

Juggling Life, Work, and Caregiving

Amy Goyer

As
seen on
**CARING FOR
MOM & DAD**
on Public
Television



Real Possibilities

Juggling Life, Work, and Caregiving

Amy Goyer

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Introduction

My Caregiving Journey

I've been a caregiver my entire adult life.

First I helped care for my grandparents. Then I helped with my mom when she had a stroke at age 63, some 25 years ago, making frequent cross-country trips from Washington, D.C., to Arizona. But when Dad showed increasing signs of Alzheimer's disease in 2008, that wasn't enough. So I adapted my work, choosing jobs that let me telecommute, and began working from Arizona a week or two a month.

When Dad stopped driving and my parents, with their service dog, Jackson, moved to a senior-living community, they needed even more support. So I reversed my life, basing myself in Arizona. I moved into the house they moved out of, worked from home, and began traveling to the D.C. area a week or so a month, where most of my work is based and where most of my friends and my boyfriend live. As my parents' health changed and they needed 24-hour care, though, they couldn't afford to stay in the senior community, so they moved back into the house with me. I rented an office nearby and hired a professional live-in caregiver. To augment that support, my sister Linda comes from Ohio to help as one of our paid caregivers when I am away on business travel. She plans to eventually move to Phoenix to take on more of the care. Susie, my sister who lives in Los Angeles, comes when she can to help. Karen, my oldest sister, lived in Maryland and developed Cushing's Disease. I became her

long-distance caregiver; yet even when she was very sick, she helped as best she could by calling every day.

In January of 2012, we lost my niece Shalee to suicide after her long battle with bipolar illness. In October of 2013, Mom passed on. We miss her terribly. Dad's Alzheimer's disease continues to progress, and it's much harder for him to stay oriented without Mom. She was his north star. Then in December 2014, my sister Karen passed on. Grief and loss have been devastating and unceasing elements of our caregiving journey.

How do I manage my role as a caregiver? I've always been organized, but I've learned to be even more efficient. I'm getting better at mindfulness, fully focusing my attention on whatever my task is at that moment—helping Mom comb her hair, singing with Dad, writing a blog post, or giving a media interview. I'm fortunate because I am in the field of aging and families, working with clients who truly get it when it comes to caregiving. They tend to be extremely flexible and understanding about all that I'm juggling and the odd hours that work gets done.

Have I missed opportunities and struggled with the unique challenges of being self-employed? Absolutely. Have I sacrificed aspects of my personal relationships, hobbies, interests, and health? Indeed. Am I sometimes frustrated and overwhelmed? Yes. But here's what sustains me: I believe that I'm doing the right thing, and I create and notice joy in the act of caring for others. Every day I've made a conscious *choice* to care for others, especially my parents, just as they have cared for our family, so I've adapted my work and personal goals. People ask me how I do it; I wonder, how could I *not* do it? I wouldn't have it any other way. I succeed because I want to and because I believe so strongly in what I'm doing.

In my heart of hearts, I know that I'm growing and benefiting from this experience too. Perhaps the most important lesson I've learned is that my goal as a caregiver is not to prevent change; it will invariably happen. My goal, instead, is to ride the waves of change. I am increasingly aware of what I can control and the ways in which I am powerless. My true success as a caregiver lies in being resilient and being fully, lovingly present with my loved ones in this unpredictable journey.

Are You a Caregiver?

At any given time, more than a quarter of the U.S. adult population—some 42 million people—are caring for adults. More than eight out of ten are caring for friends or relatives over the age of 50, according to a 2011 AARP Public Policy Institute study, “Valuing the Invaluable.” The estimated economic value of their annual unpaid effort is \$450 billion—more than the total annual sales of Wal-Mart stores! If you’re a caregiver, you are making a valuable contribution.

- The statistically typical family caregiver is a woman, age 49, who is caring for her mother. She provides 20 hours of unpaid care per week and does so for nearly five years. She also holds down a paid job.
- Sixty-five percent of family caregivers are women.
- More than half of caregivers are involved in medical/nursing tasks—including caring for wounds, managing numerous medications, and dealing with incontinence—for those with multiple chronic physical and cognitive conditions.
- Nearly half of U.S. family caregivers are caring for loved ones with Alzheimer’s or serious mental illness (cognitive or behavioral health disorders). The number of people with Alzheimer’s disease will nearly triple by the year 2050.
- One in five family caregivers is a spouse or partner, and compared to other family caregivers they are often more vulnerable, have fewer resources, and get less help from family and friends.
- Ten percent of family caregivers are African-American; about half of African-Americans are or have been family caregivers.
- Eleven percent of family caregivers are Hispanic; more than one in three Hispanic households includes a family caregiver.
- As Baby Boomers age, family caregivers will increasingly have fewer people to share the care. In 2010, there were seven potential caregivers between the ages of 45 and 65 to care for one person age 80 or older. By 2030, that ratio will decline sharply to 4:1 and by 2050, 3:1.
- Family caregivers are vulnerable and at risk themselves in terms of their finances, mental and physical health, relationships, and careers.

Many of us are primary caregivers: We lead the support team for the people we care for and often provide most of the care and coordination. Others play a role as part of the caregiving team with family, friends, paid professional therapists, health-care practitioners, and care providers.

