2005-9-18 On Caregiving
Mark Belletini

Opening Words

We are here
at the brink of coming Autumn,
to worship, to embrace the deeper Care
which helps us face our many individual cares,
and fills our heart with new power, new hope.

And so, with the fullness of our lives we say:

Mindful of the responsibility our freedom presses into us, blest by the beauty of the world, and drawn by a vision of a community known for its honesty, generosity, depth, love, and justice-work, we focus our time together by the kindling of light.

The Children's Story:

Always Gramma by Vaunda Micheaux Nelson

Sequence

The football games are back. The cheering
and fluttering pennants.
But the sad game of those who
are privileged playing those who are not
has never ebbed, even for a moment.
In New Orleans, sure. But even in Ohio.

The cool air is back in the evenings.
The hot breath of summer slowly comes
to an end. The leaves are turning crisp.
But the cool, crisp policies of the powerful
diminishing those who have little power in the first place never went away,
even in the hottest months.

The globe tilts and turns around the
great hot revelation of the sun, and the season changes and everything is transformed.

O Love, may I too be transformed.
May I tilt ever toward You, steady bright
comfort, like a glowing river of light
meandering through the meadow of this silence.
I bend low, cup my hand, lift it to my mouth,
and quench my thirst….

silence

In the flowing silence, I recall all whom I personally love, and value, and am encouraged by, and I join hands with them in this meadow of silence, this bright field of light and love, by naming them aloud, or in the silent heart.

naming

There is a time for flowing silence. And a time for strong words. And a time for healing. A time for loving. A time for struggling. A time for caring. And a time for the rich and redeeming gift of music.

Anthem: To Everything There Is A Season
Text from Ecclesiastes; Music: John Rutter

Reading

The First Reading comes from the most excellent book Caregiving, by Beth Witrogen McLeod, published in 1999 (John Wiley and Sons) I commend it to you, as well as another book:

Should Mom Be Left Alone? Should Dad Be Driving? by Dr. Linda Rhodes 2005 New American Library (Penguin.) Those of us dealing with these issues will certainly find both books helpful reading.

Assuming the care of a loved one has the potential to alter us at the core of our being, opening our heart's capacity to live fully even in the midst of loss. Because our death-denying society has few safety nets for coping with suffering, caregiving often hits people unprepared to negotiate the raw emotions that underlie our identities, our relationships and our spiritual beliefs. When those unfamiliar feelings surface, we are unprotected by what we have been conditioned to expect, unaware of the anchor that lies within us. When illness and loss find us, we discover a few sometimes shocking truths: we have not made authentic connections with others, and we don't know ourselves well, and we don't feel empowered by the institutions in which we have put our trust. Although this subject may be uncomfortable, there is support and comfort in the midst of it all: knowledge that we are not alone, that we have choice and permission, that there is a way out of confusion. For caregiving is a spiritual practice.

The Second Reading is from the Gospel of Luke.
The Fellows of the Jesus Seminar, following the work of hundreds of scholars before them, refer to this particular story using the Latin technical term Ipsissima Verba Iesu*, that is, this text is the closest we can get to the few authentic words of the Galilean teacher, Jesus, that have survived critical inquiry. For many of you, this is a well-known story:*

There once was a fellow who was making the trip from Jerusalem down to Jericho by the Sea. It chanced that some highway bandits caught up to him, beat him, stripped him of clothes and money, and left him for dead by the side of the road. Now by coincidence, a temple priest was going the same way, and walked out of his way to avoid the body by the side of the road. And not long later, a worship leader from the temple came down the pike. He took one look at the body by the side of the road, and crossed it to avoid him. But then this Samaritan fellow came by, traveling on the same route. (Samaritans, as you know, have no dealings whatsoever with Judeans.) But when he saw the unfortunate by the side of the road, he was moved with

compassion; immediately he went up and bandaged his wounds, using some wine and oil he had with him as a poultice. Then he hoisted the wounded man up onto his own animal, and brought him to an inn, and cared for him all night long. The next day, he took out some significant money from his wallet, gave it to the innkeeper and said, "Please look after him, and in a few days, on my way back, I will reimburse you for any extra expense you have had."

