

***“We’re so sorry
Grandma, but...”***

*Something that won't have to be said if
you prepare for long-term care—What to
do before it's too late!*

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While I am a Knights of Columbus Field Agent, I have not written this book in my capacity as an agent. All of the opinions and information included in this book are my own work, not that of the Knights of Columbus.

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CHAPTER ONE

HOW TO AVOID A NURSING HOME

**“You can’t do anything about the length of your life,
but you can do something about
its width and depth.”**

—H. L. Mencken

In an informal survey of people I have worked with, 70 percent said that, should they ever need it, they would like to get their long-term care in their own home. Since there is no certainty about how long our life will be or whether we will ever need long-term care, let’s make the best of things—making it a wide and deep life in any case.

Why People End up in a Nursing Home

There are essentially four reasons why people are put in nursing homes.

1. An unexpected medical crisis occurs.
2. Family Caregivers burnout.
3. The costs deplete available resources.
4. Health deteriorates and more care is needed.

Let’s look at these one by one.

Medical Crisis

The following is the real-life story of my mother-in-law. Let’s call her Grandma. She was an independent woman and, at the age of 87, lived alone as a widow. She was busy with cooking, baking, quilting, and other activities at church, at home, or elsewhere with friends. She even managed her own garden.

One day she didn’t answer the phone when her daughter called her. The daughter was concerned about her, but just figured that Grandma wasn’t at home and things were okay. In calling her later, the daughter found that there was still no answer. She decided to go to the house to check, and ended up having to break into the house. Grandma had fallen and was dehydrated, with bruises and rug burns on her body from attempts to get up. She was confused and in and out of consciousness. The ambulance took her to the nearest hospital; after having spent probably three days on the floor and being extremely dehydrated, she was near death. After four weeks in the hospital, there was still no diagnosis, but Grandma obviously could not live alone in her own home anymore. She was heavily medicated during this time and became more confused. My wife and I drove 600 miles to where she lived; we wanted to bring her home with us so that we could care for her. My wife was willing to quit her job and devote her full-time attention to her mother and her mother’s needs. My wife’s family, who lived near Grandma, did not agree that she should come live with us, even though part of my wife’s experience included work in a

nursing home as a registered nurse. They all felt that we lived too far away.

Instead, the family decided to put Grandma in a nursing home near them, where she remained for about two months. During that time, she never left the facility at all—not to go to church or anywhere else. When family members visited her, they found problems resulting from poor care. One day, one of her daughters visited Grandma and found her in her room screaming—an unnerving situation. After speaking with the staff about her condition, the daughter was told that the family was the problem, because Grandma didn’t scream unless the family visited. The staff treated her as if she were demented.

After a few phone calls, a decision was made to transfer her to a larger hospital approximately 100 miles away. Grandma was confused, disoriented, and depressed. The doctor’s diagnosis was severe constipation that took seven days in the hospital to clear up. After this occurrence, the family was more open to the idea of us taking Grandma into our home even though we lived so far away. The doctors agreed, and when she was discharged, we brought her home with us.

The doctors and hospital staff eagerly worked with us to make all the decisions and arrangements for home care. Before we made the trip to get her, we had arranged to have a hospital bed, bath chair, walker, wheelchair, and everything we would need for her care in our home. My wife took a leave at work and our family began the task of taking care of her.

Grandma was totally incapacitated when she arrived at our home. She had never received any type of physical therapy while in the nursing home and so, since she was not a small person, it took two of us to help her to the bathroom. She was confined to bed and totally dependent on us for her care. One of us was always close by, and we put a baby monitor in her room so we would be able to hear her day and night. After we consulted with local doctors, a number of medications were discontinued and Grandma regained many of her mental and physical capabilities. Within two weeks, she attended church services with us, and she continued to do so as long as she was with us. With supervision, she began walking with a walker. We took her out to eat, and her appetite was pretty much back to normal. My wife cooked many of the meals her mother had taught her to cook.

After three weeks, she actually attended our daughter's wedding. She even got out of her wheelchair for a short dance. She was never left behind again. There were grandchildren and great-grandchildren visiting her regularly, which she really enjoyed and cherished. It gave her a new life of joy and hope. She loved to read and tell stories. Her memory was great. She enjoyed her quiet time with music and grandchildren reading scripture. She even went to a great-granddaughter's piano recital, which was a real hit with her because she always loved music. We discovered her great sense of humor that we never knew she had. She really enjoyed having the grandchildren pamper her.

