Thoughts on the Meaning of Frailty

By Wendy Lustbader

We have come to fear frailty more than death. We imagine being "put" in a nursing home, like a jar on a lonely shelf. Will a parade of paid strangers take care of me someday? Such images have become the focal point of our fear. Frailty coupled with abandonment has become our most dire existential dread.

How will I let my caregivers know who I am?

Not everyone has a partner whose life would pause for an illness and for whom no other priority would compete. An otherwise loving son or daughter may be caught up in the flurry of raising a family and earning a living. Friends may be preoccupied with their own troubles and endeavors. Anyone can end up living at the mercy of strangers, having to count on kindness or ache from its absence.

Ordinary life activities, distracting and hurried as they are, tend to obscure this truth. Beneath our many doings, time and damage accrue, but we avert our eyes. Asking ourselves, Who would take care of me if I got sick? seems to threaten our other aims. We prefer to push such questions aside.

But pushing aside what we fear only adds force to it. Aikido, the Japanese martial art, teaches us to go with the force that threatens us, rather than oppose it. Without resistance, there can be no collision. Instead, there is fluid motion, more like rushing water than the intransigence of stone. Going with the question of our eventual frailty causes a cascade of meanings.

AT THE MERCY OF STRANGERS

Disability obscures individuality like a mask. When a doctor speaks to the person pushing a wheelchair rather than to its occupant, utter negation occurs. "How is she feeling today?" The one who has been negated can always shout, "I am fine, doctor," thereby declaring her continued status as a person, but the harm has already been done. To be overlooked, to be discounted even for a moment, wounds even after apologies have been extracted or hasty recognition has been won. To have to fight to be seen—that is what causes the damage.

The end of my soul's dominion will surely arrive on the day that I find myself lined up in a hallway in a row of wheelchairs waiting to be loaded into an elevator, then transported to a dining room and positioned into a row of waiting mouths. I may overhear one staff member say to another, "I've got to cut this one's meat, then I'll feed that one." At this juncture, I will have become an object rather than a subject. I will have become "that one" who must be acted upon, rather than a person engaged in her own life. I will have become someone's task. I will have become my needs.

If I do reach the point where I can no longer feed myself, I hope that the hands holding my fork belong to someone who has a feeling for who I am. I hope my helper will remember what she learns about me and that her awareness of me will grow from one encounter to another. Why should this make any difference? Yet I am certain that my experience of needing to be fed will be altered if it occurs in the context of my being known.

How will I let my caregivers know who I am? Unless I can, the eyes looking at me will merely reiterate my physical deterioration. They will perceive only my gnarled fingers and the stark metallic fact of my wheelchair. Just another old lady. Much is presumed on the basis of such surfaces. I know I will recoil from my helper's singsong voice, that well-meaning tilt of her head, her every gesture that exudes kindliness. All of this will consign me to a category, "the frail," the boundaries of which will be difficult to breach.

Are there ways to maintain the self in such situations? Perhaps we have the most to learn in the places we least want to reside. The "difficult people" in nursing homes are those who refuse to be diminished. I have watched them demand, threaten, and rage until their requests are heeded. Their dignity causes trouble in systems of care meant for efficiency. They insist on the prickly assertion of self in places where idiosyncracy is inconvenient. These are the people who will not let the staff forget what makes them different from the others. "You'd better open Martha's drapes the way she likes them or you'll hear about it." Martha's spirit survives in the very ways she makes sure her preferences disturb the routines. In the predicament we currently call long-term care, outrage remains one of the best ways for people to preserve themselves.

I want to amount to more than the sum of the tasks my body imposes. No matter how few of my powers remain, I want to go on existing in my preferences. I will find evidence of myself in the way I like to arrange things on my desk and the peace I find in looking up at the sky through the branches of a tree. Far from a trivial charade, having my choices respected will give me precious continuity with earlier versions of myself. I will want to take refuge in the habits of decades. I will still need the solitude I have always craved. It is unlikely that I will develop an interest in bingo. I will want to stay up late at night until my book is finished. I will want to know about the lives of the people I rely on, especially the one who holds my fork for me. If she would talk to me, if we could laugh together, I might even forget the chagrin of my useless hands. We would have a conversation, rather than a feeding.

