

Mercy in Decline

by **Connie Miller**

One

Somewhere in her late fifties, my mother started telling me I had to kill her. She'd reiterate the request periodically, as if to tattoo it onto my brain. "I can't bear the thought," she'd repeat, "of becoming bedridden and dependent. You have to kill me before that happens."

My mother's end-of-life plans, emphatic as they may have been, hovered like storm clouds on a far horizon, ominous but reassuringly remote. Until she started falling. She cracked her head on the corner of a table. There was blood on her carpet. The retirement community where she had stayed on after my father died was 2000 miles away from me. That distance, manageable for occasional visits, yawned, abruptly, into a chasm.

The day before Terry McVeigh bombed the Alfred P. Murrah Federal Building, she moved to my city. I'm not suggesting you compare my experience with what the bombing victims endured. It's just that I could identify with Oklahoma City. I felt as if my own way of life was exploding.

I wanted to show up, be there for my mother, accompany her with grace through the last stages of her life. But I was petrified. In search of courage, I saw a therapist. In one of our sessions, she posed a question that reached into the core of what made me most afraid. "What's so terrible," she asked me, "about needing someone's help?" Somehow, seeing things through that disarming lens gave me the courage to move forward.

Growing up, I heard my mother recite a couple of lines of poetry often enough for them to stick. The lines belong to an epitaph for a man who broke his neck falling from his horse:

Betwixt the stirrop and the ground,
Mercy I askt, mercy I found.

For me and my mother, what lay “betwixt the stirrop and the ground” was the treacherous territory of her decline. Could we summon the mercy we needed to help each other navigate that unpredictable terrain?

Two

I found my mother an apartment in an assisted living facility near our house. I got her a walker to prevent future falls. My help, combined with the minimal support the facility provided, sufficed for about three years. Then, pneumonia landed her in the hospital. After a miserable recovery stay in a nursing home, she returned to her apartment. Within days, I realized that basic assistance was no longer enough. I contacted the Autumn Years Network, a quality assurance and referral program for adult family homes.

A Network representative, whose sincerity and warmth brought Mr. Rogers’ Neighborhood to mind, shepherded me around to several homes with a private room available. Anna’s was the third home we visited. I had no clue what I was looking for but, when we walked in, I knew I had found it.

The place was immaculate and smelled of lemon cleaning oil. Five bedrooms and two bathrooms radiated out around a hub of common areas. Chairs for each resident clustered around a Formica table covered by a white plastic cloth and pink place mats. An enormous television dominated the living room.

“For the residents,” Anna told me. “Yeah, yeah. They sometimes have trouble seeing.”

Anna, the small, plump Filipina who greeted us at the door, owned the home. She lived upstairs with her husband and children. As we walked toward the bedroom that would soon be my mother's, another Filipina, Angie joined us. She was slither than Anna with a less guarded smile. As the residents' primary caregiver, Angie lived on site and was available twenty-four hours a day.

The bedroom was clean, light, and across from a bathroom. A dark gray carpet covered the floor. A narrow cupboard stood against one white wall. The window, decorated with a colorful valence, overlooked Anna's driveway and 148th Street. I glimpsed the tops of some pine trees about a block away. It stuck me, standing in the doorway of this stark but not unwelcoming space, that this was all my mother needed. A clean room, the single bed that we'd provide, a place to hang a change of clothes, a window showing a bit of green. At this stage, that was enough.

Anna and Angie described the services they offered and introduced me to the current residents, Kim, Everlynn, and Erma. I watched the capable way the two caregivers bustled about and communicated with one another. I smiled when Anna explained, good-naturedly, that locking the bathroom doors prevented Kim from unrolling the toilet paper. I listened as Angie, resting her hand on Everlynn's shoulder, told me that the resident was in the late stages of Alzheimer's.

"For the four years Everlynn has lived here, her daughter has never once visited," Angie said. "Yeah, yeah" Anna told me, nodding. "Now we are Everlynn's family."

