The Bright Misplaced Line: Persistent Vegetative State and Withdrawal of Artificial Sustenance

James A. Jaeger
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One of the most troublesome issues with end-of-life decision making is the withdrawal of tube feeding. With the decision in Wisconsin in the Edna M.F. case, the withholding of tube feeding has become more problematical. Ultimately, that decision rests on a medical issue: whether the person was in a persistent vegetative state. This article examines some of the historic case law on this issue, then reviews some of the medical literature on the effects of the withdrawal of tube feeding, then reviews case law developments in other states, and finally articulates what would be a workable approach to this difficult issue.

By James A. Jaeger

The litigation has to do, in final analysis, with her life,—its continuance or cessation,—and the responsibilities, rights and duties, with regard to any fateful decision concerning it, of her family, her guardian, her doctors, the hospital, the State through its law enforcement authorities, and finally the courts of justice.

One of the most controversial issues relating to end-of-life decision making is the question of withdrawal of what is generally referred to as "tube feeding" or "non-orally-ingested nutrition and hydration" or "artificial nutrition and hydration." For example, Wisconsin's first "Natural Death Act," which authorizes advance directives regarding end-of-life care, did not permit the withdrawal of tube feeding. It was not until passage of the Durable Power of Attorney for Health Care Act in 1990 that this option was authorized in Wisconsin. Then, in 1991, the Natural Death Act was amended to allow withholding or withdrawing tube feeding.

For those individuals who, through lack of knowledge or foresight, do not leave advance medical directives, the situation has been further complicated by the 1997 decision of the Wisconsin Supreme Court in In the Matter of the Guardian-

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ship and Protective Placement of Edna M.F., which severely limited the authority of a guardian of the person of an incompetent individual to direct the withholding or withdrawal of tube feeding. Because of this decision, persons who have not left advance directives or otherwise clearly made their wishes known during their lifetime may be subjected to tube feeding and have their dying process prolonged in situations where, given the opportunity, they might have decided that this is not what they would want.

In this article I will first examine some of the historic case law on this issue, then review some of the medical literature on the effects of the withdrawal of tube feeding, then review some case law developments in other states, and finally try to articulate what I believe would be a more workable approach to this difficult issue.

Case Development

One of the seminal cases addressing this issue was *In re Quinlan*. This case involved a young New Jersey woman, Karen Ann Quinlan, who at age 22 stopped breathing for two successive 15-minute periods. As a result, she suffered brain damage and entered a persistent vegetative state. Because she could not breathe without assistance, she was placed on a respirator. When it became apparent that she would not recover, and after much soul-searching, her father, Joseph Quinlan, petitioned for appointment as the guardian of her person with the explicit authority to remove the respirator, with the expectation that this would result in her death. This request was opposed by her doctors, the hospital, the county prosecutor, the State of New Jersey, and the guardian ad litem. The trial court appointed Mr. Quinlan as guardian of the estate but declined to appoint him guardian of the person and grant the relief he sought. He appealed and the matter was certified by the New Jersey Supreme Court.

After preliminarily finding that Ms. Quinlan “can never be restored to cognitive or sapient life” and that the “character and general suitability of Joseph Quinlan as guardian for his daughter, in ordinary circumstances, could not be doubted,” the court went on to consider the specific relief requested by Mr. Quinlan in this case. Mr. Quinlan advanced three arguments: (1) that the failure to appoint him guardian interfered with his free exercise of religion; (2) that keeping Karen on the respirator was cruel and unusual punishment in violation of the Eighth Amendment; and (3) that failure to grant the relief sought denied Karen and Joseph their rights to privacy. The court summarily rejected the first two arguments but held that Karen’s right of privacy was violated by continuing her on the respirator.

The New Jersey court balanced the interests of the state in preserving human life and defending the rights of physicians to exercise their best professional judgment against the right of privacy of the individual, as developed by the U.S. Supreme Court. In applying this balance, the New Jersey court stated:

We think that the State’s interest contra weakens and the individual’s right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual’s rights overcome the State’s interest. It is for that reason that we believe Karen’s choice, if she were competent to make it, would be vindicated by the law.

The court went on to state that because the only “practical way” for Karen Ann Quinlan to exercise her right to privacy would be through the actions of a guardian, the guardian should be appointed and allowed to exercise the right. The court concluded its opinion by considering issues related to standards of medical practice and possible criminal liability for the physicians and determined that neither one was sufficient to dissuade the court from its primary holding. Therefore the court appointed Joseph as guardian and authorized him to discontinue the respirator.

While the *Quinlan* case set standards for the use of respirators, issues related to tube feeding continued to be undecided. As discussed below, because of societal norms regarding the provision of food and liquids to ill and dying persons, this issue remains much more controversial.

The U.S. Supreme Court was confronted with the tube-feeding issue in 1990 in *Cruzan v. Director, Missouri Dep’t of Health*. The *Cruzan* case involved a young woman who was severely injured in an automobile accident. As a result of the accident, she suffered severe brain damage and was in a persistent vegetative state, defined by the U.S. Supreme Court as “a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function.” As distin-
guished from Karen Ann Quinlan, Nancy Cruzan was able to breathe without the aid of a respirator. However, there came a point when she was no longer able to orally ingest food or fluids and was kept alive only by the use of a gastric tube. At this point her parents requested that the tube feeding be discontinued. Nancy’s health care providers declined to carry out this request without court approval. The parents then applied to the Missouri courts for authority to discontinue tube feeding. The trial court held that Nancy had a “fundamental right” under the state and federal constitutions to refuse or direct the withdrawal of “death prolonging procedures.” The trial court further held that certain statements she had made some years before indicated that her desire would be to have the tube feeding discontinued. On that basis the trial court authorized the parents to withdraw the tube feeding. The case was appealed to the Missouri Supreme Court, which reversed in a divided vote.

