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Defining Moment



I like educational settings where interesting ideas grab me by the collar, confront me with opportunities to learn and solve problems. But taking classes in volunteer hospice training seemed like an entirely different undertaking. Death was the ultimate topic. Most people don't even want to discuss death briefly. To take a whole course on people dying seemed strange. I was curious about how this subject would be taught. The class schedule included twenty hours of hospice training for certification. Some institutions require fewer hours.

My first class consisted of a dozen students from varied backgrounds. All were as eager as I was to learn what hospice entailed and what our future responsibilities might be. Looking around the room, I wondered what had motivated others to come. Had they been listening to the universe, too? Everyone had questions that needed answers. Our teacher reassured us that concerns would all be addressed as the class progressed. After a warm welcome and introductions, she introduced the history of the hospice movement. I learned how attitudes about aging and dying evolved through the years and led to a new approach to caring for the terminally ill.

Americans' tendency to strive for longevity, even when people are in the process of dying, is one reason the hospice movement in the United States has been slower to advance than in Europe. The hospice philosophy embraces support of the dying and their families through high-quality patient care physically, emotionally, socially, and spiritually. Because all of these areas are interwoven in patients' lives, they must be addressed as a unit during patients' treatments. Input from patients and primary caregivers involved in the plan of care is welcomed and respected. Hospice beliefs must be understood and accepted

by all persons involved in hospice care, including patients, medical personnel, and caregivers.

Hospice care refers to non-aggressive treatment of patients who have been diagnosed as terminally ill. It is available for individuals who have a life expectancy considered to be in months, usually within six months. Cases are subject to renewal after the six-month period. Hospice neither hastens nor postpones death, a natural part of living. The primary focus of hospice care is to provide support and relief for patients. Palliative care, an approach for treating incurable illnesses, can be given no matter how long a patient is expected to live and while doctors are still seeking a cure. Relieving pain and other symptoms, palliative care extends the hospice philosophy to a larger population that can benefit earlier in the illness process. Ideally, it precedes hospice care.

I learned that hospice services should start as soon as the terminal phase of illness begins. Anyone can make a hospice referral, but doctors write the orders that begin official hospice care procedures. Patients, or those legally in charge of making medical decisions for the patient, make the decision for beginning or ending hospice care. Depending on their health progress, patients can be discharged or readmitted by the hospice team.

Patients with various kinds of illnesses, including AIDS, cancer, stroke, heart disease, dementia, and kidney disease are eligible for hospice care. Services are provided to patients whether they live in private homes, apartments, or group facilities. Medicare and most insurance plans pay for hospice care and cover people of all ages. Hospice pays for medications and provides supplies and equipment related to the hospice diagnosis.

Dying is a natural part of life, not something to be dreaded or feared. It is a process in which the body slows down and is a unique experience for each person. Several speakers joined the class periodically to share their expertise and answer questions. They gave interesting information about various aspects of hospice care such as the

use of equipment in assisting patients. They described signs of dying such as decreased desire for food or fluids, increase or decrease in pain, or increased weakness in terminally ill patients.

The basic role of a hospice volunteer is to enhance the quality of life for patients during their end-of-life stages. Patients should be comfortable. Their bodies should serve as resting places for peace, so their deaths will be positive experiences. This allows them to know dignity during this critical time in their lives. Volunteers provide companionship and assistance with normal tasks such as letter writing and wheelchair rides. Another important service volunteers provide is advocacy for patients when they need it. For example, if a patient has not been fed or cleaned properly, a volunteer brings this to the attention of those who can correct the problem.

Fortunately, a volunteer does not work alone. A hospice team, consisting of a medical director, nurse, certified nurse aide (also called CNA or certified nursing assistant), social worker, dietitian, chaplain, and volunteer coordinator, is available to serve patients. Working together, members of the hospice team provide support in decisions regarding patients' total treatment during their last phase of life, including the implementation of patients' advanced directives. These are documents that give healthcare providers directions regarding patients' treatment preferences under certain circumstances. The hospice team provides not only medical support, but also social, nutritional, and spiritual support for patients and their families.

In order to work best with the team, I needed to know the various roles each team member played. These were explained as the class unfolded. The medical director manages clinical care. Volunteers work directly under a volunteer coordinator. She manages volunteers through recruitment, record keeping, training, assignments, and recognition of their contributions as volunteers. Nurses, with the assistance of nurse aides, work closely with the medical director and other doctors to facilitate patients'

care. Dietitians address food-related concerns. Social workers help patients and their families with illness and death concerns. Chaplains assist with spiritual matters.

I listened to everything being said, wondering if my own philosophy matched those of the hospice program. At a personal level, I did not fear death. I assumed it would be a transition to a life better than this one. In that sense, I certainly didn't dread its coming. But a terminal illness has the potential for being a very difficult and painful journey for some people. Becoming a part of others' death journeys on a long-term basis presented another perspective. I had experienced this already with Jake and Sam. My ability to empathize with future patients would require frequent and intense use. Because I know I am a strong person, I felt certain I could succeed in my efforts to provide needed support. However, I still had a lot more to learn.

Class members were told to use the words "death" and "died," instead of euphemisms like "eternal rest" and "passed." As a child, I had noticed how people used indirect words when they spoke about death. Pets were "put to sleep" or "put down." Even jokingly, death was referred to as "kicking the bucket." These terms are still used today.

