The first paragraph in the hospice volunteer manual is one of the most concise and to the point description of what hospice represents:

Centuries ago the term “hospice” described a place of refuge along the rough, rugged paths of the Swiss Alps. In these shelters, weary and wounded travelers found rest and loving care. Although hospice today is a system of care rather than a particular place, it still provides support, respite, and relief to weary travelers: those walking the path of a terminal illness and the loved ones who suffer with them. (Nowack 1)

I had never heard of hospice when my mother was battling illness. For three years we had been doing different tests trying to find some reason for the problems Mom was experiencing. Finally the tumor that was on her liver became large enough to see and indicated mom had cancer. The hospital was pushing surgery and cancer treatments. Mom was very certain what she wanted and voiced it, “LEAVE ME ALONE”!

I knew we needed help and that is when hospice came into our lives. Mom went to a Hospice Home where she had a beautiful bedroom, TV, radio, common living room with a large kitchen that was stocked with food and staff to help her. She was taken care of like a queen. She was comfortable and had people caring for her when I wasn’t able to be there. The Hospice
Home emphasized a family atmosphere, which afforded comfort for all the family when visiting. Mom was in charge of her life and she loved it. Within two weeks she had passed away, but we had enjoyed our time during those last weeks. The family was able to accept her passing easier, since we had quality time together. Hospice is not a hospital atmosphere, but a much better alternative to surgery that would not cure and treatments that might cause more pain.

“My Gift: Myself,” the training guide for hospice volunteers, tells us that Hospice care is a philosophy of care that accepts dying as a natural part of life. When death is inevitable, hospice seeks neither to hasten nor postpone it. The hospice movement in the United States is based on the belief espoused by hospice physician Dr. Josephina Magno, “If we cannot comprehend why we must die…and cannot control when we die, we can at least to some extent control how we will die” (qtd.in Nowack 5).

As mentioned above hospice will not hasten nor postpone death. Anyone with a terminal illness can be referred to this care and then an evaluation by a patient care coordinator will be set up. The coordinator will need from the attending physician a diagnosis of terminal illness, with a life expectancy of six months or less, acceptance of the concept of palliative care (to alleviate without curing). In addition, a patient must have definite and definable needs, a committed primary care provider, a physician who is supportive of the hospice concept, and a place of residence that is within a hospice service area. Then an interdisciplinary team makes the decision of acceptance into hospice services.

The goals of hospice care are to provide a good quality of life for the dying patient and to help the patient and his/her family to cope with the approaching death. This system of care is focused on the individual and the involved family rather than on the disease. Once the patient has been accepted, the staff provides for the whole person, emotionally, physically, and
spiritually. Restoring dignity and a sense of personal fulfillment to the dying by listening, caring and allowing choices. Patients have the right to choose to live the conclusion of their life as naturally and comfortable as possible.

To accomplish this type of care, there is a team that shares the responsibilities of attending to the needs of the patients and their families. The hospice team is comprised of; a medical director, the patient’s primary physician, nurses, social workers, pharmacists, chaplains, home care aides, volunteers, and therapists. This team meets by-weekly to discuss ways to best meet every hospice family’s needs (Nowack 1).

In an article featured in The New Sentinel, the comfort for the families of patients hospice provides is shown in the care that Lynn Baker and his family received. Lynn lost his father and mother in law on the same day. His mother-in-law had a reoccurrence of breast cancer, which had spread to her liver and bones. She was admitted to a hospice inpatient facility. Diagnosed with lung cancer, Lynn’s father was living at home until his cancer intensified and he was admitted to the hospital. Lynn requested his father be transferred to Hospice Home. He saw the way they cared for his mother-in-law and definitely wanted his father there, not in the hospital. Lynn felt that the staff treat you like family and make the patient as comfortable as possible. Hospice provides a serene environment that focuses on caring for the families’ loved ones (1A 4A).