Sermon

I've told this story from my life a few times in private, but it really will help me set the stage for this morning's sermon better than anything else. You see, it represents the first major event in my life which propelled me to start thinking about the whole idea of care-giving.

My mother's mother, my grandmother Anna Galli, started to develop signs of Alzheimer's in her late 70's. Except we didn't know that word then. We all just said, "Oh, that's Gramma. She's always been kind of that way."

But as time went on, and she started calling her neighbors up at three in the morning on Wednesday asking them to drive her to Sunday Mass, my parents knew she could no longer live all by herself. So they took her into their home, along with my other grandmother, Carmelina Belletini. And soon the doctor confirmed that my grandmother Galli was actually suffering with the condition we now name Alzheimer's.

It was not very long before my grandmother began to lose more than a sense of time. Eventually she was not able to speak, or recognize anyone. She was not able to cooperate when my father tried to lower her into the tub to take a bath…she was not even aware, apparently, of what he was doing. My father destroyed his knee doing this…people heard the loud pop. Even after arthroscopic surgery, he still walks with quite visible pain. My mother too was visibly worn out from giving such difficult care to her ailing mother.

Now my mother and father, as do so many people of Italian ethnicity in Detroit, do a great deal of their socializing at wakes, or what people here in Columbus tend to call "a viewing." Funeral Homes are much bigger and more elaborate in the Detroit area than anyplace else I have lived.

While talking to a person she knew somewhat, at one of these wakes, my mother let down her hair a bit about how difficult it was for her and my father to give such constant care to my grandmother. This woman raised her eyebrows and said to my mother, in an accusing tone: "O Lisa, you're not thinking of putting your mother in a Home, are you?" I was very angry about what this woman said to my mother, and I told my mother so.

Nevertheless, for two whole years after this event of public shaming, my parents continued to keep my grandmother in their house.

So one holiday season when I was visiting Detroit, I came up with a somewhat wild plan to try and help move my mother past her shame. I sat her down and I asked her some questions.
"Ma, I really want you to answer these questions. If Gramma Galli needed gall bladder surgery, would you do it here at the house? I mean, would you liquor her up, lay her on the dining table, sterilize a few knives in the stove flame, then cut out her gall bladder and sew her up with your needles and thread?"

My mother was duly horrified by my impertinent question. "Why, of course not, Mark, I'm not a doctor."

"And you're not a nurse either," I added quickly. "You are not a nurse, because you didn't go to Nursing School. Which is fine…you didn't want to be a nurse. No shame there. Nothing wrong with deciding against nursing school. Or medical school. But I think Granmma *needs* a nurse. Alzheimer's is a serious illness, Ma, like cancer or any other physical illness. It requires special knowledge. Neither you, nor Dad, *have* that knowledge, again through no fault of your own. Neither of you know the techniques a firefighter uses to pick up such a heavy person. Neither of you know about nutrition for someone in her condition. And I don't know such things either.

It's not our fault that we're unfamiliar with such things. None of us, simply, were ever trained to do such advanced nursing.

And so I am convinced that, though your intentions are kind, you are not helping Gramma, but most likely hurting her, by keeping her here. I think it's time that we go looking for a place together that specializes in Alzheimer's patients that is not too far from here. That way you can see her as often as you want. But you don't have to do the principle care. It's not fair to Gramma."

"You would come and help me find a good place?"

"Of course I would. And after so many years in the ministry, I have a good sense of discernment about such places. I think I can be of help."

And so my Grandmother Galli was placed in a very fine establishment run by the United Church of Christ, our liberal Christian cousins. And that is the place, years later, where her remarkably youthful heart finally gave in and she died. That was only four years ago.

"Although this subject may be uncomfortable," our first reading reminded us, "there *is* support and comfort in the midst of it all: knowledge that we are not alone, that we have choice and permission, that there is a way out of confusion. For caregiving is
a "spiritual practice." The story of my grandmother illustrates these assertions very well, it seems to me. My mother had support in the midst of her caregiving worries. First, as the reading asserts, she was not alone. Her husband (my father) and her three grown children helped her in different ways, but she certainly was not alone. Second, she received permission to think of alternative choices that made sense. And third, she understood that there is a way out of the horrible confusion which I have named "shame."

