

## Hospice: When, Where, What, How, Why?

*by the Rev. Laura Hawkins*

I have learned over the many years that I have been a hospice chaplain that two of the scariest words for many people are *death* and *hospice*. Probably because for many death and hospice are the same thing. And while yes, in order to be eligible for hospice services, the one seeking hospice care is required to be terminal, hospice is not a death sentence. So why the fear?

One reason may be that hospice is a relatively new method of care in our health care system here in the United States. Another reason according to an article from the National Library of Medicine, may be this:

“Attitudes toward death....[have changed] with the discovery and development of bacteria and bacteriology, aseptic techniques, and anesthesia. Society....[has] witnessed people survive diseases and conditions not previously survivable. The attitude of **denial** of 'death comes to us all' [had] arrived. Patient and family expectations followed, and physicians responded with the attitude that 'death is a failure.' The centuries-old expectation that everyone would die at home surrounded by loved ones changed. Whether from the hope of families that medicine would 'save' their loved one or expectations of physicians with the 'God complex,' people began dying in medical facilities, away from the care of loved ones.”

However, with the advent of -- in particular the Medicare Hospice Benefit -- hospice care, especially for older adults, is being utilized more frequently as a way to provide comfort and care during the declining years. Because hospice treats the whole person -- physical, emotional, social and spiritual -- it can offer a powerful means of comfort care to both the patient and the patient's family, friends, and caregivers. When dying becomes something to be “cured” instead of experienced many people lose the chance to understand one of the very human mysteries of life. As people of faith, we're led by God to find comfort beyond that which we can control, or as many recovery folks have learned, to “let go and let God.”

When we or a loved one enters hospice a powerful community of caregivers enters the scene. Comfort is primary and often once comfort care begins, the hospice patient and many times their family and friends can let go of trying to control outcomes and enter a deeper relationship with one another and with God. In the book “About Hospice” the writer lists some of the qualities that make hospice special:

1. Pain control: One of the major fears of the seriously ill is the fear of pain. In hospice, the goal is to achieve control over pain without impairing alertness.
2. Living life fully: Hospice can help patients achieve physical, emotional and spiritual comfort so they can concentrate on living as best they can with the time remaining.
3. Care at home: Usually, family or friends care for patients at home, amid familiar surroundings and loved ones. (However, hospice is offered to anyone regardless of their living situation. Hospice is a philosophy of care, not a location, and care is provided wherever a person calls home)
4. Treating patients and loved ones as a unit: When someone has a terminal illness, his or her loved ones feel pain, too. Hospice programs also provide relief to caregivers who may neglect their own needs.

What is unique about hospice is that it provides as much or as little care for the family or patient as they want and need. In general, the hospice team includes a hospice coordinator, a hospice physician, hospice nurses, bereavement counselors, chaplains, home care aides, volunteers, a social worker, a pharmacist, and occasionally physical, occupational and other types of therapists. Although hospice does not provide full-time, 24/7 care, the hospice team is available 24/7 for consultation and care if needed.

Because the patients' families and friends are important members of the team, too, hospice allows the family to be family, even when they are caregivers for their loved one who is dying. Dying is a natural part of life and to share in that, just as we share in the birth of a baby, sharing the birth of our loved one as they move from this life to the next can be a very meaningful experience. Yes, it can be a time of strong mixed emotions and yet, amid all of these emotions – joy and sorrow, anger (yes, anger), forgiveness, anxiety and peace – beautiful and meaning-filled moments can occur. Yes, the end of life can be a time of peace for everyone involved, because when we're able to be there for and with our loved one -- and while doing so, learn things about ourselves that we'd never thought of before -- these can be and become life-changing moments.

Of course, not all of us have had positive relationships with our loved one who is dying, and their dying can bring up all sorts of unfinished business that had not been spoken of or felt during their life and that's where hospice can be so helpful. The social workers, chaplain, and bereavement counselors are all present to help navigate this time. Because although the dying person needs care and comfort, so do those who are watching their loved one die.

A beautiful pamphlet by nurse Barbara Karnes titled "Gone From My Sight" opens with these words: "Each person approaches death in their own way, bringing to this last experience their own uniqueness." And so she offers us a map and "like any map, there are many roads arriving [at] the same destination, many ways to enter the same city." The guidelines she offers are simply guidelines and all are "very, very flexible" She reminds the reader that "for some, it will take months to separate from their physical body, for others, only minutes. Death comes in its own time, in its own way. Death is as unique as the individual who is experiencing it." Therefore, hospice as a philosophy of care understands that death is unique, the end of our life is unique to all of us, just as our birth was unique. None of us make this journey in just the same way, each of us (if we are able) gets to decide how we want to make that journey, and hospice is there to guide and support us along the way. As the article from the National Library of Medicine says:

"End-of-life care, like all medical care, will continue to be challenged as our culture and our regulatory and financial resources change. Everyone dies and everyone faces the end of life, not only for themselves but also for their loved ones. How we choose to provide care to individuals and their families at their most vulnerable time, their time of greatest need, the very transition of life to death, is an important matter, regardless of changes in the health care system. We must hope that this significant event and the matter in which it is experienced continues to be of interest to the broader society in such a way that it unifies policy makers, regulators, administrators, and health care providers toward a common goal. As Dame Cicely Saunders eloquently advocated, 'you matter because you are, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.' Let's remember that Jesus understood suffering and death, not because he believed that our death must include suffering, but because he longed to ease our suffering, just as we are now called, as followers of Jesus to ease the suffering of others and hospice is a beautiful resource that can offer us the support to do just that -- for ourselves and others."

**Questions to ponder:**

1. What in this article was new or surprised you about hospice?
2. What experiences have you had with hospice?
3. What does it mean for you when Dame Saunders says “to live until you die”?

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