

Lessons from the Butcher Case

Third-party interests, not the patient's, inappropriately forced this family into court to discontinue their son's medical treatment.

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When Jim and Pattie Butcher decided to discontinue artificially administered nutrition and hydration for their 34-year-old son, Jamie, who had been in a permanent vegetative state for almost 17 years, they did not expect to be thrust into legal proceedings, and certainly not into the headlines. They had always made health care decisions for their son, as most families do, without being appointed legal guardians. They had sought all available rehabilitative treatment and were involved in Jamie's care every day, even while he lived in a nursing home. Their decision was consistent with prevailing medical standards in Minnesota and across the nation for patients in a permanent vegetative state. In making their decision, they had adhered to every principle of responsible health care decision making, consulting every person they knew who had an interest in and concern for Jamie. During that process, no one questioned their decision, because all who knew Jamie agreed that it was appropriate for him.

The Butchers were thrust into litigation and the limelight by others acting in their own interests, not Jamie's.

The Story

Jamie Butcher was a 17-year-old high school senior when he sustained severe brain injuries in an auto accident. He never regained consciousness and, after extensive treatment, was diagnosed to be in a permanent

vegetative state. He did not require assistance with respiration but was given nutrition and hydration through a gastrostomy tube.

His parents cared for him in their home for seven years. At one point, Jamie suffered a cardiac and respiratory arrest, which the Butchers had fully anticipated would be the way his life would end. After calmly washing Jamie and changing his gown, Pattie called 911 to report his death. However, with no home-based "do-not-resuscitate" order system in place,¹ Pattie was soon met with determined, and ultimately successful, resuscitation efforts by the 911 responders.

The Butchers placed Jamie in a nursing home in 1984 but continued to be very involved with his care and treatment. Pattie assisted with Jamie's care almost every day. She became a member of the nursing home's ethics committee and a facility volunteer in other capacities. The Butchers never became legally appointed guardians or conservators for their son, since every health care professional with whom they dealt recognized them as appropriate surrogate decision makers. Their other son, Jeff, also recognized them as appropriate decision makers, although he felt that artificial nutrition and hydration should have been discontinued years earlier.

In 1993, the Butchers came to the decision that artificially administered nutrition and hydration should be discontinued and that Jamie should be allowed to die from the effects of

his 1977 auto accident. They felt he should not live in the vegetative state longer than he had been fully alive and that they had been keeping him alive so long primarily for their own benefit, not his. As the Butchers came to their decision, they discussed the matter with every person who had an interest in and concern for Jamie. They contacted family members from grandparents to cousins, Jamie's friends from grade school and high school, and significant health care professionals who cared for Jamie. Jamie's attending physician was supportive of the family's decision and was prepared to supervise his care after discontinuing treatment. No one involved with Jamie expressed any reservation about the Butchers' decision on Jamie's behalf or about the appropriateness of the Butchers making the decision for Jamie.

The Butchers brought the matter to the nursing home's ethics committee, saying that they intended to take Jamie home when they discontinued treatment so that he could die at home surrounded by family and friends. The ethics committee was composed of nursing home staff and the facility's in-house counsel. The committee did not express any concern from an ethical perspective with the Butchers' decision or with the appropriateness of the Butchers making the decision on Jamie's behalf. However, the ethics committee did note concerns about the nursing home's legal position under the Minnesota Vulnerable Adult Act,² fear-

ing that the discontinuation of treatment might be viewed by authorities as "neglect." If it were deemed neglect that the nursing home failed to report, the nursing home could be subject to licensure sanctions. Therefore, the committee recommended that authorities be notified, in essence suggesting the nursing home report the Butchers for suspected illegal neglect. Legal counsel also noted that Ramsey County should be apprised so that it could have an opportunity to intervene by seeking the appointment of a guardian, even though there were no indications that anyone had any medical or ethical concerns about the substance of the Butcher's plan.

The ethics committee also suggested that Jamie be re-evaluated for confirmation of the diagnosis of permanent vegetative state. There was no indication that the diagnosis was in any doubt after 17 years, nor was there indication in the minutes of what purpose this re-evaluation would serve. However, wanting to be cooperative, the Butchers took Jamie to Hennepin County Medical Center, where he had been previously evaluated. Jamie's diagnosis was confirmed, and the Butchers became reacquainted with Ronald Cranford, M.D., of the neurology department, to discuss their decision to discontinue treatment.