You may not think of yourself as a caregiver per se. But if you help out with, provide support for, care for, or check up on a friend, neighbor, parent, spouse, grandparent, or other family member or loved one, you are indeed a caregiver. Whether you do these things every few months, once a week, or every single day, you are a caregiver. Whether you are the only person providing support or you share responsibilities with others, you are a caregiver. If you ever do any of these things to help loved ones, you are a caregiver:

- Help with household tasks, such as cleaning, doing repairs, and caring for the yard.
- Chauffeur them to stores, doctors, faith-community meetings, volunteer activities, the senior center, friends' or relatives' homes, or restaurants.
- Help with researching health conditions and treatment options and making health choices or medical decisions.
- Advocate or provide care in a health-care crisis, such as a hospitalization.
- Order and pick up medications.
- Perform complex medical tasks, such as caring for wounds and giving injections.
- Sort mail.
- Pay bills.
- Oversee investments.
- Understand insurance coverage and manage claims.
- Monitor or help with bathing, toileting, grooming, and dressing.
- Buy groceries and run other errands.
- Prepare meals and monitor nutrition.
- Explain, coordinate, and handle complicated personal, financial, or business matters.
- Help them make decisions about where to live.

- Cover their expenses.
- Coordinate unpaid and professional paid caregivers, therapists, or other support.
- Provide emotional support.
- Initiate or receive phone calls to check in.
- Visit them to see how they are doing.

You may have started helping just now and then, increasing your support over time. Or you may have become a caregiver instantly because of a crisis. You know caregiving is becoming a big part of your life when—

- You squeeze in other friends and family members, recreational activities, exercise, your own medical appointments, and even work only if you find time *after* you take care of your loved ones.
- You are more familiar than they are with their health, finances, and personal affairs.
- You are so worried about their needs that you become anxious and even lose sleep.
- You have their birth dates, Social Security numbers, and insurance information memorized.
- You are on a first-name basis with their pharmacist.
- You are greeted at the hospital emergency room with “welcome back!”
- You are tired from the juggling and the emotional toll. All the time.

If you’re doing these things while working a paid job—full-time or part-time, ongoing or seasonal, in an office or factory or store or from home—you are a working caregiver with an extra level of demands. And each aspect of your life comes with a unique set of circumstances to juggle. (You’ll find specific resources for working caregivers in Chapter 5.)

A Community of Caregivers

You are in the company of millions of other caregivers, whether you know it or not. The community of caregivers that I’ve cultivated has been the

driving force keeping me going. Throughout this guide, I tap into this community to help you navigate your journey of caregiving.

For many of us, caregiving is a gift of love; others struggle with difficult relationships but still step up to the plate because they feel responsible. Regardless of the motivation, we all struggle at times, and we also have a lot to learn from one another. Our situations may be similar or not, but either way we are each other's most valuable support. I encourage you to connect with other caregivers—talk with your friends, join a support group, or go online through social media such as Facebook or Twitter or online support groups and caregiving websites.

Your Job Description

If you have working experience in paid or volunteer jobs, you've likely had a job description. Your job as a caregiver is just as important. Sometimes you get experience on the job or through trial and error. But caregiving requires hard-earned skills, and you have them all! Look for job descriptions at the end of every chapter in this guide, updating the talents and abilities you hone throughout your tenure as a caregiver. Congratulations—you have earned the title caregiver. Here is your overall caregiving job description.

Job Title: Caregiver

Reports to: Self, conscience, care recipients, primary caregiver or team leader, employer (if working), higher power.

Hours: Unpredictable; days, evenings, nights, weekends, and holidays.

Qualifications: None required but many preferred: compassion, caring, love, patience, stability, humor, humility, ingenuity, energy, commitment, tenacity, strong communication and observational skills, proficiency with technology and medical/legal terminology, ability to perform medical/nursing tasks, attention to detail, organizational skills, and excellent crisis management abilities.

Summary of duties and responsibilities: Assists with or manages loved ones' mental and physical health and care, legal and financial matters,

living environment, business matters, activities of daily living (ADLs), and quality of life; serves as advocate for those who are vulnerable. Other duties as assigned with no prior notice. Juggles caregiving with duties and responsibilities from family, personal life, and paid or volunteer work.

Special and challenging demands: Prolonged commitment; sleep deprivation; financial uncertainty; exposure to intense emotions, from great sadness to great joy; precarious personal relationships. Some travel may be required.

Pay: Salary range from \$0 to personal rewards such as a clear conscience, smiles, hugs, appreciation, and lots of love. (Some family caregivers may be paid—see Chapter 5.) Potential for bonus of good karma depending on duties performed.

In This Guide

This guide aims to provide you with practical resources and tips that will help you be successful too. Whether you're caregiving day-to-day, planning for future needs, or experiencing a crisis, the resources in this book will be quick and easy to find when you need them. Here are some topics you'll learn about:

- **Reviewing your current situation.** I help you take a 360-degree look at yourself and the people you care for. You'll get a clear picture of needs and resources and create a preliminary plan of action.
- **Caring for yourself.** You may *understand* the need to care for yourself so that you'll be able to care for others, but taking the time to do so is another story. You'll find tips for infusing much-needed time and energy into your own interests and needs.
- **Creating a caregiving team.** No one is caregiving in a vacuum; we all need somebody to lean on, right? Whether you can see it or not, you have—or can form—a team to help you, with team members contributing what and when they can. I help you build your team.
- **Getting—and staying—organized.** Organizing my personal, work, and caregiving lives is the only way I stay sane. You'll learn about

low- and high-tech ways to organize paperwork, information, and environments to save you time, money, and energy.

