

# Best Quality of Life for One Another Should Be Our Abiding Concern

by Ruth Lofgren

*Author's Note: For the past few months I have been working on a lobbying concern. I've contacted the Friends Committee on National Legislation and find that it will be slow to get a new item on the lobbying agenda. Perhaps, Voz readers can help.*

I think that during the next year or two there will be a window of opportunity to deal with a cultural taboo that is costing healthcare a fortune and ignoring quality of life at the end-of-life for patients! With the present chaos come opportunities!

Within the next few years, as the safety nets of our current world: Social Security, Medicare, Medicaid, Affordable Care Act, etc. are being challenged and modified or dismantled, I hope we can lobby to expand our world view by challenging the taboo against talking about death and inserting hospice into the end-of-life options that everyone knows about and understands.

Hospice is a special concept of care designed to provide comfort and support to patients and their families when a patient is terminally ill or at the end-of-life. This palliative care is covered by Medicare and Medicaid and most private insurance plans. Most hospice care is delivered at home or in a home-like hospice residence.

Growing up I had never heard the word, hospice. Even when I had a Ph.D. in microbiology and taught at the University of Michigan's medical school, in the 1950s, hospice was not a part of my world view for end-of-life care.

After my father died in 1964, we remodeled my brother's house to create an apartment for my mother. This brother was very concerned for my mother, but it was difficult for his young wife and family. By 1969 my mother had round-the-clock nursing care. Then she was moved to a hospital where she received intravenous medication. (My mother, a proud woman who had been a community leader hated every minute of her existence in this facility.)

When my youngest brother saw her with all the tubes, etc. he told the doctor, "You take those tubes out or I will!" The doctor said, "If we remove the tubes, she will die." My sister who was a public health nurse, said, "Of course she will. She is 80 years old and in pain." My 3 brothers and my sister agreed that the tubes should be removed. I was flying in from New York. The doctor worried that I might not agree. He removed the tubes and my mother died. Of course, I agreed.

Why had my mother's quality of life not been considered by any of us in these last years or even in this last month of

life? Because, our world views were incomplete. We all feel familiar with the First of LIFE: Birth, with the Middle of Life: Development and, of course we know about the End of Life: Death. But, while we have strong opinions about

Right to Life, Pro-Choice, Prenatal Care, etc. for the First of Life, and we have lots of opinions about Education, Growth and Development, Health Care, Job Training, etc. for the Middle of Life—most of us choose not to plan for End-of-Life, not to think about it until necessary, and are uncomfortable talking or even thinking about it. Our World Views don't include hospice. They should!

What I propose is that each of us prepare to lobby our congressmen/women to broaden their developing views of healthcare to include hospice and quality of life as significant options in plans for end-of life. Also, we need to take time to consider our own attitudes and our plans for end of life. Do you know about hospice? Or will

you, like so many old folks who have had an accident, wake up to find themselves in intensive care in the hospital?

Friends Committee on National Legislation (FCNL) has a great lobbying program, The Advocacy Corps, etc. I hope these young people can be informed and be prepared to lobby Congress, especially those who are working on healthcare legislation. I have submitted the request for lobbying on a place for hospice in our end of life health care options. Quality of life is important at all stages of life.

I hope to contact medical schools with the request that they reexamine their curricula to see if hospice has a place in their end-of-life discussions with medical students. Over the years, I hope to see our world view broaden to include hospice.

*Bio: Ruth Lofgren, a supporter of the Esperanza recently completed 100 years of life. She was involved with the Friends Committee who met at the old Esperanza building on S. Flores. She remains active as an environmentalist and human rights advocate.*

