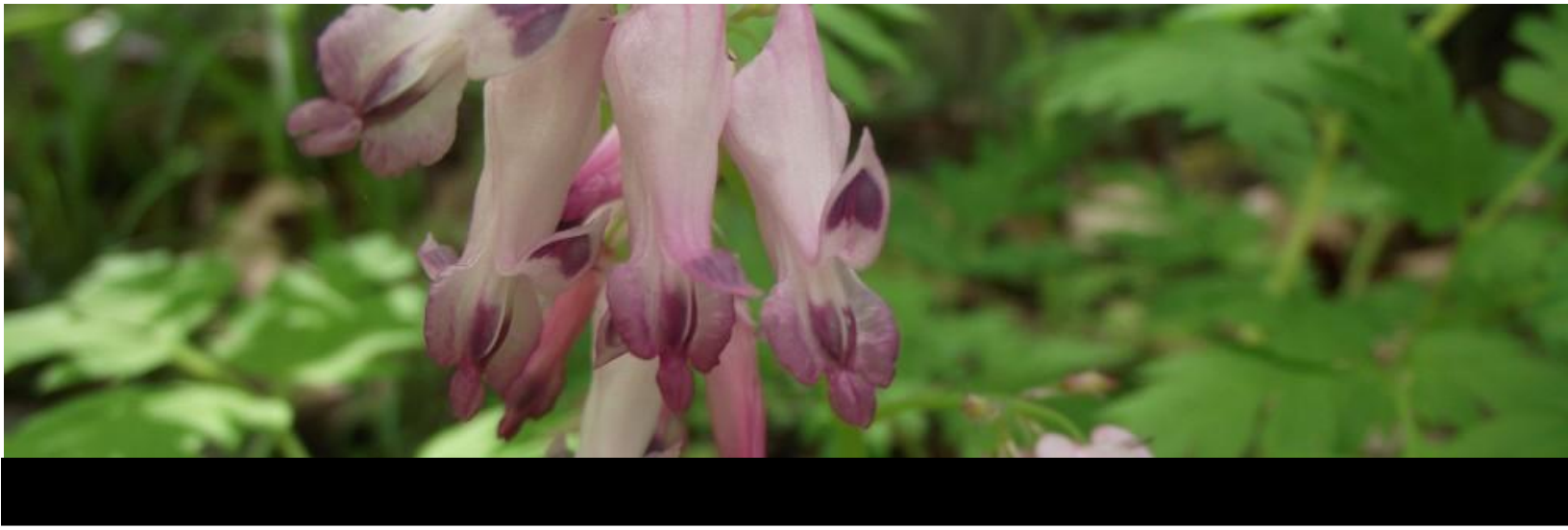
Naoma: The Guardianship

When and should someone assume responsibility for a loved one's care?



Naoma, my grandmother, died in a nursing home in 2007 at the age of 97. One granddaughter who lived nearby visited on occasion, but those relatives who were actually involved with her care, including me, lived almost 90 miles away.

There were failures in her support system. Let's call it a lack of coordination. No, let's tell it like it is. We're like a lot of other families out there. We failed to initiate communication that was useful to Naoma. Naoma had a strained parent-child relationship – one rooted in mistrust arising from the past. And among Naoma's children and grandchildren, there was long-standing strife that spawned distrust and resentment, making communication about her care even more difficult.

I will start with the ending…

The funeral almost didn't happen. My siblings and I were notified that there would be only a graveside service for my grandmother, Naoma. I was shocked. Two years before, she had asked me to go with her to the funeral home, where she purchased a prepaid funeral contract with most of her remaining meager savings. The contract included a coffin, vault, services and travel for a burial in Rocky Mount, NC.

Years before, Naoma had also made detailed notes about what her funeral should be like – hymns to be sung by choir members, some flowers, scripture to be read. She mailed those notes to the funeral director and later shared them with me.

Would her wishes be ignored? Why? Would her pre-paid arrangement not be fully utilized? It included a memorial service. In the end, the arrangements and wishes were honored but not without the intervention of her grandchildren and the acknowledgment by the funeral home that her written requests should be carried out if possible.

