

Reflections on “Between a Rock and a Hard Place: Balancing Safety and Independence with the Frail Elderly,” by Lynn Maitland, Ph.D., *Health Care Ethics USA*, Fall 2012.

Editor’s Note: These are responses to the article, “Between a Rock and a Hard Place: Balancing Safety and Independence with the Frail Elderly,” by Lynn Maitland, Ph.D. in the fall 2012 issue of HCEUSA by Susan Wilson, MD, FACP, FAAHPM and Sr. Paul Anthony Videtich, O. Carm, RN, BS

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As a geriatrician, I was impressed with the thorough summary of the issues presented in the article, “Between a Rock and a Hard Place: Balancing Safety and Independence with the Frail Elderly,” by Lynn Maitland, Ph.D., in the fall 2012 edition of *Health Care Ethics USA*. While it is true that we must respect patients’ autonomy until their plan—or the lack thereof—places them in imminent danger, we must also recognize that the more pressing issue is determining who is responsible for helping those patients when they do not have the physical, financial, emotional or mental ability to help themselves.

This issue is exemplified by a relatively new group we may call ‘elderly orphans.’ They have outlived or exhausted their friends and family members and have no one left to whom they can turn when help

is needed. While guardianship programs do exist, such programs are typically underfunded and therefore unable to meet the needs of all but the most at-risk persons, and the legal representation required to meet the needs of this group can be both expensive and time-consuming.

The most frequently utilized solution for this group lies within the health care system and the care model outlined in Dr. Maitland’s article: the patient is placed in a long-term care facility for ‘rehab’ to solve the acute safety problem, with that facility charged with the responsibility of developing a discharge plan focused on independence and autonomy. Realistically—and unfortunately—few advocate for the difficult task of returning such patients to their homes with some acceptable risks.

Scenarios such as these serve to underline the importance of encouraging patients and their families to plan for the inevitable. Many tend to believe that death comes suddenly, which, as we know, is often not the case. Death is more likely to follow long bouts of declining health and illness. We must therefore encourage patients and their families to create plans that focus on appropriate end-of-life medical care through the use of advance directives, health care powers of attorney and POLST documents and that describe what will happen when these patients are no longer able to care for themselves in their current living situations.

As a professional, I often ask, “Who will notice if you haven’t picked up your mail or put out your garbage? Who would you call if you had no food in your home and needed something?” For many, the response is, “I’d rather die than ask someone for something or live somewhere else!” While that response is a plan, it is not a *good* plan. (An excellent list of advance planning resources for patients and their families can be found at http://www.nytimes.com/ref/health/advance_planning.html.)

The number of elderly patients needing care is rapidly surpassing the number of those who can provide care at any cost. While the Affordable Care Act and the growing focus on the transitions of care may or may not improve this situation, it is undeniably a pressing problem that will require us to work together to develop workable and realistic solutions.

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As a Carmelite Sister for the Aged and Infirm, and a registered nurse, working exclusively in the long-term care arena for nearly forty years, I would like to share some observations that come from my firsthand experience, along with situations I have observed in my ministry. These reflections are prompted by the excellent article by Lynn Maitland, “Between a Rock and a Hard Place: Balancing Safety and Independence with the Frail Elderly.”

One of the duties in which I have often engaged is discussing the Sisters’ Philosophy of Care and Mission Statement with newly-employed staff members. Our first value statement is Quality of Life. After reading what is written about what that means and making a few remarks, I always say, and *never* have to complete the following sentence: “If you know any older people among your family members or acquaintances, chances are you have heard them say more than once, ‘Whatever happens to me....’” At this point, most heads are nodding, people are smiling, and someone will shout out, “Don’t put me in the nursing home.” Using this as a springboard, we can then begin to describe the way we can assure the new resident that entering the nursing home is not a “dead end,” and that their lives will still retain much meaning!

Prior to the admission for our residents, there is much that can be done to

successfully manage them at home, as mentioned in the article.

