

TESTIMONY OF SHELLY TWIFORD
SENATE SPECIAL COMMITTEE ON AGING
JULY 17, 2000

Good afternoon. My name is Shelly Twiford. My mother died about one and a half years ago and I want to tell you about our experience.

Before I tell you about how my mother died---I think you should know a couple of things about her life. I want you to know how she lived.

My mother and father were married for 52 years and lived in the same two-bedroom house for their entire marriage. They raised six children. Mom always loved children and opened our home to other kids, some of them staying for months. She had a huge rose garden and spent hours tending her flowers. She also loved to fish and crochet.

In April 1998, my mother developed a bump on her head ---we took her to the doctor. To be safe, he did a CAT scan. A week went by and we heard nothing. I was worried, so I called the doctor's office, and we were sent to see a surgeon that afternoon. The next day, my mother had surgery to remove the tumor in her head. We were told the brain tumor was a secondary cancer that had come from some other place in her body---later we found out the tumor was a lung tumor that had spread to her brain and her bone. The doctor told us she would need chemotherapy and radiation treatments. As I look back, I believe the surgeon tried to prepare us by saying that we are all given a certain number of days, hours, and minutes to live our lives.

The doctors told us that we had a choice of treatments. Either we could choose a normal course of treatment or opt for a new drug protocol. We chose the protocol therapy because we thought this might use new types of drugs and would offer more hope in treating the tumors. The tumors responded wonderfully to the chemotherapy. Mom was extremely weak, and we just chalked it up to the treatments. We were so relieved that we had made the right decision.

But Mom became weaker and weaker. The last time I remember her in the garden was in May. In two short months, Mom lost her ability to garden. Once very active and an energetic person, by September, she was totally dependent on the family for dressing, bathing, and walking. Dad found her a walker, but she was losing her balance and began falling.

My father was my mother's full time caregiver. I would help during my lunch hours and would stop off after work to lend a hand, but my father shouldered the burden without complaining. I have to admit it was getting harder. Tempers flared at times. We all thought if she would just try harder to get well, everything would be ok.

In September, my mother was in the hospital because she was so weak. My aunt asked about hospice care because her sister in law had been assisted by hospice. The physician's response was "this is not about your sister in law and I'm not going to waste my time doing a job a social worker can handle."

In October, we had to stop the chemotherapy. My mother was too weak and too sick. She began to have tremors---like she had Parkinson's disease. Her legs were tingly and she couldn't feel anything. She had no quality of life. This was not who she was, or who she wanted to be.

We were in a financial mess. My parents had no income, other than social security. We called the courthouse to find out about financial assistance. There was a ton of paperwork---we only got through

part of the papers. It was so overwhelming, because they asked for so much information. My mother started crying because she thought they were going to have to sell their possessions--the things they had been so much a part of their lives. In order to help out, my brothers and sisters divided the medical and medicine expenses to relieve some of the financial burden.

The week before Thanksgiving, a CAT scan showed there were more tumors. I remember the doctor holding the film up to the light and pointing--"here, here, here, the tumors are too numerous to count". The doctor wanted to start radiation treatments the following day. I asked if we could wait one day to think it over, and he said no--I think we need to start right away. The radiation consultation was that afternoon. The next day, the therapy began and she only received about ten treatments. Her face and hands started to swell. She was in and out of the hospital during this time. We felt if they were still doing treatments, there was still a chance of curing the cancer.

She went home but continued to get sicker and weaker. It took two of us, usually my father and myself had to support her and keep her from falling. She was unable to urinate and not knowing what else to do---we called the ambulance and went to the emergency room. We were told we could not keep bringing her to the hospital. I felt like I had to plead to find a reason to keep her in the hospital, and they finally admitted her. We were physically, emotionally, and financially exhausted--there was nothing left to give.

Realizing my mother was very sick---we needed to stop this craziness and take her home because that was where she wanted to be. The doctor wanted to move her to a rehab unit for physical therapy, but we refused. Planning for discharge, the hospice nurse came to visit my mother. She told us if we were going to take my mother home, we would need to move fast. This was Monday, and we were planning for discharge on Wednesday. During the night, my mother had a heart attack. We were not notified of the change in her condition, and when we came into the room Tuesday morning we noticed she was having trouble breathing. Later that afternoon, she slipped into a coma. That evening, a physical therapist came into my mother's room to start therapy---we told him to get out. At 1:05 AM on Wednesday morning, my mother died in the hospital, surrounded by her family.

The question that continues to haunt me---is at what point in my mother's illness, did she become terminal---and who knew. We didn't know time was so short. I do not understand how a hospice nurse knew in a few minutes that my mother was dying and no one else knew. There was such a focus on treatment---no one saw she was dying.

I tried to think of the things that could have made my mother's death better for her and us, as her family. These are a few of my suggestions:

Be honest with the patient and their family. The important part of my mother's illness was missed and it was the fact that she was dying.

We needed information about options and support services for physical, emotional, and financial needs.

We look to health care professionals to tell us when we should stop treatment---the last month and a half were living hell and they probably didn't have to be.

We needed someone to recognize we were in trouble and needed additional assistance. You shouldn't have to forge this battle alone.

Thank you, for listening to my story. I know that I can not make a difference for my mother, but if I can

help one other person, that will assist me in coping with the loss of my mother.