Withdrawal Nut./Hyd./Busalacchi case

IN THE MISSOURI COURT OF APPEALS

EASTERN DISTRICT

No. 59582

IN THE MATTER OF CHRISTINE BUSALACCHI,
Incapacitated/Disabled

MISSOURI DEPARTMENT OF HEALTH,
Appellant

vs.

PETER J.BUSALACCHI,
Respondent

Appeal from the Circuit Court of the
County of St. Louis, Missouri
Twenty-First Judicial Circuit
Probate Division
Honorable Louis M. Kohn, Judge

BRIEF OF EDMUND PELLEGRINO, M.D., LEON R. KASS, M.D., MARK A. SIEGLER, M.D., FRED ROSNER, M.D., WILLIAM J. BURKE, M.D., LESLIE STEVEN ROTHENBERG, J.D.

Edward R. Grant
Cathleen A. Cleaver
Americans United for Life
900 Second St. N.E. #204
Washington, D.C. 20002
202-289-6901

Clarke D. Forsythe
Kevin J. Todd
Americans United for Life
343 So. Dearborn St. #1804
Chicago, IL 60604
312-786-9494

Robert A. Wulff
Amelung, Wulff & Willenbrock
705 Olive Street Suite 1400
St. Louis, MO 63101
314-436-6757

Dated: January 30, 1991

TABLE OF CONTENTS

Table of Authorities iii

Interests of the Amici 1

Statement of the Case 3

ARGUMENT 5

I. THE PROBATE COURT ERRED IN FAILING TO FIND THAT THE REMOVAL OF CHRISTINE BUSALACCHI FROM MISSOURI IS FOR THE ULTIMATE PURPOSE OF WITHDRAWING HER FEEDING TUBE. 5

II. THE PROBATE COURT ERRED IN FAILING TO FIND, BASED UPON THE TESTIMONY CURRENTLY IN THE RECORD OF THIS CASE, THAT CHRISTINE BUSALACCHI IS NOT IN A PERSISTENT VEGETATIVE STATE. 11

III. THE PROPOSED WITHDRAWAL OF NUTRITION AND HYDRATION FROM PATIENTS IN MISS BUSALACCHI'S CONDITION POSES ISSUES DISTINCT FROM THOSE IN CASES OF PATIENTS IN A PERSISTENT VEGETATIVE STATE. 13

A. Removal of Tube Feeding From a Patient in Miss Busalacchi's Condition is Not Warranted Under the Guidelines Established by Such Organizations as the American Medical Association, the American Academy of Neurology, and the President's Commission. . 13

B. Removal of Tube Feeding From a Patient in Miss Busalacchi's Condition May Justify a Heightened State Interest in Preventing Such Withdrawal. 16

IV. THE PROBATE COURT ERRED IN DENYING THE APPELLANT'S MOTION FOR APPOINTMENT OF A GUARDIAN AD LITEM, SINCE SUCH APPOINTMENT IS A CUSTOMARY AND APPROPRIATE MEASURE TO PROTECT THE INTERESTS OF PATIENTS SUCH AS CHRISTINE BUSALACCHI. 17

CONCLUSION 18

APPENDICES 20

TABLE OF AUTHORITIES

CASES

Brophy v. New England Sinai Hospital, 398 Mass. 417, 497 N.E.2d 626 (1986) 10

Cruzan v. Director, Missouri Department of Health, 110 S.Ct. 2841 (1990) 12, 16, 17

Cruzan v. Harmon, 760 S.W.2d 408 (1988) 10, 17

In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985) 16

In re Grant, 109 Wash. 2d 545, 747 P.2d 445 (1987) (en banc), as modified, 757 P.2d 534 17

In re Jobes, 108 N.J. 394, 529 A.2d 434 (1987). 10, 16

In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976). 16

In re Westchester County Medical Center, 72 N.Y.2d 517, 531 N.E.2d 607 (1988). 16

OTHER AUTHORITIES

American Academy of Neurology, Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient, 39 Neurology 125 (1989). 12, 13

Berrol, Consideration for Management of the Persistent Vegetative State, 67 Arch. of Physical Med. and Rehabil. 283 (1986). 11

Burke, et al., Evidence for Decreased Transport of PNMT Protein in Advanced Alzheimer's Disease, 38 J. Am. Geriatric Soc'y 1275 (1990). 1

Council on Ethical and Judicial Affairs, American Medical Association, Current Opinions 13 (1989). . . . 13

Cranford, The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight), Hastings Center Report, February/March 1988. . . . . 7, 10, 14

Gaylin, Kass, Pellegrino & Siegler, Doctors Must Not Kill, 259 J.A.M.A. 2139 (1988) 1

Jennett & Plum, Persistent Vegetative State After Brain Damage, 1 Lancet 734 (1972). 12

Jonsen, Siegler & Winslade, Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine (1986) 1

Kass, Death With Dignity and the Sanctity of Life, Commentary, March 1990 1

Kass, Toward a More Natural Science (1986). 1

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, 171-196, 190 (1983). 7, 11, 13, 14-15

Rosner, Medicine and Jewish Law (1990). 1

Rosner, Modern Medicine and Jewish Ethics (1986). 1

Rothenberg, The Dissenting Opinions: Biting the Hands that Won't Feed, Health Progress 38 (December, 1986) . 1

