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Limiting a Surrogate's Authority to Terminate Life-Support for an Incompetent Adult

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Limiting a Surrogate's Authority to Terminate Life-Support for an Incompetent Adult

A twenty-nine-year-old mentally and physically disabled woman, Ms. Tina Cartrette, is the subject of a legal battle in North Carolina over whether her mother, as the surrogate decision-maker, may direct the termination of artificial nutrition and hydration. Cartrette has never been competent, but she is neither terminally ill[1] nor in a persistent vegetative state (PVS).[2] Cartrette's mother decided to terminate artificial nutrition and hydration[3] following Cartrette's

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1. For the purposes of this Recent Development, terminal illness means a condition with a predictably fatal progression likely to cause death within one year. *E.g.*, Deborah K. McKnight & Maureen Bellis, *Foregoing Life-support for Adult, Developmentally Disabled, Public Wards: A Proposed Statute*, 18 AM. J. L. & MED. 203, 207 (1992) (citing THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE SUSTAINING TREATMENT AND THE CARE OF THE DYING).

2. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Dec. 14, 2000) (findings of fact); *see* Karen Garloch, *Life-support Ruling Sends "Shock Waves," Doctor Says*, CHARLOTTE OBSERVER, Jan. 10, 2001, *at* LEXIS, Domestic News Library, Charlotte Observer File (on file with the North Carolina Law Review). For the purpose of this Recent Development, PVS means "a medical condition whereby ... the patient suffers from a sustained complete loss of self-aware cognition and, without the use of extraordinary means ... will succumb to death within a short period of time." N.C. GEN. STAT. § 90-321(a)(4) (1999); *see also In re* Jobes, 529 A.2d 434, 438 (N.J. 1987) (defining a PVS patient as no longer self-aware or aware of her surroundings "in a learned manner"); *In re* Quinlan, 355 A.2d 647, 654 (N.J. 1976) (stating that a PVS patient has the "capacity to maintain the vegetative parts of neurological function but ... no longer has any cognitive function"); G. Bryan Young, M.D. & Susan E. Pigott, Ph.D., *Neurobiological Basis of Consciousness*, 56 ARCH. NEUROL. 153, 154 (1999) (describing a PVS patient as alert but not aware, capable of being "aroused from sleep, with eye opening and electroencephalographic arousal," but without "perception, comprehension, meaningful interaction, or behavioral response").

3. Artificial nutrition and hydration is a form of life-support, which includes any medical treatment aimed at forestalling death, regardless of whether the treatment is intended to affect the patient's underlying disease. *See* THE COUNCIL OF ETHICAL & JUDICIAL AFFAIRS, AM. MED. ASS'N., CURRENT OPINIONS 2.20 (1989), *available at* http://www.ama-assn.org/ama/pub/category/2513.html (last visited Sept. 16, 2001) (on file with the North Carolina Law Review) (discussing ethical issues related to withholding life support) [hereinafter CURRENT OPINIONS]; American Academy of Pediatrics, *Guidelines on Forgoing Life-sustaining Medical Treatment (RE9406)*, 93 PEDIATRICS 532-36 (Mar., 1994), *available at* http://www.aap.org/policy/00118.html (last visited Sept. 16, 2001) (on file with the North Carolina Law Review). Many courts and commentators reject any distinction between withdrawal of artificial nutrition and hydration and withdrawal of other forms of life-support, such as antibiotics and respiratory aids. *E.g.*, Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 288-89 (1990) (O'Connor, J., concurring); Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 637 (Mass. 1986); *In re* Jobes, 529 A.2d at 444 n.9; Delio v. Westchester County Med. Ctr., 516 N.Y.S.2d 677, 687-88 (1987); Lynn & Childress, *Must Patients Always be Given Food and Water?*, 13 HASTINGS

hospitalization for infection, high fever, and seizures.[4] The Governor's Advocacy Council for Persons with Disabilities (GACPD) challenged that decision.[5] At a hearing on December 12, 2000, the Clerk of the Superior Court of Mecklenburg County, North Carolina, ordered the continuation of life-support for Cartrette.[6] Because Cartrette was neither "terminal and incurable," nor in a PVS, the only conditions specified in the North Carolina Right to Natural Death Law under which life-support may be withdrawn,[7] the clerk found that termination of her life-support constituted neglect.[8] On appeal, the Superior Court vacated the order, finding as a matter of law that the mother's decision to terminate life-support did not constitute neglect.[9]

Cartrette's case raises questions regarding the circumstances under which a surrogate decision maker can withhold or withdraw life-support (such as hydration and nutrition) from a never-competent adult, and under what standards that decision should be evaluated. The issue of whether the guardian of a patient has the authority to terminate life support when the patient has never been competent, but is neither terminally ill, nor in a PVS has never been litigated in North Carolina. After examining the standards courts outside North Carolina use to evaluate a surrogate's decision to refuse medical treatment on behalf of an incompetent adult,[10] this Recent

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CTR. REP. 17, 20 (1983); Alan Meisel, *Barriers to Forgoing Nutrition and Hydration in Nursing Homes*, 21 AM. J.L. & MED. 335, 379-80 (1995).