- **Balancing work and caregiving.** You'll get the scoop on communicating with your employer, taking full advantage of employer benefits such as flexible work schedules and counseling, keeping your career on track, and managing work-life balance.
- **Navigating the legal maze.** Better to deal with tricky legal issues early on than wait for a crisis. I help you understand, in plain language, the basics, including advance directives, powers of attorney, and estate planning.
- **Managing money matters.** From budgets and bill paying to bank accounts and debt, you'll learn to discern when the people you care for need help and how to take steps to increase income and lower expenses.
- **Handling health and medical care.** I spend 90 percent of my caregiving time dealing with health and medical issues. I help you navigate the rough waters of helping your loved ones get and stay happy and healthy (and hopefully *prevent* doctor appointments!), and I offer tips on how to manage complicated medical scenarios.
- **Dealing with living situations.** The people you care for may live in their own or relatives' homes, senior communities, group homes, or independent living, assisted living, or nursing facilities. I help you evaluate their living situation and manage care wherever they live.
- **Getting through a crisis.** Sooner or later, most caregivers deal with an emergency. Crises may occur regularly. You'll find ways to prepare that should decrease your stress in the long run. And I help you manage when you're in the middle of a catastrophe.
- **Experiencing the end of life.** For many of us, caregiving isn't a "short-term and then they get better" scenario. It's a journey that often leads to the end of your loved ones' lives. I provide you with information and resources about how to support the people you care for sensitively through their final days—and how to get through it yourself.
- **Grieving and moving forward.** At some point, your role as a caregiver will probably change. It will transition into a different role

because loved ones get better or move or other caregivers step in. Or it will end because your loved ones pass on. Either way, you may experience a sense of loss, guilt, and myriad other feelings. I help you deal with these changes and find your way to the next phase of your life.

- **Finding help.** In addition to helping you connect with other caregivers, I help you draw on a network of national, state, and local organizations that exist to assist caregivers. And I point you to professional caregivers and other services that may be needed for complicated personal, financial, and legal issues. This guide will help you choose the right people to help you *and* the people you care for.

In addition to this book, you may also want to consult *Checklist for Family Caregivers: A Guide to Making It Manageable* by Sally Hurme, also from AARP and the American Bar Association (AARP.org/ChecklistCaregivers). A companion guide to this book, *Checklist for Family Caregivers* walks you through getting and staying organized.

CHAPTER 2

CARING FOR YOU, THE CAREGIVER

I lay there wide awake in the roll-away bed, springs from the mattress poking me between the ribs. My chest felt tight, my heart was pounding, and I struggled to breathe. I just wanted to sleep, but my body wouldn't calm down. I got up and stretched, walked the hall a few times, sniffed lavender essential oil, and practiced a calming meditation. Nothing worked. The flashing lights didn't help much. Nor the constant beep-beep-beep of the machines. I began to panic.

I'd lost track of how many nights I'd slept next to Mom in her hospital bed—30? She'd had a bad fall and fractured her spine, developed an irregular heartbeat, contracted a horrible intestinal infection (C Diff.) in the hospital, gone into congestive heart failure, suffered a heart attack, became septic (her whole body, including her blood, was infected) . . . the list went on. She'd been through the wringer, and I'd been by her side almost the entire time. With my panic symptoms persisting, I began to wonder if I should walk down to the emergency room and get myself checked out. Maybe I was having a heart attack.

I eventually got a little sleep that night. But the incident scared me, so I went to see my doctor right away. Her diagnoses: stress to the point of burnout resulting in anxiety, insomnia, and exacerbated asthma. My body was reacting to the extended and intensive stressors of staying with Mom, making decisions about her care, losing sleep, worrying about her pain,

fearing for her life, managing Dad's care and working at the same time. That night was a wake-up call for me. We all do what we have to do in crisis situations, but sooner or later we suffer the consequences. I knew I needed to take better care of myself.

Introduction

Let's face it: Caregiving can be a very rewarding experience, but it can also be draining. As caregivers, we give and give— so it should come as no surprise when we crash. Your intentions may be good, but if you don't take care of yourself, you will not be as good at taking care of someone else or, if you're also working a paid job, performing work duties. Think of the oxygen-mask analogy: First put on yours and then help those in need. You may feel at the mercy of the needs of your loved ones, but always remember: You do have choices. You've *chosen* to care for friends or family members, and you can also choose to take care of yourself. It's not an either/or decision. Look at yourself as you do your loved ones; you are equally important in the equation, and as a caregiver you are also vulnerable. What are your basic needs? What do you need to keep going? I often remind myself that I don't expect my car to run on an empty tank of gas, but I seem to expect myself to run on an empty tank of energy. What are you doing to keep your own tank full?

In this chapter you'll learn how to:

- Understand the wide range of emotions that working caregivers feel.
- Recognize stress and how it affects you.
- Develop coping mechanisms to deal with difficult emotions and stress.
- Find help so you can take a well-deserved break.
- Keep your finances in order and your career on track.