> Naoma, 97, of The Nursing Home in Greensboro, NC, died Friday, June 22, 2007. A widow of the late [John Doe], she was a retired beautician, a member of The Baptist Church and a homemaker. She was predeceased by her husband in 1947, and by two children – in 1996 and 2001. Survivors include one son and eight grandchildren.
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> The family will receive friends from 11:00 a.m. until noon on Monday, June 25 at The Funeral Home in Oxford, NC. A brief memorial service will be held at noon, followed by burial in Rocky Mount, NC, alongside her husband. In lieu of flowers, memorials may be made to The Nursing Home in Greensboro, NC.
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> *[Obituary text is paraphrased from original. The author is a granddaughter of Naoma.]*

Nature takes its own course

Naoma was beset with some of the classic limitations of the elderly. In the last year that she lived in her modest house, she left the kitchen sink water running. She was deaf in one ear and nearly so in the other due to deteriorating auditory nerves. The condition was one not treated easily with hearing aids. She was clearly physically frail, weighing less than 100 pounds, but continued to walk up and down the dozen steps to her back yard. Her vascular dementia was clearly advancing. She left on a stove burner. She was developing some communication issues – substituting the word "hat" for "glasses", for example.

Very likely, Naoma also suffered from chronic depression due in large part to the loss of her second- and third-born children. Up until the day he died, one of her sons who lived three miles away, and worked even closer than that to her home, stopped by nearly every morning. They would enjoy a cup of instant coffee and a piece of toast – sometimes made with her homemade sourdough bread. At times, she stirred up a full breakfast with bacon and eggs. His death, along with her poor hearing and lack of transportation, resulted in a social isolation that would depress someone decades younger.

Sometimes when I visited my grandmother, we would sit nestled together in her easy chair – a simple feat given that I inherited her tiny frame. While we sat together, she would sometimes begin weeping, hopefully releasing some of the pain she felt. This time with my grandmother taught me how important physical affection could be. I had never considered that a wrinkly old person was just as soft and warm as a child and that she, too, wanted comfort the same way I had wanted comfort when I was younger.

Naoma, like many of the elderly, was not the kind to take a pill to help something like depression. Prior to going to the nursing home, her only medications were Tylenol, stool softeners and a daily aspirin.

To her credit, Naoma really did an excellent job caring for herself given her circumstances. For about 10 years, she had been bathing herself in the bathroom sink because she no longer felt safe getting in and out of the tub. She washed her hair in the kitchen sink. She was always clean. She dressed herself every day. She did not sleep late. She had fallen a few times – fortunately, without consequence. She could still make a phone call and ask for what she wanted. She made herself tea, instant coffee, fried eggs, boiled cabbage and potatoes. Up until she was 94, she still made homemade bread.

The last year that Naoma lived at home, growing inertia and a lack of interest in living set in. She was increasingly unsteady on her feet. I brought her a walker with a seat and wheels. I would take her out for a walk, but she was uninterested in walking very far. My goal for her was the end of the next block; once we made it half way. She really didn't want to try even if it did stimulate her mind. Any nurse, and of course the family, thought an assisted living community would be safer for her. However, Naoma had lived in her home for sixty years and was not interested in leaving.

A further erosion of independence and personal regrets

During the last two decades of Naoma's life, it seemed that different family members stepped in and slowly eroded her ability to influence her own social life, safety and personal affairs. Of course, some of the decisions that took away control and self-direction were made with good intent. Once she reached 85, her younger son convinced her to give up her driver's license. That probably was justifiable. But it was a blow that only compounded the growing sense of loneliness and isolation caused by Naoma's severe hearing loss.

In 1996, one of Naoma's sons unexpectedly died during his regular morning breakfast visit with her. Within weeks of his death, her other son convinced her to sign a Power of Attorney document. A few years later, I learned that her homeowner's insurance had lapsed. Further checking showed that the Power of Attorney document had been filed at the local court house, and a copy of it had been provided to the insurance agent.

> Naoma treasured her modest but fully-paid-for home – no small feat for a young widow who was left to raise three young children. I reinstated her lapsed homeowner's insurance coverage and helped her pay for it.

