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How Caregivers Develop Resilience: A Framework for Family Caregivers and Supporting Professionals

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BY AARON BLIGHT, EDD



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There are more than 53 million caregivers in America today (AARP & NAC, 2020). Despite the widespread prevalence of caregiving, family members who assume the caregiver role frequently find they are unprepared for the physical and emotional demands of caregiving. In contemplating the changes that caregiving has ushered into their lives and relationships, it is not uncommon for family caregivers to ask a question: *How do I keep doing this?*

Sometimes the immediate response to this question invokes a checklist of tasks. “Do these things,” the suggestion goes, “and you’ll get by.” While caregiving

certainly encompasses a lengthy list of tasks, ceaseless checkboxes will not produce the mindset that caregivers must acquire to successfully support a loved one over the long trajectory of caregiving. Physically, caregivers can try to take care of themselves by getting plenty of sleep, exercise, and good nutrition. They should also be able to ask for help unabashedly when they need it. But even these foundations of critical preparation are often not enough to maintain a healthy outlook.

Caregivers must develop resilience — the ability to cope with difficult circumstances — in order to overcome adversity, avoid getting overwhelmed, and continue to address the evolving requirements of a loved one in need. Resilience is more than the action required to “power through” tough situations; it’s a result of the belief that a person can survive, and possibly learn to thrive, in unexpected challenges. In fact, research shows that a growth mindset leads to increased psychological resilience (Boullion, Withers, & Lippmann, 2021).

Changing the mindset about caregiving can help caregivers who are struggling to build their resilience. When caregiving is viewed as a learning process that introduces change and ultimately leads to growth, a caregiver will find it easier to perform care-related tasks — not because the tasks are different but because the caregiver’s mindset is different.

In light of the above, I am happy to introduce a framework that helps caregivers establish the mindset needed for ongoing care-related service to their loved ones. Caregiver resilience is developed across five domains of the care experience represented by “R” words: Roles, Relationships, Realities, Rewards, and Readiness. Let’s review each of these building blocks of caregiver resilience.

Roles

Roles are positions we occupy in the social world. Roles are central to our human relationships, our place in society, and our concept of self. “Care receiver” is among life’s least-coveted roles. And yet we know that caregivers don’t exist without care receivers.

In Chapter Two of *When Caregiving Calls: Guidance as You Care for a Parent, Spouse, or Aging Relative* (Blight, 2020), I describe caregiving by using the metaphor of a stage play, borrowed from the seminal writings of sociologist Erving Goffman (1959). In a caregiving play:

- the care receiver is the star of the show,
- the script is written by the care receiver’s health conditions, and

- the caregiver is a supporting actor.

With caregiving, nobody knows precisely how the script will unfold. Nobody knows exactly when the final curtain will fall. We do know, however, that when the show is over, the star performer may not be there to take a bow.

While every caregiving storyline is unique, the care receiver and caregiver are always, respectively, the primary and secondary roles in an unfolding drama. Understanding the nature of these roles is a foundational part of being able and willing to continue service as a caregiver.

Relationships

Caregiving changes relationships. While this can be disorienting and unwelcome, it’s among the most important things for caregivers to realize as they seek to meet the ongoing needs of a loved one who is aging, sick, or disabled. By recognizing that relationships are changing, caregivers are also uniquely positioned to honor their relationships with care receivers.

Chapter Three of *When Caregiving Calls* presents research from applied gerontology suggesting that family caregiving is marked by a series of role-based transitions, which start from an initial set of family relations and change over time due to changes in the caregiving context (Montgomery & Kosloski, 2012). As the care receiver’s needs become greater, the caregiver’s actions must change — and this changes the caregiver’s role identity within the relationship.

The relationship history between caregiver and care receiver becomes intertwined with, or perhaps subsumed by, the tasks of caregiving that are now being performed. Caregivers can reach the point where they ask themselves: Who am I now in this relationship? Amid such profound changes, the historic family relationship continues to shape the caregiver’s motivation and approach to providing care. Honoring relationships is thus a critical component of caregiving.

There are three steps to honoring relationships while caregiving:

- **Remembering** your historic relationship with your loved one,
- **Acknowledging** that things are changing due to your loved one’s health conditions, and
- **Adapting** to the terms of an emerging care-based relationship with your loved one without forgetting the history you share together.

Adapting to the terms of a new care-based relationship could involve uncomfortable topics of

conversation concerning your loved one, the performance of caregiving tasks you never had to do before, and/or spending more (or less) time together. As the needs of care receivers continue to evolve over time, caregivers must make corresponding adjustments. Through it all, family caregivers remember in their minds and hearts that the person they're caring for is special.

