

The Call to Care for One Another¹

The Rev. Duane H. Fickeisen and Anne Gero²
Unitarian Universalists of the Cumberland Valley
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*“Too often we underestimate the power of a touch, a smile, a kind word,
a listening ear, an honest compliment, or the smallest act of caring,
all of which have the potential to turn a life around.”*

— Leo Buscaglia

Invitation to Worship

Anne Gero

For 3 years, I have had the privilege of leading the UUCV Support Group for Caregivers. The group has engaged in a wide variety of activities and there have been many wonderful outcomes. The most important result is that they now know that they are not alone.

In my brief introduction, I will provide a glimpse of what may happen for many support group members, by sharing the story of Ms, my cat, who joined the group.

First, a little background about Ms. She is a senior cat that was about 70 cat years old when she joined and was very much a loner. When anyone visited, she would hide and not come out until they left. If she was present when visitors came, she would hiss and sometimes bite.

At the early group sessions, Ms. pranced into the room and was very friendly. I thought this would soon end. However, it is now 3 years later and she has never missed a meeting.

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²The Rev. Duane H. Fickeisen is parish co-minister and Anne Gero leads the Support Group for Caregivers and co-chairs the Compassion and Caring Circle of the Unitarian Universalists of the Cumberland Valley, PO Box 207, Boiling Springs PA 17007; 717/249-8944; www.uucv.net.

Ms is now 91 and is a transformed cat. She welcomes visitors and is patient with children. Recently, I had a visitor with stage-4 cancer, Ms stayed at her side. With our family, she now demands time and attention. She jumps up and pats us on the arm until we pet her. To get a treat, she goes to the kitchen and bats the cupboard so it bangs open and closed until we respond.

She is social, concerned about others, seems happy, and is asking to have her needs met. While she can't really tell us what transpired, I do believe the other group members will be more specific as they describe what happened for them through the Caregivers' Support Group.

Come let us worship together.

Readings

Reflections by Participants

UUCV Support Group for Caregivers

Bee Miller

The support group has been of great help to me. Here I found understanding and encouragement, and through laughter, tears and soul-searching and the care and love, which I have received from this group, I have found ways to cope with my problems, if not solving them. Because of this group, I am now happy.

Marilyn Durr

Early in July 2006, my husband, Don, was diagnosed with lung cancer. It was an event that changed our lives---a shock to both of us.

I was more than glad to do my part in giving Don the care he needed. But the care I needed was given by the wonderful people I met at my first Caring Circle meeting. Right away

they welcomed me as a member of the group, and I felt at ease putting myself in their hands.

As Don's condition worsened, ending with his death in April 2007, those people buoyed me up every step of the way. Just being able to share my thoughts and feelings with them made me able to accept the responsibilities and the increasingly confusing feelings that came with the situation. I knew they were with me all the way.

Ever since, I have been ready to offer whatever help I can to others who find themselves in situations that seem beyond their control. It's an honor to be part of the Compassion and Caring Circle.

Art Stilson

I learned that I need the moral support of the Compassion and Caring Circle. They are always ready to help answer my questions. It is the knowledge that I gained at CCC that allows me to help others.

I value the subjects that are discussed during our circle meetings. The information applies to the caregivers and the recipients of that care.

I appreciate our growing library. The CCC bookcase in the library at the meeting house is available to all. It contains relevant pamphlets, books, CD's and DVD's available to be borrowed.

Sandy Cones

The Compassion and Caring group has been very important to me for the support they have provided. There is no support group for my illness in this area. I had always belonged to a women's group in Florida, which had helped me through difficult times in the past. Now the women and Art give me sup-

port.

Ann Sheehan

During the past five years, while my now 93 year-old mother slid deeper into dementia and my only sibling and I could not agree on a plan for her care, the CCC saved my sanity. The bi-monthly meetings gave me a place to discuss the situation with people who cared and knew similar situations. The meetings were a space for me to be able to express my grief, my frustration, to gain insights on stress relief, to discover area resources on aging.

We viewed films and held book discussions on relevant topics. We sometimes had potluck lunches with incredible food. We helped each other. If you find yourself caring for the needs of another, locally or long-distance, short-term or long term, please check out the CCC. I believe you'll be glad you did.

Bobbi Bassett

What I personally experience from the Compassion and Caring Circle now, intensifies the awareness of what I missed when caring for my father. CCC was in its fledgling stage at the time. There was little support or comfort of the kind that is now available. But, that support, comfort, and compassion was available as I dealt with the loss and grief of losing my father.

I have been privileged to witness and experience the outreach and love available to all Members and Friends of UUCV. We each have differing needs and CCC attempts to meet each of us where we are in our need. CCC especially offers a safe, secure, sanctuary where you can bare your soul and be loved and comforted no matter what. This above all of the services, equipment, information, and so on, has meant the most to me.

