

2006

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Eric C. Miller

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Recommended Citation

Eric C. Miller, *Listening to the Disabled: End-of-Life Medical Decision Making and the Never Competent*, 74 Fordham L. Rev. 2889 (2006).

Available at: <https://ir.lawnet.fordham.edu/flr/vol74/iss5/8>

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Cover Page Footnote

J.D. Candidate, 2007, Fordham University School of Law. I would like to thank my faculty advisor Professor Norton Spritz and everyone at the Mental Hygiene Legal Service, First Department, especially Karen Gomes Andreasian. In addition, I want to extend a special thanks to my wife, Brett A. Saarela.

LISTENING TO THE DISABLED: END-OF-LIFE MEDICAL DECISION MAKING AND THE NEVER COMPETENT

*Eric C. Miller**

INTRODUCTION

Chantel R. was a twenty-six year old mentally retarded¹ woman whom experts identified as having the intellectual function of a seven-year-old child² and “no ability to think abstractly.”³ In 2003, her mother sought an appointment as her guardian with the authority to withdraw life-sustaining treatment.⁴ Chantel verbally expressed both to a psychologist at her residential treatment facility and to the judge in court that she did not want food or water removed even if she was permanently unconscious because she did not “want [anything] to happen to [her].”⁵ A judge for the Surrogate’s Court of New York County disregarded Chantel’s statements based on expert testimony that Chantel could not understand the concept of

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1. Mental retardation is often defined as “an intellectual functioning level (as measured by standard tests for intelligence quotient) that is well below average and significant limitations in daily living skills (adaptive functioning).” The Gale Encyclopedia of Medicine 1911 (Donna Olendorf et al. eds., 1999) [hereinafter Gale Encyclopedia]; see also Martha A. Field & Valerie A. Sanchez, Equal Treatment for People with Mental Retardation: Having and Raising Children 30 (1999). The retarded are categorized as borderline, mild, moderate, severe, or profound. *Id.* at 33. This Note is primarily concerned with those with moderate, severe, or profound retardation, who represent approximately ten percent of the retarded population, but also implicitly applies to any mentally retarded persons that have been adjudicated incompetent. *Id.* By implication this Note may also apply to severely and persistently mentally ill individuals and those with developmental disabilities who have also never been competent to make medical decisions.

2. Mental age scoring has been criticized by some advocates for the retarded as encouraging some people, particularly judges, to see the retarded as children. Field & Sanchez, *supra* note 1, at 38. An individual’s adaptive skills, experience, and ability to function can continue to increase even if mental age remains fixed. *Id.* Mental age is more akin to academic age and therefore a poor proxy for actual age with its assumptions concerning maturity. *Id.* at 39. The average “mental age” of the entire general population under this metric is only sixteen. *Id.* at 38. If most people are considered to be sixteen years old, the problem of equating mental age to legal age is obvious.

3. *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324, 326 (Sur. Ct. N.Y. County 2004).

4. *Id.* at 325.

5. *Id.* at 326.

being permanently unconscious or kept alive through artificial means.⁶ The court decided that her decision was irrational and that only competent people can make irrational decisions.⁷

R.H. was a thirty-three year-old mentally retarded woman with Down's Syndrome.⁸ She lived in a state school in Massachusetts and worked four days a week at a business collating, folding, and stuffing envelopes.⁹ The activities she enjoyed included "dancing, bowling, listening to music and socializing with" her friends.¹⁰ She suffered from chronic pyelonephritis which was progressively destroying her kidneys.¹¹ Finally, in 1992 her medical situation became serious enough to require aggressive dialysis treatments and, ultimately, a kidney transplant.¹² Her mother opposed initiating dialysis treatment, feeling that R.H. would not tolerate it.¹³ A probate court judge spoke with members of the family, physicians, psychologists, and an appointed guardian ad litem, and decided not to permit the initiation of dialysis treatment—allowing R.H. to die.¹⁴ The court and guardian ad litem bowed to the wishes of her family that she not suffer the "unpleasant[ness]" of dialysis treatments which would require three sessions a week each of three hours.¹⁵ At no point did the probate court judge or the guardian ad litem ask R.H. what she wanted to do.¹⁶

Competent persons can communicate their wishes regarding end-of-life medical decisions through advanced directives stating their preferences to others or by designating a health care proxy to make decisions for them.¹⁷

6. *See id.* at 329.

7. *Id.*

8. *In re R.H.*, 622 N.E.2d 1071, 1072-73 (Mass. App. Ct. 1993).

9. *Id.* at 1073.

10. *Id.*

11. *Id.* at 1072-74. Pyelonephritis is an infection of the kidney and the ducts carrying urine from the kidneys. Gale Encyclopedia, *supra* note 1, at 2422.

12. *R.H.*, 622 N.E.2d at 1074. Hemodialysis involves using filtration machinery to cleanse a patient's bloodstream of toxins when the patient's own kidneys can no longer fulfill that function. *Id.* at 1074 n.3. R.H.'s treatment would require three sessions of three hours each every week and the surgical creation of a permanent access site into her circulatory system. *Id.* at 1074.

13. *Id.* Two of R.H.'s physicians and the hospital dialysis director disagreed and argued that she should receive dialysis suggesting the procedure was not overly painful and that R.H. had a history of compliance with treatment. *Id.* at 1074-75. Two other physicians concurred with the mother. *Id.* at 1075.

14. *Id.* Without treatment R.H. would be expected to die within one to three years. *Id.* at 1074. She could survive on dialysis, even without a kidney transplant for "ten or twenty more years." *Id.*

15. *Id.* at 1075.

16. *Id.* at 1077 ("The judge's findings omit entirely the issue of R.H.'s expressed preferences regarding her illness and treatment options."). The Massachusetts Appeals Court vacated the probate court's judgment and ordered the dialysis started immediately. *Id.* at 1079-80. "[T]he judge's decision against undertaking trial dialysis is unsupported by the evidence and clearly erroneous." *Id.* at 1080.

17. *See, e.g.*, Unif. Health-Care Decisions Act §§ 2, 4 (1993), 9 U.L.A. 93, 99 (2005) (allowing an individual to record instructions concerning her health care in the event of incapacity); Cal. Prob. Code §§ 4650-77, 4680-90, 4700-01 (West Supp. 2006) (enabling the designation of a health care proxy). For a list of proxy and advanced directive statutes in all

Even if they become incompetent, their preferences will usually be honored.¹⁸ But persons whose competence never rose to the level required for informed consent are in a more complex legal position. Courts have struggled with the question of how much, if at all, they are required to consult with never-competent patients, especially regarding decisions that could end their lives.¹⁹ State statutes addressing this problem are often concerned only with the best interests of the patient and not with their expressed interest.²⁰ This Note seeks to examine the jurisprudence of end-of-life medical decision making for the never competent and specifically to explore the role the never competent themselves play in surrogate decisions.

This Note will begin in Part I by looking at current legal doctrine for end-of-life decision making, first for the formerly competent and then for the never competent. The Note will examine a series of cases where courts reacted to the verbal and nonverbal expressions of the never competent and then examine how state statutory schemes apply to the never competent. In Part II, the Note will survey arguments put forward by courts and commentators regarding the extent to which surrogate decision makers have the power to override expressed preferences of the never competent. Finally, in Part III, this Note will propose that while never-competent patients need empowered surrogates to protect their right to refuse treatment, surrogates can only honor the personal autonomy of patients by first considering any expressed preference, even if the expression does not rise to the level of informed consent.

I. END-OF-LIFE DECISION MAKING FOR THE NEVER COMPETENT: AN OVERVIEW OF CONSTITUTIONAL, CASE LAW, AND STATUTORY SOLUTIONS

Traditionally, when a person stopped breathing and his heart stopped beating he was dead.²¹ Problems arose in the 1960s when medical interventions (particularly heart and lung machines) could keep some vital processes going while others, such as brain function, had ended.²² Medical technology has progressed to the point where patients can be kept "alive" indefinitely even if permanently unconscious and unable to think, eat, or

fifty states, see Alicia R. Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 Ind. L.J. 1, 3 n.7 (2004).

18. See, e.g., Cal. Prob. Code § 4683(a) ("An agent designated in the power of attorney may make health care decisions for the principal to the same extent the principal could make health care decisions if the principal had the capacity to do so."); see also *Washington v. Glucksberg*, 521 U.S. 702, 716 (1997) (recognizing state applications of living will and proxy statutes).

19. See *infra* Part I.C.

20. See *infra* Part I.D.

21. See President's Comm'n for the Study of Ethical Problems in Med. & Biomedical & Behavioral Research, *Defining Death: Medical, Legal and Ethical Issues in the Determination of Death* 13 (1981).

22. See *id.* at 21-23.

care for themselves.²³ The questions of when medical treatment should be stopped—allowing death to occur—and who should make that decision, have created a new area of jurisprudence over the last thirty years.²⁴

This part will begin with an overview of the legal doctrines regarding end-of-life medical decision making for the formerly competent. After briefly describing some legal definitions of competency, this part will outline the right of informed consent, the right to privacy, and the state's interest in preserving life by discussing some very influential early New Jersey cases, *Quinlan* and *Conroy*, the Supreme Court's decision in *Cruzan*, and subsequent state court and legislative reactions to that decision.²⁵ This part will then discuss state court decisions specifically focused on end-of-life decision making for the never competent.²⁶ The cases will be examined to determine how courts react to the expressions of never-competent patients.²⁷ Finally, this part will survey some statutory schemes and analyze their application to never-competent persons.²⁸

A. Overview of the Doctrine for End-of-Life Decision Making for the Formerly Competent

End-of-life medical decision making in the United States is based on the principle of patient autonomy: Patients have the right to make decisions about their own medical care.²⁹ The right of a person to his bodily integrity in the absence of legally justified interference is an essential component of the right to liberty protected by the Fourteenth Amendment of the U.S. Constitution.³⁰ This right includes the right to refuse unwanted medical

23. See *id.*; see also Rasmussen *ex rel. Mitchell v. Fleming*, 741 P.2d 674, 678 (Ariz. 1987) ("Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues."); *In re Quinlan*, 355 A.2d 647, 656 (N.J. 1976) (discussing how modern respirators can create a form of "irreversible coma"). Technology has fundamentally transformed the way that death takes place in this country. President's Comm'n for the Study of Ethical Problems in Med. & Biomedical & Behavioral Research, *Deciding to Forgo Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions* 16-18 (1983). In 1900, the leading causes of death were still communicable diseases and the vast majority of patients died at home because medical science could do little for them. *Id.* The most common treatments, alcohol and opiates, were available without a prescription. *Id.* By the 1980s some eighty percent of deaths occurred in an institutional setting. *Id.*

24. See Barry R. Furrow et al., *Health Law* § 16-1 (2000).

25. See *infra* Part I.A.

26. See *infra* Part I.B.

27. See *infra* Part I.C.

28. See *infra* Part I.D.

29. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 279 (1990). Anglo-American common law supports individual autonomy by making the touching of one person by another without consent a battery. See Restatement (Second) of Torts § 13 cmt. d (1979).

