



Caring for People with Alzheimer's

How do persons caring for those with Alzheimer's disease care for themselves? How can congregations support those persons responsible for the care of persons with Alzheimer's disease?

Introduction

I handed the envelope to the clerk at the post office. "To Canada?" she asked. I nodded yes. Then she looked up and said, "Are you Mrs. Kuehner?"

Startled, I answered, "Yes," although I have never used the name Kuehner, my late husband's name. Apparently the clerk recognized the return address. She was still speaking: "Your husband was such a nice man, always so friendly. He always made me smile. How is he?" Turning to the clerk at the next window, she continued, "Don't you remember Mr. Kuehner?"

"He died three and a half years ago," I answered. "You knew he had Alzheimer's disease?"

Driving home, I thought back to the day that my husband was diagnosed. Charlie barely acknowledged what the medical team was saying that afternoon. He didn't remember seeing the doctors. For two weeks he came up with every conceivable reason for why he should be permitted to drive. However, for us, everything changed the day Charlie was diagnosed with Alzheimer's disease.

Living with Alzheimer's Disease

The diagnosis meant that I had to take over the finances, which included finding a financial advisor, canceling credit cards in Charlie's name (new ones seemed to appear from nowhere), and monitoring mail and phone calls for him (or he would agree to ordering anything

ALZHEIMER'S DISEASE

A common form of dementia of unknown cause, usually beginning in late middle age, characterized by memory lapses, confusion, emotional instability, and progressive loss of mental ability.

Random House Webster's Unabridged Dictionary (2006)

over the phone). Now I was in charge of scheduling his medical appointments and seeing that he took his medications. The list of responsibilities mounted before my eyes and multiplied over the weeks.

The day Charlie was evaluated, the social worker suggested that I look at adult day care centers for him. I couldn't imagine the need except that I knew outside social stimulation would be good for this man, who enjoyed being with people. Within two months, I knew that the day care was a necessity for him—and also for me. My husband, who a year earlier could spend half the morning reading the *New York Times*, now had to know exactly where I was and preferred to sit in the rocking chair in my office, generally disrupting my office and disturbing my work patterns.

Less than three months after his diagnosis, Charlie began attending an adult day care center three days a week. The staff was wonderful. They let him use a bookcase for his "office." They asked him to look up stock quotes in the newspaper. And they enjoyed his sense of humor, often telling me of something he had

said that day. Those three days each week, which grew to five, were a wonderful gift to me. Not only was I able to work, but also I could accomplish tasks outside the home without needing to keep track of him.

People sometimes liken caring for the person with Alzheimer's disease to caring for a little child, a toddler. The resemblance is only on the surface. When you look at the toddler, you see a human being who will grow and become more independent. When you look at the person with Alzheimer's disease, you see a human being, but one who will become more and more dependent on you and will probably reach a stage when she or he will not even know who you are.

A Different Kind of Relationship

As I think back over the years following the diagnosis, I recall a tenderness that developed between us unlike anything earlier. In my most frustrating moments, I was irritated by the look of longing and dependence on his face when he turned to me. At other times, the look reminded me of the way he used to look at me after we had been apart for a few days.

This kind of tenderness can happen when a parent has Alzheimer's disease, too, as Ellen Pall described in an essay in the *New York Times*. For various reasons, she and her father had a distanced relationship as she grew to adulthood. But, as he progressed into the disease, she says: "In the gravityless reaches of his swirling, upside-down mind, he had become the kind, good little boy he must once have been on the prairies of Canada. And I was close to him now."¹ This tenderness, this closeness, is not without its sorrow. I found that the best way to approach Charlie as the disease progressed was to accept him as he was at that moment and not to remember what he had been when we married or even five years earlier. Those memories were too painful to recall. The short-term memory loss made each day a new one for him; it was also a new one for us.

