

I have been a Physician Assistant for 26 years and have lived and worked in Rosebud for the past 16 years. Before I was a PA, I was a Lay Midwife. The stage before the baby is born is called Transition and how this is experienced makes a difference in outcome for Mother, child and family.

End-of-Life is similar. It is a Transition through a challenging and unknown territory; a Sacred time when the finalities of one's accomplishments in life are reviewed, relived and communicated to those around us. Caregivers, Doctors, Nurses, Hospice workers, family members, friends, spiritual leaders as a team become the Midwives helping support and guide the sick and dying through this Transition.

Providing comfort (palliative) care is multifaceted. Just as pain demands relief and the physical body needs attention; the Soul needs to be able to heal, to comprehend, to make peace and say goodbye to the life it has identified with for the short time we are here on this earth. This is a difficult task to do alone.

I want to thank all the wonderful families in Rosebud who accepted me as a member of their family and welcomed me into their homes. I shared the happy times with them as well as the sad times. There are a few stories I wanted to share today.

Before I proceed, several facts are all too clear. We don't have a Hospice or local home health nursing on the Rosebud Reservation. Todd County is one of the poorest counties in the United States. Living conditions are substandard, crowded, remote and resources are scarce. I have known cancer patients who never had running water inside their home, as hard as we tried to get it for them. Others where the carpenters showed up to build their handicapped bathroom after they had passed away. But out of this reality opportunities to make a difference have emerged.

Our patient base is approximately 20,000. Geographically we cover 100 square miles. The Rosebud Hospital is understaffed and underfunded. Death is a constant visitor on the Reservation.

Cancer and renal failure and other complications of advanced age provide frequent opportunity to help and support patients and their families for extended periods of time.

In 1976 I went to my first Lakota Traditional (Yuwipi) Ceremonies and Sweats at the home of a Native American family whose first child I had delivered several days before. In 1990 I was invited to visit the Sundance in Pine Ridge of an elderly Medicine Man and his wife. They were very kind to me and invited me to Rosebud to their home. In the Sweat Lodge I was told I would come to Rosebud to work and live. I didn't believe it. I returned in 1993 and haven't left. When the Medicine Man and his wife became ill, since I was at their home most of the time

when I wasn't working at the hospital, they also became my patients. So many Elders were uncomfortable in the hospital, that house calls became a regular part of my practice. Finally, I was able to start a special Elder Clinic in the hospital that has been very well-attended.

In my past practice, I was more like an old country Midwife than a PA. I had cared for Old Order Amish in their homes, had delivered babies at home for them, cared for families with 12 to 20 children when they all had chicken pox and cared for their Elders at the same time. I made house calls in rural Tennessee and in the Projects in Nashville.

So when the Medicine Man needed IV fluids after a bout of food poisoning I stayed at their home and watched the bottle, the old way, counting the drops per minute. When his wife had terminal ovarian cancer which she had refused all treatment for, she stayed home and her daughter learned to administer morphine with the help of home health nurses from 50 miles away, to keep her more comfortable. Seven years later when the Medicine Man was terminally ill, a nephew came and led doctoring Ceremonies for him in his home. Home hospice would have made a huge difference in these cases.

Because we lack formal Hospice, our Indian Health Service Hospital in Rosebud, out of necessity, offers end-of-life care in the hospital. There is not a separate section of the medical ward, but it is not unusual to have 20 or 30 relatives and close friends sitting day and night with a dying Elder. Taking shifts, bringing food, making sure the patient is able to spend precious time with the youngest grandchild to the oldest friend. I have observed that in almost all cases it is an accepted belief and a common experience that relatives who are long gone, return to guide the dying to the Spirit World. This is discussed openly and seems to make it easier for the family to accept the transition and to prepare for it, just as it helps the person who is dying.

When patients are confined to home, the Tribal Community Health Representatives and Indian Health Service home health nurses go by and check on the family. The Office on Aging has a Family Caregiver program. Walking Forward out of the Cancer Care Center in Rapid City provides assistance with travel to oncology services and provides lots of other support. There is a tribal nursing home.

Advance directives has been a difficult topic to address with our Traditional Elders. The most sure thing in this life is that we will all die someday. But few are comfortable talking about it before it has become a reality. We have had a lot of success using the "Five Wishes" booklet as a guide to start the conversation.