They won me over. I gave Anna a deposit to hold the room. To fortify my instincts, I called the state agency that handles complaints against adult family homes. No one had ever complained about Anna's. I called references from a list the Autumn Years representative had given me.

"My aunt was an unpleasant woman," one reference told me. "Anna and Angie handled her beautifully." "Delightful place," another reference said. "They take wonderful care of their residents."

Three

Adult family home, the official definition: A home in a residential neighborhood that has been retrofitted to provide long term care services (not including nursing care) as well as room and board for a small number of elderly adults.

Adult family home, my personal definition: A place where you bargain away the last scraps of your mother's self-determination for your own peace of mind, for the assurance that she'll be safe, clean, kindly treated, and have a modicum of privacy. When I arrive at Anna's for one of my daily visits after work, Kim is sitting on the couch watching television. Everlynn is in her bedroom making the soft, private noises she always makes. Erma and my mother sit at the table eating. Angie is helping Erma eat. I move in beside my mother on a stool I pull over to the table. Everything is going along fine until Angie starts telling me about the night before. Then, she and my mother take up an argument they must have been having before I arrived.

"With that bed rail up," my mother says, interrupting Angie, "I can't get out of bed." She sounds indignant and pleased with herself at the same time, as if she just revealed some terrible truth that will finally enlighten me.

"It's for your own good, the bed rail," Angie tells her. "So you won't fall out of bed and hurt yourself."

"For my good," my mother spits back. "It's not for my good. It's for hers. I never fall out of bed."

Because of a throat problem, Erma can't talk. As she chews the asparagus Angie just fed her, she watches my mother and me with wide, sorrowful eyes.

"She trapped me in there with that bed rail," my mother goes on, "and then left me. I yelled for forty minutes but she paid no attention. And she had taken away my walker so I couldn't reach it. I was a prisoner in my own bed."

"I had to go help Everlynn," Angie says. She uses the bib that hangs around Erma's neck to wipe some food from the resident's chin. "Connie," she says, pointing a fork in my direction, "Connie, your own daughter, wants us to use the bed rail."

My mother looks at me, waiting to see whose side I'm on. I try not to choose. "Why did you want to get out of bed?" I ask her. From the living room, Kim burps loudly but no one pays any attention.

"To go to the bathroom," my mother says. Her indignant tone is back, but the self-satisfaction is gone. She's unsure of me now.

"But you can't manage the bathroom on your own," I tell her.

"I can too," she says. "How would you know anyway? You've never even seen me go to the bathroom."

"Of course I have," I say. Dozens of times, I've witnessed my mother's bathroom battles. She stands in front of the toilet struggling to decide which way to turn so she'll end up facing the right direction. She cries, "I'm going to fall. I'm going to fall," as Angie patiently takes down her pants and the diaper she wears and guides her into a sitting position.

"Well," my mother says to me now. She's leaning forward over her mostly empty dinner plate. Her face has turned as pink as her plastic place mat and she's shaking. "You've just ruined me completely. Now they'll never let me do anything I want."

Four

My mother was christened Rosemarie but her small size at birth earned her the nickname Wee Willie Winkie. It stuck. She went by Winkie the rest of her life.

If you know one thing only about Winkie, know this: She was a reader. Each week, at the public library, she'd exchange one armload of books for another. After she washed and put away the supper dishes, she'd curl up on the living room couch to read.

The memories of my mother I cherish most revolve around finding her there. Whatever we started out discussing usually wound its way to one of my mother's favorite poems. She'd quote a line or two and I'd hunt down the full poem in her poetry anthology, *Other Men's Flowers*, which sits now on a shelf in my office. It was during one of those living-room discussions that I first learned about that all-important interlude "betwixt the stirrop and the ground."

As I see it, my mother had the soul of an artist and a rebel. She loved words, both the sounds they made in poems and the stories they told in novels. She spent a year studying drawing and painting at the Three Arts Club in Chicago's Gold Coast neighborhood.

