



THE CENTER FOR  
PUBLIC JUSTICE



# *Called to Care:*

---

**Honoring Elders &  
the Family Care Journey**

---





# Called to Care

## HONORING ELDERS AND THE FAMILY CARE JOURNEY

By: Amy Zietlow

### TABLE OF CONTENTS

7	Introduction: Invisible Superheroes
9	Section 1: The Face of Today's Family Caregiver
22	Section 2: The Virtue of Aging and Elder Care
26	Section 3: Institutional Support for Family Care
29	Section 4: Congregational, Workplace, and Policy Recommendations
38	Conclusion: Seeing and Supporting Family Care Superheroes
39	Author's Acknowledgements
40	Endnotes



# ABOUT THE CENTER FOR PUBLIC JUSTICE

The Center for Public Justice (CPJ) is an independent, non-partisan, Christian organization devoted to policy research and civic education. Our mission is to equip citizens, develop leaders, and shape policy to serve God, advance justice, and transform public life. Learn more at [CPJustice.org](http://CPJustice.org).

Families Valued, an initiative of CPJ, researches and promotes public policies and workplace practices that honor God's call to both work and family life. Learn more at [FamiliesValued.org](http://FamiliesValued.org).

## ABOUT THE AUTHOR

**Amy Zietlow** is ordained in the Evangelical Lutheran Church in America. She is currently pastor of Holy Cross Lutheran Church in Decatur, IL and serves as a Conference Dean for their region. She is a former hospice chaplain and COO of The Hospice of Baton Rouge. Her writing has been published in *The Atlantic*, *Slate*, *Huffington Post*, and *The Christian Century*. As an Affiliate Scholar with the Institute for American Values, she led a three-year study on Generation X caregiving and grief, culminating in the publication of several co-authored articles and of the book *Homeward Bound: Modern Families, Elder Care and Loss* (with Naomi Cahn).



# INTRODUCTION

## Invisible Superheroes

The members of Holy Cross Lutheran Church gather for worship at 9:15 a.m. every Sunday. The pews are filled with family care superheroes on different types of care journeys.

A 60-year-old son is on the **roller coaster** of family care. He sits next to his 85-year-old mother, who lives independently but suffers from the side effects of congestive heart failure. She manages her day-to-day schedule well until a fall or other emergency throws everyone into a tailspin. He wonders when the next crisis will happen.

A 49-year-old spouse grieves her husband who died after an intense month in hospice care. She and her two daughters experienced the **deep end** of the family care pool. They rarely left his side for that month. They did everything from managing his pain to completing a will to reminiscing about his life as they sat vigil at his bedside.

A 57-year-old daughter is on the **marathon** of family care. She will spend the afternoon with her father, who lives in a local nursing home. She will sort his laundry for the week, play a modified game of dominoes, and, if it is a good day, he will remember her name and that she is his daughter. She has been caring for him and witnessing his slow and persistent cognitive decline for more than a decade.

Approximately 41.3 million Americans provide unpaid elder care,<sup>1</sup> and that number is set to grow substantially as the baby boomers become our next generation of elders. At first glance, the congregants look like ordinary mothers and fathers, daughters and sons, but they are family caregiving superheroes. Many juggle full-time jobs with private care responsibilities, and they must be willing to transform into “Captain Caregiver”<sup>2</sup> at a moment’s notice. They spend, on average, nearly three hours a day providing care,<sup>3</sup> and can spend nearly \$7,000 per year<sup>4</sup> on out-of-pocket expenses related to caregiving. Their love for their family is great, but the burden of care is great, too. They exhaust their physical, mental, financial, and spiritual resources in order to care.

### Rollercoaster



### Deep End



### Marathon



This report proposes pathways to better support modern family caregivers of elders. The report unfolds in four sections.

**Section One** raises the visibility of family caregivers and the common care journeys they follow: the roller coaster, the deep end, and the marathon. We meet real families and learn about the unique challenges each care journey holds.

**Section Two** makes a moral and practical case for supporting family caregivers. Providing care for an aging loved one is a core Christian value, a critical responsibility for families, and the most cost-effective method for providing elder care for American society.

**Section Three** acknowledges that family care can be challenging and that institutions such as the church, the workplace, and the government have an important role to play in contributing to a family's ability to care.

**Section Four** offers recommendations for workplace and public policies that respond to the unique needs identified in the three common care journeys. Family caregiving can feel like a roller coaster, or the deep end of the pool, or a marathon, and each journey requires access to different types of support.

For the purposes of this report, “family care” and “family caregiving” is limited to care for elders in the final third of life. The family is the institution for the care and nurture of its members, and elder care is an extension of this lifelong relationship of interdependent support. Each member of a family, of any age, bears the image of God and thus holds intrinsic dignity that family members protect and enhance. Family care presumes that by God’s design we are created to be interdependent in every season of life.

Elder care holds unique challenges that are similar to but significantly different from caring for a child or providing life-long care for a disabled loved one. The elder care journey is always one of decline, whether rapid or slow, and, eventually, death is expected. An elder’s physical and mental capabilities may change or diminish, but their God-given worth does not. Care for an elder requires a trusting partnership between caregivers and care recipients: Caregivers must respect the care recipient’s wishes regarding medical treatments. The locations of care, and the people providing care, and care recipients must be able trust their caregivers to contribute to their ability to live fully and flourish every moment of life.

Elder care is a weighty vocation that requires the full support of families, congregations, workplaces, and the government, especially as the United States becomes an aging society. A potential care crisis looms on the horizon where an increase in elder care recipients will collide with a decreased pool of caregivers.<sup>5</sup> There is much at stake. If we respond to the needs of caregivers with wise and robust support, we will contribute to flourishing at all stages of life and honor families that give care as work. If we fail today’s caregiving families, we will not only increase the number of vulnerable elders, but also increase the number of caregivers depleted in time, money, and energy, thus creating a new vulnerable class.

It is time to *see* and *support* family care.

# 1. The Face of Today's Family Caregiver

The United States is fast becoming an aging society.<sup>6</sup> Fewer children are born,<sup>7</sup> adults are generally living<sup>8</sup> and working longer,<sup>9</sup> the desired norm is "aging in place,"<sup>10</sup> and diseases like Alzheimer's and dementia have become a major cause of death due to their connection with longevity.<sup>11</sup> This section brings these phenomena to life in three common family care journeys. We first define these three journeys and then follow families on them. I have encountered these families<sup>12</sup> in my role as a pastor and hospice professional.

---

**The elder care journey is always one of decline, whether rapid or slow, and, eventually, death is expected. An elder's physical and mental capabilities may change or diminish, but their God-given worth does not.**

---

First, we meet Karen and Debra, sisters on the roller coaster ride of caregiving. They have triaged the short-term care crises of their parents for more than a decade. Reduced employment hours, flexible work scheduling, and access to paid sick leave for caregiving have supported their care journey. Then, we meet Barbara and Connie, sisters who jumped into the deep end of caregiving when their father was admitted to hospice care. Paid family leave made possible the intense, one month of care he needed. Finally, we meet marathon caregivers, Connie and Bob, who care for Bob's stepfather, Matthew, in the early stages of dementia, and Kimberly and Missy, who care for their mother in the final stages of dementia. Flexible work scheduling, early retirement, and part-time employment make their caregiving possible.

## DEFINING THE THREE COMMON CARE JOURNEYS

The prospect of an aging society can be overwhelming without an organizing framework. A gifted and pioneering hospice and long-term care physician, Dr. Joanne Lynn, provides such a framework. Her research identified three common trajectories of decline in the final third of life<sup>13</sup> that bring insight into the needs of family caregivers.

The final third of life tends to be defined by three common care journeys:

## **The Roller Coaster**



### **LONG-TERM PERIOD OF SUPPORT REQUIRING INTERMITTENT PERIODS OF ACUTE CARE.**

Care recipients tend to live independently, but will experience periods of time when acute help or immediate intervention is needed. During those emergencies, the care recipient and caregiver work together to make decisions about medical treatments and the appropriate location of care. Neurological disease and general physical decline tend to define this journey,<sup>14</sup> which can last several years to decades. Palliative care often plays a supportive role in pain and symptom management for these diseases for which there is no cure. Caregivers must be willing to drop work and family responsibilities quickly to respond to a crisis. Advanced preparation can often help, but unexpected demands reign.

## **The Deep End**



### **SHORT-TERM PERIOD OF SUPPORT REQUIRING CONSTANT, ON-SITE, ACUTE CARE.**

Care recipients tend to live relatively independent lives until an acute crisis happens, such as a cancer diagnosis, a car accident, or a fall. This care journey can last a few weeks to several months, and it ends with death. Hospice is often associated with this type of care because it serves patients in the final six months of life. Approximately 1.43 million Medicare beneficiaries receive hospice care each year.<sup>15</sup> Family care tasks can require a high level of skill, such as dressing changes for wounds, bathing, catheter care, and managing opioids and other pain medications.

## **The Marathon**



### **LONG-TERM PERIOD OF CONTINUAL SUPPORT.**

Care recipients tend to decline in mobility and mental acuity slowly, but persistently, often including changes in personality. Dementia and Alzheimer's disease are common ailments. This care journey can last several decades. Families may use long-term care policies to fund institutional care, or contract with home health aides, sitters, or senior day care services to supplement the day-to-day care required by family members. About 5.7 million Americans live with dementia and Alzheimer's disease currently, and that number is projected to increase.<sup>16</sup>

These three care journeys were already prevalent in the late 1990s when Dr. Lynn observed them, and now, as our population of elders grows exponentially, it is hard to imagine a family that will not be shaped by one or more of these care journeys. The following stories bring these journeys to life.



## **DEFINING THE ROLLER COASTER: KAREN AND DEBRA'S STORY**

Karen and Debra are sisters, both in their 60s, both married, and both living several hours away from their father, who is a member of the church I serve as pastor and who resides in a local nursing home. Their family care journey, though, began with their mother about twenty years ago.

### **Returning to Illinois**

Karen and Debra's parents, Harold and June, were married for nearly 62 years and were long-time members of the church and residents of our small city in central Illinois. After Harold retired, they moved to a small retirement community in Florida. Karen recalls that it was around the year 2000 when the sisters began noticing a decline in their parents' physical abilities. "When we would visit, less laundry would be done." After their mother fell in 2001, resulting in a broken hip, their parents decided to move back to central Illinois. For the next decade, their parents lived in various apartments, with Karen and Debra visiting once a month to check on them. Gradually, the sisters started to help with bathing, doing and fixing their mother's hair, shopping for their parents, and cooking meals and freezing them. They put many miles on their cars.

