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## WE WALKED TOGETHER

We were saddened and stunned the day the doctor told us that our 81 year old mother had cancer of the esophagus. Not that we expected her to live forever. We just assumed that she had earned the right to die quietly - perhaps to fall asleep in her reclining chair and not wake up. The choice, the doctor said, was surgery or "starvation to the end". We agreed reluctantly and mother herself with quivering hand signed for the surgery because she "had a tumor". The word cancer was not used.

Weak from not having eaten for many days - she had been unable to swallow - her face was ashen and suddenly very, very old. "Will you and Max take care of Pauline?" she asked the day I took her to hospital. She was referring to an unmarried sister with whom she lived.

"You are going to be well soon and go back to live with Pauline yourself", I answered. It was an evasion. I knew it and she knew it. I didn't sleep well that night, troubled by the fact that I had turned away from her question.

The next day my husband sat down beside her bed and said, "Grandma, we know you are worried about Pauline - that she might be lonesome and we want you to know that when the time comes, we will be close to Pauline and help her when she needs help". Mother was relieved. She had asked a question and was entitled to an answer. Max told her if there was anything else she wanted to talk about he would be there.

In the hall, I spoke with the doctor. My mother was a gentle woman. She had always had a low pain tolerance. I wished she would die under the anesthetic. He heard it as a wish rather than a plea. Three weeks later we brought her home, weak and thin. The surgeon smiled proudly - the scar had healed neat and clean; mother could swallow once more. She was glad to be away from the hospital, the parade of temperature takers, pulse takers, pill givers, technicians, doctors, nurses, aides - lots of people, but nobody to talk with, nobody to be quiet with. Even when I visited and sat quietly by her bed, the parade continued; there was no time to be together. This is not to say that the nurses were uncaring or unkind. They were skilled, efficient, overworked and trained to make every minute count.

When we drove up to mother's modest apartment, we were met by the young woman who lived next door. She helped us get mother into the house and settled in her recliner. Then Dang bent down so that her face was at a level with mother's and holding her hand, she talked quietly. When she got up, she put her arms around me and hugged me.

Later 1 learned that she was a nurse from Thailand. Dang said she loved mother; so she was going to help. She began by lining up nurses to come in a few hours at a time as we needed them. All were from Thailand; each was an experience. They held mother's hand, stroked her forehead, talked softly, at the same time doing the necessary things with quiet thoroughness.

In the days and weeks that followed, all of us thought about death but none of us spoke the word in mother's presence. We played a game - pretending she was getting stronger, looking better - that death had sidled close, almost touched her, then gone his way, not to return for a long time. Even her doctor joined in the game.

Thoughts of death brought back memories of my first husband. When he died, I had shielded the children from the experience - they were moved to the periphery where I hoped the waves of pain would ripple out and over them. It was my job to be strong. Death was too painful a subject for eight and twelve year olds. I tried to keep them occupied with their regular activities. It was summer; so I sent them to the park, to the pool, to the movies. They were too young for mourning. I cried silently behind my closed bedroom door.

Now as I looked back, I wonder if they, too, had cried - alone in their rooms. Had they secretly wanted to talk about death with its awesome mystery and finality?

Shortly after my husband's death, I found among his papers a clipping on life expectancy for persons suffering high blood pressure. He had apparently considered that he might become one of those statistics but had tucked the clipping away without ever talking to me about it. Thoughts of death were solitary, not to be shared even with those most close.

Now I had another chance - if one could call it that - to face death and dying without turning away.

With my first husband I had experienced unexpected death; now I was witness to the process of dying. Was it the pain, I wondered, running through birth, life and dying that keeps dying within the life cycle and experience? Only with death would pain cease. Until that moment, whatever the age, the dying person has feelings, emotions, fears and the right to be treated with love, care, honesty and dignity.

We bury or cremate the dead, thus physically removing them from us. But, we wondered, do we sometimes physically and emotionally remove the terminally ill by shunting them off to hospitals or rest homes?

We decided we would keep mother at home, in familiar surroundings, near people with whom she could talk, with whom she could speak of her fears and wishes. Max sat by her bed, reminding her of the talk they had had in the hospital about Pauline. Would she like to talk again?