I know little of the family story surrounding my grandmother, the death of her husband, the siblings' relationships, or her own relationship with her eldest son and his wife. What I know is speculation based on very limited facts, but there seemed to be a theme of resentment and distrust. Whatever the situation, Naoma was no longer pleased with the Power of Attorney document, and she hired an attorney to revoke it.

Her only surviving child who had once been Power of Attorney lived more than an hour away but worked about twenty minutes away. He and his wife were involved in her life. To me, their style of interaction with her seemed paternalistic and controlling. My aunt had worked as a hospital nurse for decades before retiring. In her earlier years, she had also been deeply involved in the care of one of her own family members. For her, a round trip to visit Naoma required three hours of travel time alone.

I could have been more involved with her care. I was in my late thirties and single, but preoccupied with dating and making a career change. From June 2003 until my grandmother left for the nursing home, I lived in the same building where my father had worked – less than two miles away from her home. I did not visit every day. Now, I think I should have visited daily and spent the night more often. In retrospect, it is easy to say I could have made the effort to make sure someone went by each day.

The beginning of the end

About 18 months before she died, Naoma finally agreed to let her son move her 90 miles from her home – and 90 miles away from where he and his wife lived. Shortly before moving, Naoma signed a new Power of Attorney document giving, once again, full power to her surviving son. He made an arrangement to have the skilled nursing facility accept Medicaid reimbursement but also take her home as a bequest at her death. All her wishes in her will were and would be ignored.

> When Naoma left home, she took with her only her easy chair and her clothing. When she left, she could walk without assistance and tend to her own urinary incontinence and toileting needs.

Change came swiftly. After a few months in the nursing home, Naoma was confined to a wheelchair. What I suspect she felt was increased isolation and a sense of abandonment by family, causing her to become distraught and beset with anxiety, anger and fear. She acted out. She was put on multiple medications, including injectable Ativan.

Ativan™ is a drug similar to Valium™, but it has a much shorter half-life because its molecule is less fatty. A shorter half-life means that the effect of the drug usually lasts for a shorter period of time. However, in the very elderly, a shorter half-life drug may actually have the same effect as a drug with a longer lasting effect, like Valium™. The effect of the Ativan™ put her to bed. After a few doses, her legs were so weak she could no longer walk. Not walking, in turn, made her more prone to disease, such as urinary tract infections.

The incidents that precipitated the use of Ativan™ for Naoma were supposedly as follows. She was tearing at her own clothes, crying out and expressing anger at the staff. They moved her to the locked memory care area. In an attempt to escape, Naoma picked up a fire extinguisher and used it the hit at the door. Again, I suspect she was in a great deal of mental anguish.

A granddaughter asks hard questions

By training, I was a pharmacist. I remained a registered nurse and had taught Certified Nursing Assistant (CNA) courses in North Carolina. I consulted for a rest home. I had performed drug regimen reviews for a nursing home as a pharmacist. Additionally, I had been a Certified Geriatric Practitioner. Even so, I was surprised that the nursing home had used injectable Ativan. I suspected that my grandmother's physical decline was partly due to the repeated use of the drug. I requested a state investigation into its use. They sided with the nursing home medical staff.

Concerned about my grandmother's quality of care at the nursing home, I decided I wanted to do something to get her moved closer to home where I could be of more help.

A hard lesson in guardianship

In the 2006-2007 timeframe, I decided to petition for guardianship. My grandmother's emotional anguish was too painful for me to watch. I wondered if she would fare better in her hometown where friends and family could visit more frequently, and the quality of her care might be more readily observed. As it was, sheer distance kept friends and family from visiting frequently. My best guess is that someone visited only every couple of weeks.

I hired an attorney – a local, small-town attorney with a good reputation, and one that my father had liked very much. We filed a petition for guardianship. Then the state had to appoint for my grandmother a guardian ad litem – a state attorney who would recommend what was best for her. The guardian ad litem visited my grandmother and conducted a detailed interview. His lower-toned male voice was easier for her to hear than other voices, contributing to an effective interview process.