A FURTHER WORTH

Are there ways to become more as the body becomes less? Over the years, we become accustomed to taking our worth from other people's regard or the satisfactions of our accomplishments. Yet there is a further worth awaiting us in remembering and contemplating, in thinking things over, in letting all that has been said and done assemble itself into something we can grasp. Rattled and expanded by such lessons herself, Carter Catlett Williams (1998) claims inner exploration as the chief benefit of slowing down in later life:

> More and more, I find that in this new terrain I am traveling—this elder's terrain—I am compelled to look at the view from many angles. There is the view ahead, but it is the shorter one, and there are vistas on either side through which I now travel. The great long vista is the one I have already traversed. Parts of it I cannot see now and may never look into, parts burst into view and are greeted with joyful recognition, while other parts are hard, hard things to take into myself.

Keeping physically active in later years is much praised, but movement inward may prove more momentous. A great deal ends up being deferred during the course of a busy life, even for those who strive to live deliberately. The ways to avoid ourselves are myriad and tempting; this inner work is easily set aside for another day. For most of us, the steadfastness required for sitting still and looking inward must be imposed, if not earlier by discipline, then later by necessity.

After his stroke, Ram Dass (1999) spoke about becoming "a silent stay-at-home." Years of lecturing internationally had suddenly fallen away, leaving him to live a kind of life he had never known before:

> The stroke has been what I call heavy grace. To take the external silence and use it as a vehicle to go into the silence of the heart . . . .The kernel of what wisdom is about cannot be clothed in normal words. It cannot be said. That silent place inside is the place in you that brings you close to God.

Ram Dass was ushered by his stroke into previously unknown places in himself. In the domain of immobility, where the commotion of worldly events finally ceases, we are brought closer to the sacred, a realm that thrives through silence and relinquishment.

Being stilled by illness also transports us out of our patterns with each other. Relationships bounded by privacy and self-sufficiency tend to break open. Merely the touching necessitated by need may change all the rules. A physical therapist tells how a stroke led to the reconciliation of a father and son who had not spoken in years:

> My patient was a large man, and the dead weight of his stroke made it impossible for his tiny wife to move him at all. His son agreed to come over and learn how to do a wheelchair transfer, but he came in looking so hostile I wanted to call off the whole thing. He didn't even say hello. I explained that he had to grip his father in a bear hug and then use a rocking motion to pivot him from the bed to the wheelchair. The son went over to the bed where his father was sitting and put his arms around him, just like I said. He got the rocking motion going, but then all of a sudden I realized that both of them were crying. It was the most amazing thing. They stayed like that for a long time, rocking and crying. (Lustbader, 1991)

This son was moved to linger in his father's arms for the first time since boyhood. Unexpected embraces, uncharacteristic expressions of feeling—these are only some of the ways that relationships grow through frailty's demands. We prefer to go on fending for ourselves, but the triumph of doing so can turn into a regretted isolation. To let go, to depend, to accept tender attention may satisfy yearnings long contained.

Discoveries are launched in all directions. The helper loses distance from his own fragility: This could be me. Sympathy is so ingrained in us that it can override the barriers our higher faculties would interpose; even the tiniest babies are gripped by the sound of another baby's cry. Seeing his father's desperation, the son rendered help instinctively. When another's plight is relieved, both the giver and receiver get a lesson in hope.

TO BE KNOWN

Someday I may need to be put on the toilet, but what if I am assisted tenderly because my helper has begun to love me? What if she has been assigned to me consistently for many months and we have had the time to know each other? There will be a quality of subtlety and delicacy in our exchanges, a mutual regard that will elevate this lowly act for both of us.