Shame is one of the most common feelings I find associated with the most draining kinds of caregiving. "Everyone else in the family can see I am not doing enough. I know my sister resents me for not being there enough. I live

on the West Coast! Do people imagine I am supposed to quit my job, drop everything and go be with mom?" This is the language of shame. Shame is basically our fear about what other people's opinions might be about our choices. And shame often distorts our ability to make wiser decisions in the first place. It can be a very toxic emotion.

Guilt is the second emotion that is associated with caregiving, and often, along with denial and the disruption caused by role changes, it is the most pervasive feeling. "I should be doing better than I am," and "Am I doing enough?" are common expressions of guilt.

While shame is a social concept (often made more intense by ethnic variation among the emotional make up of American families), guilt is usually interior and rarely expressed.
And it's based, not on the expectation of others, but on our own unrealistic expectations, which often are linked to the attitude we now lable *perfectionism.* "If I don't get this right, I will be at fault if anything goes wrong." Guilt weighs heavy on the caregiver, and saps strength, siphoning off energy. The most practical way to confront it is to work on claiming more realistic expectations. Compassion, after all, is not just for others. It's for ourselves first.

Role-change plays a part here too. Often, with intergenerational caretaking, roles are reversed, and children feel more like parents, which can be very confusing.

But please don't imagine caregiving is always of younger for older, or even of the healthy for the sick. There are all sorts of caregiving…parents are caregivers every day. So are librarians, and teachers, nurses and doctors, assisted living workers and, even sometimes, ministers.

But there is more to say. I have a friend who has been out of work for months, and just found a job. But as is to be expected, paychecks come weeks after the job started. So this man has been without any income for food (although, fortunately, he has a free place to stay for a couple of month). So I have made sure I pack plenty of food in my refrigerator, and

that he has a key to my place. My friend is hardly sick. In fact, he can bench press 250 lbs. But he *is* in dire straits right now, and offering him such ordinary care is a practical response to his situation.

And of course, while all of my friends were dying of problems related to HIV during the height of the West Coast pandemic in the 80's, my caregiving was for people of my own age. No roles were exchanged, children becoming parents. It was peers caring for peers. And our children's story suggests that even a little child knows how to give care to a much older person.

No, in the end, caregiving involves all of us…all ages. Although I have to admit, every book about caregiving I consulted was written by a woman, which makes me wonder about gender issues hidden in all of this.

But, in any case, clearly there is an understandably greater focus these days on caregiving for seniors, since we are all living quite a bit longer than our ancestors did. The life expectancy when both Jesus and Caesar were alive was about 40. Today it's about 75-78 if you happen to live in the States, and 85 to 90, if you are lucky enough to live in Canada, Japan, or Australia. Thus, ordinary statistics suggest there are more people involved in caregiving now than ever before in all of human history.

Now, when that Galilean sage Jesus told the story of the Samaritan caregiver, he was not trying to give a specific lesson about caregiving, as if the story was some sort of allegory with a correct moral at the end, like one of Aesop's fables. Characteristically, he was asking the people around him to think for themselves. But I want to direct your attention to some aspects of the story. First, nowhere does Jesus condemn the behavior of anyone in the story. If you heard that, read it again. The temple clerics, after all, did what many modern people would do. They avoided the problem. They were in denial. Who could be sure this beaten fellow wasn't up to something? You go to help some stranger by the side of the road, and it's a trick…he takes your wallet and knocks you on the head. What's that English proverb? "Caution is the better part of valor." Don't many of us wisely teach that to our children? How many people do you know, when they see drunks in doorways down in

the Short North, stop what they are doing and go check out the unfortunate? Not a great many, I'd wager.

And note that the Samaritan is identified by his ethnicity, and the clerics are clearly Judean since they are officers of the temple in Judea, but the fallen fellow is not identified. Was he another Samaritan perhaps? Was it a Judean? We know his place of origin and destination, but we don't know anything else about him. Maybe he was another Samaritan, and that's why the Judeans passed him by, since Judeans didn't get along with Samaritans and vice versa. Maybe the story is not telling, so that he remains a human being only.