In addition to their visits, the sisters arranged for senior services to make a home visit once a month. Counties across the states offer these types of services through local Councils on Aging or Health Departments. These visits were not in response to any acute needs, as a doctor's visit might be, but helped these long-distance caregivers monitor the general condition of their parents. Karen, a registered nurse, observed that when someone is sick, "they automatically get thrust into the health-care system and there's lots of eyes on them, but when you're not sick this is all happening in the home environment." Karen and Debra had to be detectives when they called, listening for fatigue or worry even when their father said, "Everything is fine." Monthly home visits by the community nurse helped them get a fuller picture of their parents' condition.

### **Transition to Assisted Living Care**

Then, in January 2010, Debra and Karen received a phone call from their father that began a new leg in their family care journey. He said, "I can't do this anymore. We're both in bed. I have a fever. I don't feel good." When Karen arrived several hours later, "Sure enough, they were both lying in bed, covers to their chins." Karen surmised that their father was just maxed out. She contacted senior services to do an exam on her mother to start the process for respite care at a local nursing home. To pay for this



stay, the sisters went into savings. Over three months, they paid \$15,000 dollars to have her there while their father “got stronger” and they figured out where they could live with more support. At that point, they took over his finances.

Their parents did not want to leave their hometown, and neither Debra nor Karen could imagine their parents moving in with them anyway. A local assisted living facility was the best solution, but the cost was daunting. In contrast to a nursing home, which is a skilled nursing facility, an assisted living facility is a non-medical home where a resident can pay for certain services but must retain a certain level of mobility to stay.<sup>17</sup> Debra recalled the trepidation she felt walking into the assisted living facility for the first time, “My legs were weak walking in there. I wondered, ‘How does this work? Here’s what he has financially. I want to support Mom and Dad, but we can’t be writing a six or eight thousand dollar check every month!’” The sisters cashed out their parents’ life insurance and an annuity of their father’s to pay for the care.

## **Transition to a Nursing Home**

Then, in early 2012, their father knew that a change needed to be made in their mother’s care. Harold had remained their mother’s primary caregiver in the assisted living facility, but she had several more falls. After each hospitalization she “would bounce back a little less high.” Karen described the conversation she had with her mother about moving to a nursing home as “the hardest thing I’ve ever done...I full well knew she was not ever coming back to their assisted living apartment. Dad knew it, too.”

Their mother qualified for the Medicaid Room and Board benefit,<sup>18</sup> and they were able to find a local nursing home that had an open Medicaid bed. Harold continued residing in the assisted living facility and visited her daily. The sisters continued their monthly visits until another crisis occurred on Halloween of 2012. Karen recalled the precipitating events.

Dad had brought her electric chair [to the nursing home]. She ejected herself out of it and hit her head on the floor. She fractured her collarbone, so she had to be in a neck brace. It was just downhill for the next two weeks. Then, a couple days before November 10, we got the call from the hospital, “She’s just not herself. She’s lying in bed and she doesn’t want to eat. Her urine output is down and blood pressure’s a little low.” She had a DNR (“do





not resuscitate" order). I said, "Okay, just keep her comfortable." We started visiting every day.

## Balancing Caregiving and Paid Work

During all the caregiving for their mother and their monthly visits to their parents, both Karen and Debra were working. Debra is a special education teacher in the



public schools and her husband is a firefighter. Karen is a registered nurse married to a social worker. Their children were teenagers and young adults during this decade of care for their mother. Their sons helped with moving their grandparents from Florida. Both sisters noted that the main stress has been weathering the care transitions. Those crisis periods are both expected, somewhat, and yet come out of nowhere. Karen said, "We see a possible change in location or level of care, but when it does come it's a smack in the face. You've got three days to move from here to there."

Karen recounted how being a hospital-based nurse has been a blessing in terms of scheduling time away to be with her parents. She works half time, which consists of three eight-hour shifts in one week into the next, working 40 hours in two weeks. She chooses not to work two days in a row because "if there's a code at 11:30 then I'm there till 1:00 or 1:30" so most eight-hour shifts stretch much longer. She works every other weekend, but "other than that my days are flexible . . . they can be moved." As a supervising nurse, she shares this role with six other supervisors, and they "all cover for each other." Her job flexibility has been the key factor enabling her to be responsive to her parents' sudden needs.

The hospital also offers short-term or intermittent "Leaves of Absence" (LOAs). After using a required number of vacation days, Karen explains, the leave "trips over into your sick bank. Once you get all the paperwork done, you make a phone call to the outsource agency and say, 'I'm needing my FMLA day.'<sup>19</sup> They call your employer and say, 'Karen can be gone tomorrow and the next day. She's taking it from her approved leave.'"

**“ The hardest thing I’ve ever done... I full well knew she was not ever coming back to their assisted living apartment. Dad knew it, too.”**

Karen's sister, Debra, balanced different pressures as a full-time teacher. Both sisters said that Karen did the brunt of the care for their mother because Karen had the reduced hours and flexibility that Debra did not. Debra could not leave her job as a



special education teacher on short notice, but she could cover weekends when Karen often had to work at the hospital. For Debra to take a day off during the week was a challenge because “when I left my students with multi-needs and autism, a sub came in who usually didn’t know what to do. It’s not that I’m indispensable, but those who know the students in these classrooms know their triggers. Sometimes, a sub can set off [a trigger], and they can destroy a classroom.”

In addition to their workplace leave benefits for caregiving, both Debra and Karen have needed leave for their own illnesses. Karen used her sick leave when, as a diabetic, she had an infection. Debra has used intermittent leave to recover from her chemotherapy treatments. She describes being careful with when and how she used her leave: “I never frivolously used my sick leave, ever, because I wouldn’t do that to my peers. I knew what kind of day they had when I wasn’t there with the students that we work with.”

## **Partnering in Decision-Making: From Assisted Living to Nursing Home**

After the death of his wife, Harold’s health stayed relatively stable, although the sisters noticed persistent, slow declines in mobility. Over the next few years, he developed benign positional vertigo where he had extended periods of dizziness and nausea. Debra or Karen called each day during these episodes to receive a status update. They would then text and email each other to debate whether they needed to go and assess the situation. They arranged for assistance in response to those changes. They scheduled twice a week showers with aides in the assisted living facility. The staff began assisting him with emptying his Foley catheter. He obtained an electric scooter through Medicare, which he used to get to the dining hall, the facilities’ activities, and even outside for fresh air. With me, his pastor, he arranged monthly communion services for residents, and would scoot through the

**[Debra and Karen’s] care journey highlights one of the biggest challenges of family care: honoring the decision-making capacity of a parent while trying to balance those wishes with what is best practice.**

halls posting flyers and giving personal invitations. All these additions of equipment and services (excluding communion!) had a cost. For example, Debra and Karen kept adapting his apartment at the assisted living facility to accommodate his electric chair. When he moved out, they had to rehabilitate the apartment at a cost of \$8,500 dollars, paid for by Debra and Karen.

In July 2018, they received another phone call that began yet another new leg on their caregiving journey. Harold called Karen and said, “I’ve got to leave. I need a nursing home. I need more care. They can’t care for me here.” Debra and Karen came immediately. They



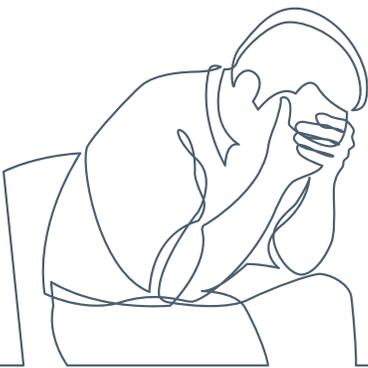
didn't want to discount their father's assessment, but they also didn't want to rush into another major life transition. Their care journey highlights one of the biggest challenges of family care: honoring the decision-making capacity of a parent while trying to balance those wishes with what is best practice. Jane Gross, the founder of The New York Times New/Old Age blog, described this paradox of family care, "[Y]ou never quite become your mother's mother. You increasingly get closer to that place, but as long as they're cognitively intact, part of the trick, I think, is taking over enough but not humiliating them."<sup>20</sup>

Debra described how the sisters had similar fears of infantilizing their father. "We want to give him the dignity of being able to make his own choices. While we do have power of attorney, he's still fully alert and cognitive functionally to make all of these decisions." While they were not confident that a move to a nursing home was the best choice, they did know that Medicare requires a two-night, three-day inpatient stay in the hospital in order to approve a change in a level of care. "While he's there, we've got 48 hours to figure out who can take him." Because he was eligible for the Medicaid Room & Board benefit, their options were limited to facilities with Medicaid beds available. They settled on a facility where the clinical care was good. However, they soon noticed that the facility did not house residents with his high level of cognitive functioning, and he was depressed.

## Finding the Right Home for Harold

Through a family friend, Harold discovered an alternative nursing home placement. Again, Debra and Karen received a phone call that would turn their lives upside down for a few intense days. In three days, they moved him to a new nursing home where his spirits improved quickly. He began scooting around in his wheelchair and enjoying

a limited amount of therapy. Through each transition, the sisters remain highly aware of the financial costs of family care. "Everything has a comma in the price. And where is this money coming from? Medicaid requires you to spend down. Dad gets \$30 a month, \$10 of which goes to getting a haircut. It takes more money than God to grow old in the United States!"



The sisters worry about what the future holds. Because Harold is no longer walking, physical and occupational therapy will soon end, and eventually, a Hoyer lift will be needed to transfer him. They will have to deal with the ongoing maintenance of the Foley catheter, which always holds a risk of infection. They will prepare for the future as best they can, but the experiences will be intense when they happen. They will care together as a family just as they have for the last nearly twenty years. Family care has bonded them to their parents and to each other in powerful ways. Karen tells Harold, "You took care of us,

---

now we're taking care of you." As before, they will be thankful for flexible schedules and leave policies that help make that care possible.

## THE DEEP END: BARBARA & CONNIE'S STORY

One of Harold's dearest friends, Melvin, is the care recipient in our next family care journey. Melvin knew Harold for most of his adult life. They had worked together in civil service and were members of the same church. When Harold and June moved back to central Illinois in the early 2000s, Melvin and Harold rekindled their friendship. At least three times a week, he visited Harold at the assisted living facility. They'd eat lunch, watch sports (they held a heated Cubs and Cardinals rivalry), and work on various "fix-it" projects together. Melvin repaired Harold's electric scooter on more than one occasion or patched dents and scratches Harold made on the walls and doorframes with the same scooter.

### The Sudden Diagnosis

While Melvin could drive, he walked with the assistance of a cane and dealt with pain in his back. His two daughters, Connie and Barbara, both lived in town. Barbara stopped by his home a few times a week and Connie saw him at least once a week at Sunday morning worship. He received ongoing treatments at a local pain clinic that included radiation treatments on the nerves in his lower back. He had an untreated tumor on his kidneys that, for several years, showed little to minimal growth. However, after a radiation treatment on his back in November 2017, he did not bounce back as usual. Connie and Barbara knew things were bad when he did not want to go to church. They took him for a scan, and "he was just full of it. Cancer everywhere." Melvin decided not to pursue aggressive treatments. He was admitted to hospice home care.