As a member of the Compassion and Caring Circle I want to be able to reach out to help others using my first hand knowledge to comfort them, as I have been comforted.

Peg Bridge

As a stranger, I found comfort in a caring circle of warmth and friendship.

Carolyn Hocker

Before I had health problems, I was used to doing any work that needed to be done by myself and I felt strong enough to tackle all jobs. When I needed help, I felt embarrassed to ask. The CCC group members have filled an enormous void for me. In my crisis, they helped with daily needs. To name a few, they drove me to appointments, helped with groceries, and filled many other interim needs. All this was done with kindness, humor, and compassion.

Pat Dietz

I was encouraged to attend a meeting of the CCC. It was a time of personal loss for me, and it was a very helpful thing to be able to talk about that with people who allowed me to have a much-needed catharsis. It was important to me to know that anything discussed in the group would not be mentioned outside the group

I hope that one way to be of service is to be helpful to those in our community, whatever the nature of need may be. This group of people is indeed very caring and willing to help.

Gisela Roethke

The Caring and Compassion Circle approached me when they heard that I was struggling with how to deal with my mother's illness, deep depression, and lack of will to continue living at the end of 2008. I will not forget the intense listening

of the group to my struggle to accept what my mother was going through, and the additional difficulties that the long distance to Germany presented.

They validated what I was going through as someone who wanted to be a caregiver, but really wasn't able to because of the great distance. Many kind and understanding words were spoken. And amazingly, not only did they care for me, but also for my brother, who together with his wife had been the primary caregivers for our mother.

When I came back from a month in Germany in April last year, during which my mother had died and my three siblings and I had buried her ashes and taken care of her estate, there were friends from the CCC, who waited to receive me into their arms and console me. They also found the right words when I talked about the horror of seeing my mother having given up on herself, having withdrawn from the world and all its physical demands, but not having found peace in her soul before she died.

Just recently, over the holidays, I have had a break-through experience of a way to revive my memories of her when she was younger and a vivacious, fun-loving person. One of my brothers-in-law made a wonderful Christmas present of digitized excerpts from films taken at family gatherings over the years.

I will never forget the affection and caring of the CCC members that helped me greatly to go through the period of the most intense grieving.

Sermon (Part I)

Anne Gero

I am going to share a secret with you, today that I have not shared before. My secret is that about 15 years ago, I thought I

was in the early stages of Alzheimer's Disease (AD). For a period of time, I had a severe case of MCI Mild Cognitive Impairment. I would go to the grocery store and be unable to remember where I had parked my car. I would believe I was going to say one word, and a totally different word would come out of my mouth. I often called people by a name other than theirs. At times, I couldn't remember where I was going as I was driving my car through town. The more I panicked about it, the worse the pattern became. It was the most frightening time of my life. I began planning for my decline, while I still had the ability to do so. Knowing that caregiving was essential for about the next 10 years, I began to explore my options. There weren't many.

Fortunately, while I had the early symptoms, AD was not my diagnosis. My thyroid gland was found to be seriously dysfunctional. When it was finally diagnosed, my physician didn't know how I managed to get around at all with how low it was. The good news is that once the replacement therapy took hold, the symptoms stopped.

Caregiving is a major need for a lot of older people and most data suggest trends that indicate that the needs are going to only get greater. Let's look at some of the key factors. For our purposes today, the focus will be the need for caregiving at home for older persons who are chronically ill or have mobility issues, aging issues and dementia, especially AD.

Alzheimers—the dreaded disease. For those 65 and older, there are now 1 of 8 who have AD. The rate is expected to increase. Currently, someone develops the disease every 70 seconds.. It is forecast that by mid-century there will be another AD case every 33 seconds.

While the trend is terrifying, it is also important to acknowledge that much progress is being made. Ten years ago

when I was assisting Shippensburg University in developing a Gerontology Program, AD could not be officially diagnosed until after death. There was no treatment. Within the next few years, medication was discovered, that if taken early would slow down the progression of the disease. Brain scans are now used to identify AD patterns. Easier diagnostic techniques are emerging. In my preparation for this sermon, I learned that simple eye scans can be used to diagnose AD. It is a very dynamic field of study. There is much reason for hope.

Besides the AD contributing to the increased need for caregivers, trends, population trends also suggest the need for more caregiving services in the future.

In Pennsylvania, we have a lot of older people. We have the third highest percent of older people in the US (Florida & West Virginia are number 1 & 2). Besides the overall percentage, we have the second highest rate of persons over 85. It is our fastest growing population segment and one that often requires caregiving. .

