

## Personal Perspectives

# The Diagnosis of Dying

George F. Davis

Many patients with far-advanced disease go through a phase of expensive, ineffective, and inappropriate medical treatments in an intensive care unit in the weeks or days before they die. If they transfer to a hospice or palliative care program at all, it is often so late that they are on the program for hours only. Conflicts on the plan of care arise often, as the effectiveness of the treatments is questioned and challenged. The problem is in the diagnosis. The missed diagnosis is called *dying*.

Diagnoses drive medical care. Quality oversight agencies organize their benchmarks based on diagnoses. Medicare pays according to diagnostic groups and private insurances follow suit. Clinical pathways are based on diagnoses. Doctors treat diagnoses, not symptoms. Symptoms, it is thought, will improve if the diagnosis is correct and the identified disease is properly treated.

In complicated cases with far-advanced disease, each specialist physician follows a treatment plan for a particular diagnosis for that specialty. As a result, the whole-patient perspective is lost. Rarely does an overlying diagnosis unify the thinking and link all the separate activities together. Unfortunately, instead, family members often become confused by the different reports from different specialists, since, for example, the neurologist and nephrologist might be pessimistic, while the heart doc-

tor could mention all sorts of hopeful treatment options. A unifying diagnosis is *dying*. Often, in these cases, the nurses and the doctors know the patient is dying, but it is not stated clearly as a diagnosis, and so no diagnosis is defined to clarify the situation for the different doctors or for the family.

The diagnosis to make in these types of patients is *dying*. Another way doctors say this diagnosis is to declare futility, but that only adds to the confusion, as no one agrees on the definition of futility. While this essay recognizes a potential risk that doctors might use this approach paternalistically to push their futility agenda on a patient or family by mentioning dying prematurely and without justification, the risk is small, as this essay addresses only far-advanced disease cases and a reluctance to use the word *dying* at all, even in cases when there is no doubt about the outcome.

Furthermore, the diagnosis of dying unifies and clarifies. The whole person who is the patient is dying. We need to say it, but say it as a serious diagnosis, not as an aside in discussing possible interventions. Until dying is declared openly, thoughts continue to focus on false hopes of dramatic improvement or denial that planning for death is needed. Discussions on a tracheostomy or gastrostomy tube often arise inappropriately in these very ill patients. Once the diagnosis of dying is made, then such interventions are put in the proper perspective. The true issue is not about the improved ventilation possible from a tracheostomy. The true issue is not about the false promise of better survival with nutritional support. The diagnosis of dy-

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ing trumps the other diagnoses. An honest assessment of the situation can then be made. The patient will not get better, no matter what temporary interventions are attempted. Death is coming. It is time to plan for it, even if we keep hoping for another outcome.

Once the overriding diagnosis is made, the treatment plans and the information to the patient and family can change dramatically. The diagnosis of *dying* puts what is happening into a context the family of a very sick patient can understand and start to absorb. The focus can now shift to how the patient is going to die. New goals of care can be developed. Palliative care or comfort care can be put in place.

Not everyone will agree with the diagnosis. There is some uncertainty in the diagnosis, of course, and uncertainty in the timing, if nothing else. The lack of the whole-patient perspective is partly why doctors' ability to prognosticate is so poor.<sup>1</sup> It has been the experience of this author that if the patient survives despite a dismal prognosis, then the remaining time with the family is seen as a gift, and the relationship between the patient and the family gets richer. If the family is given support after such an experience, many conflicts in the family might be resolved because of this gift. These benefits outweigh the risk of making the diagnosis in order to move the treatment of the patient into a more realistic and honest direction.

This essay is referring to those cases that are far advanced or so critical that this diagnosis is more certain. A sudden death would not be a surprise in these cases, except often to the family. Sudden deaths are to be avoided. Some will not agree, but once the diagnosis of dying is on the table, then it drives the discussion. We can deal with the uncertainty of the diagnosis and use short-term treatment trials, if necessary, for the family to have time to adjust to the diagnosis and to be convinced about its reality.

The communication of this diagnosis must be done properly and gently.<sup>2</sup> Palliative care consultants and ethicists can help doctors to communicate this diagnosis so that the medical team, the patient, and the family, not as antagonists but all together, can make decisions that will lead to a peaceful death. But the diagnosis is needed to put the proper perspective on the planning that is needed.

#### NOTES

1. SUPPORT Principal Investigators, "A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of

treatments (SUPPORT)," *Journal of the American Medical Association* 274, no. 20 (22 November 1995): 1591-8. <http://jama.ama-assn.org/cgi/content/abstract/274/20/1591>, accessed 19 May 2009.

2. J.S. Weiner and Jesse Roth, "Avoiding Iatrogenic Harm to Patient and Family while Discussing Goals of Care Near the End of Life," *Journal of Palliative Medicine* 9, no. 2 (2006): 451-63. For example, see the American Medical Association, Education in Palliative and End-of-Life Care (EPEC) Project. <http://www.epec.net/EPEC/webpages/index.cfm>, accessed 19 May 2009, or R. Buckman, *How to Break Bad News: A Guide for Health Care Professionals* (Baltimore, Md.: Johns Hopkins University Press, 1992).