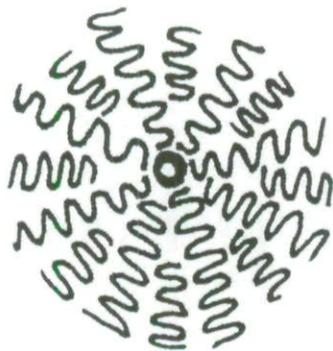


# MAMA'S MAP FOR LIVING—AND DYING

Erlene Grise-Owens, Ed.D., Spalding University

*The following narrative describes how the simple life lessons (or "Mama-isms") taught by the author's mother provided the framework for her personal and professional life. These lessons came into sharp focus when seeking out and providing end-of-life care for her mother.*



My one-of-a-kind, spunky, 86-year-old mother, Beulah Erma Jenkins Grise, died July 23, 2006. She lived her entire life within an approximately 20-mile geographic parameter. Her experience of the broader world was limited, but her experience of living was deep and complex. Along with my father, my mother raised twelve children on a family farm in rural Kentucky. Previously a force akin to the "Energizer Bunny"—which her children affectionately called our petite, lively, life-force—my mother's health declined dramatically in her later years. Because of progressive Alzheimer's and other ailments, my mother lived the last few months of her life at a nursing home in a small town near her home place. During her nursing home stay, she had several medical crises that required hospitalization.

My partner, Larry, and I were ending a two-week trip to England when we learned that Mom had been hospitalized Friday, July 21. Initially, my siblings who were with Mom thought that, like so many previous times, our resilient Energizer Bunny would bounce back from this medical incident. However, her condition deteriorated precipitously on Saturday, and we learned on Sunday morning,

July 23, that Mom's death was imminent. It was an excruciating, heart-wrenching experience to be across an ocean as my mother breathed her last. However, it was also a humbling and holy experience to recognize both the limitations of physical humanness and the unbounded grace of spiritual connectedness. This experience was somewhat metaphorical of my story of unanticipated and painful distance, and yet deep connection, with my mother during her last years.

My story is told from the viewpoint of a support role. Like any family story, it has layers of stories within the story, some of which I will articulate and others which will remain untold. I want my story to provide a perspective and serve as a resource for those family members/loved ones who may not play a starring role—i.e., primary caregivers—but, nonetheless, have a story. As my mother's health declined, some of my siblings became more distant, emotionally and/or geographically, for myriad reasons of family and individual dynamics that would constitute a novel, which I won't write! Ultimately, my three siblings who lived near Mom and an older sister who lived out of town became her primary caregivers. As well, we were most fortunate to have a long-time neighbor become a spiritually adopted daughter/caregiver during Mom's final years. In particular, one of my older brothers, who was Mom's power-of-attorney, took on the mantle of primary decision maker. For instance, he and a younger sister—who is a nurse—carried out the difficult decision of moving Mom to the nursing home.

Our father had died twenty years before our mother; she lived alone after his death.

I lived over two hours away and had a full-time faculty position in an MSW program with classes every other week-end. Typically, I visited Mom monthly. I learned early in the process, as Mom's health declined, the importance of supporting my siblings who bore primary caregiving roles. It was unrealistic for me to try to be a primary caregiver. I could flagellate and frustrate myself with guilt and regret for not doing that, or I could accept and honor my supporting role. Often, like many family members in similar circumstances, my supporting role involved listening, providing perspective, and being present, even at a distance.

However, I did not anticipate a literal ocean's distance in my mother's last hours. When we learned Mom probably would not live through the night, my dear partner began frantically—albeit, totally unrealistically—trying to get us a flight home before Mom died. That Sunday night, after hours of unsuccessful berating, bargaining, and begging the airlines, we walked wearily along the moonlit Brighton Beach. I kept saying to Larry, “I can't believe I can't be there for my mother.” I could not accept that this mere ocean could keep me from this most important person and moment.

But, returning to the small room of our inn, I asked Larry to give me some time alone. As I lay on the bed, exhausted and anguished, I accepted the limitations of my position. I came to a calm centeredness. I cannot describe the spiritual serenity that entered my hollow spirit, but I released my mother and my sense of guilt and regret for not being there. In that release, I said to my mother that I did not want her to continue to be in pain, and, selfishly, to want her to wait until I could be there to say, “Good-bye.” I recalled another time years earlier when Larry and I were traveling (as we do frequently) and I was unable to be with Mom on some special occasion. When I expressed my regret to Mom, she simply said, “Your place is with Larry. You come see me when you can.” I realized that those were the words that my Mom would have spoken (was speaking?) to me: “You are where you are meant to be.”