Guidance for those who are preparing for death is a role hospice fills. Knight Ridder Tribune published an article on Barbara Wein, diagnosed with ovarian cancer she decided to fight. Barbara tried surgery, chemotherapy, and then a second round of cancer therapies. Six months into the diagnosis, she realized she might not beat it. The medical team discussed the physical effects, but they were reluctant to discuss the emotional impact.
She wanted to live the rest of her life with hope, but needed guidance. She got progressively sicker and required help from others for her care. The only treatment the doctors offered was a course of “salvage,” very aggressive chemotherapy. This caused weeks of nausea, vomiting, and continual pain. She couldn’t sleep. Anxiety and depression consumed her and she couldn’t think straight. Sent home after 10 days in the hospital, she was surviving with an intravenous feeding tube. As death drew closer, Barbara nearly lost her will to fight. “My symptoms had taken over my life,” she later said. “I wanted to die” (qtd. in Milch 2). Knowing she didn’t want to die this way, Barbara researched alternatives and discovered hospice. She then called her local agency, asked her physician for a referral and was admitted.

With hospice care she found solace and guidance. She was given medications that controlled her pain, nausea, vomiting and depression. She was able to sleep and rest, and over the next days, she had many meaningful talks with family, friends, and staff, exploring what her goals were for the rest of her life. From these were derived a plan of care to maximize her stamina while maintaining her comfort.

Now with rest, comfort, and the support she needed, there were some things she wanted to do. Barbara elected to resume getting her nutrition intravenously. She took a number of brief road trips…a last time to her home, to a lighthouse and visits with friends. Then, she decided it was time to stop the intravenous fluids. Five days later, Barbara did beat the odds. She died the way she chose (Milch 2).

Barbara found her alternative. It was a good choice for her, but there are reasons why hospice is not given as an option to patients. Hospice is not an alternative that physicians and families always seek, because of medical ethics and lack of knowledge of the care program.
The “curing” approach to medical ethics argues that the role of medicine is to heal. This is in harmony with the person’s right to life. The conscientious physician sees death as a defect. Physicians attempt to conquer injury and disease with whatever technological weapons are available to them, and there is always the possibility of a lawsuit to consider if they waiver in seeking a cure. Malpractice insurance is so costly today that it behooves any physician to order every conceivable test and tube and to attach every available monitor in order to escape a legal challenge that begins with the questions, “But why didn’t you do X” (qtd. in Mellert 3)?

In contrast to the above approach, the caring model of medical ethics differs in that the consequences of the action determines its morality, rather than the action itself. The focus of ethics changes from saving or not saving the patient, to saving or relieving the patient’s pain. So the physician becomes a medical consultant, not a healthcare provider. Now the patient is informed and he/she is responsible for making the choice of how the physician will proceed.

There are walls between the curing and caring that separates patients with disease from those with “terminal illness.” Medicare rule: In order for you to get hospice care, a doctor must determine that you will probably die within six months. Doctors have a difficult time predicting when death will occur. Patients and their families balk at receiving an official death sentence and living on a kind of medical death row for six months, even when they know they have a lethal disease (Trafford HEO1).

Because of the above rule, too few people with severe illness get the supportive care they need to manage symptoms. More than 80 percent of people who die in the United States are on Medicare. And most die of a chronic illness where they would benefit from relief of symptoms and supportive care in the months or years before death. But only 20 percent get any hospice care, and most for only a few days or weeks.
The general public has an awareness of hospice and is receptive to the concept, but the majority lacks the specific understanding and knowledge to gain full access to hospice’s benefits. People are reluctant to broach the subject of death, even with a loved one facing a terminal diagnosis. Physicians also are reluctant to discuss the specifics of death with their patient. They lack the comprehensive medical education in end-of-life care that would lead to more referrals and earlier referrals to hospice. (qtd. in Delivering 19)

The goal of easing people’s suffering is not an end in itself. The aim of comfort is part of a larger objective: to help terminally ill patients live as full a life as possible until they die. This is where hospice departs both from traditional medicine and the advocates of assisted suicide. Hospice, by working with the emotional and spiritual aspects of suffering, is challenging the medical community to reexamine its priorities. Hospice care helps liberate patients from the afflictions of their symptoms so that they can truly live until they die. (Loconte 5)

Having been both a recipient of hospice care and a volunteer for them, I know the weight that hospice can lift from the shoulders of a caregiver. The feeling of love and caring that is extended to patient is very powerful gift. When all the unfinished lose ends, spiritual, emotional, financial, and physical, are finished. The fear passes and living replaces it. This time at end-of-life now can be full of sharing and peace, more than you can ever imagine. The hospice care, gives the gift of living to a person who is tired and has given up. They show them that there is an alternative to pain, suffering, and loneliness. No one is alone with hospice.
Works Cited