It doesn't do to force the issue. I had an Elder I had cared for for some time. I had become close to her and her family. She had terminal rheumatoid lung disease and went into respiratory failure. She was intubated and the physician at

Rosebud who had just met her was frantic that she refused to label herself as DNR before she was transferred to a level one hospital over 200 miles away. She was very alert, very sharp. I told the doctor, "she doesn't want to die in a hospital, she's not planning on it". They flew her out on a medivac to Sioux Falls. She recovered and came home. She went to the Sundance in Allen, South Dakota and participated in the center giving Indian names to all her grandchildren. When the Ceremony was complete, they wheeled her wheelchair back under the arbor. She suffered a ruptured aortic aneurysm and passed away, just as she had planned.

I have visited with innumerable patients and friends in the hospital and in their homes at their invitation and have advocated for them against systems that are sometimes hostile or inappropriate due to ignorance and lack of training in the principles of hospice and cultural sensitivity and respect.

Sometimes it is as simple as honoring patients requests and fulfilling wishes. Traditional foods, home-baked pie, a familiar song, the smell of sage smoke, religious ritual in the hospital room or home. It is just as important to find room for these things as to provide the right medications and treatments. This is medicine also.

One of my most recent experiences in end-of-life and palliative care was with my Mother. My Mother was born in New York City in 1914 to Jewish parents who had emigrated there in the late 1800's with their parents to escape the pogroms and persecution in Eastern Europe. She danced at Carnegie Hall at the age of five with her ballet school. She lived through the Great Depression, married, had children and was active in environmental protection and politics and physically active until she was 93. She visited Rosebud in 1996 and spent Mother's Day experiencing her first Sweat Lodge ceremony. She had lived independently in her own home since the death of my Father in 1979. Up until November, 2007 she watched Jeopardy every day and shouted out all the correct answers before the contestants could.

She suddenly became very ill in December, 2007. I would phone her and she was completely disoriented. I was worried and came to Nashville, Tennessee to stay with her in early January, after the roads were passable from Rosebud. Her doctor had prescribed multiple bottles of Darvocet for pain from a broken rib. She wasn't eating, she was hallucinating and could barely raise her head from the pillow. If she went to another room of her house she couldn't find her way back to the bedroom. She had lived in the house for 20 years. I was frightened. We took her to the hospital to see if she had had a stroke. She was emaciated. All medical tests were negative. They never found the cancer somewhere in her gut that was starving her. They never acknowledged how darvocet can cause dementia in the Elderly.

They sent her to assessment for dementia at an Elder psych facility. There were

bed alarms. It was a prison and they only let us be with her twice a day. We never missed a visiting hour. The darvocet was wearing off and she was less fuzzy, but still very dysphoric. They tried her on antidepressants. She knew she didn't belong there. We came to pick her up and take her home. She was coughing, she was short of breathe. We took her back to the hospital the next day. I knew she had pneumonia and they admitted her.

She had the same emergency room doctor who had seen her a month earlier and he couldn't believe she was the same person. He said she was the sharpest, most alert, communicative 93 year old he had ever met and he had visited with her a lot. Now she was paranoid, disoriented, weak. He admitted her to the hospitalist service. During this hospital stay, all signs of dementia went away once she had fluids, oxygen and antibiotics. She was lucid and conversational and told stories of when she and my Dad were first married and their life. They sent physical therapy to walk her down the hallway. She was weak, but proud, she showed off and walked all the way. When she got back to the room she was exhausted. The doctor didn't believe she had pneumonia, so they sent her home on Home Hospice and morphine and home oxygen.

After we got home, the xray report was finally ready. She in fact had pneumonia. She had never had morphine before. It made her hallucinate. She heard Gene Kelley singing, "Singing in the Rain" over and over and she couldn't make it stop. She begged me to "make the music stop". I was helpless to do anything for her. I was on the phone with the on-call hospice nurse through the night. She suggested another medication and my husband went out in the middle of the night to try to get it. She started reliving her past. The hospice nurse very matter-of-factly told us, "I'll be surprised if she makes it through the night" and tried to get me to give her even more morphine. I tried to comfort my Mother through this long night. I held her hand and talked to her. Neither of us slept and daytime was no different, except that finally a different Hospice Nurse came to the house and offered us their Residential Hospice. We went for that without actually knowing anything about the Hospice. It was amazing. When we got her settled in her room, she was comfortable for the first time in days. They gave her steroids to dry up the secretions in her airway and she could breathe.

I went to the Hospice directors office and broke down and wept uncontrollably and he was so kind. The Hospice was the first place my Mother had been that also included the entire family and we were not just a bothersome distraction the doctor's had to tolerate, like it was in the hospital. We all were part of this process and we were welcomed, just as she was, to be there.