4. Cartrette has cerebral palsy, and the extent of her cognitive and physical abilities is recognition of her own name and the ability to track with her eyes the movements of residential care facility employees—she is non-ambulatory and non-communicative. Garloch, *supra* note 2. In November 2000, Cartrette developed a high fever and seizures in response to frequently occurring infections, and she temporarily required the aid of a respirator. *Id.* When her condition stabilized and the respirator was removed, Cartrette continued to breathe independently and returned to her baseline condition. *Id.*

5. The GACPD had authority to act on Cartrette's behalf pursuant to section 143B-403.1 of the North Carolina General Statutes.

6. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Dec. 14, 2000) (granting an emergency *ex parte* motion to restore nutrition and hydration, and to remove Cartrette's mother as guardian).

7. N.C. GEN. STAT. § 90-320 – 90-322 (a)(1) (1999).

8. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Dec. 14, 2000); Garloch, *supra* note 2. Section 35A-1290(b)(3) of the North Carolina General Statutes provides that the clerk may remove a guardian who "neglects to care for" the ward, as required under Section 35A-1241(a). *Id.* § 35A-1290(b)(3) (1999). The statute, however, does not define "neglect" as it would pertain to a guardian's decision to terminate medical treatment. The statute specifically requires only that the guardian act non-negligently and in good faith. *Id.* § 35A-1241(c)(2) (1999).

9. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Mar. 14, 2001).

10. *See infra* notes 39-56 and accompanying text.

Development suggests that the best interest test should be adopted in *In re* Cartrette, and the result should be the continuation of treatment in this case.[11]

Preliminary to any discussion of how an incompetent patient can refuse life-support is whether such a patient has a legally recognized right to refuse treatment at all.[12] Competent individuals have a right to refuse medical treatment, even if such treatment is required to sustain the individual's life.[13] Courts recognize that this right to refuse treatment extends to incompetent patients,[14] who are by definition unable to make their own decisions regarding medical care. Incompetent adults may exercise this right through a surrogate decision maker.[15] The right to refuse treatment for both competent

11. *See infra* notes 57-64 and accompanying text.

12. This Recent Development focuses on surrogate decision-making on behalf of never-competent patients. For the purposes of this Recent Development, an "incompetent adult" means "an adult or emancipated minor who lacks sufficient capacity to manage the adult's own affairs or to make or communicate important decisions concerning the adult's person, family, or property." N.C. GEN. STAT. § 35A-1101(7) (1999).

13. *E.g.*, Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 1137 (Cal. Ct. App. 1986) (recognizing a competent adult's right to refuse "*any* medical treatment even that which may save or prolong her life") (emphasis in original); Satz v. Perlmutter, 362 So. 2d 160, 164 (Fla. Dist. Ct. App. 1978) (recognizing a competent patient's right to demand removal of his respirator); *In re* Conroy, 486 A.2d 1209, 1225 (N.J. 1985) ("Competent persons generally are permitted to refuse medical treatment, even at the risk of death."); *In re* Storar, 420 N.E.2d 64, 71 (N.Y. 1981) (recognizing a competent adult's right to refuse even life-sustaining medical treatment by holding that a doctor cannot be held ethically liable for honoring the patient's wishes). Patients have the right to refuse any medical treatment that prolongs life, including respirators, dialysis, antibiotics, and blood transfusions, and patients have the right to receive pain medication even though it might effectively expedite their death. MARGARET C. JASPER, THE RIGHT TO DIE 29-30 (2d ed. 2000).

14. *See* John F. Kennedy Mem'l Hosp., Inc. v. Bludworth, 452 So. 2d 921, 924 (Fla. 1984) (stating that terminally ill patients should not lose their right to discontinue life support when they become incompetent); Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 427 (Mass. 1977) (recognizing that the liberty interest in refusing unwanted medical treatment extends to incompetent as well as competent patients because "the value of human dignity extends to both"); Spahn v. Eisenberg, 563 N.W.2d 485, 489 (Wis. 1997) (recognizing that the same constitutional rights extend to incompetent as well as competent adults).

15. Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 280 (1990) (recognizing the need for a surrogate to exercise an incompetent person's right to refuse treatment); *In re* Quinlan, 355 A.2d 647, 664 (N.J. 1976) (allowing the patient's guardian or family to decide whether the patient would exercise her right is the only practical way to avoid destruction of the right altogether); McKnight & Bellis, *supra* note 1, at 213 (suggesting that never-competent patients have a "right to have appropriate medical decisions made on their behalf" rather than a right to refuse treatment, per se). The North Carolina statute provides that a patient's guardian has the authority to consent to medical treatment on the patient's behalf if the guardian acts in good faith and non-negligently. N.C. GEN. STAT. § 35A-1241(c)(1)-(2) (1999). Similar statutes in other states have been interpreted to give

and incompetent patients is often based on common law notions of self-determination[16] and informed consent,[17] the protections afforded individuals in the Fourteenth Amendment to the United States Constitution,[18] and state constitutional[19] and statutory provisions.[20]