Siegler & Weisbard, Against the Emerging Stream, 145 Arch. Int. Med. 129 (1985) 1

INTERESTS OF THE AMICI

The amici include board-certified physicians of various medical specialties, as well as medical ethicists, who are affiliated with major medical institutions and medical ethics research centers in the United States.[1] All of the physician amici are board-certified in their field of medical practice. All of the amici have taught at the graduate or professional level in the fields of medicine, neurology, medical ethics and/or law, and all have published in professional journals on subjects relevant to this case.[2] Several have held leadership positions or been otherwise affiliated with major centers for the study of medical ethics.[3] They are prompted to submit this brief

---

1. The amici and their affiliations are listed in Appendix A to this Brief.

2. See, e.g., Gaylin, Kass, Pellegrino & Siegler, Doctors Must Not Kill, 259 J.A.M.A. 2139 (1988); Jonsen, Siegler & Winslade, Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine (1986); Siegler & Weisbard, Against the Emerging Stream, 145 Arch. Int. Med. 129 (1985); Rothenberg, The Dissenting Opinions: Biting the Hands that Won't Feed, Health Progress 38 (December, 1986); Kass, Death With Dignity and the Sanctity of Life, Commentary, March 1990, at 33; Kass, Toward a More Natural Science (1986); Burke, et al., Evidence for Decreased Transport of PNMT Protein in Advanced Alzheimer's Disease,38 J. Am. Geriatric Soc'y 1275 (1990); Rosner, Modern Medicine and Jewish Ethics (1986); Rosner, Medicine and Jewish Law (1990).

3. Dr. Kass is a founding fellow and member of the board of directors of the Hastings Center, and a fellow of the Center for Clinical Medical Ethics at the University of Chicago. Dr. Siegler is founder and director of the Center for Clinical Medical Ethics at the University of Chicago. Dr. Pellegrino is former director of the Kennedy Institute of Ethics at Georgetown University, and currently professor of medicine and medical ethics at Georgetown. Dr. Rosner is chair of the Commission on Bioethical Issues of the Medical Society of the State of New York, and a member of the

memorandum to the Court in order to clarify some points of confusion that appear to be represented in the popular accounts of this case, as well as in the ruling of the probate court. The case of Christine Busalacchi raises serious questions, not previously addressed by the courts of this state, nor by the courts of sister states, regarding the proper extent of state regulation of proposed decisions made on behalf of an incapacitated patient by a court-appointed guardian; issues of informed consent to initiation and withdrawal of medical treatment; and standards of medical ethics regarding the potential withdrawal of tubel feeding from patients in Miss Busalacchi's current condition.

The <u>amici</u> seek to address these issues in the context of the record that is presently before this Court. The <u>amici</u> do not purport to state either diagnostic or prognostic judgments, or opinions on questions of medical ethics, that may arise through a fuller development of that record. Nor do they purport to state a categorical position on the proper standards for treating a patient such as Christine Busalacchi. The <u>amici</u> do wish to advise this Court, however, that based upon the record as currently developed: (1) the additional neurological, medical and diagnostic testing that is sought by the Guardian may adequately be performed in the State of Missouri, and that it is in the best

---

advisory board of the Kennedy Institute. Mr. Rothenberg was a member of the committee responsible for drafting the Hastings Center's <u>Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying</u>.

interests of Christine Busalacchi that such testing be performed in Missouri; (2) the prevailing standards of medical ethics, as set forth in statements of the American Medical Association, the American Academy of Neurology, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, do not contemplate or support the withdrawal of assisted feeding, including feeding through a gastrostomy tube, from patients in the condition of Christine Busalacchi.

STATEMENT OF THE CASE

The State of Missouri seeks an injunction against the transfer of Christine Busalacchi, an incapacitated and disabled person, from the Missouri Rehabilitation Center at Mount Vernon.[4] The injunction is sought based upon the state's belief that Miss Busalacchi's father, Peter J. Busalacchi, intends to transfer her to a jurisdiction where he can accomplish removal of her feeding tube.[5] Mr. Busalacchi has testified that he wishes to transfer his daughter to the care of Dr. Bruce Snyder and Dr. Ronald Cranford, both of Minneapolis, Minnesota, for the purpose of performing certain tests to determine the true state of her neurological condition.[6] He has further testified that if these physicians recommend removal of the feeding tube, then this is

---

[4]. Motion for Temporary Restraining Order and Permanent Injunction, filed Jan. 16, 1991.

[5]. Id., para. 5.