When Larry returned to the room, I shared this abiding acceptance. I slept deeply. Early Monday morning (British time) I learned that it had been around the same time of my release on Sunday night when my mother died. She was not alone. Several of her children were at her side. And, I believe, I was with her in my supporting role—even across an ocean with my partner.

Monday, Larry and I rambled around Brighton, England. Acute grief sensitized us to spiritual gifts encountered that day, including several small kindnesses (although is any kindness small?) from strangers. An elderly, dapper gentleman stopped to ask us, “Are you lost?” We found peculiar comfort in the studio of a lovely, whimsical artist, Sam Toft. The print we purchased, “Long Way Home,” captured some of our mood and commemorates that surreal, serene, sad day. Monday night we moved closer to the London airport to an inn owned by attentive hosts, Mary and Joseph (really!). Thankfully, we had already been scheduled to fly home on Tuesday morning and we kept our original itinerary.

On the transatlantic flight, I knew that my siblings were taking primary roles of arranging the funeral. But, the forced circumstances of sitting for hours in airports and planes opened up the space for me to reflect and write. Once again, my purpose was in a supporting role. I wrote a tribute to my mother in which I delineated twenty simple lessons that my mother taught. These lessons were not necessarily written or spoken by our mother. Rather, they were modeled in her living—and dying. The minister who officiated at Mom's funeral shared my tribute, “Some Things Mama Taught.” In our family, “Mom” was our usual reference to our mother. “Mama” is reserved as a special term of endearment and respect.

In the following pages, I share some of Mama's lessons and tell stories that illuminate and illustrate their meaning. I have decades of professional social work experience; I read materials to help deal with the illnesses assailing Mom; and I benefited from professional advice and friends' good counsel. I found workshop materials and professional

writings (e.g., Doka, 2004; Powell & Courtice, 2002) as well as websites (e.g., caregiving.org) to be helpful in my journey through this phase of my mother's life and my subsequent grief of her death.

However, in her living, Mama had provided a map for her children to use as we traveled this new territory of losing her: first, to the disease of Alzheimer's and then, to death. As anyone who has traveled a similar path knows, the journey was difficult, complex, and oftentimes we, indeed, felt map-less. However, these lessons from Mama's life-map provided sight for the path, even when we could only dimly see the present footprints and no further; solace for the journey, even when we were lost; and sustenance for our daily walk, especially when we hungered for direction in the void.

I begin with three lessons Mama taught that reflect some of her unique character as a woman, farmer, homemaker. First lesson: *A woman who can wring a chicken's neck, cut down trees, and pick up hot coals with her bare hands is to be respected.* These visuals are some of my first, and enduring, memories of my mother. Indeed, I learned to respect her tenacity and talents in providing for and protecting her family, which led to another lesson she lived: *Work hard; live with integrity; give gratefully.* In coming to know many families in both my professional practice and personal experience, I also recognized the lesson that *Motherhood is common; only a special few are called to be "mamas."* Although my mother became childlike in many ways and our relationship changed accordingly, I tried to honor her core Mama-character by following the lessons she taught.

A central Mama lesson: *Pain is just part of a full life.* At another time, when Mama was hospitalized, I asked her, "Mama, are you in pain?"—knowing that she was, but wanting to invite her to complain about it. In her inimitably pragmatic and philosophical way, Mama replied, "Oh, Erlene, pain is just a part of life." This incident summed up Mama's perspective: She accepted pain. This acceptance seemed to enable her to more fully experience deep joys and plain pleasures.

This perspective relates to another lesson: *Choose an attitude of gratitude in all circumstances.* Here's another story from this same hospital incident. Mama traveled by ambulance approximately an hour away to receive needed medical treatment. Upon Mama's arrival at the hospital in the ambulance, an attendant asked Mama how she was doing. Mama replied that she was fine. She elaborated, "What do I have to complain about? I just laid back and watched the pretty countryside on this beautiful sunny day." My adolescent niece declared, "Only Ma could turn an ambulance ride into a road trip!"