The right to refuse treatment, however, is not absolute—it may be limited by legitimate state interests.[21] The Supreme Court has

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the guardian authority to refuse treatment. Rasmussen By Mitchell v. Fleming, 741 P.2d 674, 687-88 (Ariz. 1987) (citing ARIZ. REV. STAT. § 14-5312(A)(3) (Supp. 1986) and finding that the guardian's right to consent to delivery of medical care provided therein necessarily includes the right to consent to withholding medical care); Conservatorship of Drabick, 200 Cal. App. 3d 185, 200 (Cal. Ct. App. 1988) (finding the same in CAL. PROB. § 2355(a)); *In re* Torres, 357 N.W.2d 332, 337 (Minn. 1984) (citing MINN. STAT. § 525.56 (3)(4)(a) (1982) for the same).

16. *See, e.g.*, Foody v. Manchester Mem'l Hosp., 482 A.2d 713, 717-18 (Conn. 1984) (acknowledging that the right to self-determination includes the right of incompetent adults to refuse life-sustaining medical treatment); *In re* Jobes, 529 A.2d 434, 436 (N.J. 1987) ("patient's right to self determination is the guiding principle in determining whether to continue or withdraw life-sustaining medical treatment").

17. *See, e.g.*, *Cruzan*, 497 U.S. at 277 ("[T]he common-law doctrine of informed consent is viewed as generally encompassing the right of a competent individual to refuse medical treatment."); *Saikewicz*, 370 N.E.2d at 425-26 (basing the right on the common law right to informed consent and constitutional right of privacy); *In re* Storar, 420 N.E.2d at 70 (basing the right to refuse on the common law right to informed consent); *see also* Washington v. Glucksberg, 521 U.S. 702, 725 (1997) (noting the right to refuse life-saving nutrition and hydration derives from the common law rule that forced medication constitutes battery).

18. U.S. CONST. amend. XIV, § 1 ("No State shall . . . deprive any person of life, liberty, or property, without due process of law."); *Cruzan*, 497 U.S. at 278 (suggesting that the refusal of lifesaving medical treatment is a liberty interest that can be inferred from the Fourteenth Amendment); *In re* Quinlan, 355 A.2d at 663 (basing the right to refuse treatment on the right to privacy guaranteed under the U.S. Constitution and the New Jersey State Constitution).

19. *See, e.g.*, *Fleming*, 741 P.2d at 682 (citing ARIZ. CONST. art. 2, § 8); Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 1137 (Cal. Ct. App. 1986) (citing CAL. CONST. art. 1, § 1); *In re* Guardianship of Barry, 445 So. 2d 365, 370 (Fla. Dist. Ct. App. 1984) (citing FLA. CONST. art. 1, § 23); *In re* Lawrance, 579 N.E.2d 32, 39 (Ind. 1991) (citing IND. CONST. art. I, par. 1); *In re* Quinlan, 355 A.2d at 663 (citing N.J. CONST. art. I, par. 1); Lenz v. L.E. Phillips Career Dev. Ctr., 482 N.W.2d 60 (Wis. 1992) (citing WIS. CONST. art. I, § 1).

20. *See, e.g.*, 755 ILL. COMP. STAT. ANN. 40/5 (West 1993 & Supp. 2000) (Health Care Surrogate Act); N.C. GEN. STAT. § 90-320 (1999) (Right to Natural Death Act); Conservatorship of Drabick, 200 Cal. App. 3d 185, 206 (Cal. Ct. App. 1988) (citing CAL. HEALTH & SAFETY CODE § 7186); McConnell v. Beverly Enterprises-Connecticut, Inc., 553 A.2d 596, 602 (Conn. 1989) (citing CONN. GEN. STAT. § 19A-571); Estate of Longeway v. Community Convalescent Ctr., 549 N.E.2d 292, 297 (Ill. 1989) (citing Illinois Probate Act); *In re* Lawrance, 579 N.E.2d at 38 (citing Indiana's Health Care Consent Act).

21. Courts have articulated four countervailing state interests—the interests in "preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting innocent third parties"—that may limit an individual's freedom to refuse medical treatment. *In re* Conroy, 486 A.2d 1209, 1223 (N.J. 1985) (citing Satz v. Perlmutter, 362 So. 2d 160, 162 (Fla. 1987)); *see also In re* Spring, 405 N.E.2d 115, 123

recognized that, under certain circumstances, legitimate countervailing state interests may overcome an individual's right to refuse medical treatment.[22] Specifically, in Cartrette's case, the state has interests in the protection of human life,[23] the prevention of discrimination against disabled persons by those who would devalue the disabled person's life, or view that person as too burdensome,[24] and the prevention of homicide and assisted suicide.[25] As the Supreme Court has acknowledged, however, that "the State's interest . . . weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."[26] Cartrette's prognosis, however, remains relatively the same as it has been since birth.