[6]. Affidavit of Peter Busalacchi, para. 18-21.

the course that will be followed.[7]

The court below declined to enter a finding that Mr. Busalacchi's intent in seeking the transfer is to accomplish the removal of the feeding tube.[8] The court found that Mr. Busalacchi, being "troubled" and "confused," did not know the exact nature of his own intent.[9] The court admitted that removal of the feeding tube was a "possible alternative" if Christine is transferred outside of Missouri.[10]

The medical testimony is uncontroverted that Christine is not presently in a persistent vegetative state (PVS).[11] However, the court made no specific findings in this regard. Instead, the court held that it does not make a "particle of difference" whether she is in a PVS, or in a more conscious or cognitive state.[12] It further found that the proper forum for making the decision whether to continue to feed Christine is between the closest family member, being Mr. Busalacchi, and the treating physician.[13] The court questioned whether the state had a justiciable interest in pursuing this injunctive relief, and stated the opinion that the courts ought to have no role in

---

7. Tr. at 80-81, 93, 97.

8. Tr. at 232.

9. Id.

10. Id.

11. Tr. 133-34; Affidavit of Dr. Catalino Daroy, para. 5-11.

12. Tr. at 233.

13. Tr. at 237.

making medical treatment decisions for patients such as Christine Busalacchi.[14]

The state's motion for a new hearing, and request for appointment of a guardian ad litem and restraining order pending ruling on the motion for a new hearing, were denied by the probate court.[15] Appeal to this court followed. This court entered a stay of the ruling below, and ordered this cause placed upon a schedule for expedited hearing.

ARGUMENT

I. THE PROBATE COURT ERRED IN FAILING TO FIND THAT THE REMOVAL OF CHRISTINE BUSALACCHI FROM MISSOURI IS FOR THE ULTIMATE PURPOSE OF WITHDRAWING HER FEEDING TUBE.

Based upon admissions in the record below, and evidence which was excluded from that record,[16] it would clearly be reasonable for this Court to conclude that the motive for moving Christine to Minnesota is to accomplish the removal of her feeding tube.[17] According to the record, Mr. Busalacchi told reporters, among other things, that he did not want his daughter to live anymore,[18] and that his goal was to take Christine away

---

14. Tr. at 235-37.

15. See Memorandum for Clerk, dated January 18, 1991.

16. Tr. 28-32 (denying state's request for postponement for opportunity to bring videotapes of guardian's statements).

17. See Another Right-to-Die Case Poses New Questions, N.Y. Times, Jan. 2, 1991; Father Wins a Ruling on Right to Die, N.Y. Times, Jan. 18, 1991, A16, col. 4; Gibbs, Love and Let Die, Time, Mar. 19, 1990, 62 ("I'm riding on the Cruzans' coattails.")

18. Tr. at 79-80.

from Missouri to a place where she could die.[19]

The probate court below found that Mr. Busalacchi is "confused" and "very troubled," but refused to find that the ultimate purpose for his removing Christine to Minnesota is to accomplish removal of the feeding tube.[20] However, the court did admit that such removal was a "possible alternative" in this case. Even this limited finding, when supported with the evidence of record, provides reason for greater scrutiny and oversight of the planned transfer.[21]

In response to repeated questions regarding his present intentions, Mr. Busalacchi admitted that if the doctors in Minnesota diagnose Christine as in a persistent vegetative state, and "they feel that the best care for her is the removal of the feeding tube," then the tube will be removed.[22] When questioned

---

[19]. Tr. at 92.

[20]. Tr. 232. The probate court's remarks to the effect that it is of no concern whether Missouri or Minnesota law eventually governs in this case is a curious position for a court to take when the potential stakes, life versus death, are so high. The amici take no position on which state's laws are superior, or ought to ultimately govern in this case, except to note that the state's resistance to the effort to remove Miss Busalacchi's feeding tube, based on the current record, does not contravene existing canons of medical ethics.

[21]. Mr. Busalacchi's intentions may be inferred from a letter written to the Probate Court dated July 27, 1990, requesting an extension of the time to file the Guardian's annual report: "I realize I should have gotten to you earlier, but my daughter is in a persistent vegetative state and recently the Supreme Court made a ruling that set us back." Based on his prior statements that he was "riding on the Cruzan's coattails," Time, March 19, 1990, this letter confirms Mr. Busalacchi's intent to seek the same relief as that sought by the Cruzan family.

[22]. Tr. 93.

about his choice of a hospice, as opposed to a hospital, for Christine, Mr. Busalacchi testified that the hospice "would be the place where we would go to have the feeding tube removed."[23] The affidavit of John Bagby documents other evidence of Mr. Busalacchi's expressed intent in this regard.[24] Clearly, in assessing whether it is medically appropriate for Miss Busalacchi to be transferred to Minnesota, all of the reasons for such transfer can be considered.

Mr. Busalacchi has claimed that his intent to move Christine is based upon a desire to better diagnose her condition, i.e., to discover whether she is, indeed, in a PVS. However, all relevant neurological tests can be and are performed in Missouri.[25] The diagnosis of neurological syndromes such as PVS is largely a matter of clinical judgment and observation. "Presently, there are no specific laboratory studies to confirm the clinical diagnosis [of PVS]."[26] In the case of PVS, diagnostic procedures such as electroencephalogram, computerized axial tomography (CAT) scanning, or positron-emission tomography (PET) scanning assist substantially in the diagnosis, but are not dispositive in the way that a biopsy confirms a diagnosis of a

---

[23]. Tr. at 103.

[24]. Affidavit of John R. Bagby, filed January 16, 1991.

[25] Indeed, the probate court found this to be true as a matter of fact. Tr. at 230.