The Missouri Supreme Court held that there was a common-law right to refuse treatment, but it was unwilling to elevate that right to constitutional status. However, the court held that the statements attributed to Nancy were not “clear and convincing evidence” of her wishes and therefore the state interest in the preservation of life took precedence.

The U.S. Supreme Court, in an opinion by Chief Justice Rehnquist, upheld the Missouri Supreme Court. The majority opinion first made an extensive analysis of state cases on the common-law requirement of informed consent to medical treatment and the concomitant right to refuse such treatment. It held that a right to refuse treatment does exist that may be exercised on behalf of an incompetent patient by his or her surrogate decision maker, such as a guardian or conservator.

This finding was consistent with the position of the Missouri Supreme Court. However, the next issue raised by the Cruzans was whether the Fourteenth Amendment to the U.S. Constitution prohibited the state of Missouri from imposing the “clear and convincing” evidence standard. In analyzing this argument the Court agreed that an individual had a constitutionally protected liberty interest in refusing unwanted medical treatment, including the use of feeding tubes. However, the Court held that in the case of incompetent persons the state’s right to ensure the preservation of life allowed it to insist on “clear and convincing” evidence of the wishes of the incompetent person, even in the face of such a liberty interest. The Court stated:

In our view, Missouri has permissibly sought to advance these interests through the adoption of a “clear and convincing” standard of proof to govern such proceedings. The function of a standard of proof, as that concept is embodied in the Due Process Clause and in the realm of factfinding, is to instruct the factfinder concerning the degree of confidence our society thinks he should have in the correctness of factual conclusions for a particular type of adjudication. . . . We think it self-evident that the interests at stake in the instant proceedings are more substantial, both on an individual and societal level, than those involved in a run-of-the-mill civil dispute. But not only does the standard of proof reflect the importance of a particular adjudication, it also serves as “a societal judgment about how the risk of error should be distributed between the litigants.” Santosky, supra, 455 U.S. at 755; Addington, supra, at 423. The more stringent the burden of proof a party must bear, the more that party bears the risk of an erroneous decision. We believe that Missouri may permissibly place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual’s life-sustaining treatment. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient’s intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment, at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.

After Cruzan, an incompetent individual’s right to be free of unwanted medical treatment will depend on the existence of either an “advanced directive” such as a living will or power of attorney for health care dealing with the question or some other evidence of his or her intent that will satisfy a particular state’s evidentiary standards applicable to this issue. Without such evidence, the state may insist on the continuation of life-sustaining/prolonging treatment.
The court then addressed what it considered an issue of “first impression” in Wisconsin, namely whether the right to refuse unwanted medical treatment includes the right to refuse artificial nutrition and hydration.36 The court stated:

We recognize, as other courts have, that the provision of food and water to one incapable of oral self-nourishment raises unique concerns. Unlike most medical technological advances of a mechanistic nature, it is difficult to view nourishment as anything but normal and essential human care. It is difficult not to view the withdrawal of artificial feeding as inducing death through starvation and dehydration. . . . (footnote omitted) There is however no compelling distinction between artificial feeding and other forms of medical treatment. As succinctly stated by the New Jersey Supreme Court:

Once one enters the realm of complex, high-technology medical care, it is hard to shed the “emotional symbolism” of food. However, artificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoonfeeding—they are medical procedures with inherent risks and possible side effects, instituted by skilled health-care providers to compensate for impaired physical functioning. Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own. In re Conroy, 98 N.J. at 372–373, 486 A.2d at 1236 (citations omitted).37

The court also found support for the proposition that tube feeding is more akin to medical treatment than ordinary care in Justice O’Connor’s concurrence in Cruzan: “Artificial feeding cannot readily be distinguished from other forms of medical treatment.”38

The court then turned to the question of whether the right to refuse “all unwanted life sustaining medical treatment” extends to incompetent persons and concluded that it clearly did. “An incompetent person does not relinquish the right to refuse unwanted treatment by virtue of incompe-
The guardian ad litem argued that Wisconsin should adopt the stance of Missouri and require proof of an individual's wishes by "clear and convincing evidence." The court rejected this suggestion, stating:

Relatively few individuals provide explicit written or oral instructions concerning their treatment preferences should they become incompetent [footnote omitted]. The reasons for this are undoubtedly myriad: ignorance, superstition, carelessness, sloth, procrastination or the simple refusal to believe it could happen to oneself. This failure to act is not a decision to accept all treatment, nor should society's increasing ability to prolong the dying process make it one. To adopt the clear and convincing standard would doom many individuals to a prolonged vegetative state sustained in a life form by unwanted, perhaps detrimental, means that are contrary to the person's best interest. Moreover the legislature in the adoption of chs. 154 and 155, carefully pointed out that failure to execute a living will or power of attorney for health care creates no presumption that the person consents to the use or withholding of life-sustaining procedures.

