

Blog Posts from June 2014

Monday, June 2, 2014

Washington DC

Would It Be Suicide?

On seeing an Alzheimer's patient (or any other person) lying comatose and terminally ill in a nursing home bed, almost everyone thinks, "I don't want to die like that!" (See my [last post](#)). That raises the question of suicide.

When I believed I had Alzheimer's, I didn't seriously entertain the possibility of killing myself for a number of [practical reasons](#). The most important was that people with dementia are still capable of meaningful relationship well into the course of their disease, and many readers ([Lee Ann Gerleman](#), among others) insist that the often-difficult season of caring for a person who may not even recognize family offers many joyous times, too. The only reason I could imagine for checking out early was to prevent the burden of caregiving on someone I love. No matter how deep our relationship, I didn't want to burden my wife Marja with caring for me when I became completely incapable of relationship or unable to tend to my own physical needs.

I thought often about the conflict between my unwillingness to foist upon Marja my care in the last stages of my illness and my choice not to suicide. At one point, however, a woman wrote me that her husband (who had Alzheimer's) decided upon something "in between" suicide and the burden of care in the last stage of the disease. They agreed that when he reached the point where he could no longer feed himself, no one else would feed him, either. When the time came and she withheld food and water, her husband died within two weeks.

At [Joseph's House](#), we've had analogous experiences of people *unable* to eat or drink as they neared the end of their lives. As we do for all other residents, we accompanied them around-the-clock, and death from lack of food or water seemed to us no more painful or difficult than the deaths of the many others we accompany.

I've asked myself whether deciding against food or water when I am terminally ill is a form of suicide. I don't think it is. It's rather more like deciding against what the medical world calls "extraordinary measures," for instance, choosing not to put a terminally ill patient on a respirator, an acceptable and common medical practice. I can see little moral or emotional difference between, on the one hand, not feeding a person and, on the other, choosing not to put in a feeding tube or treat an infection in the last stages of disease.

Arranging not to be fed seemed like a good middle ground. I talked about it extensively with Marja, my children and some others close to me, and we agreed upon that course. We realized that if I were in a nursing home, however, such a decision would probably not be allowed, so my family would have to take me out to die at home ... a better choice, anyway. I made my decision formal by filling out the appropriate legal documents. Legally, then, this would be my decision alone, and no one else would have to risk guilt or the disapproval of others by making such a "heartless" decision for a dying person. I'm keeping that living will intact in case my impairment begins progressing again or I'm in the same situation from another cause of death.

I would offer several cautions from my experience as a physician. First, talk the decision through with *everyone* who is close to you or might be able to cause trouble when the decision needs to be made. At Joseph's House we've had relatives come out of the woodwork at the last minute to insist upon a different course of action than that decided by the patient and close family, even threatening legal action when we, for instance, didn't hospitalize a patient for whom nothing medically could be done. Second, get it written down; everyone should have a written living will (or [advanced health care directive](#)), anyway, but especially in this situation. This does not need to be prepared by a lawyer or any third party (see [Five Wishes](#)). Third, find a hospice provider or physician in your area who will agree to provide support. Finally, review the decision with family regularly, perhaps once a year, until you are no longer capable of doing so.

There was no debate in our family; it seemed right to everyone. I'm sure Marja would never have protested the burden of caring for me, but it was important for me to protect her from those meaningless months or years when the demands of care were enormous and I was no longer aware of much of anything.

Sunday, June 8, 2014

Washington DC

More on Not Being Fed When You Can't Feed Yourself

As when I wrote [about suicide](#) in April of 2013, my [last post](#) about not feeding a person with end-stage dementia (or any other terminal illness) drew many comments and emails. If you're like me, you don't read all the comments of all the blogs you visit, but these comments seem important enough to deserve their own post.

I suppose I shouldn't be surprised, but there is an entire literature about the topic of not feeding at the end of life. It even has its own acronym, VSED (voluntarily stopping eating and drinking). A friend emailed me this [link](#) to a webpage that offers a TED-talk video of a spouse describing her husband's decision to refuse sustenance; the same page links to a number of other stories and professional articles about the choice of VSED, especially about its legality and its difference from assisted suicide.

