



In Honor of Caregivers

Rev. Sharon K. Dittmar
First Unitarian Church of Cincinnati
536 Linton Street
Cincinnati, Ohio 45219
513.281.1564
November 22, 2015

Call to Worship

The grace of God means something like: Here is your life. You might never have been, but you are because the party wouldn't have been complete without you. Here is the world. Beautiful and terrible things will happen. Don't be afraid. I am with you. Nothing can ever separate us. It's for you I created the universe. I love you. There's only one catch. Like any other gift, the gift of grace can be yours only if you'll reach out and take it. Maybe being able to reach out and take it is a gift too.

--Frederick Buechner

Reading

"The Well of Grief" David Whyte

Those who will not slip beneath the stiff surface on the well of grief
turning downward through its black water
to the place we cannot breathe
will never know the source from which we drink,
the secret water, cold and clear,
nor find in the darkness glimmering
the small round coins
thrown by those who wished for something else

Sermon

Caregiving runs the gauntlet between the opening words of Frederick Buechner, and our reading by David Whyte. If you have been hung up this far on the theology of Buechner ("I am with you. Nothing can ever separate us. It's for you I created the universe. I love you."), I ask you to release yourself from this prison of thought and focus on the larger point I am working with today, how we make meaning in a world to which we were born and suffering occurs. Our birth heralds the potential for life, and promises little else (including longevity or health). There are no promises about what kind of life, and where the life, and with whom the life and for us who live mostly privileged lives in the west, we routinely forget the randomness of this world. The sheer chaotic randomness, where less things go wrong than we would imagine, and yet when they do, we are filled with pain.

For many of us, a stark realization of the randomness occurs when we fill the role of caregiver for someone else. Those of us who work in this field, social workers, therapists of all stripes, nurses, aids, attendants, doctors, clergy, we learn very early on that life is random and "unfair." We see suffering, loss, and death in all shapes and sizes, one of the more heart rending in the neo-natal intensive care unit. To be born and for some, so quickly to die. Due to what I have experienced, the fact that I have an almost 14-year-old son who walks this earth on a daily basis, astonishes me, daily. Most of us do not think in these terms on a daily basis.

So for me a clergyperson, caregiving has brought me close to gratitude and it does not matter my theology. I don't think this universe was created for me, maybe some of you do. I don't. I am uncertain if the universe loves me. But here is what I do know, Buechner's words still resonate with me.

Here is the world. Beautiful and terrible things will happen. [Why yes, and yes] . . . there's only one catch. Like any other gift, the gift of grace can be yours only if you'll reach out and take it. Maybe being able to reach out and take it is a gift too [Why yes and yes]. I have just completed my 76th memorial service in 19 years. Seventy six times I have watched families cross this path of death and life. On many of these occasions I have read the words of the poet Khalil Gibran "Your joys is your sorrow unmasked," and because this is so, the sermon this morning is linked by two almost contradictory readings, one by Buechner, and one by the poet David Whyte.

There is grace and there are gifts (regardless of your theology) in this life. As well-known scientist and atheist Richard Dawkins writes in *Unweaving the Rainbow*, "We are going to die, and that makes us the lucky ones. Most people are never going to die because they are never going to be born." And on the other hand, the stark words of Whyte, "turning downward through its black water/to the place we cannot breathe/ will never know the source from which we drink." There is pain in this gift.

In care giving we are on holy ground by any stretch of the imagination. We are in the place of known and unknown, life and death, memory and forgetting. This is wholly, holey, holy territory. If you have felt lost and tossed in its space, now you know why. You are standing on insecure, sacred ground that strips away illusion of control, knowledge, and power. And

there are tremendous gifts, and there is tremendous pain, all together.

Sixteen of you wrote to tell me about your caregiving experiences. Having so recently been a caregiver for my father, who died last year from a host of health problems including cancer, heart failure, and dementia, and currently being a caregiver for my mother, your words resonated not just with my professional story, but my personal story as well. I was drawn to the words you cast out from within the storm of challenging caregiving, for example, when a family member had dementia (and was losing his or her personality - which is its own, unique pain) or when a family members was terminally ill and as you cared you said "good-bye."

One of you wrote to me "One of my visiting times is 6:15 a.m. on Saturday morning with donut and coffee to her bedside. She is so vulnerable and dependent in bed. Breaks my heart - repeatedly see her as a kid doing cartwheels and now this." Another one of you wrote to me "I have noted a strange feeling of sadness and loss when I see my mother under anesthesia or slowly coming out of general anesthesia. I note her vulnerability, the small size of her body lying in a hospital bed, which makes me feel vulnerable and exposes me to the increasingly close reality that she will indeed die someday."

For those of us who are not professional caregivers, we are caregivers to people we personally know, often for a lifetime, and love, or much harder still, despise. The November 2015 issue of *AARP Bulletin* notes in its "Special Report: Caregiving in America" that 40 million Americans work as unpaid caregivers for family or friends, totaling "37 billion hours of unpaid caregiving, worth \$470 billion." That is all that time washing, feeding, transporting to medical appointments, filing for coverage, straightening out coverage, cooking, cleaning, giving medication, watching, strategizing, etc.