The Emotional Roller Coaster

Being a caregiver can be physically depleting, but I find that dealing with the emotions is my biggest challenge, especially when I'm tired (which is most of the time). Our minds and hearts can feel so depleted; we're weary to the bone. I want to be tough and not let things get to me, but sometimes I have a meltdown. We caregivers may look OK on the outside, and people marvel at us—what wonderful caregivers we are, how much we get done, how we keep doing our jobs while we are caregiving—but in reality we're not sure how we will make it through the day. It's total internal overload. And that's OK. Be gentle with yourself. Whatever you're feeling—and you're probably experiencing a range of feelings—is normal.

Love, Joy, and Happiness

First, keep in mind that caregiving is not all about difficult emotions. Happiness, love, warmth, closeness, and contentment are a vital part of our caregiving experience. I have worked very hard to create moments of great joy with my parents, as well as to be mindful and notice the more subtle everyday joys. I'll never forget the elation I felt when Mom took her first tentative steps after the surgery for her fractured spine—we had worried she might never walk again. Every time I enjoy a beautiful sunset with Dad, I feel tremendous peace and gratitude. I have felt happiness when we sing or play a game together. The smile on Mom's face as I tucked her into bed is still ever-present in my mind, and I'm so glad I stopped to enjoy that moment every night. Every time Dad relaxes and is visibly relieved when I come home to be with him fills me with a deep sense of love and the knowledge that I'm doing the right thing. Just knowing that I have helped my parents, who have done so much for their family, brings me a great sense of fulfillment. These are my caregiving triumphs, and I treasure them. These emotions are so real and significant, and yet we tend to give them short shrift.

Frustration and Anger

Frustration and anger come up often when we spend numerous hours dealing with the medical system and service providers. We may feel frustrated,

resentful, hurt, and disappointed when members of our caregiving team don't live up to their responsibilities or support us. We may feel frustrated and angry with ourselves, too, when we make mistakes, don't get our work done, or forget things. If we are working while caregiving, we may feel frustrated with co-workers who don't understand the burdens we bear or, worse yet, do understand but just don't care, or make our work lives more difficult.

And often we lose patience or feel incredibly angry at the people we are caring for, perhaps when they give up or don't try to get better, complain, are difficult to please, or don't seem to appreciate or value us. We may get frustrated because they are dependent upon us and keep us from other parts of our lives. For some of us, our loved ones cause financial strain. Those caring for people with dementia may get frustrated when they repeatedly ask the same question or fail to understand what we are trying to convey.

Guilt

Once we've experienced anger at the very loved ones who need us so much, then the guilt kicks in. Guilt is our constant companion. We feel guilty when we are not with those we are caring for because we are working, taking care of ourselves, or spending time with other people. Yet when we are with our loved ones, we feel guilty because we are not doing those other things. We worry about decisions we make for the people we care for and feel guilty if things don't turn out the way we had hoped. We feel like we never do enough. We even feel guilty for feeling guilty!

Sadness

Inherently, caregiving is a process of loss. When our loved ones need support, it's never for a good reason. Even if it's temporary, they are experiencing changes that prevent them from complete independence. Whether the change is small, such as the inability to clean the house, or overwhelming, as for those who have dementia, it's still a loss. And for many, a slow process of loss continues over a long period of time. I often liken it to water torture—my parents' abilities slowly declining, one drip

at a time. One small drip doesn't get to me, but over time it eats away at me and periodically sadness overwhelms me.

Discouragement

We often feel inadequate or incapable of handling caregiving tasks. We may feel discouraged or disheartened when we are unable to keep up with all that is on our plate. Sometimes we may even see ourselves as complete failures.

Fear and Worry

Caregivers have a lot to fret about. We know worrying doesn't help, but that doesn't stop us. We worry about making decisions and what will happen "if." We agonize about the future, the bills that must be paid, and the needs that must be met. We fear the loss of our loved ones, and yet we fear that caregiving will go on and on. We panic when we realize that someday we may also need this type of support; we wonder who will care for *us*.

Powerlessness

This is, perhaps, the most challenging emotion of all. We feel unable to stop the progression of a disease or solve the financial problems, unable to find the right treatment or medication to ease our loved one's pain, unable to stop the changes happening all around us, and unable to get everything done. The sense of powerlessness can be overwhelming, and it's difficult to accept that we cannot control everything.

Recognizing Stress

Believe it or not, stress is actually not all bad! In fact, there are many good stressors in our lives. Stress is simply your body's reaction to what is going on both internally (your emotions and thoughts) and externally (caregiving, your job, a sports event, a wedding). You may react positively to stress, from the simple drive to get out of bed in the morning to the excitement of winning a new account at work. Or you may react negatively, when you feel anxiety or despair as you witness your loved

ones losing their cognitive or physical abilities. Positive stress may be seen simply as motivation: it is necessary for survival. Negative stress may be viewed as distress.

But our bodies can't differentiate between good and bad stress. Too much or prolonged stress of any kind can have negative consequences. It can suppress the immune system, cause headaches and tense muscles, overload your brain, and eliminate your sex drive. Our bodies store fat in reaction to stress, as if we are about to face a famine, making it harder for us to lose weight. Stress can undermine our emotional stability, causing panic attacks, insomnia, anxiety, and depression.