Yes, she would and she did.

She talked for almost an hour, weak though she was. Sometimes she rambled. She spoke of dreams where she had seen her mother and husband. Her mother had called to her and she had called back, "Don't worry, I'm coming". She had asked my father how it was "over there" and he had told her "dark but not so bad". She was a simple woman and made no pretense either in life or near death at sophistication.

Max held her hand and she went on to say she wished she had something to leave the grandchildren. He reminded her how she had always given each one a dollar whenever she saw them - even long after they were grown. How about leaving a dollar for each one? I could hear her loud laugh in the next room. It was the first time she had laughed in a long while. That gave me courage; I went into the bedroom to join them. It was decided - each grandchild would get a dollar. Later I wrote the notes that went with each dollar. To the older ones we wrote:

"Grandma has died. She did not have any material things to leave to those she loved. Even though you are grown, grandma continued to think of you and all her grandchildren as children. You will remember how she often pressed a dollar into your hand. Before she died, she asked us to send each of you a last dollar as a reminder of her love.

"A million dollars was never given with more love".

The younger great grandchildren each got their own notes, depending on their age. To the youngest we wrote:

"Grandma has died. She did not have money like some grandma's do. But she did have a lot of love. Remember how she used to give you a dollar when you came to her house? Well, before grandma died she asked us to give you one more dollar as a reminder that she loved you. Maybe you can buy ice cream for yourself or popcorn to feed the birdies".

In her talk with Max, mother had said that it might be nice to be buried in Pittsburgh beside Morris, her husband. But she was in California now and "it would be foolish to spend so much money to send me back". We tried to find out just how important burial in Pittsburgh might be to her but she was still tied to the practical world of money where an old woman living on social security couldn't permit herself many luxuries. We told her we thought we understood - and without promising, said we would try. She said she wanted her  $\beta$  500 life insurance policy to be divided equally among her three daughters, but we told her we had decided among ourselves that Pauline should have it. She liked that. It was what she really wanted.

She talked of her sisters and brothers and recalled her hard poverty stricken childhood. "Maybe you shouldn't send me back to Pittsburgh after all; I had it so hard there". But she really wanted to live, she said, to go back to her kitchen and to see Shawn's fourth birthday. He was one of the youngest of her great grandchildren and had just celebrated his third birthday at her home a few days before she entered hospital. Max could promise her neither life nor death. Maybe she would get strong enough to putter around her kitchen once more - to go back to her "profession" as she called her housekeeping.

She was too tired to talk more. She thanked him - not once but many times that day. The talk had brought great relief. She rested and slept well that afternoon.

Few sons could talk to a mother as Max had talked to her. She told him that she regarded him as a son and he said he would try to carry out the responsibilities of a son. A few days later, within minutes of her death, he recited Kaddish at her bedside.

Mother had many times expressed her fear of convalescent hospitals. They were caverns into which her friends had disappeared, never to return. The name was a farce. To convalesce means to recover, to return to health. These were death traps from which none of her friends had ever returned.

Talk of hospitals and convalescent homes recalled a memory of my first hospital experience when my son was born. I had entered cheerful and unafraid. My husband kissed me at the elevator and I was taken upstairs where I lay alone in a room for many hours, nurses coming in occasionally to check. As the second stage of labor began - with the baby's head emerging and receding - I became terrified. It was all so unknown to me. Only at the very end when the nurse came to stay with me did it become bearable. It was the aloneness that had been terrifying. I had needed the support of another human being.

Now, twenty-three years later, fathers were participating in the birth process, allowed in the labor room and even in the delivery room. Was it possible for families to learn to participate in the dying process, too?

We again resolved to keep mother home to the end. As things worsened my husband took a week of his vacation. We moved in, sleeping on the living room couch. I was resentful of the young people in the family who didn't drop by, even though I knew it was not out of meanness but embarrassment. They had been protected from death and dying so now they were uncomfortable in its presence.

One night, without having planned it, I hypnotized mother to sleep. Placing a cool, damp cloth on her eyes, I suggested sleep as I had seen it done in demonstrations. To my amazement when I lifted the cloth at the count of ten, her eyes were closed and she slept. I did this many times, adding suggestions of quality. "When I reach the count of ten, you will be in a **deep**, restful sleep".

