

"But This Is My Mother!" The Plight of Elders in Nursing Homes

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introduction

As discussed in the text, the globe is graying. Not only is the number of elderly increasing around the world, but also the elderly are becoming a larger proportion of the population of most countries. In the United States, a generation ago people age sixty-five and over made up 10 percent of the population. Today, about 13 percent of Americans are elderly. About the year 2050, the proportion of the elderly is expected to reach 20 percent.

By the middle of this century, then, on average every fifth person you see will be age sixty-five or older. (Of course, somewhere around this time you, too, will be elderly, so with your network of elderly friends almost everyone you see will be old.) But as you read in the text, age sixty-five is an arbitrary number, and there is no cross-cultural agreement about the age at which people become old. As you also read, neither is there a cross-cultural consensus on the meaning of "old."

There are global problems of old age, however, especially the dependency and frailty that sometimes accompany it. Around the world, the number of elderly has grown to such an extent that their medical care demands more and more of society's resources. In the United States, even though the average elderly American is independent and healthy, the costs of the medical treatment of the elderly have multiplied. No one has yet found a solution to this growing problem.

The frail elderly are especially problematic. What should be done when people grow old and can no longer take care of themselves? Every society has to find ways of taking care of their frail elderly, but, as with the Tiwi that you read about in the text, those solutions can be detrimental to the elderly. So it often is with our own particular solution—nursing homes, the topic of this selection by Cynthia Loucks.

Thinking Critically

As you read this selection, ask yourself:

1. What problems of nursing homes does the author describe? This is just the plight of one person in a single nursing home; why should we pay attention to it?

2. Inadequate care in nursing homes and the harm this does to the elderly have been documented for decades as a national problem. Why does this situation continue?
 3. How are you going to assure that you will receive adequate health care when you grow old? How will you avoid being exploited?
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Whether elders have bed sores is a good indicator of the quality of care that is being provided. Elders who can no longer move themselves must be repositioned regularly so that their body weight is not resting in any one place for too long. A head nurse on my mother's ward told me that nursing home regulations require that immobile residents be turned every two hours while in bed in order to shift their weight distribution and to vary the pressure on their body parts. If necessary, pillows can be used to position residents on their sides. But when there is a shortage of pillows, the efforts of conscientious aides who try to keep up with the necessary regimen are hampered.

In the course of a person's physical disintegration, bed sores become more difficult to prevent. When someone is very near death, subjecting them to the disturbance of repositioning can be unduly inconsiderate. However, until that point, nursing home staff need to follow the guidelines for preventing bed sores. The reality remains that in many facilities, including the one my mother was in, dependent elders are moved as little as once during an eight hour shift. Even then, most of the movements that occur are merely back and forth between bed and chair, which may not provide any relief if the weight of the body remains on the same spot. In addition, many nursing home residents are in effect lying down even when they are in their chairs, since the recliners are cranked back in order to use gravity to keep flaccid bodies from sliding onto the floor.

Other methods of preventing bed sores, such as gentle massage to stimulate circulation, are seldom employed by overworked staff in nursing homes. Although various devices can be used in chairs and beds to relieve sacral pressure—doughnut-shaped pillows, "egg crate" foam cushions and mattresses, gel-filled mattresses and pillows—these items are often in short supply in many nursing homes. A resident's personal cushion also can lie unnoticed in a closet where one staff person may have stored it and the next staff person does not rediscover it.

It distressed me a great deal to know that Mama couldn't turn herself over in bed or shift her weight in her chair without assistance. She easily could be left in an uncomfortable position for hours, unable to do anything about it. According to her last doctor, the one with geriatric training, part of the nature of Mama's condition was that she no longer felt the uncomfortable pressure or nerve stimuli that prompt

the rest of us to shift our positions frequently. I hoped he was right and that Mama never felt too uncomfortable.

When immobile residents aren't being repositioned regularly, it often means they aren't being checked on frequently, either. As a result, nursing home residents have been found stuck in some very bizarre and even potentially life-threatening positions. Sometimes I would find Mama in an incredibly uncomfortable-looking posture. She would be so still, just staring, waiting, as though resigned to something she knew she was helpless to alter. On at least two occasions I know of, Mama somehow rolled to the side of her bed and wound up with her head stuck between the bed rails for who knows how long before someone found her. At the time, I was unaware of how terribly dangerous this phenomenon can actually be. I learned later that many nursing home residents have lost their lives from getting trapped in their bed rails and not being discovered in time to be rescued.