These lessons helped me remember and hold onto who Mama was and how she would want us to handle the vicissitudes of her waning years: with acceptance of the pain so that we could be open to gratitude for unexpected gifts along the road. In relating these lesson-stories, I do not mean to gloss over the painful times of seeing my mother agitated, hurting, hurtful, angry, sad, lost, unfamiliar, fading. But, I tried to learn to accept those painful times—as just what they were, part of life—and, then, be open to other lessons.

The above lessons intertwine with the following Mama lessons: *Savor the simple pleasures; Enjoy the flowers while they bloom; Practice "porch therapy"—sit on the porch often; Enjoy the rain that cools the day and waters the parched soil.* Even in her "Energizer" days of raising twelve children and managing a farm, Mom knew how to savor the simple pleasure of sitting on her front porch, enjoying flowers, bird song, cooling rain. Early in our marriage, Larry began calling these times "porch therapy." So, during my visits with her in the nursing home, I tried to practice porch therapy with Mama.

Those familiar with Alzheimer's know its effects, including diminishing cognitive capacities, and loved ones must adapt accordingly (Strauss, 2002). Because Mama often did not know where she was, I found it important to practice Zen mindfulness—a particularly meaningful activity for a lifelong Baptist—i.e., to be present in that moment of being. In these Zen times, I savored sitting with Mama. Unlike my siblings who lived locally, I did not have encroaching demands,

nor did I experience the weight of responsibility for Mama's day-to-day care. When I was there, I tried to really be present.

When we moved Mama to the nursing home, I was disturbed and saddened by the limited, stark space allotted Mama. On a grading scale, I would give this nursing home a "C." While many staff members were caring and committed, our family experienced firsthand the many problems documented nationally in nursing home care, such as inadequate staffing levels and staff training (e.g., General Accounting Office, 2003). The nursing home frequently had offensive odors, including second-hand cigarette smoke. Second only to the unstinting dedication of our family caregiver who stayed with Mama five days a week, my favorite resource was the nursing home's tree-lined courtyard. We used the courtyard frequently, taking Mama outside for fresh air whenever possible. Early on, I explained to a staff member that Mama was an "outdoor gal" who loved nature. However, unless family caregivers took them, residents rarely ventured outside. In myriad ways, I observed the sad neglect of residents with little support.

This nursing home was chosen primarily because of its proximity to where my siblings lived, which enabled them to provide more consistent care. On my own, I would have chosen a different place, but I certainly supported the decision. I committed to making this arrangement work, which included assiduously refraining from adding to my siblings' burdens by questioning or criticizing this choice. They dealt with this decision on a daily basis. So, I tried to never speak negatively about this facility unless my siblings who were primary caregivers initiated the criticism, which they did. At times I acted in concert with them to address problems. For example, with my siblings' agreement, I wrote a letter to nursing home administrators asking them to enforce a policy of protecting residents from second-hand smoke.

Before my personal experience with this end-of-life caregiving in a nursing home setting, I knew about the barriers to ensuring quality care, including staff stress. But, my knowledge was largely academic and affected others. Through my personal experience, I

learned at deeper levels about the importance of political intervention for nursing home quality of care; valuing nursing home staff; and appreciating the complexities of navigating this life phase and care system.

In coming to terms with this nursing home situation, I found two Mama lessons helpful: *Make do with what you have; and, no matter how little or much you have, share with others. Appreciate material possessions; but, do not let them possess you.* I tried not to operate out of materialistic values. I knew that my mother valued people above things; she could find profound pleasure and peace even in the simplest surroundings and starkest circumstances. I tried to do the same.

As Mama's physical and cognitive world grew ever smaller, the sensory world became even more crucial. I evoke two of Mama's lessons: *Eat your oats! Always, always have desserts!* (Note: Emphasis on the plural!) In her salt-of-the-earth way, Mama was a proponent of healthy living. She could have done a testimonial on the lived benefits of daily consumption of oatmeal; we shared many mornings communing over oats! In this sensate, smaller world, familiar foods with familiar folks—even if she did not recognize who we were in the moment—seemed to provide comfort for Mama. Part of healthy, happy life for Mama was desserts. (Did I mention *emphasis on the plural?*) So, as I had been doing for over a decade, when I visited I brought her special treats. In particular, I brought her favorite fresh candies and cookies, medjool dates, and candied apricots purchased from my local fruit market. I knew that, although these specialty items were not essential, they brought her familiar pleasure and in a small way conveyed that she was special.