Over the last thirty years, end-of-life care has become increasingly associated with hospice. The hospice philosophy of care sees pain as physical, emotional, financial, and relational, thus hospice organizations utilize an interdisciplinary group of specially trained providers who respond to and treat dying patients' pain and other symptoms. They do not try to cure the underlying disease. Unlike all other expressions of medical care, the hospice approach considers the patient and family to be the unit of care. A person can only be admitted to hospice with a doctor's prognosis of life expectancy of six months or less. Kathryn Grigsby, retired CEO of The Hospice of Baton Rouge, explains "part of the requirement of receiving hospice care



is that the patient has a caregiver who is there with them because most patients in hospice reach a point when they are incapable of caring for themselves. They're not safe being left alone."

## Taking Time Off Work to Care

Barbara was working a full-time job that fall, but everything changed with the cancer diagnosis and hospice admission. She immediately told her boss, who said, "You need to be with your dad." Barbara's boss only had two employees and was not legally required to provide family leave. However, Barbara was given as much leave as she needed, and the leave was paid. Barbara admitted, "Having that time to be with my dad, without the added strain of not earning a paycheck, was truly a godsend, I don't think I slept for the whole month of December."

**“Having that time to be with my dad, without the added strain of not earning a paycheck, was truly a godsend, I don't think I slept for the whole month of December.”**

Barbara and her husband, Rick, were a caregiving team that December. They had already been living with Melvin that fall while Rick transitioned jobs, so they were able to be present in the home 24/7 and relied on other family members for breaks. Melvin's brother would stay for an hour so Barbara could run to the store or pharmacy. Her sister and brother-in-law, Connie and Bob, visited in the evenings and on weekends when they were not at their full-time jobs. Bob commented that both he and Connie were ready to go home at the end of their respite stints, "Even an hour could be exhausting!"

Melvin's church family also rallied around him and his family. As his pastor, I made visits to the home, bringing communion. Members of the congregation made treats for him, visited, wrote cards of encouragement, and prayed. Barbara observed his persistent decline each day that month. The day before Christmas Eve, Melvin fell asleep on the hospital bed provided by hospice care and did not wake up again. His family gathered around him and sat vigil until his death. Barbara reflected on her time as a family caregiver and said, "That month was one of the hardest of my life, but I wouldn't trade it for the world. . . It was an honor."



## **THE MARATHON: TWO STORIES**

### **BEGINNING THE MARATHON: BOB'S STORY**

At the same time that Barbara and her sister, Connie, were providing end-of-life care for their father, Connie and her husband, Bob, were beginning a long-term care journey with Bob's stepfather, Matthew.

In December 2017, the same month that Melvin was in hospice care, Connie and Bob began to notice behavioral changes in Matthew, who lived several hours away. "He was borrowing money, and his mind was slipping. With these symptoms of dementia, Matthew was on the verge of losing his apartment and his car. He had credit cards maxed out." They gave him an ultimatum: "Either you're going to move in with us or you'll end up on the street or under a bridge." There were no other family members to whom to defer so in March 2018, Matthew moved in with them. Bob and Connie adjusted their lives to accommodate Matthew's needs.

It's been a year of taking care of his bills and daily care. Eat, drink, take your medicine, and go to bed. We make him ride the bike. Get him to do his brain exercises. He's not very vocal, because he can't remember words. If he walked in here, he'd look at the Christmas tree and say, "That's a pretty, uh, that green bush there." The doctor taught us to give him clues, like "It begins with C" instead of just telling him what the word is. We'll watch Jeopardy and Wheel of Fortune. He usually just repeats the answers after I say them, but it's something. . . We got a diagnosis of dementia. He's in the early steps of stage four.

Connie works full time as a nurse at a local hospital and Bob retired last year. He manages care for his stepfather with a part-time job at a hardware store, but Connie and Bob worry about leaving Matthew alone—even for a short trip to the store. They installed cameras to monitor Matthew when they are gone.

### **The Challenges of Beginning Care**

Their first year of family care has been challenging. Now that Bob is retired, they had hoped to spend more time at the campground or being able to visit their kids in California, but as Connie surmised, "You gotta think of him." Matthew's care is now the main priority. They are thinking about the future. The doctor said "within a year, year and a half, we'll probably want to put him in a home. He hasn't started any personality changes or started to wander, but that's what will be coming." Bob and Connie also balance their own health care with Matthew's. At our interview, Connie was recovering from foot surgery and Bob was preparing for a second knee replacement surgery.



Bob and Connie stand at the relative beginning of a long family care journey. Matthew is one of 5.7 million Americans living with dementia or Alzheimer's disease.<sup>21</sup> Bob and Connie join the more than 16 million Americans providing care for people with Alzheimer's or other dementias.<sup>22</sup> Dementia and Alzheimer's disease tend to follow a long trajectory of slow but persistent decline in mental and physical ability.

## **IN THE MIDST OF THE MARATHON: KIMBERLY AND MISSY'S STORY**

Kimberly is a teacher in my daughter's school. Several months ago, she emailed me with questions about hospice admission criteria for her mother. I knew Kimberly only as a stellar teacher at that point and had no idea that she had been serving as a long-distance caregiver for her mother and two brothers for almost ten years. Once again, family caregiving superheroes are an invisible force all around us.

Kimberly and her sister, Missy, care for their mother, Margaret, who has lived with dementia for more than a decade, and for their two brothers who live with her. One brother, Wade, can be helpful with caregiving tasks, but he is not always reliable. He has high blood pressure, may have cancer, has a lot of pain but refuses to see a doctor, and so he self-medicates with alcohol. Their brother, William, has autism and has always lived with their mother. Missy and Kimberly understand that as he ages, his condition will most likely decline. For now, he can follow a checklist of tasks, but he is not able to make decisions should an emergency happen.

In the past two years, their mother's cognitive abilities have declined rapidly. Their biggest challenge lies in providing her the 24-hour supervision she needs. They wish they could afford to put her in a facility, but they do not have the means to pay for it. Qualifying for the Medicaid Room and Board benefit would require selling the house, which is William's home. "Being autistic, he needs the freedom. If he wants to crank up his music, he can. If he wants to stand there and laugh really loudly, he can."

### **The Managing Care Tasks and Costs**

About three years ago, Missy assumed their mother's power of attorney. They delegated bill payment and finances to a family friend, which helps the sisters avoid arguments with each other and their other sister who is not a part of providing care. Missy is the primary caregiver and decision-maker for their mother. She does the grocery shopping and stocks up the house with hygiene products. She also fields many phone calls from her mother each day. "She calls me constantly, or has William call me. Sometimes, it's a nice conversation. Sometimes, it's a little girl, crying, weepy. 'I want out of here. Will you please come save me?' I have to be honest with her and say, 'Mom, I'm at work.'" Missy has a way of calming her mother down and helping her redirect her thoughts.



Family care is a multifaceted job that requires a high level of physical, mental, and emotional energy. Kimberly lives several states away so she provides long distance family care. She tries to go home as often as she can to give her sister a break, but mostly she is a sounding board for her sister to process her experiences. “Every time the phone rings, I’m like, ‘Okay, is it a good day or a bad day?’ Then I just let her vent because she’s got to do that.” However, Kimberly worries about Missy’s own health.



## **The Hospice Respite Benefit**

Margaret was recently admitted to home-based hospice care. Missy and Kimberly are deeply appreciative that hospice includes a respite benefit through Medicare.<sup>23</sup>

Every 30 days, we can have five days of respite care. I call the hospice social worker on the 25th of every month. It takes five to six days for them to find a bed at a facility and for the social worker and nurse to complete all their paperwork. An ambulance picks her up and an ambulance brings her home. The stays are covered by the Medicare hospice benefit.

## **The Making Ends Meet and the Marathon**

While respite is a welcome resource, both Missy and Kimberly balance the hands-on care, decision-making, and stress of family care with full-time employment. Missy works as a full-time bank teller, which includes working every other Saturday, and as a grocery store clerk three nights a week. If she’s off on a Saturday, she may bring her mother to her house for the weekend in order to give her brothers a break. She brings her mother to church every Sunday. She uses sick leave or trades shifts with other bank tellers or grocery clerks when emergencies happen. She tries to schedule doctor’s appointments on federal holidays or on her half day off during the week, which she receives when she works a Saturday morning at the bank. Her bank offers unpaid FMLA benefits. Because of her tenure at the bank, she has four weeks of vacation, which she could use to fund leave.

Kimberly is a public school teacher, so she is able to visit during school and summer vacations. She admits that she is totally worn out when she gets back home from a visit. The administration at her school understands and supports her family care demands by providing flex time. She can text her principal and say, “I am on the phone with Mom’s doctors, can you guys handle the first 15 minutes of class?” If she has to step out of the classroom to deal with an issue, “somebody else steps in.”

Kimberly also serves as the union representative for her workplace, so she understands her leave options. “The Family and Medical Leave Act is for anybody

that needs it. It's not just for when you have a baby. . . We even donate sick days if we need to help somebody beef it up." Despite knowing what benefits for leave are available, Kimberly is reluctant to take it. Her reasoning echoed the perspective of Harold's daughter, Debra, also a public school teacher. "The issue with education is 'How are we gonna cover the classroom?' We're short on subs, and teachers are very invested in their students. We worry about our family and [our students] at the same time."

Both Kimberly and Missy know that long-term leave is available to them and that an extended leave is likely in the future, but they wrestle with getting the timing right. Kimberly even offered to retire a year early and move to Georgia to help Missy with

**“The Family and Medical Leave Act is for anybody that needs it. It's not just for when you have a baby.”**

their mother, but they anticipate the intensity of care to escalate in coming years. They decided to wait and use leave when their mother becomes bedbound. Kimberly and Missy are already tired, though, and they worry about what the future will hold. With dementia, the road of persistent decline keeps stretching out further into the future. "Mom is gonna be bedbound. It's not too far off."

All these stories demonstrate that whether responding to a crisis on the roller coaster of long-term physical decline, surviving the intense deep-end of the final month of life, or running the marathon of dementia care, family caregivers are often exhausted.<sup>24</sup> They exhaust their savings accounts to pay for nursing home care. They exhaust their minds<sup>25</sup> in thinking of new solutions to mobility, therapy, or residential challenges. They exhaust their bodies, often compromising their own health needs,<sup>26</sup> to remain present to a loved one in need. They exhaust their creativity in finding ways to balance work and care demands because all care journeys require periods of leave from employment. Despite their weariness, they are proud to be caregivers. Their faith traditions predispose them to care, to value aging and vulnerability, and to see giving and receiving care as times for flourishing. In the next section, we turn to the theological supports for family care.

## 2. The Virtue of Aging and Elder Care

As we explore the moral and practical case for supporting family caregivers, two fundamental Christian principles frame our discussion: first, flourishing as God's intent for humankind, and second, honoring elders as a familial and communal responsibility that contributes to human flourishing in all seasons of life. These principles are contextualized in the contemporary families we met in the three common care journeys described earlier.

