

Drawing its title from Psalm 41 -"Blessed is she who has regard for the weak; the Lord delivers her in times of trouble" -Blessed is She delves into the lives of more than 60 women caring for elderly loved ones.

Blessed is She: Elder Care: Women's Stories of Choice, Challenge and Commitment

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# ***Blessed is She***

**ELDER CARE**

**Women's Stories of Choice, Challenge and Commitment**

# *Blessed is She*

ELDER CARE

Women's Stories of Choice, Challenge and Commitment

Nanette J. Davis, Ph.D.



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Blessed is She

Elder Care: Women's Stories of Choice, Challenge and Commitment

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## Introduction

*While I was caring for my parents, I fought to find meaning in suffering. After my caregiving days were over and colleagues began to experience the throes of parent care, they asked me how I survived. The answer I found was in the journeys described by mystics and shamans as well as in classic mythological and wisdom traditions that reveal suffering as a path to liberation if viewed as a spiritual discipline. These teachings frame **Caregiving** to provide an accessible, workable guide through this dreaded labyrinth.*

~Beth Witrogen McLeod, *Caregiving*, 1999<sup>1</sup>

### **The Caregiving Journey**

Caregiving has been rightly described as a journey. Beth Witrogen McLeod calls it a “spiritual journey of love, loss and renewal” that transcends the dread of physical decline and death. For most of us, the journey of caregiving for an elder begins with high hopes and a seemingly clear map that plots our course. For a time, it appears we are on track—the patient has been diagnosed and properly medicated. Our goal is to allow the loved one to rest content in this new state of illness, and step in as needed to provide help, companionship and counsel. But the map in our heads is poorly envisioned; it doesn’t always take us where we want to go. Instead of a straight road, we find ourselves blocked at different points, forced to reassess our goals, and wondering if we should have started this journey at all. The needs of the patient are draining our hopes, plans and energies. Our optimism has vanished and been replaced with frustration and a bundle of negative feelings about both ourselves and our loved one. Now, we have a sense of being lost—adrift, not knowing where we are going or what the final destination will be. It seems that living under the continuous pressure of giving care offers little more than a permanent detour from our normal life.

As our elder caregivers’ stories unfold, we trace their journey from hope to despair to eventual acceptance for their many losses. For most

caregivers the task is not easy. Before moving into the final steps of the journey—the place of love, forgiveness and compassion—caregivers must recognize and confront the terrible havoc that elder caregiving brings. This book is the story of their struggle to make sense of the journey, as well as to learn, grow and transcend the difficult, frustrating or painful experiences all caregivers have as they witness their loved one deteriorate and eventually die.

### **The Heart of Altruism**

The caregiving journeys I've studied involve more than personal accounts of hope, loss and acceptance. As the title of this work, *Blessed is She* suggests, family members who undertake this moral commitment come to it out of a sense of *altruism*—a term often used interchangeably with caring, serving, helping, giving and other forms of pro-social and unselfish behavior. Such acts of mercy typically are provided at the risk of family members' own happiness and well being.<sup>2</sup> The literature on altruism suggests that the enduring significance of altruistic acts involves a heightened sense of responsibility, a testimony to the ability to care deeply and a willingness to contribute to another person's enhanced quality of life, while sacrificing one's own preferences and needs.<sup>3</sup>

As early as the nineteenth century, scholars have indicated the profound significance of altruism for keeping society going. Without exception, some form of altruism exists in every society. Emile Durkheim, an early French sociologist, wrote that whenever individuals abnegate their interests in favor of service for the sake of others, they are engaging in altruism. No society could exist unless its members acknowledge and make sacrifices on behalf of each other. Altruism is not merely "a sort of agreeable ornament to social life," said Durkheim, but its fundamental basis.<sup>4</sup>

As a moral quality, *altruism* may also be viewed as a highly developed form of prosociality—the willingness to put the interests and needs of others above our own. As a form of empathy, *altruism* implicitly points to quintessential qualities of humanness, especially self-respect. In turn, acts of care motivated by self-respect are an intricate part of empowerment, healing and the capacity for presence.<sup>5</sup>

