

become active listeners in search of smoldering feelings that might give rise to conflict.

If and when conflict erupts, end-of-life choices shouldn't be treated as purely ethical questions, divorced from the regrets and resentments involved. Psychiatric and social-work consultation should be part of the management plan, and mediation merits study as an approach. Mediators' methods of listening, exploring parties' needs, reframing problems, and proposing solutions have been well honed in work with divorcing couples, estranged business partners, and others in life-transforming crises.³ These skills are well suited to the work of guiding warring family members toward agreement on end-of-life choices for their loved one.

At times, physicians, and even insurers, become parties to these conflicts. Financial incentives, real or perceived, can shape positions and sow distrust. Cost-control strategies that engage caregivers in covert rationing can have toxic effects,⁴ particularly when medical futility is at issue. Our national unwillingness to acknowledge the conflict between efforts to limit medical spending and insistence on all possibly beneficial care worsens this toxicity. Good mediation technique can help to clarify misunderstandings, soften anger, and ease irrational distrust. But it cannot finesse contradictions that, as a country, we refuse to face.

For the last six years of Terri Schiavo's life, Robert Lynch, the local Catholic bishop, tried unsuccessfully to meet with her parents and husband to reach a solution through mediation. As their personal struggle became an international spectacle, Lynch broke with the Church hierarchy by refusing to side with the parents. Instead, he called on "both sides [to] step back" and to try for "a heroic moment of concern for the feelings of each other."⁵ In a public appeal that was ignored by all sides, he said: "The legacy of Terri's situation should not be that of those who love her the most, loathing the actions of one another."⁵ Schiavo's legacy has turned out to be worse than he feared. After her death, her parents and husband continued to battle — over access to her remains.

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Patients in a Persistent Vegetative State — A Dutch Perspective

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He is 31 years old now — Henk-Jan, the son of Gerard and Ineke Stinissen. He is the son Ineke Stinissen never knew. In 1974, as the result of a dramatic medical error that occurred during emergency cesarean delivery, she was left in a persistent vegetative state. Through most of Henk-Jan's life, his mother's condition and treatment have been matters of an emotionally fraught public controversy.

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In 1985, his father sought publicity — in a television program called "How Long Should Dying Last?" — for his view that his wife's artificial nutrition and hydration should be stopped. In 1987, he went to court to demand that the nursing home stop the feeding. On January 9, 1990, it was finally discontinued, and Ineke Stinissen died 10 days later. Behind these few facts lies a long, sad story that has been widely debated in the Netherlands. Why stop the feeding? Why not? Why now? The questions echo today, in the wake of the recent case of Terri Schiavo.

In the first hearing of the Stinissen case and again on appeal, the Dutch courts focused on the following questions: Are artificial nutrition and hydration medical treatment or basic care? If the former, is this treatment futile? And who is authorized to decide whether to stop treatment? The husband argued that he was his wife's legal representative and that the doctors were treating his wife without permission. The courts judged that Gerard Stinissen had the right to take his wife to another nursing home where the doctors might have different views. It was decided that artificial feeding was mainly medical, although an element of basic care was acknowledged to be involved. Given the varying opinions of doctors about the question of futility, the courts considered it inappropriate to come to a conclusion on that aspect.

Ultimately, the nursing home clinicians consulted outside ethicists and physicians. When the attending physicians declared that they were now prepared to stop treatment but feared that the process of dying would be terrible, the consulting physicians convinced them that it need not be.¹

The day after artificial feeding was stopped, members of a prolife Christian patient movement started a legal action, claiming that they could represent Ineke Stinissen's interests because her husband and doctors had neglected to do so. They argued that no one can judge the quality of life of incompetent patients and questioned the peculiar determination of the nursing home that now, after 15 years, it was suddenly futile to continue treatment. Their argument was rejected by the courts, which did not consider them representatives of the patient.

Nevertheless, the debate with regard to patients in a persistent vegetative state continued. The Royal Dutch Medical Association and the Health Council published reports on the topic,^{2,3} both of which turned the question around. Instead of asking whether it is acceptable to stop treatment, they asked whether it is justified to continue treatment. Both organizations answered in the negative, concluding that such treatment is medically futile.