### THE VIRTUE OF FAMILY CARE

All seasons of life—receiving and giving care, old age and youth, vigor and infirmity—hold the potential for flourishing. Theologian Miroslav Volf defines flourishing as “a life that is lived well,” like a “tree planted by streams of water.”<sup>27</sup> Flourishing is another word for peace or *shalom*.

*Shalom*, in Hebrew, is, according to Cornelius Plantinga, “universal flourishing, wholeness and delight—a rich state of affairs in which natural needs are satisfied and natural gifts fruitfully employed, a state of affairs that inspires joyful wonder as its Creator and Savior opens doors and welcomes the creatures in whom [God] delights. *Shalom*, in other words, is the way things ought to be.”<sup>28</sup>

The capacity for flourishing for people in all seasons of life, including old age, finds roots in the stories of creation, where we read that God created humanity in God's own image (Genesis 1:27). All people, of all ages and of all abilities, are made in God's image and are called to love God and love their neighbors. Elders especially are looked to for wisdom, leadership, and mentorship.

In a recent book, *Elders Rising*, pastor and long-time youth ministry expert Roland Martinson notes that elders play prominent, prophetic leadership roles in the Judeo-Christian scripture. He writes, “Scripture paints a realistic portrait of respected, able elders who are called to serve God and neighbor even as they experience life's pain and vulnerabilities.”<sup>29</sup> Abraham and Sarah were in their 90s when they claimed the promises of God through “faithfulness to God's claim on their lives, giving birth to a son, owning land in perpetuity, and becoming a blessing to all nations” (Genesis 17:15-22). Martinson profiles Moses and Aaron, Mordecai, and Job, all examples of a fullness of wisdom and a call to prophetic action that came later in life.

The New Testament also celebrates the call of elders to prophetic ministry. Mary's cousin Elizabeth and her husband Zechariah were late-life parents to John the Baptist. Elizabeth served as a safe haven for Mary after she learned of Jesus's impending birth. Elizabeth was filled with the Holy Spirit and shared in Mary's prophetic song proclaiming the redemptive and reconciling work of Jesus the Messiah (Luke 1:5-25; 39-80). After John's birth, Zechariah was also filled with the Holy Spirit and sang his own song of how this baby prepares the way for Jesus. These are just a few examples of how elders play a "generative"<sup>30</sup> role throughout Scripture, offering wisdom and prophetic insight into the world around them.



Every age, however, holds potential barriers to flourishing. For those in the final third of life, physical and cognitive decline, isolation, and financial stagnation are common barriers to flourishing, and if ignored, can lead to suffering. Family caregiving rises to meet these challenges. Karen and Debra draw on their life savings to ensure that their father lives in a safe and mentally stimulating environment while receiving the therapy he requires. Melvin spent the last month of his life in a home full of loved ones cooking for him, caring for him, and celebrating his life. Bob's stepfather might be homeless without Bob's insistence he move in with their family.

Margaret relies on four children to keep her safe, on a family friend to manage her money, on her church for fellowship, and on hospice professionals for physical care. Older adults must rely on their web of interdependent relationships to avoid suffering and find paths to flourishing.

## THE HONOR COMMANDMENT AND HUMAN FLOURISHING

The family is intended to be the first line of defense against suffering and the primary promoter of flourishing for older members. For Christians, this call to care is grounded in the Ten Commandments.<sup>31</sup> The commandment "Honor your father and your mother that your days may be long upon the land which the Lord your God gives you" (Exodus 20:12) establishes the family as the incubator for translating loving God to loving the neighbor.

The covenant to honor is shared by all people and explicitly includes both father and mother (Exodus 20:12; Leviticus 19:3), with daughters and sons equally responsible for the task and attitude of honor.<sup>32</sup> Honor—as described by Protestant, Catholic, and Jewish traditions—includes "serving them, helping them, and caring for them when they are old, sick, feeble, or poor,"<sup>33</sup> giving "them material and moral support in old age and in times of illness, loneliness, and distress,"<sup>34</sup> and accepting responsibility for managing, and sometimes actually paying, the costs related to custodial care, shelter,

and even certain medical treatments.<sup>35</sup> Honor is expressed in moments of crisis during the roller coaster of care, in the deep end of care until the time of death, or in countless day-to-day moments in the long marathon of care.

The responsibility to honor one's parents builds upon an understanding of mutuality and interdependence that is fundamental to healthy family care. Pastor Roland Martinson writes, "People were created to live interdependently. Life is what we share with each other. In the beginning, we are taken care of; then we can care for others. Then there comes a day when we will be taken care of again."<sup>36</sup> Kimberly spoke of this reciprocity when she said, "It's my turn to be there for [my mom] as much as I can be. She raised five of us, now we support her."

## RUTH AND NAOMI LIVE THE HONOR COMMANDMENT

**“People were created to live interdependently. Life is what we share with each other. In the beginning, we are taken care of; then we can care for others. Then there comes a day when we will be taken care of again.”**

The book of Ruth in the Hebrew Bible brings to life the beauty and mutuality of family care espoused in the Honor Commandment. This four-chapter book opens with Naomi and her husband, Elimelech, moving to Moab to escape drought and famine in Judah. In Moab, they marry their two sons to Moabite women, Ruth and Orpah. Immediately, all three men die, leaving three widows. Naomi decides to return to her people in Israel, and she urges her two daughters-in-law to return to their families in Moab. She advises them to no longer call her Naomi, but *Mara*, the Hebrew word for "bitter," for life has treated her bitterly. Ruth rebels against her mother-in-law's wish that she turn back, and instead pledges to honor and love her.

When they arrive back in Israel, their future looks bleak, but Naomi encourages Ruth to rely upon the social safety net set by the law for gleaning wheat from the fields. Ruth gains the attention of Naomi's distant relative, Boaz, who will become her husband. Naomi advises Ruth in her dealings with Boaz and by the end of the story, when her grandson, Obed, is born, Naomi has emerged out of bitterness to joy through her relationship with Ruth.

Ruth and Naomi embody both the spirit and letter of the Honor Commandment. Ruth provided monetary support to her mother-in-law and honored her with reverence and commitment. Naomi nurtured and mentored Ruth, advising her to find safety with women gleaners and to advocate for herself with Boaz, their family's kinsman-redeemer. Ruth and Naomi exemplified how honoring a parent extends beyond blood relations to the kin we gain by marriage or affinity.

## JESUS HONORS HIS MOTHER

Jesus also exemplified the Honor Commandment in one of his last words from the cross. Jesus recognized that he would no longer be able to fulfill the commandment to honor and support his mother. He turned to her and said, “Woman! Behold your son!” Then he said to the disciple, ‘Behold! Your mother!’ And from that hour the disciple took her to his own home” (John 19:25-27). Jesus asked them to adopt one another as family, and they did.

---

**‘Woman! Behold your son!’ Then he said to the disciple, ‘Behold! Your mother!’ And from that hour the disciple took her to his own home” (John 19:25-27).**

---

The book of Ruth and Jesus’s own life story exemplify how honoring our elders is a core responsibility for families and how social institutions, in the form of in-laws, friends, congregations, and neighbors, make fulfilling that responsibility possible. In the next section, we explore the roles and responsibilities of the church, workplace, and government during a family’s care journey.

### 3. Institutional Support for Family Care

Living the Honor Commandment is not easy. The Hebrew word for honor, *kibbud*, means “heavy or weightiness.” Because family care is both a weighty and honorable endeavor, sons and daughters are not meant to pursue it alone. Instead, God calls us to form social networks through which those tasked with heavy responsibilities can receive support. These networks may include siblings, aunts, in-laws, and step-kin. They also extend to congregations, community organizations, medical caregivers, employers, and our political community.

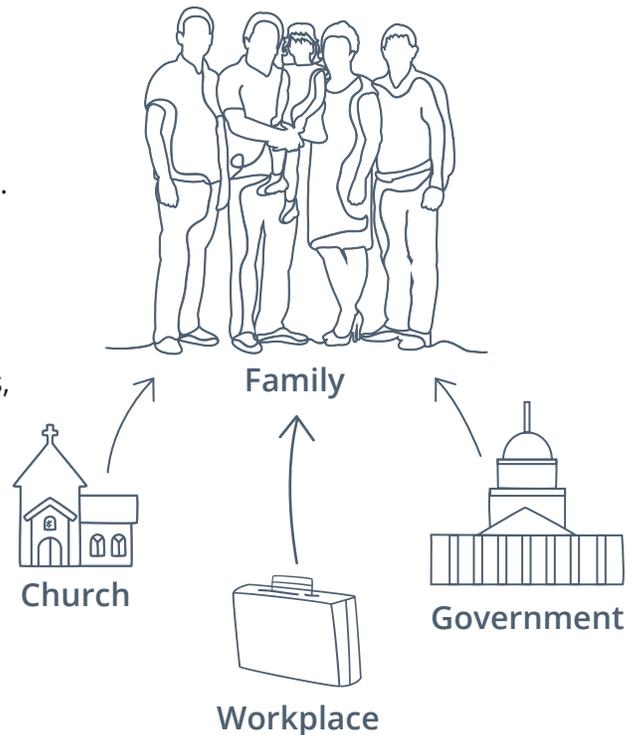
#### CRUCIAL INSTITUTIONAL ROLES RELATIVE TO FAMILY CAREGIVERS

##### The Role of Churches

In many Christian traditions, the church takes on the character of a family. It is a community in which members are brothers and sisters in Christ, called to regard one another with equality and to bear one another’s burdens (Galatians 6:2). Research,<sup>37 38</sup> indicates that caregivers who are connected to faith communities benefit from church involvement and the support of their congregations.<sup>39</sup>

Members of congregations can provide volunteer support that helps supplement the care of family members, and clergy may provide support as part of their pastoral role. Melvin and Harold formed a support network for each other because of their shared work history and church affiliation. As their pastor, I visited Melvin at his home during his weeks in hospice, and I followed Harold in and out of each residential facility. I was a participant in Harold’s formulation and sharing of his end-of-life wishes, and I was equipped to advocate for him should his daughters be delayed in arriving during a medical emergency.

Religious congregations offer a rare intergenerational place in society where care receivers and care providers worship and serve side by side. They are one of the few settings in which a person’s “invisible” caregiver status may be visible and supported.



Missy, for example, transports her mother Margaret to worship every week. Their church is a place of social and spiritual support, praying for them and supporting them in their care journey. Congregational ministry creates an environment where the potential for companionship and mutual support thrives,<sup>40</sup> and it is a space to raise and grapple with existential questions regarding death and end-of-life wishes.