Society sends a strong message that dying is not a subject that should be embraced. Death is the elephant in the room that we pretend not to see until it sits heavily in our unfamiliar laps and pokes its intruding trunk in our faces. One certainty in life is that everyone will die. Many people refuse to say actual death words because of emotions the words generate. Others refuse to discuss death, particularly their own, even when they are well. Clouds of discomfort hover over death discussions. Fears center on how they will die, what happens after they die, and how their lives mattered. I knew I would have to analyze my own feelings thoroughly if I expected to help others.

During the class, I learned about various religious practices related to death. One of the beauties of diversity is having opportunities to become familiar with the cultural

and spiritual practices of others. Ongoing evaluations of patients' spiritual needs foster greater understanding during interactions with patients and their families. Religions have varied practices for responding to death. Some religions oppose last rites at death, while others welcome these rituals. In Native American traditions, religious rituals and urban medicines differ among tribes. There are religions that encourage "laying on of hands," along with medical therapy, in order to fully treat illness. Other religions state there is no life after death or oppose organ donations and cremations. The volunteer's role is to be respectful of patients' religions. At no time should the volunteer attempt to force personal religious beliefs on patients.

An important part of the class familiarized volunteers with disease processes and treatment of terminal illnesses. This included general knowledge about nutrition, cancer, heart failure, AIDS, multiple sclerosis, renal failure, and dementia. Communication techniques, procedures for positioning patients, and use of oxygen and medical equipment were also explained. Much of this information was new to me. Having a broad understanding in these areas gave me confidence. I knew this information would be helpful in my dealings with patients and conditions encountered later.

One aspect of service that really concerned me was the depth of care I would be expected to provide patients. While I looked forward to talking, writing letters, reading, and participating in other social activities with patients, I had reservations about performing intimate procedures related to hygiene. Because questions and discussions were encouraged, I mentioned my apprehensions during the class. I was relieved to learn that bathing, diaper changing, and other intimate patient care would be performed by others.

Physical concerns were only one component of care for hospice patients. Psychosocial issues of patients and their families were also addressed. Knowledge of pending death can cause depression, stress, fear, and anger demon-

strated in numerous ways, depending on how people cope with their feelings. Previous family dysfunctions could escalate and aggravate situations. Relatives and friends might interact with one another and patients in ways that require guidance from a third party such as a volunteer, who acts in the best interest of patients. Problems related to finances, guardianship, and other legal matters can add to growing mountains of pressure that plague patients and families during this time. Hospice is also available to assist families during the bereavement process after patients have died.

The volunteer can use resources of other members of the hospice team whenever help is needed. Working as a unit focused on quality in patients' lives, they can solve problems. In order to sustain communication with team members, a volunteer must turn in a brief, confidential, written report each time patients are visited. Knowing that this supportive structure is available helps the volunteer maneuver through the maze of successful patient care.

While advocating for patients, the volunteer must always consider personal responses toward them. Honest introspection regarding choices in decision-making relating to patients must be done on a regular basis. Knowing how to act in the presence of patients is important. Treating them with the same respect one would want in their position is a good rule to follow. Without realizing it, a volunteer can become an enabler of negative behaviors in patients, or even a martyr by focusing on patients' needs at the expense of her own. Using good common sense and being positive can go a long way in establishing harmony.

A volunteer must maintain good personal hygiene and health while caring for patients. This includes wearing gloves when necessary to protect both herself and her patients, not being around patients when she is ill, and getting annual tuberculosis testing. Hepatitis shots can be taken as an additional precaution. Hand washing is considered the most effective method for preventing infections. Two verses of "Happy Birthday" are considered a satisfac-

tory time estimate for washing hands. Good health for the volunteer includes coping with personal feelings when patients die.

After several meetings, class members knew one another on a more personal basis. Opportunities to joke, express concerns, share food, and encourage one another had helped us grow into candidates motivated to make confident decisions about committing to hospice volunteer service. Several classmates had previously been involved in caring for dying loved ones. For some, their positive interactions with hospice volunteers had been catalysts for their decisions to become volunteers themselves. All were very open about sharing their inner feelings regarding their personal involvement as caregivers.

On the last day of class, I realized that my experiences with Jake and Sam had been part of a larger plan that had brought me to that point. They had taught me the importance of being with patients and advocating for them. The training class taught me what I would need to do in my role as a future volunteer offering support and assistance to patients and their families. I felt comfortable making a commitment.

I was given a choice of serving patients in nursing homes or in their own homes. Although most patients would prefer to die at home, the probability that more terminally ill patients will die in nursing homes is increasing. I chose to serve in nursing homes because I suspected terminally ill patients there might feel more isolated and because more medical personnel would be available if I needed immediate assistance.

Volunteers sign a yearly commitment form with the hospice program and are evaluated annually. Ongoing meetings, in-services, and newsletters for volunteers are also available to give them continuing support. November is National Hospice Month, a time when hospice staff, volunteers, and supporters are celebrated, along with the mission of hospice care.

Hospice could not function without the dedicated services of thousands of volunteers across America. Volunteers add life to the decreasing days in the lives of patients. I looked forward to being a part of this caring group of people who bring comfort to others during their final stages of life. I had found my song and was ready to sing.