Eldercare as Art and Ministry

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Church Publishing
19 East 34th Street
New York, NY 10016
www.churchpublishing.org

Cover design by Jennifer Kopec, 2Pug Design
Typeset by Beth Oberholtzer

A record of this book is available from the Library of Congress.

ISBN-13: 978-1-64065-307-8 (paperback)
ISBN-13: 978-1-64065-308-5 (ebook)

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CHAPTER FIVE

The Platinum Rule of Eldercare

"Treat others the way that you would want to be treated" is the golden rule. A version of this is what I call the "platinum rule of caregiving": "Treat others the way *they* want to be treated." To the extent possible, put yourself in the care receiver's shoes and treat them accordingly. To do so requires empathy on the caregiver's part. And it requires putting aside what we, as caregivers, think is right and entering the care recipient's world.

While I was writing this book, I was contacted by a fellow professional geriatric care manager who was completing research about microaggressions that occur in caregiving. The researcher and aging life care professional/geriatric care manager, Kim Kozina-Evanoski, LMSW, CMC, CDP, EdD, was collecting data for her dissertation from St. John Fisher College and asked to interview me. Her research study, "Professional Perceptions of Microaggressions and Verbal Abuse toward Aged Women," looked at microaggressions from caregiver toward care receiver, or medical provider toward patient. At first, I could not think of an example that I had encountered. Since microaggressions are subtle, they can go unrecognized. A microaggression

is a subtle verbal, behavioral, or environmental indignity, whether intentional or unintentional, that communicates slights and insults from one person to another.

After some thought and prompting from Kim, I thought of a former client, Alice, now deceased. When I met Alice, she lived in her own home. She was always neat in appearance, manicured, and well-dressed. At ninety-two, she walked the two blocks to her hair salon weekly. Her hair was always groomed in a stylish cut. When she was no longer able to live independently, she was moved to a nursing home by her guardian-conservator. When I happened to visit the nursing home where she had been for three years, I saw her, diminished and infantilized. Her hair was plaited in small braids, childlike, all over her head. The infantilization that was imposed on her was, in my view, a microaggression.

Effective caregiving requires a particular kind of competency—emotional intelligence, empathy—that includes putting aside one's own notions in service to the other person's needs and desires.

An emotionally intelligent and sensitive caregiver, Beth—who is and has been an executive director of assisted living communities in the Washington, DC, area—is an example of one who exemplifies the needed skills (and talents) for effective caregiving. Ann was a resident at Beth's assisted living community. Ann's son lived eight hours away, so he was only able to visit his mother sporadically. Beth had referred him to me, and he asked me to keep an eye on his mother. I did so for months when I visited the assisted living community where she lived.

Ann always wore pearls, lipstick, blush, false eyelashes, and coordinated ensembles. She had a wardrobe of wigs, all quite glamorous in styling. When it came time for Ann

to move to be closer to her son, I was responsible for her relocation. I wanted to make sure that the staff at what was to be her new assisted living community would know exactly how Ann liked to look in terms of her personal appearance. During the admission process, I told the staff that Ann wore false eyelashes. The admissions director at the new facility asked if Ann applied the eyelashes herself.

"No," I said. "Each morning, Beth takes time away from her work as executive director to apply Ann's eyelashes." Beth went well beyond the scope of what one would think of as caregiving. Beth understood Ann's need to wear false eyelashes. That is who Ann was before living with dementia. Ann didn't *have* to have false eyelashes applied daily; it wasn't essential to her health. But wearing eyelashes maintained her self-esteem and underscored who she was before she lived with dementia. I do not know whether Ann's new community had anyone who was as sensitive to Ann as Beth had been in terms of how Ann wanted to look. I doubt it. Wearing eyelashes enhanced Ann's quality of life. Effective and loving caregiving is the willingness to put our own notions of what is essential in the background. It's easy to say, hard to do.

