

## Dying Patients in the Intensive Care Unit: Forgoing Treatment, Maintaining Care

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End-of-life care of patients in the intensive care unit (ICU) often requires dramatic shifts in attitudes and interventions, from traditional intensive rescue care to intensive palliative care. The care of patients dying in ICUs raises both clinical and ethical difficulties. Because fewer ICU patients are able to make decisions about withdrawing treatment, careful attention must be paid to previously expressed preferences and surrogate input. Cultural and spiritual values of patients and families may differ markedly from those of clinicians. Although prognostic models are increasingly able to predict mortality rates for groups of ICU patients, their usefulness in guiding specific decisions to forgo treatment has not been established. When a decision to forgo treatment is made, the

focus should be on specifying the patient's goals of care and assessing all treatments in light of these goals; interventions that do not contribute to the patient's goals should be discontinued. Symptoms accompanying withdrawal of life support can almost always be controlled with appropriate palliative measures. After ICU interventions are forgone, patient comfort must be the paramount objective. Whether in the ICU or elsewhere, hospitals have an ethical obligation to provide settings that offer dignified, compassionate, and skilled care.

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Up to 60% of deaths in the United States occur in acute care hospitals (1), and of these, 75% occur after decisions to forgo treatment (2, 3). Although such decisions are common in the intensive care unit (ICU), the care of dying patients raises both clinical and ethical difficulties. For example, in one survey, most ICU nurses and physicians stated that ICU interventions were often burdensome and used inappropriately (4). Although ICUs present many challenges to providing excellent end-of-life care, they also have special resources available (for example, a low patient-nurse ratio that allows careful titration of intravenous medication to control dyspnea during ventilator withdrawal).

This paper aims to help clinicians improve the care provided to ICU patients and families when decisions are made to limit life-sustaining treatment. It challenges the misconception that such decisions are decisions to withdraw care (5). In addition, it challenges physicians and nurses to care for dying patients with the same attention to detail, critical thinking, and compassion that they use in caring for ICU patients who are expected to survive.

### PATIENT CASE

*Mr. McGee is a 79-year-old minister admitted with acute abdominal pain. He has been well except for complete heart*

*block, which requires a permanent pacemaker. He lives at home and cares for his disabled wife. A perforated bowel is diagnosed, and he undergoes emergency surgical repair. Post-operatively, in the ICU, he develops the acute respiratory distress syndrome, renal failure, and candidal peritonitis. Mechanical ventilation and hemodialysis are begun. During the next 3 weeks, his mental status deteriorates so that he can no longer engage in conversations or follow commands.*

*The ICU physician tells Mrs. McGee that her husband's chance of surviving is less than 10% and that even if he does survive, he will need long-term ventilator support and dialysis. Although Mr. McGee has no written advance directive, his family is certain that he would not want ICU care continued given these prospects.*

### DECIDING TO WITHDRAW LIFE-SUSTAINING INTERVENTIONS

Although the basic values underlying end-of-life decision making (6-8) are not unique to the ICU, the setting presents unique challenges to the process. The ethical aspect of forgoing treatment resides in the legal and ethical right of the patient to determine what should happen to his or her own body. An adult patient with decisional ca-

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capacity must be informed of reasonable treatment options and their possible outcomes. Patients who decide to forgo life-sustaining treatment should have these decisions honored. As a rule, a patient's considered decision should override contrary opinions of family or physicians, no matter how well-intentioned the opposing views may be.

When patients who cannot make decisions are concerned, the issues become more complicated. Before admission, Mr. McGee was fully capable of decision making, and conversations about his preferences for life support may have helped his family make decisions on his behalf. However, 60% to 70% of seriously ill patients, like Mr. McGee, are unable to speak for themselves when decisions to limit treatment are considered (3, 9). Although advance directives allow patients to specify preferences in advance, they have limited usefulness, and only 10% to 20% of patients even complete them. Living wills generally apply only if a patient is terminally ill or permanently unconscious, categories that are inapplicable to many ICU patients. Moreover, patients with advance directives may receive the same care as those without them (8) or may not want them followed literally (10).

