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Inside: 'Dying: To know the options' by David Kessler

Dying: To know the options

by David Kessler

As inevitable as aging is, so too is death. Yet, in many ways we do not celebrate and honor our longer life experience as we should because it is beginning a process that will result in the end of our life. The National Family Caregivers Association reports that more than 30 million Americans spend over 40 hours a week caring for dependent loved ones. It is estimated that in 2006, 1.3 million people utilized hospice care. There are probably 4 to 8 million people who could have used and benefited from hospice, but due to lack of education, misunderstandings



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and confusion did not.

Hospice is considered the standard for quality end-of-life care. It involves a team-oriented approach to medical care, pain management, and emotional and spiritual support. Support is also provided to the patient's loved ones. This care can be provided in a patient's home, a free standing hospice facility or a nursing home.

Having begun working in hospice more than 25 years ago, I have witnessed first-hand how medical technology can either enhance our health or prolong our suffering. Although we are grateful for hospice and advances in medical care, we also are facing a growing conflict concerning medical technology and when and where to use it.

Much has changed today with the discovery of previously unimaginable therapies and procedures. We have chemotherapies for cancer, some available in pill form. We have respirators to breathe for us, dialysis machines if our kidneys fail, and radiation to shrink our tumors. With all this available, how do we decide when enough is enough? We want our loved ones to have every possible chance to recover, and no one wants to arrive prematurely at hospice. But, we also do not want to miss the opportunity if hospice is in fact the right choice for the patient and family.

Continuing the fight with treatments or choosing the emerging medical specialty of palliative care are now viable options. In the past five years the number of hospital palliative care programs has grown by 96 percent and almost half the hospitals

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in the United States now have a palliative program. The word *Palliative* has two origins. It means either “to comfort” or “to improve care.” For those who choose to remain in the hospital and seek curative treatment, palliative care may be the better option.

Imagine a 98-year-old grandfather who is diagnosed with an aggressive cancer and told he has less than a year to live. He is presented with two options. He can decide

on aggressive chemotherapy, which at best may add months to his life. Or, he can let nature take its course and spend his last year at home with hospice care, enjoying the time he has left. In this scenario for him, hospice is a logical and medically sound choice. Now imagine a 39-year-old father of three kids, all under ten, who is given the same diagnosis and the same two options. He may feel that no matter the odds, any amount of extra time he can buy is worth it. For him, palliative care is a logical and medically sound choice.

Palliative care means continuing aggressive curative treatments, with the benefits of great symptom management and supportive care in a *hospital* setting or at home.

Hospice, on the other hand, means limited curative treatments if any, and the benefit of great symptom management and supportive care at *home* or in a *hospice* unit.

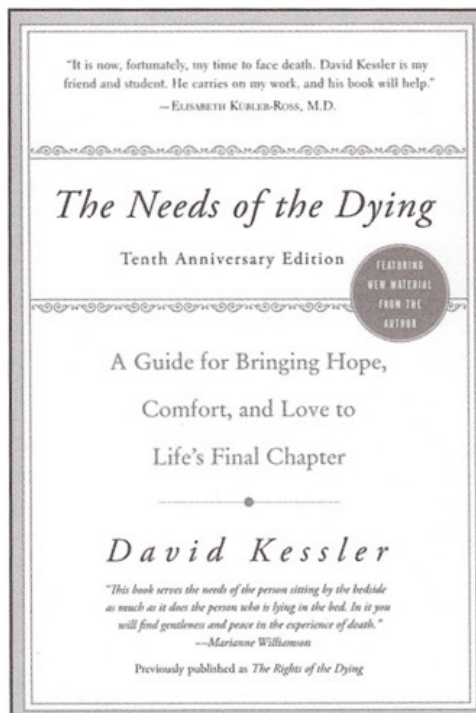
Experience learned and earned

Death and dying expert, Elisabeth Kübler-Ross could not have imagined some of these modern day medical dilemmas when she first became known for her ground breaking book *On Death and Dying*. For more than 35 years, millions around the world have turned to the legendary Kübler-Ross for guidance in the area of death and dying. It was my privilege to coauthor her last two books with her and most importantly to be there when she passed away – August 24, 2004.

My good friend was critically ill so many times during her last years, and was on and off hospice many times – epitomizing the question of when enough is enough. In fact, she always said, “Listen to the dying. They will tell you everything you need to know when they are dying. And it is easy to miss.”

Kübler-Ross was a woman who made things happen. This was exactly what she needed to do in the beginning of her career in an area of life that no one wanted to explore. Instead of a sterile, isolated death

in a far-off hospital corridor, her dream for the dying was a simple, natural death, with loved ones gathered, in a home-like setting – an ordinary death a century earlier. And, in fact, in her own dying, there were no extraordinary measures. That was not who she was. Instead, her death involved all the ordinary pleasures that she had so passionately described over the years – her room at home with lots of flowers, a large picture window, loved ones around and her grandkids and my kids playing together at the foot of her bed. In the ordinariness of her death, she achieved peace and acceptance, the kind of death that she had dreamed about for all the dying decades ago.



Benefits vs. burdens

Today, as one considers possible medical treatments, they must first understand a few key concepts. The most important is “benefits vs. burdens.” A treatment should have more benefits to your health than burdens. For instance, a chemotherapy that may add an additional five years, after you endured a challenging six months of it, is worth it. On the other hand, a chemotherapy that would last for months and only give an extra week or month to live may not be of value.

With all these factors considered, hospice palliative care programs in the last years of life