As the acronym indicates, however, most of that literature seems to be about terminally ill patients who are still quite capable of feeding themselves but *voluntarily* stop eating. VSED should be differentiated, it seems to me, from not feeding a person who has lost the capacity to feed himself. The latter is a choice

not to prolong

a life that is clearly near its end, while VSED is a decision to

shorten

one's life, a decision that anyone could make regardless of medical condition.

What is most helpful about the literature on VSED is that even this (which ethically could be considered a step closer to suicide) is legal almost everywhere. Two legal experts on the topic write in the [abstract of their law review article](#) :

Specifically, we argue that both contemporaneous [*made at the time*) and (most) non-contemporaneous decisions for VSED are legally permissible. Individuals may refuse nutrition and hydration just as they may refuse other intrusions on their personal autonomy. This right is grounded in the common law of battery, statutes, state constitutions, and even the U.S. Constitution. Moreover, VSED does not, as many believe, constitute abuse, neglect, or assisted suicide. Even ex ante [

fore the event

] decisions for VSED (exercised through an advance directive or a surrogate decision maker)

are legal in most United States jurisdictions.

Another commenter countered my implication that nursing homes won't cooperate with such a decision. He wrote that most nursing homes and hospices will agree not to feed residents who have previously prepared appropriately and left advance directives ("living wills"), documenting their desire not to be fed when they can no longer feed themselves. So, anyone contemplating either nursing home or assisted living who is interested in not being fed should inquire about the policies of the institutions being considered.

Several other comments and emails offered stories of the writers' experience with not feeding. Especially important is the point made by Lee Ann Gerleman (a nurse with lots of experience with death) that dying from dehydration is not an especially difficult way to die:

People have a real problem sometimes with withholding food or water from their loved one. Actually, dehydration takes away pain. Someone dehydrated, in a coma or sleeping most of the time doesn't feel pain anymore. Its nature's way.

I should emphasize, however, that in the process of dying, any person can experience some pain and discomfort even if the underlying illness is not painful in itself. This is usually not severe and can be controlled with pain medications if necessary, but it is a result of the dying process not the withholding of food and water.

Another writer reminded me that even without any water, it can take much longer to die than one would think, in her mother's case, six days. This was also our experience at Joseph's House when residents were sometimes unable even to be fed during their last days.

A very important comment came from someone who pointed out that the meaning of "no longer able to feed oneself" can be a little unclear:

[I]n our nursing home setting, when someone is having difficulty chewing or swallowing or pushes away food, the first step is usually moving to a food texture which is easier to manage, such as minced food, or adding extra gravy. A further step would be to pureed food. In many

cases, residents still feed themselves these meals. Another thing we see is that when people stop feeding themselves when given a fork & knife or spoon, they may still feed themselves very well when provided with finger foods such as sandwiches or cookies or a banana. And they may drink very well when the cup is placed into their hands but not drink at all if they have to reach for the cup on their own.

The obvious implication is that in prior discussions with family and writing the advance directive, you need to be clear about what you intend by “no longer able to feed oneself.”

I’m grateful to all of you who made comments or wrote emails. I encourage such comments because they are often very helpful in clarifying and adding to what I have written.

Wednesday, June 18, 2014

Washington DC

Evoking Gifts

The mission group is a key structure of our little [church](#), a place in which we share the most important parts of our inner lives, hold each other accountable for our spiritual practices (tithing, daily quiet time, a yearly silent retreat and others), study together, and engage in a common task that might make the world a better place. It’s a small group (usually three to six people), a place of more intimate belonging within the larger faith community. I belong to the interracial Racial Justice and Healing mission group. We have a vision of ending the racism within our own church and in the nation. We meet for about three hours per week.

In our faith community we have come to believe that every member has an important role to play. When a mission group organizes itself or a new member joins, we spend over an hour per person in evoking their individual gifts to help discover that unique role. By “evoking gifts” we mean discerning each person’s specific characteristics and abilities that may contribute to the group, naming them and affirming them. This past Saturday was my turn. We went around the circle, and each person described the gifts they saw in me. It’s an amazing experience! How often do we affirm the value of one another?

I was not exactly surprised by what the others said. After more than a half century of introspection, I know my strengths and weaknesses fairly well, but it's powerfully affirming to know that others see my gifts, too.

