INTRODUCTION: It’s Either HIM or ME

I’m 60 years old, and I don’t want to live this way anymore.

If nothing changes, I will surely die. At least, that’s what the statistics told me in 2012. A Family Caregiver Alliance survey revealed that elderly female caregivers face a 63% greater risk of death than their non-caregiver counterparts.

The stark reality of that grim statistic got my attention.

it is far from uncommon to find that elderly female caregivers die early. There are other surveys with frightening premature death rates ranging from 30% to 70%, usually from causes such as heart disease, diabetes, and other chronic disorders.

I already had diabetes.

I could no longer allow my husband’s untreated mental health problems to push me any further toward an early demise..

It’s the beautiful season of fall in mid October outside. But inside, our home is a garbage dump of binge hoarding. Much of it is soiled, ruined, and in need of repairs he refused to make or let others take care of. He insisted I could live with the mice and bugs and water raining in.

That was what I was facing 12 years ago.

Our home was hideous. I had willfully muffled all of my senses during the time I spent in the house. I avoided coming home (if you could call it that) as much as I could. But my strategy of avoidance and denial wasn’t working anymore. I did not need any more signs that living there was toxic, to my health, my happiness, and my soul.

He had been gaslighting me about my perceptions and feelings for years. And as of that morning, he had begun to hurl vile language at me. I had become his inadvertent caregiver, assigned to quietly take care of his rudeness to people and his mishandling of our finances in the background.

This was 20 years ago, at a time when my husband had received a complex diagnosis of many disorders, including OCD (Obsessive Compulsive Disorder), ADD (Attention Deficit Disorder–Severely Inattentive), and an alphabet of other conditions. We were told that he was hoarding to compensate as a consequence of the OCD. (Now we know hoarding is a separate disorder, which was unknown back then.)

At that time, his therapist had told me to “forget the last twenty years.” She added that I now had only one role in my husband’s life and that was to praise him for doing things right.

Yes, on top of the resentment that has been building up in me for years, I had to somehow find a way to *praise* him.

What the therapist would not explain to me was what *my husband* was going to work on. I was not considered a part of the therapeutic team since my role was to simply provide care.

I felt humiliated and anguished by her dismissal of my feelings and her unwillingness to incorporate me or our children to create a system for our family. We had asked for a solution for our family. The therapist preferred to treat one client while sidelining me and my children. Unfortunately, our ability to tolerate my husband’s erratic and inconsiderate behavior had dried up like a stream without rain. In our defense, we tried. But my husband, who was struggling fiercely to learn new behaviors, became even more anxious with the result that his challenging behaviors became worse. That was particularly true of his hoarding.

Since I could not master this invisible obedience, the therapist apparently told my husband I “might not be the right kind of wife for him.” My thoughts and feelings did not matter. You might be thinking, “*How is it possible that a therapist could insert herself into our marriage that way?”* but that is exactly what happened.

Thanks to “caregiver invisibility,” we had landed in the wild-west of neuropsychology where practitioners were experimenting, but solutions were not yet obvious.

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“Him or *me*?”

I asked myself this over and over as I walked around our house trying to see my situation as it really was.

I had been ignoring the worst conditions, hoping for a solution to fall from the sky.
We had fallen in love with that house before our children were born more than 35 years earlier. Now, our children refused to set foot in it, and they expected *me* to fix everything.

I deliberated for hours that morning. What was the best for all of us. I finally came to a resolution. I could try my usual response–wait for an apology so we could go back to business as usual for him. But this time, I added something. If he didn’t apologize for two weeks, then I would start looking for a lawyer, so I could sue for a divorce in January. The largest resolution of my life, but I knew I had to keep it.

That morning, when the obscene name-calling began, I knew I was powerless to fix anything.

I also knew I did not want to die in that house.

I had read about hoarding cases where corpses were found under the rubble. I did not want this to be my fate.

Most of all, I wanted to get well.

I was sick and tired in so many ways. Exhausted by the stress of tolerating his angry outbursts, my blood pressure became difficult to control. I could not wait to leave the house and had found myself searching for work and projects that could keep me away. I had lost hope that my husband would make progress when his therapist quit working with him because Charles* (all names aside from the author's are changed to pseudonyms to protect their privacy) couldn't focus.

I couldn't absorb the disconnect. If he had learning disabilities and attention issues, wasn't focus understood to be the core of the problem? I will never know if the therapist questioned the effectiveness of the strategies she had selected when her client couldn't achieve them.

How ironic. I kept reading about the disorders, and I asked Charles if he would try again with a new therapist. He blamed me for not helping him enough. His family blamed me for his behavior. I couldn't stop him, but I kept searching for an answer.

I finally realized that the only person I could help was me.

That was a stunning and sad moment of truth for me. While it freed me of responsibility for his condition and his progress, it was a giant admission that the problem was too big for my legendary skills. I'm being slightly ironic here, but people, including my parents, always came to me for solutions. I had labored for the first twenty years of our marriage to fix and change myself so that I could be a better wife, but now I had to recognize and accept that I had misunderstood the problem all along. While I made many good changes that helped me, the only person I could change was myself. Fundamentally, my husband preferred to remain the same, and I would never, nor should I ever, have control of someone else's identity.