Within a few days of having joined us, Grandma expressed her concern that she was a burden to us. She would ask, "Why are you doing this?" and repeated that

question until one day I responded with, "We are doing this because we love you and I am doing it because you gave me my wife." A smile appeared on her face, and she never mentioned it again.

Then one day after her nap, she called out over the baby monitor. When my wife went to check on her, she used her left hand to lift her right arm. The arm fell down. That was the alarm to call 911. She had had a stroke. She asked that we not leave her in the hospital. She wanted to go home. It took two days to stabilize her and back home she went, oxygen, IVs and all. MRIs showed that the internal bleeding had stopped and that the swelling of her brain was affecting her speech. We were told that it was a matter of time, only days to the end of her earthly life. Progressively, she lost her speech and then consciousness. Two and a half days later, she said goodbye with her favorite Taizé chant music, "Jesus, Remember Me," playing in the background.

We had the opportunity to bring Grandma to our home and provide homecare rather than nursing care in a nursing home. It took much effort on our part, but it was well worth it. It also took a great deal of emotional and physical energy, time, and money. We also had to look out for our own physical and emotional wellbeing. It was a challenge to take care of ourselves so that we would be better able to care for and support her.

Situations like ours happen every day. It could happen to any one of us. We were richly blessed that we were able to take care of her, and we would do it at the drop of a hat for anyone again.

Caregiver Burnout

Another reason for people being put in a nursing home is caregiver burnout. Again, a real-life story. This happened when my father-in-law—let’s call him Grandpa—had major health problems including diabetes, heart problems, bypass surgery, and later, breathing problems. As his breathing became more difficult, the doctors decided to perform a biopsy of his lung. This resulted in a systemic staph infection that brought him near death. The diagnosis from the biopsy was pulmonary fibrosis.

Eventually, he recovered enough so that he could be discharged from the hospital. Fortunately, his wife was in very good health and able to care for him at home with some homecare assistance and some help from the family. As I mentioned earlier, my wife had training in nursing and had worked in hospitals and in a nursing home, and so she took responsibility for looking after his medical needs. But we were living 600 miles away, and my wife—the mother of six—began driving back and forth to see him about every two weeks. She was away from home on and off about half of the time for a year. Even when she was home, she spent many hours on the phone with doctors, homecare agencies and insurance companies to help with his care and medical needs.

My wife and my mother-in-law both became exhausted. Finally it was time for a family gathering to come up with a better plan of care and support for Grandpa. It was agreed that each family member would commit to taking on some responsibility for calling or stopping in on specific days of the week. They assisted

with getting groceries, picking up prescriptions, mail, banking, cleaning house, whatever was needed. This worked fine for a while, and then there was another call. One evening, Grandpa took a bath without assistance and fell in the bathtub. The fall resulted in a ruptured bowel that ended up requiring an ileostomy. When he was discharged to come home, Grandpa began to use some home health care services. Because of an auto accident, my wife could no longer play the role she had in the past. Grandpa was then diagnosed with leukemia. My mother-in-law was no longer able to take care of everything—even with the help of the rest of the family. Grandpa now required ongoing help. Everybody was doing whatever they could and getting stressed out. He needed much more care than his loving family was able to provide. Grandpa would have to go to a nursing home because of caregiver burnout.

There was not enough help available in the community to provide him with home health care. But he had also purchased Facility Only Care insurance, and so he finally agreed to go to the nursing home on a temporary basis. He went to a nursing home for which he had served on the Board of Directors for many years. Being in the nursing home, he lost the independence of being at home, and it was easy to notice a change in his vibrancy, his energy to fight. He was giving up, especially when it began to look like the temporary situation was turning into a long-term stay. Grandpa was embarrassed and humiliated that he was not able to be independent. He now had to ask for everything. He was unable to communicate with his roommate because the roommate was deaf. Grandpa had no choices regarding food, had none of his possessions, and felt no privacy. He was missing the peace, calm, dignity,

privacy and comfort of his own home. When he saw that there wouldn’t be any changes in the future, he gave up. He refused to eat and, within days, he died.