## **The Role of the Workplace**

Karen, Debra, Connie, and Bob all balance family care responsibilities with full or part-time jobs. Between her hours at both the bank and the grocery store, Missy works more than forty hours a week in addition to caring for her mother, Margaret. Bob's part-time schedule, working 5am-9am on weekdays, allows him to arrive home when his stepfather, Matthew, wakes up so he can help him get dressed and fed. Bob is able to be present to Matthew's needs because of these work hours. These individuals are representative of the broader population of family caregivers. Three out of every five informal caregivers are in the workforce.<sup>41</sup>

For many caregivers, the ability to continue to work is critical to their own present and future financial stability. And the workplace may also serve as a place of social connection and identity that boosts caregiver resilience and well-being. Karen commiserates with and supports the other nursing supervisors, many of whom are caring for their parents as well.

Caregiving requires a careful negotiation between paid work and family care. Missy, for example, plans medical appointments with her mother on days that are work holidays or on her half days of compensatory time, which she receives for working Saturday mornings at the bank. The teachers I interviewed rely on siblings to handle many weekday caregiving tasks because their presence is so dearly needed and irreplaceable in the classroom. Those interviewed made careful decisions about utilizing or saving up precious paid time off days accrued at their place of work.

Kimberly was even willing to retire a year early in order to help Missy care for their mother. They also made conscientious choices between using paid sick days and medical leave benefits for caregiving events or for their own health and medical needs.



Workplaces can support family care by anticipating the inevitable occasions when family care calls employees away from work. When caregivers can draw on a reserve of paid sick, vacation, or other paid time off to respond to an emergency or attend a crucial appointment, their financial security is protected. Workplaces like Karen's that facilitate shift swapping empower worker-caregivers to meet their work responsibilities and meet the needs of their

families. When employers proactively communicate benefits and protections, they enable worker-caregivers to plan without guesswork or worry about putting their job in jeopardy.

## **The Role of Government and Public Policy**

Government has a vital role to play in fostering a healthy society and human flourishing. Good public policy supports primary social institutions such as the family, looks out for those who are most vulnerable in a society, and helps diverse social institutions work harmoniously.

Programs like the National Family Caregiver support program helps bring counseling, respite care, and support services to family caregivers, boosting their vital role.<sup>42</sup> The passage of the Social Security Act in 1935 and creation of Medicare in 1964 helped make a basic level of income and health care available to retirees. Both of these programs protect against the risk of economic vulnerability in the period of life in which one can no longer sustain oneself through work.

Other types of government action help mediate the relationships between major institutions—like the institutions of family and the workplace. The Family and Medical Leave Act (FMLA) is one such example. FMLA enables employees in companies with 50 or more employees to take up to 12 weeks of unpaid time off from work to care for their own or a family members' serious medical condition without fear of losing their job. Although some employers offer employees time to accompany a loved one through hospice without fear of losing their job as Barbara's workplace did, many do not. Since its enactment in 1993, FMLA has provided access to uncompensated, job-protected leave for more than 100 million US citizens.<sup>43</sup> This type of leave may be especially important for caregivers who are at the deep end of the caregiving journey and need to provide intense care to a loved one over a period of weeks or months.

As noted later in this report, government, with its role of mediating between institutions and protecting the vulnerable in a political community, needs to develop new tools to ensure that those who make significant commitments to family caregiving can remain financially secure. Without these tools, family caregivers risk their own well-being and capacity to retire in the process of caring for others.

## 4. Congregational, Workplace, and Policy Recommendations for Supporting Caregivers

Family care benefits both those who receive care and society in general. First, replacing this uncompensated family care with compensated care would cost approximately \$522 billion.<sup>44</sup> These are costs that might well require additional government expenditures. Second, family care meets cultural preferences to remain at home, with support by loved ones. And finally, family care benefits the caregivers, most of whom rate their experience as highly meaningful.<sup>45</sup> The family members interviewed for this report expressed a deep sense of meaning in the midst of the exhaustion. Connie said of her father, “It was an honor to take care of him. It was hard, but I would do it all over again in a heartbeat.” To serve in the role of caregiver is simultaneously heroic and one of the deepest expressions of one’s humanity.

**By 2030, the over-65-aged population will be 71 million strong.**

As already noted, the caregiving journey is a weighty one. Without support, family caregivers risk sacrificing their own health, well-being, and financial security in the course of their crucial service. Although public policy makers have taken positive steps in supporting family care, as have congregations and workplaces, significant gaps remain in supporting individuals who dedicate themselves to care. A growing aging population means an increase in the number of people in need of care. At the same time, some of the societal arrangements that once facilitated family caregiving are also shifting, resulting in potentially greater burdens on those who take up family care. In light of these shifts, even greater attention to the institutions that support family caregivers is needed.

### **DEMOGRAPHIC AND SOCIAL SHIFTS MEAN INCREASED PRESSURE ON FAMILY CAREGIVERS AND GREATER NEED FOR CAREGIVER SUPPORT**

In the next 20 years, 20% of people in the United States will be 65 or older.<sup>46</sup> By 2030, the over-65-aged population will be 71 million strong.<sup>47</sup> At the same time, the relationships and networks upon which caregivers and elders rely are under stress.

More baby boomers will reach age 65 without a spouse or adult child to rely on for care due to the numbers of individuals who are single, divorced, and have few or no children.<sup>48</sup> The decreased birth rate of the baby boomers has affected the old age dependency ratio. By 2050, there may be fewer than three potential caregivers for each elderly person,<sup>49</sup> thus compounding the burden on those who do undertake care. Second or third spouses and step-kin may increase the size of the caregiving pool, but those connections may also be weaker than biological connections.

These changes in family structure coincide with a general decrease in civic engagement in American society. Sociologist Robert Putnam, who first coined the phrase “bowling alone” to describe the baby boomer generation, worries that now they are “aging alone.”<sup>50</sup> As the web of “associational life,” comprised of families, communities, workplaces, and religious congregations, weakens, our capacity to face the challenges of aging weaken as well. More seniors will enter old age with fewer relatives and friends living in their neighborhood, and many may not be members of a religious community. This isolation increases their potential need for costly institutional care (recall how Debra noted that every cost in the nursing home includes a comma), and puts them at risk for abuse.<sup>51</sup> One in ten Americans over the age of 60 has experienced some form of elder abuse.<sup>52</sup>

**In the next 20 years, 20% of people in the United States will be 65 or older.**

Finally, more prospective caregivers are also in the workforce. A recent report from the Harvard Business School, *The Caring Company*, shows how family care is the new norm for today’s worker. In the employee survey, three out of four employees responded that they balance some form of care for a spouse or parent with their paid employment. These employees tend to be in their 40s, 50s, and 60s; they serve in management positions; and, depending on tenure, they hold a great deal of institutional memory and embody the ethos of the company or organization.<sup>53</sup>

---

**Sociologist Robert Putnam, who first coined the phrase “bowling alone” to describe the baby boomer generation, worries that now baby boomers are “aging alone.”**

---

Historically, women whose work was centered in the home may have taken on elder care responsibilities (once their own children had grown). Increasingly, women are bringing their gifts to workplaces outside the home. Even as labor-force participation for American women has climbed to nearly 75%,<sup>54</sup> women are still the overwhelming majority of caregivers.<sup>55</sup> Thus, the typical family caregiver is a 49-year-old woman caring for her 69-year-old mother who does not live with her.<sup>55</sup> This female family caregiver is married, employed, and most likely has children or grandchildren under 18 years old in her home.<sup>57</sup> Moreover, women tend to deal with the more difficult tasks of providing eldercare (bathing,

toileting, and dressing) than do men.<sup>58</sup>

Notably, in all of the family stories, a role was played by at least one family member who was in the workforce but not a full-time worker. For example, Karen works part-time as a hospital nurse while caring for her father, Harold. She works 40 hours every two weeks. This reduced work schedule, along with the ability to swap shifts with other nurses in her team, allows her to be present on relatively short notice when Harold's situation requires it. Because she is only obligated to work 40 hours every two weeks, she has much more "non-working" time to juggle than would a full-time worker who would struggle to find enough hours in a day to make up for time taken off for a caregiving emergency. Likewise, Bob, caring for his stepfather, Matthew, is retired and working part time. These part-time arrangements may provide crucial flexibility but mean bringing home less pay and, potentially, missing out on workplace benefits altogether, placing families in financial stress.

## INSTITUTIONAL SUPPORTS NEEDED FOR THE THREE CARE JOURNEYS

These dynamics compel us to pay special attention to supporting caregiving and caregivers so that families can fulfill their God-given role. We need new ways to encourage and enable family caregiving in our contemporary society. We need ways to help caregivers who are also in the workforce to be faithful to both work and care callings without exhausting themselves—emotionally, financially, and spiritually. This ideal requires the collaboration of multiple institutions. The family stories help to illustrate what is needed to accomplish this in different caregiving journeys.



For the **Roller Coaster** journeys, at least one family member needed to have the work flexibility to respond to emergencies. This is facilitated by a combination of benefits:

- An adequate supply of paid days off from work—whether categorized as sick days, vacation days, or paid time off (PTO)—that caregivers can access with ease and on relatively short notice; and
- Workplace systems that enable worker-caregivers to cover job obligations when they take time off for caregiving.



For those at the **Deep End**, there is often a concentrated period of intimate care. These caregivers can benefit from:

- Specialized medical support, such as hospice care or palliative care;
- Several weeks or months of paid family leave to enable periods of full-time care; and
- Respite care coverage to avoid burnout during intensive periods of care.



For the **Marathon**, a hybrid of all of these benefits may be needed at different stages of the caregiving journey.

- Because this caregiving journey is so extensive, caregivers need to protect and prepare for their own health events and, potentially, their need for medical leave.
- Some caregivers may reduce their paid work by shifting to part-time, no work, or less demanding positions. These caregivers need tools to protect their own financial security and ability to save for retirement.

How can congregations, workplaces, and public policy shift to meet the diverse needs of caregivers journeying along these caregiving paths? We take a look below at some essential steps.

## **Church Recommendations**

### **Recommendation: Congregations can provide resources for family caregivers.**

As an employer, congregations can take the lead in providing paid family leave to ordained clergy and to employees of the faith community. For example, the local congregation my husband serves provided paid leave to a member of their janitorial staff, including paying his transportation costs to spend time with his mother. This employee is highly valued by the congregation and staff. This choice reflects the congregation's commitment to honoring paid work and family work as equally dignified and holy.

As institutions, congregations can raise the visibility of family caregivers in congregations by publicizing the work of the local Council on Aging, AARP resources, The Caregiver Action Network, Family Caregiver Alliance, National Alliance for Caregiving, and the Alzheimer's Association. Congregations can raise awareness of elder abuse. With 10% of those over the age of 60 experiencing some form of abuse, those at risk are sitting in our pews.

