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1. What's It All About?

Concepts in End of Life Care

Just the facts, please...



A woman stands at the bedside of a dying man. Her eyes fill with tears as he, her husband of 65 years, takes his last breath. She begins to speak softly to him, gently touching his hands, running her fingers over each of his, telling him how much she has loved his strong hands and how he used them to provide for her and for their family. She is saying good-bye.

She feels deep sadness, but also a strong sense of satisfaction. Everything that could have been done for her husband's comfort and for her support has been offered to her. She realizes that this transition in her life could have been much different if she hadn't had the loving support of her local hospice team. Especially her beloved volunteer, who stayed with her in the long hours before her husband's death.

Without the presence of knowledgeable, skilled, and dedicated end of life care givers, she would have been alone in a frightening and unfamiliar landscape. She would be facing profound loss and

difficult medical decisions without support or guidance.

Death comes to each one of us, someday, somehow. None of us knows when that time will come. Some of us plan for it and some of us don't. Some of us think about the implications that a terminal illness might have on our plans, hopes, dreams and relationships. Some of us prefer to live in the moment and leave those possibilities in the realm of the unknown until they actually occur.

And occur they will. More than 5 million people die each year. One in ten of those deaths is from cancer, many of the others from AIDS, chronic diseases, and other life-threatening conditions. Many are in long term care facilities. Many more are choosing to die at home surrounded by their children and grandchildren, pets, and familiar personal items. All would benefit greatly from caregivers who understand the special needs of a dying person.



Chapter 1 What's It All About?



About Hospice

Hospice was a term used centuries ago to describe places 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.

The focus of hospice is on the individual and the involved family rather than on the disease. It is the goal of the hospice staff to provide for the whole person, emotionally, physically, and spiritually. Care focuses on restoring dignity and a sense of personal fulfillment to the dying by allowing choices, listening, and caring.

To provide the very best care possible, a multi-disciplinary team shares the responsibilities involved in attending to the needs of hospice patients and their families. The hospice team, made up of a medical director, the patient's primary physician, nurses, social workers, pharmacists, chaplains, home care aides, volunteers, therapists, and others, meets at least every two weeks to discuss ways to best support every hospice family's needs.

Although hospice care is not for everyone (some situations and problems are more medically complicated and the patient or family may not opt for palliative care) it offers many advantages. Some of these basic components of hospice are:

- 24-hour consultation with nursing staff, as needed
- State-of-the-art pain and symptom management
- Emotional support and counseling
- Spiritual Support
- Bereavement support
- Medications needed for pain and symptom management
- Equipment needed for comfort
- Assistance with physical care
- Therapies as needed
- Volunteers as support



Chapter 1 What's It All About?

Some questions you may be asking...



Who started the hospice movement and where did it begin?

The very first hospice, St. Christopher's in London, England, was started in 1967 by Dame Cicely Saunders. She was the first to recognize that terminally ill patients weren't getting the specialized care they needed. All too often, the medical community emphasized cure at all costs and viewed death as defeat and failure. Because of this attitude of denial of death as part of the cycle of life, terminal patients were frequently isolated. A "conspiracy of silence" was practiced where the diagnosis, prognosis, and any discussion of these tended to be withheld.

The worst fallout from this tendency to "treat the doctor instead of the patient" (pay more attention to the physician's comfort level than the patient's) usually occurred in the area of pain management. Pain tended to be treated with limited amounts of medication only when the pain became severe. Physicians feared psychological dependence and physical addiction to the drugs used to control pain. A cancer diagnosis was a dreaded death sentence because it almost certainly meant uncontrolled pain and stigma.

St. Christopher's hospice began the daunting task of changing society's attitudes toward the dying process, and in 1974 the first hospice was established in the United States in New Haven, Connecticut by Sylvia Lack, RN. In the decades since that first hospice opened its doors, thousands of others have sprung up in every corner of the nation.

In recent years, the hospice concept has spread internationally with the needs of patients in every part of the globe for improved end of life care gaining international attention. Access to trained hospice and palliative care professionals in many of the world's nations is a serious problem. Studies show that over 100 million people in the world, dying of a terminal illness and often in severe pain, are not getting palliative care. Help the Hospices in the UK and the International Association for Hospice and Palliative Care based in Houston, Texas are organizations dedicated to improving the accessibility of hospice care, including adequate pain management, in all parts of the world.





Chapter 1 What's It All About?



Does a person have to be at home to have hospice support?

