

# Introduction

*We cannot choose to have a life free of hurt.*

—Edith Eva Eger

My recognition of the special plight of family caregivers has both professional and personal roots. Over my nearly 50 years of nursing experience, I've witnessed thousands of families grapple with the expectations of the caregiver role. I've also worn the lonely shoes of a family caregiver myself, as both a daughter and a wife. However, my extensive training and expertise didn't necessarily give me an advantage in this role. I worried constantly, doubted my capabilities, and questioned my decision making when caring for my loved ones.

To this day, I continue to reflect on the many dilemmas lay family caregivers face. How could someone without a nursing or medical background take on this ominous job? This question was the driving force behind writing this book.

Being a lay caregiver is no easy task. In *When Life Becomes Precious: The Essential Guide for Patients, Loved Ones, and Friends of Those Facing Serious Illnesses*, Elise NeeDell Babcock (1997) poignantly described the dual demands of this role:

The patient's journey has now become yours. You too have heard the news. You too are going to encounter monumental changes. The patient has lost her health, her visions of the future, and her sense of control over her destiny. You have also experienced losses. You are altering *your* dreams, *your* hopes, and *your* visions of the future. (p. 9)

Many family caregivers experience feelings of abandonment, of being overwhelmed with worries of uncertainty. They fear they will unintentionally hurt their loved one and struggle with piecing together medical information on their own (Beach & White, 2015). Compare this to the typical responsibilities of life: assuming a new job, learning to drive a car, applying to a college, starting an exercise regimen, or

going through childbirth involve some prior education or orientation. Without comparable instruction, your responsibility to care for someone ill looms large. Given this, you, who I often refer to collectively as the **unknown soldiers**, can benefit from advice that offers sustenance and counsel as you begin to take on this responsibility (Boyle, 2002).

The Institute for Patient- and Family-Centered Care defines *family* as “two or more persons who are related in any way—biologically, legally, or emotionally” (Clay & Parsh, 2016, p. 41). The scope of caregivers is substantial, diverse, and inclusive of spouses, parents, children, siblings, friends, neighbors, and partners. A report by the Institute of Medicine (now the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) reported that 80% of adults requiring long-term care currently live at home. Approximately 90% of this care is provided by lay, unpaid family caregivers (Institute of Medicine, 2008). It is impossible to count the actual number of individuals providing some degree of care to a loved one in the United States, but we estimate millions walk in these shoes daily.

Today's reality is this: **Healthcare professionals don't render most patient care—you do.** Family caregivers are responsible for most of the home-based care in the United States (Boyle, 2015). At any given time, 20% of U.S. adults are serving as informal caregivers (“Support for Caregivers in the USA,” 2020). Currently, an estimated 44 million caregivers, the majority of whom are women, are engaged in hard, relentless, and uncompensated caregiving, which poses escalating ramifications for the future (Wittenberg & Prosser, 2016).

A report released by the Centers for Disease Control and Prevention on the health status of informal caregivers from 44 states, the District of Columbia, and Puerto Rico identified that nearly one in five informal caregivers (19.2%) reported their own health to be fair or poor (Edwards, Bouldin, Taylor, Olivari, & McGuire, 2020). This finding raises concern about the impact of caregivers' compromised health on their own wellness and on their loved one requiring care.

The population of family caregivers is expected to increase because of two main factors. First, the graying of the United States and other industrialized countries (often referred to as the **silver tsunami**) will

exponentially increase the number and life expectancy of older adults. Second, the increased prevalence of major chronic conditions that come with advanced age, such as heart disease, stroke, cancer, type 2 diabetes mellitus, and dementia, will necessitate more family caregivers to provide essential and complex care (Mitnick, Leffler, & Hood, 2010). These phenomena are triggered and potentiated by other trends, such as shortened hospital admissions, limited discharge planning, the absence of ongoing homecare support, fewer offspring to render care to aging parents, and the mobile nature and geographic displacement of the nuclear family within society. The convergence of these factors underscores the need for a radical shift in role preparation for caregivers, as they should not be expected to take on this critical role in the absence of preparatory education and ongoing guidance from health-care providers.

