How to care for intensive care patients at the end of their lives represents one of the hardest dilemmas facing a physician. Once agreement has been reached that the patient’s prognosis is hopeless and that any further treatment would be futile – a process fraught with difficulty in and of itself – the physician is faced with multiple and often conflicting imperatives regarding the remainder of the patient’s stay in the intensive care unit (ICU). Questions arise regarding the sanctity of life, quality of life, how much treatment is necessary to ensure that the patient is free of suffering, which aspects of the patient’s current treatment should be maintained and which discontinued, and issues of how best to utilize limited resources. These issues are compounded by the frustration and disappointment of “failed” medical or surgical treatment, the necessity to convey bad news and to reach difficult decisions with the patient and/or patient’s family and the pressures of inadequate ICU beds and staff.

Once a patient’s condition is deemed incurable, the physician and patient/family are faced with four options: (1) to continue all therapy and institute new treatments as necessary, (2) to continue existing treatments but withhold new therapies, (3) to withdraw existing treatment or (4) to expedite the patient’s demise in an active manner. Today, the majority of patients dying in the ICU do so after treatment has either been withheld or withdrawn [1]. In a recent study of 5910 ICU deaths [2], death was preceded by the withholding of treatment in 14%, by withdrawing treatment in 36%, by full treatment excluding cardiopulmonary resuscitation (CPR) in 24% and in only 26% of the patients studied was death preceded by full treatment including CPR. Similarly, up to 96% of ICU physicians have at some point withheld or withdrawn treatment [3, 4, 5, 6] and these numbers have been increasing over recent years [7, 8]. The type of treatment a particular patient will receive results from a complex, and only partially established, interaction between the physician, the patient and/or their family and their environment. The physician’s decision or recommendation to the family seems to depend on his/her assessment of the patient’s quality of life, prognosis, diagnosis, advance directives, premorbid cognitive function, chance of long-term survival and the patient’s age [5, 7, 9]. The doctor’s religion [4, 5] and specialty [10, 11, 12] may also influence decisions and older doctors [3, 4] or doctors in private practice [5] are less likely to withdraw or withhold treatment. Fear of prosecution has also been cited as a relevant factor [3, 13, 14], although this may be overrated.

The roles of the patient, family and physician in the decision-making process at the end of life are addressed in the important study by Sjokvist et al. in this issue [15]. Their data indicate that the public is interested in more autonomy for the patient and family in making decisions. What evidence is there, however, that families are able to accurately predict their loved ones desires when ill in the ICU? Several studies have shown that agreement between proxies and patients ranges between 50% and 88% [16, 17, 18, 19, 20], although only in one of these studies was agreement significantly better than chance [19]. One study showed that of the children who stated that they knew what their parents resuscitation preferences were, only 46% were willing to abide by these requests [17]. Proxy decisions have also been shown to err approximately equally on the side of “over” and “under” treatment when compared to the...
patient’s wishes [18, 19]. In any event, patients have a strong expectation that family members will decide for them and perceive this as extending their autonomy [21].

The ability of doctors to predict their patients’ wishes seems to be even poorer than that of families, with agreement ranging from 47% to 72% [9, 10, 19], but never being significantly better than chance. Doctors tended to want to withhold more treatment than the family members or patients themselves did. Perhaps a cause for this poor correlation of opinions is inadequate communication between doctors, patients and families. Indeed, only 7%–46% [4, 10, 19, 22] of patients and 6%–57% [4, 19, 22] of families reported ever discussing their resuscitation preferences with a doctor. Similarly, complaints about the degree or quality of communication between doctors, patients and families are frequently found to be high on the list of reasons for dissatisfaction with ICU care [22, 23, 24, 25, 26].

The environment is perhaps the most powerful factor influencing the decisions made at the end of life. The environment in this context may mean the country (end of life practices vary from conservative in Japan to liberal in the Netherlands), the region within a country [9, 27], or even the type of hospital (for example, withholding treatment has been shown to be more prevalent in a community hospital than an academic institution) [28]. Differences in customs, beliefs and religions in different environments clearly affect decisions made by physicians, patients and families as one. If withholding care at the end of life is not something that is spoken about, considered normal or is even taboo, then clearly the medical staff will not suggest it, nor will the patient/family request such care. The opposite may also be true. If euthanasia were to become the norm at the end of life in a particular country, then peer pressure might influence more patients, families or physicians to select this option. As the implementation of the chosen treatment plan remains in the hands of the physician, it is beholden upon him/her to maintain an objective viewpoint and to attempt to view each case as individual and advise the patient or family according to their needs and wishes. Similarly, independence of decision making must be maintained despite pressure arising from limited resources, patient overload and budgeting bodies.

At present, there appears to be no “correct” answer or formula for making end of life decisions, and this is demonstrated by the great variability in decisions made and their implementation. In the study of 5910 ICU deaths cited earlier [2], although a mean of 14% had treatment withheld, the percentage ranged from 0% to 67% across different participating hospitals. For withdrawal of treatment, the range was 0–79%, for full treatment excluding CPR, 0–83% and for full treatment including CPR, 4–79% [2]. Similarly, agreement could not be reached between physicians on patient care in 12 scenarios – the implication being that personal values seem to influence doctors’ decisions more than objective details of the patient’s case [27]. Finally, although patient autonomy is thought to predominate in the United States (and to be more prevalent than amongst “paternalistic” European physicians), many US physicians do not comply with patients’ or their families’ requests. In a survey of 879 US physicians (of whom 96% had withdrawn or withheld treatment on the expectation of a patient’s death) [3], 23% and 25% had withdrawn or withheld treatment without the patient’s or family’s consent, 12% and 14% without their knowledge and 3% despite the objections of the patient or family. At the other end of the spectrum, 34% of the physicians had continued therapy despite requests to stop them.

Enhancing communication between patient and physician has been advocated as a major method to improve patient outcome. Unfortunately, the SUPPORT study demonstrated that this may be inadequate to change established physician practices [10]. The European Society of Intensive Care Medicine’s Ethics Section has recently embarked on a major project to study the ethical, medical, legal and sociological aspects of end of life decision making in the ICU. The attitudes of physicians, nurses, patients and families throughout Europe regarding end of life issues will be assessed, and the data collected used to develop practice guidelines, consensus statements and public policy recommendations.

References