[26]. The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight), Hastings Center Report, February/March 1988, 30 (hereinafter, "Cranford, PVS").

cancerous tumor.[27] PVS in other words, is not a malignancy or pathology with a specific origin, but a syndrome that may result from a variety of causes.[28]

In this case, the record indicates that an EEG was performed several days prior to the hearing in the probate court and the results were "normal."[29] The record also indicates that the Guardian desires to have additional tests performed, under the direction of Drs. Cranford and Snyder in Minneapolis. According to Dr. John Bagby, director of the Missouri department of health, a CAT scanning and EEGs can be performed at the Missouri Rehabilitation Center (MRC).[30] Other tests could also be done within the state of Missouri. Therefore, as Mr. Busalacchi is fully aware, it is not necessary, in order for such tests to be properly performed, for Ms. Busalacchi to be removed to Minnesota.[31]

---

27. Id.

28. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, 177-181 (1983) (PVS or permanent unconsciousness may result from closed-head injury, hypoxia, hypoglycemia, degenerative neurologic conditions such a Alzheimer's disease, intracranial mass lesions, or anencephaly).

29. Tr. at 149.

30. Tr. 44-45 (Affidavit of John Bagby).

31. The parties stipulated to this at page 20 of the trial transcript.

Your *amici* understand that the State of Missouri does not object to the performance of such tests and procedures.[32] Your *amici* further submit that given the uncertainty over the precise status of Miss Busalacchi's neurological condition, and the apparent improvement in her condition as noted by her attending physician, it is in her best interests to have such tests performed. Medical personnel and facilities appropriate for such tests are available in Missouri. There is an apparent factual dispute, represented by the testimony of Dr. Cantor and Dr. Cranford, as to whether transfer of Miss Busalacchi to Minnesota would have an adverse effect on her health, or diminish the responsiveness that has been noted in the diagnoses of Dr. Cantor and others.

None of your *amici* have examined or treated this particular patient. However, based upon their collective experience of treating and/or consulting in hundreds of cases of severe neurological injury, and the medical history and condition of this patient as described in the record, your *amici* submit that this Court should err in favor of the position stated by Dr.

---

[32]. The position of the state has been attacked as inconsistent, insofar as the Mount Vernon hospital had previously requested Mr. Busalacchi to seek a nursing home placement for his daughter. It does not appear that the state specifically requested that such placement be outside of Missouri, although Mr. Busalacchi apparently contacted nursing home in a variety of jurisdictions. The state's earlier position, moreover, appears to have proceeded from two assumptions: that Christine was in a persistent vegetative state, and that she would continue to receive basic care, including nourishment, if transferred. Both of these assumptions are now in question, as reflected by the testimony of Dr. Cantor and others, and the admissions of Mr. Busalacchi.

Cantor. No evidence has been put forward stating that Miss Busalacchi's medical interests will be harmed by her remaining within Missouri for such tests and procedures as are described by Dr. Snyder and Dr. Cranford. Both annual reports filed by the Guardian describe her medical care as excellent.[33] On the other hand, the testimony of Dr. Cantor states that positive harm may well occur in the process of transferring the patient to Minnesota. Although this latter point is contested, it should be weighed in light of the excellent care being currently provided to her in Missouri.

Should the assistance of an out-of-state physician such as Dr. Cranford or Dr. Snyder be required or requested, it is less traumatic to the patient for the physician to travel the necessary distance. This Court may take judicial notice of the fact that experts such as Dr. Cranford have frequently travelled to examine patients in the course of preparing for testimony in similar litigation. See, e.g., In re Jobes, 108 N.J. 394, 529 A.2d 434 (1987); Brophy v. New England Sinai Hospital, 398 Mass. 417, 497 N.E.2d 626, 630 (1986); Cruzan v. Harmon, 760 S.W.2d 408, 421, n.16 (1988).

It would have been appropriate, as the petitioner urges, for the probate court to take into account the "possibility" of removal of the feeding tube. The attitude of the probate court is that this possibility was of no consequence to its decision.

---

[33]. See Guardian's Annual Report, filed October 2, 1990 (care described as "exceptional") and Guardian's Annual Report, filed December 1, 1989 (care described as "excellent!").

This court, and the probate court upon remand, should weigh this factor in determining whether to enjoin such a transfer.

II. THE PROBATE COURT ERRED IN FAILING TO FIND, BASED UPON THE TESTIMONY CURRENTLY IN THE RECORD OF THIS CASE, THAT CHRISTINE BUSALACCHI IS NOT IN A PERSISTENT VEGETATIVE STATE.

The testimony before the probate court is undisputed that Christine Busalacchi is not in a persistent vegetative state. PVS has been described as a form of sustained and total loss of consciousness in which the patient maintains a relatively normal brainstem function, but has lost all purposeful cortical function.[34] Although there has been some confusion regarding this term, there are recognized clinical indicia that are typical of this state:

> These include spontaneous eye opening, return of sleep/wake cycles, spontaneous maintenance of blood pressure and regular respiratory pattern, lack of discrete localizing motor responses, absence of comprehensible vocalization, inability to obey commands, and lack of sustained visual pursuit movements. Thus, the patient is described as wakeful, but devoid of conscious content, without cognitive or affective mental function.[35]

Such patients experience cycles of waking and sleeping, and when awake, their eyes [illegible]y move from side to side, without maintaining any consistent or purposeful fixation. They may smile, utter

---

[34]. <u>See</u> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, <u>Deciding to Forego Life-Sustaining Treatment</u>, 174-176 (1983) (hereinafter, "President's Commission Report"; Cranford, PVS, 27, 28.