Mama also often slipped down in her chair, another typical side effect of paralysis and other conditions that impede the ability to resist gravity. It was part of the conundrum of having to be left fully upright after meals with no wherewithal to maintain the position herself. I feared that hours might go by before anyone noticed she had slumped. She could even slip all the way out of the chair and wind up injured on the floor before anyone might come to reposition her. I vividly remember one instance when I walked into Mama's room and found that she had slid so far out of her slippery vinyl recliner that only her sacrum and the back of her neck were in contact with the chair. Her chin was pressed to her chest and her legs were sticking out straight in front of her, well beyond the support of the chair's leg rest. She was staring straight ahead, her blank expression revealing little of the soul trapped in that poor old vessel.

I often wondered what Mama was thinking at those times, unsure whether she just checked out or maybe even went into some sort of trance induced by her extreme helplessness. I would notice a particularly blank expression on her face on such occasions, as well as sometimes when the aides were cleaning her, another undoubtedly unpleasant event. This common psychological response of distancing oneself in some way when under such circumstances is called dissociation. When something in life is too disagreeable, people employ defense mechanisms in order to handle the stress. What happens to the people who have to do this every day, several times a day, in order to deal with their circumstances? It is a question that needs to be addressed on behalf of all nursing home residents.

Another highly disconcerting and recurring event in Mama's life took place whenever she had to be transferred. In medical settings, to "transfer" someone is to move an immobilized person from one conveyance to another—from bed to geri-chair or wheelchair, from chair to toilet, etc., and back again. This particular aspect of caring for disabled elders is probably the most strenuous for all concerned. Those elders who cannot bear any weight on their feet are the most difficult to transfer. Even with a small person like Mama, who weighed less than one hundred pounds by the time she was admitted to the nursing home, the bulk and stiffness of the person render the process awkward.

Mama often screamed when she was being transferred, a habit that rattled many of her aides. I think she was frightened to be picked up, afraid she would be dropped or otherwise injured, which is not an unrealistic fear for someone in such impotent circumstances. To ease fears about being transferred and to limit the possibility of injury, there is an approved procedure for moving dependent residents. Two aides or nurses lift the resident along four points—the two armpits and the backs of the two knees—so that the person's weight is evenly distributed. In Mama's case, she was often transferred, whether by one aide or two, by lifting her up by her armpits only. Not only was that a very uncomfortable way to be lifted, but it also risked injury to her unsupported lower torso and limbs. Throughout Mama's stay in the nursing home I tried constantly to get the aides to use their other hand to support Mama beneath her knees. Trying to motivate them, I pointed out that Mama surely wouldn't cry out so much if they used this method. But with each subsequent visit I would see that the aides had reverted to their armpit-only transfer. Considering that Mama was probably transferred between bed and chair an average of 6 times per day, 365 days a year, it was quite an ordeal for her to endure.

There are other chronic physical care issues, albeit non-life-threatening, that are frequently left unattended to in nursing homes. For example, Mama's feet were often cold, so I bought her several pairs of socks and focused on trying to get the aides to remember to put them on her when she needed them. I shouldn't have been surprised when I realized they were putting socks on her all the time, even if her feet weren't cold. At times I would find Mama so hot that she was perspiring. It seemed like such a small thing to pay attention to—a person's skin temperature and then dressing her accordingly. Yet, such consideration was almost totally outside the bounds of the care that Mama received.

The paralysis that followed Mama's stroke and the subsequent lack of movement that ensued resulted in the contraction of her left arm and hand. During the first few months after Mama's arrival at the nursing home, a young woman came in from time to time to perform range-of-motion movements with Mama's limbs, a means for both reducing contraction and improving circulation. When the therapy was discontinued, for whatever reason I do not know, I didn't protest. The young woman had seemed so inexperienced, and Mama clearly didn't enjoy having her arms and legs tugged this way and that. I couldn't bring myself to insist on more.

Mama spent a lot of time either in bed or in her chair with her legs outstretched. Before long, her ankles became rotated such that her feet were always turned in toward one another. Knowing she would never walk again, I didn't think it made a difference how her ankles were positioned so long as there were no indications of discomfort. The color and the condition of her skin looked all right. One of the nurses told me that people's ankles naturally rotated inward once they can no longer walk. I believed her and assumed that she had probably seen it happen many times before. But when I later learned how easily this condition could have been prevented by using pillows to hold her ankles in a neutral position, I felt remorse for having left it at that. I was not aware of the stress that this rotated position placed on all of Mama's connecting joints, and probably on the bones themselves, all the way up to her hips. (To see what this is like, lie down on your back when you are in bed tonight,

with your legs outstretched, and slowly rotate your ankles inward as far as they will go. Notice the sensations that occur immediately, even as far up as the small of your back. Ouch!)

