

Name

# The Alzheimer's Challenge

by Jessie Flynn

Why is it that nursing homes get such a bad rap? … especially when they literally save lives: both the life of the patient and the life quality of the family members involved. I found one family’s story quite amazing. I hope it will inspire you. This is a tale of loving devotion, double loss, and invaluable support.

Ted – father of three, including a multiply handicapped adult daughter named Beth Ann; husband of Barbara; college professor and patent holder of several inventions – began to show early signs of dementia in his 60’s. When he asked Barbara to grade his papers because he couldn’t, she became suspicious that things were amiss. Then when he awoke at two in the morning, dressed for work, and announced he was going to the office in the dark; she became alarmed and sought medical help. Things went downhill from there. Soon, Ted was unable to drive his car, something he missed for the independence it brought him. Weeks of roaming about the neighborhood, getting lost, and being brought back by the police followed until Ted’s family feared for his safety. Against all advice Barbara cared for her husband at home. Only after the third and final call from the nursing home they had signed up with did Barbara relent and admit that Ted’s safety was being compromised. A bed had become immediately available for him.

The next day was the hardest day of her life. She told Ted that they were going out to lunch. He clapped his hands and in a childlike way shouted, “Oh, goodie, goodie!” She packed his bag of clothing and set out with Beth Ann to have lunch outside on the nursing home patio. The trio laughed and ate while staff members wandered by and warmly chatted with them. But when it was time to leave, Barbara and Beth Ann said goodbye to Ted, went out the door, and resolutely decided not to look back as he pushed at the locked door to get out. Barbara felt like a traitor. Her sense of guilt was enormous. She deplored leaving him there.

Fortunately, doctors, social workers and nursing staff rallied around the family, making the living transition smooth for Ted, who would sit in the supervisor’s office (no doubt reminded of his own college office) for days on end. Barbara visited him daily for one year until he didn’t know anyone anymore. And even then, Beth Ann helped care for his daily needs, giving him pedicures, grooming his hair, shaving him, and providing loving attention.

Ted’s days kind of floated by. As he became more childlike and softer, his family actually treasured this new emotional expressiveness, which had been so rare when he was well. Daily and weekly visits filled up the five-and-a-half years until Ted died. He stopped eating and, according to his wishes, no extraordinary means were taken to keep him alive. The father and husband died peacefully with his family surrounding him.

Lest this scenario sound too idyllic, Barbara now shares the struggles she experienced throughout this period. At times guilt overwhelmed her. Deep in her heart she sensed that Ted resented her for placing him in the nursing home although they had previously agreed that it was the best thing to do. When she packed up his clothes and labeled them she felt like she was “washing her hands of him.” Her heart was so heavy that, to this day, she says she never wants to do that again to anybody.

And yet, Ted was not the same man. In a sense he had died long before his physical death – recognizing no one, unable to care for himself, forgetting how to sit up or down or even eat. And although still alive, the old, intellectual, competent and funny patriarch Ted was mourned by his family even as they cared so devotedly for him.

What helped this family cope? Where are the lessons here? First, Barbara sorted out her guilt feelings. She kept reassuring herself that she had done the best she could with what she knew at the time about the situation. Medical advice also eased her guilt. And, paramount, she considered the safety of both Ted and the children in their home. They simply could not keep a 24/7 watch on this man they loved. Certainly her enterprising personality helped her find a nursing home that specialized in dementia and Alzheimer’s patients. Any regrets about past unhappiness became reconciled by the fact that she couldn’t really know for sure how Ted had been feeling about his life. She wished they had played more, yet rationalized that Ted probably found fun and fulfillment in his work. She decided to stop second-guessing the past and focus on the present and what she could do to make his life better. In truth, Barbara felt a sense of relief. The responsibility for Ted’s welfare could now be shared with those professionals in the nursing home who deeply understood the challenges that accompany Alzheimer’s.

Second, she adopted a pragmatic approach to the venture. Barbara admitted that this was going to be a long haul. She’d think, “What a way to spend a Sunday!” And then when she’d visit Ted, she felt so good, seeing him being well cared for and seemingly content. How did she do it? “Well, you just align your feet and head and go forward and do what you feel you should.” Probably the hardest part of her situation was the ongoing nature of Ted’s illness. There was no discernible ending time frame. And so Barbara “stayed in the day” and dealt with her situation moment-by-moment, week-by-week, never going too far into the future.

Third, while Ted was in the process of dying, people in the nursing home kept coming and going from the room, reminiscing about Ted and celebrating his life. They created a wondrous support system for the family. Indeed, they had guided the whole family through the painful process of admitting Ted, caring for him, and preparing for his eventual death. Still, as ready as they were, Barbara and her children could not believe Ted’s death was happening. The nursing home had become their second home. In fact, Ted’s memorial service was held in the very chapel they had prayed in down the hall from his room. His cremated remains were divided among the children, who continue to celebrate his birthday and the anniversary of his death five years later.

Last, Barbara depended heavily on her spiritual philosophy of life. She turned to God and her belief system. Although filled with questions like: Why?, prayer became the cornerstone of her life. Reading various inspirational books got her through. Talking with clergy, social workers, and those who had previously walked this path also helped.

But dealing with Alzheimer’s was and is NOT an easy journey! If you talk to this wife and mother today, she’ll share that she now accepts the struggles and joys of life, holds fond memories of the old as well as the dementia-ridden Ted, and absolutely cherishes the love and support of community – whether it be church, family, or nursing home – that gets one through this journey of living and dying. Barbara has finally found a peaceful place in her heart.