Because Cartrette's case involves a never-competent patient who is neither PVS, nor terminally ill, the state's interests may outweigh the patient's right to refuse treatment through a surrogate. In cases involving abortion and blood transfusion, courts frequently have approved of states restricting individual rights to protect a vulnerable life incapable of protecting itself.[27] Even if these state interests are insufficient to outweigh Cartrette's right to refuse life-support, they should at least be sufficient to impose safeguards to ensure that the

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(Mass. 1980); Comm'r of Correction v. Myers, 399 N.E.2d 452, 456 (Mass. 1979); *Saikewicz*, 370 N.E.2d at 425; *In re* Torres, 357 N.W.2d 332, 339 (Minn. 1984); *In re* Colyer, 660 P.2d 738, 743 (Wash. 1983); PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUPPORT 31-32 (1983); Carol Ann Colabrese, Note, *In re* Storar: *The Right to Die and Incompetent Patients*, 43 U. PITT. L. REV. 1087, 1092 (1982).

22. Washington v. Glucksberg, 521 U.S. 702, 721 (1977) (acknowledging that compelling state interests may overcome individual liberty interests); *see also In re* Farrell, 529 A.2d 404, 411 (N.J. 1987) (acknowledging the state's interest in preserving human life); *In re* Storar, 420 N.E.2d 64, 71 (N.Y. 1981) (stating that a patient's right to refuse medical treatment may "yield to superior State interests," such as the interest in preserving human life).

23. *See* Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 282 (1990).

24. *See* Spahn v. Eisenberg, 563 N.W.2d 485, 490 (Wis. 1997) (quoting BARRY R. FURROW, ET AL., BIOETHICS: HEALTH CARE LAW AND ETHICS 325 (1991)).

25. *See Glucksberg*, 521 U.S. at 728-29; *Cruzan*, 497 U.S. at 280.

26. *In re* Quinlan, 355 A.2d 647, 664 (N.J. 1976); *see also In re* Jobes, 529 A.2d 434, 444 (N.J. 1987) (quoting *In re* Peter, 529 A.2d 419, 427 (N.J. 1987)) (finding it unlikely that any State interest could be strong enough to subordinate a PVS patient's right to terminate life-support).

27. *See, e.g.*, Roe v. Wade, 410 U.S. 113, 163 (1973) (authorizing state restrictions on right to abortion to protect viable fetus); State v. Perricone, 181 A.2d 751, 757-59 (N.J. 1962) (authorizing restriction on parents' ability to refuse blood transfusion for their infant). In Cartrette's case, the court would be restricting the surrogate's ability to act on behalf of a never-competent patient, indirectly restricting the patient's right to refuse treatment.

surrogate's decision to terminate treatment is medically, legally, and ethically appropriate.[28]

North Carolina statutes provide one such safeguard; however, the scope of the provisions does not cover Cartrette's case. North Carolina recognizes, by statute, the rights of both competent and incompetent individuals to consent to or refuse medical treatment,[29] and the ability of surrogates to exercise those rights on behalf of incompetent individuals.[30] The Right to Natural Death Act provides some guidance in North Carolina for evaluating a surrogate's decision to terminate life support.[31] The Act provides that life-support may be withheld or withdrawn from a patient who is either mentally incapacitated or comatose with no reasonable chance of returning to a cognitive state,[32] when two physicians determine that the patient is terminal and incurable or in a PVS.[33] These statutory provisions, however, do not apply to Cartrette's case, because though she is mentally incapacitated, her treating physicians have neither declared her in a terminal and incurable condition nor in a PVS.[34] The Act, however, is not conclusive. It was established, in part, to provide health care practitioners with an absolute defense if they abide by the statute's procedures, but it was not intended to set forth an exclusive procedure for evaluating a surrogate's decision to terminate life-support.[35] In light of this non-exclusivity, one should consider other

28. *See In re* Truesdell, 313 N.C. 421, 430-31, 329 S.E.2d 630, 636 (1985) (recognizing that the patient's guardian does not have absolute discretion to act on the ward's behalf—the guardian must act in the ward's best interests, and his actions are subject to judicial review); *see also In re* Guardianship of Eberhardy, 307 N.W.2d 881, 896 (Wis. 1981) (recognizing that severely mentally retarded persons deserve special protection from the state when a surrogate makes an irreversible medical decision on their behalf because they are a distinct class albeit with the same constitutional rights as competent persons).

29. N.C. GEN. STAT. § 32A-15(a) (1999). The statute recognizes an individual's fundamental right to control medical care decisions, including the right to "give, withhold, or withdraw consent to medical treatment." *Id.* § 32A-15(c); *see id.* § 90-321(b) (2000) (allowing a patient to refuse life-prolonging extraordinary means, including nutrition and hydration, if the patient is ever terminally and incurably ill or in a PVS).

30. *Id.* § 32A-15 (1999); *id.* § 90-320.

31. *Id.* § 90-322(a) (1999).

32. *Id.*

33. *Id.* § 90-322(a)(1)-(2).

34. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Dec. 14, 2000).