The AARP Special Report noted that the average family caregiver is a 49 year old woman, not the elderly, but someone in the "sandwich" generation simultaneously caring for children and probably trying to keep a job. More woman are caregivers than men, though those numbers continue to even out with now 40% of men serving as caregivers. Finally, "one-quarter of all caregivers are now between the ages of 18 and 34." These are young people, postponing marriage, jobs, education, and children to care for someone else. They are often doing long distance caregiving and subject to "tremendous guilt."

Please know that you are considered a caregiver if you care for someone out of state too. You don't have to see them every day. Are you dealing with an insurance claim for your father in Wisconsin, getting updates from the rehabilitation staff in Tennessee? Are you working on power of attorney, selling a car or an estate? You are a caregiver.

Young caregivers also feel more isolation since their peers are mostly enjoying young adulthood. This is the well of grief. If the AARP article taught me anything, it was how universal it is to be a caregiver, regardless of race, age, gender, ethnicity, sexual orientation, etc.

Everyone seems to agree that caregiving is much harder than it used to be a few decades ago. Hospital stays are shorter, people live longer, and caregivers are expected to perform medical tasks that were previously done by professional (catheters, injections, etc.). Loved ones don't

get training on how to do the work and often feel at a loss. AARP profiled one man who has been caring for his wife for 10 years. His experience with his wife left him with pieces of advice, "It's nothing to be ashamed of," and "Just do the best you can. If you try to be too perfect, you're going to frustrate yourself."

Many of you sent me thoughts about what you had learned, similar to this man. One of you wrote to me "Balance? That comes later, when the caregiving is done. The truth is, there are times when balance involves taking deep breaths at red lights. What did I learn? Don't beat yourself or anyone else up." Another one of you wrote, "Something always happens that you didn't plan for . . . just roll with it. Don't judge . . . it might look crazy but it probably makes sense." Another person wrote "I learned how important one day at a time was . . . I learned to avoid concentrating on his illness and instead sharing stories and conversations. He taught me to deal with his disease, but to not let it define him." Someone else added, "Find some humor in the events that are taking place," and "Acknowledge that you can't 'fix it' and return someone to what they were before they needed help." Another person added, "She's giving me a gift by letting me feel that I am helping . . . I wish people would be more open to accepting help when it is offered." Finally someone noted "After she died, I decided that I was going to change my life." This person changed where she lives and what she does based on what she learned as a caregiver.

That last paragraph is full of huge life lessons that probably took everyone who wrote in years to learn. They were not changed by reading on self-help book. It was day in and day out learning, confusion, trying, adjusting, trying again, etc. That last paragraph also contains an invaluable list of important and helpful life lessons. I wished they could be learned under easier circumstances, but my guess is that everyone who learned these things is grateful for what they now know. These are the gifts we can reach out and take.

One of you wrote to me "I think being a caretaker has an opportunity to be an unspeakable moment of intimacy that has previously eluded the relationship." This can definitely be the case in astonishing and illuminating ways. One of you shared, "Up until she had dementia she really hadn't talked about anything negative or that wasn't "proper" that happened to her. She was an ambulance driver in London from 1936 - 1945, yet never shared any stories until living with me about that time. My father-in-law was CIA and that topic was strictly forbidden until then. All of a sudden I was hearing about Saipan, Salvador, Hawaii, and D.C."

I too learned previously unspoken family stories in my father's last six months of life. On one day he twice said that my mother miscarried twin boys late in a pregnancy. I thought he was confused, because he was confused, but then something in me thought I was hearing the truth so I asked more questions and I put the story together. My mother miscarried twins at 6 months. Without dementia, my father would have gone to the grave with this story, as will my mother. But I am grateful to know because it explains certain odd, formerly unexplainable things that have happened in my family. I am glad to know, and maybe, maybe if there is another moment of grace there will be a chance to speak to my mother about it because she suffers with this secret. But I won't count on it.

Morita Marmo spoke of caring for her husband Mike, and noted that she appreciated his "high entertainment value" far into his illness. Lyn Martin wrote to me that "the privilege

part, in my case, is knowing that I'm walking down a very sacred path with my mom toward her eventual death." Susan Christy shared this story: After years of being a newshound, Dad would only watch Marcus Welby, MD on TV, because anything more complicated agitated him. My mother of course acquiesced, but the burden of an intellectual wasteland was telling on her. One evening, Dad fell asleep in his chair during the last few minutes of Marcus Welby, and the next show on was the romantic comedy "Moonstruck." Mom and I didn't make a sound for two hours, laughing into our sleeves, tears rolling down our faces as we tried to control ourselves when Cher yelled, "Snap out of it!" at Nicholas Cage. An odd moment of grace, but grace nonetheless.

