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FIVE

*Death Without Denial
Grief Without Apology*



A GUIDE FOR FACING DEATH AND LOSS

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Hospice

My experience with the hospice program feels like a large beautiful quilt.

Each piece is a different color, shape, and fabric. Some memories I touch gently, feeling the sheen and softness of that particular experience. Other memories are rough yet add beauty and unique pattern. Some of these I can only glance at briefly before quickly looking away to more soothing, comforting parts.

My hospice quilt began in 1992 on an escalator in a shopping mall during the holiday season. As I viewed the

scene from the slow-moving stairs, I focused on a fir Christmas tree covered with dozens of identical shiny metal ornaments. Two pleasant looking women sat near the large tree at a table with brochures, and a modest identifying sign that read “Mid-Willamette Valley Hospice.”

As I arrived at the bottom of the escalator I was suddenly facing the tree and I realized that each shiny ornament was engraved with a name. I glanced away, moving quickly to avoid eye contact with the two women at the table.

Go buy another Christmas gift! Get in the spirit! I told myself. This would be a very important Christmas with Frank. I wanted everything to be perfect. Perfect. But how would I make someone’s last Christmas perfect? Frank did not seem sick, even though his prognosis was terminal. By next Christmas he wouldn’t be here. *Next Christmas Frank would be dead.*

I stopped, turned around, and walked back toward that special tree and the hospice table. A multitude of silver ornaments shimmered with reflected light—individual remembrances for loved ones, especially during this difficult season. I wrote a check so that my late father’s name and ornament could be on the tree. *This hospice contact is about Dad and not about Frank*, I reassured myself.

I exchanged holiday greetings with the women at the table, picked up one of their brochures without looking at it,

put it in my coat pocket and walked away. One more second and I would have been sobbing openly right there in the middle of the mall. I held my hand on the folded brochure in my pocket where the printed words soothed me as if they had been written in Braille.

The hospice brochure remained in my coat pocket for several days, unread. By New Year’s Day it was in my bedside table, still folded, still unread. Each night as I climbed into bed, the brochure beckoned to me, waiting to be read. It reminded me of one of those movie cartoons where the item of temptation takes on a bright, pulsating glow that can be seen through the refrigerator door or through the closet door. But I simply couldn’t muster the courage to read the small booklet.

I needed to understand hospice so Frank and I could talk about it and Frank could decide if it was right for him. But I also understood that this hospice choice was about me. What if Frank said “Yes” and then I didn’t have the strength to follow through? What if I couldn’t bear to watch him in pain, watch him deteriorate, watch him die at home? I had so many questions and I knew some of them would be answered in the brochure. I needed to read it soon. Soon!

When I finally opened the bedside drawer and took out the brochure, I noticed the logo for the first time. It was a circle with four layered sets of hills and then mountains

and the words “Sharing the Journey.” The first page began, “It’s called Hospice.” And then it explained in one sentence all I needed to know:

*Hospice is a philosophy
of neither shortening nor prolonging life
but rather letting the terminal illness
take its natural course with care
and comfort of symptoms to provide the goal
of a peaceful death with dignity.*

I read the sentence again. And then again. And then I devoured every word written in the brochure. My chest grew tight with emotional pain and unshed tears. I loved what the brochure said yet I hated what it meant for Frank and me. How could anything so painful be right for Frank? How could choosing something that seemed so right cause such wracking sobs? How could I discuss this pain and this confusion with strangers? I thought about it for a long time that night and then mentally added another piece to my hospice quilt.

Finally, I decided I would visit the hospice office—alone. I wanted to prepare myself for the discussion Frank and I would share later, and for the meeting that would likely follow between Frank and the hospice providers. Thank

goodness for my decision to go alone! Three questions into my intended “professional” interview with the hospice director, I fell apart. Everything I was feeling came pouring out. Fear. Anger. Self-doubt. Frustration. Hopelessness. And a hundred questions.

The hospice director handed me a box of tissue, held my hand, held me. Clearly she had been here before with family members. When it was over I was totally drained but I felt ready to help Frank through this same set of questions, this same need to understand, this same valley. After that visit, I began to understand part of what the hospice logo meant about “sharing the journey.”

