

Dementia: Caregivers and Caring Communities

Rev. Roger Jones, Unitarian Universalist Society
Sacramento, Father's Day, Sunday, June 21, 2015

Hymns: #21, For the Beauty of the Earth; #118,
This Little Light of Mine; #1064, Blue Boat Home.
Shared Offering for the Relationship Skills Center.

Father's Day Testimony by Kevin Sitter

Reading: "Caregiver's Time Off," by Lynne G.
Halevi, p. 114 in *Mosaic Moon: Caregiving through
Poetry* by Frances H. Kakugawa

Gift of Music: Rondo a la turca, piano W. Mozart

Sermon

Twenty years ago I was a minister in training at an urban church on the southeast coast of Massachusetts. A woman from the local area asked me to conduct a graveside memorial service for her father. She was the caregiver to her mother, now a widow, a slight gray haired woman living with the confusions of dementia. The daughter worked in town as a school bus driver. Every morning she took her mother out with her, on the bus, transporting students to school and then back home on the afternoon shift. She couldn't afford at-home care and wanted to know her mom was safe. As we planned and conducted the service, we were holding our breath, worried that her widowed mother would ask, one more time, who the funeral was for.

Just over a century ago (1901), in a hospital in Germany, Dr. Alois Alzheimer identified symptoms of a strange neurological disease. He was 37 years old, and his patient was a woman of 51. She was too young for her confusion and erratic behaviors to result from old age, to be merely what people called *senility*. From Alzheimer's work we came to understand this condition as a disease, as an attack on the brain.

As all people get older, 1/3 to 1/2 of us will experience mild memory loss, like "taking longer to learn directions, ... or having some difficulty recalling names or numbers." Yet memory loss from aging is not the same thing as dementia from

Alzheimer's Disease, Frontal Temporal Degeneration, or similar neurological diseases. (Shenk, 19)

Author David Shenk says Alzheimer's is a "relentless undoing" of one's capacities, a gradual stripping back of who we've grown to be. It removes new memories first, later savaging our thought processes, our communication skills, and our ability to walk. (Shenk, 13) It's not yet curable.

If we get it, and if we don't die of something else first, like pneumonia or stroke, we lose all the skills we learned. We end up with only our infant reflexes, and then with a shutting down of the functions operated by our brain stem, like breathing. (Shenk, 222) According to Stephanie Zeman, a nurse in the field, as the body is shutting down, "a person does not feel discomfort from either hunger or thirst." (Shenk, 223)

After taking us through hell, Alzheimer's often takes us away in peace, with a quiet passing.

In the early stage of the disease, or even before a diagnosis, changes in one's behavior can feel *hurtful* to a partner, child, sibling or friend. For example, a person has accepted a job transfer or quit a job, without conferring with his family. Another person stomps around the apartment, demanding: "Why do you always hide my glasses from me? --- Oh yes you do!" This comes as a shock to the spouse who was used to hearing a simple, "Have you seen my glasses? I can't find them."

Later, a loved one easily gets confused and scared. They may act out in agitation: shouting, staying awake all the time, yelling paranoid thoughts, running. They may soil their clothes and their bed. If they feel overwhelmed, they may lash out with a fist. It can be hard not to take it personally, hard to remember: *this is the disease. They are not doing this on purpose.* Twenty years ago, my late uncle looked at his wife embracing him in bed, as they had for decades. But this time, he shrieked with fear, "Who are YOU?"

One of our members, who lost her husband to dementia, told me: "Taking care of someone with dementia is a triple whammy. The caregiver is being drained both emotionally and physically. The one they love is less and less able to love back. And

they are living with the heartbreak of seeing their unique loved one become lost to themselves and the world around them.”

Another member told me that she was the caregiver to her mother for 13½ years due to dementia. She writes “The last few years I had to put her in a nursing home. At home there were too many NO's: *No you can't go outside, no you can't put the towel in the toilet, no, no, no.* And she would get mad. Making the decision to put her in the nursing home was the hardest decision I have ever had to make. Thank goodness she made friends there and liked it, until she got so bad.”

Caregiving for a loved one is hard and lonely work. Caregivers need care.

Caregivers have told me they've grown over time, gained wisdom, gotten resourceful, and been surprised. For example, one member told me this:

“The most valuable thing I learned in dealing with my mother as she started down the dementia path was that I could not deal with her rationally.” Examples of this are complaints and accusatory statements. She explained: “When [my mother stated] that the assisted living facility wasn't giving her any food, I didn't try to debate with her that yes, she really had eaten and she'd just forgotten. I had to recognize that I wasn't dealing with a mind that thought rationally. She might say something outlandish and then [even] recognize that it was [wrong], but wouldn't want to own up to it, so she'd keep sticking to her story.”