30. See *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891) ("No right is held more sacred, or is more carefully guarded . . . than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.").

treatment:³¹ "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."³² The right to refuse medical treatment includes the right to be informed of all information necessary to make a reasoned decision regarding medical care.³³

Competency is a prerequisite for the ability to provide informed consent.³⁴ A competent patient's refusal of medical treatment must be respected no matter how irrational.³⁵ The law presumes competency—one must be adjudicated incompetent.³⁶ No generally accepted legal definition of incompetency exists and, in practice, courts rely on the judgments of physicians.³⁷ But no test or procedure is generally accepted among physicians in determining competence.³⁸ Physicians generally look to their patients' ability to absorb, comprehend, and remember information; to relate to their situation and reason through alternatives, to make and accept a choice, and, finally, to explain the reasons for their decision.³⁹

31. *Cruzan*, 497 U.S. at 279. The government's police power can override the right to refuse unwanted medical treatment to protect public health and safety. See *Washington v. Harper*, 494 U.S. 210, 227 (1990) (recognizing that a prisoner can be involuntarily medicated because he was dangerous to other prisoners when off medication); *Jacobson v. Massachusetts*, 197 U.S. 11, 26-28 (1905) (holding that the state can compel vaccination to prevent the spread of smallpox).

32. *Cruzan*, 497 U.S. at 269 (citing *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (Cardozo, J.)).

33. See *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170, 181 (Cal. Ct. App. 1957) ("A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.").

34. See *Cruzan*, 497 U.S. at 280; Restatement (Second) of Torts § 892; Bruce J. Winick, *Competency to Consent to Treatment: The Distinction Between Assent and Objection*, 28 *Hous. L. Rev.* 15, 21-27 (1991).

35. See Winick, *supra* note 34, at 21 & n.17.

36. See *id.* at 22.

37. See Becky Cox White, *Competence to Consent* 10-11 (1994); Winick, *supra* note 34, at 24-25. But see *Rivers v. Katz*, 495 N.E.2d 337, 344 n.7 (N.Y. 1986). The court in *Rivers* suggested an eight-factor test:

(1) the person's knowledge that he has a choice to make; (2) the patient's ability to understand the available options, their advantages and disadvantages; (3) the patient's cognitive capacity to consider the relevant factors; (4) the absence of any interfering pathologic perception or belief, such as a delusion concerning the decision; (5) the absence of any interfering emotional state, such as severe manic depression, euphoria or emotional disability; (6) the absence of any interfering pathologic motivational pressure; (7) the absence of any interfering pathologic relationship, such as the conviction of helpless dependency on another person; (8) an awareness of how others view the decision, the general social attitude toward the choices and an understanding of his reason for deviating from that attitude if he does.

Id.

38. See White, *supra* note 37, at 11; D. Don Welch, *Walking in Their Shoes: Paying Respect to Incompetent Patients*, 42 *Vand. L. Rev.* 1617, 1627 (1989).

39. White, *supra* note 37, at 154-83; see also President's Comm'n for the Study of Ethical Problems in Med. & Biomedical & Behavioral Research, *Making Health Care Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-*

While conscious, competent patients had clear rights to refuse medical treatment; thirty years ago, medical technology advanced to the point where patients were kept alive indefinitely because they could not expressly refuse treatment while unconscious.⁴⁰ Did surrogates have the right to refuse medical treatment on their behalf? The Supreme Court of the State of New Jersey said they did and based its decision not just in the common law right of informed consent, but also in the right to privacy found in the Constitution.⁴¹ In *In re Quinlan*, a father wanted the authority to withdraw a respirator from his adult daughter, Karen Quinlan, who was in a persistently vegetative state.⁴² The court held that the constitutional right to privacy protected Karen's right to refuse invasive medical treatment and that a guardian may assert that right on her behalf.⁴³ While the state had an interest in preserving Karen's life, the "[s]tate's interest [in life] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."⁴⁴

In cases subsequent to *Quinlan*, courts tended to move away from the right to privacy and toward common law principles of informed consent in cases involving the refusal of medical treatment.⁴⁵ While the right to privacy required a weighing of the patient's privacy interests against the state's interest, the common law right of informed consent generally outweighed any state interest.⁴⁶ But, because informed consent requires a competent choice, courts began to seek evidence of a patient's choice to refuse life-sustaining treatment in statements made prior to incompetence.⁴⁷

The New Jersey Supreme Court applied the principle of informed consent to surrogate decision making in *In re Conroy*.⁴⁸ Here, the court created a balancing test between the state's interest in preserving life and a

Practitioner Relationship 57 (1982) [hereinafter President's Commission: Consent] (suggesting that capacity requires, "(1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one's choices"). For a discussion of the practice of identifying incompetency, see *infra* Part II.B.1.

40. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 310-13 (1990) (Brennan, J., dissenting).

41. *In re Quinlan*, 355 A.2d 647, 663 (N.J. 1976). *Quinlan* is considered the "seminal" case in the field. See *Cruzan*, 497 U.S. at 270.

42. *Quinlan*, 355 A.2d at 654. Persistent vegetative state can be defined as "a permanent and irreversible condition of unconsciousness in which there is: (a) The absence of voluntary action or cognitive behavior of any kind [and] (b) An inability to communicate or interact purposefully with the environment." Fla Stat. Ann. § 765.101(12) (West 2005).

43. *Quinlan*, 355 A.2d at 664.

44. *Id.*

45. See *Cruzan*, 497 U.S. at 279 n.7 ("Although many state courts have held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy, we have never so held. We believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest."); *In re Conroy*, 486 A.2d 1209, 1223 (N.J. 1985).

46. See *Conroy*, 486 A.2d at 1225.

47. See *id.* at 1229.

48. *Id.* at 1223. *Conroy* differed from *Quinlan* in that it involved the removal of nutrition and hydration from a terminally incompetent eighty-four year old woman who was not on a respirator. *Id.* at 1216-19.

surrogate's interest in making decisions on behalf of a formerly competent patient.⁴⁹ In most cases the court required evidence of a patient's preference based on statements made prior to incompetency.⁵⁰ But, if a terminally ill patient experienced "recurring, unavoidable and severe pain," a court could permit doctors to cease treatment even in the absence of any evidence of the patient's preferences while competent if the best interests of the patient clearly lay in ending treatment.⁵¹ The court therefore held open the possibility of basing an end-of-life decision not on the preferences of the patient, but on the surrogate's or court's determination of the patient's best interests.⁵²

The Supreme Court of the United States addressed the right of surrogates to terminate life-sustaining medical care for incompetent patients in *Cruzan v. Director, Missouri Department of Health*.⁵³ In *Cruzan*, the parents sought to remove nutrition and hydration from their daughter, Nancy, who was in a persistently vegetative state following a car accident.⁵⁴ The Court constitutionalized the common law right to refuse medical treatment (the informed consent doctrine) by finding that the Fourteenth Amendment Due Process Clause included a liberty interest in refusing medical treatment.⁵⁵ Recognized state interests could, however, limit the exercise of this right by surrogates.⁵⁶

The Supreme Court found that the state has an interest in both the process of withdrawing life-sustaining treatment and the life of the incompetent patient.⁵⁷ The state also has an interest in guarding against abuse of the power to withdraw life-sustaining treatment.⁵⁸ Furthermore, the state has a basic interest in the preservation of human life.⁵⁹ To guard against abuse of

49. *See id.* at 1227.

50. *Id.* at 1229.

51. *Id.* at 1231-32 ("Under [a pure objective] test . . . the net burdens of the patient's life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane."); *see infra* I.B.3.

52. *Conroy*, 486 A.2d at 1231.

53. 497 U.S. 261 (1990).

54. *Id.* at 265.

55. *Id.* at 278 ("The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions."); *see also id.* at 287-89 (O'Connor, J., concurring). Justice William Rehnquist later sought to limit this principle in *Washington v. Glucksberg*, 521 U.S. 702, 725 (1997), but the proposition has been consistently supported by a majority of the Justices and by lower courts, *see Blouin v. Spitzer*, 356 F.3d 348, 359 (2d Cir. 2004).

56. *See Cruzan*, 497 U.S. at 281-82; *see also Blouin*, 356 F.3d at 359 (interpreting *Cruzan* as saying "it does not follow . . . that an incompetent person whose death is imminent has a constitutional right to have a surrogate make critical medical decisions, including a decision to withdraw life support").

57. *Cruzan*, 497 U.S. at 281-82.

58. *Id.* at 281.

59. *Id.* at 282 (finding that a state can "simply assert an unqualified interest in the preservation of human life"); *see also id.* at 295 (Scalia, J., concurring) (stating that "[t]he life of those to whom life has become a burden—of those who are hopelessly diseased or

surrogate power and protect human life, the Court held that Missouri was free to establish a clear and convincing evidentiary standard and free to require judicial proceedings for the "added guarantee of accurate factfinding that the adversary process brings with it."⁶⁰

While the Court in *Cruzan* left the broad outlines of legal doctrine on end-of-life medical decision making to the "laboratory of the states,"⁶¹ several themes emerged from the decision, particularly the presumption in favor of preserving life.⁶² While a court may require clear and convincing evidence that an individual would not want life-sustaining treatment to continue, there is no such requirement for proving a patient would prefer to continue such treatment.⁶³ While most states require clear and convincing evidence that an individual would not want treatment sustained,⁶⁴ in practice the burden of showing clear and convincing evidence is applied differently from state to state.⁶⁵

State legislatures assist individuals in making end-of-life medical decisions by enacting statutes permitting living wills and health care proxies.⁶⁶ A living will is a writing by a patient outlining their preferences regarding end-of-life treatment.⁶⁷ A health care proxy is a form appointing a surrogate decision maker for medical decisions in the event the executor

fatally wounded—nay, even the lives of criminals condemned to death, are under the protection of the law, equally as the lives of those who are in the full tide of life's enjoyment, and anxious to continue to live'" (quoting *Blackburn v. State*, 23 Ohio St. 146, 163 (1873))).

60. *Id.* at 281.

61. *Id.* at 292.

62. *See id.* at 283; *see also In re Conroy*, 486 A.2d 1209, 1233 (N.J. 1985) ("When evidence of a person's wishes . . . is equivocal, it is best to err, if at all, in favor of preserving life.").

63. *See In re K.I.*, 735 A.2d 448, 456 (D.C. 1999) (requiring clear and convincing evidence that ending treatment is in a patient's best interest); *Conroy*, 486 A.2d at 1232 ("[E]ven in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who had previously expressed a wish to be kept alive."). *But see* Norman L. Cantor, *Making Medical Decisions for the Profoundly Mentally Disabled* 118-25 (2005) (arguing that permanent unconsciousness is an intrinsically undignified state for any human being and therefore individuals should have to actively choose to be maintained in that state).

