diagnosis, looking at a lifetime of caring for a disabled child, or facing the end of life. I helped family caregivers deal with the enormous responsibilities that they faced every day and learned the importance of self-care: that it really isn't selfishness; *it is self-preservation*. I loved my work, I respected and cared about my clients, and I discovered that this was incredibly important and necessary work, even more than I had realized going into my profession.

Then, out of nowhere, in 1997, my husband became disabled. He experienced constant, excruciating pain and was unable to work. This began our family's immersion in a world I had been professionally engaged in for almost twenty years. We had two young children (ages eleven and four) to love and care for as well as a home and my career to manage. I now had to walk the talk I had been practicing. The world looked different from the inside, as every caregiver knows. I thought I would be immune from the

pitfalls so many caregivers experience, because I understood this world. I was in for a very intense awakening.

I learned to be very organized; operated on autopilot; compensated for my husband's significant limitations; took on ever-growing responsibilities, demands, and obligations; and resisted asking for the help that would have made my life easier and more balanced. I learned what it felt like to be a martyr, and, as you know all too well, there is no joy in martyrdom. While my practice had been thriving for many years, in 2013 I knew I had to do one more thing. I created the powerful and life-changing program for caregivers, *Take Back Your Life: The Art of Self-Care*. This program guides caregivers to live free of chronic, daily anxiety, and overwhelm without having to constantly feel guilty, angry, and resentful.

In 2013, my parents' health and physical abilities took a downturn. They needed to downsize, and we helped them move into an independent-living building where they managed fairly well, with help, for over a year. As their needs increased, their help at home increased as well, and my younger sister was able to increase her involvement. She went with them to doctors' appointments, managed their medications, visited them daily, handled their finances, and was completely devoted to them every step of the way.

My older sister and I each had our roles as well, as our parents' needs continued to grow unabated. We learned and respected each other's strengths and learned to communicate with each other in new ways to best meet our parents' needs and our desired outcomes. My parents struggled at times with their declining abilities and the fact that they needed so much help. They were also able to express gratitude for the love and care they received.

Everyone is not so lucky to experience the good, since so many aging, frail parents resist help, express a great deal of anger at their limitations, and take their anger out on those they love the most.

My parents passed away within six months of each other in 2015. The work and relationship between my sisters and me continues to evolve, as is true for all families who are creating new, healthy, adult relationships. This is an offshoot of caregiving and learning to take as good care of yourself as you do of the others in your life. Although this has been my career for decades, it's always different when you're doing it for yourself. Reaching out to get the necessary and deserved support is imperative.

My husband's disability has been a constant source of learning, growing, and evolving for him, our children (who are now adults), and for me. We were blessed to have found an amazing physical therapist who introduced us to cold laser therapy, through which, miraculously, after intensive and extensive treatments, my husband is now pain-free. This has given him back a huge portion of his life, which he had lost over the past twenty years.

His pain began receding two years ago, and he is now off all pain medications, which is an enormous blessing on many levels. He is working on reintegrating into the daily rhythm of our lives, which has changed over the past two decades, and that is a process which also requires many of the coping strategies, skills, and tools that we work on in the Take Back Your Life group program. He is able to work part-time now, and he is so very grateful to be able to provide meaningful and worthwhile services that make a difference.

There is no right or wrong way to read this book. It is meant to provide guidance, support, and encouragement on your journey as

a caregiver. You may choose to read this book and do the workbook pages straight through from beginning to end, or you may find yourself struggling with a particular issue and open up to that chapter for the guidance you need. You might even choose to pull out the Step-by-Step Guide and work through the issue you are facing in order to get started right away, on making changes in how you take care of yourself with the love, respect, and compassion that you so richly need and deserve.

Throughout the book you will read the phrase “and we breathe.” It is a phrase I use as a reminder to catch my breath and pause to prevent reacting and allow space for responding to situations that cause stress, upset tension, and aggravation. I explain its use throughout the book, and I hope you will find it both useful and beneficial on your journey to take as loving care of yourself as you do of others in your life.

Life is a constant, ever-evolving journey full of learning opportunities, challenges, and wonderful celebrations, if we allow them. I am grateful for all the curves in the road that I have experienced and that I am able to bring my professional expertise, my personal experiences, and my years of learning to the caregivers who are the unsung heroes every day. I am grateful for all I have learned from every caregiver I have worked with over the past thirty-five years. Thank you.