But, at each significant turning point, caution and convention triumphed over soul. She was a chemical reaction, full of heat and light, to which the creators had forgotten to add a catalyst. The only art-related job she had, drawing shoes for a department store catalog, ended when the war was over. She drafted a children's book about a parrot. That draft never found its way out of her bureau drawer. She married my father, a geologist who worked at an oil company, and became a fulltime wife and mother. Her passionate defense of liberal values at company cocktail parties, so at odds with her oil company lifestyle, earned her the nickname Mrs. Oil.

My mother recognized her inertness and, perhaps for companionship, pasted it onto me the way you paste clothes onto a paper doll. We both, she explained on more than one occasion, want to express things artistically but we simply lack the talent. Maybe her perception of our shared brokenness was why she came to me, rather than to one of my siblings, to die.

My mother approached her death in that same bifurcated way she approached her life. About her end-of-life plans, she was as passive as she was outspoken. What if, instead of "You have to kill me," her refrain had been: "At a point where I become unable to take care of myself, I'm going to commit suicide. I hope you'll support me and even help me if you see fit." Would this story have an entirely different ending?

Five

At Anna's, eating meant cleaning your plate. I'm sure the practice stemmed from some section in the adult family home guidelines. Decreased appetite and physical limitations make weight loss and poor nutrition a significant risk factor for the elderly.

When my mother arrived at Anna's, she weighed eighty-six pounds. From where she had bumped herself, large bruises the color of summer plums dotted her extremities. After only a few weeks as a resident, her cheeks were round and plump as if they contained a day's worth of gathered nuts. Her skin looked healthier. She didn't bruise as often.

Anna and Angie pointed to her cheeks with pride. "See how much healthier she looks," they said. But my mother felt overfed. "Like a stuffed goose," she often told me. I'd never known my mother to eat three full meals a day. A snack here, a snack there, and then a good dinner was her customary approach. By exercising vigilance and control, she'd always kept her figure (not easy for a woman five foot one or two). She had nothing but contempt for people who, in her words, let themselves go to pot. In restaurants, she'd point with her fork toward generously proportioned diners. "Look at those fat slobbs swilling down all that food," she'd say, too loudly for my comfort.

Initially, my mother bargained to maintain her eating habits. "I don't need three big meals a day," she'd say each morning as Angie helped her to the breakfast table. But Anna and Angie persisted. "Finish your oatmeal," they'd coax if she tried to leave food on her plate. "Just a few more bites," they'd urge if she didn't finish her mashed potatoes. In a remarkably short time, they wore down her resistance.

"We eat all the time in this place," she continued to complain to me. But, when I was there during a meal, I noticed that she'd resigned herself to finishing her food. Each time I visited, my mother's round cheeks reprimanded me. I recognized them for what they were: symbols of something that had been taken away. I suggested that Anna and Angie let her eat what she wanted, that it was fine if she didn't finish. They didn't

argue with me, but my words bumped up against an impregnable wall. If the guidelines said feed, my mother was going to be fed.

Six

My mother delivers the accusation as if it's the punch line of a caustic joke. "Angie manhandled me," she says. "She made my arm bleed."

It doesn't surprise me that my mother is accusing Angie of some form of abuse. On one level, it feels valid, a legitimate lashing out against dependency, against never getting your own way.

But, by the time she makes the accusation, I have observed Anna and Angie long enough to utterly trust their care. I can see Anna's point when she asks me to write a letter explaining that I know my mother is safe and in good hands. "For our records," Anna tells me, pointing to the locked cupboard where she keeps meticulously arranged binders filled with rental agreements, living wills, medication charts, and Do Not Resuscitate orders.

I write the letter.

Anna faces periodic inspections by the state. I understand why she complies, to the letter, with adult family home regulations. I understand how her obsessive compliance benefits me by ensuring that her residents receive the highest level of care.

But I also recognize how that same compliance denies the residents freedom of choice, possibly even denies them their humanity. How it imprisons them in a system designed to keep them safe.