35. Cartrette's physicians and Cartrette's mother's attorney, bolstering their argument with a North Carolina State Attorney General's opinion, *see* Right to a Natural Death: Procedures for Natural Death in the Absence of a Declaration, Op. Att'y Gen., (Jan. 5, 1995), *at* http://www.jus.state.nc.us/lr/agfopn.htm (last visited Sept. 16, 2001) (on file with the North Carolina Law Review), contended that although the law permits withholding life support under those conditions, "it does not exclude other decisions." Garloch, *supra* note 2.

means of allowing Cartrette, or her guardian, to exercise her right to refuse medical treatment, as well as any safeguards to ensure the propriety of the decision.

The North Carolina courts should consider how other states have adjudicated similar issues. Cartrette's situation parallels reports of guardians' decisions to withdraw or withhold life support from incompetent patients though none are exactly on point in other states.[36] Cases from other jurisdictions resolving such disputes can be divided into the following two variables: (1) whether the patient previously indicated an inclination toward or against medical treatment, whether the patient failed to indicate her wishes, or was never-competent to do so,[37] and (2) whether the patient was in a PVS or terminally ill condition, or in neither condition.[38] Although Cartrette is a never-competent patient who is neither in a PVS nor

36. *See In re* Baby K, 832 F. Supp. 1022, 1031 (E.D. Va. 1993) (holding that physicians cannot withhold life-support from an anencephalic infant against the mother's wishes); HCA, Inc. v. Miller, 36 S.W.2d 187, 191–92 (Tex. App. 2000) (citing TEX. HEALTH & SAFETY CODE ANN. §§ 166.002(13), 166.031, 166.035 (Vernon Supp. 2000) to support a parental right to refuse life-support for a child only when the child's condition is certifiably terminal"); *see also* Maura Dolan, *Out of a Coma, Into a Twilight*, L.A. TIMES, Jan. 2, 2001, at A1 (discussing the dispute between the mother and wife of a "minimally conscious" car accident victim over whether his verbally conveyed wishes should be effectuated by terminating his life-support); Anita Kumar, *Lawyer Dies Amid Feud Over His Living Will*, ST. PETERSBURG TIMES (Florida), Nov. 2, 2000, at 1B (discussing heart-attack patient's wife's legal battle with patient's mother and children over whether to continue life-prolonging treatment in light of the patient's living will); Richard Willing, *Who Decides Whether a Baby Lives or Dies*, USA TODAY, Nov. 29, 2000, at 1A (reporting a Texas hospital overruling parents' decision not to put their premature and disabled baby on life-support).

37. *See, e.g.*, Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 431 (Mass. 1977) (applying the substitute judgment test to determine whether to withhold chemotherapy from a never-competent patient); *In re* Quinlan, 355 A.2d 64, 72 (N.J. 1976) (holding that a formerly competent patient—now in a PVS—failed to sufficiently indicate her wishes regarding treatment upon a comatose state); *In re* Eichner, 420 N.E.2d 64, 68 (N.Y. 1981) (holding that a formerly competent patient—now in a PVS—previously indicated desire not to be kept alive in a persistent vegetative state).

38. *E.g.*, John F. Kennedy Mem'l Hosp., Inc. v. Bludworth, 452 So. 2d 921 (Fla. 1984) (terminally ill patient); *Saikewicz*, 370 N.E.2d at 417 (terminally ill patient); *In re* Jobes, 529 A.2d 434 (N.J. 1987) (PVS patient); *In re* Quinlan, 355 A.2d 647, 664 (N.J. 1976) (PVS patient); *In re* Storar, 420 N.E.2d 64 (N.Y. 1981) (terminally ill patient); *see In re* Westchester County Med. Ctr., 531 N.E.2d 607, 608 (N.Y. 1988) (concerning a surrogate decision-maker for patient with irreparable brain damage, but not unconscious or PVS, who was unable to prevent physicians from inserting feeding tube for patient because patient had never expressed her wishes specifically regarding nutrition and hydration). Courts distinguish between PVS and non-PVS incompetent patients because PVS patients have no hope of recovering any cognitive functioning, and they are generally unable to sense pain. *See supra* note 2; *see also* Mack v. Mack, 618 A.2d 744, 760 (1993) (quoting 73 Op. Att'y Gen. 162, 189-90 (Md. 1988)).

terminally ill, cases falling under the other categories provide guidance in resolving her case.

The substitute judgment test and the best interests test are the predominant standards used to evaluate the propriety of a guardian's decision to terminate life support for an incompetent patient.[39] The substitute judgment test is a subjective approach. It attempts to respect the patient's autonomy and self-determination by effectuating the decision that the patient would have made regarding withholding or withdrawal of life-support.[40]

An alternative to the subjective substitute judgment test is an objective "best interests test," which requires the surrogate to demonstrate to the court that terminating life-support serves the patient's best interests.[41] In contrast to the substitute judgment test, this test more aptly applies to patients who have given no indication

39. CURRENT OPINIONS, *supra* note 3 (discussing the application of the substitute judgment and best interests tests). *But see* Susan Busby-Mott, *The Trend Towards Enlightenment: Health Care Decisionmaking in* Lawrence *and* Doe, 25 CONN. L. REV. 1159, 1175 (1993) (suggesting a third standard—the family-based model—which allows family members to decide unilaterally that the patient would have made the same decision). Justice O'Connor suggested that the states can develop their own standards for evaluating the propriety of a guardian's decision to terminate life-support for an incompetent adult, and that imposing a clear and convincing evidentiary standard is constitutionally acceptable but not required. Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 292 (1990) (O'Connor, J., concurring).

