



## Guest Editorial

# The Opportunities of Caring at the End-of-Life

by David A. Fleming, MD

Physicians often withdraw from the dying patient. Paradoxically, trust and continued commitment to patients and families are never more important than at the end-of-life.



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### Introduction

More than a million Americans die each year and physicians are challenged almost every day with patient suffering and the often-agonizing process of dying. Patients and their families also face difficult choices about the quality of life they desire and the kind of care they need at the end-of-life. Though death can be dramatically delayed by the ever-expanding capabilities of medical technology, ultimately it cannot be defeated. Unfortunately, the culture of medicine has been slow to accept death, and only then when further treatment is clearly futile. This delay in acceptance also tends to delay referral to hospice and palliative care services at a time when patients may need these services the most. Physicians may also be prone to withdraw from the patient, as death is eminent, feeling that their skills of diagnosis and treatment are no longer necessary. Paradoxically, trust and ongoing commitment by the physician are never more important, nor is it ever more needed, by the patient than at the end-of-life.

Over the past several years patients and health care providers have recognized this concern and are developing greater understanding about death and dying. Physicians are now

learning the importance of knowing and respecting the wishes of their patients' and optimizing care at the end-of-life. The Study to Understand Prognosis and Preferences for Outcome and Treatment (SUPPORT) study in 1995 documented that dying is unnecessarily painful and costly, and that physicians often do not understand patients' wishes.<sup>1</sup> In 1997 the Institute of Medicine reported, "People have come to fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress."<sup>2</sup> In 1996 the Robert Wood Johnson Foundation launched *Last Acts*, a national campaign to promote improvements in care and caring near the end-of-life. This initiative has promoted health policy and communicated with health care provider and consumer groups about the need to optimize end-of-life care.<sup>3</sup> These initiatives are working to insure that seriously ill and dying patients receive the best care available and have the fullest understanding about the kinds of care available at the end-of-life.

*Missouri Medicine* is joining in this effort with the publication of this two-issue series on the end-of-life and palliative care. In attempting to address

these concerns the authors emphasize that much can be offered to patients and their caregivers to ease the many forms of suffering and the burden of care. We have learned that pain relief is often a major challenge, but that satisfactory relief can be attained by a systematic clinical approach to the patient with appropriate use of the various modalities available.<sup>4</sup> Using

terminal illness is an important consideration. Such referrals can often be the most effective means by which physicians address the needs of their patients in the terminal months of life. Bringing together multidisciplinary expertise meets the multiple needs of patients and their caregivers.<sup>9</sup>

End-of-life care encompasses more than assessing the needs of

state of end-of-life care is the 1999 American Medical Association introduction of EPEC Project (Education of Physicians on End-of-Life Care).<sup>13 14</sup> The goals of EPEC are to help physicians and other health care providers develop the skills and confidence that will enable them to provide good end-of-life care, strengthen physician-patient

relationships, and enhance personal satisfaction with the interaction and care they provide patients and their caregivers. EPEC is a modulated program with four plenary presentations and 12 modules that cover a wide range of clinical decision-making and the basic concepts of interdisciplinary supportive care. Though EPEC is not an attempt to make every

physician an expert in palliative care it will enable greater competence through skill building and enhance confidence for physicians who face the difficult and challenging circumstances of suffering and dying. EPEC instructors are available in Missouri, including several faculty of the University of Missouri – Columbia School of Medicine, and the authors of this end-of-life series.

The barriers and pitfalls to effective end-of-life care may be challenging but they are not insurmountable.<sup>15</sup> The means to provide effective relief of suffering and to optimize the quality of life of patients and their caregivers are available and can be accessed through the resources provided in this series of articles and through referral to specialists in palliative care and hospice services. As the needs and expectations of patients and their families become more challenging with the progression of disease and effective treatment

## End-of-Life Information

ON THE WEB

*The Inter-Institutional Collaborating Network on EOL Care (IICN)* <http://www.growthhouse.org/iicn.html>

*EPEC Curriculum and more* <http://www.epec.net>

*The EOL Physician Education Resource Center* <http://www.eperc.edu>

*Last Acts* <http://www.lastacts.org>

controlled substances effectively and fearlessly is necessary to optimize pain relief for the patient, but this is not done without compelling ethical and legal considerations.<sup>5</sup> We have also learned that there are many forms of suffering besides pain, such as dyspnea, gastrointestinal symptoms, and edema, that are equally challenging to the physician and often more disconcerting to the patient than pain.<sup>6</sup> Addressing the needs of the patient also includes assessing spiritual and emotional distress, which can be overwhelming for the patient and their loved ones as they struggle with the fear and anxiety that surrounds death.<sup>7</sup>

How and whether information is introduced in end-of-life discussions may also be culturally influenced.<sup>8</sup> This is an important understanding for Missouri physicians because we are becoming increasingly culturally diverse in our state. The effective use of palliative care services and referral to hospice care early in the course of

patients, and extends beyond the care of patients with cancer. We are in the midst of an aging population and there is an exponential growth of patients being diagnosed with Alzheimer's disease.<sup>10</sup> This is of major concern when considering the use of health care resources and the increasingly important challenge to physicians to help older patients and their families decide about end-of-life care.<sup>11</sup> As our country ages there will be more cancer patients and others with terminal illnesses. This also means that nonprofessional, and unreimbursed, caregiving is increasingly important in the overall scheme of end-of-life care. The risks of caregiving are significant and recognition of caregiver needs is important to the overall success of end-of-life care and the trust relationship that forms between the physician and the patient-caregiver unit.<sup>12</sup>

Another contribution to help bridge the gap between patient and family expectations and the current

diminishes, the opportunities for care become more compelling. Through skill building, awareness, and insight physicians have the opportunity to enhance their relationship with patients near the end-of-life. By doing so they meet the needs and expectations of patients and their families by crafting a trusting and committed relationship of care.

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