While everyone has heard of hospice and has some idea of the care provided, myths and misunderstandings about this type of care abound. Having frequently found myself in the position of needing to provide a clearer picture of modern hospice care, I am taking this opportunity to record the basics that all physicians should know.

Hospice is not about giving up hope and resigning oneself to death, leading to a self-fulfilling prophecy. The current state of the science is such that physicians can determine when a cohort of individuals with certain characteristics are likely to die, within a six-month time frame. I would emphasize that these deaths will occur regardless of the presence or absence of hospice. Hospice is about relieving distressing symptoms and improving the quality of life for those whose death is already likely to occur. Hospice doesn’t emphasize the death part, but rather the living to the fullest part during those days, weeks, and months leading up to that final departure.

While prognostication is relatively accurate for populations, it is less so when considering individuals. That is why the standard to which physicians are held in determining an individual’s prognosis, as codified in the law authorizing the Medicare Hospice Benefit (MHB), is that the “individual’s prognosis is for a life expectancy of six months or less if the terminal illness runs its normal course.” Regulatory clarifications have added further light that this is a ‘more likely than not’ standard, rather than one of ‘beyond reasonable doubt.’ If someone lives longer than six months, that reflects prognostic uncertainty and there are no penalties when this occurs. Because an individual’s prognosis does sometimes change, the MHB has provisions for ongoing periodic review of prognosis in order to continue hospice services.

While six months is the standard, 50% of American hospice patients die within three weeks of hospice admission. Over one-third receive hospice services for only one week. Such late referrals often stem from a lack of consideration of the patient’s prognosis until the trajectory toward death is far advanced, meaning many futile or nonbeneficial treatments, with associated treatment burdens, are being offered instead of hospice care. Studies show that the better a physician knows a patient, the more likely he or she is to defer having a conversation about hospice.

This is unfortunate since several well-designed recent studies have shown that changing to a more palliative course of care actually increases longevity, presumably by reducing a person’s stress – both physical in terms of symptoms and emotional in terms of improved support. This is also associated with improved satisfaction ratings regarding the care from patients, family members, and healthcare providers.
Virtually every other certification that we, as physicians, complete is based on medical necessity; however, this is not the case for hospice, which is based purely on prognosis. This is because hospice provides interdisciplinary care involving not just medical/nursing care, but also emotional/spiritual/psychosocial support by chaplains, social workers and others, personal care by hospice aides, and whatever other care is deemed necessary for someone who is coping with a terminal prognosis. Such interdisciplinary care ensures that treatment is specifically individualized to meet all of a patient’s care requirements. Many of these needs have nothing to do with medical necessity, but are still covered by the MHB that pays for >85% of the hospice care provided in the U.S. Most other insurers offer similar coverage.

Cancer is the diagnosis most commonly associated with hospice care; however, in the U.S., cancer diagnoses represent neither the most common cause of death nor the majority of hospice diagnoses. Any diagnosis that may be listed on a death certificate may be a patient’s hospice diagnosis. In addition to cancer, heart disease, COPD, and other pulmonary conditions, chronic neurologic conditions such as Alzheimer’s disease and Parkinson’s, stroke, liver disease, renal disease, and other conditions such as adult failure to thrive are routinely managed by hospice. Because of the broad diversity of conditions now managed by hospice, greater expertise is demanded in managing the care and symptoms associated with these conditions. This has led to the rapid emergence of Hospice and Palliative Medicine (HPM) as a field that was virtually unknown two decades ago to a completely recognized subspecialty certification for physicians today.

More and more, hospice care is provided with the benefit of HPM-certified physicians who work with the patient’s attending either as consultants, or if preferred by the attending, as the primary managing physician. Increasingly, this has led to improved quality of care and efforts to systematically evaluate and quantify such quality care using evidence-based measures.

Hospice should no longer be considered fringe medicine outside the scope of standard medical practice. With over 44% of Medicare decedents receiving hospice care at the time of death, hospice is mainstream medicine. A colleague once asked me, “Are you saying that all dying patients should receive hospice care?” I answered that hospice should not only just be offered, but actively encouraged for every patient eligible to receive it. These are truly the sickest of the sick for whom hospice care has a clear track record with the best outcomes by providing carefully tailored care that meets each individual’s unique needs.