Primary caregivers are the main course on the menu of caregiving: essential elements. A support role, however, like desserts, is somewhat non-essential. But, as support caregivers, we can make life a bit sweeter for our loved ones. By the way, Mama's last meal consisted of cake and ice cream. I hope to continue the family tradition.

Another inside family joke Mama-lesson that I shared in my Tribute was: *You can never have too much shampoo*. My mother collected shampoo—seriously. Having been poor, Mama experienced times when shampoo was a luxury item. So, a pleasure of her comparatively comfortable lifestyle in later years was to purchase shampoo—every time she shopped! Also, Mama's cheap therapy was combing her hair. Growing up, we twelve children often observed Mama's stress-reduction strategy of rhythmically combing her thick, red hair. So, whenever I visited, I would simply sit with Mama and comb her hair. A sacred time was sitting in the sunshine combing Mama's hair, savoring the silence. Words did not have to be spoken; nature and this lifelong tactile habit communicated comfort and serenity.

Similarly, especially when my partner or another family member was present, we would wheel Mama into a commons area that held a piano. (My parents had sacrificed to afford my piano lessons.) I would play piano and sing old hymns, at times joined by other family members or visitors. Mama would contentedly listen to the music. On my last visit with Mama—a couple of days before leaving for England—Larry, some of my siblings, and I shared a wonderful afternoon with Mama, singing hymns. She even hummed along with some of them. I shall forever be grateful for that time. I believe these familiar expressions of her faith soothed her soul.

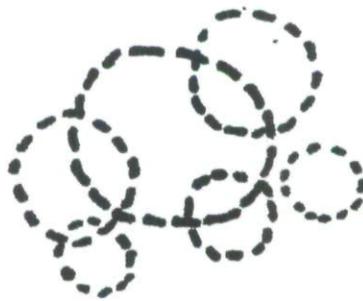
Lessons from Mama's simple, unadorned, abundant faith include: *Jesus loves me. Living one's faith is more important—and more difficult—than participating in religion*. To unpack this faith perspective could require a theological treatise; but, basically, Mama's life of simple faith meant that gifts of grace would be there for her even in the darkest times. When Mama needed her most, her long-time neighbor became an incredible adopted spiritual-daughter. We refer to this woman—quite seriously—as an angel. In her later years, Mama was not connected to a particular church. But, Mama's last roommate at the nursing home (a middle-aged woman with a neurological disease) was the spouse of a minister. This minister came to know Mama

through his encounters with her and our stories about her; he gave a loving eulogy that captured Mama's character and honored her life. Mama trusted that "It's all in God's hands." I honor that.

Another lesson from Mama was: *Laughter is good medicine—tears can be too*. As a coping strategy during this time, our family collected both "Mama" stories and "Alzheimer's" stories. Here's a favorite, which we call "Dr. Freud Meets Mama." A few months into her nursing home stay, the staff called in a psychiatric consult, whom we later dubbed Dr. "Freud." When Dr. Freud came to talk with Mama, our adopted sister, Jo Freida, was with Mama and reported the following (mis)communication. Dr. Freud greeted Mama and asked her name. She replied, "Beulah Jenkins." (Jenkins is her birth name, which she had not used in over 60 years.) Next, he asked, "Do you know where you are?" Mama, with an incredulous and somewhat haughty tone, said, "Why! Yes! I'm right here! Do you know where you are?" Next, Dr. Freud asked, "Can you tell me how old you are?" Mama looked at him with astonished disgust and declared, "Well, that's a nosey question!" To his credit, Dr. Freud recovered nicely, and said, "Oh, that's right you never ask a lady her age!" After that interchange, Dr. Freud seemed to try a different tack. He pointed to Jo Freida and said, "Who is this?" Mama confidently said, "That's my cousin." The doctor followed up with, "Oh, what's her name?" Leaning toward Jo Freida, Mama whispered, loudly and conspiratorially, "What's your name?!" Jo Freida told her and Mama promptly repeated this information to the doctor. Then, Dr. Freud said, "Now, Mrs. Grise, I understand that you have been crying a lot..." Mama looked at him with much wonderment, and said, "Well, yes, anybody with a lick of sense knows you have to have a good cry every now and then." Nonplussed, Dr. Freud hastily made social niceties, left the room, and increased Mama's medications. The doctor did not speak to any family member about his rationale for this increase; we conjectured that he thought Mama's audacious answers warranted sedation. My sister, who is a nurse, worked

with Mama's family doctor, who had a long-term relationship with Mama, to recalibrate the medications; Dr. Freud did not return.