In the Netherlands, the withdrawal of artificial nutrition and hydration from a patient in a persis-

tent vegetative state is not considered euthanasia, which is a category that is restricted to measures taken by a doctor to actively end the life of a person at his or her explicit request — actions that are considered to be justified only as a means of ending unbearable and hopeless suffering. The distinction between euthanasia and discontinuing medically futile treatment was stressed in the Stinissen case — in part because the development of the Dutch euthanasia law was at a delicate stage, and its proponents feared that the Stinissen debate would jeopardize that process. And indeed, people who believed that artificial nutrition and hydration are necessary medical treatment or essential care and who therefore regarded stopping such treatment as a means of killing conflated this practice with euthanasia to bolster their argument that both should be banned.

There now seems to be a consensus in the Netherlands that artificial hydration and nutrition are medically futile for patients in a persistent vegetative state

and therefore can and should be stopped. There are legal rules for proxy consent to this action. Under Dutch law, a doctor generally cannot treat someone without his or her consent. In the case of an incompetent patient, the legal representative makes the decision regarding the continuation of treatment. It is illegal to defy a negative advance directive (a refusal of treatment). If there is no written directive, the wish of the person is to be reconstructed with the help of persons close to him or her.

Since artificial feeding is considered medically futile for patients in a persistent vegetative state, the burden of judgment rests on the doctors, although the assent of the family is sought. As soon as Dutch doctors are certain about the diagnosis and the prognosis, they discuss the situation with family members, so that the family can adjust to the idea that the point of no return has been reached. But real life can be unruly. If the patient's family does not agree to the withdrawal of treatment, and if there is no statement of the patient's wishes, treatment is sometimes continued. In 2003, there were 32 patients in a vegetative state in Dutch nursing homes. Of the 30 patients whose data were analyzed, 26 had survived for more than a year, 5 of

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them for more than 10 years.⁴ The heartbreaking dilemma for the families of these patients was perhaps expressed best by the parents of a boy who had been in such a state for more than 16 years: “This is a fate worse than death, but we don’t want to lose him.”¹

There are two possible explanations for the practice of continuing to treat such patients, which is at odds with the general view in the Netherlands. First, although such treatment is considered futile by many people, others (who might include the patient’s doctors and relatives) disagree. They may believe that such a life has an objective value that does not depend on the subjective experiences of the patient (or the absence thereof). This view is respected. Second, physicians, on the strict condition that they will not be inflicting suffering on the patient, are prepared to “err” on the side of the family, providing what they consider to be futile treatment at the request of and for the benefit of the family, at least for a while. Patience may be essential for a family torn between hope and acceptance. Here the question “Why stop now?” becomes pertinent. What is it about today that is so different from yesterday or a month ago? Sometimes, no adequate answer can be given.

We must be cautious when comparing the Dutch debate about Ineke Stinissen with the U.S. debate about Terri Schiavo, although some considerations were central to both: the role of the patient’s wishes, the nature and quality of life in a persistent vegetative state and the subjective or objective meaning attached to such a life, and the distinction between basic care and treatment in relation to futility. The differences between the two cases seem to lie primarily in the way the disagreements were handled.

Like most of their American counterparts, Dutch patients and doctors generally try to solve their moral problems among themselves, within the existing social and legal boundaries, rather than ask judges to cut the Gordian knot. The Dutch are, generally speaking, not of a litigious disposition, and doctors may even regard the need for a judicial decision as an indication of their own shortcomings of skill in communication or deliberation. The people involved will keep talking until a mutually acceptable

solution is reached. This approach suits a pluralist society, in which we try to show respect for others and demand respect for our own views. When cases involving end-of-life decisions are brought to court in the Netherlands, they — unlike the Schiavo case — are usually put forward as test cases after the decisions have been made. They are used primarily to change or challenge policies.

Of course, politics have always been well represented in debates about end-of-life decisions. The government of the Netherlands supports both financially and morally several extensive Dutch research projects on such decisions, knowing that the world is looking over the shoulders of the Dutch — particularly given our reputation as iconoclasts with respect to end-of-life decision making. Therefore, the Dutch people look over the shoulders of the doctors, dissecting their decisions under the microscope of public opinion. Although we in the Netherlands may try to respect others’ choices regarding dying and to recognize the private nature of these choices, the exploitation of human tragedies for political purposes is all too familiar. We have held our breath as moral hurricanes swept over the country and harsh words were spoken in the political arena and in the media. But we have, so far, not witnessed any politicization as extreme as that seen in the Terri Schiavo case.

Most of us, given the opportunity, would want to orchestrate the way in which we die. The tragic stories of Terri Schiavo and Ineke Stinissen teach us that we must think seriously about — and communicate to our family members and friends — what we would want if we were ever left “awake but not aware.”

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