I was very uncomfortable going into the guardianship hearing. It was rather quickly determined that my grandmother was no longer competent. That was the first part of a two-part hearing that can occur on the same day. We moved directly into the second part of the hearing where the Clerk of Court determines who will be guardian.

> I felt that my attorney was not adequately prepared. He told me that only a decision regarding her competence would be made on that day. But that is not necessarily how the guardianship hearing process works.

The state-appointed guardian ad litem recommended that the state appoint me as her guardian. This recommendation is directed to the Clerk of Court. The state attorney had described my grandmother's distress and had also cited a concern about the physical distance between her and family members willing to be involved in her care at the nursing home.

My attorney was not prepared for this second part of the hearing although I had tried to ask him to help me prepare details and documentation about care, family behavior, and facts to support the recommendation made by the guardian ad litem. Not only was there a question about why a son would place his mother in a nursing home 90 miles away from family support, there was a meaningful paper trail. Part of the paper trail was the revocation of the first Power of Attorney document, its use and what appeared to be an intentional lapse of the homeowner's insurance, and the diagnosis of dementia with need for skilled care on almost the same day that the new Power of Attorney document was signed.

As they say, hindsight is 20-20. The Clerk of Court made my uncle the guardian. Perhaps the Clerk of Court may have known my uncle from high school. My attorney may have already known how the Clerk would decide. It has since occurred to me that such decisions might have a strong generational influence. The Clerk of Court was essentially my uncle's generational peer, and the state-appointed guardian ad litem was my generational peer.

> Possibly, the clerk felt that it was inappropriate for a granddaughter to interfere in the parent-child relationship. Is it? With respect to Naoma, it's only a rhetorical question now…

The hearing was a sad disappointment for me. Still, I cannot imagine not going through with it if placed in the same situation again. I could have decided to go take the Clerk of Court's decision to court. Due to the personal cost to me – both emotional and financial – I chose not to go further.

Naoma was eating vanilla ice cream, a favorite snack, when she died in the nursing home dining room.

Case Study Questions

Confronting Emotions

1. What were the emotions that came to play in this situation? (Consider emotions of the author and other family members and caregivers). How did emotions complicate the situation? How might the feelings have been brought into the open to achieve better quality of life for Naoma?
2. When should someone intervene in a parent-child relationship, and how?
3. What are ways that unresolved parent-child conflict can be addressed when suddenly the child and parent are making major decisions about the parent's healthcare, finances, residence and of end-of-life preparations?
4. What is the best way for an individual to protect his or her final wishes regarding bodily remains and funeral services?

Advocate

1. Why do people grant power of attorney? What are the some of the issues to consider before appointing an attorney-in-fact?
2. When do circumstances make the use of guardianship appropriate? What are the consequences for the adult ward (the person declared incompetent) of a successful petition for guardianship?
3. Who is the "principal" and who is the "agent?" What is self-dealing? What can be done if the power granted an attorney-in-fact (agent) or guardian is being abused?

Nursing Home Care

1. How does someone learn what is good nursing, medication and medical care in nursing homes? What information is the staff *required* to provide to the patient's caregivers – about injuries, about changes in the patient's wellbeing, diagnoses and medications?
2. What documents are required and what communication techniques can help a caregiver better communicate with staff about caregiving?
3. What is the state of North Carolina's appeal process for cases of inadequate or improper treatment in a nursing home?

Notes

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Virginia Clay

About the Author

The author of this story is Virginia Clay, a CERTFIED FINANCIAL PLANNER™ Professional and Registered Nurse (RN). Virginia received an MSc in Healthcare Policy and Management from Harvard School of Public Health, and a Doctor of Pharmacy degree from Campbell University. She has two decades of healthcare, business and personal finance experience.

In 2012, Virginia Clay founded the Living and Care Giving Project (LCG Project), a publication and education service of Blackwood Administrative and Consulting Services, Inc. The purpose of the LCG Project is to help families better coordinate and use healthcare, financial, governmental, professional and community resources. The goal is to temper the flood of emotion and influx of information with understanding and insight. The result can be a comprehensive plan that is compassionate, prudent and effective. See www.lcgproject.com for more information.