Looking back, this daughter has realized “When I finally relaxed and let her be in whatever place she was mentally, our relationship could be loving and not aggravating.” So instead of trying to convince her that she had eaten, the daughter would say: “Sometimes I am so hungry it's like I forgot to eat lunch!” or “Shall I buy a couple of those energy bars you like, to keep in your room to eat when you get really hungry?”

It's important to notice changes in mental or emotional status. One church member told me of a parent whose behavior took a terrible turn. A medical examination revealed her mother to have a painful urinary tract infection. Even with that

ordeal, some humor could emerge. They sat in a gynecologist's waiting room. The mother looked around at a room of obviously pregnant young women and asked for assurance that she wasn't pregnant.

There is no “right way” for a caregiver to feel about the situation they face, or the condition of their loved one. There is no “right way” to feel about the final passing of a loved one with dementia. Emotions are complicated and varied with *most* of our losses. To be of support for others, it's good to cultivate an ability to be present with uncertainty, mixed emotions and complicated grieving.

A member has reminded me of the wisdom of those rote instructions of airline flight attendance: “In case of sudden loss of cabin pressure, secure your own oxygen mask before assisting anyone else.” Take care of yourself, not only so you have the ability to be of help to others, but also because every one of us is a human being, deserving of respect, needing attention, affection, rest and renewal. Many caregivers find support from committed, wise professionals, and from books and support groups with others on the same path. Some find reassurance in seeing paid care providers tend their loved ones with kindness, patience and good cheer. Some ask for practical assistance from people in a caring community like this one. One member of the congregation says: be sure to ask for help. Don't get so isolated or overwhelmed that you don't ask. If you get an offer of help that's useful, accept it! If it's not useful right now, just say: “Thanks. I'll let you know.”

What about those of us who'd like to support someone who has dementia? How can we help? I've read that the best way to help *a person with Alzheimer's* is to support their caregiver. I've been asking members for advice on this. The number one wish I've heard from current and former caregivers has been: respite. Respite means giving a few hours of time so the caregiver can take a break, or perhaps do errands or familiar tasks that restore their sense of normal life.

In addition to offering respite, one member said, we should ask questions of the caregiver, and listen more than we talk. “Don’t assume that because you had a relative with dementia that your experience closely relates to what your friend is going through. Listen. Don’t be afraid to ask questions.”

Offer help, and make it specific. General offers of help add one more task for the caregiver: having to remember to make the effort to ask, or having to schedule you. Instead you might say: “I made too much dinner last night. May I drop some by?” “I’m going to Costco, or the Co-Op. Can I pick up anything for you?” “Can I help with a few phone calls [or] emails next week?” “May I take your father out for a ride?” “Would your wife like me to visit with my dog, or with my grandbaby?”

The well-known book *The 36-Hour Day* recommends offering to do tasks the confused person used to do: “[deliver a] home-cooked meal, or take their car to the mechanic.” (Mace and Rabins, 200) If you don’t have any idea how you can help, just ask.

A friend who is a gerontologist told me not to forget this: Ask the caregiver: “How are YOU doing?” Of course we want to show concern for the patient. Yet many caregivers get weary from answering questions, over and over, about the person with dementia. They need to hear some interest in them, concern about them. Losing someone to dementia is always a cause for grief. Experts on grief recommend asking the person “How are you doing now?” The loss is so huge that the larger question of “How are you?” can be overwhelming. Most people *can* answer about the right now. *How are you doing right now?*

We can ask, and then listen. Don’t feel you need to make it all better, or give a super-wise answer. Remember that your quiet presence all by itself can be a gift.

If you are interested in being of support to people with dementia or their loved ones here at UUSS, please be in touch with Rev. Lucy or with me. But you need not wait. In words attributed to

Aesop, the ancient storyteller: “No act of kindness, no matter how small, is ever wasted.”

You can reach out to offer a handshake to that quiet person with a pleasant expression on their face, or the one with a blank expression. You can greet them and their caregiver. When I greet members who may have dementia, I try not to assume they will recognize me. Usually I speak their name and then say “Good morning! It’s good to see you today. It’s Roger.” Some of them shoot right back: “Of course you are!”