Congregations can also provide a volunteer support network for care recipients and caregivers. A member could serve as a health navigator or community health worker. These volunteers are trusted mentors who specialize in communication between the care recipient and the medical world. Congregations can employ a Parish Nurse or Deacon who focuses on the care needs of the elderly and sick in the congregation. Congregations can invest in or publicize the work of the Stephen Ministry, the National Volunteer Caregiving Network, or the Shepherd's Centers.<sup>59</sup> These visitation programs can reduce the isolation of elders, provide transportation for homebound individuals, and offer counseling and emotional support to family members. An

**Visitation programs can reduce the isolation of elders, provide transportation for homebound individuals, and offer counseling and emotional support to family members.**

emerging set of congregation and faith-based programs provide respite for caregivers by offering individuals living with dementia a safe and supportive place for activity, care, and worship.<sup>60</sup>

Finally, congregations can welcome home "prodigal elders."<sup>61</sup> Sociologist Vern Bengtson, in his work on the generational transmission of faith and values, says that even though some elders may be "prodigals" for a time, in their elder years, many return to the flock. It will be

important to welcome these elders warmly, knowing that the church may play an important supporting role in their flourishing in the decades to come.

## **Workplace Recommendations**

Workplaces owe their employees a fundamental respect for their dignity and the dignity of their families. Respecting workers' full humanity entails respect for the various seasons of human life, including family care. Workplaces can fulfill this duty by enabling employees to take time away from paid work for crucial caregiving events and welcoming their return to the workplace after spending days or weeks focused on caregiving. As the need for elder care increases, it will be important for employers to anticipate and support caregiving by both male and female employees.

### **Recommendation: Workplaces should establish systems to enable flexible work.**

Proactive managers who assure individuals of their value to the workplace throughout their caregiving journey make a generous contribution to caregiver well-being. Likewise, managers who facilitate systems of flexibility empower their employees to fulfill their work responsibilities, even when they cannot be physically present at work. Kimberly, a public school teacher, texted her school principal if she was running late when on the phone with her mother's doctor or insurance provider. An administrator or aide at the school stepped in to cover her classroom for 30 minutes to an hour so that she could finish her care work. Karen, a hospital nurse, appreciated the collective support of the six other nursing supervisors who helped swap shifts so that she could continue to receive pay for her normally scheduled hours yet have the flexibility to spend several days transporting her father to doctor's visits or assisting him with care transitions.

Not all workplaces or job types offer the flexibility enjoyed by Kimberly and Karen. According to the National Study of Employers, published every other year by the Society for Human Resource Management, only 44% of employers allow some employees to have choice and control over which shifts they work.<sup>62</sup> Very few employers allow all employees flexibility options such as shift control. Yet embracing and operationalizing systems of flexibility would serve employers well in boosting retention. Sixty-nine percent of highly qualified female employees who dropped out of the workforce to be family caregivers said they would have stayed in the workforce if their workplace had arrangements that allowed for flexibility.<sup>63</sup>

**Reduced work schedules often enable a level of care and dignity that elder family members require.**

A best practice for workplaces is to establish flexible work agreements with employees.<sup>64</sup> These agreements stipulate the arrangement of work hours, location of work, or scheduling adjustments. Reduced work schedules often enable a level of care and dignity that elder family members require. The formality associated

with these agreements (and the process that goes into developing them) enables fair treatment across an organization's workforce. It also promotes clear lines of communication and expectation between employees, managers, and co-workers.

Workplace support for family caregivers must go beyond flexibility. Along each of the three caregiving journeys are events and seasons that require a caregiver's full-time attention for a short period of time, such as admission to the hospital after a fall or managing a change in residence. These periods of leave from a job cannot always be anticipated, yet responding quickly and adequately to a crisis is critical. When a phone call comes at 2 a.m., Debra and Karen know that they need to be ready to drive to their father. Many family caregivers rely upon paid sick, vacation, or paid time off (PTO) days to leave to handle the dips and turns of the care roller coaster or milestones in the marathon of care.

**Recommendation: Workplaces should provide adequate paid days off and enable their use for family care.**

Caregivers on the roller coaster of care need the flexibility and immediacy of benefits like sick or vacation days. Using sick leave helps regulate the amount of leave that can be taken, streamlines the process for requesting and receiving approval for leave, and enables employers to plan for staffing adjustments and to compensate for the loss in productivity for those days.<sup>65</sup>

Caregivers also need to be assured that these days are paid, lest they are forced to add "meeting monthly expenses with reduced income" to their lengthy list of things to do. Many workplaces provide time off in the form of either paid sick days and vacation days or paid time off packages that lump all paid time off (PTO) together and offer employees (and their managers) discretion as to its use. For worker-caregivers, the type of benefit is less important than its features.

First, paid time off should be offered to all employees. Currently, nearly three in ten private sector workers do not have paid sick days benefits, and access to paid sick days varies by job status. Employees in professional positions and those with health, education or human service occupations are more likely to receive paid sick benefits than are those in service, administrative, agricultural, construction, or manufacturing occupations.<sup>66</sup> Access also varies by wage level. Nearly seven in ten of the lowest-income workers do not have access to even a single paid sick day.<sup>67</sup> Altogether, more than 34 million US workers do not have access to this basic protection.<sup>68</sup> Absent workplace commitment to provide paid time off, lower-income workers find themselves doubly disadvantaged: less likely to receive paid time off as a workplace benefit and less likely to have access to savings or wealth to make up for lost wages when they take time off from work.

Second, workplaces that designate paid time off for sick days (as opposed to more general PTO) should affirm that the benefit can be applied to family caregiving. At

present, worker-caregivers receive mixed signals about this benefit. The vast majority of employers report that they allow employees to take time off to care for a family member. However, many employers also say that they take into account the purpose of paid time off before agreeing to grant it.<sup>69</sup> Faced with the prospect of case-by-case scrutiny from their manager or supervisor, employees may avoid using sick or vacation benefits even when they need to. Some states are addressing this problem by mandating any paid sick days provided by an employer be made available for caregiving responsibilities. Other states mandate provision of a certain number of paid sick days outright.<sup>70 71</sup> Regardless of the status of a state's law, employers should operate proactively to guarantee paid days off and affirm their use for family caregiving. AARP has set a model that could be followed, where employees accrue not only sick leave but also up to two weeks of care leave.

## **Public Policy Recommendations**

**Recommendation: Public policy should ensure adequate paid family leave for caregivers in the deep end.**

When Melvin received a cancer diagnosis and was admitted to hospice care, his daughter, Barbara, was thrown into the deep end of the caregiving pool. Melvin needed intensive care during his final weeks of life. It was more than a full-time job. Barbara's employer, upon hearing about Melvin's diagnosis, allowed her to take time off of work, which ended up being about four weeks, and to receive pay. "It was a Godsend," she said. During that month of care, Barbara's husband was in between jobs, so without Barbara's income that month, the couple would have needed to draw on savings or make other arrangements for Melvin's care. Their stress would have increased exponentially, and their mental and emotional attention would have been diverted towards financial needs and away from maximizing their precious time left with Melvin.

As mentioned previously, the Family and Medical Leave Act (FMLA) requires larger employers to provide 12 weeks of unpaid leave to care for one's own or a loved one's serious medical condition. Securing FMLA protections typically involves more documentation than does accessing paid sick days or PTO. But once granted, family leave can protect full-time or near full-time care of a loved one over the course of several weeks or months.

Adding a paid benefit to FMLA's protected family care time would support family caregivers, particularly those who find themselves in the deep end of the caregiving pool. FMLA protections plus a paid benefit means that employees, who could not otherwise afford to take time off, can spend the time with family that Barbara did. This is especially crucial for low-wage earners. Lower-income workers, earning under \$30,000 annually, report that they are less likely to take the family leave they need. When they do, they also report "taking on debt, putting off paying bills and going on public assistance when they don't receive full pay for their leave."<sup>72</sup>

Select states are beginning to adopt a paid leave program to complement FMLA.<sup>73</sup> As of 2018, six states and the District of Columbia had adopted some form of paid family leave. Each state offers different lengths of leave, but both full- and part-time employees, are eligible, without a waiting period. Structuring these programs varies from state to state; some build upon existing temporary disability insurance programs while others develop new programs funded by employee or employer payroll contributions.

A variety of paid family and medical leave policies have been introduced at the federal level. Some of these proposals would fill in FMLA-protected care for a family member with serious medical condition with a paid benefit. Projections based on existing state paid leave programs and FMLA indicate that family care leave will represent only a fraction of any new program.<sup>74</sup> Parental leave and personal medical leave are far more common.

Paid family leave for family caregiving should be included in any federal policy. Doing so would empower the necessary but intense periods of caregiving called for in situations like Melvin's. It would also lift the cost burden of providing weeks or months of paid leave from individual employers, some of whom may lack the capacity to self-fund extensive paid leaves. The public cost of such a program, by contrast, is relatively small.

**Recommendation: Public policy makers should develop new tools to aid those in the marathon of care.**

To meet the long-term needs of an aging loved one, 69% of working caregivers report making changes to their work schedules and accommodations.<sup>75</sup> These caregivers could be significantly compromised when it comes to their own retirement, income, job prospects, or savings. Over a lifetime, caregivers lose on average \$659,139 in wages, social security, and pension benefits that they would have otherwise received.<sup>76</sup>



Ensuring that family members who dedicate significant time to care are supported requires creative new tools. A full examination of these tools is beyond the scope of this report, but two approaches that deserve further exploration are family caregiver agreements and social security caregiver credits. The former is a private, intra-familial tool that families can currently use. The latter, refreshing our social security system to better reward the work of caregiving, is a much broader proposal implicating our whole political community.

Family Caregiver Agreements represent a private, family-based approach to compensating care work and enabling access to broader work benefits. FCAs stipulate

**To meet the long-term needs of an aging loved one, 69% of working caregivers report making changes to their work schedules and accommodations.**

pay for a family member to provide care. These agreements validate caregiving as work and, as such, enable caregivers to earn social security credits. In being compensated to provide care, a family member could also be eligible for disability insurance and worker's compensation.<sup>77</sup>

A caregiver agreement can enable a family care provider to reduce hours of paid employment if long-term caregiving is required. This arrangement can save money for the family as well as for the health-care system in the long run. Paying a loved one to care can mean the difference between staying at home, where most elders would prefer to be as they age, to being admitted to costly nursing home care.

FCAs may not be the best choice for every family and must be considered with care. Not all caregivers will be willing and able to provide extensive care. Many care recipients, like those described in the three care journeys, may not have the assets to pay a caregiver. But they represent a creative way to support the virtue of family care in the contemporary economy.