Between the never-ending set of strains of our paid jobs and our caregiving demands, it's no wonder we have stressful lives. Most of us have no idea how long the high stress levels will continue. So be aware that stress is a part of your life and watch for negative physiological or emotional symptoms; they're red flags that you need to make some changes before you have a catastrophic health situation to deal with on top of working and caregiving.

Burnout

In the extreme, stress results in burnout. As caregivers, we give and give and give. The prolonged stress builds up, we are robbed of energy, and sometimes we reach a point of total emotional, mental, and physical exhaustion. We may lose motivation completely or feel we just don't care—about our loved ones' care, our other relationships, or our work. We may feel that we've lost ourselves in the vastness of caregiving. Hopelessness is a hallmark of burnout—the feeling that nothing we can do will make a difference. We may see drastic changes in our health, including constant, severe fatigue. The inability to perform routine everyday tasks is also a red flag. If you feel like this most of the time, or you feel yourself shutting down, you may have reached burnout. Some caregivers are so depleted that they simply walk away from their loved ones without a backup plan. Be sure to reach out for help if you are experiencing burnout.

Learning How to Cope

You can't avoid the emotional roller coaster or the stresses of caregiving. If you try to hold your feelings in, they will likely come out suddenly and unexpectedly anyway. If you ignore stress building up, you'll likely suffer the repercussions emotionally and physically sooner or later. But caregivers have found many healthy ways to cope with these challenges.

Monitor Your Mind-Set

Acknowledge Emotions

Often emotions bubble up when you can't safely express them in healthy ways—maybe you're in the middle of caregiving, in a crisis, or at work. When that happens, you may have to contain your emotions temporarily, but don't deny them. Take deep breaths and actively acknowledge to yourself what you are feeling. If you can and it helps, quickly write your feelings down or share them with a trusted friend or relative.

Be Mindful

Caregivers are constantly multitasking and feeling distracted: We worry about our loved ones when we are grocery shopping or performing a task at work; when we are helping our loved ones with personal care, we worry about tomorrow's appointment or myriad other things. While multitasking can be useful at times, studies show that too much distraction leads to inefficiency. Practicing the technique of "mindfulness"—focusing fully on the current moment—has lowered my stress levels a great deal, and I get more accomplished in the long run. It also lets me experience each moment with my loved ones more fully. I notice more joy when I'm aware and mindful, and that helps me cope.

Ask Yourself Whether You're Operating from Fear or Love

When you experience difficult emotions, ask yourself if they're coming from a place of fear or love. If they are fear-based, try to view the situation from a place of love—for yourself and others—and see how your emotions adjust. One day, I got incredibly anxious and angry when Mom's doctor's office performed a lab test incorrectly. When I stopped

to evaluate my response, I realized I was coming from fear: The bottom line was I was terrified that she would get sicker, and I was desperate for answers and a course of treatment. I shifted to a love-based motivation, calmed down, and focused on getting her well. The anger dissipated, and I was able to reschedule the test. This process kept me moving forward and brought me a sense of peace.

Remember Why You Made the Choice to Care

Love, a sense of responsibility, the desire to do the right thing or give back—these are some of the reasons you are here. Even if you feel obligated or forced into caregiving, in actuality everything is a choice, so you *have* made a choice to do so—you could have walked away (some people do). Sometimes consciously revisiting the choice you've made can empower you and help you feel good about what you are doing, even when it's stressful.

Know What You Can Control

If you accept the fact that, in reality, the only things you have control over are your own behavior, reactions, and choices, you'll save yourself a great deal of stress. You can't control other people's motivations, consciences, actions, or choices. You cannot change others' personalities or lifetimes of behavior patterns. You cannot come up with all the answers, cure your loved ones' illnesses, or check off everything on the list. But you can control your own attitude.

Choose Positivity

When I begin to fall into the abyss of emotional despair, the thing that works the best for me is to replace negative with positive feelings. When I feel overwhelmed with all that I've not accomplished, I list things I *did* get done for my parents or my job. When I feel sad about Dad losing his cognitive abilities, I think about how great it is that his personality is still basically the same and that he can still experience happiness. When I feel stressed about an upcoming work deadline, I think about all the deadlines I've met and how much work I've accomplished since I started caregiving. When I feel discouraged about solving one of my parents' health

challenges, I fix my sights on the rewards of caring for them. Yes, it's a conscious choice to switch to the glass half full. Sometimes it's a struggle, but it always makes me feel better and more able to press on.

Don't "Should" on Yourself

You are a caregiver, not a saint. As much as you try, you will never be perfect. You may always feel there is more you "should" be doing. But Anne Samaan, a wise friend who cared for her husband with Alzheimer's disease for more than 20 years, told me repeatedly: "Don't should on yourself." Second-guessing your decisions is simply unproductive; you know you can't go back. And piling on a list of additional tasks that you should be doing only leads to guilt. That doesn't mean you should be selfish, absolve yourself of responsibilities, dump the care on others, walk away from those who need you, and have a devil-may-care attitude. Just do your best and allow life to flow—it will be what it will be, and you will have a clear conscience.

Monda DeWeese, executive director of a correctional facility in Ohio, was primary caregiver for her mother, who battled Alzheimer's disease for many years. Monda says trying to meet the needs of her mom as well as those of her husband, teenage daughter, and job often felt insurmountable. "Attempting to be truly present in each aspect of a sandwich generation life is a challenge for a working caregiver," she says. "Some days it can feel like there is always some area that is shortchanged. Making peace with that feeling, realizing that you are doing the best you can, making the most of where you are and who you are with, is the only way that you, as well as those around you, receive the gift of your presence."

