

# Toward Increased Patient Autonomy and Choice of Terminal Care Options

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In this issue of *The Journal*, Davidson and Mosely have contributed an important article on the use of advance directives in family practice (eg, methods by which patients can express their desires regarding their future medical care and treatment options).<sup>1</sup> They provide a useful review of the types of advance directives currently in use; their advantages, limitations, and implications; related ethical and legal considerations; and implications for the family physician. At the same time, they provide evidence that anticipatory discussion and negotiation of these matters between patient and physician are too often overlooked or deferred in everyday clinical practice, frequently to the detriment of the patient and family.

The increasing use of advance directives in the United States in the last few years is part of a fundamental societal shift in attitudes toward terminal care and dying. In 1900 most Americans died at home surrounded by family, friends, and clergy.<sup>2</sup> Today, about 80 percent of the terminally ill die in institutions, which tend to separate the patient from family and support systems.<sup>3</sup> Today's emphasis on specialization and subspecialization, together with advanced diagnostic and therapeutic technology, often places "curative" care in conflict with "carative" care for the terminally ill. One study, for example, of the last two weeks of care of terminal cancer patients showed that diagnostic and therapeutic interventions were continued until the day of death for most inpatients.<sup>4</sup> Keene<sup>5</sup> has observed that "the real terror for the institutionalized dying is not death, but mechanical maintenance without medical purpose, wrists restrained by leather bonds so that tubes cannot be removed, potentially continuous pain, and the ultimate indignity of having one's remaining days controlled by strangers." In response to these concerns, there is a growing wave of public sentiment for rehumanization of the dying process, as reflected in the passage of natural death acts in many states, the growth of hospice programs in the United States from one in 1974 to more than 1,600 today, and the growing use of living wills or other forms of advance directives.

There is ample evidence that much remains to be done in order to meet the individual needs for dying patients in everyday practice. For example, in a recent study of "do not resuscitate" (DNR) decisions in a medical intensive care unit of a 1,000-bed hospital, Youngner and his colleagues<sup>6</sup> found that 14 percent of more than 500 study patients received DNR designations. There were no written justifications for the DNR decisions in 42 percent of these patients. The extent to which patients participated in these decisions was unclear for many of these patients, and only 12 percent of justifications were recorded as based on patients' desires as such (most justifications were based on poor prognosis or unsatisfactory prospective quality of life). Moreover, the DNR patients actually consumed more resources than non-DNR patients, both before and after DNR orders (eg, use of ventilators, vasoactive drugs, antiarrhythmics and Swan-Ganz catheters).<sup>7</sup> In yet another large teaching hospital, only 19 percent of patients experiencing resuscitation had discussed this matter before the occasion arose, and one third of resuscitated patients later stated that they had not wanted to be resuscitated.<sup>7</sup> In another important study, Freeman and his colleagues<sup>8</sup> found that physicians tend to avoid discussing potential treatment options with patients who have a potentially short trajectory of dying (eg, coronary heart disease), doing so more often with patients with longer dying trajectories (eg, cancer, and other advanced chronic diseases).

Until recently, the individual patient and his or her physician had relatively few guidelines to assist them in working through these difficult issues, especially in terms of ethical and legal considerations. Today the situation is quite different, and there are a variety of mechanisms available to patients and their physicians in providing on a prospective basis for individualized advance directives that are ethically and legally sound. For example, legislation has been passed in 20 states assuring binding legal force to advance directives for palliation-only treatment of terminally ill patients who

are no longer competent to make treatment decisions; 42 jurisdictions extend the durable power of attorney to health care decisions, and 17 states provide for proxy consent for medical procedures on the patient's behalf.<sup>9</sup> Two publications are now available to physicians that are especially useful in clarifying the role and limitations of advance directives<sup>1</sup>:

1. *President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to Forego Life-Sustaining Treatment*. Government Printing Office, 1983.

2. *Quality of Care for the Terminally Ill: An Examination of the Issues*. Gardner, K (ed). Chicago, The Joint Commission on Accreditation of Hospitals, 1985.\*

In a paper describing terminal care in a rural practice in Australia, Gates<sup>10</sup> has pointed out that dying patients have five basic requirements: (1) independence, (2) dignity, (3) acceptance by others of an individual approach to dying, (4) relief of symptoms, and (5) physical care. Family physicians are in an ideal position to assist their patients to meeting their individual needs by encouraging prospective discussion of loca-

tion and type of terminal care while at the same time providing sufficient advice that advance directives can be prepared to assure that the patient's desires are carried out.

References

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\*Available from the Joint Commission on Accreditation of Hospitals, 875 N. Michigan Avenue, Chicago, IL 60611