In the absence of a proxy designated by the patient, it is helpful to identify a single surrogate decision maker (or, if decisions are made by consensus within the family, a single spokesperson). The surrogate should know the patient well and be willing to serve as the patient's representative. In order of preference, decisions should be made on the basis of 1) the patient's previously stated wishes; 2) inferences based on the patient's values or life goals; or 3) the patient's best interests, as judged by weighing the benefits and burdens of treatment. Many states stipulate surrogates by using a legal hierarchy. However, the legally mandated person and the ethically appropriate person may sometimes differ. For example, a daughter may know much more about her father's preferences than a separated wife. For this reason, all capable patients should be urged on admission to the ICU (if not before) to advise caregivers about how to make decisions and should designate a health care proxy.

Clinicians in the ICU should guide the proxy or surrogate through the decision-making process. Information should be given by using understandable terms and avoiding jargon. In addition, ample time should be allowed for discussion and repeated conversations. If a patient is expected to remain in the ICU for more than 2 days, holding a meeting with the patient and family within 48 hours of

admission (and periodically thereafter) can help identify the appropriate goals of ICU treatment. These goals should be reevaluated by considering the patient's course and determining whether current interventions remain consistent with the treatment goals. Participants in such meetings vary but often include the patient's ICU and primary care physicians, nurses, consultants, family, close friends, religious advisor, and, most important, the patient (if possible).

### Spiritual Needs and Cultural Values

Spiritual and religious issues are often significant factors for patients and families who are confronted by the possibility of death. An overwhelming sense of personal loss, with associated emotional and spiritual suffering, are often at the core of a dying person's and family's experience (11). Clinicians should routinely ask patients and families whether spiritual needs are being met and, if not, how the hospital's resources might be more helpful. Chaplains, social workers, and others skilled in supporting people through personal loss can be invaluable. The importance of dealing with the grief, spiritual issues, and emotions of family members emphasizes the need for multidisciplinary approaches.

In addition, clinicians in the ICU should be aware of cultural differences in making decisions at the end of life. People from some cultures may be less willing to discuss resuscitation status or to forgo life-sustaining treatment (12–14) and may be less likely to complete advance directives (15, 16). Cultural and religious knowledge, sensitivity, and respect are essential when ICU staff discuss limiting life support.

### Use and Limits of Prognostic Models

Recent advances in the use of prognostic models have improved objective predictions of hospital mortality rates for ICU patients. However, difficulty in determining if and when an individual patient will die remains a major obstacle to providing end-of-life care in the ICU. For example, the Acute Physiology and Chronic Health Evaluation (APACHE) III prognostic system (17) provides point estimates of mortality with 95% confidence intervals for the day of ICU admission, with updated predictions for subsequent ICU days. This and other models have been validated to predict outcomes of groups of patients (17–19). No controlled evidence, however, shows that prognostic models improve end-of-life decision making for individual

**Table 1. Limitations of Prognostic Models for End-of-Life Decision Making in the Intensive Care Unit**

Prognostic models give probabilities of survival or death rather than a “yes” or “no” answer; because of 95% confidence intervals, no model can statistically exclude survival even in the most severely ill patients

Individual accuracy of these predictions depends on whether a specific patient’s medical condition was reasonably well represented in the population from which the model was derived

Most models derive their predictions from factors present at or shortly after admission to the intensive care unit and do not provide updated mortality estimates as the patient’s condition changes

Some patients have inherently unpredictable courses

Conventional models of patients in the intensive care unit predict only hospital survival, not long-term survival, functional status, or quality of life after hospital discharge

patients. The prognostic model developed for the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) provides 2- and 6-month estimates of survival, but this information has been shown to have minimal impact on end-of-life care for patients with serious illnesses (20).

