

Family caregivers and the different journeys they're on

## **The roller coaster, the marathon, and the deep end**

by [Amy Zietlow](#) in the [September 11, 2019](#) issue



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My church gathers for worship at 9:15 a.m. every Sunday. The pews are filled with family caregivers who find themselves on different types of elder care journeys. Some are on a roller coaster, some are in a marathon, and some are in the deep end.

One son 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. Her son wonders when the next crisis will happen. He is on the roller coaster of family care.

One daughter will spend the afternoon with her father, who lives in a local nursing home. She will sort his laundry for the week and play a modified game of dominoes. If it's a good day, he'll remember her name and that she's his daughter. She has

been caring for him and witnessing his slow and persistent cognitive decline for more than a decade. She is in the marathon of family care.

One spouse grieves her husband, who died after an intense month in hospice care. She and her two daughters rarely left his side during that time. As they sat vigil by his bedside, they did everything from managing his pain to completing a will to reminiscing about his life. They were experiencing the deep end of the family care pool.

Approximately 41.3 million Americans provide unpaid elder care, according to 2017 data from the federal Bureau of Labor Statistics. That number is set to grow substantially as the baby boomers become our next generation of elders. These congregants, who look like ordinary mothers and fathers and daughters and sons, are modern family caregivers. 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 provide care. Many juggle full-time jobs with private care responsibilities. BLS reports that they spend an average of nearly three hours a day providing care, and a 2016 AARP survey found that they spend as much as \$7,000 a year on out-of-pocket expenses related to caregiving.

This call to care is grounded in the Ten Commandments. The commandment to “honor your father and your mother that your days may be long upon the land which the Lord your God gives you” (Exod. 20:12) establishes the family as the incubator for translating love of God to love of neighbor. Honor extends beyond parents as well, to all elders in our communities. The book of Ruth, which features an honorable relationship between mother and daughter-in-law, serves as a prime example for how the honor commandment should be interpreted broadly to include kin by birth, marriage, and affinity. For many people—especially unmarried people and those without children—church is family.

Martin Luther’s Large Catechism says that honoring elders includes “serving them, helping them, and caring for them when they are old, sick, feeble, or poor”; the Catholic Catechism says it involves giving them “material and moral support in old age and in times of illness, loneliness, and distress.” According to Michael Fishbane, in the Jewish tradition honoring elders means accepting responsibility for managing—and sometimes actually paying—the costs related to custodial care, shelter, and even certain medical treatments. Honor is expressed in moments of crisis during the roller coaster of care, in countless day-to-day moments in the long

marathon of care, and in the deep end of care in the time just before death.

How can we honor modern-day family caregivers themselves? We can begin by trying to understand the complex needs of the different family care journeys. I have found the distinction between being on a roller coaster, in a marathon, and in the deep end a useful framework for thinking about the variety of caregiving experiences. The categories come from pioneering hospice physician Joanne Lynn's work in the 1990s. These three common trajectories of decline, which Lynn identifies as taking place in the final third of life, offer insight into the needs of family caregivers. You may see yourself or someone you know in one of these three common care journeys.

The roller coaster is a long-term period of support that requires intermittent periods of acute care. Care recipients tend to live independently, but they will experience periods of time when acute help or immediate intervention is needed. During these 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, which can last years or even decades. Palliative care often plays a supportive role in pain and symptom management for those 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 help, but unexpected demands reign.

The deep end is a short-term period of support that requires 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. According to the National Hospice and Palliative Care Organization, 1.43 million Medicare beneficiaries receive hospice care each year. Family care tasks can require a high level of skill: they might include dressing wounds, bathing, catheter care, and managing opioids and other pain medications.

The marathon is a long-term period of continual support. Care recipients tend to decline in mobility and mental acuity slowly but persistently, and this often includes 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 they may contract with home health aides, sitters, or senior day care services to supplement the day-to-day care required by family members.

The Alzheimer's Association reports that 5.7 million Americans currently live with Alzheimer's disease, and that number is projected to increase. Many caregivers reduce their work hours, take a leave of absence from paid employment, or retire early, thus jeopardizing their own future retirement savings.

Each of these family care journeys requires a different type of support. Congregations, in their capacity as a volunteer base, can play a crucial role in helping to meet this variety of practical and spiritual needs.

They can also advocate for better public policy. For example, one thing that's especially helpful for caregivers on the roller coaster of care is access to sick leave that can be used for care responsibilities. Several states have caregiver leave acts that follow the model legislation promoted by AARP.

For caregivers at the deep end of caregiving, when full-time care is needed for a short period of time, access to up to 12 weeks of paid leave would be helpful. Seven states and the District of Columbia currently mandate paid family leave, and bipartisan support exists for building on the federal Family and Medical Leave Act, which currently guarantees unpaid leave to most workers, to create a paid form of support at the federal level.

For caregivers in the marathon of care, the ability to earn Social Security credits for caregiving could be especially helpful. It would give them the flexibility to curtail full-time employment, retire early, or take a leave of absence from paid employment without jeopardizing their own retirement and safe aging.

Can churches encourage and support family caregiving? Can they help caregivers who are also in the workforce be faithful to both callings without exhausting themselves emotionally, financially, and spiritually? If families are going to fulfill the role of caregiver, then congregations need to pay special attention to supporting them—to honoring family care.

*This article was adapted from Called to Care: Honoring Elders and the Family Care Journey, a report published by the Center for Public Justice. A version of this article appears in the print edition under the title "Journeys of care."*