

My name is Peggy Gulotta and I am here today to tell you the story of the last months and weeks of my husband's life. My husband, Dr. Carl Gulotta, was a physician with a specialty in

internal medicine. I am proud to say that he practiced for fifty years and didn't have one lawsuit filed against him.

The years from 1995-1999 were very difficult years for my husband and myself. We both had medical complications-Carl's were more severe, as he required bypass surgery, was diagnosed with prostate cancer and lost his ability to speak, something we found out later was the result of Alzheimer's Disease. The effects of one treatment after another seemed to make things much worse. The really difficult one was the radiation treatments for the prostate cancer, which affected his bowels. That problem paired with his confusion made it very difficult to manage his care. We were able to get help and really managed quite well using a variety of resources that included day centers for Carl.

During this period, Carl and I got into a fairly bad car accident and the accident created a permanent disability for me. When I required multiple surgeries and a long rehabilitation period, I had to make the decision to place Carl in 24 hour care. In many ways this was a wise decision for both of us. He adjusted well to it and we actually were able to spend time together. We were fortunate to find a small group home that specialized in the care of Alzheimer's patients. It was a lovely homelike environment that provided supervision and care without feeling institutional.

But this is all background to the piece of the story I am really here today to tell you. What I most want to share with you is a description of the final few weeks of my husband's life. It is not something that one often talks about, because there is nothing worse than the loss of one's spouse. However, the last few weeks of my husband's life were very good in that we found services-services that we didn't know existed--that made all the difference in the world to my family.

As my husband's Alzheimer's progressed, he began to experience a symptom that I later learned was very common in advanced Alzheimer's patients--difficulty swallowing. Carl's final hospitalization resulted in a conference that stated that without tube feeding Carl would likely live a very short period of time. Hospital physicians suggested a skilled nursing unit where he could be kept comfortable. But, years earlier, in his living will, Carl had made the decision not to have a feeding tube so we all knew what Carl's wishes were on that.

Fortunately, the representative from the Alzheimer's group home where he lived introduced us to another option--hospice. All we wanted as a family was his comfort. I just wanted him to be able to go back to the place he called home and we learned that was possible with hospice care. It was hospice that allowed our family to share my husband's dying process with him just as we had shared his life with him.

There were several things that were most important from the time we knew that Carl was really dying. First of all, I was able to contact all of my children and allow them the chance to be with Carl as he lived through his final days--they were all around him as he died. Carl's brother--a retired judge--was also there with us. Another was the fact that my husband had a choice about where he could die and he truthfully had a say in that decision--even in his confusion. Where he was restless and uncomfortable in the hospital he relaxed in his familiar environment. Also, we were all encouraged by the hospice folks to cry whenever we felt the need to--even my sons. I said I didn't want Carl to see me upset. They told me that Carl might be more upset if he didn't see how much I cared. We received support and encouragement. We were introduced to new ideas about how to interact as a family and especially with Carl. Most important of all is the fact that I can tell you that my husband died in my arms.

We were given an opportunity to tell him goodbye and to see him go in a manner that was comfortable and peaceful. The medical needs were met, he was comfortable and peaceful, and he was not in pain. We were able to be together as a family one last time. It was a process that I didn't know existed and I think most people don't know about it either. It becomes a very natural part of the life process. We need to learn a way to share the process so that everyone has access. People should know that there is a way to finish life with comfort, dignity, love, family and peace. It is equally important to know that the services should not end with the memorial service. I know in my instance, Carl died last November and people from the home where Carl lived are still in contact with me. This is what makes a difference in difficult times for those who leave through death and for those of us who remain in life.

Thank you for giving me the opportunity to testify today. I hope my comments can make a difference for others who face the same situation.