40. Rasmussen By Mitchell v. Fleming, 741 P.2d 674, 688 (Ariz. 1987); Mack v. Mack, 618 A.2d 744, 757 (Md. 1993); *In re* Jobes, 529 A.2d 434, 436-37 (N.J. 1987); Busby-Mott, *supra* note 36, at 1171. The substitute judgment test subjectively focuses on the patient's previously expressed desires and requires that the patient was competent at some point and in fact expressed those desires with some degree of specificity. *Fleming*, 741 P.2d at 688; Busby-Mott, *supra* note 36, at 1171. Though courts recognize that never-competent patients have a right to refuse treatment, *see supra* note 14 and accompanying text, states applying the substitute judgment test, whether requiring the guardian to demonstrate by clear and convincing evidence or by a preponderance of the evidence what the patient would have wanted, essentially leave the never-competent patient unable to exercise this right. *See* Mack v. Mack, 618 A.2d 744, 768 (Md. 1993) (Chasanow, J., dissenting) (criticizing the majority's imposition of the substitute judgment test because it denies never-competent patients court authorization to forego life support); PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUPPORT 132-36 (1983) [hereinafter PRESIDENT'S COMMISSION] (recommending the best interest test be applied for never-competent patients because it would be impossible for a surrogate to meet the evidentiary requirements of the substitute judgment test).

41. *See* Spahn v. Eisenberg, 563 N.W.2d 486, 486 (Wis. 1997); Lenz v. L.E. Phillips Career Dev. Ctr., 482 N.W.2d 60, 70 (Wis. 1992); Foody v. Manchester Mem'l Hosp., 482 A.2d 713, 721 (Conn. 1984). *But see* Robert M. Veatch, *Limits of Guardian Treatment Refusal: A Reasonableness Standard*, 9 AM. J. L. & MED. 427, 448 (1984) (suggesting courts should allow bonded guardians to act on behalf of never-competent patients using the best interest test plus the guardian's own subjective values).

of what their desires would be under the circumstances. Under the best interests test, the court can consider factors other than the patient's expressed desires to determine what treatment decision is in the patient's best interest. Such factors include the terminal nature of the patient's condition, the possible adverse side effects of life-prolonging treatment, the discomfort caused by treatment, the psychological impact of treatment on a patient incapable of understanding why such intrusive treatment is being imposed, the chance that treatment will facilitate recovery, and the treating physician's recommendation.[42] The court weighs the burden of treatment against the benefits of continued life under the patient's given condition. If the burdens significantly outweigh the effectiveness and benefits of treatment, the court may find termination of life support justified. [43]

Although both the substitute judgment test and the best interests test have been applied to evaluate decision-making on behalf of never-competent patients,[44] both tests present problems when applied to such patients. Because these patients have never been able to appreciate or articulate the life or death decision of whether to withdraw life-support under their current condition, the substitute judgment test is inappropriate.[45]

Although the best interests test is arguably more suitable for never-competent patients than the substitute judgment test because it allows consideration of factors other than the patient's previously expressed wishes,[46] it is still problematic because it opens the door to result-oriented decision-making and abuse of discretion by the guardian,[47] and may make termination of care too easy.[48] Advocates

42. *See* Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 434–35 (Mass. 1977) (describing factors the probate judge considered in determining whether to withhold chemotherapy from a terminally ill incompetent adult); Foody v. Manchester Mem'l Hosp., 482 A.2d 713, 719 (Conn. 1984) ("Whether serious burdens of treatment are worth enduring should depend upon how long the treatment will extend life and under what conditions.").

43. *See also* Edmund D. Pellegrino, MD, *Decisions to Withdraw Life-support*, 283 JAMA 1065, 1066 (2000) (discussing clinical futility, defined as the relationship among effectiveness, benefit, and burden of the treatment, as the central criterion for determining when to terminate treatment).

44. *See, e.g.*, *Saikewicz*, 370 N.E.2d at 431 (applying the substitute judgment test).

45. John F. Kennedy Mem'l Hosp. v. Bludworth, 452 So. 2d 921, 924 (Fla. 1984) (noting that the procedure for implementing an incompetent patient's right to refuse treatment must not be so cumbersome as to eliminate the right).

46. *See supra* note 42 and accompanying text.

47. *See* Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 286 (1990) (acknowledging that even close family members may not be entirely disinterested decision-makers); Ardath A. Hamann, *Family Surrogate Laws: A Necessary Supplement to*

for persons with disabilities argue that a competent individual's evaluation of the burden of a given medical disability is unlikely to reflect how burdensome the person living with that disability considers it.[49] Even though this valuation discrepancy is not inevitable, the best interests test could result in termination of care for some incompetent disabled adults because the competent decision-makers, whether judges or guardians, think that they would not want to live under such conditions. The decision-maker might place greater weight on the burdens of treatment and less weight on the benefits of living than the patient would.[50]

Despite its drawbacks, the standard applicable in the case of a never-competent patient should be the best interests standard.[51] For a never-competent patient, like Cartrette, who is neither in a PVS nor terminally ill,[52] the best interests test should result in continuation of treatment.[53] For such patients, the significant state interest in

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Living Wills and Durable Powers of Attorney, 38 VILL. L. REV. 103, 117 (1993) (discussing how the best interest test places the patient at the mercy of the decision maker's personal value system).