And because caregiving is different in every situation, one of you wrote to tell me, "My brother spends much time in front of a computer. He is getting conspiratorial and come up with beliefs that I cannot tolerate but bite my tongue - last week it was doubting the Holocaust - I did not bite my tongue on that one . . . hard to balance love with duty to be honest in dialogue." One of the most significant caregiving challenges I read about is when someone's personality changes, either from dementia or brain injury. The sense of humor changes and the person you know, disappears. This is a slow, painful, stressful journey. On the flip side I once knew someone with a very difficult mother, who became pleasant after dementia settled into her brain. But in general, it goes the other way.

Stress among caregivers is high, very high. The 15 million people caring for loved ones with dementia generally experience high or very high levels of stress (the long term changes are painful to see and experience). One of you wrote to me about being verbally berated on a weekly or daily basis by the person you cared for, something that can be common with dementia. You wrote "I was tired and found it difficult to not take personally." The AARP article notes that 17% of caregivers are caring for someone in or discharged from the military. Veterans struggle with health and physical ailments along with PTSD and brain injury. 68% of these caregivers consider their situation "highly stressful."

One of you wrote to me about needing to take more than a month off of work while caregiving. Two of you who wrote to me are professional caregivers and you both wrote about the strategies you use to sustain yourselves. One of you relies on music anywhere you go, as well as needlepoint, coloring and puzzles. These are all individual activities that require focus on one thing - a needed counterpoint to caregiving. Another professional caregiver wrote about her reliance on exercise and nature - again individual activities away from caregiving.

Several of you wrote about the help you received from family and friends and how it made all the difference. Lisa Littner wrote about the irony of caring for her mother during leukemia treatments, and supplying the same care to her small children when she came home - cook, remind them to brush their teeth and go to the bathroom. But she noted that spending time with my "sweet children also helped me too." Morita wrote to me about the normalcy she felt that friends and family brought over dinner when Mike was ill, stayed for an hour meal and left. She cherished these visits and noted "I was blessed to have the incredible support of friends, many of whom are members of this church." She then noted how difficult it was to go to Minnesota to care for her mother which meant she was alone without family and friends and worried about all her responsibilities at home.

Some of you wrote to me about the importance of a support group where you could meet people with similar experiences. As one of you put it "I became part of the parents of cancer kids group which was very valuable when enduring and sharing hardship." I would encourage anyone in a long term caregiving role to consider a support group. And yet one of you also shared with me that your husband would not permit you to tell the grown children about his illness. What an extraordinary burden. Please don't ask this of someone. This wife finally told one of the children and found it a great relief though advising the son that if "Dad finally told him, he was to be surprised." So here we have a moment of "don't judge." It "might look crazy but probably makes sense."

Long term caregivers need respite. The AARP article had a list of places that provide resources. I also recommend for those of you with loved one that have dementia, the Alzheimer's Association in Cincinnati. I have called them numerous times for professional and personal reasons. They even have an advice nurse (no one has an advice nurse today! This is wonderful).

One of you wrote to me and noted that people don't like to ask for specific help, so just reach out and suggest things, "make a phone call, stop by for a chat, bring some food, reading materials, offer to take him/her out for lunch, to a doctor's appointment, offer to do housecleaning, grocery shopping, laundry." Someone else wrote to me "My sister welcomes time with people that she is not paying. 90% of her interactions are with people she is paying." Finally, one of you wrote to me about the enormous hole that is created when caregiving ends, when that loved one dies. Often there is relief, but also sadness and alienation. Now what? Now what. Reach out to caregivers then too.

Caregiving. It rests between these two poles - the gift of life and the well of grief. It swings wildly between them. One day gratitude, another day devastation, and hopefully many days in between of an average life that is good, blessed the lessons of both the gift of life and the well of grief.

"Oddjob, a Bull Terrier"

Derek Walcott

You prepare for one sorrow,
but another comes.
It is not like the weather,
you cannot brace yourself,
the unreadiness is all.
Your companion, the woman,
the friend next to you,
the child at your side,
and the dog,
we tremble for them,
we look seaward and muse
it will rain.
We shall get ready for rain;
you do not connect
the sunlight altering

the darkening oleanders
in the sea-garden,
the gold going out of the palms.
You do not connect this,
the fleck of the drizzle
on your flesh,
with the dog's whimper,
the thunder doesn't frighten,
the readiness is all;
what follows at your feet
is trying to tell you
the silence is all:
it is deeper than the readiness,
it is sea-deep,
earth-deep,
love-deep.

The silence
is stronger than thunder,
we are stricken dumb and deep
as the animals who never utter love
as we do, except
it becomes unutterable
and must be said,
in a whimper,
in tears,
in the drizzle that comes to our eyes
not uttering the loved thing's name,
the silence of the dead,
the silence of the deepest buried love is
the one silence,
and whether we bear it for beast,
for child, for woman, or friend,
it is the one love, it is the same,
and it is blest
deepest by loss
it is blest, it is blest.