And we breathe...

Chapter 1

My Desired Outcome



*Your own self-realization is the greatest
service you can render the world.*

—*Ramona Maharshi, modern Indian guru*

DO YOU KNOW THE EXACT moment you became a caregiver? Was it a sudden crisis or did your role evolve over time? Have you always been the one everyone counted on to help out, or was this role thrust upon you? Whatever the occurrence, what may have started as an acute, short-term condition has now evolved into a long-term, chronic situation and lifestyle. For me, it was three months after my husband's surgery, when we realized that he would not recover normal functioning, would not be able to return to work, and that he now had severe, debilitating nerve pain that interfered with all his activities and severely limited his ability to participate in life.

Most of us can handle anything for a limited period of time: running extra errands, spending time at the hospital, taking on extra responsibilities, making phone calls and appointments. Over time, though, having to reconfigure your days and even your nights can become an exhausting and overwhelming existence. Life is now filled with a never-ending stream of demands, needs, and obligations to someone else, or maybe even more than one

person, and it is nearly impossible to think about what else you might want or do.

You're caught in the loop of caregiving and have lost sight of your own needs, feelings, and desires. You've put them on hold until... who knows? Well, we're going to change that overwhelming cycle, and help you find your way out of fatigue and burnout to create fulfillment and empowerment. And, yes, it is possible to take your life back. It begins with one question: *What is my desired outcome?*

Your desired outcome must fulfill two major requirements:

1. It must be something you want, not something you *don't* want and
2. It must be something over which you yourself have control.

What is your desired outcome? is my favorite question, and as you go through this book it may become both your favorite and your most demanding question, one that always requires an answer.

Desired outcomes can be both long-term and short-term goals. They all require small, individual steps that you have to choose to take in order to make them realities. Every situation brings both challenges and opportunities if you are willing to take time to explore and examine what you want, need, and feel. Focusing on a *desired outcome* helps you create a laser-focus on steps you can take to achieve it.

It's important to become clear about what you want in order to move forward in your life with direction and purpose. Otherwise, you may end up floating or struggling through each day feeling

unfulfilled, empty, numb, or even depressed—not a very pretty picture.

This habit of blinding ourselves to what we need to feel happy, *right now*, is something of an epidemic in our modern society. How many times have you thought, *Someday, things will be better*, or, *Someday, I'll be able to do what I want*, or, *Someday I'll be able to relax and enjoy life*? How long have you been telling yourself those things, without ever reaching *someday*?

All too often, we are asked what we want, and the answer is “I don’t know,” or, “It doesn’t matter,” or maybe even, “I don’t know what I want, but I know I don’t want _____” (fill in the blank with one of an array of predictable sources of caregiver stress and frustration).

The reason we so readily flip the question to what it is we *don't* want is that most of us have not been taught that it's okay to *want* something. Many of us are taught that it's not *polite* to ask for something and that we should settle for whatever is offered and be grateful for it.

Many women have been taught to defer to their friend, boyfriend, or husband, especially after growing up dutifully deferring to their parents. Often, at best we are only vaguely aware that something is missing. We know there's significant stress or struggle in our lives, but we're not too clear on what we want that could help alleviate the problem, beyond the temporary Band-Aid of one less errand or doctor appointment... or maybe a nap. The story we tell ourselves is that this is all normal or that this is life, and who are we to expect something more?

As you read this book and do the workbook pages, you'll learn to come up with more long-term solutions that are directly based

upon your desired outcomes. A desired outcome gives you clarity and direction; even if you're not quite sure how to get where you want to go, a desired outcome gives you something to focus on. This is especially helpful when you're feeling overwhelmed by stress, guilt, and fatigue.

Dr. Martin Luther King, Jr. once said, "Faith is taking the first step even when you can't see the whole staircase." I can confidently predict that once you get clarity on your desired outcome, even if you have no idea how to get there, you will find that first step.

This book is going to open your eyes to new possibilities and new options. It is imperative that you learn to become aware of what it is you want. If you don't acknowledge what you want or need, unless you have someone in your life who is a mind reader, chances are you'll walk around feeling deprived, frustrated, upset, resentful, angry, or even all of these at once.