48. *See* Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 445 (1988) (discussing courts' leniency in allowing unrelated surrogates to terminate life support).

49. Jill A. Rhymes, M.D., et al., *Withdrawing Very Low-Burden Interventions in Chronically Ill Patients*, 283 JAMA 1061, 1063 (" 'Observers of persons who are disabled frequently underestimate the quality of life experienced by those persons.' ") (quoting A. Leplege & S. Hunt, *The Problem of Quality of Life in Medicine*, 278 JAMA 47–50 (1997)). One commentator explained that a logical difficulty is inherent in this method of decision-making as applied to never-competent patients.

> That difficulty proceeds from the realization that reasonably healthy persons cannot weigh the burden of treatment against the benefit of life in a diminished state ... [They cannot] dispassionately weigh a life of disease or incompetence; the prospect of trading rationality for confusion, comprehension for bewilderment, asks too much of those who must choose between the two from the perspective of health.

EDWARD D. ROBERTSON, JR., PERSONAL AUTONOMY AND SUBSTITUTED JUDGMENT: LEGAL ISSUES IN MEDICAL DECISIONS FOR INCOMPETENT PATIENTS 39 (1991).

50. However, one commentator found that more often, the best interest standard results in continuation of treatment, rather than withdrawal. Robertson, *supra* note 49, at 51.

51. PRESIDENT'S COMMISSION, *supra* note 40, at 132-36; *In re* Storar, 420 N.E.2d 64, 72 (N.Y. 1981) (finding it unrealistic to try to determine what a never-competent patient would have wanted regarding potentially life prolonging treatment); American Academy of Pediatrics, *Guidelines on Forgoing Life-sustaining Medical Treatment (RE9406)*, 93 PEDIATRICS 532-36 (Mar. 1994) *available at* http://www.aap.org/policy/00118.html (last visited Sept. 26, 2001) (on file with the North Carolina Law Review).

52. *In re* Cartrette, No. 90-SP-35 (N.C. Super. Ct. Dec. 14, 2000) (stating that as a matter of fact Cartrette is neither "terminally and incurably ill," comatose, in a persistent vegetative state, nor "in the process of dying").

53. *See* McKnight & Bellis, *supra* note 1, at 207 (permitting termination of treatment for never-competent public wards only when the patient is PVS or terminally ill).

preserving life and the "irreversible nature of the decision" to withdraw life-support favor continuation of treatment.[54] Courts that have recognized the right of an incompetent non-PVS patient to refuse life-sustaining medical treatment have only allowed a surrogate decision-maker to exercise that right on the patient's behalf when the patient was either previously competent and indicated his desires,[55] or was terminally ill and the treatment was viewed as prolonging life temporarily rather than permanently.[56] Such cases provide little guidance for patients in Cartrette's situation.

In Cartrette's case, application of the best interests test should result in continuation of Cartrette's life-support because, as Cartrette's physicians testified, she is not "terminal and incurable," comatose, in a persistent vegetative state, or "in the process of dying."[57] The court found as a matter of fact that the cause of her temporary hospitalization had been treated successfully and Cartrette had returned to her baseline condition—the same condition she had been in for the past fourteen years—at the time her guardian decided to terminate treatment.[58] Because her disability is not a terminal illness, continuation of life-support will not merely result in "some uncertain but limited extension of life."[59] The status quo for Cartrette has been dependence upon tube feeding, hydration, and medication.

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54. Spahn v. Eisenberg, 563 N.W.2d 485, 490 (Wis. 1997) (refusing to allow termination of nutrition and hydration for a terminally ill, non-PVS patient who did not clearly state her intent to have life-support withheld under her current condition). *E.g.*, Conservatorship of Drabick, 200 Cal. App. 3d 185, 190 (Cal. Ct. App. 1988) (stating that a PVS patient is unable to sense painful stimuli). Conversely, life support may be withheld if the treatment itself would cause undue suffering only to result in "some uncertain but limited extension of life." Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 419 (Mass. 1977).

55. *See In re* Westchester County Med. Ctr., 531 N.E.2d 607, 615 (N.Y. 1988) (stating that even though an irreparably brain damaged patient previously, while competent, indicated her desire not to have extraordinary treatment under her present situation, her daughters cannot refuse insertion of a feeding tube because the patient never specifically mentioned her desires concerning nutrition and hydration).