Thus the stated legislative policy is to leave the decision, if not declared by the patient, to be determined as a matter of common law—and the common law, where the individual was never competent or where the conduct of the individual while competent never was of a kind from which one could draw a reasonable inference upon which to make a substituted judgment, requires that decision to be resolved by a surrogate decision maker acting in the best interests of the incompetent. The court then faced the question of whether the standard to be used by the decision maker in making the end-of-life decision is to be the "best-interests" or "substituted judgment" standard. The primary concern of the court was that applying the substituted judgment standard to L.W. was all but impossible because that standard requires that the decision maker know what the ward wanted. In the case of L.W., it was impossible to know what he wanted, since as the court found he was probably never competent. Thus the court opted for a best-interests standard, while recognizing that if the incompetent person's wishes are known, it is in his or her best interests to follow those wishes. The court then reached its penultimate holding in this case:

In conclusion then we hold that a guardian may consent to the withholding or withdrawal of life-sustaining medical treatment on behalf of one who was never competent, or a once competent person whose conduct never was of a kind from which one could draw a reasonable inference upon which to make a substituted judgment, when:

(1) the incompetent patient's attending physician, together with two independent neurologists or physicians, determine with reasonable medical certainty that the patient is in a persistent vegetative state and has no reasonable chance of recovery to a cognitive and sentient life; [footnote omitted] and (2) the guardian determines in good faith that the withholding or withdrawal of treatment is in the ward's best interests, according to the objective factors outlined below [footnote omitted].

The court identified the following "objective factors" to be considered by the guardian as follows:

The degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.

In applying these factors the court cautioned guardians to

Assess these factors from the standpoint of the patient, and . . . not substitute his or her own view of the "quality of life" of the ward. As the Rasmussen court explained, the guardian's determination of what is in the ward's best interests necessarily involves an assessment of "the value that the continuation of life has for the patient," but should not involve "the value that others find in the continuation of the patient's life. . ." The court also pointed out other considerations, such as the view of the institution's ethics committee and the views of relatives of the ward.
Finally, the court discussed the potential state interests that must be considered in cases of this type.

Courts have identified four relevant state interests: (1) preserving life; (2) safeguarding the integrity of the medical profession; (3) preventing suicide; and (4) protecting innocent third parties."

The court addressed each of these in turn and concluded that none of them overcame the right of the guardian for L.W. to assert his right to refuse unwanted treatment. As a result of the L.W decision, Wisconsin guardians appeared to have the right, without seeking court approval, to consent to the withdrawal of life-sustaining treatment, including artificial nutrition and hydration or tube feeding, at least in the case of persons in a persistent vegetative state.

Five years later, the Wisconsin Supreme Court revisited this issue in the Edna M.F. case. This case, which appeared at first blush to have facts only slightly different from L.W., came to a dramatically different result.

The ward in Edna M.F. was described in the majority opinion as follows:

Edna M.F. is a 71-year-old woman who has been diagnosed with dementia of the Alzheimer's type. She is bedridden, but her doctors have indicated that she responds to stimulation from voice and movement. She also appears alert at times, with her eyes open, and she responds to mildly noxious stimuli. According to these doctors, her condition does not meet the definition of a persistent vegetative state. In 1988, a permanent feeding tube was surgically inserted in Edna's body. Edna currently breathes without a respirator, but she continues to receive artificial nutrition and hydration. Edna's condition is not likely to improve."

The other principal difference between Edna M.F. and L.W. is that Edna was an individual who, prior to succumbing to Alzheimer's disease, was described as a vibrant individual who would have been competent to execute an advance medical directive but did not do so. The court found that the only statement she made regarding her wishes as to life-sustaining treatment was a 30-year-old statement to the effect that "I [Edna] would rather die of cancer than lose my mind."

Edna's niece requested that the tube feeding be discontinued. The request was referred to the ethics committee of the nursing home, which decided it would permit the withdrawal of the tube feeding if all family members agreed. One refused to do so in writing on religious grounds and so the guardian filed a petition with the Wood County Circuit Court to approve withdrawal of the feeding tube. The circuit court denied the petition and the case was brought to the supreme court on a bypass procedure. The supreme court, in a majority opinion by Justice Steinmetz, upheld the circuit court.

The court reviewed the Quinlan, Cruzan, and L.W. line of cases and concluded that incompetent persons have the right, through their surrogate decision makers, to refuse unwanted medical treatment. However, relying on In re Guardianship of Eberhardy, the court observed that while all persons, whether competent or incompetent, have the same constitutional rights, "the uninhibited exercise of those rights may be hedged about with restrictions that reflect the public policy of protecting persons of a distinct class."

The court then considered whether a guardian of a person who is not in a persistent vegetative state could consent to the withdrawal of tube feeding. The court held that "if [a] person is not in a persistent vegetative state, this court has determined that as a matter of law it is not in the best interests of the ward to withdraw life sustaining treatment, including a feeding tube, unless the ward has executed an advance directive or other statement clearly indicating his or her desires." The court explained its rationale for this "bright line" test as follows:

One of the main reasons that this court in L.W. limited the scope of its holdings is the fact that The American Academy of Neurology explains that people in a persistent vegetative state do not feel pain or discomfort. L.W., 167 Wis. 2d at 87, note 17. In the case at bar, Edna M.F. is not in a persistent vegetative state and could therefore likely feel the pain and discomfort of starving to death. Even a competent person cannot order "the withholding or withdrawal of any medication, life-sustaining procedure or feeding tube" if "the withholding or withdrawal will cause the declarant pain or reduce the declarant's comfort" unless the pain or discomfort can be alleviated through further medical means. Wis. Stat. 154.03(1).
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155.20(1). In the case where withdrawal of life-sustaining medical treatment, including nutrition or hydration, will cause pain or discomfort, then, the competent and incompetent person have exactly the same rights.48

The court then tried to bolster its position by positing a “slippery slope” to euthanasia if the position of the guardian for Edna were adopted.59 I will suggest below that, given the criteria established in L.W., there is no reasonable basis for the slippery slope argument.