Marathon caregivers who anticipate a low to mid-grade level of constant care for up to and over a decade may need to reduce their work hours to part time or take an extended leave of absence. Being able to contribute to their own safe aging and retirement is critical; care for their loved one should not come at the expense of their own safe and honorable aging. Long-term caregivers need to continue to accrue social security benefits and have the ability to contribute to a retirement account during their years of care. Law Professor Richard Kaplan recommends deemed wage credits under Social Security as a way to stave off the intergenerational transmission of poverty.<sup>78</sup> Professor Don Taylor also advocates for allowing family care work to count towards social security credits, and he stresses that "women are disproportionately harmed" without them. Social Security Caregiving Credits could address this penalty for taking time to care. They can either limit the Social Security penalty for time spent out of the labor force to provide family care or require Social Security to deem the time off to provide care as paid for the purposes of receiving credit toward Social Security retirement income.<sup>79</sup>

The number and variety of potential congregational, workplace, and policy recommendations covered in this section reminds us that no one solution alone will work. Each family care journey requires different types and intensities of support, and one individual may need to access all of them over a lifetime. We need a multi-faceted approach to best honor our society's elders and honor the family members willing to care for them.

## CONCLUSION

# Seeing and Supporting Family Care Superheroes

Family caregivers are superheroes. By day, they may look like a coworker in an adjacent cubicle, a parent at a school meeting, or the widow sitting in the next pew, but when a loved one calls, they transform into chauffeurs, nurses, cooks, counselors, advocates, and cheerleaders for an aging loved one. This care holds great value to society. Practically, family care provides dignity for our society's oldest members as well as significant cost savings for society as a whole. Morally, care is the responsibility of families that honors the intrinsic worth and gifts of care recipients.

In our economically and efficiency-driven society, we risk overlooking the important gifts of our elders. But in reality, aging is and can be a period of human flourishing. Elders continue to bring their gifts to our families and communities during the aging journey, including gifts of teaching, prophecy, and faith. Each of these gifts can be further nurtured in family relationships. And those who take the time to provide care are blessed in turn.

—  
**The best superheroes lean on others just as much as others lean on them.**  
—

However, honoring an elder can be a weighty responsibility. In idealized stories, superheroes are written as singular forces making a better world. Real superheroes make their true impact within interdependent networks of compassion and care. The best superheroes lean on others just as much as others lean on them. Whether their care journey feels like a roller coaster, the deep end, or a long marathon, family caregivers are at risk of emotional, financial, and spiritual exhaustion as they balance both work and care and are tempted, often by necessity, to journey alone. We need congregations, workplaces, and public policies that honor and support these superhero caregivers. Employers, private citizens, church members, and government all have a part to play in contributing to a family's ability to care.

In the coming years, few citizens will be untouched by family care. People were created to live interdependently. Life is what we share with each other in all seasons and in all times. In the sunrise of our lives, we receive care. In the middle, we can care for others. In the sunset of life, we may receive care again. A flourishing society acknowledges this reality and provides support for families willing to care.

The time is now to see and support family care.

## AUTHOR'S ACKNOWLEDGEMENTS

A gracious thank you to all who helped make this report possible.

Thank you to the Center for Public Justice for recognizing the need for a report that focuses solely on family care for elders. Thank you to Stephanie Summers and Rachel Anderson for giving me the opportunity to research and write this report. Thank you to Chelsea Maxwell for her insights and research assistance. Thank you to Meg Henry and Rebecca Dimler for their creative design and promotion work.

Thank you to the family caregivers willing to be interviewed for this report. Your family stories are sacred, and I hope that I represented your journeys well. Any errors or misinterpretation are mine entirely. Thank you to Richard Kaplan, Naomi Cahn, Diane Meier, Amy Goyer, Laurie Vial, Kathryn Grigsby, and Don Taylor for your professional insights into the challenges and joys of family care. Thank you to Naomi Cahn for reading an early draft of the report. As always, your insights make my writing so much better. Thank you to Rachel Anderson, Chelsea Maxwell, Stephanie Summers, and Jessica Wright for your diligent and insightful editing.

Thank you, most of all, to my family. Both my mother and father are examples of the honor commandment writ large. You are an inspiration to me. Thank you to my husband, Michael, and our children, Thomas, Isabella and Luke, for all the ways that you care for me and allow me to care for you.

- <sup>1</sup> Bureau of Labor Statistics, U.S. Department of Labor, “Unpaid Eldercare in the United States. 2015-16 Summary,” September 20, 2017 <https://www.bls.gov/news.release/elcare.nro.htm>
- <sup>2</sup> I first coined the phrase “Captain Caregiver” in a blog post for the Institute for Family Studies blog, December 13, 2018 <https://ifstudies.org/blog/an-aging-society-needs-caregiving-superheroes>
- <sup>3</sup> Bureau of Labor Statistics, U.S. Department of Labor, “Time Spent Providing Eldercare, 2015–16,” September 27, 2017, <https://www.bls.gov/opub/2017/time-spent-providing-eldercare-2015-16.htm>
- <sup>4</sup> Chuck Rainville, Laura Skufca, and Laura Mehegan, “Family Caregivers Cost survey: What They Spend and What They Sacrifice,” American Association of Retired Persons (AARP), November, 2016, <https://www.aarp.org/research/topics/care/info-2016/family-caregivers-cost-survey.html>
- <sup>5</sup> Donald Redfoot, Lynn Feinberg, and Ari Houser, “The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” American Association of Retired Persons (AARP) August 29, 2013, <https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>
- <sup>6</sup> U.S. Census Bureau, “2017 National Population Projections,” September 6, 2017, <https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html>
- <sup>7</sup> Brady E. Hamilton et al., “Births: Provisional Data for 2017,” National Center for Health Statistics, Centers for Disease Control and Prevention (CDC), <https://www.cdc.gov/nchs/data/vsrr/report004.pdf>
- <sup>8</sup> National Center for Health Statistics, Centers for Disease Control and Prevention (CDC), “Table 14. Life expectancy at birth and at age 65, by sex: Organisation for Economic Co-operation and Development (OECD) countries, selected years 1980-2015,” 2017, <https://www.cdc.gov/nchs/data/2017/014.pdf>
- <sup>9</sup> Aparna Mathur, “The Baby Boomers Are Doing Just That. Booming,” American Enterprise Institute, February 8, 2019, <https://www.aei.org/publication/the-baby-boomers-are-doing-just-that-booming/>
- <sup>10</sup> National Institute on Aging, National Institutes of Health, “Aging in Place: Growing Old at Home,” May 1, 2017, <https://www.nia.nih.gov/health/aging-place-growing-old-home>
- <sup>11</sup> National Institute on Aging, National Institutes of Health, “Table 19. Leading causes of death and numbers of deaths, by sex, race, and Hispanic origin: United States, 1980 and 2016,” 2017, <https://www.cdc.gov/nchs/data/2017/019.pdf>
- <sup>12</sup> Interviews were conducted with each family. The names and identifying details of families have been changed to protect their privacy. All quotes were taken from the transcripts and lightly edited for grammar and repetitive words such as “er” or “um.” Similar to Naomi Cahn’s and my work on qualitative interviews in *Homeward Bound*, I used Donald Braman’s methodology in *Doing Time on the Outside* when addressing quotations.
- <sup>13</sup> Joanne Lynn and David M. Adamson, “Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age,” *RAND Health*, 2003, [https://www.rand.org/content/dam/rand/pubs/white\\_papers/2005/WP137.pdf](https://www.rand.org/content/dam/rand/pubs/white_papers/2005/WP137.pdf)
- <sup>14</sup> *Ibid.*
- <sup>15</sup> National Hospice and Palliative Care Organization, “Facts and Figures: Hospice Care in America,” 2017, [https://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2017\\_Facts\\_Figures.pdf](https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf)
- <sup>16</sup> Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 2018, <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- <sup>17</sup> National Institute on Aging, National Institutes of Health, “Residential Facilities, Assisted Living, and Nursing homes,” May 1, 2017, <https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes>
- <sup>18</sup> Medicaid, “Institutional Long Term Care,” (n.d.), <https://www.medicaid.gov/medicaid/ltss/institutional/index.html>
- <sup>19</sup> FMLA refers to the Family and Medical Leave Act which ensures job protection to workers who need time off for personal medical or family care needs. FMLA will be discussed in more detail in Sections Three and Four.
- <sup>20</sup> Jane Gross, “The Far Shore of Aging,” *On Being* with Krista Tippett, July 21, 2011, <https://onbeing.org/programs/jane-gross-the-far-shore-of-aging/>
- <sup>21</sup> Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 2018, <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>
- <sup>22</sup> *Ibid.*
- <sup>23</sup> Centers for Medicare & Medicaid Services, “Medicare Hospice Benefits,”(n.d.), <https://www.medicare.gov/pubs/pdf/02154-medicare-hospice-benefits.pdf>
- <sup>24</sup> M. Pinquart and S. Sörensen, “Differences Between Caregivers and Noncaregivers in Psychological Health and Physical Health: A Meta-Analysis,” *Psychology and Aging* 18 no. 2 (2003): 250-267.
- <sup>25</sup> Markay Hopps et al., “The burden of family caregiving in the United States: Work productivity, health care resource utilization, and mental health among employed adults,” *Journal of Multidisciplinary Healthcare* 10 (2017): 437–444.
- <sup>26</sup> Heidi Mochari-Greenberger and Lori Mosca, “Caregiver Burden and Nonachievement of Healthy Lifestyle Behaviors among Family Caregivers of Cardiovascular Disease Patients,” *American Journal of Health Promotion* 27, no. 2 (November 2012): 84-89, <https://doi.org/10.4278/ajhp.110606-QUAN-241>
- <sup>27</sup> Miroslav Volf, *Flourishing: Why We Need Religion in a Globalized World* (New Haven, CT: Yale University Press, 2015).
- <sup>28</sup> Michelle Kirtley, “Biblical Shalom and the Health Care Debate,” *Public Justice Review* 8, no.3 (2018), [https://cpjustice.org/index.php/public/page/content/PJR\\_vol8\\_issue3\\_article1\\_michelle\\_kirtley\\_biblical](https://cpjustice.org/index.php/public/page/content/PJR_vol8_issue3_article1_michelle_kirtley_biblical)
- <sup>29</sup> Martinson, *Elders Rising: The Promise and Peril of Aging* (Minneapolis, MN: Augsburg Fortress, 2018), 43.
- <sup>30</sup> Erik Erikson defined elderhood as a time stage of generativity. [http://journals.sagepub.com/doi/abs/10.1177/0164027514527974?url\\_ver=Z39.88-2003&rft\\_id=ori%3Arid%3Acrossref.org&rft\\_dat=cr\\_pub%3Dpubmed&](http://journals.sagepub.com/doi/abs/10.1177/0164027514527974?url_ver=Z39.88-2003&rft_id=ori%3Arid%3Acrossref.org&rft_dat=cr_pub%3Dpubmed&)
- <sup>31</sup> Much of my thinking on the Honor Commandment can be attributed to my partnership in research and writing with Naomi Cahn. Our full perspective on the twenty-first century expressions of the Honor Commandment can be read in *Homeward Bound*, and “The Honor Commandment: Law, Religion, and the Challenge of Elder Care,” in the *Journal of Law and Religion* 30, no. 2 (2015), 229-259
- <sup>32</sup> Gerald J. Blidstein, *Honor Thy Father and Mother: Filial Responsibility in Jewish Law and Ethics* (Brooklyn, NY: KTAV Publishing House, 2005).
- <sup>33</sup> Martin Luther, *The Large Catechism of Martin Luther* (Philadelphia: Fortress Press, 1981), 387.
- <sup>34</sup> Catholic Church, *Catechism of the Catholic Church* (London: Geoffrey Chapman, 1999).
- <sup>35</sup> Michael Fishbane, “Honor Thy Father and Thy Mother: Intergenerational Spirituality and Jewish Tradition,” in *Spiritual Resources in Family Therapy*, ed. Froma Walsh (New York, NY: The Guilford Press, 1999).
- <sup>36</sup> Martinson, *Elders Rising*, 69.
- <sup>37</sup> S. Burgener, “Predicting Quality of Life in Caregivers of Alzheimer’s Patients: The Role of Support from and Involvement with the Religious Community,” *Journal of Pastoral Care & Counseling: Advancing Theory and Professional Practice through Scholarly and Reflective Publications* 53 no. 4 (1999): 433-446.
- <sup>38</sup> P. Sun et al., “Racial Differences in Perceived Burden of Rural Dementia Caregivers: The Mediating Effect of Religiosity,” *Journal of Applied Gerontology* 29 no. 3 (2009): 290-307.
- <sup>39</sup> R. Schulz and J. Eden, eds., *Families Caring for an Aging America*, Washington, DC: National Academies Press, 2016.
- <sup>40</sup> S. Burgener, “Predicting Quality of Life in Caregivers of Alzheimer’s Patients,” 433-446.
- <sup>41</sup> Amalavoyal V. Chari et al., “The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey,” 2014, <https://onlinelibrary.wiley.com/doi/abs/10.1111/1475-6773.12238>
- <sup>42</sup> Administration for Community Living, National Family Caregiver Support Program, <https://acl.gov/programs/support-caregivers/national-fam->