Closer to home in our region, we have a very high percentage of older persons—one of the highest rates in PA. We are also in a culture where people assume that they will provide for their own and do not seek help. Our Area Agency on Aging finds that overall people don't plan for aging needs. Instead they wait until they are in crisis, which greatly limits options.

Ok. While these data give us some idea of the scope of the problem, it is still abstract and impersonal. Let's look at this more personally.

I am going to ask a series of questions and ask you to stand up if your answer to the question is yes. Please stay standing until I have asked all the questions.

Question 1. Are you currently a caregiver? [Including if you are caring for someone at a distance.]

Question 2. Have you been a caregiver?

Question 3. Do you anticipate being a caregiver in the near future (5 years)?

Please stay standing. Look around. These are our demographics. This is why we must be more aware. Caregiving is and will be an increasingly major part of the lives of many members of our community.

Thank you for your cooperation in this exercise.

Now that we have a sense of the magnitude of the problem and the need for caregivers, let's shift to what their realities are likely to be.

While there is much diversity among caregivers e.g., some young, some old, some men, some done by non-family members, sixty percent of the caregivers are women, near 50, who are caring for a parent or parent-in-law. Many have given up paying jobs to do the caregiving. There is a classic caregiver's handbook, The 36-Hour Day now in its 4th edition. The theme, of course, is that there never is enough time.

Caregivers report that they don't have enough time for their: families, friends, hobbies, exercise, and community. In other words, they give up meeting their own needs, to meet the needs of others. A new name for this syndrome is Compassion Fatigue. The stress wears the person down.

Actually, the stress manifests itself in many devious ways. It is not innocuous; it can be extremely harmful and damaging. To broaden our recognition of the ways that stress appears, I find it is useful to illustrate a category system of 4 parts, physical, behavioral, emotional, and cognitive types of symp-

toms. I will provide representative examples to help us recognize them.

In the physical realm are: headaches, high blood pressure, breathing problems, exhaustion, and compromised immune system resulting in chronic illnesses.

In the behavioral realm are: eating disorders, abuse of substances, tics, sleeping disorders.

In the emotional realm are: depression (at least 1/3) , anger, isolation, and resentment.

In the cognitive realm are: forgetfulness, blaming, loss of concentration and obsessing.

There is also evidence, that without help in reducing stress and in finding balance, that caregivers lives are shortened by as much as 2 years compared to non-caregiving peers.

While my part of this sermon focused on defining the problems, Duane will now move us into the problem solving. He will describe how caregivers can maintain their balance and reduce stress. Then he will help us understand how this is an integral part of our principles of UUCV.

Sermon (Part II)
Duane Fickeisen

The numbers and trends establish a context, but being a caregiver impacts individual people and their lives. The changes caregivers experience in their own lives usually come uninvited, and often unexpected, linked to the role of caregiver whether we have embraced being a caregiver out of love or it has been thrust on us by familial obligation.

The role of caregiver is usually in the context of an existing relationship. So we're also talking about the complexity of unique, individual, and often special relationships with a

partner, a parent, a sibling, a child, or another person who is close to us, and may have been for some time. Some of them are tender and loving, having been nurtured through years of commitment. Others are perhaps strained by a long history that might include emotional or physical abuse.

There may be other family members involved and our relationships with them may be strained or strengthened through the experience.

The complexity of our relationships together with the role of being a caregiver leads to conflicting feelings. Joy and compassion, a deepening love and care, closeness among those offering care and the one who receives it may be present. At the same time, resentment, anger, and frustration might also be present. Add to that the grief and sadness of witnessing the person you love and care for suffer and perhaps lose abilities or approach the end of their life as the nature of your relationship with him or her changes.

You may find yourself in a role-reversal, being the caretaker for someone who you have come to expect would care for you, and you may find yourself taking on tasks that were the primary responsibility of the one you are caring for — paying the bills, driving, taking out the trash, cooking, housecleaning, laundry, and yard work come to mind. You will likely feel the weight of responsibility of making significant decisions about medical care, financial management, and household concerns. Paperwork and regulations may become overwhelming.

Hard decisions may need to be made and the choices may not include any you want. The myriad small decisions may compete with big ones.

There can be a fine balance between respect for the free agency of the person you're caring for and quality care, par-

ticularly if he or she is making choices you don't agree with and don't feel are in his or her best interest.

Sometimes the decision must be made to seek professional care, either to supplement or to substitute for your own day-to-day caregiving. Or the best course of action might be the tough love one of letting someone fail rather than enabling behavior that is ultimately dangerous. These are not easy decisions. You may want to seek help in thinking them through and finding alternative resources. Seek the support of companions through the process — voices of people who will affirm your struggle and the decisions you reach with compassion.