64. *See In re Jobs*, 529 A.2d 434, 441 (N.J. 1987); Furrow et al., *supra* note 24, § 16-52(a).

65. *Compare Jobs*, 529 A.2d at 441 (finding that evidence meets the burden when it "produce[s] in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established"), *with In re O'Connor*, 531 N.E.2d 607, 613 (N.Y. 1988) (requiring "proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life supports under the circumstances like those presented," and the court must be convinced "as far as is humanly possible" that the strengths of those beliefs make a "change of heart unlikely"). Two states besides New York have high evidentiary burdens: Missouri and Michigan. *See In re Martin*, 538 N.W.2d 399, 410 (Mich. 1995); *In re Warren*, 858 S.W.2d 263, 267 (Mo. Ct. App. 1993).

66. *See Washington v. Glucksberg*, 521 U.S. 702, 716 (1997). For an exhaustive list of state statutes in this area, see Ouellette, *supra* note 17, at 3 n.7.

67. Furrow et al., *supra* note 24, § 16-21; *see also* Unif. Health-Care Decisions Act § 1(1) (1993), 9 U.L.A. 88 (2005) (referring to a living will as an "advance health-care directive").

becomes incompetent.⁶⁸ It functions as a simplified power of attorney and can include written instructions regarding the patient's preferences.⁶⁹ These documents generally enable individuals to overcome evidentiary burdens and permit surrogates to decline treatment without judicial intervention.⁷⁰ Health care proxies are now the preferred method because living wills cannot usually anticipate the exact circumstances in which future decisions must be made.⁷¹

B. Court Decisions Addressing End-of-Life Decision Making for the Never Competent

A substantial portion of the jurisprudence of end-of-life decision making focuses on determining what the person's expressed wishes were while competent.⁷² This creates obvious problems in the case of the moderately or severely retarded or persistently mentally ill who may never have had the competence to exercise informed consent.⁷³ The two traditional doctrines in this area are: (1) substitute judgment—which seeks to ascertain what the patient would have wanted were he actually competent,⁷⁴ and (2) the best interest doctrine—where a surrogate attempts to determine what the best course of action is for the patient in his situation.⁷⁵ In practice, these two

68. See, e.g., N.Y. Pub. Health Law §§ 2981-85 (McKinney 1996 & Supp. 2006).

69. See, e.g., Unif. Health-Care Decisions Act § 4, 9 U.L.A. 99-104 (showing a sample form).

70. See *O'Connor*, 531 N.E.2d at 613-14.

71. See President's Council on Bioethics, Taking Care: Ethical Caregiving in our Aging Society 81-91 (2005). The basic hypothetical situation involves an individual with a living will indicating that he does not wish to be kept alive if he cannot enjoy his normal activities and is dependent on other people. Subsequently, he develops dementia. While not able to engage in his former activities and dependent on others, the demented individual can, in fact, be very happy and contented with life, often happier than he was while competent. If the person gets a treatable illness can a health-care provider really refuse treatment in accordance with his living will? *Id.*; see also Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 Rutgers L. Rev. 609, 624-27 (1994).

72. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286-87 (1990).

73. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 430-31 (Mass. 1977).

74. *Id.*; see also *In re L.H.R.*, 321 S.E.2d 716, 722-23 (Ga. 1984); *In re Conservatorship of Torres*, 357 N.W.2d 332, 341 (Minn. 1984); *In re Guardianship of Ingram*, 689 P.2d 1363, 1372 (Wash. 1984). The origins of the substitute judgment doctrine trace back to 1816 when an English court allowed an incompetent person to grant an allowance to a relative. The court reasoned that it should make the lunatic act "as . . . the [lunatic himself would have acted if of sound mind." *Saikewicz*, 370 N.E.2d at 431 (citing *Ex parte Whitbread in re Hinde, a Lunatic*, (1816) 35 Eng. Rep. 878 (Ch.)). Only Massachusetts and Washington state courts have applied the substitute judgment doctrine to end-of-life medical decision making for never-competent adult patients. *Id.* at 430-31; *Ingram*, 689 P.2d at 1372. Other states have applied the substitute judgment doctrine in cases involving formerly competent patients without ascertainable wishes regarding end-of-life decisions. See *Torres*, 357 N.W.2d at 341. Some have applied it to decision making on behalf of infants. See *L.H.R.*, 321 S.E.2d at 722-23.

75. *In re Grady*, 426 A.2d 467, 481-83 (N.J. 1981); see also *In re K.I.*, 735 A.2d 448, 450 (D.C. 1999); *In re L.W.*, 482 N.W.2d 60, 70 (Wis. 1992). The best interest doctrine is rooted in the Anglo-American tradition of the sovereign's authority to protect helpless

doctrines are very closely entwined and often interchangeable.⁷⁶ Court decisions broadly look to both subjective and objective standards in determining what course of action is best for patients facing end-of-life decisions.⁷⁷

1. Substitute Judgment Doctrine

The substitute judgment standard requires a surrogate to determine what the incompetent individual would want to do if competent.⁷⁸ The leading case on the application of substitute judgment to never-competent patients is *Superintendent of Belchertown State School v. Saikewicz*.⁷⁹

Joseph Saikewicz was a profoundly retarded, nonverbally communicative sixty-seven year old man with an IQ of 10.⁸⁰ Diagnosed with leukemia, he was given a thirty to fifty percent chance of remission for two to thirteen months if he underwent chemotherapy.⁸¹ Without treatment he would die in a "matter of weeks or, perhaps, several months," but his death would not be painful.⁸² The problem arose in the lower court, because, while most competent people would normally choose the therapy, doctors would probably have to restrain Saikewicz for extended periods to allow a painful course of chemotherapy.⁸³

The court reasoned that under an objective, "best interest" standard, as typically applied to never-competent individuals, treatment would be compelled for Saikewicz because that is what most competent patients would have chosen.⁸⁴ However, the court rebelled against applying the standard of a competent patient to Saikewicz because "significant decisions of life are more complex than statistical determinations."⁸⁵ Unlike a

populations, also known as *parens patriae* power. See *Grady*, 426 A.2d at 479 (describing *parens patriae* power as "the inherent equitable authority of the sovereign to protect those persons within the state who cannot protect themselves because of an innate legal disability"). The watchword for exercising *parens patriae* power is the best interests of the incompetent person because the purpose of the government's power is protection. See *In re Martin*, 538 N.W.2d 399, 408 (Mich. 1995); *Grady*, 426 A.2d at 479-80; *L.W.*, 482 N.W.2d at 70, 71; see also *K.I.*, 735 A.2d at 461-62; Norman L. Cantor, *The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons*, 26 J. Legal Med. 155 (2005).

76. See Cantor, *supra* note 63, at 105 (arguing that even when courts are nominally applying a substitute judgment standard they use a best interest standard because "there is no basis for ascribing a personal choice . . . among competing values and interests . . . to a profoundly disabled person").

77. See *Martin*, 538 N.W.2d at 408.

78. See *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 430-31 (Mass. 1977); see also *In re A.C.*, 573 A.2d 1235, 1249-50 (D.C. 1990).

79. 370 N.E.2d 417.

80. *Id.* at 420. He was given a mental age of two years and eight months. *Id.* For a discussion of mental age scoring, see *supra* note 2.

81. *Saikewicz*, 370 N.E.2d at 420.

82. *Id.* at 421. Saikewicz died on September 4, 1976, four months after the original probate judge ordered that no treatment be administered. *Id.* at 422.

83. *Id.* at 420-21.

84. *Id.* at 427-28.

85. *Id.* at 428.

competent person, Saikewicz's inability to understand the reason for the pain involved in chemotherapy would create tremendous fear and disruption in his life.⁸⁶ He would not have the understanding from which competent patients draw strength.⁸⁷ While substitute judgment required a court to force Saikewicz to choose as if competent, it also required the court to assume Saikewicz would take into account the fact of his incompetence in reaching the decision.⁸⁸

2. Best Interest Doctrine

An alternative to the majority standard—substitute judgment—is the best interest doctrine, wherein the court tries to find the course of action which produces the greatest net benefit to the incompetent person.⁸⁹ The leading case on the application of the best interest standard in medical decision making for never-competent patients is the New Jersey Supreme Court case, *In re Grady*.⁹⁰

In *Grady*, parents wanted to sterilize their twenty-year-old daughter, Lee Ann, who had Down's Syndrome, to allow her to live more independently from her family in a group home.⁹¹ Lee Ann could not consent to sterilization because "Lee Ann herself [could] comprehend neither the problem nor the proposed solution."⁹² The court found that Lee Ann had a right to privacy interest in controlling her reproductive choices, but found that the interest was valueless unless it could be exercised by a surrogate.⁹³ The court required, and found, clear and convincing evidence that sterilization was in Lee Ann's best interest, specifically that "the proponents of sterilization [were] seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience."⁹⁴

The New Jersey Supreme Court rejected considerations outside the direct interests of the never-competent person.⁹⁵ Specifically, the court rejected an application of a state interest in preventing the birth of "genetically

86. *Id.* at 432.

87. *Id.*

88. *Id.* at 431-32 ("[T]he decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision making process of the competent person.").

89. See *In re Grady*, 426 A.2d 467, 482 (N.J. 1981); see also Cantor, *supra* note 75 (discussing what factors should go into making a best interest determination). Most courts restrict the application of substitute judgment to cases where the individual was once competent and therefore evidence can be found as to the person's subjective preferences. See *In re K.I.*, 735 A.2d 448, 455 (D.C. 1999).

90. *Grady*, 426 A.2d 467.

91. *Id.* at 470.

92. *Id.* at 473. For an excellent discussion of child-rearing by the mentally retarded, see Field & Sanchez, *supra* note 1.

93. *Grady*, 426 A.2d at 474-75.

94. *Id.* at 483.

95. See *id.* at 481.

defective" children or not allowing never-competent persons to become parents.⁹⁶ Surrogates only have authority when acting in the best interests of the never competent, not when acting in their own interests or society at large.⁹⁷ Applying this best interest standard to end-of-life decisions for never-competent persons, courts essentially ask whether the burdens of continued treatment outweigh the potential benefit.⁹⁸

Because the state is either functioning as the ward's guardian or supervising the ward's guardian, the principles of guardianship also bind the state to determine what is in the best interests of the ward.⁹⁹ However, wide variation exists in deciding what factors to consider in a best interests calculation.¹⁰⁰

96. *Id.* There is a long history in the United States and abroad of attempts to eliminate "genetically defective" persons by preventing them from having children. *See* Buck v. Bell, 274 U.S. 200, 207 (1927) ("It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind."); *see also* Shoshana K. Kehoe, *Giving the Disabled and Terminally Ill a Voice: Mandating Mediation for All Physician-Assisted Suicide, Withdrawal of Life Support, or Life-Sustaining Treatment Requests*, 20 Hamline J. Pub. L. & Pol'y 373, 378-82 (1999) (surveying the history of the eugenics movement in the United States and Germany).