One of the things I've known about myself is that I can be a good leader; I do have those gifts, which were again mentioned on Saturday. I have rarely, however, found joy in active leadership. Because I usually see and appreciate the many sides of an issue, for instance, it's painful to try to lead a group to a decision. I'm quite sensitive to the needs of others (and have a fear of conflict besides), so, as another example, it's hard to cut someone off who's talking too much or whose point is only tangential. Responsible for the meeting, I worry about whether we're being productive. And so on. I don't enjoy it.

I grew up believing, however, that if a need existed and I had the gifts to meet that need, I had the *responsibility* to take it on. Not only did that sense of responsibility lead me into doing too much, but it also led me into positions of active leadership that often made me miserable. I had the gifts ... so I had to take the role.

When I realized two years ago that I was losing some of my cognitive ability, I began [turning down opportunities](#) that didn't give me joy ... including active leadership. It's one of the reasons I've been so much happier since my diagnosis. As my cognitive impairment seems to have stabilized, I have continued to avoid active leadership, but I've felt a nagging guilt about "shirking my responsibility."

On Saturday, as I allowed myself to acknowledge the gifts others saw in me, however, I began to understand that I could offer leadership from behind as well. Having insight and discernment without being attached to the outcome is a gift, as are listening deeply, understanding and affirming others, offering an elder's wisdom, or supporting the group in its process.

The act of listening is not only a prelude to getting something else done but also a gift in itself. Listening doesn't require me to march into action. It's enough to listen with compassion, love, wisdom and discernment.

I would call this “leadership from behind,” and, over the last two years, it’s become part of who I am. Sometimes I hear something said that others don’t seem to hear, and it’s helpful to point it out. Sometimes there are seemingly contradictory opinions or suggestions, but I may see common themes that, when I articulate them, can bring the group together rather than divide us. What my mission group was saying, I think, is that these are important gifts to the community.

This, too, is leadership ... only this time I enjoy it.

This willingness to draw back and listen without the need to *do* anything has been one of the paradoxical gifts of my impairment. I have learned to let go of some of a previously overdeveloped sense of responsibility, and I’m grateful.

Oh, and, by the way, a couple of people mentioned that I could be funny. I like to think I am but since most people either don’t get my humor or don’t think it’s funny, it was good to be affirmed ... by a few anyway.

Monday, June 23, 2014

Washington DC

Several Sundays ago, I was walking home from church and thinking about how I would spend the rest of the day. The afternoon seemed more wide open than I had anticipated. Suddenly I realized why: I was supposed to be at a church leadership team meeting. I had looked at my calendar several times during the week so I had known it was coming. I’d even remembered it during the morning service. Nevertheless, I’d forgotten. I walked back quickly and was only a little late.

Part of our agenda was for each of us to report whether we wanted to stay on the team another year. Kent asked me whether I thought my cognitive impairment would interfere with my work. I told him the impairment had been almost stable for a year. Later, I worried that Kent’s own judgment was that I should leave the team because my memory was so bad. I asked him.

He agreed it was obvious that I had memory problems, but my awareness of my impairment made it a non-issue for the team. He encouraged me to stay on.

Our church meets in a room that is used by others during the week. Someone has to arrive early, get the chairs out, and set up for the service. A small group of us takes the fourth Sunday of the month, so this past Sunday was our turn. I've done this every month for several years. I have it in my calendar as a regular task. Nevertheless, I forgot completely. Even when I got to the service and said hello to Maria, the person in charge of our setting up, I didn't remember. It was only half way through the service when I wondered why Maria (who ordinarily leads worship on our set-up Sunday) was leading today that I realized I'd forgotten.

I apologized to Maria after the service, of course, and she was as gracious as always. It was more than graciousness, though. Like Kent, Maria knows me well. She's been with me through the ups and downs of this long struggle. We both know that we can't count on my memory. I do my best, and she knows it. When I screw up, we both know what's happening, so there's easy forgiveness on her side and little embarrassment on my side. I am grateful.

Over the past year, my memory impairment may have gotten a little worse, but my episodes of confusion are considerably less severe than they were. One of the big changes is that I'm no longer having those episodes that *anyone* would recognize as impairment. Rather, as with the two stories above, people to whom I describe them are more likely to respond that they could happen to anybody. I've written about the difference [before](#).

The slightly worsening memory could even be the influence of aging. So it seems I'm recovering a little. I tend to see the gifts of my decline more than the limitations. It's an interesting space I inhabit. Impaired, forgiven, loved and included. The future is, as it always is,

unknowable, but I'm as [content as at any time in my life](#) .

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