

Expect the
Unexpected:

Understanding Hospice Care

“To expect the unexpected shows a
thoroughly modern intellect.” —Oscar Wilde

EXPECT THE UNEXPECTED: HOSPICE

Mark Twain once said, “I’ve lived through some terrible things in my life – some of which actually happened.” I suspect that, like me, Mark Twain was a bit of a worrier. The irony for most of us is that

we often spend a lot of time worrying about things which never even happen – and too little time planning for events which are far more likely to impact us.

Perhaps one of the best examples of this tendency is reflected in this statistic: 70% of people would prefer to die at home, surrounded by loved ones. Only 30% of people actually do.

I wanted to understand why this was the case and what we can do to prepare ourselves and our loved ones more adequately for end of life care. My capable teacher was Anna-Gene O’Neal, President and CEO of Alive Hospice in Nashville.

Patients begin hospice care when two physicians certify that their life expectancy is six months or less and the patient agrees to forego any other life-prolonging treatments. Hospice neither hastens nor postpones dying, and hospice care is palliative rather than curative. What does this mean for patients? As an example, a hospice patient could receive treatment to manage pain but would not be given a feeding tube. The hospice decision is not permanent, but in practice it is rarely revoked.

Most people pay for hospice care with Medicare or private insurance. Hospice care can take place in the patient’s home or in a residential hospice facility. If the patient chooses residential hospice care, room and board fees are billed directly to the patient. Patients without insurance should work with their hospice provider to identify if there are other coverages or private funds available to offset costs.

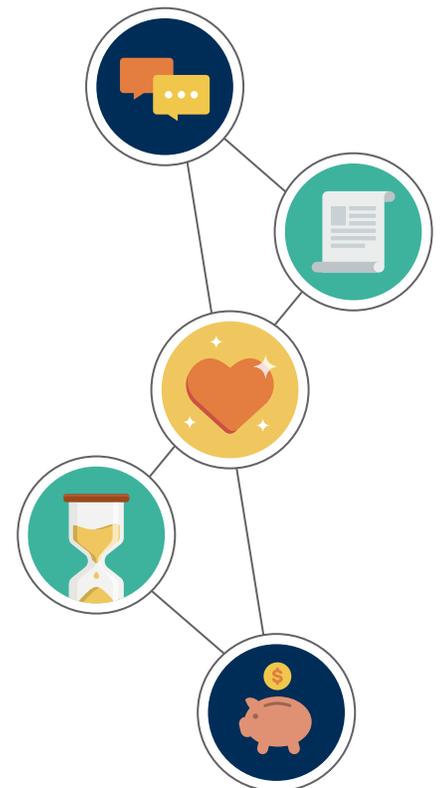
Hospice is not affiliated with a religious organization, but the care directly addresses patients’ spiritual and emotional needs. Hospice professionals are trained to recognize and treat spiritual distress just as they do physical pain. It makes sense to me that patients who know they are dying soon would need spiritual care, but I wondered how those needs are addressed in practice. Anna-Gene explained to me that Alive Hospice patients are assigned an interdisciplinary care team consisting of a chaplain, nurses,



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physicians, social workers, and volunteers. This team works together to ensure that both the patient and his or her loved ones are prepared for the patient's death. I learned that over and over again the end-of-life conversations between the patient and his or her "people" involve these five phrases:

**please forgive me, I forgive you,
thank you, I love you, and goodbye.**

Many of us know of a friend or loved one who has provided care for a family member. Caregivers experience physical and emotional depletion as they work to keep up with the endless needs of terminal patients. Hospice helps caregivers in several ways. Respite care allows the caregiver to have a temporary break from attending to the patient as hospice provides the care. Additionally, when a patient begins hospice care, the patient's team, including a pre-bereavement specialist, provides support and counseling for the caregiver. After the patient dies, hospice continues to support bereaved loved ones through grief counseling and support groups.

Anna-Gene put into words what many of us already know: We die differently today than we did thirty or forty years ago. While advances in medicine allow patients to live longer, we have seen a simultaneous increase in deaths from diseases of cognitive impairment. This disconnect makes clearly defining what we want our end of life treatment to look like even more important. I left our meeting with four copies of The Gift Initiative booklet which prompts consideration of health care preferences and provides guidance on establishing an Advance Care Plan (ACP). While there is no need to work with legal counsel to complete the documents, Anna-Gene emphasized that to ensure that our wishes are followed it is important to store the ACP with other legal documents and in the hearts of our loved ones. I plan to complete my ACP and work with my parents and brother to ensure that they do the same. Ideally I will never have to make decisions about their end of life care. Realistically, I probably will, and I will feel better about doing so knowing we have discussed their preferences in advance.

Watching someone we love decline and die leaves a deep wound. Caregivers are asked to make decision after decision as they weigh options which are often equally unappealing. Partnering with an experienced support team during the end of life and bereavement process gives caregivers and loved ones a source of comfort and guidance as they move through the fog of grief. Anna-Gene told me that one of the nicest compliments Alive Hospice has received came from the son of one of their patients. "I expected that you would take excellent care of my father," he told them. "What I had not imagined is that you would take such good care of me."

REFERENCES

HELPFUL LINKS:

National Hospice & Palliative Care Organization
nhpco.org/resources

thegiftinitiative.org

theconversationproject.org

SUGGESTED READING:

Life Is a Gift: Inspiration from the Soon Departed
By Bob & Judy Fisher

Having Your Own Say
Getting the Right Care When It Matters Most
Edited by Bernard J. Hammes, PHD





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