[35]. Berrol, <u>Consideration for Management of the Persistent Vegetative State</u>, 67 Arch. of Physical Med. and Rehabil. 283 (1986).

unintelligible sounds, and exhibit reflex reactions to noxious stimuli. There is no evidence, however, of purposeful interaction with the environment.[36]

Christine Busalacchi is not in a PVS. According to the unrebutted testimony of Dr. Cantor, in the course of his two and a half hour medical and neurological examination on January 6, 1991, Miss Busalacchi smiled and laughed in an appropriate manner, said "Hi" upon request, and followed instructions to turn her head and her limbs. Such responses indicate an awareness, comprehension, and responsiveness that is inconsistent with the diagnosis of PVS. As noted by the American Academy of Neurology, "[PVS] patients will show no behavioral response whatsoever over an extended period of time."[37] The testimony of her treating physician, Dr. Daroy, while not as detailed as that of Dr. Cantor, supports the findings of Dr. Cantor,[38] as does the testimony of nurses and therapists providing direct care to Ms. Busalacchi, including that of a speech pathologist that Christine "functions at the Rancho III level of cognitive recovery from the traumatic brain injury," and "processes mostly immediate

---

[36]. See Cruzan v. Director, Missouri Department of Health, 110 S.Ct. 2841, 2845, n.1 (1990). See also, Jennett & Plum, Persistent Vegetative State After Brain Damage, 1 Lancet 734 (1972); Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient, 39 Neurol. 125 (1989) ("AAN Statement") (Appendix C).

[37]. AAN Statement, supra, 39 Neurol. at 125.

[38]. Tr. 33-35.

information with delayed responses."[39]

III. THE PROPOSED WITHDRAWAL OF NUTRITION AND HYDRATION FROM PATIENTS IN MISS BUSALACCHI'S CONDITION POSES ISSUES DISTINCT FROM THOSE IN CASES OF PATIENTS IN A PERSISTENT VEGETATIVE STATE.

A. Removal of Tube Feeding From a Patient in Miss Busalacchi's Condition is Not Warranted Under the Guidelines Established by Such Organizations as the American Medical Association, the American Academy of Neurology, and the President's Commission.

During the past decade, several medical associations, as well as a presidential commission, addressed the question of withdrawal of artificial nutrition and hydration from patients with terminal illness, and patients who are permanently unconscious. See Council on Ethical and Judicial Affairs, American Medical Association, Current Opinions 13 (1989) (Copy attached as Appendix B); Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State Patient, 39 Neurology 125 (1989) (Copy attached as Appendix C); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment, 171-196, 190 (1983). These statements have concluded that the withdrawal of medical treatment, including nutrition and hydration, is permissible in cases of permanent unconsciousness,

---

39. Tr. 42-44 (Affidavit of Ann Parsons). See also Tr. 38-39 (Affidavit of Annette Smith); Tr. 41-42 (Affidavit of Debbie Schnake).

including PVS.[40]

None of these statements, however, specifically address the provision of "artificial" feeding to a patient in the condition of Miss Busalacchi. The AMA statement, for example, states that for patients who are "beyond doubt permanently unconscious," it is permissible to discontinue all means of life-prolonging medical treatment, including "artificially or technologically supplied" nutrition or hydration. The AAN statement declares: "When a patient has been reliably diagnosed as being in a persistent vegetative state, and when it is clear that the patient would not want further medical treatment, and the family agrees with the patient, all further medical treatment, including the artificial provision of nutrition and hydration, may be foregone." AAN Statement, III. The President's Commission addressed the issue as follows:

> Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions -- nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such increasingly burdensome interventions is sustaining the body to allow for a remote possibility of recovery. The sensitivities of the family and of care giving professionals ought to

---

[40]. As noted by Dr. Cranford in his 1988 Hastings Report article, some discrepancy exists between the terminology used in these documents to describe the persistent vegetative state. However, the AMA, AAN, and President's Commission reports all refer to what Dr. Cranford describes as "permanent unconsciousness": the category of patients with complete and permanent loss of consciousness or awareness. Cranford, PVS, supra note 30.

determine whether such interventions are made.

President's Commission Report at 190.

Not all of your _amici_ agree with the standards set forth in these pronouncements: some do, and some do not. However, all are in agreement that these statements do _not_ provide support for the withdrawal of nutrition and hydration on the facts presented in this case. The issues involved in removal of food and fluids from patients who _are_ conscious of their surroundings, and do have limited interaction with people and other aspects of their environment, are different from those involved in cases of PVS. Several distinguishing factors are: the benefit to the patient, who is able to gain a modicum of conscious pleasure from continued life; the potential for improvement in the patient's condition; the potential of suffering if feeding is removed; and the societal and legal question of whether removal of such basic means of life support constitutes abandonment of the patient, or euthanasia. Christine Busalacchi is profoundly disabled, but is not permanently unconscious. The medical and ethical authorities cited above, as well as other authorities in this field, have not systematically addressed the question of withholding life support from persons with such profound disabilities. Indeed, the consensus in practice appears to be that such patients should be supported with appropriate nutritional therapy.

