Despite his incurable illness and untimely death, Ron’s friend was fortunate compared to many Americans who succumb to life-limiting illnesses. He had a friend with medical expertise to help with the complex and confusing choices that patients face at the end of life; however, he died wishing he had better communication with his oncologist. He maintained a large degree of control over the type, amount and settings in which his care was provided, and ultimately died peacefully at home surrounded by loved ones.

Sadly, many Americans experience circumstances where their choices for care at the end of life are unheard or overlooked and often end up dying with poorly controlled symptoms in hospitals or nursing homes. Why does this happen and what can we as physicians in Arizona do to improve end of life care for our patients?

By the late twentieth century the impression that technology could stave off dying became very powerful and to many in the medical establishment, death became equated with failure, rather than as a natural inevitable part of the life experience. Discussing death or providing a negative prognosis became virtually taboo under the false premise that providing honest information would destroy hope for both patients and their families.

The American health care system remains heavily focused on sophisticated acute inpatient care and is woefully inadequate to address the needs of frail elderly patients with multiple chronic conditions who comprise a majority of those who die in the United States, particularly as the Baby Boomer generation ages. “As an Emergency Medicine physician, I am saddened at how many patients end up in the [Emergency Department] when they would be far more humanely served in a palliative or hospice care setting,” states Alan Molk, MD.

A substantial percentage of Medicare spending continues to occur in the last six months of life, often on interventions...
that provide little or no benefit, which is neither clinically appropriate nor financially sustainable. There are myriad reasons for this, including “perverse” financial incentives that favor more care, regardless of the chance of benefit; perceived legal risks for physicians who do not acquiesce to “do everything,” even when they believe such efforts are futile; avoidance of advance care planning; and lack of understanding by both patients and physicians alike of the role and benefits of palliative care and hospice and/or the availability of such services.

Jud Tillinghast, MD, a retired critical care specialist reflects, “Addressing the difficult questions surrounding end of life is a daily problem in the ICU. I have seen family members divided and agitated, demanding aggressive care even if it only prolongs a patient’s suffering. We need more physicians (primary care, specialists, hospitalists and critical care) to communicate clearly and sensitively with patients facing a terminal condition, with assistance from the palliative care team, to help families honor the wishes of their loved ones and ideally to do this before a crisis occurs that results in the ICU admission.”

Many of the deficiencies in end of life care in the United States, and possible solutions, were highlighted by the Institute of Medicine in its 2015 report, Dying in America. A key message for physicians was to initiate advance care planning discussions as early as possible for individuals with serious illness. This is a role that most physicians fail to address, most often citing lack of time, inadequate reimbursement and inadequate training. Furthermore, when they do conduct such discussions and prognosticate regarding survival, physicians tend to be overly optimistic and overestimate life expectancy in order to not decrease their patients’ hope, which may be well-intentioned but is usually counter-productive.

Cottonwood cardiologist Bruce Peek, MD, states: “How we assist patients and their families during the dying process is just as important as how we assist them to prolong life. Educating patients and families regarding the nature and prognosis of their disease throughout the course of their illness, and eliciting their goals and preferences along the way is essential to what we do.”

The increase in palliative care programs and the recent emergence of hospice and palliative medicine as a recognized medical specialty have been beneficial. “Palliative care is specialized supportive care for people with serious illnesses and is provided by a team of doctors, nurses and other specialists. Unlike hospice care which is indicated for patients with a life expectancy of 6 months or less, palliative Care is focused on providing comfort and appropriate at any stage of a patient’s illness to help with symptom management, address psychosocial and spiritual aspects of illness, and define and meet patients’ and families’ goals of care,” explains Stacie Pinderhughes, MD, Director of Palliative Care at Banner Health. “Numerous studies have demonstrated that the involvement of Palliative Care teams can increase patient and family satisfaction with their care and a landmark study in the New England Journal of Medicine demonstrated that Palliative Care services reduced the incidence of depression and actually prolonged survival in patients with advanced lung cancer.”

Still, major gaps in end of life care persist. Many patients today also want more options as they face the end of life. This has fueled efforts and passage in numerous states of so-called “Medical Aid in Dying” or “Death with Dignity” legislation that provides a legal framework for physicians to prescribe medications by which patients with terminal illness can end their lives.

The Task Force on End of Life Care created by the Arizona Medical Association (ArMA) and the Arizona Osteopathic Medical Association (AOMA) is a multispecialty group of physicians from around Arizona. The mission of the Task Force is to assess the state of end of life care in Arizona and offer practical options to improve care for patients across our state. The group initially prioritized three areas:

1. **Education.** How can we provide effective, convenient and accessible educational efforts for both physicians and the public, and to help physicians increase their skills in end of life care? We also want to determine the level of interest of primary physicians, hospitalists, and specialists in Arizona if such training were made available.

2. **Access to Palliative Care.** How can we assist to increase the availability and accessibility to hospice and palliative care services for patients across Arizona, and to enable advance care planning to occur earlier when it may be more beneficial?

3. **Policy.** Assess Arizona physician attitudes regarding Aid in Dying legislation and other end of life care issues which may be subject to legislative efforts.

The first goal of the Task Force is to gather as many physician views as possible on these issues. To that end, the Task Force will send a survey to as many Arizona physicians as possible. Your feedback will help us transform the care our patients receive at their most vulnerable time in life. As Carla Denham, MD, a psychiatrist and member of the Task Force, observed, “I was not really surprised to learn that conversations about death and dying are often rewarding to patients and their families, since they frequently help to reduce fear and clarify treatment goals. What was surprising was how those same conversations alleviated my own fears as well.”

To learn more about the Task Force and its members, view article references, or to sign up for updates from the group, please visit www.azmed.org/general/custom.asp?page=endoflifecare.

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Ron Fischler, MD, is a pediatrician in Scottsdale who has developed a strong personal interest in end of life issues. He has held leadership roles at Scottsdale Healthcare and in the Arizona Academy of Pediatrics and Arizona Medical Association. He is an Associate Clinical Professor at the University of Arizona College of Medicine.