Mama's skin had gotten as thin as an old shirt that's been worn and washed so many times it has become transparent and easily torn. Yet, the aides would take a terry washcloth, coarse from heavy bleaching, and scrub her as though she had been digging ditches all day. Although stimulating the skin is beneficial, their methods looked excessive. When I suggested that Mama didn't need such vigorous bathing, they humored me and washed her more gently; but I had no doubt that as soon as I wasn't available to monitor them, they returned to doing it their way.

It wasn't long before Mama developed a skin rash. Considered a redhead (though her hair was more a deep auburn), Mama always had sensitive skin, so it was not surprising that it protested the treatment it received in the nursing home. The doctors and nurses discussed prescribing medication for her, both cortisone-based pills and lotions. As usual, the medical approach was to suppress the symptom without attempting to alleviate its cause.

Aides give bed baths by bringing a plastic tub of warm, soapy water to the bed of a resident, who then gets washed down with a washcloth. To my dismay, I discovered that after washing Mama, some of the aides simply dried her off without first rinsing her skin. Others would bring fresh water for rinsing her but would still use the same sudsy washcloth. The source of Mama's rash seemed obvious to me. When I pointed out the detrimental shortcuts, the aides countered that it was difficult to rinse her properly without getting the bed unduly wet. I suggested that they might try rinsing out the washcloth first with clean water and that if they used less soap when they filled up the plastic tub—it was usually frothing with suds—the rinsing might go more easily. They grudgingly agreed to try it, and Mama's rash soon subsided.

I also had to lobby to add moisturizing lotion to Mama's required skin-care regimen. I scrawled Mama's name in big black letters on her lotion dispenser in the hope that it would actually remain in her room. Since care supplies are seldom adequately stocked in nursing homes, staff freely "borrow" from one resident to give to another—the best solution they can find when needing something otherwise unavailable. Thanks partly to the ongoing vigilance of Aunt Margaret and the steady supply the family provided, lotion was always available. How often it was used on Mama, however, was less reliable. I bought facial moisturizer for Mama, too, but I could tell by how much remained in the jar that it was seldom applied by anyone else but me. I enjoyed rubbing the lotion onto her face. It was a chance to express the gentleness and tenderness that I felt for her, to nurture her in some small way.

It was also apparent that duties such as providing oral care were getting checked off on Mama's chart when they were not actually being performed. Her dentures had disappeared within a few weeks of her arrival at the nursing home. A nurse speculated that they were probably thrown out with her soiled laundry. Their loss, of course, did not preclude her need for oral care. One method of providing this care involves using a little sponge that is attached to the end of a stick. When dipped in water, the sponge emits a mouthwash-like substance. The sponge is then

used to massage and freshen a person's mouth and gums without the need for rinsing. But like most medical supplies, these implements are ridiculously expensive and are invariably in short supply at nursing homes.

The physical care of nursing home residents is further complicated by the maladies that are endemic in today's long term care facilities, and Mama certainly wasn't immune to any of these problems. Urinary tract infections, diarrhea, congestion, dehydration, rashes, and bed sores—these ailments never seem to surprise the doctors, who attribute them to residents' advanced ages and poor physical conditions. While elders do tend to have diminished immune systems and increased susceptibility to sickness, especially when they are inactive, this knowledge should be a warning for increased preventive care rather than an excuse for the various skin, digestive, and bacterial problems that occur. These afflictions could be greatly reduced with good, consistent attention to residents' hygiene as well as to their prescribed care regimens. There should be no excuse for failing to avert the preventable.

When nursing home residents are no longer able to control the flow of their urine, they develop rashes from the prolonged exposure of their skin to the urine in their bedding and diapers. In typical fashion, nursing homes respond to the frequency of these rashes by inserting catheters into aged urethras. While reducing the need for frequent cleanup, catheters provide ideal conditions for the proliferation of infection-causing bacteria. Improperly used and monitored, as they often are in nursing homes, they can present other hazards as well. I once found that my mother had been placed in her bed lying on the tubing, which of course blocked the flow.