Let's move forward and change this storyline.

Is This You?

AS A CAREGIVER, YOU HAVE been committed to providing support, compassion, help, and care for someone in your life. If you've been a caregiver for a long time, then some truly significant and powerful habits and beliefs have already set in. Most caregivers, whether they came into this role by choice or by default, are compassionate, nurturing, and selfless individuals. If you are like them, you'd much rather do things for others than have others do anything for you.

You rarely, if ever, actively think about what you want, or need, though it may be a nagging thought or feeling in the recesses

of your mind. And when it does pop up as more than a vague awareness, you ignore it, deflect it, silently implode, or—for the moment—loudly explode, and then the cycle resumes. While not very pleasing or inspiring, this has been a pattern in your life. You put one foot in front of the other and just keep on going.

For most caregivers I have worked with, their number one desired outcome, after ensuring their loved one is safe and well cared for, is simply *to get a break*. Yet somehow, getting a break always seems so elusive. They tell me something inevitably pops up to interfere with satisfying even this modest goal.

More distressing, too often over time they start to feel permanently defeated. When there is something that they really want, or when they know they *need* something that seems vital to their health and well-being, even then they are stuck in an old belief and habit that reinforces, *Later, Never mind, It'll never happen*, or, *I'll get a break when _____*, or even the sarcastic, *Who am I kidding?* How many of these expressions of defeat and resignation sound like you?

Here's the reality of a desired outcome:

1. It has to be something you really want, and
2. In order to hope to achieve it, you first have to be aware of it.

Making any kind of change in your life requires conscious and specific acknowledgment of what you are feeling, dealing with, and experiencing. There is no room for minimizing, ignoring, or denying that stressful, overwhelming, and frustrating situations exist. It's time to use these moments as learning opportunities to bring in new awareness, new possibilities, and new outcomes.

Lucy's Story

WHEN I FIRST MET LUCY, she had been responsible for her elderly mother's care for a number of years. Initially, her mother's needs were minimal: primarily emotional demands, complaints about minor inconveniences, and an occasional doctor's visit. Lucy was accustomed to her mother's depressed and demanding nature, so she didn't consider how much of her emotional energy was drained during their interactions.

The result—feeling put out, somewhat annoyed, and frustrated—was a normal state of mind for Lucy. It wasn't until her husband pointed out that they hadn't had a free night or weekend in what felt like *forever* that she suddenly realized the magnitude of the intrusion into the other important areas of her life. Whenever Lucy came to see me she would sit rigidly on the couch, reflecting her intense need for the control that she was clearly not really feeling.

"I think my husband is being overly dramatic and demanding," Lucy told me during a session. Her response didn't surprise me. After all, their life seemed normal to her. Running on a regular basis to handle her mother's latest complaint, demand, or need was par for the course. Lucy hadn't thought about how she was feeling; she was used to a high, ongoing level of stress and tension, especially when it came to dealing with her mother. She hadn't thought about the impact her constant devotion and involvement with her mother had on her marriage and herself.

When I first asked Lucy what her desired outcome was, she said, "I want my husband to be more understanding. It's not like

my mother will live forever, and she's all alone—there really isn't anybody else to help out.”

I explained that a desired outcome had to be something over which she, herself, had control and her husband being more understanding didn't fit that criterion. Deep breath... So, what was it Lucy wanted? It had been such a long time since she had thought of her own wants and needs, it took her a long time to answer that question. She sat quietly, seemingly holding her breath, and her dismay became evident as tears flooded her eyes.

“My mother really is taking up all of my free time. I can't believe I couldn't see that, and that I didn't notice my husband felt deprived and annoyed,” Lucy said finally. At last she acknowledged to herself that there was a real problem. “My desired outcome is,” she continued, “I want some time to myself, when I don't have to take care of anything for my mother.”

Now that Lucy was aware of the stress and tension that her husband felt, she became aware of her own feelings regarding the time and care that her mother demanded of her. It's not that Lucy wasn't feeling this before, it's that she was so used to living with the ongoing stress and tension that she hadn't allowed it to come into her conscious awareness. She was so worried about everything that her mother needed that she hadn't taken time to think about what *she* might want or need, or that *her* habits *actually mattered* to someone else, especially her husband.

