



# The Ethics of Aging

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I wish you'd known my Grandma Sara. She lived in Dayton, Ohio, and for most of her life she worked "in chocolate" as she put it, either making chocolates for Maud Muller candies or selling chocolates in a department store. For our birthdays, we would always get a big box of chocolate in the mail.

Despite her love for chocolate, Grandma only weighed about 90 pounds. She was a snazzy dresser. She could play about a hundred kinds of poker, and she never seemed to grow tired of playing cards with us kids.

When Grandma was 92, she became too frail to live on her own and she moved to a nursing home. Knowing Grandma, she probably didn't want to be a burden on her children. But something happened to her after she moved there. The fun-loving person we had always known seemed to fade away and morph into a generic Old Person.

The last time we saw her, we brought our daughter, her namesake, to see her great grandmother. Our little Sarah was two years old. When we entered the nursing home, there was a long row of old women, wearing house dresses and sitting in wheel chairs. When they saw our daughter, they leaned over and stretched their hands out to touch her as she walked solemnly by. Their faces were filled with such longing at the sight of a little child and such hunger for life.

That was the image of nursing homes that was frozen in my mind for more than 20 years.

Sadly, things haven't changed much in most nursing homes. I recently asked a group of young psychology students at Ohio State University what was the first thing that came into their minds when I said the words "nursing home." Here's a sampling of what they said:

- Illness
- Lonely
- Smell
- Yellow walls

- Depressing
- Yucky food
- Prison
- Hopeless
- Delirium
- Anger
- Suicide
- dying

Don't you find it strange that we accept such places for our loved ones? Perhaps, like me, you never imagined that things could be different for people who live in nursing homes. There, we think, but for the grace of God—whoever that might be.

But in 2002, while I was on an assignment for the Washington Post, I stumbled upon a remarkable story. I discovered that around our nation visionary people were re-imagining nursing homes. And they were coming up with the some pretty radical ideas.

For one, they believed that each of us, no matter how old, how sick, how disabled, how forgetful we are, each of deserves to have a home—not an institution, but a genuine home, where we feel we belong.

Another radical notion these rabble-rousers had was that the lives of people who are very old or frail still matter, that they have meaning, and that disability doesn't define who we are. By the same token, those who are paid to care for our elders also have lives of meaning and their work should be valued and appreciated by the rest of us. Imagine that. I was hooked, and I set about to write a book to tell their story.

I traveled from Rochester, New York, to Seattle, Washington—from Big Fork, Minnesota, to Tupelo, Mississippi, and I saw some remarkable places, staffed by amazing people. At many of these homes, I was invited to spend the night, and I interviewed dozens of staff, residents and family members. The more I learned, the more I came to view the leaders of this movement as heroes. I see them acting as ethical agents in the world in a way that is truly inspiring.

Felix Adler, the founder of ethical culture, described what he called the Ethical Manifesto. This ideal is a community of people, each unique and interconnected, who elicit the best from each other. It not only is the foundation of ethical culture, it is the foundation for a new way of living for those who have been marginalized by age and disability.

Fundamental to the notion of an ethical community is the idea of human worth, a bed-rock belief that each of us deserves to be treated as an essential participant in the life of the community. According to ethical culture, and I quote a passage here from a WES document, “We violate the ideal and destroy ethical culture whenever we assume that a person is worthless... In contrast, whenever we value the worth in a person and treat him or her with respect—especially when that person is without obvious usefulness to us—we create ethical culture.”

A person without obvious usefulness to us. What words could better describe how we as a society feel about the people who live in nursing homes?

These people are often invisible to us. But there are one and a half million who live in nursing homes—nearly three times the number who live in Washington D.C. Two-and-a-half million employees work in long-term care—that’s twice the number that work at all the Wal-Marts in our country. In fact, there are 4,000 more nursing homes than there are McDonald’s in our country.

Christa Hi-lo, a nurse leader who is in charge of nursing homes for the Veterans Administration, told me, “We have an ethical obligation in this country, not just the V.A. If we’re going to save people’s lives, we have a responsibility not to dump them, for God’s sake. Do we spend megabucks on medications and treatment, just to be warehoused? What are we becoming as a culture? I find it abhorrent. I come to work every day hoping to make a little tiny dent in transforming the social system.” Christa Hi-lo is one of my heroes.

So what does it mean to apply the tenets of ethical culture to a nursing home? What are these places like?