The court then discussed what the guardian would have to show regarding Edna’s wishes when it came to end-of-life care.

Even though Edna M.F. is not currently existing in a persistent vegetative state, if her guardian can demonstrate by a preponderance of the evidence a clear statement of Edna’s desires in these circumstances, then it is in the best interests of Edna to honor those wishes [footnote omitted]. See L.W., 167 Wis. 2d at 79–80. The reason this court requires a clear statement of the ward’s desires is because of the interest of the state in preserving human life [footnote omitted] and the irreversible nature of the decision to withdraw nutrition from a person.60

The court concluded that the evidence presented regarding Edna’s wishes was not sufficient to overcome the state’s presumed interest in maintaining her biological life, and the relief sought by the guardian was denied.61 There were several concurring opinions expressing different views on how to prove the existence of a persistent vegetative state, but none differed with the underlying rationale of the case, namely that a persistent vegetative state was the appropriate “bright line.”62 It is that underlying assumption that I question.

The Medical Issue
Ultimately, the decision in Edna M.F. turned on a medical issue, namely whether Edna was in a persistent vegetative state (PVS). But, I think it important to look behind that question to what I believe to be an even more important one: what was the justification for establishing PVS as the “bright line” test for deciding when a guardian could withdraw artificial nutrition and hydration? This was not an issue in L.W. because it was agreed that he was in a persistent vegetative state. However, in two footnotes, Chief Justice Heffernan set forth his views at length:

Footnote 15 to the majority opinion in L.W. stated:

We stress the unique status of individuals in a persistent vegetative state, and the fact that this opinion is strictly limited to persons in such a condition. As the President’s Commission concluded:

The primary basis for medical treatment of patients is the prospect that each individual’s interests (specifically, the interest in wellbeing) will be promoted. Thus, treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.63

At footnote 17, the court continues the discussion:

The dissent urges that the incompetent patient must be protected against the potential pain and discomfort involved in the withdrawal of artificial nutrition and hydration. Dissenting Op. at 96-99. However, this concern is inapplicable to this case because individuals in a persistent vegetative state cannot experience pain or discomfort. The American Academy of Neurology states:

Persistent vegetative state patients do not have the capacity to experience pain or suffering. Pain and suffering are attributes of consciousness requiring cerebral cortical functioning, and patients who are permanently and completely unconscious cannot experience these symptoms. There are several independent bases for the neurological conclusion that persistent vegetative state patients do not experience pain or suffering. First, direct clinical experience with these patients demonstrates that there is no behavioral indication of any awareness of pain or suffering. Second, in all persistent vegetative state patients studied to date, postmortem examination reveals overwhelming bilateral damage to the cerebral hemispheres to a degree incompatible with consciousness or the capacity to experi-
ence pain or suffering. Third, recent data utilizing positron emission tomography indicates that the metabolic rate for glucose in the cerebral cortex is greatly reduced in persistent vegetative state patients, to a degree incompatible with consciousness.44

In the majority opinion in Edna M.F., Justice Steinmetz restated the L.W. rationale:

One of the main reasons that this court in L.W. limited the scope of its holdings is the fact that The American Academy of Neurology explains that people in a persistent vegetative state do not feel pain or discomfort. L.W. 167 Wis. 2d at 87, note 17. In the case at bar, Edna M.F. is not in a persistent vegetative state and could therefore likely feel the pain and discomfort of starving to death. Even a competent person cannot order “the withholding or withdrawal of any medication, life-sustaining procedure or feeding tube” if “the withholding or withdrawal will cause the declarant pain or reduce the declarant’s comfort” unless the pain or discomfort can be alleviated through further medical means. Wis. Stat. 154.03(1). See also Wis. Stat. 155.20(1). In the case where withdrawal of life-sustaining medical treatment, including nutrition or hydration, will cause pain or discomfort, then, the competent and incompetent person have exactly the same rights.45

The concurring opinions in Edna M.F. all seem to accept the basic rationale, namely that PVS is the appropriate “bright line.” They merely discuss how PVS should be diagnosed. No one questions the basic premise, namely that PVS is the appropriate standard.

The underlying rationale of both L.W. and Edna M.F. can be stated as follows: (1) withdrawal of nutrition and hydration causes pain; (2) pain is to be avoided; (3) persons in PVS do not feel pain; and therefore (4) it is only appropriate to withdraw artificial nutrition and hydration for those who feel no pain—namely those in the PVS condition.

What if this argument could be attacked at one or more of its logical connections? What if, for example, it were shown that the withdrawal of artificial nutrition or hydration did not cause pain but in fact may ease pain? And, what if there are other conditions where the patient does not feel pain? What then is left of the basis for the conclusion, begun in L.W. and continued in Edna M.F., that PVS is the only condition where withdrawal of nutrition and hydration is permissible? As the following discussion will show, there is a considerable body of medical authority for the proposition that the withdrawal of artificial nutrition and hydration in dying patients may relieve rather than cause pain and discomfort. In light of that authority, I submit that the decision in Edna M.F. should be reexamined and that guardians of incompetent individuals should have broader authority to make end-of-life decisions for their wards.

