

## THE SHADOW OF YOUR SMILE



### The End of Life Story of Jerry Eilers

Denise Eilers, RN, BSN  
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My best friend and soul mate died on October 23, 2004. In the thirty five years we were married, I was in awe of Jerry's ability to wring joy and laughter from every moment of life, no matter the circumstances or difficulties.

Diagnosed with post-strep glomerulonephritis<sup>1</sup> in 1965, Jerry began a twenty-five-year stint on conventional home hemodialysis in June of 1980 with me as his care partner. We felt that the home treatment option would provide us the best chance to lead a normal life. Neither of us ever regretted our decision.

In 1967, I was introduced to Jerry on a blind date. The more time we spent together, the more I came to realize what a remarkable man he was. I knew I had met the love of my life and my hero. On April 5, 1968, while a crooning pianist sang "The Shadow of Your Smile," I said "yes" to Jerry's proposal. We were married in 1969.

During his nearly quarter century on home dialysis, Jerry, who was a CPA, worked full time as the CFO for a multi state corporation, played golf several times a week, and volunteered for various community organizations. Together with our son Marty, who was born in 1982, we traveled from coast to coast. Jerry also managed to squeeze in yearly golf trips with his friends and camping adventures with Marty. Being the personification of the doting Dad, Jerry never missed a school play, a softball game, or a science fair. As a couple, we also took on the daunting project of restoring a home in an historic area of Davenport. In our spare time, we tried every new restaurant, shopped for antiques and danced to rock and roll music.

The years passed far too quickly. In 1994, we celebrated our silver anniversary by hosting a dinner party for our family and friends. We danced for hours as "The Shadow of Your Smile" played once more.

Jerry's commitment to his family was always absolute and unwavering. Both Marty and I constantly felt his deep and abiding love for us. For example, the "family hug", which began as a sort of lighthearted silliness, became a heartwarming daily after-work ritual, even long after Marty was admittedly "too old for that stuff."

My husband was equally committed to his continued good health. Besides exercising every day, Jerry was the essence of the compliant patient, never shortening or missing dialysis treatments, eating a healthy diet, and taking medication as prescribed. He dealt with kidney disease and dialysis in his usual fashion—with quiet courage, determination and a wacky sense of humor. In fact, he told more than one unsuspecting person that he was sleeping with his dialysis nurse. Life was very, very good and very, very normal. The only bumps in our lives involved Jerry's heart bypass surgery in 1998 and a complicated hip replacement in 2000.

By late 2003, however, Jerry had begun the downward spiral that would ultimately lead to his death. In his last year, several hospitalizations, surgery on his dialysis access, and repeated infections took their inevitable toll.

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Dr. Bruce Bartlow, in his book *Medical Care of the Soul*, begins by stating, "All of us will come to the end of our lives, but so few of us will die well."<sup>2</sup>

To be perfectly honest, death and dying *well* were not subjects Jerry and I discussed very much except in offhanded conversations that usually began with a comment like, "If something should happen to me...." Ironically, Jerry was far better at initiating those conversations than I. Dr. David Kuhl said it well: "Talking about death is very difficult. We are afraid that talking about death beckons it."<sup>3</sup>

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1 A disorder of the kidneys that occurs after infection with certain strains of Streptococcus bacteria

2 Bartlow, Bruce, MD, *Medical Care of the Soul*, Johnson Books, Boulder, CO, 2000

3 Kuhl, David, MD, *What Dying People Want*, Perseus Book Group, NY, 2002

As a nurse who for many years dealt almost exclusively with geriatric patients, I had certainly witnessed my share of deaths. However much I grieved for those patients though, facing the decline and death of a spouse is unimaginably different.

Jerry died in the ICU at Genesis Medical Center in Davenport, IA, three days after surgery for ischemic bowel disease.<sup>4</sup> Even that clinical setting was acceptable because of the compassionate care he received. Naturally, it would have been preferable to have had more time with an opportunity to be referred to hospice but, under the circumstances, it wasn't to be.

Ensuring that patients “die well” is definitely not the exclusive province of formal hospice programs, however. Hospice is much more than a place or a service provided – it is first and foremost an attitude and a mind set, regardless of where death occurs. Furthermore, end of life issues are not one dimensional but could benefit from a multi-pronged approach—including legal, spiritual, palliative care, and hospice—and should include the patient, the family and the entire care team. Education about end of life issues needs to permeate every facet and every level of health care. After all, death is a part of every person's life.

While I strongly believe that every adult should execute Advance Directives, so often these legal documents only address what type of treatments a person does *not* want. In his chapter entitled “Advance Directives and Other Confusions,” Dr. Bartlow not only provides several samples of Advance Directive forms, but also focuses on the importance of goals, hopes, and fears. Although discussions involving death are often difficult, it is imperative to begin those talks early, integrating them into the overall care of each patient from the very beginning.

Personally, we were truly blessed to have had a health team who was sensitive to our needs and fears. Doctors, nurses, secretaries, housekeepers and a host of others were there to support us. During Jerry's hospitalizations in the ICU, no one on the nursing staff thought it strange when I tacked up family pictures on the bulletin board, covered Jerry with his favorite afghan, or played his favorite music—everything from Chopin to the Beatles. Although I am an RN, I am forever grateful that the staff never assumed I was assimilating information and, therefore, still explained everything to me. As my husband was dying, I was not a nurse. I was simply a wife.

Small kindnesses became exceedingly meaningful. A glass of fresh water would magically appear by my chair or I would return from a break to find a fresh pillowcase on my pillow. ICU staff would ask me to share their homemade desserts. Another time, a nurse who had previously cared for Jerry stopped by to see him.

Dr. Walid AlSheikha was Jerry's local nephrologist and the steadying force as we made the decision to withdraw all treatments and medications. His wise counsel took on added importance since Jerry was unable to participate in decisions in those final days. Rather than shying away from us and chalking up another death/failure, Dr. AlSheikha found ways to spend more time visiting Jerry and talking with me. After Jerry died, when I thanked him for this, he looked a bit baffled at my remark and said, “Jerry was still my patient and I wanted to take good care of him. I just changed my focus.”

Technology reigns supreme in most health settings today, but high tech treatment should never be confused with caring. Caring may involve a timely referral to hospice or bringing the hospice attitude into the ICU. At the end of life, caring may be something as simple as holding a patient's hand, easing their pain, giving a hug, or listening as family members relive precious memories.

**“When I remember spring,  
All the joy that love can bring,  
I will be remembering  
The shadow of your smile.”**

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4 A condition resulting from a reduced blood flow to the intestines