We stayed in her room with her, taking turns on a cot, a chair and the floor. if you can call it sleeping, because yet another amazing time was taking place. Now she was trying to eat a little. A few crackers and a little water, but clearly she was not really eating. She was talking to us some of the time, but then she started talking non-stop. It made sense, it was her life, her story. I barely slept. I lay there and

listened, because I knew how precious our time with her was and somehow where the physical body had almost faded to nothing, her Spirit had taken its place. There was an easiness and a joy between us that we had not always had. I placed my hand in hers. She held it gently and lovingly. She made a face and said the word, "cold, you need gloves". We laughed, we made a shorthand joke about my cold hands. Another time she held my hand over her heart. "I'm going to miss you, Mom". She whispered, "I'll miss you too". Then the words came through me I wasn't expecting to say, "We'll find each other again, we always do". It was true.

We were able to tell her how much we loved her, many times a day and this was the best medicine for all of us. My husband, my Sister, her daughter, my Son, my mother's sister and close friends, the Rabbi. Mom was surrounded by people who loved her and wanted to let her know that and to say goodbye.

We were shy to mention anything about death around my Mom, but then she was the one who let us know that she Knew it was close. She said, "I thought this would be easy, that you could just go, but I found out you have to have an Appointment! This man came to me and he made me an appointment, and it was wonderful!" This was about 3 days before she died.

Two days before she remembered all the words to a popular World War 1 song and we sang it together. She wanted to eat. She couldn't, but she tried.

Most of the time in the last week, she stared up toward the ceiling and with her arms outstretched upward for hours at a time she conversed with relatives I had never met. She warmly greeted visitor after visitor. Sometimes she spoke in Hebrew or Yiddish as her Grandparents had, most of the time in English. She told them about her life, her husband, about us, her children. Once she was talking about my Father to someone and I added a comment. She turned to me and said, " I wasn't talking to you". Oops.

I met my family, my ancestors, I felt their presence and she took us with her for a glimpse of The Other Side. Her Spirit was healing and growing as her body disappeared. She started as my Mother. She became my Ancient Ancestors before my eyes. She was transformed and wise and loving and appreciative of the physical help we gave her to keep her clean and comfortable. She was hyper aware of our presence and where we were in the room. Sometimes we had to go down the hall so she could rest.

When she finally left it was very quietly and peacefully. I do not know if she was aware that I was sitting next to her, watching her. I was alone with her. I pressed the nurse call and Stephanie came in. I told her, "this is it" and in a moment my Mother was gone. I was not surprised, I was numb with shock. I sat with her, but I think she moved on very quickly and without resistance. My sister came in first, then my husband. We sat with her for a long time.

In Nashville, although there is a thriving Jewish community and several synagogues, there is no traditional Chavra Kadisha, the secret society of volunteer men or women who prepare a Jewish body for burial and say the prayers and perform the 5000 year old rituals of purification. My idea was to do this for my Mother. To go the journey with her as far as I could. I checked with the Rabbi and she could find no reason against it. I thought this would be hard, but I was reluctant, even driven to be with my Mother for as much of this final journey as I could. The Rabbi gave us copies of the prayers and rituals that other cities with active Chavra Kadishas were using. I was glad to do this for her too. It felt right not to let outsiders perform our rituals for us that were traditionally performed by families and close relatives in ancient times.

The same Traditions are part of Native American ritual regarding death, but in many ways have also been taken out of the hands of the immediate family and Spiritual Healers.

I will never see a person at end-of-life the same way again. I will never turn it into just a medical event, with medication to manage the symptoms, without being aware of the effect these medications have on the important Spiritual work that happens during this time. Do the medications and treatments help or hurt? You have to ask yourself. Because when it is over, it is over. Somethings in life you don't get to rehearse or repeat.

We need Hospice for the very reasons I have shared this very personal story. Hospice made it possible for death to happen in a culturally, spiritually, physically and emotionally appropriate way for my Mother and the whole family. If she could have gotten better, she would have had a better chance of recovering in Hospice than in the hospital. A good Hospice is that good. It affirms life, just as the Kaddish prayer, the ancient Aramaic prayer for the dead, never mentions death.

I know this was very personal and I hope by telling some private stories, I may have triggered positive thoughts or reflections or memories that will allow all of you to find encouragement and hope in your path in life and that at the end of the day, your Sunset will be the most beautiful one you have ever seen.