Know Your Best Outlets

Keep a Private Journal

Writing about your feelings, daily events, and the joys and challenges of caregiving can be cathartic. You can keep a handwritten or electronic journal. Articulating all the positive and negative emotions in one place can allow you to move on.

Use Technology

Write a blog, post on a social media venue such as Facebook or Twitter, or share with an online support group or message board. But when you do, remember that your post lives forever. Be judicious about what you share and who might be hurt by what you post. Posting your emotions about a sibling who won't help may get back to him or her and make the situation worse.

Talk It Out

Someone who is not deeply involved in your caregiving situation may be the ideal sounding board, but for some, a relative, spouse, or partner can play this role. You want someone who knows how to listen supportively without giving advice or judging. I know which friends can handle a quick call when I just need to vent—they are on speed dial!

Get Moving

The mind-body connection is a reality; you can help release your stress and overflowing emotions through your body. I talk more about exercise later in this chapter, but I want to mention a few quick suggestions here. For some, a vigorous workout or run does the trick. For others, dancing or aerobics lifts their spirits and works out emotions. Walking is an excellent, easily accessible way to ease stress, clear your mind, and boost your energy. This is one outlet you can often use with other people, including the loved ones you care for. Dad used to love going for a quick walk with me, which was good for both of us. (As his Alzheimer's progresses, he isn't as excited about taking walks.) And when I feel especially stressed out, I often just stop where I am and do squats, jumping jacks, or punch the air. It works!

Maintain Your Identity

Nurture Yourself

You have spent a lifetime developing your own identity—but it's easy to get so engulfed in caregiving that you lose yourself. Think about all the great things you laid out in your self-assessment in Chapter 1. You are a fantastic individual. Don't lose those important components of the most

important person in your life: you. Take time to do things that nurture your soul, stimulate your personal growth, and excite you. It's absolutely necessary to keep your own tank full of energy.

Cultivate Your Interests and Hobbies

You may have to sacrifice some of your activities to fit in the demands of working and caregiving, but strive to engage in things you like to do at least occasionally to maintain balance in your life. If you find yourself often feeling sad and saying, "I used to like to do that, but I don't have time anymore," that's a clue you need to *make* time. And yes, you probably can make time.

Cultivate Your Relationships

Your relationships with your friends, spouse or partner, children, grandchildren, siblings, and other loved ones are part of who you are. As caregiving increasingly takes up your time, these relationships are often the first things to suffer. You may feel emotionally drained and unable to give in any other relationship. Your schedule may be so jam-packed you do not have time to make a phone call, much less spend a relaxing evening with those you love. Furthermore, they may not be able to identify or understand the extent to which you are barely able to keep up with the basics of your life. Realistically, something's gotta give! Still, do your best to stay in touch, prioritize time together, take vacations or breaks together, and be there for these important people. When your caregiving comes to an end, you'll want them in your life.

Sustain Your Professional Identity

If you work a paid job, volunteer, or have a hobby that you've been devoted to, your identity in those realms can be a great comfort. There are times when all caregivers feel inadequate or incompetent: We are not all trained or fully prepared for the tasks and challenges of caregiving. Balancing those feelings with the competence we feel in other areas of our lives can boost our confidence levels.

Watch Your Health

Sleep

I'm convinced that sleep deprivation is the biggest enemy of caregivers. When we are tired, we are robbed of the ability to cope, and we can't adequately process the myriad emotions we experience—we simply don't have the reserves to deal with them. Our cognitive functioning is also depleted, affecting our work and our ability to make good decisions. If you are not sleeping because of anxiety and worry, you might want to seek professional help from a therapist or doctor. If you sleep well but not enough, then it's time to adjust your work and caregiving schedules. When Mom came home from rehab after her fall, she was up every two hours all night long. Since it wasn't safe for her to go to the bathroom by herself, I got up with her. After two months of sleep deprivation, I could hardly function. I finally began to pay professional caregivers to take the night shift a few days a week so I could sleep. It was miraculous what a few good nights' sleep a week did for me in all areas of my life!

Eat Well

You're an on-the-go caregiver, and I bet you sometimes substitute quick-and-easy eating on the run, snacks, and comfort food for healthy meals. I gained a great deal of weight when I started intense caregiving for my parents, and I know I'm not alone. As I mentioned before, weight gain for caregivers isn't just about not eating well; it also can be about our body's reaction to stress levels and lack of sleep. Still, we know that letting our nutrition go is the first step on a downhill health slide. We have control over what we put in our mouths, so why don't we choose better for ourselves? Here are a few ways to approach our nutrition needs:

- Consult a nutrition professional. You don't always need to pay a lot of money on an ongoing basis to get results. One or a few consultations might be very helpful for you to identify negative eating patterns and get yourself back on track nutritionally.
- Join a group. Caregivers tend to find each other when they join Jenny Craig, Overeaters Anonymous, Weight Watchers, or other groups

focused on healthy eating. Many find the one-on-one support incredibly effective.