B. Removal of Tube Feeding From a Patient in Miss Busalacchi's Condition May Justify a Heightened State Interest in Preventing Such Withdrawal.

Regrettably, the probate court in this matter failed to make any specific findings as to the condition of Christine Busalacchi.[41] In this respect, the decision below is unique in the annals of recent jurisprudence regarding the withdrawal of life-sustaining treatment. Specific findings regarding the patient's condition have constituted an important aspect of such decisions. See, e.g., Cruzan, 110 S.Ct. at 2868 (Brennan, J., dissenting). For example, the courts of New Jersey have adopted distinct procedural standards for patients who are diagnosed in a persistent vegetative state, See In re Quinlan, 70 N.J. 10, 355 A.2d 647 (1976); In re Jobes, 108 N.J. 394, 529 A.2d 434 (1987), and patients who are diagnosed in a semi-comatose state of limited responsiveness, See In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985) (requiring that prior to withdrawal of life-sustaining treatment, there be either clear and convincing evidence of a patient's intent to refuse life-sustaining treatment, expressed before incompetence, or evidence that the patient is suffering intractable pain). New York's highest court has also imposed the strict evidentiary requirements in the case of an elderly patient with limited responsiveness, but who was not in a persistent vegetative state. In re Westchester County Medical Center, 72 N.Y.2d 517, 531 N.E.2d 607 (1988). In

---

[41]. Tr. at 229.

Washington, the state supreme court has refused to permit the removal of feeding from an incompetent young woman with a degenerative condition known as Batten's disease. In re Grant, 109 Wash. 2d 545, 747 P.2d 445 (1987) (en banc), as modified, 757 P.2d 534 (noting change in listing of Durham, J.). In Missouri, the state supreme court has imposed the clear and convincing evidence requirement to removal of life-sustaining nutrition and hydration from a patient in PVS. Cruzan v. Harmon, 760 S.W.2d 408 (1988), affirmed sub nom Cruzan v. Director, Missouri Department of Health, 110 S.Ct. 2641 (1990). No less a standard ought to be applied to a case, such as this, where the diagnosis is less severe than that of persistent vegetative state.

IV. THE PROBATE COURT ERRED IN DENYING THE APPELLANT'S MOTION FOR APPOINTMENT OF A GUARDIAN AD LITEM, SINCE SUCH APPOINTMENT IS A CUSTOMARY AND APPROPRIATE MEASURE TO PROTECT THE INTERESTS OF PATIENTS SUCH AS CHRISTINE BUSALACCHI.

The record indicates that there is a fundamental disagreement between Christine's court-appointed guardian, and the physicians, therapists and nurses caring for her, over the future course of her medical treatment. Ordinarily, medical treatment decisions should not require the intervention of a court. However, such proceedings may be necessary when a dispute of this nature arises. In Cruzan, the Supreme Court clearly held that a state may require judicial proceedings to resolve such disputes; even the Cruzan dissenters acknowledged that such proceedings may be necessary to ensure the accuracy of the

patient's diagnosis, as well as the accuracy of her intentions regarding the use of life-sustaining medical treatment. 110 S.Ct. at 2876 (Brennan, J., dissenting). Such proceedings have typically involved appointment of a guardian ad litem to protect the interests of the incompetent patient. Given the nature of the dispute in this case, Christine's interests warrant the protection of a guardian ad litem. Upon remand, the probate court should be directed to make such an appointment.

CONCLUSION

The issue before this Court is a narrow one: whether Missouri's interest as *parens patriae* over the life and welfare of Christine Busalacchi can override the decision of her father and guardian, Peter Busalacchi, to remove his daughter to another jurisdiction, with the ultimate purpose that the feeding tube currently sustaining her life would be removed in that jurisdiction. This single question, however, raises several questions of medical ethics, including the nature of the physician-patient relationship when the patient is incompetent, and the duty to provide basic care to those who are profoundly disabled. Your *amici* conclude that contrary to the opinion of the probate court, it makes more than a "particle of difference" that Christine Busalacchi is not is a persistent vegetative state. Any decision to permit withdrawal of feeding from such conscious, but profoundly disabled patients, especially without the expressed consent or direction of the patient, raises profound issues of law and medical ethics that should not

dispatched in the summary fashion accorded them by the probate court. Your <u>amici</u> urge a remand to the probate court, with specific instruction to appoint a guardian ad litem to represent Miss Busalacchi's interests to enter findings of fact on the neurological condition of Miss Busalacchi, and to follow applicable legal guidelines, as set by this Court, that will protect Miss Busalacchi's interest in continuation of her life.

Respectfully submitted,

Robert A. Wulff
Amelung, Wulff & Willenbrock
705 Olive Street Suite 1400
St. Louis, MO 63101
314-436-6757

Edward R. Grant
Cathleen A. Cleaver
Americans United for Life
900 Second St. N.E. #204
Washington, D.C. 20002
202-289-6901

Clarke D. Forsythe
Kevin J. Todd
Americans United for Life
343 So. Dearborn St. #1804
Chicago, IL 60604
312-786-9494

Dated: January 30, 1991

APPENDIX A

List of Amici and Affiliations

Edmund Pellegrino, M.D., FACP
Professor of Medicine and Medical Ethics
Georgetown University Medical Center
Washington, D.C.