ily-caregiver-support-program

<sup>43</sup> Wage and Hour Division, U.S. Department of Labor, “The Employer’s Guide to the Family and Medical Leave Act,” <https://www.dol.gov/whd/fmla/employerguide.pdf>

<sup>44</sup> Amalavoyal V. Chari et al., “The Opportunity Costs of Informal Elder-Care in the United States.”

<sup>45</sup> Gretchen Livingston, “Adult Caregiving Often Seen as Very Meaningful by Those Who Do It,” Pew Research Center, November 8, 2018, <http://www.pewresearch.org/fact-tank/2018/11/08/adult-caregiving-often-seen-as-very-meaningful-by-those-who-do-it/>

<sup>46</sup> Joint Center for Housing Studies of Harvard University, “Projections and Implications for Housing a Growing Population: Older Households 2015-2035,” December 13, 2016, <http://www.jchs.harvard.edu/research-areas/reports/projections-and-implications-housing-growing-population-older-households-2015>

<sup>47</sup> U.S. Census Bureau, “Decennial Census of Population and Housing: By Decade,” 2010, <https://www.census.gov/programs-surveys/decennial-census/decade.2010.html>

<sup>48</sup> Mark D. Hayward and Malay K. Majmundar, eds., *Future Directions for the Demography of Aging: Proceedings of a Workshop*, National Academies of Sciences, Engineering, and Medicine, Washington, DC, August 17-18, 2017 (Washington, DC: The National Academies Press, 2018) <https://doi.org/10.17226/25064>

<sup>49</sup> Jennifer M. Ortman, Victoria A. Velkoff, and Howard Hogan, “An Aging Nation: The Older Population in the United States, Current Population Reports,” May, 2014, <https://www.census.gov/prod/2014pubs/p25-1140.pdf>

<sup>50</sup> Hearing on the State of Social Capital in America, 115th Congress, May 17, 2017 (statement of Robert Putnam), [https://www.jec.senate.gov/public/\\_cache/files/222a1636-e668-4893-b082-418a100fd93d/robert-putnam-testimony.pdf](https://www.jec.senate.gov/public/_cache/files/222a1636-e668-4893-b082-418a100fd93d/robert-putnam-testimony.pdf)

<sup>51</sup> AARP Foundation, “Framework for Isolation in Adults over 50,” 2012, [https://www.aarp.org/content/dam/aarp/aarp\\_foundation/2012\\_PDFs/AARP-Foundation-Isolation-Framework-Report.pdf](https://www.aarp.org/content/dam/aarp/aarp_foundation/2012_PDFs/AARP-Foundation-Isolation-Framework-Report.pdf)

<sup>52</sup> R. Acierno et al., “Prevalence and Correlates of Emotional, Physical, Sexual, and Financial Abuse and Potential Neglect in the United States: The National Elder Mistreatment Study,” *American Journal of Public Health*, 100 (2010): 292-7.

<sup>53</sup> Joseph Fuller and Manjari Raman, “The Caring Company: How Employers Can Cut Costs and Boost Productivity By Helping Employees Manage Caregiving Needs,” Harvard Business School, 2019, <https://www.hbs.edu/managing-the-future-of-work/research/Pages/the-caring-company.aspx>

<sup>54</sup> Bureau of Labor Statistics, U.S. Department of Labor, “Civilian labor force participation rate, 25-54 years, women, seasonally adjusted, Raw data,” 2018, [https://data.bls.gov/timeseries/LNS11300062?include\\_graphs=false&output\\_type=column&years\\_option=all\\_years](https://data.bls.gov/timeseries/LNS11300062?include_graphs=false&output_type=column&years_option=all_years)

<sup>55</sup> Institute on Aging, “Read how IOA views aging in America,” 2016, <https://www.ioaging.org/aging-in-america>

<sup>56</sup> G. Hunt, L. Barrett, and S. Lutz, “Caregiving in the U.S., 2009,” National Alliance for Caregiving and AARP, 2009, [https://www.caregiving.org/data/caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](https://www.caregiving.org/data/caregiving_in_the_US_2009_full_report.pdf)

<sup>57</sup> Ibid.

<sup>58</sup> Ibid.

<sup>59</sup> Stephen Ministries, National Volunteer Caregiving Network, and Shepherds’ Centers are visitation programs churches can utilize as a model for caring for elders in their communities.

<sup>60</sup> Sari B. Shuman, Patricia Yuen, and Kate Gordon, “Faith-Related Programs in Dementia Care, Support, and Education,” National Alzheimer’s and Dementia Resource Center, February 2017, <https://nadrc.acl.gov/sites/default/files/uploads/docs/FaithRelatedDementiaPrograms%20FINAL%20FullRpt%20021317.pdf>

<sup>61</sup> Vern Bengston, interview by Amy Zietlow, “Religion Runs in the Family,” *Christianity Today*, September 20, 2013, <http://www.christianitytoday.com/ct/2013/august-web-only/religion-runs-in-family.html>

<sup>62</sup> Kenneth Matos, Ellen Galinsky, and James T. Bond, “National Study of Employers,” *When Work Works*, 2016, <http://whenworkworks.org/downloads/2016-National-Study-of-Employers.pdf>

<sup>63</sup> Gretchen Livingston, “Opting out? About 10% of highly educated moms are staying at home,” Pew Research Center, May 7, 2014, <http://www.pewresearch.org/fact-tank/2014/05/07/opting-out-about-10-of-highly-educated-moms-arestaying-at-home/>.

<sup>64</sup> Society for Human Resource Management (SHRM), “Managing Flexible Work Arrangements,” June 14, 2016, <https://www.shrm.org/resource-and-tools/tools-and-samples/toolkits/pages/managingflexibleworkarrangements.aspx>

<sup>65</sup> Fuller and Raman, “The Caring Company.”

<sup>66</sup> Won Kim Cook, “Paid Sick Days and Health Care Use: An Analysis of the 2007 National Health Interview Survey Data,” 2012, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3168716/#R42>

<sup>67</sup> Bureau of Labor Statistics, U.S. Department of Labor, “National Compensation Survey: Employee Benefits in the United States, March 2018,” July 20, 2018, <https://www.bls.gov/news.release/pdf/ebs2.pdf>

<sup>68</sup> Ibid.

<sup>69</sup> Matos, Galinsky, and Bond, “National Study of Employers.”

<sup>70</sup> Christina Hernandez Sherwood, “Sick Leave Law Helps Family Caregivers,” *AARP New Jersey*, July 1, 2018, <https://states.aarp.org/sick-leave-law-helps-family-caregivers/>

<sup>71</sup> California Dental Association, “Paid Sick Leave Compliance and Management Explained,” February 25, 2019, <https://www.cda.org/news-events/paid-sick-leave-compliance-and-management-explained>

<sup>72</sup> Juliana Menasce Horowitz et al., “Americans Widely Support Paid Family and Medical Leave, But Differ Over Specific Policies,” Pew Research Center, March 23, 2017, <https://www.pewsocialtrends.org/2017/03/23/americans-widely-support-paid-family-and-medical-leave-but-differ-over-specific-policies/>

<sup>73</sup> National Conference of State Legislatures, “State Family and Medical Leave Laws,” July 19, 2016, <http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>

<sup>74</sup> Ben Gitis, Sarah Jane Glynn, and Jeffrey Hayes, “Comparison of Methods for Cost Estimates of Federal Paid Family and Medical Leave Program Using Public Data,” In *The AEI-Brookings Working Group Report on Paid Family and Medical Leave: Charting a Path Forward* (Table 1, 91), September 7, 2018, <http://www.aei.org/wp-content/uploads/2018/09/The-AEI-Brookings-Working-Group-Report-on-Paid-Family-and-Medical-Leave.pdf>

<sup>75</sup> Hunt, Barrett, and Lutz, “Caregiving in the U.S., 2009.”

<sup>76</sup> MetLife Mature Market Institute, et al., “The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved,” National Alliance for Caregiving, 1999, <http://www.caregiving.org/data/jugglingstudy.pdf>

<sup>77</sup> Kerry R. Peck, “Creating Effective Agreements for Payment of Family Caregivers,” *Bifocal*, A Journal of the ABA Commission on Law and Aging 37 no. 3 (January-February 2016): 63-65, <https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALJan-Feb2016.pdf>

<sup>78</sup> Richard L. Kaplan, “Family Caregiving and the Intergenerational Transmission of Poverty,” *The Journal of Law, Medicine and Ethics* 46 no. 3 (October 18, 2018): 629-635, Retrieved from <https://journals.sagepub.com/doi/10.1177/1073110518804216>.

<sup>79</sup> Alicia H. Munnell and Andrew D. Eschtruth, “Modernizing Social Security: Caregiver Credits,” Center for Retirement and Research, Boston College, August 2018,

[https://crr.bc.edu/wp-content/uploads/2018/08/IB\\_18-15.pdf](https://crr.bc.edu/wp-content/uploads/2018/08/IB_18-15.pdf)