The delivery of support and professional instruction to family caregivers has numerous benefits. For example, caregivers can be taught methods to reduce a patient's biopsychosocial distress by promoting comfort through medication management, physical care measures, dietary interventions, and communication. Enhanced caregiver skills that keep the patient out of the emergency department, hospital, or a long-term care facility can augment the patient's trust in a caregiver's abilities. Family-focused instruction can reduce the negative corollaries of caregiving by teaching self-care and resilience strategies. Unfortunately, these competencies don't emerge following a cursory 10-minute review of printed instructions and require extensive focus.

Deliberative approaches in family skill building also foster the recognition of the caregiver role within the healthcare team (Glazer & Alhaj, 2017). Because they spend considerably more time with the patient than nurses and physicians, the caregiver's voice has elevated importance in planning and delivery of patient care. Hence, a new lay-professional collaborative model is needed to improve the caregiving process (Kent et al., 2016).

Currently, state and federal calls to action help to address the need for formal instruction and training for family caregivers (Reinhard, Levine, & Samis, 2012). Although individual states are implementing

needed caregiver programs, significant resource gaps remain for the majority (Reinhard, Young, Ryan, & Choula, 2019).

To this end, a comprehensive review is needed to guide lay caregivers through the hurdles of caregiving. I have chosen 10 major themes to address in this book based on my clinical and personal experiences. There is no right or wrong order to this reading. Chapters can be read and reread as often as you require reflection and information. Importantly, four overarching elements within these pages transcend much of what you will read and are key to your ability to grow with—not languish in—your caregiver role.

First, **you must acknowledge your limitations and not expect perfection.** The caregiver role most likely was imposed on you with no warning and, most certainly, no training. Because of your lack of preparedness, you won't be able to instantly recognize critical or emergency situations, know when to ask for a change in medication, or, for example, know how to troubleshoot an ill-fitting colostomy pouch. Nurses require years of education and practical experience to master these elements of patient care. For the lay caregiver, learning and mastering these new skills will not be easy, especially with the added corollaries of anxiety and worry.

Second, to engage in optimal caregiving, **you must repeatedly ask for help.** Despite the best of intentions, it is often impossible to perform caregiving duties alone. Over the years, I have observed countless family caregivers struggle in providing home-based care in isolation while simultaneously working outside the home. These caregivers disregarded their own needs and compromised their health. Ignoring your well-being will not benefit your loved one. It takes concerted introspection to realize your limitations. Think of caregiving as a team sport rather than an isolated marathon.

Third, **you must care for yourself with the same rigor and intention that you care for your loved one.** You can't give to others if you're running on empty. Family caregivers frequently feel that they do not have the luxury to "take a sick day," especially when they compare their complaint to their loved one's illness (Reinhard et al., 2019). Self-care is *not* selfish care. Caring for yourself is an investment in providing the necessary support for your ill family member.

Finally, **you must constantly reflect on your intention.** You are trying to do the best you can in a highly stressful situation. You will be limited in what you can accomplish. For example, you may forget to give your loved one a medication on time, become impatient with your spouse's confusion, or not catch your mother when she falls. Remember, it was not your desire to forget a pill, be short-tempered, or allow your loved one to slump to the floor. Be compassionate with yourself.

As you embark on reading the 10 themes shared in this book, I'd like to leave you with this summation from *Cancer in the Family*, a publication from 2000:

Despite widespread evidence of the profound impact of serious medical illness on family life, as well as equally compelling data concerning the role of family behavior in shaping both detection and the clinical course of medical illness, families are still often ignored or, at best, tolerated in many health-care settings. (Baider & De-Nour, 2000, p. xxiii)

Although poignant in its message 20 years ago, this excerpt reflects what little has been done to support family caregivers in a formal manner.