In addition, many elderly recipients of these contraptions, no longer constrained by subservience to authority, yank them out, causing subsequent irritation to tender tissue. After Mama suffered through several urinary tract infections, I decided that she, too, had had enough. I told the staff that I did not want any more foreign objects inserted anywhere into my mother and vetoed the further use of a catheter on her. While the doctors never seemed to question writing an order for a catheter and following it with the almost inevitable antibiotic prescription a week or two later, the nursing staff, who saw the human result of that cycle in increased bowel difficulties due to the loss of healthy intestinal flora, were more willing to break the cycle and acquiesce to my request, even though they had requested the catheter in the first place. One nurse admitted to me that she knew I was right, although overall, the staff was miffed that I expected them to keep Mama clean and dry enough to avoid further rashes.

Such medical aspects of Mama's care were never ending. I had to function as a conduit of information among the ever-changing nursing home staff, the doctor, and hospital staff whenever Mama was hospitalized for conditions such as internal bleeding episodes. It was especially important to provide the hospital staff with information because they never seemed to be notified of the particulars of Mama's health care. Once I was just in time to prevent a hospital nurse from attempting to feed Mama solid food, an act that would almost certainly have choked her.

I also had to keep trying to get Mama a diet that took into consideration her pre-existing condition of chronic colitis (inflammation of the colon). I needed to be on the lookout for cuts, sores, infections, and problems with her G-tube, so that these

problems were attended to promptly, regularly, and effectively. I tried to be sure that she was not given treatments that would precipitate yet another condition requiring treatment. I checked that she was given sufficient fluids to avoid dehydration, which became a problem due to her inability to consume sufficient quantities at meal times and the unavailability of staff to provide the fluids she needed between meals.

It was very frustrating to review Mama's treatment and consider that she was in a reputable nursing home. At best, her care was tolerable, with rare instances of very good. Frequently, it was heedless, insensitive, rough, and even dangerous. Yet, I was determined to keep fighting for Mama, to keep taking yet another grievance to the head nurse, the doctor, the social worker, whomever I thought might be able to help us. There was never any question of giving up, even though overseeing Mama's care in that nursing home was truly the most demanding, frustrating, and disheartening job I have ever had.

It galled me again and again to witness the indifference with which so many of the nursing home staff treated my mother. They seemed unwilling to look at what they were doing and apparently regarded my efforts to intervene as just so much nagging. Even those who responded positively to my suggestions would either soon revert to their usual methods or not be taking care of my mother any more. Between staff rotations and people quitting, Mama never had the same caregivers for long, which deprived her of the comfort and reassurance that familiarity and continuity could have provided.

The unkindness that some of the aides displayed toward Mama—and that they would behave that way right in front of me—was not only distressing but downright baffling. Throughout her stay at the nursing home, when she wasn't too ill or too sleepy to respond, Mama always had an enthusiastically friendly greeting for one and all. To me it was a reflection of the wonderful graciousness that she managed to retain throughout so much of her ordeal.

One day a young male aide came into Mama's room to attend to her. True to form, Mama called out a cheery "Hi!" when the young man approached her bed. Silence. Seconds passed. Undaunted, Mama said "Hi!" again, with no less warmth or cheer. Her voice and what she said were clear and unmistakable. Still silence. Despite my pounding heart and the fury rising in my throat, I remained calm so as not to make a scene in front of Mama. I said to the young man, "She said 'hi' to you." As though coming out of a trance, he finally uttered a dull, flat "Hello." And without another word, he proceeded to perform his duties in an efficient but perfunctory manner. Mama fell silent.

When I later saw the aide in the corridor, I questioned him about his thoughtless behavior. Vaguely apologetic, he informed me that he had a lot on his mind. I was less than sympathetic and complained about the incident to the head nurse. She shared my dismay at the aide's behavior, agreeing that professional caregivers should leave their personal problems at the door when they come to work. It was good to have her agreement, but it didn't change anything.

I winced whenever I watched aides and nurses tend to Mama without speaking to her or speak to her without looking at her. I desperately wanted them to act in a manner that was kind, civil, and respectful. I knew what a difference it would

make for Mama if they took a moment to explain what they were going to do and if they made an effort to listen to her, responding as much as possible to what she indicated.

All nursing home residents have psychological, emotional, and social needs regardless of their conditions. They need eye contact and whatever else seems appropriate to foster a feeling of connection and respect for their basic humanity. The lack of such behavior constitutes an assault on the human spirit and is, in many ways, the most painful offense for people to bear. It wounds more deeply than the discomfort and indignity of poor physical care.