What if I had moved my mother into my own house? Would she have been less of a prisoner, preserved more of her humanity? In my house, my mother could have eaten as much or as little as she wanted. But wouldn't I too have relied on a bed rail so I could manage time to myself and still know my mother was safe? Would my mother have

accepted the bed rail if she decided how much and how often she ate? Is it the bed rail that bothered my mother or simply that she needed one?

A friend sent me a quotation she found on a bookmark. The quotation is attributed to a theology professor named James Keenan. "Mercy," Keenan wrote, "is the willingness to enter into the chaos of another." My friend suggested that, for a caregiver, mercy means willingly entering the chaos of another person's decline.

Having watched my mother grapple with the conventions foisted on her at Anna's, it occurs to me that mercy factors in to both sides of a dependency equation. As caregivers, Anna and Angie and I faced the task of entering into the chaos generated by my mother's decline. My mother's task was no less daunting. Her dependency meant relinquishing control over the routines that determined the rhythm of her days. Mercy for my mother meant willingly entering the order that living at Anna's adult family home imposed.

She didn't always succeed. Witness the bed rail revolt and abuse accusation. And yet, there were signs that she broke through. Around Christmas, Angie took a month off to visit relatives in the Philippines. When I arrived at Anna's the day after Angie left, my mother was agitated.

"I want to know Angie's last name," she said, as I was taking off my coat. I told her the name. I'd written it on a piece of paper I taped to the wall above her bed but she always forgot to look.

"Now I need her address in the Philippines. I want to send Angie a telegram."

"A telegram?" As I begin convincing her we'd be better off buying a card to give Angie when she came back, my mother interrupted me.

"I want to tell her how much I miss her." She was quiet for a few seconds. Then, she added, "We have our troubles, Angie and I, but I've gotten used to her ways."

Seven

Decline is a sly companion, one who patiently accompanies you down a long, gradual slope and then, without warning, nudges you over a cliff. My mother never suffered a major stroke. Instead, a series of smaller strokes ate away at her ability to stand, walk, and, finally, speak. She spent her last months at Anna's bedridden and silent. Her plump cheeks deflated. She withered into a tiny bedridden being. To move her to the table for meals, Angie winched her in and out of a wheel chair with the help of a crane-like device called a Hoyer lift.

Her left arm developed an odd repetitive tic. It arced from the bed at her side up over her face and then back down onto the bed. Up over her face. Back down to the bed. For my visits during this period of her decline, I read books out loud, the cadence of my sentences accompanied by the rise and fall of her metronomic arm.

Eight

In the end, I did kill my mother. Immobility builds up secretions in the lungs and chest, which is why pneumonia is a common health problem for the bedridden. At Anna's, my mother suffered her second bout. Referring to my mother's living will, in which she declined interventions to prolong her life, I refused to let Anna administer antibiotics.

Surely, I reasoned, the life my mother was living at Anna's was exactly the kind of life she had begged me to help her avoid. But would my mother have chosen that life over none at all? How do the wishes we express earlier in life stack up against the instinct to cling to what we know, to gobble whatever morsels of life may be left us? I don't know if my silent, bedridden mother would have chosen treatment for her pneumonia. I never asked her. And what if I had? Would she have nodded or shaken her head? Would she have gestured with her hands? How much, at this point in her decline, did my mother even understand?

I read something recently about Paul Goodman, an American novelist, playwright, poet, and psychotherapist. He claimed that silences disclose as much as speech and that not all silences are the same. He defined nine kinds. What Goodman didn't spell out is how to know which kind of silence you're confronting. It seems to me that the story behind a

silence must reveal itself through the eyes. What silence story did my mother's eyes tell?

I wish I could say that her eyes told a story of “peaceful accord with other persons or communion with the cosmos.” Or of “awareness, pasturing the soul, whence emerge new thoughts.” My mother did, after all, evolve. Time and experience transformed her early abuse accusations into acceptance, and even appreciation, of Angie's kind and capable caregiving.