Perhaps you'll second-guess your own best decisions. Maybe you'll have to make a choice that the person you are caring for doesn't like. Often it is wise to trust your intuition.

The struggles and feelings may make it hard to talk about the challenges of being a caregiver and perhaps even more difficult to practice good self-care.

But taking good care of yourself is crucial to your ability to continue effectively in a caregiver role. The stress factors and related symptoms that Anne mentioned are danger signs. While ignoring them may seem easier than responding to them in the short term, and you may be tempted to put your own needs aside until later — until the crisis passes — that's usually not a healthy approach.

Ignoring self-care may very well result in your experiencing an emergency need for care yourself, and that won't help you or the one you are caring for. It isn't good for your mental, physical, or emotional health and wellness.

Good self-care means having a solid and reliable support system; a healthy spiritual life with practices that help you stay grounded; access to resources for information, referrals,

and equipment; and activities that help you remember that there is more to your life than being a caregiver.

Good self-care might include making time for a respite from the demands of being a caregiver. Treat your body well — consider massage, acupuncture, eating well, and getting regular exercise. Seek the professional help of a therapist or guide to maintain emotional health, particularly when the role begins to feel overwhelming, depression seems to be setting in, or you feel angry or frustrated in the role.

Your church community, with its mission of transformation and care, can be a source of support that helps with both the practical day-to-day tasks of caregiving and with maintaining your own balance and spiritual wellness. As we sang earlier, joy and woe are woven fine. The more we are able to know and accept their interplay as a necessary part of living, the more safely we are able to move through the world.

Maintain social interactions and activities that encourage creativity and help you keep a healthy balance in your life. If music or tending plants or knitting or writing or long walks have been a source of grounding and balance for you in the past, make time for them. But mostly be gentle with yourself. Be sure to ask for help and accept it when it is offered. The more specific you can be about what you need, the more likely you'll find help.

The Compassion and Caring Circle has been a very helpful resource for caregivers as you heard in the testimonials we read earlier. They stand ready to offer support and assistance to anyone in a caregiver role. Most of the members have traveled that stony road, and while their experiences are not exactly the same as yours, they have learned from them. In return for the care and support they have experienced, they offer you a compassionate and caring circle of embrace.

The support and resources they offer include regular gatherings to listen and offer assistance to anyone who is a caregiver. You can drop in once and come back as often as you like. Their gatherings are in a comfortable, inviting space. They seek care for all who come with compassion.

They have gathered resources — books, tapes, videos, referrals, and equipment for loan — that may well prove to be of practical assistance. They have navigated some of the challenges of hospitals, nursing homes, Medicare and health insurance, and hospice. They can help with advice on getting access to home care services, choosing a nursing home, or finding public and private agency services.

The newly revised brochure that I hope you picked up on your way into the service this morning lists some of the ways they can be helpful and includes contact information.

Our affirmation of the inherent worth and dignity of every person and our aspiration to bring compassion into our relationships together with our recognition of our interdependence call us to be responsive to the needs around us. When someone we are especially close to needs care, of course we are drawn to do what needs to be done — to offer care.

The practice of compassion is a spiritual and religious impulse. Despite our sometimes fiercely defended independence, we are relational beings. Being in any meaningful relationship implies reciprocity and the potential for personal change. Our relationships change who we are — they transform us.

Even though the role of caregiving is nearly always challenging, it can have benefits. Your relationship with the person you care for will no doubt be changed — the potential for drawing closer and for more intimacy in the relationship may increase. Expressing compassion opens your heart, and with an open heart, you are likely to feel more deeply, to experience

both joy and woe, and to weave them together into the silken twine that connects you more deeply with the world and with what matters most.

When you are the recipient of someone's care, be grateful, for you are receiving a great gift and participating in a life-changing dance. When you are a caregiver, be gentle with yourself, seek balance and support, and practice good self-care. Ask for help.

And when you know someone else is a caregiver, make a point of offering her or him your support — a hug that acknowledges that their caregiving is both hard and tender, a listening ear, an invitation, an offer to help. Their work is hard, rewarding, exhausting, and vitally important. We can all support that.

Amen.

Benediction

from Commencement Address at Xavier University
New Orleans, August 11, 2006
Barack Obama

You know, there's a lot of talk in this country about the federal deficit. But I think we should talk more about our empathy deficit — the ability to put ourselves in someone else's shoes; to see the world through the eyes of those who are different from us — the child who's hungry, the steelworker who's been laid off, the family who lost the entire life they built together when the storm came to town.

When you think like this — when you choose to broaden your ambit of concern and empathize with the plight of others, whether they are close friends or distant strangers — it becomes harder not to act; harder not to help.