As the illness worsened, manifested by severe diarrhea, we staggered under tons of laundry and lack of sleep. Small tasks loomed large; nights were endless. Mother's brother arrived from Pittsburgh. "She needs to be hospitalized", he said. Some of our friends and neighbours who dropped in thought we were either cruel or crazy. "That's what rest-homes and hospitals are for", they told us.

Only Dang, mother's neighbour, our Thai nurse, understood. She appealed to her friends and reported back, "They will come at night, too, because they are my sisters". And they came on successive nights - Mookda, Daranee and Jaroon.

They sat by mother's bedside in constant vigil. When Jaroon arrived, she told us that her sister, Daranee, had told her about us - as though we were an oddity. In her country it was customary for old people to die in their homes, close to their families, but in this country only three months, she already knew that most Americans send their parents to die in convalescent hospitals.

We went into the kitchen for a cup of coffee - the only time I ever saw Jaroon or any of the Thai nurses leave mother alone for a few minutes. We talked about American attitudes towards death; how in early America it had been the custom for families to live together in one large home; in that home babies were born and grandmothers died. But often babies were stillborn or mothers died in childbirth. Sometimes grandmas dies at 41 instead of 81. Modern hospitals with all their efficiency and technology had prolonged the life span. But now maybe it was time to step back to examine each sick person as an individual to determine where personal family care might have priority over modern technology. On that last night, this gentle woman sat at mother's bedside with a medicine dropper, dropping water, drop by drop into her mouth to cool her throat. Stroking her jowl, she leaned close to her ear, whispering, "Swallow, mama, swallow". With the end of a spoon handle she placed a bit of ice cream on the back of mother's tongue, allowing the coolness to drip into her throat. Gently she closed her eyes as they were pulled open by taut muscles. She moistened mother's lips, cooled her forehead, brushed her hair.

Jaroon explained the dying process to us - the accumulation of fluid in the lungs, the irregular pulse, now fast, now slow. She said mother was no longer breathing with her lungs but with her chest.

Even in a deep coma, could there be stirrings in the deep recesses of the brain? We knew mother could not see when her eyes did not respond to a flashlight, but could she hear? As the night wore on, Jaroon felt not. We were uncertain. Who among us had been there and back?

All the wrinkles were gone. Mother looked thirty years younger. We learned this is a rather common phenomenon of death - some call it the hypocritic face.

All this took place at five in the morning. when sue arrived to take over at eight, Jaroon explained that just before we had come into the room at five, mother's breathing had stopped. Driven by her nurse's instinct, she had massaged the chest to restore breathing.

Sue sensed our feelings and said quietly, "Nest time, when she wants to go, I will leave her go".

A few days earlier, unable to watch the suffering - certain of the end - we had thought of "helping her to go" but how? Would the doctor order an injectible instead of pills? No, he would not. "We want to be careful not to overdose her", he had said in reply to our indirect appeal.

Only when she could barely swallow - the day before the end - would he order phenobarb and demerol by injection; the phenobarb at night, the demerol every four hours. Now on this last morning, we called the doctor to appeal for phenobarb again in the morning. He agreed. After getting the order on the phone, Sue returned to the bedroom and said that in another hour she would administer the phenobarb. To our question, "Why not now?" she replied, "I just gave demerol and the two given together could kill her".

She was willing to "leave her go when mother was ready", but to "help her go" would be a violation of her nurse's pledge. Neither doctor nor nurse would hear our anguished plea.

When the last breath was drawn and mother lay still, we left the room while Sue made her ready with a fresh gown, combed her hair, straightened the bedding.

Again I was reminded that I was 55 and this was the first time I had ever seen a dead person in bed. Unlike the experience of "viewing" in a mortuary, it seemed natural to look at mother for the last time lying peacefully in her own bed, released from pain and fear. Sue, who had spent many days with her, kept her vigil by the bedside till they came to take her away.

Even the most independent mothers long for closeness to their children. Now we had done one last thing together. We had walked in the slow cadences of dying, right up to that thin line called death, over which each of us must finally step alone.