Alzheimer's disease affects each person differently, although there are many similarities. Most people go through personality changes, some more dramatic than others. They gradually lose the ability to conduct their own lives and to take care of their own needs. Often the loss of the ability to perform simple mathematical operations, such as making change, is the one we notice

first. Most people reach a point when they no longer recognize family members, even the caregiver. When my husband looked at me and no longer saw Carol, his wife, he did recognize me. When I appeared, he would pat the seat next to him, his way of saying, "You have come to see me; come sit next to me."

Caring for Yourself

As my husband became more affected by the disease, I discovered I needed to care for myself in order to care for him, both when he lived at home and when he moved to the memory care residence. Too many people ignore their own signs of health and emotional problems as they immerse themselves in the problems of the person with Alzheimer's disease. I found that the better I felt physically and mentally, the better caregiver I could be.

Physical exercise and meditation gained a new importance in my daily routine, along with the basics of good nutrition and adequate sleep. The advantages of physical exercise are well known for the stimulation of body and mind. For me, it was walking. When I could no longer leave Charlie alone in the house, I purchased a treadmill.

However, getting adequate sleep became increasingly difficult. A woman who was caring for her husband told me, "I go to bed later than he does, hoping that I might get some time for myself. I get up earlier than he does so I can be dressed and ready for the day before I need to help him. Bedtime and the time to get up are gradually coming closer together." I have yet to talk with a caregiver who isn't weary at the end of the day but who sleeps lightly in case the person gets up during the night. When the person with Alzheimer's disease confuses night and day, the problem is compounded. Figuring out how to get enough rest is a serious matter. It was one factor in my decision to move my husband to the memory care center, a residence for people with any type of dementia.

Spiritual Practices for Caregivers

During my years of caregiving, my spiritual practices changed too. I discovered again the value of the sentence prayer. I have no idea of the number of times I must have prayed, "Help me, God" or "Please give me

patience.” This usually unspoken prayer got me through many moments, times when I had to answer the same question for the fifth time in as many minutes or walked into the bedroom to find all the clothes out of the dresser and my husband still not dressed.

Although the sentence prayer got me through many days, the spiritual practice that grew to mean a great deal to me was examen. Each night I thought back over my day, giving thanks for the moments when I felt God’s presence as I cared for Charlie and asking God’s forgiveness when I felt I had missed the mark. Over time I added giving thanks for the good moments of the day and turning the difficult moments over to God. When the outlook for us seemed especially bleak, I decided to write down my observations from examen in a daily journal. As I looked back over a week or a month, I was always surprised to find that the good outnumbered the difficult. I think that practice helped me to look more positively at Charlie and at life in general, staving off the bitterness that can creep into one’s outlook, especially the primary caregiver.

The Role of the Congregation

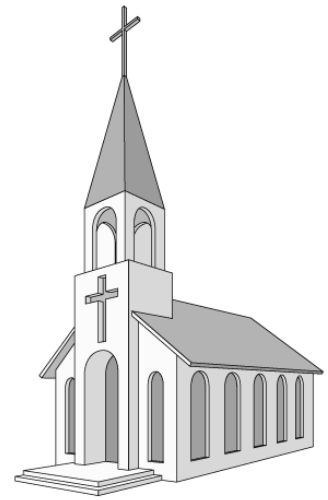
Charlie and I needed and wanted to maintain a close connection with our congregation. To help my husband maintain that connection, we continued to go to church each Sunday. The autumn after his diagnosis, I was invited to teach a church school class. I wanted to teach, but what to do with Charlie? A solution was found by asking a couple who knew him to meet him in my church school room and take him to an adult education class. I did not hide Charlie’s diagnosis, so it was easier for others to accept his not-quite-on-target comments or questions in a group discussion. The friends with him could answer “Where’s Carol?” the several times he asked it. With their help, he was able to participate as he could, and I was free to teach the children, something that fed my spirit as well.

