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Caring Well for One Another Through the End of Life

We're prepared for fires and hurricanes, but what about death, the natural disaster that awaits us all?

By Ira Byock, MD, physician, author, patient advocate. Founder, Institute for Human Caring at Providence St. Joseph Health



Photo by Jean Sabeth on Unsplash

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 palliative care and hospice 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, these programs provide skilled professionals when you need them. The specialized palliative care and hospice 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. The Conversation Project and Everplans 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 Dartmouth Atlas and Medicare.gov 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 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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Dr. Byock is also active emeritus professor of medicine and community & family medicine at the Geisel School of Medicine at Dartmouth. He served as director of palliative medicine at Dartmouth-Hitchcock Medical Center in Lebanon, N.H., from 2003 through July 2013.

Dr. Byock has been involved in hospice and palliative care since 1978. His research has contributed to conceptual frameworks for the *lived experience* of illness that encompasses a continuum from suffering to wellbeing; related measures for subjective quality of life during illness; and effective life-completion counseling methods. From 1996 to 2006 he directed *Promoting Excellence in End-of-Life Care*, a national Robert Wood Johnson Foundation program that developed prototypes for concurrent palliative care of people with life-threatening conditions. He is a past president of the Academy of Hospice and Palliative Medicine.

Byock's first book, *Dying Well*, (1997) has become a standard in the field of hospice and palliative care. *The Four Things That Matter Most*, (2004) is used as a counseling tool widely by palliative care and hospice programs, as well as within pastoral care. *The Best Care Possible* (2012) tackles the crisis that surrounds serious illness and dying in America and the transformation that is possible.

Dr. Byock has been a featured guest on national television and radio programs, including CBS' 60 Minutes (on three separate occasions), PBS News Hour, Fox and Friends, and NPR's All Things Considered, Talk of the Nation, and On Being.

More information is available at <u>IraByock.org</u> and <u>InstituteForHumanCaring.org</u>.

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