

BE WELL

My Experience with Hospice

By Debbie DeAngelo August 2024



What do my dad, stepdad, and two young adult friends all have in common?

They passed away peacefully, at home, with hospice care. I know because I was there.

I have always considered it the greatest of privileges to be with someone as they draw their last breath. As a nurse, I have witnessed many deaths in a hospital, many of which wouldn't be considered peaceful or desirable. With hospice care, I have always found the experience to be patient and family oriented, and death was viewed for what it is — a natural part of the life spectrum. I particularly appreciated that they coordinated all care, so I didn't have to make calls to numerous doctor's offices and agencies. The multi-disciplinary team included nurses, doctors, social workers, and trained volunteers, who not only provided

physical care, but also tended to the emotional needs of the patient and entire family. Unbelievably, this support continued for 13 months after loved ones passed.

As a society we put an inordinate amount of time, effort, and planning into bringing a life into this world, yet we don't devote much, if any, attention to the experience we would like to have when exiting this world. I get it. Death is a tough topic. Since it's a subject that is generally avoided in our culture, so too is end-of-life care. A dichotomy exists between the results of national surveys and polls about what people want at the end of their life, namely a pain-free passing at home surrounded by family, and acceptance of hospice care.

By definition, hospice is an option that focuses on quality of life, and relief of pain and suffering, for those nearing the end of their life. So why such trepidation? Even though hospice care has been offered in this country since 1974, many people continue to hold misconceptions about it. Here are some commonly held myths that often lead to resistance of the concept.

Myth #1 - Entering hospice means you've given up.

This couldn't be further from the truth. Whether treatment for a serious illness hasn't been successful or the patient no longer wishes to pursue and endure treatment, they are acknowledging that they may be reaching the end of their life and would like it to be as comfortable and peaceful as possible. I view it as a testament to desiring comfort, dignity, and as high a quality of life possible for themselves and their loved ones.

Myth #2 – Hospice should only be considered within a few days of death.

There's nothing more tragic than an emergency hospice admission. Waiting until death is imminent before entering hospice care robs the patient and family of the gift of time. In fact, surveys show that family members often comment that they wished their loved one had received care sooner. Hospice can be started up to six months before the expected end of life. Once again, hospice doesn't hasten death. The focus is to allow for a natural, peaceful, dignified death. Towards this goal, medication is used to relieve symptoms such as anxiety, breathlessness, and pain.

Myth #3 – If my doctor doesn't mention hospice, then it's not needed.

Not only is it important to discuss end-of-life care with your family, and secure the appropriate legal documents, such as a will, advanced directive, medical power of attorney, as well as prefuneral planning to be sure your wishes are carried out, but also it is imperative to engage your physician in this discussion. As mentioned, many families and patients remark that they wish they had initiated hospice services earlier. Given this, if you are diagnosed with a serious or life-threatening illness, let your doctor know that, if and when the time comes, you are receptive to discussing hospice. It's equally essential to know that you can contact hospice facilities directly to ask questions, inquire about their services, and find out how to go about initiating care.

Myth #4 - Hospice is only for cancer patients.

Patients enrolled in hospice have been diagnosed with a variety of conditions. These include end-stage diseases, such as heart, lung, kidney, neuromuscular, or dementia, in addition to cancer. Keep in mind that hospice is an approach to care, so it can be provided in your home, a long-term care facility or an inpatient hospice center.

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