

Caring Well for One Another Through the End of Life

Ira Byock, MD September 27, 2013

Front-page headlines frequently carry news of a killer storm that has ravaged someplace in the country. Our hearts go out the victims and we reflect that, fortunately, most people who live in regions prone to hurricanes, tornados, forest fires and floods wisely prepare to weather the forces of nature. It would be foolish not to.

In contrast, when it comes to death, the natural disaster that awaits us all, relatively few Americans are sufficiently informed or have taken basic steps to keep themselves and their families safe from harm when dying.

The danger is real. Despite decades of efforts and significant improvements in end-of-life care, studies reveal that many Americans still suffer as they die or spend their last days in places or situations they would never have wanted.

There are no villains here. Life is precious and no one wants to lose people they love. However, by acting as if death can always be forestalled, well-intentioned doctors and loving families can inadvertently make dying much harder than it needs to be.

Here are a few things worth considering:

First, in every community there are specialized teams ready to support you and the people you love through these inherently difficult experiences. A bit like the Red Cross and FEMA in weather-related catastrophes, palliative care and hospice programs provide skilled professionals when you need them. These doctors, nurses, social workers, spiritual counselors and others treat people's pains and help with bodily basics of eating, sleeping, eliminating, grooming, and getting around. They provide practical and emotional support to families as well, because whenever one person receives a life-threatening diagnosis, every member of his or her family shares the experience of illness. With skillful care and reasonable comfort, a person's dying can hold opportunities to complete a life, rather than merely have it end.

Second, necessary preparations begin simply with a conversation with people you trust. Share your thoughts about circumstances in which you would want – or not want – treatments, such as CPR, mechanical ventilation, kidney dialysis or medical nutrition. The right plan for one person might be entirely wrong for another. Complete a directive giving one or two individuals formal authority to speak for you if you become incapacitated. <u>The Conversation Project</u> and <u>Everplans</u> websites provide valuable resources and forms at no cost. If you or a loved one is seriously ill, work closely with your physicians to develop a plan of care that is tailored to your particular condition and honors your personal values, preferences, and priorities. These days, enlightened insurers, hospitals and health systems make palliative care available to people before crises occur. Research shows that when palliative care is provided along with cancer or cardiac treatments, patients tend to not only feel better, but also survive longer! Websites such as <u>Dartmouth Atlas</u> and <u>Medicare.gov</u> make comparative data available to help in choosing hospitals and health systems.

As the end of life approaches, being well-informed and prepared allows us to effectively use of the best institutions and professionals available. Because illness and dying are fundamentally personal, each of us must do whatever we can to look after ourselves and those we love.

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