

## **Debunking the Myths of Hospice**

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As a psychotherapist specializing in grief and loss and as a hospice bereavement coordinator, I am saddened by how underutilized hospice care is. This is largely because of people's misconceptions about hospice: Many people hear the word "hospice" and think it means a place where a loved one goes to give up and die, alone and on too many medications. Nothing can be further from the truth. Hospice is not a place, but a valuable service that supports dying patients and their family members to maintain hope, dignity and quality in all domains of life — physically, emotionally and spiritually — at this important stage in the lives of patients and their loved ones. The services provided by hospice allow a patient to spend his or her final days among family and friends, as alert and comfortable as possible and away from the hospital and dehumanizing high technology equipment. Hospice is about life. When there is nothing more that can be done to cure a disease, there is still much that can be done to enhance the patient's life and to support the patient and the family.

### ***The Services of Hospice***

Hospice care is available to anyone who has a life-threatening condition or terminal illness with a prognosis of six months or less if the illness or condition were to run its normal course, as certified by the patient's attending physician and a hospice medical director. Nonetheless, many people stay on hospice for more than six months, as long as they continue to meet the foregoing requirement at the end of each certification period. In addition, in electing hospice care, the patient elects palliative or comfort care, rather than curative or life extending treatment. In fact, as discussed further below, palliative or comfort care is a hallmark of hospice care, and hospice clinicians are expert in providing effective pain management.

In keeping with the hospice movement's mission to provide care in all domains of life, each hospice's program provides support to the patient and his or her family through the interdisciplinary team, consisting of the medical director, nurses, social workers, home health aides, chaplains, bereavement counselors, volunteer coordinator and volunteers. Also available, if necessary for comfort and quality of life related to the hospice diagnosis, are dietitians, speech, occupational and physical therapists.

### ***What Does Hospice Care Look Like?***

After a patient is admitted to the hospice program, each member of his or her clinical team—a registered nurse, social worker, chaplain and home health aide or certified nursing assistant—meets with the patient and his or her family and assess initial physical, emotional, social and spiritual needs and develop a plan of care for the patient, which may change as the patient's condition changes. It is noteworthy that the patient and family or other caregivers are involved in formulating and changing the plan of care. Psychosocial needs are assessed by the social worker,

including any needs for community services, and assessing the need for volunteers to provide companionship or other support, including massage, music or art therapy, or respite for family caregivers. The chaplain will provide spiritual support and also help the patient resource those in his or her spiritual community, as needed. The chaplain, in coordination with the social worker, will also help with funeral or memorial arrangements. The home health aide will assist with bathing and grooming. The need for pre-bereavement support will also be assessed, which is provided by the bereavement coordinator and grief counselors.

Bereavement support is provided for at least one year after the patient's death to family members and others affected by the death. Many hospices provide this service for thirteen months, to guide the bereaved through the first anniversary of the death.

### ***The Importance of Managing Pain***

The management of pain—physical, emotional and spiritual—is one of the most important missions of hospice care. Unrelieved physical pain results in unnecessary suffering in the terminally ill. In a hierarchical needs system, the first step in managing global pain is to manage physical pain. Unfortunately, misconceptions about pain and pain control continue to interfere with the acceptance of hospice care. Some picture loved ones dying in hospice alone and in abject pain. The picture of the terminally ill dying in pain is, unfortunately, historically accurate. Before the advent of the hospice movement, under-treatment of cancer-related pain was common, and the terminally ill did often die alone in hospital beds. “[They were often handled as bundles of physical symptoms or simply as failures of the medical system, But lost in all this ‘expert treatment’ was a human being with fears, questions, desires, needs and rights” (Callanan & Kelley, 1997, p. 25-26).

Fears about over-medication and addiction also discourage the wider use of hospice services. Addiction is very rare in the use of narcotics to treat pain. Hospice clinical staff is specially trained in the effective use of narcotics and other pain-relieving drugs, as well as drugs to counteract the side effects (such as nausea and constipation) of those drugs. In addition, anti-anxiety and anti-depressant drugs are used as needed to enhance the terminally ill patient's quality of life.

It is impossible to work with a person's emotional and spiritual pain if he or she is experiencing unrelenting physical pain. Unrelieved physical pain can lead to feelings of hopelessness and fear, and can also cause the patient to isolate him or herself from family and other support. With this in mind, Cicely Saunders, the founder of the modern hospice movement, developed the concept of “total pain”: “an understanding of pain as the complex interaction between physical pain caused by disease and pain caused by mental, emotional and spiritual malaise” (Brown, 2008, p. 190). If the patient is in chronic pain, he or she may give up hope of a peaceful and dignified death. Effective pain control allows the patient to maintain a sense of autonomy and control and focus on quality of life issues, unfinished business and spiritual concerns. Thus, the interdisciplinary team approach of hospice is indispensable for the treatment of “total pain.”

Hospice chaplains, social workers and bereavement counselors, as well as those in the hospice patient's spiritual community play an important role in maintaining the patient's quality of life

and helping to relieve spiritual and emotional pain. Those facing death commonly search for essence and connectedness (Stephenson & Draucker, 2003, p. 57). Concerns about essence include questioning whether one's life and death have meaning and purpose, questions about values, doubts and beliefs. Concerns about connectedness stir questions about how one is connected to family and others in one's life, as well as to a higher being, and also bring to the surface the individual's unfinished business in his or her relationships.

Listening to a dying patient's fears and concerns is at the heart of the services provided by hospice (Callanan & Kelley, 1997, p. 28). Fears cited by hospice staff in working with the dying include fear of the process of dying, fear of loss of control, fear for loved ones, fear of dying alone, fear that one's life has been meaningless, and fear of the unknown (Callanan & Kelley, 1997, p. 27-28).

### ***Conclusion***

Impermanence and death are part of the natural order of things, not something to be hidden away in fear and despair. Death and dying are integral parts of human existence, and indeed, of human development and growth. As Elizabeth Kubler-Ross has observed: "If you can begin to see death as an invisible but friendly companion on your life's journey...you can learn to live your life rather than simply passing through it" (Kubler-Ross, 1975, p. x). Hospice care is available as a companion on that journey, enabling patients and loved ones to embrace this special and sacred stage of life with dignity, autonomy and peace.

### ***References***

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