Given these limitations, would sophisticated ICU prognostic models have aided decision making for Mr. McGee? Possibly. However, most clinicians already incorporate some type of probabilistic reasoning when discussing prognosis with patients and families. Having objective estimates of survival may complement physician estimates and may help “plant the seed” in the minds of family members who have difficulty accepting that their loved one may die in the ICU. Because current prognostic models have considerable limitations, however, clinicians should use them only as an adjunct to the process of shared decision making (Table 1).

### WITHDRAWING LIFE-SUSTAINING INTERVENTIONS

*After discussions with Mrs. McGee, a do-not-resuscitate order is written and dialysis is stopped. The ICU attending physician suggests that the ventilator also be discontinued, and the family agrees. Before ventilator support is stopped, vasopressors and all medications except morphine and midazolam are withdrawn. The resident discontinues enteral feedings but restarts them an hour later at the attending’s request.*

### Practice Variations

Mr. McGee’s care presented physicians and family with many decisions. Was the ICU the best place to care for him? Which interventions should be continued, and which should be stopped? Is “artificial nutrition” different from other life-sustaining treatment?

The practice of withdrawing treatment in ICUs has evolved during the past 20 years. When initial recommendations for discontinuing ventilator support were published in 1983, withdrawing ventilators was rare (21). Since then, withdrawing dialysis, ventilators, and other interventions has become much more common (22, 23). A study of 136 ICUs found that 74% of 5910 dying patients had some form of treatment withheld or withdrawn before death (2). However, interinstitutional variation was striking. Individual ICUs reported that anywhere from 21% to 96% of deaths were preceded by treatment limitation, and some ICUs reported no instances of withdrawing life support. This variation raises the question of whether these practice differences reflect physician or institutional values that ignore patient preferences.

### Patterns of Forgoing Life Support

Forgoing treatment may occur as a single, complete change in direction or may occur over time as specific treatments are gradually discontinued. In either case, procedures involved in forgoing treatment are inherently complex in ICUs, where several interventions are often in simultaneous use (24). It is important to note that in Mr. McGee’s case, not all life-sustaining treatments were stopped simultaneously, enteral feedings were restarted at the attending’s request, and inactivation of the pacemaker was not considered.

When several interventions are in use, a somewhat predictable pattern of withdrawal often occurs. First, dialysis, further diagnostic workups, and vasopressors are discontinued. Next, intravenous fluids, hemodynamic and electrocardiographic monitoring, laboratory tests, and antibiotic treatment are stopped, and finally artificial feedings and mechanical ventilation are withdrawn (24). The reasons for this “stepwise retreat” are complex and may in some cases be related to the symbolic importance of an intervention (such as artificial feeding) or to how immediately withdrawal of an intervention (such as a ventilator) leads to death. Physicians may also be less likely to withdraw interventions that treat iatrogenic problems and more willing to withdraw therapies related to their own subspecialty (25, 26). Surrogates may find it easier to decide to avoid beginning new interventions or to withhold antibiotics or dialysis because in these cases, the link between forgoing the intervention and death is not so obvious. However, many of these rationales do not reflect patient values and may not be ethically justified.

When considering the array of interventions that might be forgone, clinicians and surrogates should focus on clearly articulating the goals of care. Even when treatment is being withdrawn, goals vary considerably. Occasionally, the goal may be to remove a particular treatment perceived to be burdensome (for example, a ventilator that impairs communication and separates the patient from his or her family). Goals of short-term survival until important loved ones gather may justify continued ventilator support. Maintaining the ability to communicate may justify continuing vasopressors, whereas if the only goal is patient comfort, such treatment should be stopped. In general, interventions that do not contribute to achieving agreed-on goals, regardless of whether they are burdensome in their own right, should be discontinued. Throughout this process, explicit attention should be paid to measures that provide comfort to the dying patient and family. This includes assistance in completing important life tasks, such as family reconciliation, to the extent possible. Consultations with experts in palliative care can often help ICU staff provide comprehensive end-of-life care for patients and families.