97. *Grady*, 426 A.2d at 483.

98. *See In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985) ("By [the burdens test] we mean that the patient is suffering, and will continue to suffer throughout the expected duration of his life, unavoidable pain, and that the net burdens of his prolonged life (the pain and suffering of his life with the treatment less the amount and duration of pain that the patient would likely experience if the treatment were withdrawn) markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life."); *In re Guardianship of L.W.*, 482 N.W.2d 60, 68 (Wis. 1992) ("A dignified and natural death may outweigh the interest of maintaining a physiological life as long as medically possible.").

99. *See Grady*, 426 A.2d at 481-84. It is important to distinguish between the terms "surrogate" and "guardian." A surrogate is any individual making a decision for another. A guardian is a deputized surrogate who receives their decision making power from a court. *See, e.g.*, N.Y. Mental Hyg. Law § 81.03(a) (McKinney Supp. 2006) (defining guardian as "a person . . . appointed in accordance with terms of this article by the [court] . . . to act on behalf of an incapacitated person in providing for personal needs and/or for property management"). States typically do not require court action before a surrogate can make medical decisions for an incompetent person. *See In re Lawrance*, 579 N.E.2d 32, 44 (Ind. 1991). In situations where there is some dispute over who can act for the best interests of an incompetent person, guardianship proceedings are usually undertaken. In the case of end-of-life decision making for never-competent adults they are often required. *See* N.Y. Surr. Ct. Proc. Act § 1750-b (McKinney Supp. 2006).

100. *See, e.g.*, Cantor, *supra* note 75, at 156. One definition of best interests can be found in N.Y. Mental Hyg. Law § 80.03(d) (McKinney Supp. 2006). The statute reads as follows:

[P]romoting personal well-being by the assessment of the risks, benefits and alternatives to the patient of a proposed major medical treatment, taking into account factors including the relief of suffering, the preservation or restoration of functioning, improvement in the quality of the patient's life with and without the proposed major medical treatment and consistency with the personal beliefs and values known to be held by the patient.

Id.; *see also* Md. Code Ann., Health-Gen. § 5-601(e) (West 2005) (defining best interests as "the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from that treatment" with factors including the effect of treatment, level of pain, "extreme humiliation and dependency," life expectancy, prognosis, side effects, and

3. Beyond Traditional Doctrine: Subjective Versus Objective Standards

The traditional categories of substitute judgment and best interests are often not very well differentiated.¹⁰¹ When applying the substitute judgment doctrine to never-competent patients, courts basically assume that a never-competent patient, if competent, would choose what is in their best interests.¹⁰² When courts apply the best interest standard, they are never truly applying a completely objective approach because they consider the best interests of the patient including concerns specific to the patient and their situation.¹⁰³ A more meaningful distinction is between objective standards outside the person (i.e., what other people do or what medical professionals prefer) and standards subjective to the person (what this person herself wants).¹⁰⁴

The Supreme Court for the State of Michigan issued an opinion illustrating the distinction between objective and subjective standards in *In re Martin*.¹⁰⁵ Michael Martin suffered a head injury in a car accident but was not unconscious or in a persistent vegetative state.¹⁰⁶ Although doctors found him to have a limited ability to interact with others and respond to simple commands, he could not feed or care for himself.¹⁰⁷ Michael's wife asserted that he would never wish to be kept alive in his present condition and sought to have a feeding tube removed over the objection of his mother and sister.¹⁰⁸ The lower court found clear and convincing evidence that Michael would refuse medical treatment under these circumstances, but the Supreme Court of Michigan reversed.¹⁰⁹

The Michigan court associated the best interest standard with an objective standard and the substitute judgment standard with a subjective standard:

"religious beliefs and basic values" of the individual); Unif. Health-Care Decisions Act § 2(e) cmt. (1993), 9 U.L.A. 94, 95 (2005) ("In determining the principal's best interest, the agent is to consider the principal's personal values to the extent known to the agent. The Act does not prescribe a detailed list of factors for determining the principal's best interest but instead grants the agent discretion to ascertain and weigh the factors likely to be of importance to the principal.").

101. See *Care & Protection of Beth*, 587 N.E.2d 1377, 1381 n.11 (Mass. 1992) ("It is true that, when applying the 'best interests' test, the inquiry is essentially objective in nature, and the decisions are made not by, but on behalf of, the child. . . . Nevertheless, the best interests analysis, like that of the substituted judgment doctrine, requires a court to focus on the various factors unique to the situation of the individual for whom it must act. . . . As a practical matter, the criteria to be examined and the basic applicable reasoning are the same."); see also Cantor, *supra* note 63, at 158-59.

102. See *Beth*, 587 N.E.2d at 1381 & n.11.

103. See *id.*

104. *In re Martin*, 538 N.W.2d 399, 408 (Mich. 1995) ("The subjective standard is based on a patient's right to self-determination, while the objective standard is grounded in the state's *parens patriae* power.").

105. 538 N.W.2d 399.

106. *Id.* at 402-03.

107. *Id.* at 403.

108. *Id.* at 402.

109. *Id.* at 401-02.

The best interest standard is an objective analysis under which the benefits and burdens to the patient of treatment are assessed by the surrogate in conjunction with any statements made by the patient if such statements are available . . . best interest analysis is generally invoked, if at all, only as a secondary approach when subjective evidence of a particular patient's decision is lacking because it involves a qualitative assessment of the patient's condition, a decision the state may legitimately decline to make. . . .

The substitute judgment standard has subjective and objective components . . . [A] surrogate attempts to ascertain, with as much specificity as possible, the decision the incompetent patient would make if he were competent to do so. . . . [W]here there is no explicit evidence . . . the surrogate may still decide to terminate treatment on the basis of evidence of the patient's "value system."¹¹⁰

The court applied Michigan's stricter evidentiary standards, particularly in refusing to accept statements made in response to another person's death when that person's medical condition differed substantially from Michael's present condition. As a result, the court held that the wife did not meet a clear and convincing standard.¹¹¹ Because Michael was at one point competent, it was only in dicta that the court considered testimony from doctors that Michael, although incompetent, presently seemed content with his situation.¹¹² While courts apply subjective standards to persons that were once competent, they often apply an objective best interest analysis to the never competent. The extent to which the courts consider the subjective expressions of the never competent varies widely.

C. Listening to the Incompetent: What Are the Courts Hearing?

This section will analyze a series of representative cases where courts consider the expressed statements and actions of the never competent in evaluating whether to discontinue medical treatment. In all the following cases the individual has been adjudicated incompetent. But that does not mean the individuals have not expressed opinions or preferences, just that those opinions and preferences do not rise to the level of informed consent required for medical decision making. Expressions commonly asserted by incompetent patients include pushing against restraints, noncooperation with treatment, verbalization, and actively trying to remove nutrition/hydration tubes.¹¹³ The question becomes: What weight are surrogates (and by extension, courts) to grant these expressions? Are they gestures of frustration or do they indicate subjective preferences?

110. *Id.* at 407 (citations omitted).

111. *Id.* at 411.

112. *Id.* at 412-13.

113. *See infra* Part I.C.1-3.

1. Physical Resistance and Noncooperation: *Saikewicz* and *Storar*

The court in *Saikewicz*, in refusing to permit treatment, did look at the patient's presumed physical resistance to the intravenous administration of chemotherapy drugs as a complicating factor in the treatment but did not consider evidence of his subjective preference for treatment or nontreatment.¹¹⁴ Saikewicz was a very strong and "well-built" sixty-seven year old man, and his lack of cooperation with treatment would have required him to be restrained for twelve to twenty-four hour periods of time.¹¹⁵ Like the lower probate court, the Massachusetts Supreme Court considered his noncooperation with treatment as one of six factors weighing against treatment.¹¹⁶ The concern was not that resistance indicated his preference to refuse treatment but the effects of the restraints themselves.¹¹⁷ Saikewicz would suffer fear of being restrained, and his noncooperation increased the risk of medical complications from chemotherapy drugs.¹¹⁸ The court substituted its judgment for Saikewicz's by trying to anticipate his personal reaction to the experience of chemotherapy, but the court did not consider any physical expression of Saikewicz's will prior to or at the start of treatment.¹¹⁹

While the court was very concerned with the subjective desires of Saikewicz in coming to a substitute judgment of his preferences, it never considered his physical resistance to treatment as evidence in itself of subjective preference to refuse treatment.¹²⁰ In effect, the court entirely abstracted Saikewicz, separating his moral presence from his physical expressions. The court cited a commentator as suggesting that, were Saikewicz to miraculously become competent, he would consider himself "fairly treated" by the court.¹²¹ The court determined that Saikewicz was unable to cooperate with the treatment due to his profound retardation and so that even if the "competent Saikewicz" preferred treatment, he would still resist it.¹²²

In contrast to *Saikewicz*, the Court of Appeals for the State of New York, in *In re Storar*, ordered John Storar to undergo treatment in the face of opposition by his guardian and despite his physical resistance to

114. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 432 (Mass. 1977).

115. *Id.* at 420, 421 n.5.

116. *Id.* at 432 (outlining six factors: (1) Saikewicz's age; (2) side effects of treatment; (3) probability of remission; (4) immediate suffering from the treatment; (5) Saikewicz's inability to cooperate with treatment; and (6) quality of life following successful treatment).

117. *Id.*

118. *Id.*

119. *Id.* at 430.

120. *Id.* at 430-32.

121. *Id.* at 430 n.15 (citing John A. Robertson, *Organ Donations by Incompetents and the Substitute Judgment Doctrine*, 76 Colum. L. Rev. 48, 63 (1976)).