The Medical Literature

A review of the medical literature on the topic of the effects of dehydration on terminally ill patients has led me to conclude that it is more likely than not that the pain and suffering referred to by Justice Steinmetz in the Edna M.F. opinion46 does not occur. The nature of the problem is stated as follows:

The general impression among hospice clinician (sic) is that starvation and dehydration do not contribute to suffering among the dying and might actually contribute to a comfortable passage from life. In contrast, the general impression among the public and non-hospice medical professionals is that starvation and dehydration are terrible ways to die. Scientific support for either viewpoint has been scanty, and yet modern medical practice has reflected an aversion to allowing a person to starve to death.47

As many commentators point out, the issue is often the “symbolism” that is associated with providing food and fluids to dying persons. It is thought that this is “ordinary care” and the least that one can do for a dying person. However, as one commentator pointed out,

Although tube feeding has been likened to the provision of food and water [footnotes omitted], it does not resemble eating or drinking in any way except for its symbolism . . . . In addition to these problems arising from tube feeding, there are less obvious ones. Tube feeding is a passive process that bypasses the sensory input of the patient . . . . A feeding tube may produce anxiety or fear in the confused patient who has some awareness. These patients may not understand the purpose of the tube and may attempt to dislodge it . . . . Tube feeding, in general, is devoid of the interpersonal aspects of ordinary feeding, which in itself can be a comforting encounter; tube
feeding also lacks the sensory qualities of real food and drink, which might provide the patient with a modicum of pleasure.\(^6\)

Of course, for many of the patients we are considering, oral ingestion of food and water is not a possibility. Even if they are not in a persistent vegetative state, they may be in another condition that similarly renders them unable to eat or drink.\(^9\) In fact, in the \textit{Cruzan} case, the Supreme Court agreed that the provision of artificial nutrition and hydration constituted medical care rather than ordinary care for the patient.\(^7\)

However, the issue posed by the court in \textit{Edna M.} was not whether the provision of artificial nutrition and hydration was ordinary care, but rather whether the withdrawal of such nutrition and hydration caused pain and suffering. The conclusion of a number of commentators, based both on general observations in the clinic and specific studies, is that such withdrawal does not cause pain and in fact might actually enhance the comfort of the dying patient. A monograph containing case studies of three terminally ill patients in 1993 concluded that “there are benefits to dehydration and detriments to hydration in this population.” In each case reported, there was an increase in alertness and apparent comfort when artificial nutrition and hydration were discontinued.\(^7\) The article suggested the reason for this phenomenon is that

\[\text{in patients in advanced stages of dehydration, enhanced comfort may be due to the release of pain relieving substances. . . . Another possible explanation for the absence of symptoms is that ketones produced during starvation have an anesthetic effect which has been shown in the squid axon.}\]

Another study, reported in the \textit{Journal of the American Medical Association} in 1994, monitored 32 “mentally competent terminally ill patients” in a nursing home. The conclusion of the study was summarized as follows:

In this series, patients terminally ill with cancer generally did not experience hunger and those who did needed only small amounts of food for alleviation. Complaints of thirst and dry mouth were relieved with mouth care and sips of liquids far less than that needed to prevent dehydration. Food and fluid administratio-
spread malignancy” whereas none of the hospice physicians would do so. The authors suggested that a benefits/burden analysis is appropriate in this situation:

However, it may be that the issue we need to address is our assessment of likely benefit, rather than attempting to quantify medical intrusion. Our responsibility here is not to take a stance on the appropriateness of artificial rehydration, but to make individual unprejudiced clinical assessments in the light of the patient’s (or their representative’s) own preferences for treatment and our knowledge of the evidence concerning that treatment. In the uncomplicated deterioration from end-stage metastatic malignancy, in which the patient becomes unable to take oral fluids, there is no evidence that artificial hydration will provide any benefit... Doctors need to be careful that a decision to prolong life temporarily in the terminal phase is an objective one in the interests of the patient, rather than a means of minimizing their own feelings of responsibility and even guilt.

This review of the medical literature leads to the conclusion that the withdrawal of tube feeding and hydration does not, as asserted by the majority in Edna M.E., cause pain and suffering. If this is the case, then the “bright line” test asserted in Edna M.E. (and drawn from the prior L.W. case) does not hold up in light of the apparent medical facts. In fact, it appears from this literature that the provision of artificial nutrition and hydration may be causing the very pain and suffering that the court is trying to avoid. For this reason, I submit that the approach adopted by the court in Edna M.E. does not lead to an appropriate resolution of the dilemma faced by guardians of incompetent individuals who are in conditions where withholding or withdrawal of artificial nutrition and hydration is medically indicated.

Decisions in Other States
In addition to reviewing the Wisconsin cases on this topic, I also looked at cases in nine other states that were decided after Cruzan. While there were a number of other decisions, these seemed to present a representative sample of the decisions that followed Cruzan. To analyze these cases, I have identified a number of key issues and compared how other states dealt with the problem in contrast to Wisconsin. I have included a table in the appendix to this article that summarizes my findings. Again, this will not be an in-depth analysis, but it will attempt to provide an overview of what is going on.

Persistent Vegetative State
In both L.W. and Edna M.E., the wards were in a persistent vegetative state. In Edna M.E. the existence of this condition was deemed the critical problem in the case. In five of the cases reviewed, the ward was also in a persistent vegetative state. In three of the cases, the ward was not. One of the cases does not explicitly state the medical condition. All of the wards in these cases were severely incapacitated. There is no real correlation between the existence of PVS and the outcome of the case. In only three of the cases is there any discussion of PVS and then only to assert that persons in that condition do not feel pain. This is done to counteract arguments regarding pain from withdrawal of hydration and nutrition.