### Forgoing Specific Interventions

#### Dialysis

As in Mr. McGee's case, dialysis is often discontinued when other life-sustaining interventions are stopped. Unlike withdrawing a ventilator, however, stopping dialysis is unlikely to cause immediate death. In a small series of patients discontinuing chronic hemodialysis, death occurred after a median of 9.6 days (range, 2 to 34 days) (27). When dialysis is initiated for acute renal failure, patients occasionally recover renal function after dialysis is stopped, a possibility for which families should be prepared.

Several symptoms may accompany the cessation of dialysis. Dyspnea from volume overload can be controlled by restricting fluids, by administering opioids, and, rarely, by using ultrafiltration. Pruritus may be minimized by using emollients and antihistamines. Uremic nausea may be palliated with phenothiazines or butyrophenones, which also have sedating effects and may treat coexisting mental confusion (28).

#### Artificial Feeding

The clinical and ethical issues surrounding decisions to discontinue artificial nutrition have been discussed exten-

sively elsewhere (29–32). In Mr. McGee's case, enteral feedings did not contribute to his overall comfort, nor were they specifically desired by his family. Some may feel that it is wrong to stop feedings and may even find that the feedings have symbolic benefits regardless of their nutritional benefits (33). Although attempts at oral feeding were not possible for Mr. McGee, patients able to swallow without aspirating should be offered fluids and food as part of comfort care.

Continuing Mr. McGee's enteral nutrition only because it was valued by the ICU attending physician opened the door to continuation of other, more burdensome therapies on the basis of physician preferences. In end-of-life care, the patient's values should carry more weight than those of clinicians.

#### Mechanical Ventilation

*Mr. McGee has been receiving intravenous morphine, 8 mg/h, and midazolam, 4 mg/h, for several days. Just before ventilator withdrawal, he receives intravenous boluses of 4 mg of morphine and 2 mg of midazolam. The ICU resident decreases the rate of the ventilator from 20 to 10 per minute, fractional inspired oxygen from 0.6 to 0.21, and tidal volume from 750 to 600 mL. Shortly thereafter, Mr. McGee's respiratory rate rises to 26 breaths/min. Despite no other signs of distress, the resident returns the ventilator rate to 20 per minute and the tidal volume to 750 mL.*

Although the ultimate outcome of ventilator withdrawal is almost always death, methods of withdrawal vary considerably among physicians and specialties (34–39) (Table 2). The question of which method is best calls for a critical examination of practices currently driven by tradition and emotion, as well as research into family perceptions during ventilator withdrawal. In Mr. McGee's case, his family believed that he would literally be removed from the ventilator and die shortly thereafter. In contrast, the resident expected that modest reductions in ventilator support would be sufficient to lead rapidly to death without extubation.

Patient comfort must be assessed frequently, and signs of discomfort should be treated with adequate doses of sedatives and opioids. If terminal weaning is chosen, a limited time course should be agreed on. Terminal weaning that lasts for many hours only prolongs the dying process and should be avoided. Families and staff should be prepared for the possibility that up to 10% of patients may

**Table 2. Methods of Withdrawing Ventilator Support**

Method	Positive Aspects	Negative Aspects
Prolonged terminal weaning	Allows titration of drugs to control dyspnea Maintains airway for suctioning Creates more “emotional distance” between ventilator withdrawal and patient’s death	May prolong the dying process May mislead family to think that survival is still a goal of therapy Interposes a machine between family and patient Precludes any possibility of verbal communication
Extubation	Allows patient to be free of unwanted technology Is less likely to prolong the dying process	Family may interpret noisy breathing caused by airway secretions or agonal breaths as discomfort May cause dyspnea at time of extubation, especially if anticipatory sedation is not given
Rapid terminal weaning	Maintains airway for suctioning Is less likely to prolong the dying process	Interposes machine between family and patient Precludes any possibility of verbal communication

unexpectedly survive 1 or more days after ventilator withdrawal (39).