I had lunch with three ladies at an assisted living community where I have several clients. Each one was "present" in her own way. Here's what I observed. Pat asked the server for a turkey sandwich. The server asked, "What kind of bread do you want?" Pat answered, "Toasted." Pat has difficulty using utensils because of Parkinson's disease. Pat's sandwich was served with soft bread, not toasted as she had ordered. The soft bread made it difficult for her to pick up and hold the sandwich. I watched the sandwich fall apart as she struggled to hold it together to eat it.

Another resident at the lunch table ordered what she wanted from the menu. When her meal was delivered, she just looked at the plate and picked at the food, rather than eating it. Observing this, I asked, “You’re not eating. Do you want to order something else?”

“No,” she answered. “I just don’t want so much food on my plate at one time.”

The third resident at our table had also ordered a turkey sandwich. I noticed that she seemed not to be enjoying her lunch. I asked, “Is the sandwich fixed the way you like it?”

She answered hesitantly, “Yes, it’s okay.” I probed a little more to discover that she had asked for mayonnaise on the sandwich. Instead, her sandwich had mustard on it.

Juan, the dining room chef, makes a round during meals to check on dining residents. When he came to our table and asked if everything was okay, they all answered, “Fine,” in unison, which was not the case. I spoke up for each of the women, pointing out that their food had not been served the way they had ordered it.

Caregiving is advocacy—speaking up on behalf of the person who requires care. Caregiving is being fully present, observing and listening for the unspoken. Far too often, care receivers are compliant, especially if they must depend on a caregiver. In many ways, care receivers feel powerless and simply give in. Each one of the women thanked me for speaking up on their behalf. But they also realized that Juan listened to each one of them and promised to pay better attention to how their meals were prepared and served in the future. Juan promised to use a version of the platinum rule of caregiving: respect the person, ask what they want, and then give it to them to the extent possible and without harm.

CHAPTER SIX

An Ultimate Gift

Eldercare takes many forms. An eldercare-giver can be an activist, advocate, nurturer, helper, organizer, observer, questioner, entertainer, problem-solver, investigator, peacemaker, coordinator, and researcher, to cite a few roles.

W. Steven Carter, a participant in the 2005 White House Conference on Aging, proposed, "[There is] no cohesive theology of aging that exists to define values and roles of elders and those caring for and responding to them." Carter urged that local and regional centers be developed to train, support, and counsel family caregivers. He further recommended that churches should ensure appropriate recognition of and response to the spiritual, emotional, and psychological needs of caregivers. This was a clarion call to congregations.

In 2001, at a Duke University conference, "Faith in the Future: Religion, Aging, and Healthcare in the 21st Century," the late bioethicist Daniel Callahan spoke to the question, "Caring: What does it really mean?" He examined the imbalance in our society between *curing* and *caring*, with lesser societal support for caring. He pointed out that the imbalance will become more dramatic as the elderly *live* with chronic illnesses that cannot be *cured*.

Callahan went on to offer a most poignant reflection: "Caring is an art and the ultimate gift from one special person to another who can no longer provide for him or herself."

A. Wayne Schwab, in his book *When the Members Are the Missionaries: An Extraordinary Calling for Ordinary People*, puts forth an understanding of where people can be called to be a missionary—at home, at work, in the local community, in the wider world, at leisure, and in the church. Eldercare is an explicit opportunity for the laity to minister in a specific mission field: the home.

My thinking about "the mission field" has been enlarged, particularly through working with Reverend Schwab on his book. He emphasizes "the missions of each of the baptized" and includes the home as a mission field.[1]

A publication, "A Study of Religion, Ministry, and Meaning in Caregiving Among Health Professionals in an Institutional Setting in New York City," published in the *Journal of Pastoral Care & Counseling,* surveyed the religious practices of the staff of a large New York nursing home.[2] Respondents were asked about the degree to which they saw their work as a ministry and the meaning they obtained from being caregivers. The survey concluded that for those who were "religious," religiosity appeared to enhance the meaning the caregiving staff received from their work.

