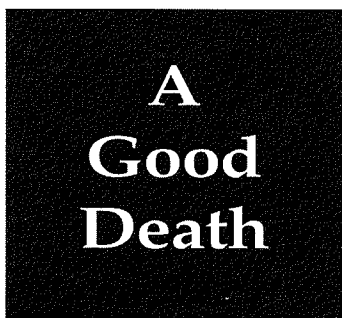


A good death is a strange concept, one not thought about often by those unfamiliar and uncomfortable with life's most predictable culmination. But once one is caught up in the dying process of a loved one, the notion becomes significant, and one becomes acutely aware of the opposite possibility that often exists in health care: dying alone and forgotten, in a sterile hospital room, without comfort — a kind of dying that robs the individual and family of the meaning of the life that preceded it.



**A
Good
Death**

by Alice Kitchen

Almost six years ago my husband Ron was diagnosed with progressive supranuclear palsy (PSP), a neurologic disease that has no known cause or cure. People with this disease live, on average, between three to nine years. Ron made it to the five-year mark. This disease was horrible for Ron to endure and dreadful to watch. This disease forced us both to consider dying, its meaning, and in doing so we experienced what, to us, was a good death.

What made Ron's final days a "good dying" and a good death, if there is such an experience? Ron's last two days were humane and lacked the tragedy often associated with death. There were several reasons for this. It was clear from the research on his disease that there was no known cure or treatment. This knowledge led to early acceptance and a series of activities that allowed us to focus on Ron's life — on his living — and not get caught making difficult decisions with little time to consider them carefully. Early in Ron's illness we completed our advance

directives, do-not-resuscitate declarations; we made burial plans and did our financial planning. With these things completed, we were free to focus on Ron's life while he was alive.

What was "good" about how Ron died? His death was natural; he had little pain, medical intervention, and discomfort. Ron died in our home, surrounded by family and friends, by familiar sounds and smells, by the comfort of pets.

Although Ron had lost his ability to talk, he was fully conscious and communicated through writing and visual cues. One of the most difficult junctures in his illness occurred when Ron began to lose weight because he could no longer chew, swallow, and digest food. His doctor suggested a feeding tube. "It is only humane," he told us. I talked to a nutritionist experienced in ethics and also read about the pros and cons of feeding tubes. Staff from the home health agency gave Ron information on feeding tubes.

Finally, through written notes, he let us know that he didn't want the feeding tube. This decision, I believe, resulted in a less-painful death. He had no infection or pain often associated with feeding tubes. Ron did not aspirate or contract pneumonia, two common causes of death for persons with PSP. Instead, his body shut down naturally.

Two days before Ron died, our home health aid caring for him called me at work to tell me that he was not doing well and wanted me to come home. On that day Ron stopped eating and drinking. We called in our hospice nurse who ordered oxygen for comfort and helped our family and friends understand what was happening and what we could expect during the next hours. Ron's breathing was loud, laborious, and echoed through the house. Each breath sounded as if it would be his last.

My sister, Julie, kept vigil with me through the first night. Ron's heavy, loud breathing, she said,

reminded her of the breathing process she experienced giving birth to each of her five children — the labor, the agony, the relief when it was over. Throughout that night the sound of Ron's breathing was with us, filling the house.

We played soft, reflective music that seemed in sync with Ron's breathing. The music soothed us all — Ron and those who loved him. When our priest came to give Ron the Sacrament of the Sick, we lit a candle, held hands, and prayed together.

Don and Bill, two of Ron's close friends, came to be with him during that time. Unafraid to see him in total helplessness, they squarely faced their own mortality whenever they looked at Ron. I sense they are stronger for their friendship and for being with Ron in his dying. One beautiful moment came when one of them stood to go, then bent over, kissing Ron's forehead. "You have been a good buddy," he said softly.

I was with Ron the whole time and that was important to me. We revisited old times, told stories, watched home movies. We all said our good-byes to Ron in our own way; we let him know how much he was loved, and that it was all right to let go.

Ron's dying was accompanied by people and sounds and smells that soothed him, and not interrupted with intrusive, heavy-duty medical tasks. As he breathed his last breath he exuded a beautiful smile. In his dying and in the light of that smile, our healing began.

Ron's "good death" meant we were there with him in a very natural way, attending to his final journey.

Ron died January 9, 1997 at 7:30 PM.

Written by Alice Kitchen, spouse of twenty-one years, friend, and caregiver — social work administrator, activist in health care insurance reform and issues of the uninsured