

## **A Promise to Auntie Bini: Lessons from a ‘Work Around’ and the Value of Delaware Medical Orders for Scope of Treatment (DMOST)**

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Auntie Bini was born on December 16, 1920 in Chicago. She was born at home and never hospitalized. She lived in the same home for most of her life and cared for her parents until their deaths. She worked as a hairdresser until she was in her 70’s. Once retired, she downsized from her home in Bucktown, and moved to an apartment two miles north in Chicago. She lived alone and never married (she had a serious beau, however). In December of 2000, Auntie Bini celebrated her 80th birthday in Delaware with her nieces and nephews. She was surprised; this was the first birthday party she ever had, as Christmas always took priority around that time of year.

During frequent phone calls we were always told “not to worry” about her. We trusted her but were concerned about her determined independence, and shocked by some of her stories. She attended church regularly, even during the harsh Chicago winters. When driving was hazardous by her high standards, she chose to walk. Once, undeterred during a blizzard, she slipped and fell into a snow ditch. She was delighted, though somewhat embarrassed, when two large tow truck drivers helped her from the ditch, and she continued on to church.

Failure to reach her on several occasions resulted in calls to her nearby hospitals and police stations, we then arranged for “well person” checks on a regular basis. Not deterred by her age, she continued to drive, walk, shop, visit friends, and participate in her church. She even joined a mended hearts group, even though she had no history of heart disease.

September 11, 2001 marked the start of a new era for Auntie Bini and our family as worries about her safety were mounting; unable to reach her by phone that day, plans were made for a drive to Chicago to ensure Auntie Bini’s well-being. A niece who was not involved in this plan, was designated to be the driver.

Many conversations took place concerning Auntie Bini moving from her home in Chicago to Delaware. The Easter following her 80th birthday, she travelled east to celebrate what would be her eldest niece’s last birthday. She returned again in late July for her beloved Mary’s funeral. Moving Auntie Bini to the east coast was a frequent topic of conversation during that visit.

By the summer of 2004, she decided it was time to move permanently, but only on her terms. By firm agreement, she would maintain her high degree of independence. Her car soon arrived at her new home. The residence was modified to meet her needs and standards, and included a glass enclosed elevator (no small, dark places). She maintained her own set of rules: her dogs would be spoiled solely by her, her housekeeper would be Polish, and she would say who was and was not welcome to visit her, when, and for how long.

She adjusted well to her new residence, but still missed her home in Chicago. She kept in touch with her many friends and regularly received news of deaths which she accepted as a “fact of life”. She gifted her car to a great nephew who travelled from Chicago to drive it back there, much to her delight. In terms of her health, she loved Dr. Heldt, her new internist, as well as her new dentist, and ophthalmologist. She still enjoyed her frequent pedicures, too.

She had outpatient cataract surgery. Her first inpatient hospital experience was by ambulance, for an incarcerated umbilical hernia. An ambulance was resisted but needed. She stayed overnight at the hospital after surgery, and was determined that would be her last hospitalization.

After her return home from the hospital, she was determined her wishes for receiving further medical treatment would be honored. In her closet, an old suitcase contained her advanced directive, as well as her many insurance policies. She wanted assurance that these wishes would strictly be honored. She wanted no heroics and wished to die at home, in her own bed. There was agreement and a promise was made to honor all of her requests; however, there were some questions as to whether these promises could be kept.

She continued to do well and her only medication was a low dose thyroid supplement, as well as a mild antihypertensive prescription drug. Degenerative disc and joint disease were treated with increasing doses of Acetaminophen after an 'open MRI.' An outpatient arthroscopy then confirmed progressive joint deterioration. Injections gave her temporary relief, as she would not even consider joint replacement as an option. Walking continued to be a challenge. She started to walk with a cane and welcomed wheelchair assistance. She was quite upset with her increasing lack of mobility. However, she did continue to knit and work on her much treasured afghan blankets.

Throughout the year, she spent most of her time during the week in Delaware, and spent the weekends and summers at the Jersey shore. She was always in the company of her beloved Bichons, Myocardium (known as My My or Mya) and Bradycardia (known as Brady).

