



Thoughts on The End-Of-Life Doula Movement

by Barbara Karnes, RN

I started as a hospice nurse in 1981 after spending several years trying to learn how to care for people who were dying. There just wasn't any material about end of life. People generally died in the hospital, in a private room at the end of the hall, alone. No one was there, no one saw how death came. If and when a person was in their home, dying with family present, the family brought their own fears and misconceptions about death and generally just had "horror" stories to tell about what happened when Dad died. Hospice was the "new kid" on the block saying, "We can support, comfort, and guide people and their families as the end of life approaches. No one needs to be alone anymore during this life moment."

It was from my experience being a hospice nurse, whose goal was to be with the patient and family during the months, weeks, days, hours, and then at the moment of death, that I began to actually learn about how people die.

I saw that there are just two ways to die, gradually or quickly. Quick death is an accident, a heart attack, suicide. You are alive one minute and dead the next. Gradual death occurs either from old age (your body wears out and then dies) or from disease. Gradual death has a process to it. If it just happened it would be a quick death. Knowing that process gives us an opportunity to guide and support a person and their family.

Jump forward 38 years to today. Hospice care is no longer a new concept. It is reimbursed by Medicare and insurance companies. It has regulations and requirements of care. It has become a viable part of the health care system. Where end of life care was outside of the medical model in the '80s, providing care that wasn't being addressed by healthcare, now, in 2019, it is very much a part of our medical system.

With hospice being absorbed into the medical model changes to the idea that the

patient and families were not to be alone at the moment of death seem to have diminished. In the '80s I was not regulated by wage and hour restrictions and consequently, stayed many a night with my families as death approached. Now most families are alone with their loved one at the moment of death. There are just too many regulations to justify a standard policy of being with the family during that undetermined time.

From the late 1970s to the present a void has developed in hospice care. That void was once filled by presence. We were present for longer periods of time.

We, as hospice staff, were there, not as paid shift workers but there often for hours at a time as death approached and arrived. Not so much anymore. That void, that lack of attendance at a most critical time, has brought forward a new concept. New caregivers in the name and form of End-of-Life doulas. *Hospice Transition* volunteers, and *No One Dies Alone* volunteers have evolved.

As I look back on my service in end of life care, I see my beginning as a staff nurse was what today is considered an End-of-Life Doula. My care was to support, guide, nurture and be a presence during the months, days, and hours before death. I didn't come with a lot of medical services (pain management when appropriate and basic physical comfort care was what was provided). I came with time and touch, that was my presence. I came with "you will not be alone during this journey" and "I can't make this life experience go away but I can walk with you through it."

The End-of-Life Doula movement today is akin to my 1981 moment, a beginning moment, an addressing a need that is not being addressed moment. The National End of Life Doula Alliance, NEDA, is the organizing element that will give this idea, this concept of care, stability and credibility. NEDA will give consistently to this emerging career. It will take the individuality of the various doula training programs and tie them together in a standardized goal of providing end of life care, end of life guidance, to the community.

I am pleased to be involved in this new movement. From my many years of working with end of life I have come to see that families as well as patients still bring fear and lack of knowledge to the end of life experience. It is education, support, and tender

guidance during that time that brings comfort. It is the presence of someone who understands that what is happening is not pathological, is not bad, that turns an otherwise frightening experience into a sacred time and creates a sacred memory for the family. That is the goal, the mission of an end-of-life doula.

— Barbara Karnes, RN

Barbara Karnes is an internationally respected speaker, educator, author, and thought leader on matters of end of life. She is an award-winning nurse and end-of-life educator. In 2018, Barbara Karnes has received numerous awards, including being honored by the National Hospice & Palliative Care Organization as a Hospice Innovator. Learn more about [Barbara Karnes, RN here](#).