As we learn from reading *The Altruistic Personality* by Samuel and Pearl Oliner, even ordinary persons can risk their health and well-

being because they are called to undertake acts of human decency and kindness.<sup>6</sup> The caregivers described in this book may not be the heroic rescuers of threatened Jewish citizens of Nazi Germany that the Oliners depict in their penetrating study. However, caregivers do share with these rescuers certain similarities. Many of the caregivers we followed in this research believe they have a revered mission to serve. This necessitated overlooking the risks involved—the loss of careers and financial resources, even jobs, relationships and cherished activities—to carry out their subjectively defined personal commitment. In carving out new relationships and roles and redefining old ones, caregivers—similar to the rescuers of condemned Jews—learn to cultivate contacts and networks to support them through the ordeal, as well as to generate needed resources for the task.

In *The Heart of Altruism*, author Kristen Renwick Monroe defines altruism as “habits of caring.”<sup>7</sup> Such habits of the heart challenge the presumed inescapability and universality of the idea that only self-interest characterizes human nature. Altruistic acts essentially raise a basic moral question: Why does one person act out of concern for another, instead of pursuing individual self-interest? Moreover, how does this concern relate to a strong, often overpowering sense of obligation and responsibility? What essentially do we owe our loved ones—and at what cost to our own well-being? What boundaries can be placed around this self-imposed obligatory act of caring? And finally, at what point do presumably altruistic acts of caring degenerate into a pathological condition, where the self has been swallowed up by duty and responsibility? When does the ethic and feeling of caring become lost? In the chapters ahead, I show caregivers’ responses when confronting such questions, and how they eventually resolved or failed to gain closure on the contradictions they faced.

In my formal interviews with 61 elder caregivers—and informal conversations with hundreds of caregivers in all walks of life—I was deeply moved by their nearly universal feelings of responsibility. Not that this sentiment was an externally imposed norm dictated by a church, religious body or other institution. Instead, their acts of altruism—giving beyond measure—reflected internalized standards of conduct, which became a normal and everyday part of their value system. One source of

this overpowering sense of responsibility appeared to be their empathy for the other—a cognitive and emotional understanding of sensitivity to their loved one’s needs and feelings. These women also demonstrated an enormously strong sense of personal integrity that served as the motivator and rationale for giving. The idea that humans are motivated only by rational choice does not stand up among these caregivers. Most admitted they “had little or no choice,” but only a compelling sense that no one else could or would assume this responsibility.

### **Gender and Caregiving**

Are these perceptions of personal commitment to care for a disabled elder a socialized response restricted solely to women? Certainly, men find themselves equally challenged to give care to their aging mother or sick wife. But in our culture, primarily women are expected to take on the caregiving duties, and who are more likely to sacrifice careers, hopes and dreams to care for the younger—and in this case—older generation.

A special report by the Family Caregiver Alliance on the status of women caregivers emphasizes that although men also provide assistance, female caregivers may spend as much as fifty percent more time providing care than male caregivers.<sup>8</sup> Caregiving apparently involves explicit gender styles. Women are far more likely to intensify their care, investing more time and being more psychologically involved, especially for spouses. Men who give care to their wives take a different path, tending to delay retirement to bolster declining family finances. Moreover, women’s tendency toward intense care contributes to significant economic losses—a point we cannot overemphasize. Along with decreased work hours, failure to receive job promotions or training, being forced to quit their jobs or to retire early, women’s caregiving places a significant strain on their retirement incomes. Smaller pensions, as well as reduced Social Security amounts and other retirement payments are the consequences of both reduced hours on the job and fewer years in the workforce. Gender also matters: Women are much less likely to receive a pension than men, and when they do, their pension is about half what men receive.<sup>9</sup>

And, the toll that caregiving takes is not just a financial one. Higher levels of depression, anxiety and other mental health challenges are

common among women who care for an older relative or friend. One four-year study found that middle-aged and older women who provided care for an ill or disabled spouse were **six times** more likely to suffer symptoms of depression and anxiety than were women who were not caregivers.<sup>10</sup>

Compounding this dismal mental health picture, physical ailments are a common problem. More than one-third of caregivers provide intense and continuing care to others while suffering from poor health themselves. Elderly women caring for a loved one with dementia may be particularly susceptible to the negative health effects of caregiving, due largely to significantly less help from family members for their own disabilities.<sup>11</sup>

