

Hospice: Facts, Myths and Misconceptions

By Tracy Riggs, R.N.

The word “hospice” originated in England as the name for a form of respite for weary travelers. Today, hospice means something far different in people’s minds.

Hospice care is most often associated with death and dying. There are many misconceptions about hospice, including that it is only for the elderly or cancer patients, and focuses on death.

Dying is one aspect of what hospice care deals with, but it certainly is not what hospice is all about. Hospice is about life and living to the best of one’s ability. Hospice cares for people of all ages, from babies to individuals older than 100. Hospice is appropriate for anyone with physical problems that are “end stage” or for which there is no further treatment. Some people who need hospice care have diagnoses, such as cancer, dementia, heart failure, renal failure or failure to thrive. Hospice care is for anyone in need of end-of-life assistance.

When is it time for hospice?

End stages of scleroderma are different for every patient. In many, an enlarged heart is seen, as well as pulmonary fibrosis or interstitial lung disease. Shortness of breath, pain, and swelling in the lower extremities are common problems associated with scleroderma.

Hospice is an option when your physician notifies you and your family that there are no further aggressive treatments available or when as a patient you decide that you are looking for comfort measures rather than treating the scleroderma or problems associated with the disease. For hospice to be appropriate, your physician must determine a prognosis of six months or less to live.

What questions to ask when choosing hospice?

Government regulations state that a hospice service has to provide physical, spiritual and emotional care to all hospice patients. All hospice care providers have to provide nursing, social work, volunteer, spiritual and personal care or nurse aid services.

Hospice care can take place in a home setting or a residential facility. Independent hospice facilities are becoming more popular across the country.

Some hospice organizations are available 24/7 only by telephone, but when choosing a hospice for in-home care, you should be able to have a nurse come to your home at any hour. Some hospices provide incontinence supplies, music

and massage therapy and non-pharmacologic treatments for symptoms. You will want a hospice that works with a compounding pharmacy to ensure comfort you lose your ability to swallow.

There are differences in how a hospice operates, many are for-profit and some are non-profit. If you don't have insurance, you may want to look for a non-profit that will do charity hospice care (at no charge). Free care depends solely on individual care providers.

Many hospice providers have their own medical directors, usually a physician, who will follow your hospice care. Some hospices allow you to keep your own health care provider or primary care physician. You will want to know which physician will be prescribing medications and following your care.

What is the function of hospice?

The primary function of hospice care is to provide support not only to the patient but also to the patient's family and friends. Hospice nursing care focuses on symptom management such as pain, nausea, shortness of breath, swelling, depression, and anything associated with the end stages of a disease.

Medical social workers who work with hospice focus on life review, funeral planning, developing durable power of attorney and coping with changes in life. Hospice staff members work as a team to make the best of life in the end stages.

How to get hospice?

Discussing hospice with your family and caregivers is an important first step. You can call hospice providers individually and inquire about hospice services. Also, you could ask your physician to refer you to hospice care.

How do I manage end stage problems?

Should you find yourself in need of hospice care, some common treatments for scleroderma-associated symptoms include but are not limited to:

- Anti-anxiety medications to control shortness of breath and assist other medications to work more effectively
- Nebulizer medications to moisten lung tissues, help expectorate or "cough up" sputum, and control pain in the lungs
- Humidified oxygen that can help with shortness of breath
- Different kinds of medications for different types of pain.

Most people don't like to think about the end of life but having help preparing yourself and your family makes any hard time easier. Hospice care is about hope, happiness, comfort and all together preparation for changes in life.

About the Author

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