Realities

Family caregivers often report that caring for a loved one is among the hardest things they've ever done. Until you've assumed the responsibilities of caregiving, you're probably unaware of the multi-faceted commitment that must be made to meet the ongoing needs of a loved one who depends on you. Nevertheless, when caregiving calls, you eventually discover how the physical, emotional, relational, and spiritual dimensions of caregiving can cause deep distress and dissonance in your life.

Caregiving has a way of rudely introducing you to things you never wanted to think about. You may choose to ignore some of these things, preferring to avert your eyes from the stark view in front of you. Avoidance can become a default position because it may be more comforting to choose not to think. Denial is a related but slightly different strategy: you know what may occur but refuse to accept that it applies in your situation. Another approach is busyness, where you can be so focused on your to-do list that you don't have time to manage the tough stuff.

As difficult as it may be, the best way to handle the hard realities of caregiving is to confront them. Here are five hard realities that are commonly found when caregiving:

1. Bodies fail.
2. Sometimes the treatment is worse than the disease.
3. Caregiving causes stress.
4. Caregiving can be an emotional roller coaster.
5. Death happens.

Every caregiver will face a unique set of hard realities. However, when caregivers honestly confront the most troubling aspects of their experiences, they place themselves in positions to find support and solutions that will help them deal more effectively with their challenges.

Rewards

Caregiving offers rewards that you don't necessarily expect amid the struggle of providing daily service to

a loved one. The rewards may pop up in a single moment, or they may become perceptible only after the long, arduous slog of care is over and your loved one is no longer with you. Often the hardest things to do are also the most rewarding things to do, and caregiving reflects this reality.

Unfortunately, so much of our research has focused on the hard parts of caregiving, like burden and stress, that social science has yet to develop a comprehensive and robust view of positive outcomes associated with being a family caregiver.

Are there rewards associated with caregiving? There most certainly are. Here is what three family caregivers told me about the positive dimensions of their service to loved ones:

- "Being a caregiver for my dad was the toughest job I have ever had, and yet what a privilege to be there for my parent during the last year of his life as he was for me during my first."
- "In my case, it was the fact that my mom had total confidence in me and there are no words to describe that feeling."
- "It was tough but caregiving did a lot for my soul. I was able to make sure he knew I loved him, not just in deed but in words. I was able to help him deal with his pain, and what an amazing feeling to know you have comforted someone you love. The greatest reward is being able to give back to him. He was my big brother and he did a lot for me and there is no price I can attach to how great I feel even now — that I had the opportunity to give back AND let him know I loved him so."

These heartwarming and profound thoughts are merely a sample of the responses I have received when asking family caregivers about the rewards they find in their caregiving experiences. Their insights never cease to touch me.

Caregiving is not wholly about illness, aging, disability, burden, and stress. Caregivers who persist in the role, despite its challenges, often discover the beauty from the ashes. Caregiving delivers moments you'll remember forever, lessons you'll apply to the rest of your life, and attitudes that will be permanently adjusted as a result of the experience. These are but a few of the significant rewards that caregiving offers.

Readiness

People don't receive certification or education to fulfill the family caregiver role. It's easy for caregivers to feel like they're not prepared to do what their loved one needs them to do. To improve their readiness to care,

wise family caregivers adopt a learning orientation to caregiving.

First, they seek information about their loved one's specific condition, including the diagnosis, prognosis, and potential treatment options. Such study will allow caregivers to understand what is happening to their loved one and discover what to expect over time.

Beyond the "book knowledge" that is acquired, caregivers must also learn how to handle unfamiliar challenges arising in connection with the tasks of caregiving. This can be anything — such as helping a loved one get in and out of a car, providing hands-on personal hygiene assistance, assisting with medications, or responding to dementia-induced behaviors. Often family caregivers feel most unprepared when they've never performed a care-related task before.

How do families learn to deliver the different

tasks of caregiving? The answer can be found in a study of staff members working in a care facility for people with dementia. The employees who worked at the facility were unskilled, direct-care aides who had not received specialized formal schooling in managing dementia-related behaviors. Despite their lack of formal education, the aides learned ways of effectively managing these challenging behaviors through their own process of "showing, guessing, and trying" (Beckett & Hager, 2002). This three-step approach can be summarized as follows:

- **Showing** involves a demonstration of what must be done;
- **Guessing** suggests a choice that is made amid the uncertainty of alternative approaches, and
- **Trying** is a "trial and error" process which allows

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Understanding ROLES involves making adjustments to an emerging caregiving story. Resilient caregivers learn what it means to fulfill a caregiving role. They know that the care receiver didn't choose to be in this position, and they adapt to the changing conditions of their loved one.

Honoring RELATIONSHIPS allows caregivers to nurture, and continue to be present, for the important people in their lives. While the functions of caregiving may change the nature of social interactions between participants, the historic relational bond between caregivers and their loved ones motivates resilient caregivers to continue to be there.