Instead, the story I saw in those eyes, the eyes that tracked my comings and goings and traced the restless arc of her own metronomic arm, was a fraught combination: “the noisy silence of resentment and self-recrimination...” mixed with the simple silence of “bafflement.”

Writer Lynne Tillman tells an interesting anecdote about an open mic event at a workshop. After a bunch of other men had stepped up to the microphone, the musician John Cage came up. He started talking from the middle of the stage without amplification. People in the audience shouted at him to use the mic. Cage said you can hear if you listen. Everyone shut up and, when he spoke again without the mic, they could hear him just fine.

My mother had stopped using a microphone. I had so many jabbering voices in my own head—discomfort with how she spent her days, my selfish desire to end what I perceived as her suffering, guilt over how I carried out her end-of-life wishes, exhaustion with five years of visiting, monitoring, and managing her life—I'll never know for sure if I achieved what John Cage's audience achieved: shutting up enough to let my mother's message come through.

Nine

Throughout my mother's stay at Anna's, I struggled to keep her enrolled in hospice. Enrollment gave Anna an alternative to 911. Enrollment protected my mother from the emergency room with its invasive and often brutal treatments aimed at prolonging life.

Instead, with the supervision of a hospice nurse, she could stay at Anna's and receive palliative comfort care.

Hospice, though, doesn't play well with gradual decline. Enrollees still alive after six months are dropped. My mother kept cycling in and out. At the time of her pneumonia, she was out. I rushed to sign her back up. Because of the Thanksgiving holiday, I braced myself for a delay. But the Powers that watched over my mother during her lifetime came together to help her die. Hospice reenrolled her almost immediately. So, when Anna phoned the day after Thanksgiving ("Yeah, yeah. You better come," she told me), we had everything in place.

When I arrived at Anna's, an inhuman sound like a metal chair grating across cement ambushed me at the door. The sound came from my mother's chest, from her battle to draw oxygen into her fluid-filled lungs. Anna and Angie had her propped on some pillows. Her face, the way her skin molded so tightly around her bones, made me think of a grasshopper. Each gasp hoisted her away from the pillows under her back. She appeared, at best, semiconscious.

I followed hospice protocol and called for a nurse. Because of a cancellation, she arrived within twenty minutes (those beneficent Powers!) and immediately applied a morphine patch to my mother's arm. That drug was my mother's permission slip. Within seconds, her gasping softened and slowed. Her noise, her struggle, ended. "Your mother is dying," the nurse told me, "but when she might die is unpredictable. It could take hours or minutes." Looking hard at me, the daughter, the supporting actor in this drama starring my mother, she added, "Hearing is the last sense to go." I had a final opportunity to comfort my mother, say whatever still needed saying.

Actress and playwright Anna Deavere Smith believes that you reveal the truth about yourself in those moments when language fails you, when your grammar falls apart, when you're forced to dig deep for unrehearsed words. It's a verbal shipwreck. You're on your own to make it all work out.

In that small bedroom, crowded with well-meaning observers, my grammar fell apart. I approached my mother's side. Inhibited by the audience, I whispered, "Mother, I'm here. You're not alone. I love you."

I don't think my awkward whispers qualified as shipwreck heroics, but maybe they were enough. Maybe, if you add it all up—inviting my mother to live in my city, finding Anna's, visiting regularly, reading, refusing treatment for her pneumonia, bringing in hospice, overcoming my self-consciousness enough to murmur commonplace yet heartfelt words—maybe the total came to mercy.

Half an hour after the nurse applied the morphine patch, my mother fulfilled what Roman Emperor Marcus Aurelius calls one of our assignments in life. She died.

Connie Miller's essays and articles have appeared in *Under the Sun*, *Iowa Woman*, *Web del Sol*, a collection called *Women and Stepfamilies*, and other publications. She lives in Seattle. When she retired, Connie adopted an eight-week old black Labrador puppy named Victor. Her goal is for Victor and her to become a Reading with Rover pet therapy team. The process of training a dog, she's learned, is as challenging and as humbling as writing.