122. *Id.* at 421.

treatment.¹²³ Storar was a profoundly retarded fifty-two year old man who required blood transfusions following a diagnosis of inoperable bladder cancer.¹²⁴ Storar found the transfusions “disagreeable” and physically resisted to the extent that he required sedation prior to treatment.¹²⁵ Storar’s guardian (his mother) saw his dislike of the transfusions as evidence of his subjective preference not to have them and, on that basis, sought to have them stopped.¹²⁶ When the facility where he lived applied to the courts for permission to continue the transfusions, they were denied by the lower courts but won an appeal to New York’s highest court.¹²⁷

The Court of Appeals found Storar’s dislike of the transfusions unremarkable and looked to the kinds of physical activities that he engaged in as evidence that the transfusions maintained him at his normal level of activity.¹²⁸ Prior to the transfusions his slow loss of blood made him increasingly lethargic.¹²⁹ Following the transfusions he had more energy and “was able to resume most of his usual activities—feeding himself, showering, taking walks and running—including some mischievous ones, such as stealing cigarette butts and attempting to eat them.”¹³⁰ Therefore, the court saw the transfusions as analogous to food and asserted they “did not involve excessive pain.”¹³¹ While Storar’s physical activity was indirect evidence of his preference to live, the court found little relevance in his physical resistance to treatment.¹³²

Similarly to *Saikewicz*, Storar’s resistance to treatment was a natural result of his incompetence: “Of course, John Storar did not like [the transfusions], as might be expected of one with an infant’s mentality.”¹³³ But, unlike *Saikewicz*, the court in *Storar* looked to the patient’s increased activity level following the treatments as evidence of his desire to keep living.¹³⁴ More importantly, the Court of Appeals directly analogized Storar’s situation with that of a child, and held that since parents were not permitted to deny a child life-saving treatment, the court could not do so here.¹³⁵ Essentially, the court determined that its role required protecting Storar’s life from the decision of his mother to refuse medical treatment.¹³⁶

123. *In re Storar*, 420 N.E.2d 64 (N.Y. 1981). Storar has been read as prohibiting any refusal of life-saving treatment to never-competent patients. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 192 (N.D.N.Y. 2002), *aff’d* 356 F.3d 348, 364 (2d Cir. 2004).

124. *Storar*, 420 N.E.2d at 68-69.

125. *Id.* at 69.

126. *Id.* at 70.

127. *Id.*

128. *Id.* at 73.

129. *Id.* at 69.

130. *Id.*

131. *Id.* at 73 (footnote omitted).

132. *Id.*

133. *Id.*

134. *Id.* at 69.

135. *Id.* at 73 (“Mentally John Storar was an infant and that is the only realistic way to assess his rights in this litigation.”).

136. See *id.* at 73.

2. Pulling at Tubes: *Hier* and *O'Brien*

Mary Hier was a ninety-two year old woman with mental illness and an obstructed esophagus who had a surgically implanted abdominal feeding tube to provide her with nutrition.¹³⁷ Hier repeatedly pulled out the feeding tube.¹³⁸ Reinsertion, unless performed promptly, required surgery.¹³⁹ Two of three doctors did not want to perform the surgery after she had pulled out the tube several times in one week,¹⁴⁰ and the lower court agreed.¹⁴¹ Hier could not speak, but she could gesture and shake her head no.¹⁴² The court gave great weight to her expressions of opposition, even though she was incompetent.¹⁴³ Applying the substitute judgment doctrine "focuses attention on, and requires giving weight to, the subjective wishes of the incompetent patient."¹⁴⁴

In contrast, a New York Court in *In re O'Brien*¹⁴⁵ refused to see the pulling out of a naso-gastric tube as evidence of a subjective refusal of treatment.¹⁴⁶ Thomas O'Brien was an eighty-three year old formerly competent priest disabled by a stroke which left him bedridden, incompetent, and incapable of speech.¹⁴⁷ While O'Brien was a formerly competent person, the court made no finding of any wishes made while competent and so analyzed the case from the same perspective as a never-competent patient.¹⁴⁸ After he attempted to pull out a naso-gastric feeding tube at least fifteen times, he expressed irritation at the abdominal tube inserted to replace it.¹⁴⁹ However, the court did not see these actions as evidence of a desire to refuse treatment.¹⁵⁰ "This court is not prepared to order discontinuance of this life support based upon gestures of irritation or

137. *In re Hier*, 464 N.E.2d 959, 960 (Mass. App. Ct. 1984) (finding that Hier suffered from a hiatal hernia and a large cervical diverticulum which together prevented her from ingesting food orally).

138. *Id.*

139. *Id.*

140. *Id.* at 961.

141. *Id.* at 960.

142. *Id.* at 961 n.3.

143. *Id.* at 965 ("[H]er opposition to surgery all may be seen as a plea for privacy and personal dignity by a ninety-two year old person who is seriously ill and for whom life has little left to offer.").

144. *Id.* A contrasting story is put forward by George Annas who reported that Hier was in fact fully conscious, and merely lonely and dissatisfied with her new surroundings. Annas reported that Hier regularly stole food from other patients, that she derived substantial satisfaction from life (she believed she was the Queen of England), and that one of the physicians who recommended against the surgery stated that he felt Hier had consumed enough of the state's resources. Dresser, *supra* note 71, at 655-56 (citing George J. Annas, *The Case of Mary Hier: When Substituted Judgment Becomes Sleight of Hand*, Hastings Ctr. Rep., Aug 1984, at 23-25).

145. 517 N.Y.S.2d 346 (Sup. Ct. N.Y. County 1986).

146. *Id.* at 348.

147. *Id.* at 346-47.

148. *See id.* at 347-48 (citing *In re Storar*, 420 N.E.2d 64 (N.Y. 1981)).

149. *Id.*

150. *Id.*

annoyance. . . . Pain, humiliation and indignity do not of themselves warrant the cessation of life."¹⁵¹

In these two cases similar expressions on the part of the incompetent persons elicited opposite reactions based primarily on quality of life considerations. The *Hier* court considered the patient's resistance and saw that as justification for refusing treatment.¹⁵² In contrast, the New York court set the bar very high for an expression refusing treatment.¹⁵³ Where the Massachusetts court valued dignity over the preservation of life,¹⁵⁴ the New York court put first the interest of the state in preserving the life of the incompetent.¹⁵⁵ Both views directly affected how the courts ultimately viewed the patients' expressions.

3. Verbal Objections: *Ingram*

Opal Ingram was a sixty-six year old woman with dementia who was unable to care for herself but was "alert, [had] fluent speech, and for the most part [was] goal directed."¹⁵⁶ She held the unswerving belief that her throat cancer was caused by a bad heater in her apartment.¹⁵⁷ She faced three treatment options: without treatment she would die within six to eighteen months by strangulation; with radiation therapy she had about a forty percent chance of survival; with throat surgery her survival chance rose to between seventy and eighty percent.¹⁵⁸ Unfortunately, the surgery would have the side effect of removing her voice.¹⁵⁹ Ingram repeatedly expressed opposition to surgery for that reason.¹⁶⁰ While the trial court ordered surgery, the Supreme Court for the State of Washington reversed and Ingram received radiation treatment.¹⁶¹

The Washington Supreme Court applied a substitute judgment standard and considered all the factors outlined in *Saikewicz* but added an additional consideration: the patient's expressed wishes.¹⁶² "[T]he ward's expressed wishes must be given substantial weight, even if made while the ward is incompetent. . . . [H]er opposition to the surgery must be regarded as a strong indicator of what treatment she would choose if competent to do so."¹⁶³ Furthermore, the court must judge the weight of her statements based on how well she understands the problem and choices she faces.¹⁶⁴

151. *Id.* at 348.

152. *See In re Hier*, 464 N.E.2d 959, 965 (Mass. App. Ct. 1984).

153. *See O'Brien*, 517 N.Y.S.2d at 348.

154. *See Hier*, 464 N.E.2d at 965.

155. *See O'Brien*, 517 N.Y.S.2d at 348.

156. *In re Guardianship of Ingram*, 689 P.2d 1363, 1364 (Wash. 1984).

157. *Id.* at 1365.

158. *Id.* at 1366.

159. *Id.* at 1365.

160. *Id.*

161. *Id.* at 1364.

162. *Id.* at 1370.

163. *Id.*

164. *Id.* at 1371.

The intensity of her preference was also a factor in the court's refusal to order the surgery.¹⁶⁵

The obvious difference between *Ingram* and the other cases in this section is that *Ingram* was able to speak. While incompetent, her ability to verbally express her preferences directly to the court gave those preferences more power than the silent physical expressions in *Saikewicz*, *Storar*, *Hier*, and *O'Brien*. It was also relevant that the court found her preference to refuse a treatment which would render her mute to be understandable.¹⁶⁶ In *Ingram*, the individual's personal autonomy was elevated above her strictly objective best interests and the state's interest in preserving her life.¹⁶⁷

D. Statutory Solutions

Sheila Pouliot was a forty-two year old, profoundly retarded woman dependent on others for all basic functions and admitted to the hospital for gastrointestinal bleeding.¹⁶⁸ Pouliot's guardian asked physicians to withhold nutrition, hydration, and antibiotics.¹⁶⁹ The hospital ethics committee decided to provide only palliative care, but then sought legal advice from New York's Attorney General.¹⁷⁰ The Attorney General's Office said that New York law requires clear and convincing evidence of a patient's previously expressed wishes before withholding life-saving treatment.¹⁷¹ Because Pouliot was never competent, there was no clear and convincing evidence of Pouliot's wishes and so the burden was impossible to reach. Therefore, New York law did not authorize anyone to withdraw artificial hydration and nutrition from the never competent.¹⁷² A compromise to provide only artificial hydration resulted in two months of continuing deterioration.¹⁷³ Finally, a series of court moves allowed hydration to be withdrawn pending an appeals court hearing, and Pouliot died three days later.¹⁷⁴

165. *Id.*

166. *See id.* at 1370.

167. *See id.* at 1371-72.

168. *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 186 (N.D.N.Y. 2002), *aff'd* 356 F.3d 348, 352 (2d Cir. 2004). An extensive discussion and analysis of this case, including substantial medical information not contained in the court record, can be found in Ouellette, *supra* note 17, at 13-21.

169. *Blouin*, 213 F. Supp. 2d at 186.

170. *Id.*

171. *Id.* at 192 (citing *In re Storar*, 420 N.E.2d 64 (N.Y. 1981)).

172. *Id.* at 192-93.

173. *Id.* at 187; *see also* Ouellette, *supra* note 17, at 16-17. She spent the last two months of her life curled up in a fetal position; her physician believed she was in significant pain. According to her physician's progress notes, hydration only allowed Pouliot to be kept alive for her body to "consume/eat itself." *Id.*

174. *Blouin*, 213 F. Supp. 2d at 186; *see also* Ouellette, *supra* note 17, at 17-18 (noting that the judge who issued the order to end hydration acknowledged that New York law did not permit the withdrawal of life-sustaining treatment but said, "There's the law, and there's what's right").

Public outrage over the Attorney General's interference in the case led the New York State Legislature to pass the Health Care Decisions Act.¹⁷⁵ The law permits legally appointed guardians for the mentally retarded to have decision-making power that includes end-of-life decisions.¹⁷⁶ They must be based on the patient's best interests and, "when reasonably known or ascertainable with reasonable diligence, on the mentally retarded person's wishes, including moral and religious beliefs."¹⁷⁷ Even after the guardian has been granted the power, a complicated process follows, including having multiple physicians confirm incapacity, and notification provisions for state agencies.¹⁷⁸ The medical condition must be terminal or permanently unconscious, or an irreversible condition that imposes an "extraordinary burden" on a person in light of retardation and expected outcome.¹⁷⁹ The statute adopts a best interest standard for never-competent patients in New York.