Depleted Financial Resources

Some people go to live in nursing homes because the cost of care at home or in an assisted living facility has used up their money—their retirement nest egg. Unlike Grandpa’s situation, in which there were not enough people available to hire to take care of him at home, sometimes money for care runs out long before the care is complete. In the beginning, hiring outside help may be possible so that the caregivers can rejuvenate and continue a “normal” life. But often, as a disease progresses and the need for care increases, money to pay for adequate care is no longer available. When all of one’s personal financial assets are depleted, the only option may be Medicaid—welfare. After a lifetime of being financially self-sufficient, it can be a devastating emotional blow to have to begin relying on a government “handout”. But there may be no alternative, and if Medicaid is paying the bills, the patient may have to receive care in a Medicaid-approved nursing home. Medicaid will not provide the in-home care that may be desired, so there is no option but going to a nursing home to get care.

Gradual Deterioration of Health

The fourth reason it becomes necessary to go into a nursing home is a gradual and continuing deterioration of health while living in an assisted living facility.

When someone’s health deteriorates so that he or she can no longer manage alone, and the need for care is greater than what the assisted living facility provides, moving to a nursing home—where sufficient care is available—may be the only option.

This happened to my brother, Father Pete Kramer, to whom I have dedicated this book. In 1994 he developed lymphoma, requiring surgery and radiation in addition to chemotherapy on numerous occasions. He continued working as a parish priest until 1999, but because his treatments for lymphoma had leached the calcium from his spine, he could no longer stand long enough to say Mass. After being on a waiting list for Emmaus House, which is an assisted living facility supported by the diocese, he was finally able to go there to live. There he had a bedroom, a small kitchen, and shared living facilities with other priests who also needed to be in an assisted living facility. After two years there, Fr. Pete’s health deteriorated and his need for care grew to the point where the staff would no longer allow him to stay. He ended up going to live in a nursing home. The move to the nursing home triggered several health problems including clinical depression requiring treatment, numerous doctors’ visits, hospitalizations, and so on. After three years in the nursing home interspersed with several hospital stays, he died.

Why Get Your Care at Home?

With proper planning and support systems in place, any or all of these four situations—unexpected medical crisis, caregiver burnout, depleted financial resources,

and the gradual deterioration of health—could be dealt with.

Unfortunately, nursing homes can’t always afford to pay what it would take to hire capable people for the jobs that are so demanding. Nursing home pay is notoriously low. Imagine yourself being paid \$9 an hour with no health insurance coverage to dress, bathe, and change the diapers of your neighbor’s 90-year-old parent. And yet, that’s the typical nurse’s aide position. The special people who embrace this type of work—who would provide excellent care to those who need it most—often can’t afford to take these jobs and if they do, they can’t afford to stay for very long.

A nursing home is one of the most demanding work places on earth. The level and quality of care given to patients in a nursing home are more likely determined by the availability and quality of staff to give that care, rather than by the needs of patients. To increase the staff and offer higher salaries for staff best suited to give the emotional and physical care for patients would bankrupt the nursing home. And yet without adequate staff, a patient may not be able to be moved from an uncomfortable position until the next time the assistant visits the room. Imagine a diapered patient left for hours with a soiled diaper because there’s no one to take care of it. If there isn’t time to work on a patient’s rehabilitation, he or she may become even more impaired, which could very well lead to the patient becoming completely bedridden. I don’t share this information and my personal insights with you in order to place blame on nursing home administrators, and I don’t want to paint a depressing picture of the quality of care that nursing homes provide. There are very caring and dedicated people doing the best they can in many

nursing homes. Sometimes they are just simply faced with impossible situations. This is a reality that has to be faced by many nursing home patients and family members every day.

In upcoming chapters, we will look at what can be done to improve the quality of your long-term care, in any setting, if and when you need it. In Chapter 4, we will take a look specifically at what plans you can make to receive long-term care in your home, if you choose to do that. Yes, there are things you can do—if you start now. The key is knowing what to do and doing it. The “what to do” is what you will find in the following chapters. The fact that you are reading this shows that you are starting now.