Frank and I soon learned about the services available: medication, pain control, oxygen, patient bathing, respite care, volunteer help, equipment, counseling. As Frank grew more ill and his needs greater, hospice would be there to fill those growing needs: a hospital bed, liquid morphine, special bed pads, and bathroom equipment. Hospice emphasized that each new service or equipment would come with an explanation and supportive reassurance. Step-by-step we would learn.

We also found that hospice care was for all ages and any terminal diagnosis when life expectancy is initially predicted to be six months or less. Cancer, AIDS, Lou Gehrig’s disease, kidney failure—whatever the situation, hospice was

prepared to help. Financial coverage could be by insurance, Medicare, Medicaid, or on a sliding scale based on one's ability to pay.

But most importantly for me, the hospice staff made clear their commitment to help keep Frank free of pain. Hospice care is committed to the belief that the *quality* of life is as important as the *length* of life. Hospice staff works hard to give the dying person as many choices as possible, to help him or her feel in control until the end. When you are caring for a terminally ill patient it is easy to make decisions for him or her about what *you* think is best. It takes constant reminders to give your loved one every freedom possible. As a dying person begins to lose so much, this is something you can help him or her hold onto. Hospice continued to gently remind us of the need for personal choice throughout Frank's final months.

Within a few weeks of hospice's first visit to our home in February 1993, we made the decision. After many questions, reading, and talking, Frank knew this was the right choice for him. I couldn't have been more in agreement. I was scared and sad and had much to learn but I felt good about our decision. In the months ahead those good feelings would turn into a lifelong gratitude to hospice.

When we first began our actual working association with hospice in April, Frank was still going to the Oregon

State Capitol every day in his role as a state senator. Two or three times a week, the hospice nurse came at night to help Frank. Frank's motorized wheelchair allowed him to *appear* somewhat vigorous and active at work but each day he grew weaker. His increased weakness, pain, and breathing problems were not yet obvious to everyone. Our decision to keep his pending death a secret was still firm.

Once Frank arrived home each afternoon his world changed. Rest and sleep and pain medication were the late afternoon's first requirements. His food intake slowed down. He had trouble with his vision and reading. Frank's hands became weaker and shaky. Many nights neither he nor I slept longer than four hours. Hospice helped us understand all these changes and gave us the information and support to face what was happening. We always had new questions and they always offered useful explanations.

As Frank struggled with his increasing physical deterioration and his determination to complete his final legislative session, my own personal pressures and heavy job demands added to the weight of those months. I was in the middle of my first four-year term as Governor of Oregon.

My days were filled with back-to-back meetings and conferences, constant decision-making, traveling throughout the 97,000 square miles of Oregon, recognizing the varied issues of over three million Oregon citizens, and reading at

least a briefcase full of reports and briefings every night. I also faced a grueling legislative session in full swing with way too little sleep and far too many personal worries.

As Frank's health issues grew worse, I traveled less, made fewer evening speeches, and found more ways to do part of my work at home. My personal and professional responsibilities seemed constantly on a collision course.

Several times every week I telephoned my two sons and Frank's two daughters to keep them posted on Frank's condition. Most of our five grandchildren were still quite young and had trouble understanding that their grandfather's illness was serious. The three grandchildren, all under age five, could hardly be expected to grasp the fact that their grandpa would soon be gone from their lives.

During this time of increased demands for help and support, Frank and I both felt fortunate to have a dear and long-term friend sharing our home. Only two years earlier Arlene had cared for her husband through his long illness and his death. Now, she was helping us through the same difficult process. Our respect and love for Arlene grew by the day and our gratitude immeasurable for this ultimate gift from a friend. To this day, Arlene and I remain the best of friends.

In June 1993, after months of silence, Frank publicly announced his latest cancer diagnosis and his plans to resign his state senate seat at the end of the legislative session. He could

no longer be silent about what was happening to him. The physical and emotional costs of Frank's illness had become so taxing that honesty and directness came as a huge relief.

Soon everyone seemed aware of Frank's situation and we both talked openly and publicly about his terminal status, his choice to forgo further treatment, and his decision to make hospice his *final* medical caregiver.