- Keep a food journal. Write down everything you eat for a week or two. You'll become much more aware of where the calories are coming from.
- Attend a nutrition seminar. Learn all you can about healthy nutrition.
- Address the psychological aspects of nutrition. Why do you eat the way you do? How are you handling stress? Are there triggers in your caregiving or work life that spur you to unhealthy eating? A food journal could help here, too. Next to what you eat, write down why you're eating—whether it's actual hunger or a response to emotions or stress.

Exercise

Staying physically active is vital to all aspects of your health, including your brain health. You need your full strength and a strong immune system when you're a caregiver. But regular exercise is one of the first things to drop off the list when work and caregiving converge. Find a regimen that works for you. Some get up early in the morning to work out; others exercise on their lunch hour, after dinner, or in short breaks throughout the day. Try armchair yoga, or stretchy bands for resistance, which are easy to stash in a desk drawer or suitcase if you travel for work. I try to work exercise into time I spend with Dad because he loves it and we can do it together, adapting difficulty for both of our abilities. If your workplace offers a gym, a trainer, discounts to health clubs, or other incentives to exercise, take advantage of them!

Visit Your Doctors

You may find yourself putting off your annual physical, vaccinations, and dental and vision appointments. After all, the people you care for are more vulnerable, and therefore their health needs are more important, right? Wrong. Studies show that the stress of caregiving makes you more vulnerable as well. I find that if I schedule regular doctor appointments ahead of time—even a year ahead—I am more apt to keep up with them. Get out your calendar and schedule those visits!

Be Practical

Set Limits

The needs of the people we care for can be so great that when we strive to meet them all, we set ourselves up to fail. Or maybe you have an employer that will keep taking and asking for more of your time than is reasonable. We all have to develop boundaries, and knowing our limits is something that is learned over time. Start by noticing when you feel uncomfortable about giving more than you really have to give. Think about setting some boundaries around your time as well as your responsibilities. Be clear when you've reached your limits at home, at work, and in your caregiving role. You can also set limits in your leadership role in caregiving—perhaps you don't mind being the primary caregiver, but that doesn't mean you have to do everything; learn to delegate. Finally, you can set boundaries around how you'll share information about the people you are caring for. Instead of spending time constantly sending out emails and making phone calls, post the information on a closed website and ask family members to seek it out. You'll find more on this in Chapter 4.

Just Say No

When you are overburdened but still keep adding tasks to your list, you put more stress on yourself; it's the perfect equation for a meltdown. And if you say "yes" but you don't follow through, you'll likely suffer repercussions. You can't add more time to your day, so be very judicious about saying "yes." That said, "no" may not be an option if you are being asked to live up to your basic caregiving or work responsibilities. If so, something else may have to be taken off your list instead.

Get Help

Accept Offers

How many times have friends or family told you, "If there is anything I can do, just let me know." Take them up on it. Many of us find it hard to ask for help, but when it's been offered, you have no excuse for going it alone. When I first moved to Arizona in 2009, two wonderful employees at our local grocery store offered to check on Mom and Dad when I went out of town. They had both been fond of my parents for many years, and

I knew both of them well enough to trust them. Another friend offered to do the same. So I took them up on it, and they often stopped by to bring bananas, share a meal, or just chat and monitor my parents' status while I was away. They didn't need to stay long, but it eased my worries immensely and gave my parents a lift as well. Unless you know people who offer to help very well, you'll want to check references and get a background check (contact the local police department to find out how to get one for free).

Get Support for Your Own Life

This is often the last thing caregivers think of, and the last thing others think to do to help a caregiver. But it should be the first. When you start to notice emotions, exhaustion, and stress building up, recruit friends, volunteers, or paid professionals to help you. Your first instinct may be to get help with caregiving, but consider channeling resources to support your own life, such as cleaning, mowing the lawn, running errands, or sorting mail. It's a huge relief to know these things are being taken care of so I can focus on my paid job and the tasks that only I can do for myself and for Dad. Concierge services can help, and you'd be surprised how affordable their prices are; even an hour or two a week can make a big difference in your stress levels. A growing number of both online and in-person concierge or personal assistant services are available; to find them, search online or check your local Yellow Pages. Be sure to check references and make sure they are insured for liability and bonded in case they cause any damages to your home or property.

Seek Professional Counseling or Medical Care

If you're experiencing overwhelming emotions, stress, or burnout, it may be time to get some help from a counselor, therapist, or doctor. You may experience mood swings, sleeplessness, or profound hopelessness or depression. Anxiety symptoms may manifest physically, such as tightness in your chest, a pounding heart, or difficulty breathing. If you notice any of these signs, or if your co-workers, family members, or friends are concerned about you, get an evaluation.

Try Mediation

Are you having trouble convincing your loved ones to accept care or change their living situation? Are anger and resentment building up toward your siblings or others who might not be helping out as expected? You might consult with a professional mediator who specializes in family or eldercare mediation. Sometimes an objective third party is the best person to negotiate agreements about plans, roles, contributions, and responsibilities. Keep in mind, though, that all parties have to be willing to participate and communicate openly for mediation to work. No pulling punches in a mediation session or setting someone up to be ambushed.

Lean on Other Caregivers

No one will understand what you are going through quite like another caregiver. You can build friendships with other caregivers and talk, text, or email each other. You can connect online via caregiving support groups, message boards and groups (visit aarp.org/caregiving to find AARP's online groups), Facebook groups, and Twitter chats for caregivers. Or you can join a local caregiver support group to meet regularly in person. (See the Resources section for information about how to find a support group.)