On a visit back to Indiana a few summers ago, I visited one of my late mother’s cousins living with dementia in a nursing home. A good-hearted, sweet-natured woman, Matilda was plump and motherly with a kind smile and a Hoosier twang. I didn’t know what to expect. I walked in the home and nearly ran into her: she was sitting by the nursing station, in her wheelchair. “Hi, Matilda. It’s Roger!” I bent over and gave her a smooch.

“It’s good to see you!” she said.

“I’m your cousin Leah’s son,” I said.

“Well I figured you were some relation to me or I wouldn’t have let you kiss me,” she joked. In twenty minutes we had the same conversation three or four times. “You know Ray died, didn’t you?” Her husband had been gone for years.

A frequent refrain of hers was: “They really do a good job here. They’re so good to me.” Since the nursing desk was her hangout, I wondered: How many times do they hear that every day? But, how lucky they were that she was happy, and not reciting complaints all day long.

Some other good advice: bring some humor and lightness to a situation you’re managing or going through. Even silly jokes can help. In the stress of caregiving, finding a way to laugh or smile can make the journey somewhat easier.

One of our members wrote this: Say, for example, that “my mother had said that she had been an exotic dancer when she was young.... I knew that of course that wasn’t true. My first inclination would be to try to talk her through how that wasn’t true, that she wouldn’t have done

anything like that, etc.” Instead of trying to convince her mother of the truth, this daughter said: “I found ways to listen and respond: ‘Wouldn't it be *fun* to be an exotic dancer? You know, they even have classes in doing pole dancing!’”

If we have Alzheimer's, according to what I've read, some of the first memories we lose are those of location and placement. Such a loss can be distressing to a patient. Some of the last memories we lose, on the other hand, are musical ones. This is true even if you don't have dementia: music stays with us. Joan is at a care home for her dementia; her husband Delmar died in May. Joan's conversations are brief, simple and sweet, but her daughter Ruth says her mother enjoys hearing people read rhymed poetry to her.

A few years ago we lost Rich. He had been a peace activist, music lover, and medical doctor. His wife Marily is still active here. Rich's decline from dementia included occasional agitated moments in our services, and countless ones at home. One evening we had a concert at church, a one-man tribute to the music of Woody Guthrie. I saw Rich standing in the back of the sanctuary, too restless to stay seated. Standing three feet from him was a little boy from our church, also notable for his unquiet behavior. As the performer led us in “This Land in Your Land, This Land is My Land,” both of them swayed to the music and sang the words.

During the memorial service for Rich, Marily told us one of the last things he said before he stopped speaking. He was lying down, quieter than he'd been for a long time. He looked up at her and said, “You're wonderful. Are you married?”

Of course, not all of us have such easy memories of loved ones in their final days. Sometimes it's agonizing and hurtful. This makes one last word of advice so crucial. One more word of advice, from caregivers and books, is this: remember the good times.

Even if your loved one no longer can, you need to sustain yourself with recollections of great moments, times of joy, even challenges you met and overcame together. Remember your reasons for

gratitude. For those of us who seek to be helpful, we can ask a caregiver for stories about their loved one and their shared life. The life they have shared need not be defined only by current hardships.

When it robs us of so much of a person we know, dementia can feel like oblivion. Yet in the unfolding of the universe, every good time, every act of goodness or beauty, becomes an everlasting part of the universe.

In physics, matter is neither created nor destroyed. In Process theology, my favorite school of theology, none of our contributions is lost; they all become part of the unfolding of creation. They belong forever to the divine life in which we participate. Every gift of music or poetry, every meal cooked and enjoyed, every garden we tend, every kind word, every loving touch, every moment – these gifts are everlasting parts of creation. The fruits of one's life extend beyond its conclusion.

When we try to be of help, a kind word might seem pointless if the other person forgets it in a few minutes. Yet in words of the ancient storyteller: “No act of kindness, no matter how small, is ever wasted.” In the unfolding of in the unfolding of the divine life in which we participate, whatever we give, however we serve, such gifts are not lost.

Whoever we are, in the days to come: let us remember to be gentle with ourselves and with others. To reach out for help, and to offer help, including the gift of our presence. Let us remember to be grateful for the good moments. Let us be grateful for every good gift. Amen.

Works Cited

Mace, Nancy L., and Peter V. Rabins. *The 36-Hour Day*. 4th. Baltimore: Johns Hopkins Press, 2006.

Shenk, David. *The Forgetting*. New York: Doubleday, 2001.