In August, only two days after adjournment of the longest legislative session in Oregon history, Frank began to have serious trouble breathing. I rushed home from a meeting forty-five miles away. Hospice came immediately with oxygen equipment. But it turned out that the hospice counselor who came that day was almost as much of a lifeline as the oxygen.

Frank had never been in denial about his illness, but the oxygen requirement was a clear wake-up call that his time was narrowing. He was very upset and disturbed about it. Our bravery went temporarily out the window. Frank needed the oxygen but Arlene and I, too, felt near to hyper-ventilating. The hospice counselor talked with us for almost an hour. She asked about our fears and concerns. We all talked and held hands and cried, admitting how scared and shaken we all felt. Frank asked questions about what to expect next, and what further deterioration would be like. He wondered about being able to leave the house for his retirement dinner only days away. Arlene and I worried

about operating the oxygen machine. What if the electricity went off? We were frightened that his need for an oxygen tank meant he could die at any time.

After we talked, Frank's courage and emotional strength returned. But his failing body was ready for rest. While Frank slept peacefully, the hospice staff again demonstrated their full support for family members, which is such an integral part of their caregiving. They assured Arlene and me, as his primary caregivers, that we had come through the crisis like troopers. We had faced reality, didn't panic, comforted each other, called hospice when we needed help, and we did not even hint at moving Frank into an alternative setting. Although upset for Frank, we remained committed to keeping him at home until the end. Frank felt safe and supported, and so did we. All my doubts vanished at that point. Hospice would be there for us. We would be all right, and we had clearly made the right choice.

Our reality changed that day. It was like looking through a pair of binoculars at our situation. Now death looked way too large and near, and time appeared small and out-of-focus.

During the next few weeks Frank's condition worsened. Even with oxygen his breathing was more labored. Frank's strength drained away and he needed help turning in bed. His retirement dinner would become his last time out of the house. He understood it was a farewell dinner. No one in the

audience that night doubted that was the case. The physical price Frank paid for stretching his endurance to attend was overshadowed by the joy that evening brought him. Several hundred people came to celebrate his career, his contributions, and his life. The president of Portland State University announced an on-going graduate student scholarship in his name. Family, old friends, former students, fellow senators, and community leaders praised Frank, thanked him, and expressed their love and respect for him. Frank struggled through the evening both emotionally and physically. But whatever the physical cost may have been for Frank, he glowed in the love of this retirement dinner.

After that special night Frank slept more, ate less, and physically weakened. With his apparent decline and my increasing anxiety, I read and reread the hospice materials on pending death and the physical signs of a body shutting down. Some things I read were not quite clear until I saw them occur, especially when the hospice staff came daily to bathe Frank. The color began to leave his legs, moving from toe to knee to hip. His hands were less warm to the touch. We started to keep someone in Frank's room all night, trying to meet his every need. When he awoke in the middle of the night, I didn't want him to find himself alone. Until the end, we were committed to being at his bedside. But when that time might arrive, was an overshadowing uncertainty.

We shared bedside duty: Primarily Arlene and I, with help from close friends like Nancy, Chuck, Celia, Roger, Mary Beth, Laurel, Donna, and Leslie. And on the worst nights, our hospice nurse, Cecelia, arrived. Hospice staff and I worked with these friends, explaining how to keep Frank's pain under control, talk to him, reassure him, and in the event of a medical crisis to call hospice, *not* 911. Frank did not need a hospital or life support, and he definitely did not want resuscitation. He wanted relief from this long ordeal. His wishes were clear, his path was inevitable.

Three weeks before his death, Frank suffered a stroke. Hospice came immediately. They confirmed he had a stroke and that his speech was severely affected. Hospice described Frank's attempts to speak as "tossed salad." Frank was confused and frustrated. Hospice arranged for a speech therapist to come the next day to work with Frank.

Even though Frank's body and vision had been failing, and he was incapable of using his wheelchair any longer, his ability to speak had remained his outlet, his salvation—and our joy. Frank was a storyteller, a former speech professor with a wonderful imagination and an exciting vocabulary. Even on his worst days, his sense of humor was intact. Now, Frank was unable to communicate. For me, the day of Frank's stroke was one of the hardest days I faced. I had depended on his words to give me strength until the end.