Take Breaks

Grab Some Quick R & R

Caregivers are busy, and if we're also working a paid job, we are even more crunched. It's difficult to find time for substantial breaks, but it's amazing how quickly I can refresh my attitude and energy with just a short break in my routine. Here are some of the refreshers that work for me when I'm feeling stressed out or overwhelmed. Make a list of refreshers that work for you!

- **Relax.** Do something you enjoy just for the sake of enjoying it no matter how big or small. It may be getting a cup of coffee, watching a favorite TV program, going for a walk, cuddling a pet, savoring a piece of chocolate, watering your garden, meditating, or napping.
- **Have fun.** Laughter really is good medicine. Watch a humorous TV show or movie, read a funny book, peruse funny greeting cards, play

a game, or just be silly. This is something you can do with the people you care for, too.

- **Be creative.** Creating often brings out the best in us. Write a poem, sing a song, play an instrument, paint a picture, work on a scrapbook, make crafts, decorate your home—anything that gets your creative juices going.
- **Enjoy plants and flowers.** Watering plants can be calming, and even a single beautiful flower can be so cheerful. Look for the beauty around you.
- **Connect with animals.** Our furry friends can be therapeutic, and studies show they make us healthier and happier too.
- **Get intergenerational.** There is nothing like the laughter, energy, and enthusiasm of children to energize us and give us hope. Make sure you have opportunities to connect with other generations.

Arrange for Respite Care

Respite is a period of rest or relief from something difficult—in this case, a break from caregiving. It may be an ongoing or one-time arrangement for an hour or two to get together with friends, see your doctor, or run errands; an overnight so you can get some sleep; or a longer period of time to take a vacation, focus on work, or meet other family obligations. Here are a variety of ways to get respite care.

- Ask friends or relatives to care for your loved ones, either coming to their home or taking them out for dinner, shopping, or to a movie. It will be good for your loved ones to get out, and good for you to have some quiet time as well.
- Find a volunteer-staffed respite program in a faith-based organization or volunteer placement agency.
- Pay a professional from a home-health agency, or hire one directly yourself, to care for your loved ones in their home.
- Arrange a short-term stay for the people you care for at a hospice respite, assisted-living or nursing facility, or a group home.
- Have your loved ones attend an adult day services (or day health) center that offers group activities, services, and meals. These centers

are usually open five days a week, although some have weekend and overnight programs.

- Join with other caregivers in your community to create a respite cooperative in which you take turns caring for each other's loved ones.
- If your state has one, use a state voucher program in which you select the respite provider and the state supplies vouchers to pay them.

To locate an organized respite program in your community, contact your local area agency on aging (www.eldercare.gov), visit the respite locator (www.archrespite.org/respitelocator), or contact your local senior center, volunteer agency, or faith-based initiative.

Maintain Your Own Finances

We often get so caught up in caregiving and working that we neglect the basics of our own lives, including finances. Many caregivers suffer financially if they cut back on work or get so busy they forget to pay their bills or keep up with financial records or taxes. I often hear from caregivers that they manage their loved ones' finances meticulously, but their own finances are a mess. Frequently caregivers have to make financial sacrifices, but in the long run you won't do your loved ones any good if you are financially unstable. (See Chapter 7 for more tips on budgeting.) Take the time to keep up with the basics.

- Create and maintain your own budget, track expenses, pay off debt, and pay your bills. You might consider autopay for some of your bills; just make sure you always have enough money in your account to cover them.
- Keep up with your taxes. As a family caregiver, *you* may be able to take some deductions. If you are paying more than half of your family members' expenses and their income meets IRS requirements, you may be able to declare them as dependents on your tax return or take the Child and Dependent Care Credit. Consult a tax professional for more about how you can maximize deductions as a caregiver.

- Save for retirement. Usually, when caregiving makes the budget tight, saving is the first thing to go. But as a caregiver, you know better than anyone how important it will be to have savings when you are older and may need care yourself. If you don't have retirement savings goals, create them, and if you do have them, monitor your progress and prioritize your own future.
- Educate yourself about insurance policies, such as disability, life, and long-term care insurance. It may or may not be a good time to purchase these policies.

Take Care of Your Career

I go more deeply into this in Chapter 5, but if you are working or wish to return to work at a later date, I want to remind you that your work and career are an important part of who you are, so taking care of yourself includes keeping your career goals in sight. Given your caregiving responsibilities, it's understandable and perhaps admirable if you decide to make sacrifices and adjust your career goals. Despite your amazing multitasking skills, maybe you can't actually have it all. But try to adapt your career plans while you keep moving forward. Get creative. You may adapt your goals for now, or change fields, or get new training. You may need to postpone advancement, but perhaps making a change in your career path will actually end up advancing your career in unexpected ways.

Your Job Description: Self-Care Coach

Great work! You've mastered an understanding of the emotions and stress associated with working caregivers. You merit an additional component of your job description:

Observes and evaluates one's own emotions and stressors. Identifies personal vulnerabilities. Recognizes stress overload, identifies

stressors, and takes action to ameliorate negative effects using proven coping mechanisms. Nurtures identity and maintains personal care.