Advance Directives
In both of the Wisconsin cases, there were no advance medical directives. Not surprisingly, that was also the case in all but one of the nine other cases reviewed. In the one case where there was an advance directive, there was an issue of whether it was in effect since there was a factual question as to whether the ward’s condition was terminal. I say this is not surprising because where there is an advance medical directive, the guardianship court should not get involved.

Source of Right to Refuse Treatment
The Wisconsin cases based the right to refuse treatment both on the common-law notion of informed consent and on the U.S. and Wisconsin Constitutions. In contrast, six of the nine jurisdictions reviewed based the right of refusal strictly on the common-law right of informed consent and most explicitly refused to reach the constitutional issue. Two of the courts relied on constitutional grounds, typically the right to privacy, and one court based the right on public policy as announced by the legislature. It is interesting that all of the courts found that there was a right to refuse treatment. The big issue was how that right is to be implemented in the case of an incompetent patient.
Standard for Decision
The Wisconsin cases adopted a best-interests test to guide the guardian in making his or her decision. These cases then discussed the criteria to be used by the guardians to make their decisions. In seven of the nine other decisions reviewed, the courts applied some variant of the substituted judgment standard. They felt that the most important inquiry was what the ward said he or she would want with respect to end-of-life care and directed that the guardian must do his or her best to ascertain what that intent was. The intent could be expressed orally or in writing and could sometimes be inferred from other facts of the individual's life. These courts rejected the best-interests test out of a fear that it would impose someone else's ideas as to quality of life. In only one of the cases was the best-interests standard adopted, and in one of the cases the standard was not discussed. Note that in Edna M.E, for persons not in a persistent vegetative state, the inquiry as to the previously expressed wishes of the ward does not differ markedly from the substituted judgment adopted by the other courts.

Standard of Proof
The Wisconsin Supreme Court explicitly rejected the clear-and-convincing standard approved by the U.S. Supreme Court in Cruzan, opting instead for a preponderance-of-the-evidence test. This is clearly against the trend disclosed in the nine cases reviewed. Six of the nine cases adopted a clear-and-convincing evidence test, while one adopted a preponderance-of-the-evidence approach. In two of the cases it was not possible from the opinion to ascertain what evidentiary standard was applied. Given the fact that most of these courts were looking to the intent of the ward as to end-of-life decisions, it is not surprising that a high level of proof would be required.

The Outcomes
Given the foregoing discussion, one might assume that the courts would be hostile to the withdrawal of artificial nutrition and hydration, given the substantial hurdles established for the guardians. Yet in six of the nine cases reviewed (not counting the Wisconsin cases that split evenly) in the final analysis, the courts permitted the withdrawal of artificial nutrition and hydration. Even though the procedural and substantive barriers have been high, in the end the courts have appeared sympathetic to the individual situations of the wards as they applied their standards. In one of the cases in which an individual was found not to be in a PVS, the court refused to allow withdrawal of tube feeding. Yet, in two other cases where PVS was not shown, the court nonetheless allowed tube feeding to be withdrawn.

Conclusion
What may we conclude from this brief review of other cases? First, concerning a number of questions, Wisconsin's position differs from the norm in other states. Second, as a general rule the other courts, like the court in Edna M.E, seek to place high barriers to exercise of the right to refuse treatment when that treatment is artificial nutrition and hydration, even though all of the courts agree that such provision is medical treatment rather than ordinary care. However, notwithstanding such barriers, the courts remain sympathetic to the plight of seriously incapacitated individuals and find ways to permit the withdrawal of artificial nutrition and hydration.

A Suggested Resolution
Just as in the Wizard of Oz, where the solution to Dorothy's problem of how to return to Kansas was always at her feet, so too I believe the solution to the problem of withdrawal of artificial nutrition and hydration has been presented to us by the Wisconsin Supreme Court in the L.W. case. L.W., when you take away the unfortunate language relating to persistent vegetative state, provides a workable framework for resolving the tube-feeding question. As we recall, the Wisconsin Supreme Court held in L.W. that where an incompetent person's own wishes could not be identified, the guardian should apply a "best-interests" test based on objective factors:

In making the best interests determination, the guardian must begin with a presumption that continued life is in the best interests of the ward. Whether that presumption may be overcome depends upon a good faith assessment by the guardian of several objective factors.

Objective factors the guardian may consider include:
The degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.\footnote{83}

This analysis is similar to the “benefits/burdens” analysis used by medical ethicists:

Doctors are both morally and legally justified in withholding or withdrawing any treatments that are not beneficial to their patients. Given that the patient is certainly dying, the ethical imperative remains that of imposing no greater burden than benefit on the patient (i.e., optimum symptomatic management) rather than attempts to postpone the point of death.\footnote{84}

By adopting such an approach, the guardian who is making a decision regarding tube feeding for an incompetent patient, and the patient’s doctor, are placed in the same position as if the patient were competent. The doctor can make the same benefits/burdens analysis he or she would make in the case of any other patient and make an informed medical decision based on that analysis. The guardian can weigh the various “objective factors” noted above, as well as the guardian’s personal knowledge of the views and values of the ward, and make an informed judgment that should be in the ward’s best interests.

It seems to me that this approach avoids many of the problems created by the substituted judgment test applied in the other states. Under substituted judgment, there can be a long, involved, and frankly often tortured analysis of the desires of the incompetent person when, in all likelihood, he or she may never have really considered or discussed the issue with any particular insight. Thus, the search for the intent of the individual will often be quite futile or facile. This tends to render the presumed basis for this test, carrying out the ward’s wishes, ineffectual.