I wanted to forgive him for lashing out in his helplessness, but I realized that was my innate caregiver impulse talking. I waited a few weeks for him to say something to apologize for his cruel, angry statements, but he said nothing. His outbursts became more frequent. I became frightened that physical violence would be the next step, and I knew it was time to rely on my brain instead of my heart.

I began to consult attorneys to come up with a clear plan to remove myself from our marriage.

Why had I stayed so long? Everyone wanted to know.

Explorer*, *Tourist*, or *Prisoner

I remembered a framework I once learned about life being a journey, and how you could approach it in one of three main ways: as an *Explorer*, a *Tourist*, or a *Prisoner*.

Until the situation of my husband's disabilities had overwhelmed us, I had always considered myself to be an Explorer, meaning I would try out new ideas and pursue new experiences. Now, I was barely holding myself together; I was less curious than a Tourist; indeed, there was no itinerary for me to follow, and I just wanted to get out of this trip.

In reality, I was a Prisoner of my own refusal to accept that something needed to be done.. Until this point, we had tried tiny, serial fixes for our problems, but these were patches that always failed. I did not have the strength either physically or emotionally to continue this journey.

I needed an enduring solution. I could put the Explorer hat back on and find a way of traveling that would work for me, even if this meant that my husband wasn't able to travel with me. I wanted to stop fighting, and I wanted to remain compassionate. What I had trouble accepting was that an enduring solution might mean I would become a solo traveler.

It was heartbreaking to imagine, but a necessary reality check. It was the only way to save my own life.

If you find yourself in a situation where, as the unacknowledged or otherwise frustrated caregiver; if you feel you are overlooked, ignored, and disregarded, I understand. I know exactly what it's like to feel the weight of guilt, shame, and helplessness and how it can feel like there is no way out.

If you have embraced the role of caregiver as fundamental to your existence, it can be devastating to let go. If it has been the sustenance of your emotional and psychological survival, you may feel like you are starving. However, accepting and permitting this necessary new boundary is vital to your survival. I've shared the statistics on stress-related death with you. There aren't other civilian jobs that I can think of where this level of sacrifice is expected or required.

When service becomes servitude, it's awfully difficult to feel hopeful about a solution. But if you start helping yourself, hope can grow.

The reason I do the work I do is because of my firm belief that clear and *informed* thinking can help us make the most of our impulse to care for our loved ones in mutually beneficial ways. Much of the research you can find has focused on the benefits of keeping caregivers healthy *so they can serve others*, ignoring their own needs for a fulfilling and comfortable life.

Caregivers' lives are no less important.

Unless we understand what caregiving really entails, and the emotional, financial, and physical cost to the caregiver, we are literally putting our lives at risk. Because far too many caregivers are dying before the people they serve, we run a global risk of having no caregivers left as our population ages and more dire health conditions continue to emerge.

The decision, however, is not binary: there is a way to be a caregiver with grace, that is…respectful of your thoughts and feelings and can deliver good care to a receptive family member.

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For many years, I taught communication, time management, and stress reduction strategies to corporate, university, and non-profit professionals, never dreaming how critical these skills would become in my own life. My busy and rewarding professional life distracted me from my husband’s issues and, as a university professor, he was able to conceal and deny a great deal of his woes.

Earning a PhD helped me refine my own research skills, and I could see a great divide building between us.

I thought divorcing my husband, would allow me to turn the page in my story and start a new life, but four years later, he died by suicide, and that changed everything.

I began to reexamine my own life and to see where feelings and unconscious behavior had overruled my rational capability. I wrote a novel based on my experiences called *The Hoarder’s Wife,* and I became a Certified Caregiver Advocate and Life Coach because I wanted to help others who might be trying to survive similar circumstances and unmet needs.

Becoming a Rational Caregiver

My personal story became the impetus behind my mission to find a way to provide care for caregivers, a quiet and almost invisible part of our society that we can no longer afford to ignore.

The Rational Caregiver Framework I've developed helps caring people to assess their life situations for deficits and strengths in order to create caregiving agreements and understandings that respect both thoughts and feelings to serve themselves and the people they care for.

Put simply, this framework could very well save the lives of caregivers who don't know when to save themselves. The assessment emphasized self-compassion and the validation of your own goals. While caregiving may be innately satisfying, too much of a good thing can be harmful to a person in spite of that pleasure.

If you do not know what you are agreeing to and you have not explored the resources available, you may be walking into a deadly failure trap that won't serve you or anyone else. Most caregivers form agreements based on their feelings of love or duty; they do not take the time to think through their own needs in these arrangements.

While researchers are starting to say that we need to put caregivers' well-being and quality of life front and center, their attention is still focused on helping the family member patient rather than the caregiver. So many caregivers experience poor health and financial perils while caregiving. It's clear that we need to put rational limits on caregiving to balance the demand with their feelings of duty and love.

My framework addresses how to make the family caregiver and the family memberpatient equally important rather than looking only at one person's ability to serve another. Caregivers are often stressed by their lack of financial or personal benefits, and these worries contribute to the life-shortening servitude that caregiving can become.