Also notable is a study, "Religion and the Meaning of Work," published in the *Journal for the Scientific Study of*

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1. A. Wayne Schwab, *When the Members Are the Missionaries: An Extraordinary Calling for Ordinary People* (Essex, NY: Member Mission Press, 2002), 3.

2. Jon A. Overvold et al., "A Study of Religion, Ministry, and Meaning in Caregiving Among Health Professionals in an Institutional Setting in New York City," *Journal of Pastoral Care & Counseling* 59, no. 3 (September 1, 2005): 225–35.

Religion, that surveyed over 3,400 members of more than 30 Protestant and Catholic congregations.[3] The study tested the hypothesis that the more "religious" an individual was, the more they saw their work as a calling or ministry, as opposed to a job. In all, 15 percent of those surveyed agreed with the statement, "My work has special meaning because I have been called to do what I'm doing regardless of how much time it takes or how little money I have; I was put on earth to do what I am doing."[4]

An individual who provides care for an adult loved one or bears caregiving responsibilities often does not recognize himself or herself as a "caregiver." Caregiving is central in the ministry of Jesus. Scripture makes it clear that caregiving is central to the Church's life and that we are called to care for one another. And caring for God's people is not the exclusive responsibility of the *ordained* ministers.

Society undervalues caregiving and caregivers, and religious bodies continue to do too little in being intentional about equipping the laity for this ministry. Evidence suggests that religious bodies provide little support, training, and even affirmation of eldercare-giving as a ministry.

Christians are fully authorized, by baptism, to do ministry in the world. "Lay people," as the late theologian Verna Dozier wrote, "become weary of the struggle and give over the responsibility to ecclesiastical hierarchy."[5] Ordained ministers must enable the laity to fulfill their peculiar, inalienable ministry and equip them for their primary function—to be servants *in the world*. I want to lift high the authority of the

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3. J. C. Davidson and D. P. Caddell, "Religion and the Meaning of Work," *Journal for the Scientific Study of Religion* 33, no. 2: 135–47.

4. Davidson and Caddell, "Religion and the Meaning of Work," 138.

5. Cynthia L. Shattuck and Fredrica Harris Thompsett, eds., *Confronted by God: The Essential Verna Dozier* (New York: Seabury, 2006), 67.

laity as they carry out a ministry of eldercare where Jesus can be made manifest. We follow Christ as we provide care.

Gift Given, Gift Received

Caregiving touches all of us. A paraphrase of former first lady Rosalyn Carter's wise words sums this up.

There are only four kinds of people in the world:

1. People who have given care;
2. People who are giving care;
3. People who will be giving care;
4. People who will need care.

Giving the gift of care requires thoughtfulness. And receiving the gift of care with gratefulness and appreciation is not necessarily apparent to the gift giver.

Here's what I mean. "How To" books have been plentiful for years. In my teens, my mother gave me a copy of *Amy Vanderbilt's Complete Book of Etiquette*. When it was published in 1952, it was touted as "the most authoritative book of its kind," according to the description of the book on Amazon. I remember how annoyed I was when I received that gift. I was not grateful. Yet, I did a similar thing with my son and other young family members and friends when I gifted them an instruction book of good and proper etiquette. I gave them each a copy of a little blue book called *Tiffany's Table Manners for Teenagers* (March 18, 1989). They were not appreciative.

Instruction and "How To" books for caregivers are a recent phenomenon. I don't remember there being a book on caregiving "etiquette" or instruction when I began my caregiving journey. I certainly could have used such a resource and guidance. The guidance eventually came in

the form of a geriatric care manager, the late Dr. Denise Dolan, a psychologist who was among the few aging specialists in the still relatively new field of geriatric care management in 1992. The first professional association for this field was created in 1985 as the National Association of Professional Geriatric Care Managers, now called the Aging Life Care Association (ALCA, www.aginglifecare.org).

ALCA has grown over the decades since its inception. However, the benefits of using a geriatric care manager remain relatively untapped. Geriatric care managers are aging experts and offer knowledge, best practices, and a hand to hold to guide a family in caring for and preparing to care for an older loved one.