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A Care Giver and End of Life Experience

In the last six months of 2010 my husband began a decline in his health and ability to help himself. He was using a cane and walker most of the time but had frequent falls and needed help to get up. I began to depend on family, neighbors, and Westminster Fire and Rescue to help. On several occasions I called on the expertise of the Westminster Cares nurse to help with scrapes and bruises and to tell if we needed to see the doctor. Somehow he never broke a bone.

His decline was slow but progressive over the next six months, and I put to use many of the services I had learned about as a member of the Council on Aging Advisory Council. I wanted to continue working part time but felt that my husband shouldn't be home alone. We started out with Life Line but he didn't use it because it was difficult for him to understand and he was rarely alone for more an hour or two. I decided to hire someone to stay with him while I was at work so that I could then have some time to run errands as well.

The Life Line and caregiver were the first paid expenses. It worked well for both of us and we had a delightful caregiver. I could still help him get in and out of the car and take him to appointments, the store or for a ride. When that became more difficult we bought the kind of walker that had handlebars and a seat so that he could sit down when his knees were giving out. That type of walker was great to use at the table and for getting around in the house as well as walking on the street.

However, it wasn't too long before walking was painful and my husband needed a wheelchair. We needed to see the doctor in Brattleboro every week and it became very difficult to transfer him from the car to the wheelchair. My husband was also having difficulty swallowing because of an atrophied epiglottis. The doctor decided it was time to ask a nurse from the Visiting Nurse Association (VNA) to come to the house and check my husband's vital signs and take blood checks, saving us the trip to town each week.

This was a big change because we couldn't go out any longer. The VNA nurse came to the house to do assessments and set up a schedule with the occupational, physical and speech therapists. The VNA speech therapist would come to the home and teach my husband specific exercises. The nurses were caring and professional in every way. Medicare covered eighty percent of the VNA expense. The deductibles in our supplemental insurance had not been met at this point.

I learned how to prepare special foods. A home health aide came every day to help with showering. We found someone to build a ramp to our front door. Before long we were using a wheel chair all of the time.

I had information about The Gathering Place Adult Day Center in Brattleboro and after visiting there, decided to sign up my husband to attend twice a week. The Connecticut River Transit picked him up at our house and brought him home. This was a wonderful service to have for about four months. He enjoyed his time there and was painting and participating in group activities. That gave me time to shop, work in the yard or just be alone. I knew my husband was



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trying his best to help himself and I know he knew that I was tired and he wanted to give me some time alone.

We could still communicate about the day-to-day activities. But we didn't get much sleep because we got up several times in the night. Finally, we hired help to come for one overnight each week. We paid for these services out of our pocket. (This might not be the case for everyone who wants to attend adult day.) Our daughter, son and son-in-law were also helping in many ways.

Although the services were very helpful and necessary there now were people in and out of our house all the time. Sometimes we would have four or five visits and many phone calls during the day. We were trying to complete the exercises that had been suggested by the speech and physical therapist. Furniture had to be moved so the wheel chair could fit through the house.

Special food needed to be prepared to help prevent choking. We were both anxious when he choked. We knew that if he ingested food into his lungs he would get pneumonia. This was all becoming overwhelming, and everyone was getting more and more tired. I had to do a lot of lifting. It was difficult. We absolutely needed all the help we could get. The nurses were always helpful and kept telling me I was doing a good job. It was our family's wish to make my husband's life as normal and pleasant as possible.

We frequently had visits from our clergy and friends for which we were thankful. Our daughter and her husband came over in the evenings to help out and visit. It became apparent that no one person could give this much care, particularly if that person was an elderly spouse or had health issues of their own.

On one visit the nurse called 911 because my husband had become very weak and she suspected that he was dehydrated. This was the case and he was in the hospital for a week with pneumonia.

When it was time to bring him home from the hospital, he needed a hospital bed, a Hoyer lift for transferring in and out of bed and oxygen. How all of these items fit into the bedroom was a puzzle. We had to keep a sense of humor through all of this. Thankfully, my husband was always pleasant and thanked everyone for all they did for him.

The hospital discharge planner and the doctor at the hospital talked to us about going on to Hospice Care. This was a very difficult decision because it was admitting that we were heading toward the end of life.

To make the best of it we decorated the room for Christmas and had soft lights and music in the bedroom. It was a very pleasant atmosphere despite the wheelchair, lift, and oxygen tank and hospital bed. The hospice nurses came every day, the hospice doctor talked to us at length about the pain medications that we would be using. Hospice was on call 24/7. I did call several times and the nurse was calming and helpful. A hospice counselor came to talk with the family about end of life wishes and concerns. They were caring and compassionate. On two occasions a hospice volunteer sat with my husband but I was nervous to leave him. I thought



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he might be frightened to be alone with a stranger with no family around in case of an emergency.

Between myself, our caregiver, daughter, son, and son-in-law we shared the round-the-clock care giving. It was a difficult six months mainly because things just kept changing so quickly, but hospice gave us lots of information so we could help my husband and also know what to expect as his body shut down. We made his end of life the best we could. Hospice came right away when we called. They stayed with us and were there to pronounce his passing. Hospice also sent a counselor to visit with us the next day.

I am thankful that he could be at home and would wish that for most people. However it is all consuming, tiring and takes many helping hands. This would be impossible for many families. It would also have depleted most of our savings without Medicare.

To give you an idea of the cost of all of this I broke it down into the following approximant numbers:

Private care and Adult Day Care	\$17,000	Private pay
Medicare for VNA/Hospice	20,297	
Medicare – Hospital	8,942	
Medicare – Ambulance	1,000	
Medicare - Doctor and Lab work	2,822	
Equipment	<u>1,700</u>	Private pay
Total	\$51,751	