

On the Horizon...

A Physician's Newsletter on End-of-Life Care

Spring 2001

## Hospice and Hospital Palliative Care Collaborations

As end-of-life care issues become of greater importance with the aging of the baby boomers, many hospitals are looking to improve their treatment of terminally-ill patients by establishing palliative care units. As more hospitals take on this role, the hospices that have traditionally cared for such patients and their families are trying to predict how this trend will affect them. The National Hospice and Palliative Care Organization (NHPCO) and Center to Advance Palliative Care (CAPC) have put senior writer Larry Beresford on special assignment to examine hospice-hospital collaborations in inpatient care for a monograph due out later this year. An article in *Hospice Management Advisor* describes how Birmingham's hospitals and hospices worked together to create an inpatient unit that benefited the community and the institutions. It also describes CAPC's step-by-step approach to productive collaborations in other communities. (Vol. 6, No. 6, June, 2001; phone 800-688-2421) ■

## The Seven Promises for Patient Care — A Vision of a Better System

from *Improving Care for the End of Life*  
*A Sourcebook for Health Care Managers and Clinicians*

By Joanne Lynn, M.D. Janice Lynch Schuster,  
and Andrea Kabcenell, R.N.

Foreword by Donald M. Berwick, M.D.  
The Center To Improve Care of the Dying  
The Institute for Healthcare Improvement  
Oxford University Press, 2000

A better health care system for the end of life would follow through on these seven promises:

- 1 GOOD MEDICAL TREATMENT**  
You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
- 2 NEVER OVERWHELMED BY SYMPTOMS**  
You will never have to endure overwhelming pain, shortness of breath, or other symptoms.
- 3 CONTINUITY, COORDINATION, AND COMPREHENSIVENESS**  
Your care will be continuous, comprehensive, and coordinated.
- 4 WELL-PREPARED, NO SURPRISES**  
You and your family will be prepared for everything that is likely to happen in the course of your illness.
- 5 CUSTOMIZED CARE REFLECTING YOUR CHOICES**  
Your wishes will be sought and respected, and, whenever possible, followed.
- 6 FAMILY CONCERNS TAKEN SERIOUSLY**  
We will help the patient and family to consider their personal and financial resources and we will respect their choices about the use of their resources.
- 7 MAKE THE MOST OF EVERY DAY**  
We will do all we can to see that you and your family will have the opportunity to make the best of every day. ■

- To make a referral to Horizon Hospice, call Liz Carney, Admissions Coordinator, at 312/733-8900.
- Questions or comments on newsletter contents? Call editor Melanie Kubale at 312/733-2233 or e-mail to [mkubale@horizonhospice.org](mailto:mkubale@horizonhospice.org)
- Visit the "Physician's Guide to Hospice" page on our website at [www.horizonhospice.org](http://www.horizonhospice.org).

## Excerpt from *Death Foretold: Prophecy and Prognosis in Medical Care*

by Dr. Nicholas Christakis

University of Chicago Press, 2000

*An Assistant Professor of Medicine and Sociology at the University of Chicago, Dr. Christakis also treats Horizon Hospice patients and sits on the board of directors. The following excerpt from his recent book illustrates a level of excellence for physicians to strive toward.*



Nicholas Christakis, MD, PhD, MPH

see optimal prognostication at the individual level as involving a number of steps. When caring for patients who are seriously ill, physicians, if they lack the requisite knowledge, should identify objective measures of prognosis in the literature, where available, and assess their validity, utility, and relevance. The physicians should evaluate how the patients' unique clinical or social attributes affect the prognosis. Next, they should specifically consider how the prognostic assessment informs the plan of action under consideration and how the patients' values or preferences regarding future outcomes (which must themselves be explored) influence the decisions made. The physicians should also consider how their own personal attributes or values may influence the prognosis that is formulated and the way it is communicated (since, as we have seen, physicians may vary in these respects). Finally, physicians should give thought to how best to discuss the prognosis with the patients and their families. As with good medical care more generally, all this should be done with utmost probity and compassion.

In the course of my discussions with physicians about prognosis, I encountered examples of prognoses that were sensitively, accurately, and usefully communicated to patients. Some of these can serve as a template for what I have in mind regarding the fulfillment of a duty to prognosticate. For example, one oncologist provided the following description:

"How do I determine what to tell patients in terms of disease outcome? Well, if someone is newly diagnosed, I'll sit down and first ask them what their understanding of their disease is. I hear what they have to say, and usually it's right. But if it's not, I tell them what *my* understanding is. And I tell them the prognosis if this is relevant.

Recently, a man was referred to me by the surgeons. He had a gastric cancer that was metastatic to lymph nodes and tissue in the peritoneum. And that's a terrible prognosis, and it's terrible even with chemotherapy. It's one of these things where you can't really justify giving them chemotherapy and radiation; that is, it's hard to justify because it's going to make them so sick. This was a middle-class man whose mother also had just died of gastric cancer. When he came, he wanted this experimental therapy, but he had no health insurance, so he wanted to

pay out of pocket. And it was going to cost \$20,000 a cycle. It was incredible. And it was not likely to work: at best, eight percent of people will have some kind of shrinkage (though not elimination) of their tumor. And it was going to make him sick. It probably wouldn't have extended his life. He probably only had eight months to live.

So that was a case in which we really talked long and hard about the treatment options. We talked about experimental therapy, and we talked about hospice, and we talked about standard of care, and I basically explained that the outcomes were all going to be the same, and that with this therapy he was going to feel worse. He wanted to know how much it was going to cost. We worked all that out. We had a very frank discussion. But I think he needed to know all this prognostic information to make a decision—to help him to decide if he was going to bankrupt his family to do this therapy that really had little chance of helping. And he decided not to."

This physician employed prognosis on numerous levels, and she did not shy away from her responsibility. Indeed, the entire clinical encounter was basically about prognosis in the broadest and most commendable sense.

The doctor chose the correct outcomes to predict, predicted them with precision ("eight percent" and "eight months"), predicted the outcome of the disease with and without treatment, foretold the expense and suffering associated with treatment, helped the patient to understand his unfortunate plight, and showed respect and sympathy for the patient. The doctor, what is more, "sat down," "had a frank discussion," and "worked it all out." To me, this is a sterling example of how prognosis can be used optimally in clinical practice, and not just because this example involves the avoidance of potentially painful therapy. [Such] physicians, by their actions and words, communicate an essential element when they are rendering the prognosis: one of the most important gestures that a doctor can make, especially in the face of giving a prognosis during a serious illness, is to promise that the patient will not be abandoned, symbolically or literally. Such a gesture uncouples the prognosis itself from the care and concern the patient will receive. This would be easier for physicians to do if they could change their *own* perceptions about the meaning of death. ■

**"...promise that the patient will not be abandoned..."**