To behold another is a spiritual act. In the context of illness, knowing and seeing are reflexive. Once my helper takes the trouble to know me, I will begin to feel seen. In the course of feeling seen, I will reveal more of myself into the safety of being known. Our giving and receiving will move into a sacred dimension. This knowing and seeing will be expressed in small moments of intimacy which will loom large to both of us.

In 1987, the Nursing Home Reform Act attempted to mandate such "knowing," in part through administration of an assessment instrument, the Minimum Data Set (MDS). Detailed information was to be collected about each individual's needs and preferences. Nationwide, the data are being duly noted, but few facilities turn this information into actually *knowing* the person. In most nursing homes, relationships are still considered secondary to tasks. Front-line workers are still supervised in a regimented manner that precludes the very responsiveness that frail people crave. These caregivers spend the most time with residents but are still relegated to the bottom of the hierarchy, receiving the least pay, the least training, and the least respect. They have so little power that caring too much about the plight of those they assist leaves them feeling helpless and frustrated. They remain the powerless serving the powerless.

We go on supplying empty care, then equate frailty with emptiness. What if we recognized that relationships are the core of care for frail persons? What if we decided that hands-on caregivers should minister to needs beyond the physical? What if these caregivers were seen as doing the most valuable work in the facility? Their relationships with residents would then be regarded as the hub of nursing home life, with all other functions supporting what goes on at this level. We would value the time these workers spend with frail people and make sure they received compensation, training, and recognition commensurate with this worth.

When my time to receive care comes, I hope my helper will read aloud a few of my favorite poems and inscribe an insight for me in the pages of my journal. This way she will help me elevate my day into something I can abide. If I awaken in the night with a poem of my own and she gives me a hand jotting it down, she will help turn sleeplessness into satisfaction. As earnestly as she strives to keep me clean and clothed and fed, I hope she will feel free to help me transport myself beyond my physical diminishment.

THE SOUL'S DOMAIN

If so many of us would rather die than go to a nursing home, why do these configurations of care continue in spite of our fear and revulsion? Traditional nursing homes seem to express the limits of our hope. So long as we believe that little meaning can be found in frailty, so long as we presume a wasteland of degradation, then we will see nothing about these settings that can be changed. We will conclude that frailty itself drains life of meaning.

There is a Sufi saying that two veils separate us from the divine—health and security. When we lose our health and must face the insecurity of needing help, we may be overtaken by questions belonging to other realms. Humbling circumstances may enlarge us, in spite of ourselves. An 86-year-old woman once recounted to me how severe arthritis brought her "kicking and screaming" into the domain of her own soul:

> One morning, I was sitting at my kitchen table, staring into space. It was one of those windy days when the sun keeps coming out and going in. All of a sudden, a sunbeam crossed my kitchen table and lit up my crystal salt shaker. There were all kinds of colors and sparkles. It was one of the most beautiful sights I'd ever seen. But you know, that very same salt shaker had been on that kitchen table for over fifty years. Surely there must have been other mornings when the sun crossed the table like that, but I was just too busy getting things done. I wondered how much else I'd missed. This was it, this was grace. I needed crippled hands before I could sit still. Sometimes you have to be stopped right there in your tracks before you can see that all the beauty in life is right in front of you.

It should not be necessary to wait to be incapacitated. We can look for beauty and embrace our ultimate fragility any time we choose. Doing so would tell us what kind of life to lead. Once we begin living in terms of the question, Who would take care of me if I got sick? the whole of life transforms. The question mandates a shift in the order of things, making a life rich with generosity and kindness more desirable than any other kind of fortune.

From this vantage point on the extreme edges of vulnerability, it is clear what needs to be done. The elements necessary for hanging onto meaning in frailty are there, if only we dedicate ourselves to putting these elements into practice. What if we started by fashioning places where more than just our physical survival were assured? What if we put the question of care in times of sickness at the center of our lives? Just as the civil rights movement and the women's movement resulted from a convergence of urgency and opportunity, there would be a burst of collective will to transform the lives of vulnerable people. The deterioration of our bodies may not be preventable, but the meaning of frailty would be altered. ∽

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