Now, he could no longer speak.

That day I left Frank's bedroom and cried. *It wasn't fair. It just wasn't fair! Didn't he have enough to cope with already?* The hospice nurse comforted me, held me, and let me vent my pain. Then, quietly and kindly, Cecelia explained about some of the side effects of a body shutting down. "This stroke," she said, "is one of those effects, just like his colorless legs and his lack of food intake." A body shutting down didn't need new fuel. A body without fuel begins to close down. The time was narrowing.

For the next three mornings I made sure I was at Frank's bedside when he awakened. His inability to communicate made it difficult to know what he understood. So each morning I explained to him, "Frank, you've had a stroke and your speech is not clear. We'll do our best to understand you. Do you know what I'm saying?" For thirty-seven years Frank had taught speech communication as a college professor. So each morning I reminded him of that life experience in the hope he could call on that background to understand what had happened to him. "Frank, remember when you studied speech therapy at Madison and helped stroke victims learn to speak again? Can you help yourself speak again? Do you think you can do that?"

On the fourth morning after Frank's stroke, I was sitting on his bed when he opened his eyes. I went through my

morning routine, explaining about the stroke and reassuring him that we would work hard to understand and help him. Then I asked him if he understood about the stroke. He paused a few seconds, gave me that endearing, mischievous smile of his, and reached his hand up to my face. Gently running his fingers across my cheek, he said clearly, “Stroke, stroke.”

When I shared that story with the hospice staff over the next few days, we marveled together about Frank’s resilience and humor. His speech improved and soon those shared stories became the buoys that I clung to in a sea of approaching loss. These stories would become some of my most special memories of Frank’s last days and memories of the remarkable bond between our hospice team and our family.

As the days dwindled to a precious few, Frank needed more pain medication, more sleep, little food, almost total physical help, and lots of love. Our caregiving circle read to Frank, sang to him, talked to him, massaged his back, and added more and more pillows to his bed. Hospice came more frequently, held more hands, answered new questions, and readied us for what was coming. Hospice was clear that the end was approaching and helped us to prepare for the reality of our impending loss.

There was no denial about approaching death in the house. Some moments I would wish for all this to end for Frank. Other times I would sit beside him, watch him

breathe, grateful for each breath. Sometimes in the night, restlessly dozing in Frank’s big chair near his bed, I would suddenly get up, draw close to his bedside, and listen to him breathe. Reassured, I would gently touch his face. *Stroke. Stroke.*



Three weeks after Frank’s stroke, all the signs of impending death that hospice had described were now evident. Family members began to gather. But there were no doctors, no injections or tubes, no intrusion—just Frank, his loved ones, and the hospice staff who I now thought of as the “wind beneath our wings.”

The doubts I once had about having the strength, endurance, and emotional stamina to travel this road with Frank were gone. Hospice had given me the knowledge and wisdom to make this precious final journey with Frank in the most gentle, natural, realistic way possible. Forever, I will be grateful for Frank’s decision and hospice’s commitment to teach me about the art of dying.

To the end, hospice was always there for us. After Frank took his final breath, I looked at our hospice nurse who had stood at the foot of Frank’s bed for hours. Our eyes held for

a few seconds. Cecelia nodded “yes” to me, smiled gently, and then, as I had requested earlier, walked across the room and shut off the oxygen machine that had run constantly for two-and-a-half months. I have never known such silence.

Weeks later, an unusual thought occurred to me. In every personal situation I have experienced regarding someone’s death—my grandfather, my niece, my father—and in every movie and television depiction of a death announcement, the people who delivered the news would always shake their heads back and forth sadly, meaning the person had died. Our hospice nurse had nodded “yes.” “Yes, he is gone. Yes, this path we have taken together has led us to the destination we have worked toward for months. Yes, Frank’s suffering has ended.” I will never forget her affirmative nod, her gentle smile, and her final favor so I could hear the silence.

Hospice taught me not to dread the silence.