Dyspnea and anxiety should be anticipated when ventilator support is withdrawn by any method. Intravenous opioids and benzodiazepines are the drugs of choice to treat dyspnea and anxiety or agitation, respectively. Both should be immediately available and titrated to effect. These drugs may also be given before ventilator withdrawal to prevent anticipated symptoms from occurring. The ICU clinician’s primary goal should be to ensure patient comfort and prevent suffering.

The amount of opioid or benzodiazepine necessary to relieve symptoms varies widely and depends on previous drug exposure (which induces tolerance), drug metabolism, and level of awareness. Typical doses of morphine given by continuous intravenous infusion (or repeated boluses) range from 10 to 30 mg/h. Occasionally, opioid-tolerant patients require doses of morphine at least one order of magnitude higher (for example, 500 to 1000 mg/h). Physicians and nurses should explicitly document that medications are being titrated to control symptoms. Care should focus on relieving the patient’s discomfort regardless of the amount of medication needed. In Mr. McGee’s case, ventilator support was decreased after inadequate doses of opioids and benzodiazepines. The increases in his respiratory rate that occurred after reduction of ventilator support should have been treated with additional doses of both agents, not by restoring full ventilator support.

Paralysis caused by neuromuscular blocking agents precludes the assessment of patient discomfort and the possibility of patients communicating with loved ones. For these reasons, these agents should be avoided when ventilators are being withdrawn. They should never be given

merely to make the patient “appear” comfortable. Before ventilator withdrawal, paralytic agents already in use should be stopped and their effects should be allowed to clear, or, if possible, they should be pharmacologically reversed (34, 40). If the effects of these agents persist beyond several hours (which is unusual), physicians and families should discuss the appropriateness of proceeding with ventilator withdrawal, given that patients in this situation remain at risk for unrecognized pain and discomfort (41).

#### *Electrocardiographic Monitoring and Pacemakers*

*After 30 minutes of terminal weaning, the family discusses what will happen to the pacemaker when Mr. McGee dies and how they will know he is dead if the pacemaker is still firing. Two hours later, Mr. McGee’s son asks, “How low does the blood pressure have to go for it to be over?” After another hour, he says, “Enough is enough; it’s time to stop.” The resident is contacted and decreases the ventilator rate to 15 per minute.*

*Two hours later, Mr. McGee’s oxygen saturation and blood pressure decrease precipitously. His blood pressure becomes unobtainable, although the monitor shows a paced rhythm at 80 beats/min. The ICU nurse pages the cardiology fellow, who disables the pacemaker. The monitor shows ventricular fibrillation, and Mr. McGee is pronounced dead.*

Mr. McGee’s family relied on his electrocardiographic monitor and vital signs to gauge the trajectory of his dying, even though such monitoring is relatively useless in assessing comfort or accurately predicting the time remaining until death. Why was monitoring continued at all? In some cases, its presence may distract families from attending to the patient. To avoid this, some ICUs turn off the bedside electrocardiographic display but continue to monitor the

patient at a central station. This allows staff to determine when the heart's electrical activity ceases without distracting the family.

Although Mr. McGee had a pacemaker in place, the ICU team did not consider its inactivation when the decision was made to stop life-sustaining interventions. Temporary pacemakers are more likely to elicit such considerations, but a permanent pacemaker often goes unnoticed. Pacemakers, once implanted, rarely cause discomfort. However, if a patient wants to refuse all life-sustaining treatment, a permanent pacemaker or an implantable defibrillator should be inactivated (42, 43). The outcome of this action is unpredictable, however, because it is difficult to know what intrinsic rhythms will persist.

In Mr. McGee's case, no one anticipated that the pacemaker would interfere with the pronouncement of death. This exemplified the overall lack of detailed planning by the ICU attending physician, housestaff, and nurses in coordinating Mr. McGee's end-of-life care. At several points during ventilator withdrawal, the ICU resident was left alone to make treatment decisions without adequate knowledge or a clear plan of how to proceed. The resident's actions and inactions attest to the need for expert guidance from experienced clinicians. Attending physicians should not assume that residents instinctively know how to go about withdrawing treatment, much less that they know how to effectively palliate patient symptoms or address emotional or spiritual issues.