Auntie Bini wore a medic alert medallion at all times to reassure her and her family she was safe (she thought). She had one brief episode of dizziness while getting off of her elevator. She was subsequently helped to the couch and thoroughly examined for signs of a neurologic event. When asked if this had ever occurred before she responded "Yes, but I was told it was my blood sugar." The 911 call was then aborted and orange juice administered. Once again, there was a firm discussion about advanced directives, and Auntie Bini was reassured. She spread the word to her companions.

All was well until she slipped hurrying into the bathroom during a bout of gastroenteritis. No injuries were sustained, but efforts to reposition her failed. A reluctant call to 911 was made through her medical alert device. A booming voice projected from the base station located on the first floor. The landline was then taken over and we were told the call could only be handled by Emergency Medical Responders (EMRs). A neighbor responded and soon several others were present in the bedroom.

While all thought the crisis had been averted, it soon became clear that the excitement was just beginning. The emergency medical responders arrived and responded to the scene. Auntie Bini was alert, and was attempting to answer questions EMRs were directing to others. Despite her protests, EMRs insisted on placing an immobilizing collar on Auntie Bini's short, thick, neck, which had been deformed by arthritis, but was uninjured. She had significant kyphoscoliosis, and this extreme curvature of her spine made it difficult to place her on the backboard.

She pleaded with emergency responders to refrain from using the backboard, but was told the EMRs are in charge and have to protect their license. The police were next summoned to control the "unruly" family member that was trying to "interfere" with their care. Amidst Auntie Bini crying, her niece protesting, and the neighbors standing by in amazement, EMRs proceeded to

place her small, though stout, frame on an ill adapted backboard. To add to the discomfort, she was taken down the stairway instead of the elevator which would have safely accommodated her. Throughout the trip down the stairs, EMRs struggled while loudly yelling “slipping, slipping!” That trip to the hospital, confirmed gastroenteritis and no evidence of trauma. This was her final entry into a medical facility. Again, Auntie Bini’s promises were reaffirmed. The summer of her 89th year went well, spent at her Jersey shore home, and with the changing seasons, she returned to her home in Delaware.

In the fall, a syncopal episode resulted in her caregiver calling her physician, her dog walker contacting her niece, and her Polish housekeeper comforting her. Knowing full well Auntie Bini’s wishes, the dreaded medical alert medallion would not be touched, and no one dared to call 911. A long discussion later that afternoon in her physician’s office reaffirmed her goals and wishes of remaining in her home. Hospice was next consulted. In addition to enjoying the company of her caregiver, housekeeper, dog walker, neighbors, family, and church members, she now had additional company of hospice staff, including a care planner, social worker, a chaplain, and nurses. She remained busy and secure with exceptional care.

She prepared for her not-so-surprise 90th birthday party by making gifts for all who attended. She celebrated a wonderful life and looked forward to a natural death. She was able to see her family grow, as her great-great nephew turned 2 ½ years old, and 2 new babies were born that April. She joined them at the Jersey shore in early June. Although her pain worsened, and her mobility decreased, she was able to enjoy time with the new mothers, Abby and Paige, and her great-great nephew Jack, and her two dogs, as her constant companions. The transition of the hospice teams and care teams from Delaware to the Jersey shore was seamless. She loved her caregivers and nursing team.

She had positive interactions with them, entertaining them with tall tales until a sudden deterioration occurred. She was cared for in her own bed, in her own home by a professional team as well as her family and friends, including Dr. Curtin and the nuns from Villa Maria by the sea. She died peacefully after watching a Phillies victory. She always wanted to celebrate with others; so her funeral entailed a Mass and luncheon at the Jersey shore, followed by another Mass and luncheon in Delaware, all prepared by her favorite caterers, who were also friends.

The promise for Auntie Bini to die naturally in her bed was honored through a “work around.” Today, with DMOST (The Delaware Medical Orders for Scope of Treatment Act), promises, such as Auntie Bini’s, can be assured through legislation. The emergency medical responders would also be able to support her decisions and requests through provisions of the statute. Physicians and patients are now able to work together regarding decisions in end-of-life planning, even in cases without a terminal illness but frailty, when death is anticipated. Individuals in similar conditions to those experienced by Auntie Bini, as well as their family members, can be confident in their decisions, and the commitment to their promises can be fulfilled.

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