Leon R. Kass, M.D., Ph.D.
Addie Clark Hastings Professor
The College and the Committee on Social Thought
University of Chicago
Chicago, Illinois

Mark A. Siegler, M.D., FACP
Director, Center for Clinical Medical Ethics
University of Chicago
Chicago, Illinois

Fred Rosner, M.D., FACP
Director, Department of Medicine
Queens Hospital Center of Long Island Jewish Medical Center
Queens, N.Y.

William J. Burke, M.D.
Associate Professor of Neurology
St. Louis University School of Medicine
St. Louis, Missouri

Leslie Steven Rothenberg, Esq.
Medical Ethicist
Los Angeles, California

APPENDIX B

APPENDIX

AMERICAN MEDICAL ASSOCIATION

Opinion 2.20 Withholding or Withdrawing Life-Proloning Medical Treatment (formerly Opinion 2.18)

reprinted from Council on Ethical and Judicial Affairs, American Medical Association, *Current Opinions* 13 (1989)

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. If the patient is incompetent to act in his own behalf and did not previously indicate is preferences, the family or other surrogate decisionmaker, in concert with the physician, must act in the best interest of the patient.

For humane reasons, with informed consent, a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to permit a terminally ill patient to die when death is imminent. However, the physician should not intentionally cause death. In deciding whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient who is incompetent to act in his own behalf, the surrgoate decisionmaker and physician should consider several factors, including: the possibility for extending life under humane and comfortable conditions; the patient's values about life and the way it should be lived; and the patient's attitudes toward sickness, suffering, medical procedures, and death.

Even if death is not imminent but a patient is beyond doubt permanently unconsicous, and there are adequate

safeguards to confirm the accuracy of the diagnosis, it is not unethical to discontinue all means of life-prolonging medical treatment.

Life-prolonging medical treatment includes medication and artificially or technologically supplied respiration, nutrition or hydration. In treating a terminally ill or permanently unconscious patient, the dignity of the patient should be maintained at all times. (I,III,IV,V)

APPENDIX C

NEUROLOGY 1989;39:125-126

Position of the American Academy of Neurology on certain aspects of the care and management of the persistent vegetative state patient

Adopted by the Executive Board, American Academy of Neurology, April 21, 1988, Cincinnati, Ohio.

I. The persistent vegetative state is a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiological sleep/wake cycles, but at no time is the patient aware of him- or herself or the environment. Neurologically, being awake but unaware is the result of a functioning brainstem and the total loss of cerebral cortical functioning.

A. No voluntary action or behavior of any kind is present. Primitive reflexes and vegetative functions that may be present are either controlled by the brainstem or are so elemental that they require no brain regulation at all.

Although the persistent vegetative state patient is generally able to breathe spontaneously because of the intact brainstem, the capacity to chew and swallow in a normal manner is lost because these functions are voluntary, requiring intact cerebral hemispheres.

B. The primary basis for the diagnosis of persistent vegetative state is the careful and extended clinical observation of the patient, supported by laboratory studies. Persistent vegetative state patients will show no behavioral response whatsoever over an extended period of time. The diagnosis of permanent unconsciousness can usually be made with a high degree of medical certainty in cases of hypoxic-ischemic encephalopathy after a period of 1 to 3 months.

C. Patients in a persistent vegetative state may continue to survive for a prolonged period of time ("prolonged survival") as long as the artificial provision of nutrition and fluids is continued. These patients are not "terminally ill."

D. 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 experience 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.

II. The artificial provision of nutrition and hydration is a form of medical treatment and may be discontinued in accordance with the principles and practices governing the withholding and withdrawal of other forms of medical treatment.

A. The Academy recognizes that the decision to discontinue the artificial provision of fluid and nutrition may have special symbolic and emotional significance for the parties involved and for society. Nevertheless, the decision to discontinue this type of treatment should be made in the same manner as other medical decisions, ie, based on a careful evaluation of the patient's diagnosis and prognosis, the prospective benefits and burdens of the treatment, and the stated preferences of the patient and family.

B. The artificial provision of nutrition and hydration is analogous to other forms of life-sustaining treatment, such as the use of the respirator. When a patient is unconscious, both a respirator and an artificial feeding device serve to support or replace normal bodily functions that are compromised as a result of the patient's illness.

C. The administration of fluids and nutrition by medical means, such as a G-tube, is a medical procedure, rather than a nursing procedure, for several reasons.

1. First, the choice of this method of providing fluid and nutrients requires a careful medical judgment as to the relative advantages and disadvantages of this treatment. Second, the use of a G-tube is possible only by the creation of a stoma in the abdominal wall, which is unquestionably a medical or surgical procedure. Third, once the G-tube is in place, it must be carefully monitored by physicians, or other health care personnel

working under the direction of physicians, to insure that complications do not arise. Fourth, a physician's judgment is necessary to monitor the patient's tolerance of any response to the nutrients that are provided by means of the G-tube.