Meadowlark Hills in Kansas was a traditional, good quality nursing home. But the administrator, Steve Shields, realized, when his own mother was dying there, that something was fundamentally wrong. Somehow in the midst of alarms, blinking lights, nurse’s station, harried staff, the individual elder had been lost. They were being treated like cogs in a machine, rather than people who had earned the right to live—and die—in peace and dignity. Steve went on to lead his staff through a six-month consciousness raising. They met regularly in small groups, looked around them, and identified what in their nursing home would you not find in an ordinary home—the nurse’s station, for example, the big linen carts, the plastic trays to eat off of, and so on. “I knew we were there,” Steve told me, “when a nurse said there’s nothing left.”

So they started from the ground up. Today when you walk into Meadowlark Hills, instead of a long sterile hallway with people slumped in wheelchairs, you see a front porch with rocking chairs and hanging plants. You ring the doorbell—just as I would if I were going to visit you in your home—*imagine* that. You enter into a living room that opens into a dining area and a big country kitchen, accessible to people day and night. You might smell fresh coffee brewing or cookies baking.

There are family photos and books. Did you know most nursing home residents don’t even have a simple shelf in their room to display things of meaning to them? How would you like to live without a single shelf to call your own?

What you don’t see at Meadowlark are staff members sitting around a nurse’s station, talking to each other. Instead, the staff are hanging out with the elders. You hear laughter and conversation. It feels good to be there. These are people with the same ills and afflictions of other nursing home residents. Yet they seem healthier and happier.

The physical changes of the building, while the most obvious, are only one piece of a deep cultural transformation. To truly honor the worth of each individual, transformative nursing homes not only enrich the environment, they enrich daily life for both residents and staff. They no longer try to mold people into the institutional regime. People are free to wake up when they wish and to eat normal food—not specialized restrictive diets. I don't know about you, but sometimes Ross and I love to have a bowl of ice cream before we go to bed. Such simple pleasures have been denied nursing home residents. But at Meadowlark, you can indulge yourself. If you're a diabetic, say, the staff will let you know what risks are involved in that midnight bowl of ice cream. But ultimately it's your choice. Why? *Because this is your home.* That's why we all love our own homes, no matter how humble. It's where we can be ourselves, where we can call the shots. Restoring that basic sense of belonging and control is an essential part of what this new movement is all about. Steve Shields said to me, "We have an intrinsic need for a home—our dreams are around it... Why, when you need home the most, do you suddenly not have one? Wherever you live has to be home. Wherever you live has to be home. Period. It's a basic fundamental flaw in our planning for people with special needs—we don't expect them to be home. So they become wards and responsibilities. We dehumanize them." Steve Shields is also one of my heroes.

My mother was recently in the rehabilitation wing of a nursing home on the campus of the retirement community where she lives, out in Gaithersburg. It was a nice enough place, clean, lots of activities—none of which interested my mother—but they were trying to do a good job. The staff was pleasant. But I soon realized that what my mother most needed wasn't available to her. What she needed was an ally, someone who said, okay, Mrs. Baker, I'm going to look out for you and make sure you have what you need. I'm here for you. What she got instead was a constant stream of well-meaning strangers, popping in and out, one for the blood pressure, one for the weight, one for the pills, one for the water pitcher, another for the advanced directive, another for the tray of food, and so on.

Not one of them stayed more than a moment. They did their assigned task and rushed on to the next patient. It was confusing, tiring, and frustrating for my Mom. Why, for example, did she have to be awoken at 5 a.m. to have her blood pressure taken—she's 87 years old and has never had high blood pressure. But it wasn't really about Mom, it was about the institution and the schedule.

Not only is this mindset not honoring the individual, but how satisfying do you think this is for the staff? I would imagine they don't like it much better. Their lives are a constant harried stream of tasks performed for people whose names they know only by referring to a daily assignment sheet they have stuffed in their pocket. I think they might have enjoyed being allowed to pull up a chair and get to know my mom—she's funny and nice. She could have talked about the NCAA basketball tournament or politics. She keeps up with the news. And the staff, almost all of whom were immigrants, I'm sure they could have shared interesting stories with her about their own backgrounds.

But she left there after three weeks, and I can safely say no one got to know her and she didn't get to know them. And this is typical. Ninety percent of nursing homes in our country have the intentional policy of NOT giving staff permanent assignments, thus ensuring they will not form close relationships with residents. And another important statistic—70 percent of aides in nursing homes leave their jobs every year. Seventy percent. That's how high turnover is. Which brings me back to the Ethical Manifold. Another essential piece is this: "In a mutually respecting community, individuals relate by encouraging in each other their full capacity for greatness and harmony." Let me say that again: "In a mutually respecting community, individuals relate by encouraging in each other their full capacity for greatness and harmony." You cannot have an ethical community inside a nursing home unless the staff is given the opportunity to form deep, strong, loving relationships with the residents. It can't happen.