Only New York's statute specifically addresses a never-competent population.¹⁸⁰ End-of-life decision making for the never competent in other states often requires analogizing to formerly competent patients who have left no instructions regarding their preferences and made no reliable statements while competent.¹⁸¹ Except for Michigan¹⁸² and Missouri,¹⁸³ all

175. Health Care Decisions Act (HCDA), ch. 500, 2002 N.Y. Sess. Laws 105 (McKinney) (codified at N.Y. Surr. Ct. Proc. Act §§ 1750, 1750-b (McKinney Supp. 2006)); see also Ouellette, *supra* note 17, at 18. Prior to the HCDA, New York statutes that permitted guardians to make medical decisions for the retarded specifically excluded the withdrawal of life-sustaining treatment. N.Y. Mental Hyg. Law § 80.03(a) (McKinney Supp. 2005). The HCDA should not be confused with the Uniform Health Care Decisions Act ("UHCD"), which does not apply specifically to the never competent. See *infra* notes 193-98 and accompanying text.

176. N.Y. Surr. Ct. Proc. Act § 1750-b(1) (providing that decisions a court-authorized guardian can make "may include decisions to withhold or withdraw life-sustaining treatment"). There is some current legal controversy as to whether the statute grants guardians who were appointed prior to the statute's passage power over end-of-life decision making or whether older guardians need to have their authority reexamined and expanded by new court action. See *In re M.B.*, 797 N.Y.S.2d 510 (App. Div. 2005) (denying guardians appointed prior to the statute's effective date from making end-of-life decisions). In 2005, the legislature extended the statute to include incompetent developmentally disabled persons with mental capacities equivalent to the retarded. Act of Oct. 18, 2005, ch. 744, 2005 N.Y. Sess. Laws 1723 (McKinney).

177. N.Y. Surr. Ct. Proc. Act § 1750-b(2)(a). But see *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324, 325, 329 (Sur. Ct. N.Y. County 2004); *supra* Introduction.

178. N.Y. Surr. Ct. Proc. Act § 1750-b(4).

179. *Id.* § 1750-b(4)(b)(ii).

180. *Id.* § 1750. New York's statute only addresses the severely mentally retarded and developmentally disabled, and, presumably, would not apply to the persistently mentally ill.

181. See Ouellette, *supra* note 17, at 7-9.

182. *In re Martin*, 538 N.W.2d 399, 411 (Mich. 1995). While *Martin* held that evidence of a person's statements while competent was necessary for terminating life-sustaining treatment, it stated in dicta that this rule may not apply to patients in persistent vegetative states or in severe pain. *Id.* at 408 n.15.

183. See *Cruzan v. Harmon*, 760 S.W.2d 408, 424-27 (Mo. 1988), *aff'd*, 497 U.S. 261 (1990). Some Missouri intermediate-level courts have held that the limitation only applies to artificial nutrition/hydration. See, e.g., *In re Warren*, 858 S.W.2d 263 (Mo. Ct. App. 1993) (holding that surrogates can issue do-not-resuscitate orders if in the patient's best interest).

states have some statutory or judicial provision for terminating medical treatment for patients who have not expressed a preference while competent.¹⁸⁴ Wisconsin¹⁸⁵ and Hawaii¹⁸⁶ restrict the withdrawal of nutrition and hydration to permanently unconscious patients when those patients have no preferences expressed while competent.

Other state statutes generally permit surrogates to withdraw life-sustaining treatment from the never competent with some exceptions for institutional guardians¹⁸⁷ or children.¹⁸⁸ While these statutes do not specifically address the never competent, they apply them by analogy to the formerly competent who leave no instructions.¹⁸⁹ Many states require the surrogate to go through a series of procedures, generally including review of the case from multiple physicians.¹⁹⁰ A few require that the patient be permanently unconscious or terminally ill.¹⁹¹ Some require the surrogate to be a court-appointed guardian.¹⁹² Generally, many state statutes follow the principles outlined in the influential Uniform Health Care Decisions Act of 1993 ("UHCDA") which the National Conference of Commissioners of Uniform State Laws wrote in reaction to the *Cruzan* decision.¹⁹³

184. See Ouellette, *supra* note 17, at 21-29.

185. See *In re Edna M.F.*, 563 N.W.2d 485, 486 (Wis. 1997) (holding that a "guardian may only direct the withdrawal of life-sustaining medical treatment, including nutrition and hydration, if the incompetent ward is in a persistent vegetative state and the decision to withdraw is in the best interests of the ward").

186. Haw. Rev. Stat. § 327E-5(g) (Supp. 2004) ("[A]rtificial nutrition and hydration may be withheld . . . only when [physicians] certify . . . [that] the patient is highly unlikely to have any neurological response in the future.").

187. Miss. Code Ann. § 41-41-211(9) (Supp. 2005) ("A surrogate may not be an owner, operator, or employee of a residential long-term health-care institution at which the patient is receiving care unless related to the patient by blood, marriage, or adoption, except in the case of a patient of a state-operated facility who has no person listed in subsection (2) reasonably available to act as a surrogate.").

188. See, e.g., Utah Code Ann. § 75-2-1107(1) (2005) (requiring an individual be eighteen years or older before medical services can be terminated). For an excellent overview of statutes on surrogate end-of-life decision making, see Ouellette, *supra* note 17, at 48-55.

189. See Ouellette, *supra* note 17, at 7-8.

190. See, e.g., Iowa Code Ann. § 144A.7 (West 2005); N.Y. Surr. Ct. Proc. Act § 1750-b(4)(a) (McKinney Supp. 2006).

191. See, e.g., Haw. Rev. Stat. § 327E-5(g) ("[A]rtificial nutrition and hydration may be withheld . . . only when [physicians] certify . . . [that] the patient is highly unlikely to have any neurological response in the future."); Ohio Rev. Code Ann. § 2133.09(C)(2)(a) (LexisNexis 2002) (requiring the patient to be in a permanently unconscious state for at least a year).

192. See, e.g., Ariz. Rev. Stat. Ann. § 36-3231 (2003) (stating that a surrogate may not direct a physician to withdraw or withhold life-sustaining nutrition or hydration, unless the surrogate is the patient's agent or guardian); N.Y. Surr. Ct. Proc. Act § 1750-b(1); Vt. Stat. Ann. tit. 14, §§ 3069(5), 3075 (2002).

193. Unif. Health-Care Decisions Act (1993), 9 U.L.A. 83 (2005). While the UHCDA has only been enacted by eight states (Alabama, Alaska, Delaware, Hawaii, Maine, Mississippi, New Mexico, and Wyoming), its provisions are still generally typical of state statutory schemes. See Nat'l Conference of Comm'rs on Unif. State Laws, Health-Care Decisions Act Legislative Fact Sheet, http://www.nccusl.org/Update/uniformact_factsheets/uniformacts-fs-uhcda.asp (last visited Mar. 9, 2006).

The UHCDA permits competent individuals to appoint agents through a written advanced directive which would include instructions on the writer's preferences regarding end-of-life medical decisions.¹⁹⁴ The agent could make decisions for the incompetent patient without court action.¹⁹⁵ In the absence of a directive, the UHCDA grants surrogate decision-making power to a family member or close friend in the order of listed preference.¹⁹⁶ These decisions are made under a best interest standard with the surrogate required to consider any known information regarding the incompetent's values.¹⁹⁷ Decisions can be made without judicial approval, and the UHCDA imposes no limitation on making end-of-life decisions.¹⁹⁸

In many states, therefore, surrogates have wide-ranging powers to act in making end-of-life decisions for never-competent individuals without court intervention. The next part outlines arguments regarding the powers these surrogates should have in end-of-life medical decisions, particularly in cases where they may be overriding a person's expressed preference for or against treatment.

II. COMPETING VISIONS OF THE PROBLEM: ARGUMENTS FOR STRONG AND WEAK SURROGATE DECISION MAKERS

Decisions regarding end-of-life care are ultimately made for the never competent by surrogate decision makers, whether they are relatives, legally appointed guardians, or guardians ad litem.¹⁹⁹ Overriding the expressed preferences of the never competent in such matters as financial planning or routine medical procedures may be indicated by the need to protect the interests of the never competent.²⁰⁰ However, when the decision involves an end-of-life medical decision that could result in the never competent's death, how much power should surrogates have?

This part focuses on the arguments put forth by courts, litigants, and commentators regarding the amount of power surrogates should have to overcome the expressed preferences of the never competent regarding end-of-life medical decision making. Part II.A begins with the argument that only a strong guardian can adequately protect the never competent's best interests and prevent unnecessary suffering. Then Part II.B presents arguments for limiting the authority of surrogates to override the expressed

194. Unif. Health-Care Decisions Act § 2, 9 U.L.A. 93-94.

195. *Id.* § 2(f).

196. *Id.* § 5. The order is spouse, adult child, parent, adult sibling, or "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available." *Id.* § 5(b), (c). Operators or employees of health care institutions where an unrelated incompetent person lives cannot be agents under the act. *Id.* § 5(i).

197. *Id.* § 5(f). The UHCDA does not outline what factors should go into a best interests consideration, leaving that to the consideration of individual states. *Id.* § 2(e).

198. *Id.* § 5(g).

199. See Cantor, *supra* note 75, at 155-56.

200. See Dresser, *supra* note 71, at 636-37.

preferences of never competent in end-of-life medical decisions out of respect for their autonomy and to protect them from abuse.

A. *The Strong Guardian Model*

Advocates for a strong guardian model argue that the rights and interests of the never competent can only be protected by a strong guardian.²⁰¹ Furthermore, guardians are already bound to express the interests of the ward; any expressed preferences of the ward are therefore taken into account by a strong guardian.²⁰² Also, it is entirely appropriate to hold the expressions of wards to a higher standard of competence when they seek to act against expert medical advice.²⁰³ Finally, granting too much power to the expressions of never-competent persons invites outside parties to manipulate vulnerable persons into expressing preferences that are against their best interests.²⁰⁴

1. The Necessity of Surrogate Action to Realize the Constitutional Rights of Incompetent Patients

The strong guardian argument is premised on the never competent having the same rights of patient autonomy that competent patients have, but finding that those rights are meaningless unless exercised by a surrogate.²⁰⁵ Limiting the powers of the guardian only serves to deny the ward the same constitutional rights that formerly competent patients have.²⁰⁶ While a formerly competent patient can exercise her constitutional right to refuse unwanted medical treatment by designating a proxy to make those decisions, a never-competent patient never has the power to designate such a proxy.²⁰⁷ Limiting surrogate power can result in situations where withholding medical treatment from a never-competent person is impossible because she was never competent to refuse it.²⁰⁸ Proponents of the strong guardian approach believe that the case of Sheila Pouliot²⁰⁹ and

201. See *infra* Part II.A.1.

202. See *infra* Part II.A.2.

203. See *infra* Part II.A.3.

204. See *infra* Part II.A.4.

205. A major proponent of this reasoning is Norman Cantor, a law professor at Rutgers University School of Law. See Cantor, *supra* note 63. Cantor also assisted the guardian's attorney in *Chantel R.* Memorandum in Opposition to the Motion to Deny Petitioner the Authority to Withhold or Withdraw Life-Sustaining Treatment at 1, *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324 (Sur. Ct. N.Y. County 2004) (No. 528/03) [hereinafter Cantor Memo]; see also *Thompson v. Oklahoma*, 487 U.S. 815, 825 n.23 (1988) (stating in dicta that rights have meaning when exercised by a surrogate).