The L.W. approach (without PVS) also responds to Justice Steinmetz’ “slippery slope” argument in Edna M.F. The L.W. factors provide a reasonable framework for end-of-life decision making by guardians. They would not sanction euthanasia for its own sake. Rather, a careful analysis of the circumstances of the patient and the benefits and burdens of the continuation of artificial nutrition and hydration to the patient would be the paramount considerations. Will mistakes be made and decisions made for improper reasons? Perhaps. But the fact that the individual is or is not in a persistent vegetative state will not change the possibility and consequences of a wrong decision. And I maintain that it is more likely that a correct decision (one in the best interests of the ward and probably closer to what the ward would have wanted in most cases) will be made under the analysis in L.W. (free of the PVS restriction) as opposed to the Edna M.F. analysis.

**Conclusion**

In the final analysis, the thesis of this article is that the Edna M.F. decision should be revisited in a case where the scientific and medical basis for its con-

### Appendix

**Comparison of Right-to-Die Cases**

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<th>Case Name</th>
<th>PVS</th>
<th>Std. of Decision</th>
<th>Std. of Proof</th>
<th>Source of Right</th>
<th>Discuss Pain</th>
<th>Outcome</th>
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<tr>
<td>In re Fiori</td>
<td>Yes</td>
<td>Sub. judgment</td>
<td>Other</td>
<td>Common law</td>
<td>No</td>
<td>Withdraw</td>
<td>No</td>
</tr>
<tr>
<td>In re Meyers</td>
<td>Yes</td>
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<td>Common law</td>
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<tr>
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<td>Withdraw</td>
<td>No</td>
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<tr>
<td>In re Martin</td>
<td>No</td>
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<td>Mack v. Mack</td>
<td>Yes</td>
<td>Sub. judgment</td>
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<td>No</td>
<td>Not withdraw</td>
<td>No</td>
</tr>
<tr>
<td>Land v. Edwards</td>
<td>Yes</td>
<td>Sub. judgment</td>
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<td>Common law</td>
<td>No</td>
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<tr>
<td>In re Longway</td>
<td>Not clear</td>
<td>Sub. judgment</td>
<td>Not discussed</td>
<td>Common law</td>
<td>Yes</td>
<td>Not withdraw</td>
<td>No</td>
</tr>
<tr>
<td>In re Browning</td>
<td>No</td>
<td>Not discussed</td>
<td>Clear and conv.</td>
<td>Constitution</td>
<td>No</td>
<td>Withdraw</td>
<td>No</td>
</tr>
<tr>
<td>In re Tavel</td>
<td>No</td>
<td>Sub. judgment</td>
<td>Clear and conv.</td>
<td>Constitution</td>
<td>Yes</td>
<td>Withdraw</td>
<td>No</td>
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</tbody>
</table>
clclusions can be reexamined in light of modern experience, especially in the hospice setting. The current position of the court often creates an untenable situation for families and their advisors since there is often more flexibility in end-of-life decision making where there is no guardian (even in the absence of an advance directive) than where a guardian has been appointed. In addition, the fact that feeding tubes, once installed, might not be able to be removed could lead to unintended consequences. For example, doctors and families might be more reluctant to start the feeding tube when it could possibly do some good, out of the fear that if things do not work out as planned, the ward and his or her family might be condemned to a prolonged dying process. Providing more flexibility to guardians can avoid these problems without jeopardizing other significant community interests. It is time to take another look.

Endnotes
5. 563 N.W.2d 485 (Wis. 1997).
6. For purposes of this article I will use the generic term “tube feeding” to refer to the provision of nutrition and/or hydration by means of a feeding tube, whether a nasogastric tube, a gastronomy, or other means.
7. Note that neither the review of the case law nor of the medical literature is intended to be an exhaustive review of this topic. Rather, some of the key cases are identified to set a framework for the discussion.
9. This was described in the opinion as involving a “subject who remains with the capacity to maintain the vegetative parts of neurological function but who . . . no longer has any cognitive function.” See 355 A.2d at 654. However, she was not “brain dead.” Id.
10. Id. at 655.
11. Id. at 657.
12. Id. at 651–58.
13. See 355 A.2d at 664. The court rejected Mr. Quinlan’s claim of a parental right to privacy under these circumstances.
15. 355 A.2d at 664 (emphasis added).
16. See id.
17. What happened next is of some interest. After the respirator was disconnected, Karen continued breathing on her own, was moved to a nursing home, and continued to live for several years, albeit being subject to tube feeding.
18. See generally 355 A.2d at 647.
20. Id. at 266.
21. See id. at 268.
22. Id.
23. Id. at 287.
25. See id. at 278.
26. Id. at 282–83.
27. See generally 482 N.W.2d 60 (Wis. 1992).
28. See generally 563 N.W.2d 485 (Wis. 1997).
29. See Wis. Stat. §§ 155.20(4), 154.03. This was not always the case. When Chapter 154 was first enacted, it did not permit the withholding or withdrawal of tube feeding (then referred to as “non-orally ingested nutrition and hydration”).
30. 482 N.W.2d at 63.
31. Id.
32. See id. at 64–65.
33. Id. at 65.
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34. Id.

35. 482 N.W.2d at 65–66.

36. Id. at 66.

37. Id. at 66.

38. Id. at 66.

39. Id. at 67.

40. 482 N.W.2d at 67–68.