To help Charlie follow the order of worship, I pointed to congregational responses and prayers that were spoken aloud; my finger followed the lines of hymns. These simple actions allowed him to participate in the worship experience as he was able. Otherwise, he might have sat there, an observer impatient or frustrated because he could not follow the order of worship. As is often the case with dementia, Charlie never forgot the Lord’s Prayer and those hymns he had sung all his life.

My congregation played an important role in helping me, the caregiver, too. Our board of deacons is organized around critical times of life, one of which is older age. A deacon from that group called me a few months after Charlie’s diagnosis and offered to set up a group of visitors to stay with Charlie when I needed to be away from home for anything from a session meeting to attending a play.

Initially I thought the offer was nice but not really necessary. After all, we had many friends who were willing to lend a hand, along with relatives in the area. We could also afford to hire someone to come in. But strangers were difficult for Charlie to accept, and a familiar face made it easier for me to leave. At the time of Charlie’s diagnosis, I was serving as an elder and chair of a committee. This required at least two evening meetings a month. I also attended two support groups for caregivers, one specifically for caregivers of Alzheimer’s patients that I did not want to miss. Both met monthly during the day.

After trying to coordinate people to come stay with Charlie, I soon realized that I was likely to resign and pull out of commitments that took me away from home rather than make all the calls necessary to provide for his safety. I called the deacon and accepted her offer. She arranged for Charlie’s visitors. Thirty-three people came during the three years that Charlie lived at home after the diagnosis. One woman brought sticky buns because she remembered how much Charlie liked them. Another couple brought books about World War II, since the man and Charlie were both veterans. When people knew what to expect, they were more comfortable and willing to come for a visit. I let them know that Charlie will ask many times where I am and when I will be back. I told them to answer him briefly each time, assuring him that I will be back soon. If he wants to go to bed, they should say “good night” and send him upstairs. If he comes back twenty minutes later and sits down to chat, no problem. It is important that they know he is



What can your church do to support persons with Alzheimer's and those who care for them?

in the house at all times because he may try to leave to look for me.

After Charlie moved, the deacons continued to visit him, asking me how best to interact with him or what to expect. These visits may have been more important for me than for him, especially since the visitors reported to me on what happened. I also believe that having visitors improves the quality of care as the person becomes more detached from reality. Knowing that Charlie regularly had visitors from his church provided a bridge to him for those who cared for his daily needs.

Another way my congregation helped during this time was to begin a support group for any persons with a family member with Alzheimer's disease. Anyone affected by the disease was invited to join us, whether the person was caregiving at home or from a distance. Because of its origin, this group included prayer—a time to pray for one another, for our families, and for the persons with Alzheimer's disease. The group has never been more than five people, and some months I am the only one there. So by number count it doesn't appear to be successful. However, notices about the group in the church newsletter and Sunday bulletin have led people to come for one or two meetings to get information as well as to call me on the phone to talk about their experiences. That too is a valuable ministry.

Summary

If you are caring for someone with Alzheimer's disease, take care of yourself physically and mentally. Get to know

others who are in the same or a similar situation, and turn to them for encouragement and support. They can talk with you in ways that no one else can. If your congregation does not offer the help that you need, talk with your pastor. All too often no one knows what to do or that help is needed. Don't hide the diagnosis. Alzheimer's disease no longer carries a stigma. Discussing it as openly as you can is helpful to everyone. Above all, keep your faith alive through the spiritual practices that nourish you.

About the Writer

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Select Resources

Alzheimer's Association, www.alz.org. Go to this Web site for a myriad of information and resources and to sign up for the Safe Return program.

Alzheimer's Daily News, <http://alznews.org>. This daily newsletter points you to articles in magazines, newspapers, and journals about research in Alzheimer's disease.

Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease*, 4th ed. (Baltimore: Johns Hopkins University Press, 2006). Originally published almost two decades ago, this book (now revised and updated) is still the single most helpful source for families about Alzheimer's disease.

Endnote

1. Ellen Pall, "Father and Daughter: One Final Connection," *New York Times*, December 25, 2005.