206. See *In re Guardianship of Grant*, 747 P.2d 445, 449 (Wash. 1987); Cantor, *supra* note 63, at 33-68; see also John H. Garvey, *Freedom and Choice in Constitutional Law*, 94 Harv. L. Rev. 1756 (1981).

207. See Cantor, *supra* note 75, at 158.

208. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 192 (N.D.N.Y. 2002), *aff'd* 356 F.3d 348, 359 (2d Cir. 2004) (interpreting New York law as refusing guardians the right to make end-of-life decisions for the never competent).

209. See *supra* notes 168-74 and accompanying text.

the state of the law in New York State prior to the passage of Surrogate's Court Procedure Act section 1750(b) illustrate the harsh outcome when medical treatment is forced upon a suffering patient.²¹⁰ A guardian-focused argument attempting to limit the power of guardians to make decisions only violates the rights of their wards who may now be prevented from exercising those rights.²¹¹

2. A Guardian's Duties to a Ward: The Best Interest Doctrine

Under the strong guardian argument, the issue of unreasoned expressions on the part of the never-competent ward is not a problem because the guardian is bound to consider the statements of the ward.²¹² No new judicial decision or statute is necessary as the guardian is required to distinguish between reasoned and unreasoned expressions of the ward.²¹³ The relationship between guardian and ward is one of loyalty; the guardian is generally expected to honor the expressed wishes of the ward.²¹⁴ It is the guardian's responsibility to make the determination of the ward's best interests, and any statements by the ward will be one factor among many that are considered.²¹⁵

3. Assent and Dissent—The Importance of Following Medically Preferred Courses of Action

Some argue that a more physician-centered approach is appropriate for end-of-life medical decision making.²¹⁶ Courts should accept the truth that

210. See *supra* notes 168-74 and accompanying text; see also Ouellette, *supra* note 17, at 18-21. Pouliot spent the last two months of her life curled in a fetal position, and her physician believed she was in significant pain. According to her physician's progress notes, hydration only allowed Pouliot to be kept alive for her body to "consume/eat itself." All of this happened because, as a never-competent person, she could never prove she would not wish this to happen to her. *Id.* at 16-17.

211. See *In re Grady*, 426 A.2d 467, 481 (N.J. 1981) ("We do not pretend that the choice . . . is her own choice. But it is a genuine choice nevertheless. . . . We believe that having the choice made in her behalf produces a more just and compassionate result than leaving Lee Ann with no way of exercising a constitutional right."); Norman L. Cantor, *The Relation Between Autonomy-Based Rights and Profoundly Mentally Disabled Persons*, 13 Ann. Health L. 37, 56-57 (2004).

212. N.Y. Surr. Ct. Proc. Act § 1750-b(2)(c), (4) (McKinney Supp. 2006); see also N.Y. Mental Hyg. Law § 81.20(a) (McKinney 1996) (requiring that (1) "a guardian shall exercise the utmost care and diligence when acting on behalf of the incapacitated person; [and (2)] a guardian shall exhibit the utmost degree of trust, loyalty and fidelity in relation to the incapacitated person").

213. N.Y. Surr. Ct. Proc. Act § 1750-b(2)(c), (4); see also Cantor Memo, *supra* note 205, at 16-17.

214. See N.Y. Mental Hyg. Law § 81.20(a)(3); 39 Am. Jur. 2d. *Guardian & Ward* § 1 (2004) ("A guardianship is a trust relation of the most sacred character, in which one person, called a 'guardian,' acts for another, called the 'ward,' whom the law regards as incapable of managing his or her own affairs.").

215. See Cantor Memo, *supra* note 205, at 17.

216. See Winick, *supra* note 34, at 43-44. Winick argues,

competence decisions are essentially subjective: Decisions made by individuals that are congruent to those preferred by physicians and guardians are not generally tested for competence.²¹⁷ Unless there is gross evidence of incompetence, a patient's capacity will not be challenged.²¹⁸ However, when an individual wishes to take an action that is against medical advice, courts will hold him to the standard of informed consent and probably attack his competency.²¹⁹ Physicians are not only ethically bound to the best interests of their patients,²²⁰ but they are also in the best position to evaluate these interests.²²¹ Therefore, it is appropriate to require the expressed preferences of mentally retarded patients to meet a higher standard of competency when they conflict with medical advice.²²² When a patient is never competent, a strong guardian can help ensure that decisions are made based on the best medical advice.

4. Protecting the Never Competent from Manipulation

The strong guardian approach assumes that granting preference to the statements of mentally retarded individuals who are adjudicated incompetent exposes them to abuse and manipulation.²²³ A minimally skilled interviewer can phrase a question to get a preferred answer from a mentally retarded person.²²⁴ Outside parties opposed to the guardian's viewpoint may be able to interfere with important medical decisions. Indeed, never-competent individuals typically live in inherently coercive environments.²²⁵ Giving the never competent's expressed answers legal

When the competing values at stake are respect for autonomy and a desire to act in the best interests of the individual's health, the competency question should turn on an assessment of the degree of autonomy present and the risk/benefit ratio of the therapeutic intervention involved. Thus, while a patient should be allowed to choose conventional treatment without demonstrating a high degree of competency, a greater showing of competency is appropriate when the intervention chosen is of questionable value and carries great risk.

Id.

217. *Id.* at 25-26; see also Milton D. Green, *Proof of Mental Incompetency and the Unexpressed Major Premise*, 53 Yale L.J. 271, 306-07 (1944) (suggesting that judges find competence when the subject makes a decision they agree with and incompetence when the subject makes the "wrong" decision).

218. See Winick, *supra* note 34, at 34.

219. See *id.*

220. See *Washington v. Harper*, 494 U.S. 210, 222 n.8 (1990).

221. See Winick, *supra* note 34, at 32.

222. See *id.* at 43-44.

223. Cantor Memo, *supra* note 205, at 17-18; see also Cantor, *supra* note 63, at 212 ("A high potential exists for eliciting expressions from the patient—however uncomprehending—that are favored by the surrogate decisionmaker or medical staff."); President's Commission: Consent, *supra* note 39, at 67 (finding that even competent patients can have their consent extracted by the skillful presentation of information by their physician).

224. See Cantor Memo, *supra* note 205, at 17-18.

225. See James W. Ellis, *Decisions by and for People with Mental Retardation: Balancing Considerations of Autonomy and Protection*, 37 Vill. L. Rev. 1779 (1992). Ellis observes,

weight may violate the responsibility of the state to protect them from harm.²²⁶

Furthermore, expressions of incompetent patients are often difficult to interpret.²²⁷ Expressions such as moaning, pulling at tubes, resisting needles, and noncooperation with medical treatment may simply reflect discomfort or confusion instead of opposition to treatment.²²⁸ The recent *Schiavo* case is directly on point.²²⁹ While the court and numerous physicians found Terri Schiavo to be in a persistent vegetative state and incapable of cognition, representatives of her parents, who objected to the withdrawal of nutrition and hydration, interpreted many of her actions as responses to their words and presence.²³⁰ Evidence of this interpretation

People with mental retardation often believe, accurately for the most part, that, as a practical matter, they must obtain "permission" from nondisabled individuals to do things that no other adults in society must obtain permission to do. Both people with mental retardation and nondisabled individuals who deal with them on a regular basis assume that such authority is natural, necessary and appropriate.

Id. at 1802.

226. *See id.* at 1809; *see also In re Martin*, 538 N.W.2d 399, 408 (Mich. 1995) (describing *parens patriae* power as the state's obligation to protect defenseless individuals); *In re Grady*, 426 A.2d 467, 479-80 (N.J. 1981).

227. Cantor, *supra* note 63, at 211.

228. *Id.*; *see also Dresser, supra* note 71, at 654-55 (discussing court interpretations of noncooperative patients with mental disabilities). The dramatic variations in interpretation of John Storar's behavior by the majority and dissent in *In re Storar*, 420 N.E.2d 64 (N.Y. 1981), are instructive. The majority found that noncooperation was simply a product of discomfort and that treatment "did not involve excessive pain" and following treatment he returned to normal activity. *Id.* at 73. Judge Hugh Jones, in a dissenting opinion, found that his condition, inoperable bladder cancer, carried tremendous pain generally and that following the treatments he "ventured outside his room infrequently," and the transfusions created frequent clotting in his urine making urination painful. *Id.* at 78 (Jones, J., dissenting).

229. *Schindler v. Schiavo*, 358 F. Supp. 2d 1161 (M.D. Fla.), *aff'd*, 403 F.3d 1289 (11th Cir.), *stay denied*, 125 S. Ct. 1722 (2005) (reviewing a request for injunction from jurisdiction granted by Pub L. No. 109-3, 119 Stat. 15 (2005)); *see also In re Schiavo*, No. 90-2908GD-003, 2000 WL 34546715 (Fla. Cir. Ct. Pinellas County Feb. 11, 2000), *aff'd*, 780 So. 2d 176 (Fla. Dist. Ct. App. 2001), *rev. denied*, 789 So. 2d 348 (Fla. 2001) (finding that there was clear and convincing evidence from the original trial that Terri Schiavo would decline life-sustaining treatment while in a persistent vegetative state).

230. *See* Brief for Plaintiff-Appellant at Exhibit 7, *Schiavo*, 403 F.3d 1289 (No. 05-11556) (March 22, 2005, Declaration of Robert Schindler), *available at* <http://www.miami.edu/ethics/schiavo/032205%20Schindlers%2011%20Cir%20App%20Exhibits.pdf>. Robert Schindler, Terri Schiavo's father, observed,

5. For the first few days after the feeding tube was removed, Terri continued to interact and respond to me with verbalizations and smiles. She continued to look well.

6. In the early morning hours of March 21, 2005, immediately after Congress passed a bill permitting Terri to protect her rights in federal court, Terri was still looking relatively well. When I told Terri she would be soon taken out of the hospice to have breakfast, she appeared to comprehend what I said and responded to me with a smile.