56. *See, e.g.*, *In re* Doe, 418 S.E.2d 3, 6 (Ga. 1992) (noting a lack of state interest to sustain the life of a terminally-ill child with degenerative neurological disease); *In re* Spring, 405 N.E.2d 115, 117–20 (Mass. 1980) (allowing life-prolonging hemodialysis to be withheld from conscious but profoundly senile and terminally ill patient); *Saikewicz*, 370 N.E.2d at 435 (allowing life-prolonging chemotherapy to be withheld from a profoundly retarded, terminally ill leukemia patient when treatment would not cure the leukemia); *In re* Hier, 464 N.E.2d 959, 964–65 (Mass. App. Ct. 1984) (upholding the denial of gastrostomy—highly intrusive surgery necessary for providing nutrition—from an incompetent patient pursuant to the substitute judgment test).

57. *In re* Cartrette, 35-SP-90 (N.C. Super. Ct. Dec. 14, 2000).

58. *Id.*

59. *Saikewicz*, 370 N.E.2d at 419; *In re* Cartrette, 35-SP-90 (N.C. Super. Ct. Dec. 14, 2000).

She is not similar to an unsuspecting patient who will be confused and mentally anguished over unfamiliar, intrusive treatment.[60] Finally, the discontinuation of life-support would essentially starve and dehydrate Cartrette, ultimately causing a very painful death.[61] Under these circumstances, it would be in Cartrette's best interests to remain on life-support and continue living her normal life.

Furthermore, Cartrette's mother's decision to withdraw life-support absent any subjective evidence of Cartrette's wishes, or any objective basis for finding that it would be in her daughter's best interests is fundamentally a quality of life decision. Cartrette's mother is imposing her moral and philosophical view as to what quality of life is worth living. Even though, arguably, a patient's mother would be the preferred decision-maker,[62] reliance solely on a quality of life assessment as the basis for surrogate decision-making for a never-competent patient should not be allowed under any test.[63]

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60. *Cf. Saikewicz*, 370 N.E.2d at 419.

61. Under PVS conditions, some courts have allowed termination of life support, including nutrition and hydration, with the comfort of knowing that the patient will not suffer pain from the withdrawal. *Id.* When the incompetent patient is terminally ill, but aware, the courts have determined that life support may be terminated if it would be in the best interest of the patient and the patient will not experience pain in the withholding of treatment. *See id.* at 421.

62. Courts give deference to the judgment of family members in determining whether to terminate life-support for incompetent patients. Such deference, however, should be limited to situations in which the patient was previously competent, and the family is in the best position to consider the patient's present values and beliefs, and to determine what the patient would have wanted. *See In re* Jobes, 529 A.2d 434, 445 (N.J. 1987) (giving deference to family members' decision regarding termination of life-support for a previously competent PVS patient). *But cf.* Cruzan v. Director, Mo. Dep't of Health, 497 U.S. 261, 286 (1990) ("[T]here is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent.").

63. *Saikewicz*, 370 N.E.2d at 432 (rejecting consideration of the patient's quality of life as it relates to the valuation of the patient's ability to experience life in his mentally disabled state, but not as it relates to the pain and disorientation that would result from chemotherapy); Pellegrino, *supra* note 43, at 1066 (stating that quality of life is a morally acceptable criterion for the surrogate to consider only when the incompetent patient previously indicated a desire to terminate life-support under similar conditions); American Academy of Pediatrics, *supra* note 51, at 532-36 (stating that "quality of life" pertains only to how the patient perceives her existence); *see also* Brophy v. New England Sinai Hosp., Inc., 497 N.E.2d 626, 635 (Mass. 1986) (suggesting that quality of life decisions should be left to the individual, and the court's role should be limited to "ensuring that a refusal of treatment does not violate legal norms"); Conservatorship of Drabick, 200 Cal. App. 3d 185, 196 (Cal. Ct. App. 1988) (stating that courts are not well-qualified to decide by weighing the benefits and burdens of treatment because such a decision "engages personal and medical values, including ideas about the quality of life"); Garloch, *supra* note 2 (quoting a statement from the Assistant Director of Programs for Accessible Living that " 'We can't define quality of life for someone like that. Maybe just being alive is fine for her.' ").

When all that remains is a quality of life decision, courts prefer to err on the side of life.[64] North Carolina courts should recognize the imperfect application of the substitute judgment test to the case of a never-competent patient, and instead look to the best interests test. Given that Cartrette is neither terminally ill, nor in a PVS, the courts should follow other jurisdictions addressing similar issues and deny the guardian's decision to terminate life-support, erring, if at all, on the side of life.

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64. *See In re* Baby K, 832 F. Supp. 1022, 1030, (E.D. Va. 1993) (discussing a presumption in favor of life deriving from the U.S. CONST. amend. V and XIV, VA. CONST., Art. 1, §§ 1 and 11); Rasmussen By Mitchell v. Fleming, 741 P.2d 674, 691 (Ariz. 1987) (arguing that because of the irreversible nature of a decision to terminate treatment the court will assume the patient wishes to continue treatment); *In re* Conroy, 486 A.2d 1209, 1233 (N.J. 1985) ("When evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life."); *see also* Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 1140 (Cal. Ct. App. 1986) (stating that patients are best served by "maintaining a presumption in favor of sustaining life") (citing Report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research).


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