

Hospice isn't spelled "h-o-p-e-l-e-s-s"

There is **Hope** in **Hospice**

By Bill V. Cox M.Ed., SSW

©2008

As a worker in the field of hospice I have often felt that individuals and families who are facing a terminal illness diagnosis have a sense that admitting a hospice provider into their lives is paramount to giving up to death, that to receive this service is to give up on life and participation in it.

I was reminded of the other side of this today while I was serving one of my patients whose delight comes from serving others in spite of his heart problems and difficulty in catching a breath. Before I took him grocery shopping we had to stop at a nearby facility to drop off what I called his "care package" to a woman who "is worse off than I am because at least I have some help to get things done." It was a package of liverwurst, three bananas and two avocados, all from his groceries purchased earlier in the week with the help of his hospice company. He found a way to serve and be involved in spite of his own weakened state.

Another woman wishing to remain involved in her community of faith insisted on remaining active in visiting a few of her neighbors once a month. This was in spite of her heart disease that left her breathless and a walk that was more of a shuffle and left her vulnerable to falls. A friend of the patient has made it possible for her to remain a part of her congregation of faith and connected to her neighbors.

A dear friend of mine, whose mother's kidneys were functioning at a mere 20-30% and had been in and out of the hospital, was approached about receiving hospice care. The idea was being considered until she spoke with her sibling who made the comment, "you don't want to be on hospice, that means you are going to die." Immediately the idea of getting that service was denied and rebuffed. She was not ready to die but had decided that dialysis was out of the question and that no medical intervention would be sought if things got worse. She was not going back to a facility.

The major requirements for receiving hospice service are met but her attitude keeps her from participating. She has returned to live her days at home and the family struggles to provide the support that she needs to maintain an independent life style.

When one is admitted to receive hospice service it is not about giving up; it is not about being on your death bed in order to get the support for all parties involved. It is not about giving up on life. Most of us think death is something that will happen to someone else and when we are given a diagnosis of a terminal illness it brings us face to face with our own mortality. How we respond to such a challenge is very individual and personal. Mortality appears to be so present and physical, while death presents itself as so permanent. It is difficult to stand on the cusp of death. Hospice is about bringing in resources to support your loved ones and you during a very difficult time. Hospice is a word that has “HOPE” contained in it even though it will require work to find it.

A dear patient of mine whose heart disease made her life difficult made the most wonderful caramels you could wrap your tongue around. Everyone who visited her got to take a few home with them as she kept a supply in the freezer. She had a gift to share and even though cutting out the wax paper and stirring the ingredients to just the right consistency required a great deal of effort she found a way to share. Her depression often assaulted her sense of having a purpose in life but in spite of the difficulty she was a participant.

Hope can be found in hospice but its discovery comes in a variety of ways and often with a will to find purpose. A dear friend whose life is full of treasured stories requested of me to listen to his memories of growing up in England, the Second World War, and finally the migration of his young family to America. He is 96 and his brain cancer is taking a toll on his body. His pants cling to his hips in a most fragile way. But just this week he remembered some songs he had learned as a teenager and had performed in front of his peers in a youth organization. He reviewed them with me and we decided that they needed to be recorded. The next day I brought equipment to capture his remembered treasure. There was a spark in his eye that I had not seen in a while.

Once the recorder started, he was like a new man. With energy and emotion he recited the lines he could no longer sing. What a delight to see. For those few moments he was transformed and carried back to a long ago era when he was full of energy and life. Many of his family had not heard these lines before and now we had them captured. For those moments he had purpose, he had a place in time and someone to share with. That day there was hope in his life in spite of the ravaging disease.

When one takes **hope** out of **Hospice** all one has left is the letters **s-i-c**, which is another word for sickness. Finding hope in illness is not an easy task and everyone will struggle to find the divine in their challenges. Having a purpose in spite of our trials is a task worthy of our energy. Finding purpose in spite of our terminal illness gives meaning to our life. When we invest in life, we can keep hope alive in spite of our frail mortality.

My wife and I have a dear friend, Vickie, who survived breast cancer. Shortly after her fifth anniversary she received word of another cancer that has no cure at this time. She enrolled in treatment and is currently receiving an experimental drug every twenty-one days. She has seen the cancer recede in its aggressiveness but the outcome is uncertain. In spite of her terminal illness she is reaching out to another woman, Joan (not her real name). This mutual friend is also a breast cancer survivor. But her story has a different spin. After her battle with breast cancer she developed ovarian cancer and during treatment it was discovered that she had leukemia. The medical world has sent her home with what some would call a death sentence. Our friend, Vickie, has taken time to give of herself and talk to Joan about the struggle with cancer and facing mortality. She has gotten out of her own pity and has sought to support another in her despair and grief and sought to give Joan hope. Joan says she is not ready for hospice. But I believe she needs hope and one of the best sources of hope is to find a hospice provider to support her and her family in this difficult time.

The service provided by hospice covers the wide range of human necessity including medical, daily living needs, emotional, spiritual and social. The medical needs are supported by the CNA whose attention to daily living can relieve the burden on

family members. Hospice addresses medical concerns through visits by a nurse and doctor. This greatly lightens the work load on those who are providing care. The emotional and spiritual requests for help are available with the support of a chaplain and a social worker on an as-needed basis. These professional roles are augmented by an additional member available to the patient – a volunteer, who provides companionship and a bright spot in the day. Social needs are supported by all hospice team members and this adds quality to an individual's remaining life. The time and talents of a hospice team do not remove the effects of a terminal illness, but they do lighten the burdens on families who allow others to assist them. There is **hope** in **hospice**; hospice is not spelled h-o-p-e-l-e-s-s.