My mother was mentally alert, living independently, and nearing her 80th birthday, when she sustained a pathological fracture of her femur. This was the second time this bone was broken, the first resulting from a car accident at age 16. On this particular day, she found herself on her bedroom floor, unable to get up. After several minutes of hard work, she was able to scoot herself along the floor to reach the phone and was lucky enough to find my brother, an x-ray technician on the night shift in a local hospital, at home. He instructed our mother to remain on the floor and told her he was on his way. When he arrived, he called 911 and was able to let the ambulance personnel into the house.

After successful surgery to repair her fracture, my mother began PT in the hospital and was told that she would need to continue that process in a long-term care facility. She was agreeable to this because she had made multiple visits with me to nursing homes over the years. She consented to come to the facility where I was assigned at the time of this incident, despite the fact that it was in the neighboring state.

My mother was admitted as a resident and grew to truly enjoy the others with whom she had meals, was cheered along and encouraged in physical therapy, etc. She was also most grateful to be able to attend daily Mass and enjoyed other activities as well. I stopped in to say hello when I had a chance, but she was otherwise among

the residents and staff on her unit with whom she developed friendships that continue to this day! I can honestly say that she grew so comfortable with the environment, the schedule, and especially with her caregivers, that the challenging time for me was to have to tell her she was ready for discharge. “Do you mean that I will have to cook for myself again, order my meds, get someone to go grocery shopping for me,” were some of the questions that came flying at me. “What if something like this happens again and I can’t get to the phone and reach your brother?”

She did return home and one of the first things we did was get a Life Alert system installed. Her townhouse is in an Active Adult Community and is one-story. She has an attached garage, on which she herself installed a keypad on the outside to raise the door. She never locks the door leading from the garage into the kitchen. Life Alert has phone numbers of a few family members and friends who know the combination for raising the garage door and getting inside the house if an ambulance is ever needed. This incident was nearly ten years ago and my mother continues to live independently.

There have been multiple residents’ family members with circumstances similar to mine, with whom I have been privileged to work over the years. I would say that many are pleasantly surprised to witness how their loved ones adjust to their new living arrangement in a good nursing home when that occurs.

As mentioned in Dr. Maitland's article, it is always best if the person can participate in the conversation about their declining condition and about when they can no longer live alone if that time should come. While this may not always be possible at the time of a life-altering situation, as in the case of my mother, I often encourage families to engage in this discussion whenever an opportunity arises, or to schedule the time to explore this topic with a loved one. Visit various nursing homes with other family members when possible. Speak to the Admission Coordinator in the facilities that seem acceptable. Request an Admission Application and tell them that placement is not imminent at this time. Ask if the person you are concerned about could be put on a waiting list and alert them to expect a call from you in the future if circumstances should change.

In addition, if it is evident that independent living is becoming more difficult for the person, despite implementing some of the suggestions that have been offered, I would strongly urge that after much dialogue with the individual and other persons involved, alternate placement be sought *before* a crisis arises. I say this because many are unaware of how this process proceeds, and are of the opinion that skilled care facilities/nursing homes are much like hotels that you can simply call when it is time and say that you need a room. In fact, an appropriate vacancy needs to become available.

In closing, I want to restate what I said at the beginning—there is still quality of life in a nursing home. Residents still have the autonomy to make many of their usual decisions about how to spend their days. They are relieved of the stress of worrying about things that could break down in their homes; they can be assured of adequate food; they will have their medications administered; the physician can be called and will often visit in that location; the temperature in the environment will be comfortable and, most of all, they will not be alone.

The long-term care facility will also evaluate the resident on a continual basis, and if his/her condition improves, measures will be taken to help make discharge home or to a lighter level of care, such as assisted living, possible.

It is *no* surprise to anyone that living in a nursing home is hardly the situation we willingly embrace in our plans for the future, however, it should not be dreaded as much as it is. It might, in fact, be a peaceful alternative when the time comes when we can no longer manage on our own in the place where we may have lived a good part of our lives and which holds so many fond memories for us.

It is my hope that planning of this nature becomes a topic that is deserving of some reflection and effort as the aging process moves forward for all of us!