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**Abstract:** Presents case studies on the treatment given to patients by their family care physicians. Indepth look at a seventy three year old woman who died after being removed from a hospital ventilator; Information on the legal rights of patients; Indepth look at how to determine the wishes of critically ill patients.

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**AN ALERT AND INCOMPETENT SELF****The Irrelevance of Advance Directives  
Case Study**

A seventy-three-year-old woman with a history of emphysema and manic depression was admitted to the hospital with shortness of breath. She was treated with steroids but developed progressive respiratory failure and psychosis. She was intubated and transferred to the intensive care unit where she was found to have a blood clot in her lung. She was treated with a blood-thinning agent and had a major blood episode. She remained confused, presumably because of oxygen deprivation, infection, and chemical imbalance, though the staff could not rule out permanent brain damage. She was transferred to the chronic ventilator floor and with the consent of her primary care physician a feeding tube was placed and a tracheostomy was performed for long-term ventilator support. The critical care team hoped to wean her from the ventilator; the neurology consultant believed the patient might be able to be weaned successfully from the ventilator, but that it would take months at best.

The patient remained confused but awake and alert. She interacted with staff and visitors and spent much of the day sitting up in a chair watching television. The psychiatrist who had followed her for manic depression found her cognitively impaired and incompetent for decisionmaking. Although the patient was widowed and without children or other living relatives, two close friends who said they had known her for fifty years spoke on her

behalf. They were not legally designated proxies, but held and had witnessed the patient's living will, which the patient had executed twice, most recently five years earlier. The will indicated that the patient did not want to be kept alive by life-support technology if she had no "reasonable expectation for recovery from extreme physical or mental disability." On the basis of their history with the patient and this will, the patient's friends and her primary care physician requested that she be removed from the ventilator. The critical care physician and nursing staff objected. The friends wrote a letter to the ethics committee explaining that this woman was an extremely independent-minded person, who would have hated being kept alive in this dependent condition. The patient's primary care physician who had known her for seven years supported this view.

The critical care staff, however, were reluctant to have the tracheostomy tube removed because the patient appeared to be comfortable and gave no indication that she wished to be withdrawn from life support. When asked whether she wanted to be removed from life support she would indicate "no." The patient's friends and primary care physician, however, believed she was too confused to understand the question. Citing the psychiatrist's report, they argued that she was incompetent to make this decision.

The hospital's ethics committee was consulted and eventually supported the critical care team's decision to defer withdrawal of life-support while continuing to evaluate the patient's decisionmaking capacity and wishes. Committee members were influenced by the critical care physician's opinion that the patient was showing signs of improved cognitive function. They suggested that if the primary care physician remained committed to withdrawing life support immediately, he should arrange a transfer of the patient to another hospital. The physician had the patient transferred to another hospital where a physician indicated willingness to comply with the wishes of the two friends. On the day of the transfer the patient and nursing staff cried. The patient was transferred to the other hospital. The ethics committee was consulted and neurologic and psychiatric evaluations were ordered. The psychiatrist found the patient incompetent and the neurologist thought she had suffered permanent brain damage. The ventilator was removed and she died a week later.

**Commentary** Existing legal, policy, and ethical analyses fail to delineate clearly the range of permissible decisions on lifesustaining treatment for conscious incompetent patients. Cases such as this one illustrate persisting uncertainties and values conflicts underlying decisionmaking on behalf of this group of patients.

Two dimensions of this patient's care merit close consideration. One is the proper interpretation of her living will. Like many patients' living wills, this document fails to convey precise instructions on treatment. Instead, the document requests nontreatment if there is "no reasonable expectation for recovery from extreme physical or mental disability." Ethical and legal support for honoring living wills rests on the moral principle of respect for autonomy. Respect for autonomy, it is argued, requires clinicians and policymakers to respect the competent person's decisions about future treatment as an incompetent patient. But if respect for autonomy is the justification for implementing a living will, the document must reflect the patient's actual choice as a competent person.

In this case, the patient's actual intent is unclear. Did she want her living will to authorize nontreatment in these circumstances? Did she understand that the document might be invoked as grounds for removing life-support technology when physicians disagreed on her prognosis, and some believed that her physical and mental status could improve? Did her concept of "extreme physical and mental disability" include a state in which she remained sufficiently responsive to indicate a wish for continued life support? By asking her friends to act as witnesses to the document, did she intend to make them the authoritative interpreters of the document? Alternatively, by failing to designate her

friends as proxy decisionmakers, did she mean to deny them interpretive authority?

In light of these uncertainties, the decision to remove the respirator may have been inconsistent with the patient's preferences as a competent person. Another troubling issue is whether the patient's later desire for continued life-sustaining treatment constituted a revocation of her earlier living will. Many statutes follow the Uniform Rights of the Terminally Ill Act in providing that living wills may be revoked "at any time and in any manner, without regard to the declarant's mental or physical condition."

The revocation issue is tied to a second general topic relevant to this case: the appropriate balancing of the incompetent patient's prior treatment preferences against her current interests. In the usual treatment situation, a patient's living will conveys treatment instructions that are reasonably protective of the patient's interests as an incompetent person. Thus, when directives are applied to authorize nontreatment of permanently unconscious patients or terminally ill patients in pain or distress, patients are not harmed by the decision.