Hospice patients usually prefer to remain at home, surrounded by family and pets, amid familiar sights, sounds, and smells. Hospice is primarily geared to helping people stay home. Needed equipment and supplies are offered, as well as the assistance of the hospice team. Sometimes, however, it is impossible for the patient to stay at home and in these cases family may opt for an adult foster care or nursing home placement. In most cases, hospice can still provide care and support to the patient and family with adjustments made according to the care situation.

Should the care provider in the home setting become exhausted and need a break from caring for the patient, hospice offers respite care in a nursing home or hospital for a few days (usually five) to allow the care provider to rest. Many cities in the U.S. have inpatient hospice centers where hospice patients can go when symptoms are out of control or family is unable to provide care at home. These centers focus on providing a home-like atmosphere and amenities for the family's comfort as they stay close in the final days of their loved one's life.



What are the criteria for admitting a patient to hospice services?

To be accepted onto the hospice program, a patient must have:

- *A diagnosed terminal illness*
- *An acceptance of the concept of palliative care*
- *Life expectancy of six months or less*
- *Definite and definable needs*
- *The availability of a committed primary care provider*
- *An attending physician who is supportive of the hospice concept*
- *A place of residence that is within the hospice' service area*
- *Acceptance onto services by the interdisciplinary team (The decision may be made by the core team, consisting of the medical director, a spiritual counselor, a social worker, and a nurse. This group also meets once a month or so to review policies and make program decisions)*



Chapter 1 What's It All About?



Who pays for hospice services?

The majority of people who use hospice services are on Medicare. The Medicare Hospice Benefit is available to any Medicare beneficiary that meets hospice criteria and lives close to a Medicare certified hospice. Under this benefit, the hospice is paid a per diem rate for every day the patient is on services and the hospice team provides staff support, medications that are controlling the patient's pain and other symptoms related to the terminal diagnosis, any equipment the patient may need for comfort and safety, and respite care as needed.

Many private insurance companies now provide hospice coverage for their beneficiaries. Some follow the Medicare model and pay a per diem rate, asking the hospice to provide services to the patient identical to those available under Medicare. Others prefer to pay for individual visits by hospice team members. Many hospices provide services free of charge to those in their community who have no insurance coverage and need the support and symptom management expertise that hospice offers. Donations from the community often help to offset the cost of providing these services.



Who initiates the referral to hospice?

Anyone can make a request for hospice services by contacting the hospice office or the patient's physician and asking for a hospice evaluation.

If the request comes to the hospice office first, the patient care coordinator makes the appropriate follow-up telephone calls to be sure the physician wishes the patient to be evaluated. The hospice team will make the final determination as to whether or not hospice is appropriate for this particular person. This decision is based on the admission criteria.

The hospice movement in the United States is based on the belief promoted by Dr. Josephina Magno, a hospice pioneer,

“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.”





Chapter 1 What's It All About?



How does the hospice team interact to provide care to terminally ill patients and their families?

Continuity of care is a major focus in hospice. Team members meet at least once every two weeks for an interdisciplinary team meeting to discuss each hospice family and share ideas about how to provide the best care possible. Each problem that comes up is examined by the team from as many different perspectives as there are team members present.

A Case History:

Betsy Miller, a 79 year old woman with end stage heart disease, has been restless at night and is experiencing pain in her back. Her daughter is worried about her kidneys, since she has a history of kidney failure as well. The hospice team brings up her case in team meeting.

The nurse, June Felding, shares that Mrs. Miller's blood sugars have been elevated and she is running a low grade fever. Dr. Roberts, the medical director, suggests giving her a low dose of morphine for the pain and adding a mild sedative. He orders a urinalysis to check for infection. Ms. Felding makes a notation to increase her nursing visits from once a week to three times a week until the symptoms are resolved.

The volunteer coordinator, Bob Wild, reports that Mrs. Miller's volunteer, Rose, has noticed an increase in the patient's anxiety and restlessness since the daughter's arrival from out of town.

Chaplain John Ross speaks up and suggests that the tension the patient is experiencing could be attributed to something she is worried about talking to her daughter about, and asks the social worker, Wanda Townsend, if she has had a chance to talk to the patient this week. Ms. Townsend adds a visit to Mrs. Miller to her list of patients to visit that afternoon.



Chapter 1
What's It All About?



At the Heart of the Matter



Exercise:

Referring to the story of the "Alps Traveler" on the DVD. Answer the following questions.

Be prepared to discuss your answers with the group if you are comfortable doing so.

1. Have you known someone who has had a terminal illness? Did they have the support they needed to deal with their diagnosis? Why or why not?

2. Who could the traveler represent?