Since the nursing home intended to report the Butchers to the authorities, the Butchers contacted Ramsey County on their own before arranging to bring Jamie home. They wanted the county to have all relevant information before it took a position on the issue, and they did not want to take Jamie home and find the authorities at their doorstep with legal papers. The county received complete information concerning Jamie's condition, including his recent re-evaluation and pertinent medical-ethical guidelines concerning withdrawal of medical treatment for persons in a permanent vegetative state. The county was also given the opportunity to discuss the matter with Cranford.

The Ramsey County Attorney's Office did not take much time to reach the simple conclusion that discontinuation of artificial nutrition

and hydration was failure to provide "necessary food" since it would result in Jamie's death and, therefore, that it was illegal neglect under the Vulnerable Adult Act. If the Butchers were to withdraw treatment, they could be subjected to criminal penalties for neglect. This interpretation was given regardless of the fact that medical treatment is discontinued

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daily, including the withdrawal of artificially administered nutrition and hydration, in Ramsey County as a matter of standard medical practice in appropriate cases and that no one had, to anyone's knowledge, been faced with a neglect charge under those circumstances. Ramsey County suggested that, for their own protection, the Butchers could proceed to court to be appointed conservators for Jamie and ask for court authorization to discontinue treatment. The county also suggested that there would be no opposition by the county to their petition.

The Butchers were in a quandary. On the one hand, they were being told that withdrawal of treatment was illegal neglect, which could subject them to criminal penalties, even though similar decisions were being made by families for their loved ones every day in Ramsey County, throughout Minnesota, and across the country, consistent with good medical practice, without sanction, and without court involvement. On the other hand, they were also being told that, if they just went to court to be appointed conservators for Jamie and received authorization to with-

draw treatment, the withdrawal of treatment would suddenly not be considered neglect—as if the court's blessing would transform what the county thought was an illegal act into a legal one.

Rather than taking the easy path to resolve their legal dilemma—by being appointed conservators for Jamie and obtaining court "protection"—the Butchers decided to resolve it by bringing a head-on challenge to Ramsey County's unrealistic and unprecedented interpretation of the Vulnerable Adult Act. By so doing, they would be able to have the court find that they were not "neglecting" their son and would also be able to help other families faced with similar decisions; perhaps Ramsey County would not accuse other families of illegal neglect or force them into court to be appointed conservators for loved ones when no one who knew the patient questioned the appropriateness of their decision.

On February 18, 1994, the Butchers filed a Declaratory Judgment Action against Ramsey County and asked for two rulings:

- first, that withdrawal of artificially administered nutrition and hydration, consistent with prevailing medical practice, does not constitute neglect under the Vulnerable Adult Act even if it results in the patient's death; and
- second, that they, who had been recognized and respected surrogate decision makers for Jamie for his entire life, again consistent with prevailing medical practice, need not be appointed his conservators in order to make this last health care decision on his behalf.

With no dispute about the facts of the case, Referee and Court Commissioner James R. Finley of the Ramsey County District Court made his decision based on stipulated facts, legal briefs, and oral arguments. Ramsey County made a motion that a guardian ad litem be appointed to represent Jamie. The Butchers argued against that motion on the grounds that a guardian ad litem could not add anything to the proceeding in these circumstances, even though in other cases the appointment of a guardian ad litem would be

appropriate. The only questions to be determined were legal questions, and Ramsey County could be counted on to vigorously represent the public interest and public policy. Furthermore, since Jamie had never been conscious as an adult, he had never been able to formulate or express any preferences about his health care treatment that the guardian ad litem could express. His medical condition was not in dispute, nor was there any dispute about the support of his family, friends, and medical advisers for the decision. Anything the guardian ad litem might say would be mere speculation and conjecture, when everyone who knew him agreed on the appropriateness of the Butchers' decision.

On September 7, 1994, Referee Finley issued his order.³ He found that a "decision to continue or terminate artificial administration of nutrition and hydration is a health care and ethical decision," that "termination of artificially administered nutrition and hydration for a person in a permanent vegetative state is within the scope of accepted medical and ethical practice in Minnesota," and that it is not neglect under the Vulnerable Adult Act.