It’s enough of a concern that we’re starting to hear from governments and social researchers about the coming shortage of caregivers, particularly for the elder population. According to Vicki Hoak, executive director of the Home Care Association of America, By "2030, we will have more people over the age of 65 than under the age of 18."

Telling a caregiver to take a nap or a hot bath may be wonderful suggestions for temporary relief, but they do not address ongoing quality of life issues for caregivers. Hobbies are nice and rewarding, but many caregivers cannot give adequate time to pursue them so that they do offer the satisfaction of achievement.

Most advice for caregivers is built on a framework of temporary, occasional respite, and it is always worked around another person’s needs, so it can be dropped if the patient has extended issues. We need to address the actual “pursuit of happiness” in concrete rather than abstract terms if we’re going to give more than lip service to this problem.

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It’s been said that failing to plan is the same as planning to fail. In a very real way, if caregivers fail to think about the impact that caring for another person 24/7/365 will have on their lives, they will fail at it and become chronically ill or die before the person they are meant to care for.

I know this because I saw my own mother become my father’s caregiver following his diagnosis of blocked arteries and treatment with a quadruple bypass. He continued to work as a physician, accepting stressful conditions and compromising his own health. Although my mother had developed emphysema, she continued to work by his side, supporting him while trying to limit his stressful practice, carrying oxygen tanks with a walker in her final years. One day she called me to say he had fallen on top of her outside a grocery store, and she ached all over. “No,” she said, “Please don’t come. I can handle it. I just wanted to tell someone.”

I felt confused and upset, but I didn't want to hurt her pride about being self-sufficient. That's an important lesson for people who live around the periphery of family caregiving. Family caregivers are often wired to accept sacrifice, and their emotions can get in the way of their self-care. It's tough for people to interfere. It was tougher still to hear from a person whom my mother hired to grocery shop for her that I wasn't close to my mother.

Please don't let your pride come between you and your family. At least ask them to help you think of a strategy. The grocery shopper didn't know the whole picture of my mother's stubbornness coupled with the fact that I did help her find and contact resources when she would let me.

One of the problems my mother faced was that even her own expertise as a nurse wasn't enough to navigate the journey she and my father faced. Although she might not have said it out loud, I believe she felt like a Tourist on a high-paced itinerary that didn't allow much time for looking and savoring. Her knowledge and life experience were no match for the emerging technology of the later twentieth century. I'm sure she would have asked for a refund for the unpleasant journey she was forced to join. Why wouldn't her knowledge work for her?

It's easy to slip into self-martyring behavior. On occasion, I did it myself when the overwhelm of dealing with so many systems caught up with me. Denise Brown, of Careyearsacademy.com , has assessed that caregivers have to navigate 17 different human systems, including everything from their own nervous systems to medical and legal systems, all the while learning new technologies in order to take care of an adult. That's a lot of negotiating for one person. All of that stress could happen in the space of a morning.

I did not realize how close my mother was to the end of her life. She died at 71 a few months before my dad, so weak she could not leave her bed. He died at 80, a couple of months later, but not before I jumped in to try to fill her impossible shoes. And I hear this story over and over from daughters who try to pick up where their moms had to leave off.

I think if more people – women especially –went into caregiving with their eyes wide open and were able to ask for what they needed from society and other family members, the situation for everyone, families and professionals alike, would improve greatly. It is not sufficient for us to rely on the unexamined, well-meaning emotional responses of (mostly elderly) women who provide care.

The saddest of all was that my mother didn't survive her caregiving hardships. After she died, a mere two and a half months before my father, I realized that I didn't want this to happen to me.

Please don't try to fool yourself that your situation will be different. If you join a support group, in person or online, you will hear these issues repeated over and over. You aren't alone, and you can explore other options. That's where hope comes in.

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Looking back, I realized I was an emotional caregiver. I meant well, believing I could take care of anyone. I also felt sure that I should take care of anyone, so I didn't stop to think about what obstacles I might face or what I could do about them. Now that I understand both what motivated me and how much it was costing me to ignore myself, I moved over to a rational understanding of the caregivers' role that allowed me to set boundaries and stop acting on feelings and to try to respect them instead. I became a thinking caregiver because I wanted to thrive in my own life. Regrets? Only that I wish I had understood this earlier in my life.

What awaits you at the end of a journey such as this is the ability to care for others while maintaining a healthy boundary that allows you to care for yourself. Those boundaries will protect you from feelings of guilt and shame when someone else asks for more than you are willing to give. You will live securely in the knowledge that you're doing the "right" thing by protecting *your* limits, *your* health, your life.Even an explorer like Anthony Bourdain, who was willing to risk eating street food everywhere, had a few rules for smart consumption!

In the following chapters, we'll delve into my Rational Caregiver Framework, starting with where you are right now. How strong and organized do you feel if you're considering this journey of caregiving with a loved one? Whether it's love, honor, obligation, or duty that motivates you, it is a job. What are the working conditions you expect to live with?

Though it may seem impossible to give so much of yourself while still maintaining boundaries, I promise you that it can be done.

Let me show you.