Now I can admit that the Samaritan fellow responds to the situation immediately and with class. He dresses the wound carefully with good first century medical knowledge, and he spends money to help get room and board for the man, in order that he might recover. Note also, he doesn't give up his whole life to take care of this man…he goes off on his way, because he has other commitments. He does vow to come back when he is done with his other commitment and offer more financial help. This is certainly a very generous gesture, and it reminds us that caregiving often involves our finances. (This can be a serious problem in caregiving…I know…but how else could it be?)

Judeans and Samaritans didn't get along. Jesus was asking, in this famous story, "But can they?" If faced with a crisis, aren't all people equally human? Aren't all the silly notions we use to keep us apart from each other foolish when push comes to shove? He is asking, "What are the spiritual roots of caregiving? Don't all of our religious principles ask us to imagine a beloved community rather than a circle of enemies? Isn't care for a single individual a way of imagining a better world for us all?"

While examining this famous story this week, I couldn't help but think of some of the photo captions I saw this week from down in Louisiana. Black Americans taking food from a store so they won't starve are described as *looting*. White Americans taking food from a store so they won't starve are described as "finding" the food.

Samaritans and Judeans.

The temple leaders in those days had lots of money. They *were* the government, basically, and had the power to tax. It was a theocracy, after all, despite certain Roman limits on their power. The Samaritans, on the other hand, didn't have the power to tax. Yet this Samaritan was giving of his livelihood to care for the beaten man. Thus, I'm convinced Jesus was asking the same question by his story as many are asking today about the unbalanced economic reality in Louisiana i.e. the destruction of human life that existed *before* the hurricane. He was asking about balance of power, and equality of care for *all* people, no matter their ethnicity or class. He wanted people to talk about this, to have conversations. That's why he told stories. To pose questions and get people off their comfort level of self-congratulation. You know: "We're the greatest nation that ever was. God's chosen people."

Caregiving certainly *can* knock us off our comfort level as much as a storm. It demands a lot of us, whether it's long term or short term, whether it's a single individual down on his luck, as in the stories of both my friend and of Jesus' story, or whether it's about social calamities like a flood, or a huge Alzheimer's home where hundreds of grammas are being cared for at great expense. Caregiving almost always confronts us with the unfairness of things. It pushes our own mortality and our dependence on mere fortune right into our face. Caregiving can pry us open with guilt or shame, or it can tighten our resentment or let loose our feelings of helplessness, one of the hardest feelings for us independent types to negotiate. It can ask us questions about our own expectations…for ourselves as well as others. And it can touch on social issues as well as deeply personal issues. In Beth McLeod's words "When illness and loss find us, we discover a few shocking truths: we have not made authentic connections with others; and we don't know ourselves well; and we don't feel empowered by the institutions in which we have put our trust."

But, as she concludes, there is comfort to be found in the midst of these difficulties, and a way out of the confusion, for in the end, caregiving is a *spiritual practice*. The phrase "spiritual practice" is a shorthand way of

saying that it confronts us in our depths, not merely superficially. It's a shorthand way of saying that we are not alone, and that we can make good, if not flawless, decisions together. It's a way of saying we can give each other permission to do the most rational, loving things possible, transcending our hopelessness and any sense of unwarranted despair. And like all things spiritual, at least in my persuasion, the practice of caregiving reminds us in the end that we are not at all like the God of traditional and popular theology…that is, we are not the Almighty, we cannot do all things or accomplish any measure of perfection. So the spiritual practice of caregiving pulls the carpet of our perfectionism out from under us, and invites all people to consider a more selfless way of moving through life. It demands that we suffer our limits. And if we are not trained nurses or physicians, it asks us to find those who *are* trained and let go our need to do all the work. It asks us to slowly transcend any shame we fight, and any guilt we bear, and trade them in for the view of a larger world, where Judean and Samaritan, poorer and wealthier, sick and healthy, the privileged and disenfranchised, the lucky and the unlucky begin to find the humane ties that bind us all, as they have always bound us, into one single humanity.

Offering

Blessed are the moments in our lives when giving and receiving are one, reminding us at the same time that giving strengthens us, while "thank you" are two of the finest words in our language.