Confronting REALITIES enables caregivers to deal with the hard parts of caregiving. Instead of denial or discouragement, resilient caregivers realistically assess and strive to overcome the challenges they experience while caregiving. Although some things cannot be changed, acknowledging and embracing what is hard enables caregivers to endure and occasionally triumph.

Cultivating REWARDS opens the mind and heart to the good parts of caregiving. Sometimes adversity reveals unexpected blessings, such as personal growth, moments of joy, paradigm shifts, or enhanced relationships. Resilient caregivers seek and recognize the good even as they struggle with the bad.

Practicing for READINESS is how caregivers prepare themselves to offer appropriate support to their loved ones. Resilient caregivers are not innately endowed with the ability to deliver the tasks of caregiving; it is only through practice (trial and error) that they develop the sustainable capacity to do what is physically required for a loved one in need.



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you to evaluate the attempted approach and gather new information about what may or may not work.

Family caregivers essentially follow the steps of “showing, guessing, and trying” to develop their readiness to perform the caregiving tasks that a loved one requires. Showing, guessing, and trying gradually teaches caregivers how to handle their own challenging care situations more effectively.

It all comes down to the proverbial saying, “Practice makes perfect.” As caregivers practice performing requisite care-related tasks, they grow in their capacity to meet the needs of their loved ones — both now and in the future.

How Professionals Can Help Family Caregivers Increase Resilience

In consideration of the five domains of family caregiving described above, I created a model of caregiver resilience (see graphic on previous page). The model serves as a tool for caregivers and supporting professionals to impose a frame onto a caregiving situation, assess the implications, and determine where adjustments can be made that will lead to greater resilience.

There is a wide range of professionals who routinely engage with families in care-related situations. Social workers, counselors, and care managers have assumed responsibility to professionally support individuals and families through challenges associated with aging, illness, and disability. Skilled medical professionals treat their patients and interact with the families of the patients. Moreover, there are other professionals — such as attorneys, financial planners, clergy, Realtors, and funeral directors — who find themselves in discussions with families struggling to care for loved ones.

The model of caregiver resilience is a handy resource that professionals can use in a problem-solving dialogue with family caregivers. Professionals may facilitate such discussions through a three-step process of framing, prompting, and thinking, as follows:

- **Framing.** The professional presents the model of caregiver resilience, explaining it within the context of the family caregiver’s individual situation.
- **Prompting.** The professional asks questions and makes comments to help the family caregiver engage in thoughtful reflection.
- **Thinking.** The family caregiver and the professional “let their minds flow” about how the model can be applied in the family caregiver’s situation.

Note that the professional is instrumental in not only introducing the model but also joining with the family caregiver in applying the model to the care circumstances at hand. The model thus enables the professional to: 1) use shared language to analyze the situation with the family caregiver, 2) listen to the family caregiver’s thoughts, and 3) bring professional guidance to the discussion.

Both participants thereby engage in an exchange that has the potential to reshape the family caregiver’s mindset about caregiving, which is the key to building resilience. An effective discussion will produce insights as to how the family caregiver could approach caregiving more effectively. In turn, actions can be taken that will ultimately make the situation better for both the caregiver as well as the care receiver. The model may be revisited again and again to evaluate progress and identify new ways to foster resilience as care-related circumstances change and evolve over time. •CSA



Dr. Aaron Blight is the author of *When Caregiving Calls: Guidance as You Care for a Parent, Spouse, or Aging Relative*. He is the founder of Caregiving Kinetics (www.caregivingkinetics.com) and serves as an Adjunct Professor at Shenandoah University. Dr. Blight has served as a family caregiver, home care company owner, caregiving scholar, and leader at the Centers for Medicare & Medicaid Services. He may be reached by email at aaron@caregivingkinetics.com or by phone at 540-532-8282.

■ REFERENCES

- AARP & National Alliance for Caregiving. (2020, May 14). *Caregiving in the United States 2020*. Retrieved from <https://doi.org/10.26419/ppi.00103.001>
- Beckett, D. & Hager, P. (2002). *Life, work, and learning: Practice in postmodernity*. New York, New York: Routledge.
- Blight, A. (2020). *When caregiving calls: Guidance as you care for a parent, spouse, or aging relative*. Irvington, New York: Rivertowns Books.
- Boullion, A., Withers, M., & Lippmann, M. (2021). Mindsets: Investigating resilience. *Personality and Individual Differences*, 174, 110669, ISSN 0191-8869, <https://doi.org/10.1016/j.paid.2021.110669>.
- Goffman, E. (1959). *The presentation of self in everyday life*. Garden City, New York: Doubleday.
- Montgomery, R. J. V. & Kosloski, K. (2012). Pathways to a caregiver identity and implications for support services. In R. C. Talley & R. J. V. Montgomery (Eds.), *Caregiving across the lifespan* (pp. 131-156). New York, NY: Springer Science + Business Media.