My goal in writing this book is to help family caregivers feel less alone. My ultimate hope is that caregivers will be recognized for their importance in healthcare delivery. An ideal future includes a comprehensive national package of education and support initiatives to teach lay caregivers the necessary skills required to care for their ill loved ones. To accomplish this, caregivers must be included in all aspects of novel care model planning. Our call to action is underscored by a more formal awareness that illness and disability are indeed family affairs.



# Chapter 1. Finding Meaning

*Life's under no obligation to give us what we expect.*

—Margaret Mitchell

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## Struggling With the “Why”

*Suffering demands that others bear witness, and family members unfortunately are assigned front-row seats.*

—Angelo Volandes, MD

Central to engaging in the practical elements of caregiving is the need to process the “why” of the situation. News of a catastrophic illness or health crisis challenges our universe. It disregards our notions about the way the world is supposed to be and what is fair and just. Regardless of religious orientation, most of us are raised with the belief that if we are good people, are kind and considerate of others, and generally live a good life, we will be rewarded. Thus, when these basic tenets have been followed, it’s hard to reconcile the “why” of a brain tumor, early-onset Alzheimer disease, or a near-fatal car crash.

Darkness remains a natural part of life (Rupp, 2016). Upon the discovery of a significant illness in a loved one, the questioning that results is often deep-seated and troublesome. No matter how hard we search, we can’t find an answer or tangible rationale as to why our loved one was burdened with such a fate. Ultimately, when this unknown can’t be emotionally processed, we get stuck—often in anger—and the nature and quality of our caregiving are negatively affected.

I vividly remember a unique case involving a daughter whose mother was unexpectedly diagnosed with a very unusual late-stage cancer. The daughter’s anger was so palpable that you could *feel* it when you entered the mother’s room. Every time I spoke to the daughter, she would repeat the same lament. Her mother didn’t smoke or drink; she ate organic foods, walked every day, and didn’t even use a microwave in her quest to stay healthy. “How could cancer happen to a woman so ritualistic about her health?” the daughter would repeatedly question.

Personally, I remember struggling with the “why” when my father suffered a stroke, and years later, when he was diagnosed with lung cancer. Wasn't one life-threatening diagnosis enough? Why did this generous, loving, big-hearted man have to deal with two major illnesses? Why couldn't this have happened to a single man with no family to love and support? It just wasn't fair. The absence of an answer to my questions, and my continued ruminations over such, left me angry and unable to think through what I needed to do to help my father in his recovery.

*The less we make peace with our pain, the more we tend to make war on others.*  
—Stephen Levine

Don't get me wrong—I'm not suggesting that unwavering acceptance is the best response; however, I do believe that finding a way to move beyond anger-based questioning enhances your ability to assume the necessary tasks of caregiving.

In his book *When Bad Things Happen to Good People*, Rabbi Harold S. Kushner wrote about his existential struggle with the “why” in his life. He ultimately concluded, “The God I believe in does not send us the problem; He gives us the strength to cope with it” (Kushner, 1981, p. 140).

Negative thoughts can take a toll on your energy. A conscious effort must be made to target how and where you invest your emotional time and effort. Try channeling the momentum keeping you angry into a strength with benefits. Ask yourself, can you redirect your anger over a situation you can't change into a positive reaction? For example, you direct this anger-based energy toward getting the house ready based on the occupational therapist's recommendations following your wife's stroke.

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## Guilt

*There is hardly any life that is not shadowed in some place by guilt. Guilt in itself is useless. It belongs to the past, and the past is over and gone.*

—John O'Donohue

Guilt is often a principal feature within the caregiving experience (Potts & Potts, 2011). Those who use guilt as a coping strategy most



likely learned to do this as they were growing up. Guilt is often a component of religious teaching, invented as an effort to control behavior associated with self-blame (Spillers, Wellisch, Kim, Matthews, & Baker, 2008).