2. The fact that the placement of nutrients into the tube is itself a relatively simple process, and that the feeding does not require sophisticated mechanical equipment, does not mean that the provision of fluids and nutrition in this manner is a nursing rather than a medical procedure. Indeed, many forms of medical treatment, including, for example, chemotherapy or insulin treatments, involve a simple self-administration of prescription drugs by the patient. Yet such treatments are clearly medical and their initiation and monitoring require careful medical attention.

D. In caring for hopelessly ill and dying patients, physicians must often assess the level of medical treatment appropriate to the specific circumstances of each case.

1. The recognition of a patient's right to self-determination is central to the medical, ethical, and legal principles relevant to medical treatment decisions.

2. In conjunction with respecting a patient's right to self-determination, a physician must also attempt to promote the patient's well-being, either by relieving suffering or addressing or reversing a pathological process. Where medical treatment fails to promote a patient's well-being, there is no longer an ethical obligation to provide it.

3. Treatments that provide no benefit to the patient or the family may be discontinued. Medical treatment that offers some hope for recovery should be distinguished from treatment that merely prolongs or suspends the dying process without providing any possible cure. Medical treatment, including the medical provision of artificial nutrition and hydration, provides no benefit to patients in a persistent vegetative state, once the diagnosis has been established to a high degree of medical certainty.

III. When a patient has been reliably diagnosed as being in a persistent vegetative state, and when it is clear that the patient would not want further medical treatment, and the family agrees with the patient, all further medical treatment, including the artificial provision of nutrition and hydration, may be forgone.

A. The Academy believes that this standard is consistent with prevailing medical, ethical, and legal principles, and more specifically with the formal resolution passed on March 15, 1986 by the Council on Ethical and Judicial Affairs of the American Medical Association, entitled "Withholding or Withdrawing Life-Prolonging Medical Treatment."

B. This position is consistent with the medical community's clear support for the principle that persistent vegetative state patients need not be sustained indefinitely by means of medical treatment.

While the moral and ethical views of health care providers deserve recognition, they are in general secondary to the patient's and family's continuing right to grant or to refuse consent for life-sustaining treatment.

C. When the attending physician disagrees with the decision to withhold all further medical treatment, such as artificial nutrition and hydration, and feels that such a course of action is morally objectionable, the physician, under normal circumstances, should not be forced to act against his or her conscience or perceived understanding of prevailing medical standards.

In such situations, every attempt to reconcile differences should be made, including adequate communication among all principal parties and referral to an ethics committee where applicable.

If no consensus can be reached and there appear to be irreconcilable differences, the health care provider has an obligation to bring to the attention of the family the fact that the patient may be transferred to the care of another physician in the same facility or to a different facility where treatment may be discontinued.

D. The Academy encourages health care providers to establish internal consultative procedures, such as ethics committees or other means, to offer guidance in cases of apparent irreconcilable differences. In May 1985, the Academy formally endorsed the voluntary formation of multidisciplinary institutional ethics committees to function as educational, policy-making, and advisory bodies to address ethical dilemmas arising within health care institutions.

IV. It is good medical practice to initiate the artificial provision of fluids and nutrition when the patient's prognosis is uncertain, and to allow for the termination of treatment at a later date when the patient's condition becomes hopeless.

A. A certain amount of time is required before the diagnosis of persistent vegetative state can be made with a high degree of medical certainty. It is not until the patient's complete unconsciousness has lasted a prolonged period—usually 1 to 3 months—that the condition can be reliably considered permanent. During the initial period of assessment and evaluation, it is usually appropriate to provide aggressive medical treatment to sustain the patient.

Even after it may be clear to the medical professionals that a patient will not regain consciousness, it may still take a period of time before the family is able to accept the patient's prognosis. Once the family has had sufficient time to accept the permanence of the patient's condition, the family may then be ready to terminate whatever life-sustaining treatments are being provided.

B. The view that there is a major medical or ethical distinction between the withholding and withdrawal of medical treatment belies common sense and good medical practice, and is inconsistent with prevailing medical, ethical, and legal principles.

C. Given the importance of an adequate trial period of observation and therapy for unconscious patients, a family member must retain the ability to withdraw consent for continued artificial feedings well after initial consent has been provided. Otherwise, consent will have been sought for a permanent course of treatment before the hopelessness of the patient's condition has been determined by the attending physician and is fully appreciated by the family.

CERTIFICATE OF SERVICE

The below signature certifies that two true and correct copies of the foregoing document were sent by overnight delivery to Attorneys of Record listed below; Cathleen A. Cleaver, an attorney at law, certifies and states that she caused a copy of the foregoing Brief Amicus Curiae to be served upon the following counsel, by overnight delivery from Washington, D.C., deposited before the close of business on January 29, 1991.

Mr. Timothy W. Kelly
315 St. Francois
Florissant, MO 63031

Ms. Kathleen Wojciehowski
Chief Counsel, Department of Health
1738 East Elm Street
Jefferson City, MO 63102

Mr. John A. Kilo
Mr. Robert E. Trame
Ms. Janice M. Geiss
5840 Oakland Ave.
St. Louis, MO 63110

Cathleen A. Cleaver

Dated: January 29, 1991

WASHINGTON)
) SS
DISTRICT OF COLUMBIA)

Subscribed and sworn to before me, a notary public, this 29th day of January, 1991.

Notary Public

My Commission Expires:
3/14/91