Aside from gender, consider the fact that minority and low-income caregivers face special challenges. For these caregivers, having access to paid sources of care is especially difficult. One study concluded that lower-income caregivers are **half as likely** as higher-income caregivers to have paid home health care or assistance to provide either support or relief from their caregiving duties.<sup>12</sup>

## **Nanette's Story**

Although every caregiver's story is uniquely her own, at the same time, each echoes that of other caregivers. As such, I have chosen to introduce the book with my own narrative. I weave my story throughout various chapters to demonstrate my personal connection to caregiving, and to emphasize how the road I have traveled is like that of so many others.

A heart attack in 1998 on Jim's 78<sup>th</sup> birthday alerted me to the precarious state of my husband's health. As he was wheeled into surgery by the "swat team" of intervention specialists, he continued a refrain I would hear for weeks: "I don't even feel as though I've had a heart attack; I can't believe I've had a heart attack." And once released from the hospital, he continued "business-as-usual" without taking the precautions necessary to avoid another attack, because, after all, he felt he wasn't at risk.

The doctor's initial prognosis was excellent—stent installed, patient stabilized, family relieved, job done. Jim resumed his normal life, seemingly without missing a beat. On the other hand, I was apprehensive and vigilant, fearing the worst, as he had waited to seek medical care after his

initial symptoms, thinking the pain and lethargy would pass. Less than four months later, the day after Thanksgiving, with all the family assembled at the house for the holiday, we received a call from the hospital. Jim had had another, more serious heart attack, after collapsing on the first hole of his favorite local golf course. Hope appeared futile; the crisis had begun.

Over the next few years, as his condition deteriorated, physicians continued to add more drugs to his cornucopia of medicines, and attempted different treatments—all to no avail. Medical crisis followed medical crisis. Trips to the hospital, as well as to various doctors and care centers accelerated. I was in shock, as were our children. What can we expect? Will our beloved husband and father emerge from these trials alive or dead? We did not know then that the answer would be: both alive and dead. Jim was alive, in that his heart beat, he retained the power of speech, he ate (little), slept (even less) and eliminated. But he was dead, as well: dead to the significance of his relationship to self, family, friends and the world. Dead to cherished roles, dead to a life commitment to scholarship and writing, dead to independence and creativity, dead to physical wholeness, dead to the possibilities of a future or even a present that has meaning and purpose. He survived, but without strength, without joy, without courage, and most tragically, without hope.

This personal tragedy started me on a journey that has brought much grief, yet much heart-opening wisdom. I have experienced an intense adventure that has taken me deep into the recesses of myself and my capacities for coping, as well as opened my eyes to the profound contradictions surrounding elders within our culture.

## **What's Ahead**

Our society remains wholly unprepared for the vast number of elderly persons—ten times greater than in 1900, for instance—and their end-of-life needs that further threaten the already precarious American medical institutions. Outside help from family and communities is not up to the task. We are indeed facing a caregiving crisis of major proportions as the baby boomer generation moves into retirement. The elder caregiving deficit—too few people to support the primary caregiver—is a major reason family caregivers feel so overwhelmed.

Talking with caregivers about their burdens, one is reminded of the medieval fable of St. Christopher, who, offering to take a small child across the river on his back, was confronted with a wholly different reality. At first, the child appeared to weigh nothing at all, but as the saint laboriously pushed his way against the current—more fearful each moment they both would drown—the tiny burden became oppressively heavier. The saint could only groan and bewail his fate. Once Christopher successfully navigated the passage, exhausted, he turned to the small one, and asked: “Who are you?”

“I am the Christ Child,” he replied. “Whoever takes up my burden will be heavily laden.” The story depicts the ultimate price of love and altruism: To give oneself so completely to humanity, whether that sacrifice is collective or individual, implies that survival of self becomes intricately linked to the well-being of the Other.

Drawing its title from Psalm 41 -"Blessed is she who has regard for the weak; the Lord delivers her in times of trouble" -Blessed is She delves into the lives of more than 60 women caring for elderly loved ones.

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