The prominence of your use of guilt as a coping response should be considered. In their historic guide for family caregivers of patients with Alzheimer disease, Mace and Rabins (2017) stated that the first step in managing guilt is admitting it is a problem. Guilt is always a negative response, as it stems from the belief that you have done something wrong and interferes with optimum caregiving (Crane-Okada, 2018). Guilt is a useless emotion with no merit. It represents a version of “magical thinking” (J. Lynn & Harrold, 2011). Excessive guilt may drive one’s need to “do it all” and to not accept help or praise. In his book, Kushner (1981) described an excessive sense of guilt as “a tendency to blame ourselves for things which are clearly not our fault” and noted that it “robs us of our self-esteem and perhaps of our capacity to grow and to act” (p. 104). Author Diana Denholm (2012) referred to this unfavorable inner dialogue as one’s “guilt factory.”

If you acknowledge that guilt is a prominent issue for you, consider how it is related to being stuck in the “why” of your situation. Over my decades of nursing, I’ve heard family members languish over why they didn’t force their loved one to pursue suspicious symptoms sooner or why they didn’t notice changes in their loved one’s appearance. Do any of the following statements sound familiar to you?

- I should have made him stop smoking.
- I didn’t realize that he wasn’t eating and was hiding it from me.
- I thought his pain was from his arthritis.
- He watched his dad die of colon cancer. He knew he needed to get checked regularly. I should have just gone ahead and made an appointment for him.

**A caregiver’s cautionary note:** It is not *your* responsibility to accept fault for another’s behaviors or decisions. It is *their* call, not yours.

Potts and Potts (2011) described the unrelenting guilt of those caring for loved ones with Alzheimer disease. Yet many of these reflec-

tions also apply to caregiving within other illness scenarios. The following triggers offer testimony to the prominence of caregiver guilt:

- Not spending more time with the loved one
- Neglecting work and family
- Being short-tempered, impatient, and frustrated with an ill loved one despite knowing that the loved one can't help it
- Feeling embarrassed over a loved one's odd behaviors
- Questioning God
- Perceiving the stress of caregiving as self-pity
- Going behind the back of a loved one to do things that must be done (e.g., hiding car keys, obtaining medical power of attorney)
- Placing a loved one in a care facility

Caregivers can't win for losing. They frequently undervalue the gift they are giving, namely, making decisions based on their loved one's best interest. For example, your decision to take the car keys away from an older parent is not because you are uncaring or insensitive to their desire to remain independent. Rather, the intention is to minimize the possibility of injury to your parent and others in the event of a serious accident.

Coming to the realization that you can no longer remain the caregiver of a loved one can be a very difficult experience. Early in my nursing career, I read *When Love Gets Tough: The Nursing Home Decision* (Manning, 1988). Despite its publication more than 30 years ago, this book is such a valuable resource that I continue to recommend it to struggling families to this day. Recently, a nurse colleague shared with me her internal struggle with placing her mother in an extended care facility. Her mother couldn't take care of herself and required around-the-clock monitoring. My colleague and I spoke at length about her concerns for her mother's safety, such as her potential for falls and need for hospitalization. These issues justified the need for care beyond what the family could provide. Rather than viewing an extended care placement as a decision made in her mother's best interest, my colleague considered it a broken promise, as she told her mother she would never put her in "one of those places." It wasn't until

my colleague's mother went missing, requiring law enforcement in the area to issue a "Silver Alert" (a public notification of an older missing person), that she realized her mother's existing living situation was unsafe and no longer worked.

Another guilt-related issue is comparing yourself to someone else and devaluing your caregiving experience. Saying, for example, "She kept her mom at home for more than a year, and I couldn't," negatively portrays your abilities and doesn't recognize your unique circumstances. When you compare your situation to others, you probably aren't aware of the unique variables distinguishing these cases from your own. Perhaps the daughter who was able to care for her mother at home for more than a year didn't work or had the resources to bring in supplemental care. Maybe this person's mother had a less-aggressive variant of dementia than your mother. One of the most profound lessons I have learned over my decades of nursing is that **no two patient experiences are ever alike.**

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## Moving Beyond the "Why"

*You can keep pedaling, get off the bike, or fall over.*

—Cynthia Copeland

There is no answer to the "why" that you ruminate over. This bad hand of cards has been dealt, and there is no going back. The longer you stay focused on trying to find an answer to an impossible question, the more time you waste. You only have the future. As the Cherokee proverb cautions, "Don't let yesterday use up too much of today."