We tell this family story to remember Mama's strong character, including her pragmatic disdain for silly questions. We enjoy the humor. Also, we tell this story because it underlines another Mama lesson: *Education is a priority, wisdom even more so.* My parents did not go to high school. But, they ensured that all twelve children graduated from high school and could go to college, and many completed graduate degrees. Mom proudly declared, "None of my kids stayed home from school to work on the farm." This accomplishment was significant in a farming community where the pressures of ensuring the family livelihood often depended on children missing school to tend crops.



The "Dr. Freud" story reminds us that Mama—even with dementia—had wisdom beyond full cognitive capacities and multiple educational degrees. This incident, and many others in this phase of Mama's life, taught me the importance of balancing professional knowledge with human connection and honor of personhood: education and wisdom. As both a personal caregiver and professional social worker, I am always reminded to ask: Whose reality? Do we really know where we are? Do we respect our loved one's/clients' privacy, self-determination, identity, and humanity—even though it may not fit with our "reality"? Do we honor and access their "anybody-with-a-lick-of-sense" wisdom? Do we engage the joy, humor, and surprise of interchanges like these to both enlighten and lighten our understandings of humanity and outlooks on life?

Mama's final lesson: *A good night's rest is a blessing*, brings us back to the beginning of this story. Especially before her failing health, a typical bedtime benediction from Mama was: "Love you. Have a good sleep." Mama would frequently count the fact that she slept well as one of her many, simple blessings. She would comment about how so many people had restless nights and say with heartfelt gratitude that she "always slept." Whenever I helped Mama to bed in the nursing home, I repeated this familiar benediction. My funeral benediction for my mother was from her lesson: "Love you. Have a good sleep." Just as, I believe, that night in Brighton, Mama's benediction across the ocean and all time was "Love you. Have a good sleep." I rested in another lesson I learned from Mama: *Love—while in human form imperfect—is constant, deep, immeasurable.* I had a good night's rest, with Mama's blessing. And, I believe that—although I do not comprehend the spiritual mysteries—Mama truly is at rest.

My friend, Kim Crum (2006), in reflecting on her parents' deaths and her long-distance caregiving role in their last years, cites Kierkegaard as saying, "Life can only be understood backwards" (p. 25). She offers this further advice: "Trust the process and accept its endpoint" (Crum, p. 25). Jacobs (2007), in writing about the intersection of personal grief and therapy with dying persons and their families, relates that "...grief unfolds in a variety of guises, and the lingering sense of loss never entirely disappears, but continues to shift and change gradually as time goes on" (p. 39). Through writings and conversations, others remind me that there comes a time when we must release those we love, with benediction. Yet, this release opens up new experiences and connections.

In my career, I have taught in my social work classes and practice about such professional concepts as the importance of relationships, honoring our clients, complexities of caring, and the dynamics of death and grief. I deeply value the importance of professional knowledge to inform competent practice. But, now, I understand at new levels that some of the best wisdom comes from life—and death. I know the importance of honoring personhood,

even when that personhood becomes both stunted and unfathomable at times. I know the power of presence, albeit not always in a physical sense. I know the essence of love as both tangible and inexpressible; in the moment and unending. I know that grief is not a static event or a single emotion. Rather, grief is a complex process of celebrating the lessons of living and honoring the lessons of dying.

Mama often philosophized: *Life is short—even if you live to be old.* (One of many Mama-isms I treasure.) So, I try to live this short life learning the lessons Mama taught in both her living and dying. These lessons inimitably inform and shape my teaching, learning, life. I offer these lessons for those of us who share a love connection of both grief and gratitude. May we be present and live forward, even as we learn backwards.

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Erlene Grise-Owens, Ed.D., is an Associate Professor at the School of Social Work at Spalding University in Louisville, Kentucky. Comments regarding this article can be sent to: EGrise-Owens@Spalding.edu.



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