The situation is more complex, however, when a living will requests nontreatment of a conscious incompetent patient who is comfortable and able to interact with others. In such cases, the moral principle supporting respect for the patient's former autonomous wishes conflicts with the moral principle supporting protection of vulnerable persons from harm.

This case appears to present such a situation. While she was maintained on the ventilator, the patient seemed to gain pleasure from certain activities and interactions. All indications were that she was comfortable receiving ventilator support. If an objective best interests standard had been applied, life support would have been continued as long as the patient failed to experience clear burdens from the medical interventions or her underlying condition. Should her living will have produced a different decision?

Commentators disagree on this matter, with some assigning priority to the competent patient's interest in controlling future care, and others to the incompetent patient's best interests. Courts and other policymaking bodies have not taken a clear position on which interests should control. The lack of ethical consensus and clear legal rules leaves cases such as this to clinicians, families and friends, and ethics committees to resolve. Inconsistent outcomes are inevitable in the absence of additional policy guidance.

Two factors combine to make this a disturbing case. A living will was applied to justify forgoing treatment in a situation not clearly covered by the will's nontreatment request. Moreover, the ambiguous document was invoked to allow the death of a patient who appeared content and able to enjoy her diminished quality of life. At the very least, the nontreatment decision should have been postponed until clinicians obtained a better indication of the patient's prognosis.

**Commentary** This case shows how difficult it can be to determine the wishes of critically ill patients who have developed profound confusion yet remain mentally alert, and how the emotions aroused by such patients may make consensus impossible to achieve. Emotional attachment to patients, while important to caring for the sick, can sometimes complicate their care and the resolution of ethical dilemmas.

The patient's close friends and her primary care physician had known her for years and had good reason to argue passionately that this woman would not have wished to be kept alive in a totally dependent state. The friends in particular had a relationship with her that spanned five decades. They knew the patient as a free spirit--a socialist and political activist, an avid reader and theater-goer, a creative film editor, and a person who

struggled to maintain her independence in the face of serious psychiatric and medical illness. They had witnessed her signing of a living will in which she documented that she did not wish to be kept alive if she was not likely to recover. The patient's friends admired her unconventional life journey; they saw the choices she made along the way as reflecting her values and deep desire to live independently. To see her institutionalized must have seemed to contradict everything about her life.

Yet the position of the critical care physicians and nurses is understandable. It is one thing to wean a comatose or barely responsive patient from a ventilator, or to take this step at a competent patient's express request. In this case doctors and nurses were asked to withdraw life support from a patient who while brain damaged, perhaps irreversibly, remained awake and responsive. She was able to converse with visitors and enjoy watching television. She was clearly capable of expressing distress at her condition and indicating that she wished to be allowed to die but did not do so. Where the friends and primary care physician saw primarily a body whose soul had departed, the critical care team detected the embers of this woman's quirky fighting spirit, likely the same qualities that her friends and primary care physician had previously cherished in her.

While the patient had an advance directive, advance directives are generic and sometimes unhelpful documents. When the patient signed it, she may not have anticipated that she might still take some pleasure in living even with "extreme physical or mental disability." Faced with the alternative of death, people may adapt to new life circumstances in ways that they could not have previously imagined. Given the patient's uncertain status and the critical care staff's growing relationship with the patient, one could see why the representation of the patient's life story by the patient's primary care physician and friends would carry less weight with them. Their growing engagement and attachment to the patient surely encouraged them to interpret ambiguous gestures as clear evidence that this patient wanted to live. This allowed the critical care doctors to argue with some justice that whatever the patient's previous views, her current behavior showed them that she had changed her mind.

The first hospital's ethics committee hoped that with more time it might be possible to clarify the patient's wishes and achieve consensus. But consensus was unlikely given that the parties involved had such different understandings of the patient. While the stereotyped view of intensive care units sees them as inhuman citadels of high-technology; the tears shed by the nursing staff when the patient departed reveals just how human a place it is. Indeed, the underlying dispute here turned out to be as much about love as about the uses of technology. Each side could justly claim to be acting out of loving concern for the patient. The problem was that each party loved somebody else.

The critical care team, having invested immense time and energy in "saving" this patient, took pride in her progress, were gratified to see that she was again able to take pleasure in her existence, and held the hope that she might continue to improve. The primary care physician and friends, in contrast, knew and loved a different person. That person had for all intents and purposes died when she was admitted to the hospital. Where the critical care team could see hope and progress, they could see only irretrievable loss. The staff at the second hospital did not have the degree of emotional investment in this patient as did the first staff, making what was clearly a painful decision for them at least a possible one. As it turned out, the patient was able to be withdrawn from the ventilator without suffering immediate distress and she died in relative comfort. It's hard to say that this was the right outcome but it doesn't seem wrong.

Doctors and nurses need to love their patients, especially in fields such as critical care in which patients may lose many of the attributes that make them seem human. It is love for such patients that motivates the staff to go the extra mile and save patients whose cause

may seem hopeless and to treat with respect and dignity those whom they cannot save. Ironically, in this case the staff may have identified too closely with the patient. It was fair to give this patient every possible chance to recover. If in fact, however, she was not going to regain mental and physical function, the hospital would eventually have had to transfer her to a chronic care facility attached to ventilator and feeding tube, regardless of the staff's feelings for her. Since those who knew her longest and best testified convincingly that the patient had while still lucid rejected such an outcome for herself, the staff's inability to separate emotionally from the patient might have frustrated her true wish.

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