He also found that the Butchers were appropriate surrogate decision makers for their son, that they were not required to be appointed guardians or conservators, and that there was no need for a court order authorizing the termination of artificial administration of nutrition and hydration. Referee Finley found that "this is a private health care and ethical decision to be made by plaintiffs after consultation with James D. Butcher II's health care providers and immediate family members." He did not appoint a guardian ad litem to represent Jamie in the legal proceedings. He went on to refer with approval to numerous medical-ethical guidelines developed by health care professional organizations. He found that recognition of the Butchers as surrogate decision makers for Jamie without court involvement is consistent with the standard of medical and ethical practice in Minnesota and that there is no provision in Minnesota law that requires the appoint-

ment of a guardian or conservator under these circumstances.

A few days after the court's order, Ramsey County announced that it would not appeal, leaving the Butchers free to implement their decision. The Butchers began preparing themselves to take Jamie home and discontinue treatment. They decided to wait a few weeks so that Jamie's brother, Jeff, could return from Europe to be there when Jamie died.

The last day before the expiration of the 30-day automatic stay of the court's order, two groups filed petitions seeking to have a guardian ad litem appointed for Jamie, the same issue Ramsey County had raised and the court had denied. The petitioners, Arc Minnesota, Inc., and the Ethics and Advocacy Task Force of the Nursing Home Action Group, had been aware of the litigation since it was filed but had made no previous attempt to become involved. They had no personal connection with Jamie or the Butcher family. They were represented by local counsel and by the National Legal Center for the Medically Dependent and Disabled, Inc., from Indianapolis, Indiana.

The Butchers were concerned about other legal actions the petitioners might take because they knew that the National Legal Center had obtained emergency legal control of patients in other states when families sought to discontinue treatment under similar circumstances. Therefore, they brought Jamie home a few days after the motions were filed.

On the day of the hearing, Arc of Minnesota voluntarily dropped its petition. The Ethics and Advocacy Task Force maintained its petition to have a guardian ad litem appointed and also asked that the entire case be dismissed. Its reasons for seeking dismissal were not made entirely clear, but seemed to focus on a desire to eliminate the case as a precedent for other patients and families, particularly persons with extensive disabilities.

Referee Finley heard the petitions on October 17, 1994, and from the bench ordered that the petitions be dismissed. He ruled that he had pre-

viously decided the guardian ad litem issue after full consideration and that the petitioner had no standing to bring what were essentially motions for reconsideration or appeals of previously determined issues.

The Butchers held a brief religious ceremony in their home when they terminated Jamie's artificially administered nutrition and hydration on October 19. He died peacefully 11 days later.

The Ethics and Advocacy Task Force has pursued further legal review with another Ramsey County District Court judge. As *Minnesota Medicine* goes to press, no ruling has been issued. The Task Force's first allegation in its review papers is that the court violated the Task Force's "statutory right to advocate on behalf of vulnerable persons" by denying its petition to have a guardian ad litem appointed.

Significance to Health Care Professionals

There are important lessons to learn from the Butcher case.

First, it appears that consideration of the nursing home's legal position diverted the ethics committee from its focus on the ethical issues involved in the Butcher family's situation. This case illustrates the ease with which discussions of ethics are overwhelmed by discussions of legal liability. Ethics committees should not be the place in which a health care facility's legal decisions are made; when they are, true value to the institution is greatly diminished.

Second, both the nursing home and Ramsey County appeared to act under single-dimensional analyses of the legal issues and forced the Butchers into legal proceedings for their own protection rather than Jamie Butcher's protection. Neither appeared to consider that decisions to terminate medical treatment, whether it be something as dramatic as withdrawing artificially administered nutrition and hydration or something as mundane as discontinuing an antibiotic, happen hundreds of times every year in Minnesota, in hospitals, nursing homes, and

clinics, in accordance with prevailing standards of medical care when treatment offers insufficient likelihood of benefit to the patient. A simplistic determination that a health care treatment or artificially administered nutrition or hydration is "necessary" under the Vulnerable Adult Act if death results in its absence flies in the face of logic and other laws, such as the living will and health care power of attorney statutes.⁴ Hundreds of Minnesota families and their physicians and other health care providers would be criminals if that were a reasonable interpretation of the Legislature's intent in creating the law. Health care providers and government must carefully evaluate the laws under which they operate to avoid forcing patients and families into court for the protection of the institutions rather than the patients.