So how do these transformative nursing homes accomplish this? How do they elicit the best?

Let me tell you about Tupelo, Mississippi. Tupelo used to be known mainly for its favorite son: Elvis. Now it has another claim to fame: it has the most cutting edge home in the nation for elders. It's based on a new model called a Green House, meaning a home that is full of life, a nurturing place.

In a Green House, miracles happen. I'm here to tell you, miracles do happen. Take Mrs. Mildred Adams, a resident there. Mrs. Adams used to live in the old traditional nursing home on the same campus. While there, she had pretty much stopped living. She never got out of bed, she refused to eat and had to be coaxed into swallowing pureed food. She appeared not to recognize her family and she hadn't spoken in a couple years. Everyone assumed she was close to death.

But from the first moment she was wheeled into the Green House, she began to re-awaken. She looked around the comfortable surroundings that look like a normal home, and she perked up. At dinner time that first day, she sat at the big dining room table with other residents, staff and family members. When her son tried to feed her, she took the spoon from his hand, and she began to eat by herself. When a staff member asked if she'd like a cup of coffee, she responded, "I believe I will—with a spoon of sugar and a dash of milk." This was someone who hadn't spoken in two years.

I met her a year and half later. She had gained 15 pounds, which, in a nursing home, is a good thing—malnutrition is epidemic in nursing homes. Mrs. Adams told me that Renee, her regular caregiver there in the Green House, was a good cook. Mrs. Adams' daughter-in-law, Becky, urged her to sing for me. Mrs. Adams asked what I'd like to hear, and I said whatever she was moved to sing. She sang Amazing Grace and The Old Rugged Cross. It was beautiful.

I asked Becky how to explain this rebirth of her mother-in-law. She said the family had come to believe that Mrs. Adams had gotten depressed in the old institutional nursing home. Now she felt she was at home. How many Mrs. Adams are there, languishing in nursing homes?

At the same time, the staff was much happier. The Green House re-defines the job of aides. They are no longer even called aides, but “shahbaz.” They told me they felt respected and empowered. They’d received a modest wage increase. But more important, they were given much more responsibility than traditional nurse’s aides, and they were expected to be loving companions to those who lived there. They were called on to use their energy, creativity, and affection to make each elder’s life as pleasant as possible. And they loved it. No one I interviewed wanted to return to the old institutional way of doing things.

And I have to tell you—because I know you’re going to ask—that these places do not have to cost more to operate. A truly ethical community honors the worth of all, including those who are on Medicaid, the government insurance program for people who are low-income. In Tupelo, for example, the Green Houses were designed to be affordable for those on Medicaid, and they’ve succeeded in doing that. We’re talking here of a heart-change, a culture change, a deep transformation—it’s not about insurance or regulations—It’s about honoring individual worth and creating community. And when you do that, you solve costly problems like staff turnover.

I often hear people say, well, this all sounds very nice, but nursing home residents are too far gone to appreciate a high quality of life. And it’s true, that nursing home residents are sicker and older, on average, than they were in the past. But think about the sentiment behind this idea that people in nursing homes are “too far gone.” Would we ever want people to feel that way about us? Do we really believe that anyone, no matter what their physical or mental impairments, would be better off in a sterile institution with constantly changing faces, than in a home surrounded by people who care about them? How do we know they wouldn’t enjoy petting a cat, or smelling bread baking, or hearing a favorite piece of music, or holding someone’s hand, or watching the sunset? Wouldn’t all of us prefer that?

When I was in Tupelo at the Green House I also met Mrs. Cynthia Dunn who told me grandly when I entered, this is my home. Mrs. Dunn, who uses a wheel chair, likes to go to yard sales with Ida Cummings, a young shahbaz. The day I was there, Mrs. Dunn and two other residents, one of whom was deaf, blind, and couldn’t walk, were going to a shopping mall, with Ida. Mrs. Dunn wanted to buy a silk pillowcase, and the other two were just going out for fun. Mrs. Dunn was also looking forward to a family reunion. She was going to bake a special cake, there in the normal, family-sized kitchen, and the staff would make sure she had the ingredients and the help she needed. I also witnessed the children of staff running into the nursing home after school, hugging the elders, and sitting down at the dining room table to do their homework. It was real life, it was normal, it was a community in which people were eliciting each other’s best.

Glenda Buchanan, a nurse there and a leader of the transformation, said to me, “What touches my heart is to know the elders in their winter years will actually have a home. Some of these people, we’re the only family they have. It is exciting to wake up and come to work every day. What more could you want? I’m ready to step out in faith.”