### WHERE TO CARE FOR PATIENTS FORGOING LIFE-SUSTAINING TREATMENT

After invasive measures are discontinued, transfer to a general floor may be appropriate. However, an ICU patient should not be discharged to an inpatient unit that lacks resources to provide medically necessary care and ensure comfort. If such a transfer must occur because of triage pressures, the institution has an ethical obligation to provide additional resources that will ensure delivery of care at the necessary level. When available, a dedicated palliative care or hospice inpatient unit may provide excellent care to the patient and family. Some hospitals have palliative care units for patients being withdrawn from life-sustaining treatment, and these allow a level of expertise that is unattainable in less specialized settings (44). However, transfers to such units may disrupt established relationships between clinicians and patients or families.

If the patient remains in the ICU, continuity of nursing and physician care is provided. However, this option may be too expensive or may result in unavailability of ICU beds for other patients. Most patients die within several hours of withdrawal of life-sustaining treatment (45, 46). They should remain in the ICU if they require intensive palliative care that no other unit has the resources to provide. Under these circumstances, the ICU staff must be knowledgeable in providing such care and must accept the fact that intensive palliative care is as legitimate a part of their mission as rescue care (47).

When the ICU is judged to be the best available place for the dying patient, attention should be paid to the ICU environment (48). People often prefer to die at home in familiar and comfortable surroundings, with friends and family nearby (49). Although going home to die is impossible for ICU patients, bringing aspects of "home" desired by the patient into the ICU may be feasible and should be strongly encouraged (Table 3).

### CONCLUSION

The care of patients dying in the ICU often requires a dramatic shift from the "rescue" mode to approaches that recognize death's inevitability and focus on patient and family comfort. Such a shift requires reaching consensus with the patient or family about the goals of ICU care. In addition, clinicians must have a well-developed plan and the clinical skills and knowledge to meet the physical, emotional, and spiritual needs of dying patients and their families. These skills must not be assumed but can be learned through formal education programs and by observing positive role models. Further research on decision making;

**Table 3. Ways in Which Intensive Care Units Can Simulate a Home Environment for Dying Patients**

Transportable Aspect of a Patient's Home	Ways To Provide This Aspect in the Intensive Care Unit
Privacy	Provide a private room Close doors and curtains
Ready access to family	Suspend restrictive visiting hours Provide comfortable chairs, recliners, and cots for family members in the patient's room
Access to patient's own possessions and amenities	Allow family to bring in favorite music, clothes, religious icons, food, and pets
Family serving as personal caregivers	When appropriate, allow family to assist with patient care
Access to religious rituals and spiritual support	Provide religious and spiritual resources Encourage religious and other family rituals at the bedside before and after death

family and patient values at the end of life; and clinical outcomes beyond survival, including comfort and quality of dying, will help ICU clinicians better meet these challenges.

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One day there is life. A man, for example, in the best of health, not even old, with no history of illness. Everything is as it was, as it will always be. He goes from one day to the next, minding his own business, dreaming only of the life that lies before him. And then suddenly, it happens, there is death. A man lets out a little sigh, he slumps down in the chair, and it is death. The suddenness of it leaves no room for thought, gives the mind no chance to seek out a word that might comfort it. We are left with nothing but death, the irreducible fact of our own mortality. Death after a long illness we can accept with resignation. Even accidental death we can ascribe to fate. But for a man to die of no apparent cause, for a man to die simply because he is a man, brings us so close to the invisible boundary between life and death that we no longer know which side we are on. Life becomes death, and it is as if this death has owned this life all along. Death without warning. Which is to say: life stops. And it can stop at any moment.

Paul Auster  
*The Invention of Solitude*  
New York: Penguin; 1988

Submitted by:  
Jorge Goldberg, MD  
Mexico City, Mexico

Submissions from readers are welcomed. If the quotation is published, the sender's name will be acknowledged. Please include a complete citation (along with page number on which the quotation was found), as done for any reference.—*The Editor*