Third, the Butcher case illustrates the importance of professional guidelines for health care decision-making issues. As had many other judges across the country, Referee Finley gave considerable weight to guidelines from the American Medical Association, the Minnesota Medical Association, and other professional groups on the issues presented. In the absence of a Minnesota law prohibiting families from making decisions when there is no dispute, Referee Finley looked to the professional guidelines for articulation of community practice. He stated that health care decisions are medical and ethical decisions to be made by appropriate decision makers in consultation with their health care advisers. Even for patients incapable of making their own health care decisions, most decisions, including those related to termination of treatment, do not involve legal issues with which courts need be involved.

A legal process does not add anything to the health care decision-making process when there are no disagreements among those involved. Courts are often used to rubber-stamp appropriately made health care decisions because families, guardians, health care providers, or government seek protection from some unarticulated, and largely illusory, legal exposure. Courts should be, and are,

available to resolve disputes between patients and families, or between patients/families and health care providers, when disagreements or other circumstances dictate the need for impartial third-party review and issue resolution. The practice in many counties in Minnesota to seek court orders for medically and ethically appropriate termination of treatment should be carefully scrutinized under the principles emphasized by Referee Finley in the Butcher case.*

Fourth, the Ethics and Advocacy Task Force's attempt to become involved further illustrates how easy it is to be diverted from considering the patient's interests. During the hearings, the Task Force's counsel repeatedly stated that it did not disagree with the decision the Butchers were making for Jamie, yet it asserted a right as an advocacy group, not acquainted with Jamie or his family and not representing any specific clients or patients, to have its say on legal issues already determined by the court. Even after Jamie's death, it persists in the litigation, arguing its own alleged "statutory right to advocate on behalf of vulnerable persons" as its primary concern. To his credit, Referee Finley was not diverted from his thoughtful analysis, and his approach should be noted in other situations as well.

A Look to the Future

The Butcher case has already had an impact on laws concerning health care decision making in Minnesota. A task force led by the Minnesota Office of the Attorney General has drafted new language intended to revise the Vulnerable Adult Act to clarify that appropriate withdrawal

of health care treatment does not constitute "neglect." The Vulnerable Adult Act may be amended in the 1995 legislative session, and the proposal should be watched carefully.

Discussion continues about whether Minnesota should enact a health care decision-making act, such as exists in many other states, to establish a statutory hierarchy of decision makers for patients who do not have guardians or conservators and who have not formally appointed surrogate decision makers through a living will or a health care power of attorney. Such a law would relieve the uncertainty many families, health care professionals, and legal professionals face about who are appropriate surrogate decision makers for incapable patients. However, there is concern that a health care decision-making act would confer authority upon family members high on the statutory hierarchy when, in fact, they are not the most appropriate decision makers for the patient in the context of overall family or personal relationships. The Minnesota Medical Association guidelines⁵ recognize the responsibility of physicians to identify the appropriate surrogate decision maker for each patient in the context of the patient's entire family and personal relationships. Patients may not be well served by enactment of a rigid statutory hierarchy that could replace physician judgment. MM

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REFERENCES

1. Blumer BJ. Communicating DNR orders in non-hospital settings. *Minn Med* 1994; 77(4):41-3.
2. Minn. Stat. § 626.557.
3. James D. Butcher and Patricia A. Butcher v. Thomas Fashingbauer, et. al, Ramsey County District Court, File Number C7-94-1717, Findings of Fact, Conclusions of Law and Judgment dated September 7, 1994.
4. Minn. Stat. Ch. 145B and 145C.
5. Minnesota Medical Association. Policy Compendium, 1994 ed. Minneapolis: Minnesota Medical Association, 1994:41-3.

* See also: In re the Guardianship of Arthur Voeller, Ramsey County District Court Civil File No. Co-94-3874, Findings of Fact, Conclusions of Law and Judgment dated March 23, 1994, in which Referee Finley found that a guardian need not receive court approval for a decision to terminate treatment when there was no disagreement concerning the appropriateness of the decision. ["There are no judicial issues to be decided."]