It can't be stressed enough how very common this issue is for caregivers, and that it is something you really can change going forward.

Oftentimes, until you stop and check in with yourself and how you're feeling, autopilot takes over. Asking yourself, *What is my*

desired outcome? helps to create conscious awareness. This is critical in the change process in order to break old habits and beliefs. Do you want to? Do you feel ready to embrace the truth that your needs, feelings, and wants really do matter?

Even if, at the moment, you do not know what you specifically want, focus on allowing yourself to feel relaxed, peaceful, empowered, and maybe even deserving of some free time in your life. As you go through this book, you will learn that you have choices and do not have to simply accept what is and what has been.

Being open to and embracing change is not easy, but every challenge you face in life that you don't automatically dismiss or shy away from helps you to learn, grow, and evolve. Take a deep breath and give yourself permission to face and overcome the habits and patterns that have become your life as a caregiver. It's normal to feel fear when embarking on something new in your life, but fear does not mean *Don't do it*. It means, *Proceed with awareness and with conscious purpose*. You can now consciously choose how you want to care for yourself while you are still caring for others.

Lucy was able to awaken to new possibilities in her life, including spending more time with her husband, exploring new options for handling her mother's needs and demands, and recognizing that she needed to take better care of herself. Lucy actually smiles now; she can sit relaxing on the couch as she shares stories about time with friends and weekends with her husband, and she breathes more easily as she describes not running in response to every demand her mother makes.

Lucy says quite frequently, with awe in her voice, "I cannot believe the change in me and in my life." She says that she still

shakes her head in gratitude that she can enjoy some of her visits with her mother as well. As Lucy put it one day, “What a concept!”

Asking yourself, *What is my desired outcome?* and taking the steps that follow in this book is where self-care begins: within yourself, in your heart, in your mind and in your soul.

My desired outcome for this book is to provide you with strategies, tools, support, and encouragement that you can use, so that you really can take as good care of yourself as you do of others in your life. You deserve this, and now is the time. Remember, it’s only too late if you don’t start now.

And we breathe...



Chapter 1 Worksheet

What is Your Desired Outcome?

1. List my desired outcome(s). "I can take as good care of myself as I do of those I love and care for." My desired outcome has to be what I want and has to be something over which I have control.

2. What are the circumstances or situations that interfere with my desired outcomes and how are they contributing to the ongoing cycle of deprivation, overwhelm, and guilt?

3. What changes am I willing to implement in my life that will reduce or eliminate my feeling overwhelmed, stressed, and burnt out?

4. What specific beliefs do I hold that contribute to the cycle of deprivation, overwhelm, and guilt?

5. What new beliefs am I willing to embrace and practice to end the cycle of deprivation, overwhelm, and guilt?

You can download the Caregiver's Step-by-Step Guide or see Appendix 1 to help you on your journey of learning to take as good care of yourself as you do of others in your life. You can find the guide at TakeBackYourLifeGuide.com.

More Tools for Change:
Emotional Freedom Contract with Myself
*My reminder to take as good care of myself
as I do of others... I matter*

I, _____, RECOGNIZE MYSELF AS an adult with options and choices and I commit to the process of actively taking care of myself with respect, consideration, and compassion. In order to achieve this desired outcome, I make the following promises to myself:

1. I promise to *Stop! Breathe!* and *Focus!* so that I am better able to choose to ask for and expect the respect I deserve, and better able to see how I allow others to treat me.
2. I promise to respond to situations with clarity, respect, and love for myself, knowing that each time I am able to do this, I am one step closer to living my truth, that *who I am is enough*.
3. I promise myself that when I slip into old habits along the way, I will *not* beat myself up. I will learn and grow from the experience.
4. As I work through this process of taking my life back (and beyond), I promise to treat myself with the love, respect, and compassion that I deserve.
5. I promise to recognize the importance of caring for myself and focusing on my desired outcomes while respecting others' feelings and opinions.
6. I promise I will acknowledge and appreciate myself for each positive step along this journey, no matter how small each step may seem.
7. I remind myself each and every day that I can and do cope with the circumstances in my life with empowerment, *not* martyrdom.

In moments of stress, tension, and uncertainty, especially when interacting with others, take a deep breath and say the following:

*I treat myself with the love, respect, and acceptance I deserve
and I teach others that I expect the same from them.*