Sustaining yourself in your caregiver role will require you to learn new skills. What has helped you cope in the past may not be enough. This necessitates considerable and honest introspection of where you are and where you want to be in your role as a caregiver. Put a name to your worry. Be sensitive to your "hot buttons." What situations are the hardest for you to cope with?

Generally, I have found that the most important skills caregivers need to obtain are communication and emotional support, specifically

the abilities to ask for help and talk about personal feelings. A societal stigma about mental health often precludes a willingness to admit that you need help coping. Feeling the need to “be strong” and “stand on your own two feet” fosters a reluctance to ask for help. We need to recharacterize what it means to be strong. It doesn't mean being stoic. Rather, it requires building a support structure around yourself and your ill loved one. It takes stamina and strength to mobilize people and resources to get you through this difficult time. When a team is assembled, the best outcomes ensue.

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## Talking It Through

*A good listener is someone who puts their backside on the bedside,  
their mind in their ear, and their mouth in neutral.*

—Michael Quinn, MD

You may have had forewarning to the diagnosis of a serious illness in yourself or a loved one, or maybe such an illness has struck out of the blue and taken you by surprise. Either way, the psychological consequences can be considerable. Some degree of emotional disclosure, or talking through your feelings, facilitates your ability to navigate the future.

Find someone you trust and respect who has a good listening ear. Optimally, this should be someone who has offered a willingness to support you in the past. In *The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself*, Denholm (2012) identified discussion starter prompts that can help caregivers and ill loved ones alike navigate through emotional issues (p. 11):

- I am frustrated about . . .
- What I hate the most is . . .
- I'm afraid of . . .
- I need to know . . .
- I feel guilty about . . .
- I don't think I can . . .
- What am I supposed to do about . . . ?

- What do I do when . . . ?
- What do I say to people about . . . ?
- What concerns me a lot is . . .

Tell your trusting friend that it is their ears you want them to lend—not a voice laden with opinions and advice. The following are examples of what a willing ear might hear from a caregiver:

- I'm really struggling with guilt over Mary's diagnosis. She kept saying how unusually tired she was, and I kept reassuring her it was all the wedding planning that got to her. Maybe if she got checked sooner, her cancer wouldn't be so advanced.
- I feel awful admitting this, but I keep wishing this happened to someone else's child and not my own. I don't know how I'm going to make it through this.
- I'm afraid my anger is consuming me. I can't stop thinking of the unjustness of this happening to my wonderful mother.

Until our thoughts and feelings are articulated, we remain unaware of the intensity of our emotional responses. Articulation gets these feelings “out on the table” and enables us to address them directly.

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## Courage

*Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, "I will try again tomorrow."*

—Mary Anne Radmacher

Moving beyond the “why” takes courage. Philosopher Søren Kierkegaard noted, “Courage isn't the absence of despair and fear but the capacity to move ahead in spite of them.” Taking that first step into the future is a major turning point in assuming the caregiver role.

Embracing the caregiver role is a monumental task. As biologist Henry Drummond pointedly stated, “Unless a man undertakes more than he possibly can do, he will never do all that he can.” Stepping into this uncharted territory represents an enormous leap of faith. You must acknowledge your lack of experience and expertise; however,

with courage, a mindset that doesn't expect perfection, and the help of others, you can do it!

### Exercise: My Personal Inventory

On a sheet of paper, answer the questions below. Use this information to help you move beyond the “why” in your life.

- **Exploring the origins of guilt:** Ask yourself what you feel guilty about. Is it realistic? Do you have control over it?
- **Moving beyond the “why”:** How stuck are you on the “why” of the situation? How can you refocus this energy?
- **Identifying listening ears:** Who are two people you can talk to about feeling guilty and struggling with the “why” in your life? Rather than waiting until you are in a crisis, ask them if you could schedule a time to talk over coffee.