41. See id. at 68. One should note that even for persons who were competent at one time, but who never executed advance medical directives, it is often equally impossible to know what their wishes are regarding life-sustaining treatment. Many people simply are unwilling to discuss this topic or have never done so. Anecdotally, I would observe that in my practice of doing powers of attorney for health care, I cannot remember any case where a client chose to check “no” in the box relating to tube feeding, meaning, as I tell them, that this would probably result in tube feeding in every circumstance. Nearly everyone I have dealt with wants the agent to have discretion to remove feeding tubes when the agent decides that the only result of the feeding tube is to prolong the dying process.

42. See 482 N.W.2d at 70.

43. Id. at 71–72. In the next section of this paper, I will discuss the appropriateness of limiting a guardian's authority to persons in a “persistent vegetative state.”

44. Id. at 72.

45. Id. at 73.

46. See id. at 73–74.

47. 482 N.W.2d at 74.

48. 563 N.W.2d at 485.

49. It is probably no coincidence that the author of the majority opinion in Edna M.E., Justice Steinmetz, was the sole dissenter in L.W.

50. 563 N.W.2d at 487. Justice Abrahamson, in her concurring opinion, suggests that the statement of facts in the majority opinion does not, in her words, “do justice” to the factual record. She states: “Ms. F. breathes without assistance but in all other respects is dependent on others for her care and continued existence. Ms. F.’s muscles have deteriorated to the point where her limbs are contracted and immobile. She demonstrates no purposeful response, such as withdrawal, to tactile, aural or visual stimuli; she makes non-specific responses to pinching or tapping of the arm or sternum. There is also some testimony suggesting Ms. F. occasionally may track movements in the room with her eyes. Two attending physicians testified; only Dr. Erickson, however, was asked to opine on whether Ms. F. was in a persistent vegetative state at the time of his examination of her. Dr. Erickson testified as follows: The definition [of persistent vegetative state] as described in the Journal of Neurology in January 1989 requires that there be no behavioral response whatsoever over an extended period of time, and that no voluntary action or behavior of any kind is present. As I testified before, Edna, in my opinion, has provided evidence of some minimal response to stimulation from her surrounding, and so in the strict definition, I would have to say that she approximates but does not entirely meet that definition of the persistent vegetative state.” 563 N.W.2d at 492.

51. 563 N.W.2d at 492.

52. Id. at 487.

53. See id. at 487.

54. See id. at 487–89.

55. 307 N.W.2d 881 (Wis. 1981). Eberhardt involved a petition to authorize the guardian of an incompetent person to consent to her sterilization. The court in Eberhardt declined to permit the sterilization.

56. 563 N.W.2d at 489.

57. Id. at 489–90.

58. Id. at 490.

59. See id.

60. 563 N.W.2d at 490.

61. See id. at 491.

62. Id. at 490–91.
63. 482 N.W.2d at 72.

64. Id. at 73.

65. 563 N.W.2d at 490. To be sure, the Steinmetz opinion also raises the specter of “euthanasia” and asserts that the court will not go down that “slippery slope.” Id. However this seems to be added baggage to the opinion and is not central to the position that he takes.

66. Id. at 490. While I make no pretense that this is an exhaustive review of the literature (or that I have any medical expertise), as will be seen I have reviewed a significant number of different sources and they are fairly uniform in their conclusions. I invite someone with more medical knowledge than I have to make a more complete review of this area. I am satisfied from my review to make the conclusions that I will make in the body of this article.


69. “In the most advanced stages of Alzheimer’s disease, cumulative strokes, advanced Parkinson’s disease, other neurodegenerative conditions, and profound traumatic brain injury, patients are totally dependent on others for all aspects of care, and may be mute, bedridden and unable to eat [footnotes omitted]. In some cases they are indistinguishable for those in a persistent vegetative state.” Ahronheim, supra note 69, at 379.

70. 497 U.S. at 274.

71. Maria Andrews et al., Dehydration in Terminally Ill Patients, 93 POSTGRADUATE MED., 201, 201-203 (1993).

72. Id. at 203, 206.

73. Robert McCann et al., Comfort Care for Terminally Ill Patient, 272 J.A.M.A. 1263 (1993).

74. Id. at 1266.

75. Id.


77. Id. at 226.

78. Additionally, the passage quoted from the Ahronheim article is instructive. There are many illnesses that can create conditions that have the same effect as persistent vegetative state. Ahronheim, supra note 69, at 379. Thus, even if the court’s rationale has any basis, using persistent vegetative state as the “bright line” still does not make sense.

79. In re Fiori, 673 A.2d 905 (Pa. 1996); In re Doe, 583 N.E.2d 1263 (Mass. 1992); In re Martin, 338 N.W.2d 399 (Mich. 1995); In the Matter of Tavel, 661 A.2d 1061 (Del. 1995); In re Guardianship of Myers, 610 N.E.2d 663 (Ohio Com. Pl. 1993); Mack v. Mack, 618 A.2d 744 (Md. 1993); Land v. Edwards, 858 S.W.2d 698 (Ky. 1993); In re Estate of Longway, 549 N.E.2d 292 (Ill. 1990); In re Guardianship of Browning, 568 So. 2d 4 (Fla. 1990).

80. While there are numerous pre-Cruzan cases discussing this issue, the post-Cruzan experience is more relevant because of the issues resolved in _Cruzan_, namely the affirmation by the Supreme Court that there is a protected right to refuse unwanted medical treatment.

81. 482 N.W.2d at 72.

82. Dunphy et al., supra note 76, at 226–27. See also Byock, supra note 67, at 11. “Proportionality is commonly explained as a weighing of the risks versus potential benefits of a proposed intervention.”