Step out in faith. I love that.

I met other nursing home residents and staff around the country whose lives have meaning and joy—people whose individual worth was being honored.

I met Louisa, at a nursing home in New Hampshire. She told me about all the volunteering she does. She calls people from her church and organizes contributions to a food pantry. And she and a few other residents make gift baskets and raffle them off to raise money for a local charity. She made it clear that she wanted to be seen as the same person she had always been—not as some generic nursing home residents, but as someone who made a contribution and served others.

I met Cathy Butler who lives in Seattle at Providence Mount Saint Vincent, a Catholic nursing home. I looked for Cathy all day and couldn't find her, because she was so busy. It turned out she'd been in the art studio where she was framing some photographs she'd taken that were going to be in a show of resident's art work. Then she had some computer work to do, followed by dinner with a friend. I finally caught up with her in the evening. A big cat stalked out of her room—one of the nursing homes many pets. The cat had adopted Cathy and slept on her bed. Cathy was only 62, but had had disabilities all her life. She had lived in traditional nursing homes that that ranged, she said, from hellish to average. "Then," she said, spreading her arms to encompass her surroundings, "here." A look of pure joy came over her face. She said, "I wake up trying to decide which of the people I love here will I get to see today."

She was expressing what all of us here at WES know—that having strong relationships is the most important quality of life issue for everyone. Residents and staff of nursing homes are no different from us. In survey after survey, the single most important thing valued by nursing home residents—more than good food, more than good medical care, more than clean facilities—is relationships. It is what matters most—and it's what nursing homes traditionally have paid the least attention to.

Carter Catlett Williams is a social worker who has fought for decades on behalf of nursing home residents. She helped lead the successful battle to free nursing home residents from restraints. She writes:

"The days of our lives, even the days and years in a nursing home, are for living, not merely for physical safekeeping. They are days for nurture of mind and spirit as well as body, and for the richness of community...In order to be people that matter... we must be heard and responded to individually as we try to make sense of our daily lives." Carter Catlett Williams is also one of my heroes.

So how did things go so wrong in nursing homes? Why, for half-a-century, have we accepted them for our parents and grandparents? What's wrong with us? The problems are twofold: in the past, we have lacked the imagination to envision profound change. In addition, our culture devalues people who are old and disabled: traditional nursing homes are the result. Indeed, Steve Shields calls nursing homes and the warehousing of elders the sin of the twentieth century in our nation. If that is the case, redemption is possible.

Regardless of whether you know anyone who lives in a nursing home or assisted living for that matter, there's a role for each of us in changing the culture of aging. It begins with a simple commitment that we will reclaim elders as an integral part of the tribe. We are not going to put them on the ice floe and wave good bye. There are subtle ways we shove people aside that we probably don't even recognize. Maybe it's not making sure that at family dinners, each of us can hear the conversation. Maybe it's noticing that the conversation doesn't include everyone. We may assume that we all understand Ipods and Google and that Blackberries aren't always fruit. We may not make space for listening to stories about the past, or express pride in the legacy being handed to us.

Here at WES, we do a pretty good job. We accommodate those who are hard of hearing, and we print copies of the program in large-font type. And at long last we're investing in our building to make it accessible to all. But we can do more. Do we notice when our older members stop coming? Do we call and tell them we miss them and ask if they would like a ride? We can't expect Mary Herman to do it all.

And in the broader community, do we work to address issues that marginalize elders, whether it's lack of transportation, or businesses that are difficult to patronize? I can no longer take my mother grocery shopping because the Safeway has no chairs or benches to rest on. And how about folks in nursing homes? We might consider as part of our social justice agenda, befriending people in a deep way, not a just on Christmas charity kind of way, a deep way, connecting to an older person who is lonely, wherever they live. We can also do our part to help create the demand for these pioneering elder homes. Today, only a few hundred of more than 16,000 nursing homes have embarked on a deep transformational change of their culture. We need to raise expectations and push for the transformation of all nursing homes, including those that serve people of limited means.

I'd like to conclude with some words written by Bill Keane of Illinois, someone who's advocated for older people for decades. This is what Bill wrote:

Fundamental change begins in the human heart. If we really don't believe that people are still people because they have a dementia, we will not care for them as persons, but as objects of medical maintenance. If we really don't believe that elderhood can be a great age of enlightenment and societal participation, then we will continue to relate to elders as retirees on the golf course. Each of us must work deeply on our own journey of aging, transforming our traditional fears and uncertainties into a hopeful, joyful embrace of who we are and our new capacities for growth and giving.