Id. For a comprehensive timeline and collection of documents related to the *Schiavo* case, *see* Kathy L. Cerminara & Kenneth W. Goodman, Key Events in the Case of Theresa Marie Schiavo, *available at* <http://www.miami.edu/ethics/schiavo/timeline.htm> (last visited Mar. 27, 2006).

was circulated in the media through an edited videotape.²³¹ The expressions and statements of incompetent individuals are usually, by their very nature, difficult or impossible to interpret.²³² Therefore, never-competent individuals must have a strong guardian to prevent manipulated or poorly interpreted statements from disrupting the application of the individual's best interests.

B. *The Weak Guardian Model*

The principle of patient autonomy underlying the jurisprudence of end-of-life decision making may require that surrogates defer their decisions to the expressed statements of patients, even if incompetent.

This section will look at three arguments for limiting the power of surrogate decision makers to overcome the expressed intentions of never-competent patients: a constitutional equal protection argument for treating the statements of the never competent under the same standard as able-bodied persons,²³³ the fundamental autonomy of the never competent,²³⁴ and case law rules on the standards necessary for terminating life sustaining treatment and the presumption in favor of life.²³⁵

1. The Right of Incompetents to Equal Protection

Holding the statements of the never competent to the standard of informed consent in situations where the same statements by the competent or formerly competent would not be held to that standard violates the principle of equal protection.²³⁶ When a competent person executes an advance directive indicating that he wants all measures taken to preserve his life, no inquiry into the rationality of the statement is made.²³⁷ The level of cognitive functioning necessary for informed consent is not a requirement.²³⁸ But when a never-competent person makes the same statement, he is held to the standard of informed consent.²³⁹ Requiring informed consent only from the mentally retarded (or other never-competent patients) creates a different standard of decision making involving a life and death decision.²⁴⁰

231. See Timothy E. Quill, *Terri Schiavo—A Tragedy Compounded*, 352 New Eng. J. Med. 1630 (2005) (noting the misinterpretation of a patient in a persistent vegetative state from a highly edited videotape).

232. See Cantor, *supra* note 63, at 211; Quill, *supra* note 231, at 1630.

233. See *infra* Part II.B.1.

234. See *infra* Part II.B.2.

235. See *infra* Part II.B.3.

236. Notice of Motion to Deny Petitioner the Authority to Withhold or Withdraw Life-Sustaining Treatment at 10-11, *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324 (Sur. Ct. N.Y. County 2004) (No. 03-528) [hereinafter Chantel Notice of Motion].

237. See *Chantel R.*, 791 N.Y.S.2d at 329.

238. See *id.* (finding that a competent person is free to make "emotional or irrational decisions" concerning medical treatment).

239. See *id.*; Chantel Notice of Motion, *supra* note 236, at 10-11.

240. See Chantel Notice of Motion, *supra* note 236, at 11.

Similarly, when an incompetent patient has an advance directive made while competent, he is free to revoke it without the necessity of competence.²⁴¹ Many state statutory schemes allow formerly competent patients to revoke an advanced directive that would permit withholding end-of-life treatment.²⁴² These statutes allow the revocations even by persons adjudicated incompetent without having to prove their competence.²⁴³ The incompetent person must merely demonstrate a desire for treatment.²⁴⁴ These statements are not held to the higher standard of informed consent.²⁴⁵

There is no rational basis for according the statements of a formerly competent person less weight than a never-competent person.²⁴⁶ Without such a basis, dismissing a life-affirming expression by a never-competent person based on the decision of a strong guardian violates the Equal Protection Clause of the Fourteenth Amendment.²⁴⁷

2. Greater Autonomy for Incompetent Persons and the Downside of Surrogate Decision Making

Some argue for substantially more autonomy for the never competent.²⁴⁸ There are substantial reasons for doubting the ability of surrogate decision makers to ascertain the best interests of never-competent patients. The emotional connections of family members can be a dangerous element for

241. See, e.g., Ga. Code Ann. § 31-36-5(c) (2001) (stating that agents cannot override a patient's knowing decision, even if the patient has been adjudicated incompetent); *In re Guardianship of Ingram*, 689 P.2d 1363, 1370 (Wash. 1984) ("[T]he ward's expressed wishes must be given substantial weight, even if made while the ward is incompetent."); Unif. Health-Care Decisions Act § 3(b) (1993), 9 U.L.A. 98 (2005) (indicating no explicit competency requirement and no writing requirement for revocation of an advanced directive).

242. See Thomas J. Marzen & Daniel Avila, *Will the Real Michael Martin Please Speak Up! Medical Decisionmaking for Questionably Competent Persons*, 72 U. Det. Mercy L. Rev. 833, 852-54 (1995) ("A majority of these laws permit an individual to revoke an advanced directive refusing life-sustaining treatment even when the individual is not legally competent and by means considerably less formal than those required to execute the advance directive."); see also Unif. Health-Care Decisions Act § 3(b), 9 U.L.A. 98.

243. Unif. Rights of the Terminally Ill Act § 4(a) (1989), 9C U.L.A. 324 (2001) ("A declarant may revoke a declaration at any time and in any manner, without regard to the declarant's mental or physical condition. A revocation is effective upon its communication to the attending physician or other health-care provider by the declarant or a witness to the revocation."); Marzen & Avila, *supra* note 242, at 852 n.79 (citing the statutes of twenty-eight states and the District of Columbia that expressly permit revocations by incompetent patients).

244. Marzen & Avila, *supra* note 242, at 854.

245. See *Ingram*, 689 P.2d at 1371 ("[The] court need not place on any party any particular burden of proof or persuasion.")

246. Chantel Notice of Motion, *supra* note 236, at 11; see also *Francis S. v. Stone*, 221 F.3d 100, 111 (2d Cir. 2000) (applying an intermediate level of scrutiny to classifications based on mental illness).

247. See Chantel Notice of Motion, *supra* note 236, at 11; see also *Francis S.*, 221 F.3d at 111.

248. See *Field & Sanchez*, *supra* note 1; see also Martha A. Field, *Killing "The Handicapped"—Before and After Birth*, 16 Harv. Women's L.J. 79 (1993).

an incompetent person.²⁴⁹ Also, able-bodied persons cannot understand the subjective experience of the mentally disabled; the personal fears and prejudices of the able-bodied often interfere with their decision making.²⁵⁰ Surrogates or other actors with a vitalist ideology may force unwanted treatment on a never-competent patient.²⁵¹ How can an able-bodied individual know what is in the best interests of a disabled one?²⁵²

Applying a best interest analysis to incompetent persons is to impose normative views on what constitutes quality of life.²⁵³ These views may include concepts like "dignity" which have little meaning to the experience of incompetent persons.²⁵⁴ Some suggest that best interest calculations include the interests of third parties.²⁵⁵ A traditional best interest standard is better left to situations involving financial matters where best interest

249. See James Bopp, Jr. & Richard E. Coleson, *A Critique of Family Members as Proxy Decisionmakers Without Legal Limits*, 12 Issues L. & Med. 133, 143-46 (1996). Bopp outlines several problems with family members as surrogate decision makers. "[T]here is no generally applicable legal presumption that parents automatically become the decisionmakers for their incompetent adult children." *Id.* at 140. "Emotional reactions such as shock, denial, anger, and guilt . . . may prove disastrous in the decision making process." *Id.* at 143. Family members may feel resentful of the incompetent patient, they may seek the quickest route free of an emotionally difficult situation, or they may insist on inappropriate treatment out of feelings of guilt. *Id.* at 145-46. The incompetent may be a drain on the financial and emotional resources of the family. *Id.* at 149. Bopp cites studies which indicate that families are very poor predictors of the treatment preferences of their relatives. *Id.* at 149-50. One study indicated that the predictions of doctors or family members of an elderly individual's preference for a do-not-resuscitate order, "did not exceed that of pure chance." *Id.* at 150 (quoting Dallas M. High, *A New Myth About Families of Older People?*, 31 *Gerontologist* 611, 613 (1991)).

250. See Dresser, *supra* note 71, at 618-66 (arguing that individuals project their own fears of death and disability onto incompetent patients).

251. See Ouellette, *supra* note 17; see also Schindler v. Schiavo, 358 F. Supp. 2d 1161 (M.D. Fla.), *aff'd*, 403 F.3d 1289 (11th Cir.), *stay denied*, 125 S. Ct. 1722 (2005) (denying the appeal of the family seeking to continue treatment despite a lower court finding that the patient would not wish to be kept alive in a persistent vegetative state).

252. For a general discussion of what factors can (or should) go into a best interest evaluation, see Cantor, *supra* note 75.

253. See Bopp & Coleson, *supra* note 249, at 161 ("It is discriminatory for any person other than a competent individual him- or herself to pass judgment on his or her quality of life for the purpose of deciding whether or not that person should have medical treatment. If such discrimination is done under color of state law against incompetent persons, it is likely unconstitutional under the due process clause.").

254. See Dresser, *supra* note 71, at 659 ("[I]f relatively sophisticated concerns such as dignity and privacy are deemed to justify nontreatment, then it seems that the vast majority of mentally impaired patients' lives will be placed in jeopardy."); see also Field & Sanchez, *supra* note 1. But see Cantor, *supra* note 75, at 171-75, 178 (arguing that the never competent have intrinsic human dignity even if they could never ascertain it).

255. See Cantor, *supra* note 75, at 192-204 (suggesting that third-party needs can effect medical decisions for incompetent patients in marginal cases, specifically in cases of permanent unconsciousness); John Hardwig, *The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions*, 1992 *Utah L. Rev.* 803, 809 (arguing that family members' interests are defensible and that an exclusive patient-centered ethics should be abandoned).

calculations can be made.²⁵⁶ The law should not apply the standard to incompetent patients whose interests cannot be so easily measured.²⁵⁷

3. The Presumption in Favor of Life: Applying End-of-Life Evidentiary Standards to the Never Competent

Overriding a life-affirming statement by a never-competent person substantially conflicts with case law at the national and state levels.²⁵⁸ Numerous states and the Supreme Court have endorsed a clear and convincing evidence standard for the withdrawal of life-sustaining treatment.²⁵⁹ It can therefore be inferred that any expression to the contrary would make it difficult to reach the clear and convincing standard.²⁶⁰ Courts have also held that when evidence of intent is equivocal it is best to err in favor of preserving life.²⁶¹

The surrogate's court in *Chantel R.* sought to get around this problem by erasing Chantel's life-affirming statement by declaring her incompetent.²⁶² This creates a competence trap for the never-competent patient.²⁶³ While guardians may be obligated to take into account the wishes of their wards, because the wards are adjudicated incompetent, their wishes have no weight.²⁶⁴ This problem existed in *R.H.*, where, because R.H. was adjudicated incompetent, the court interviewed the guardian ad litem, physicians, and family members, but never the incompetent ward herself.²⁶⁵ Any statement the ward makes that contradicts her best interests, as perceived by the guardian, is simply further evidence of incompetence.²⁶⁶

The major criticism of the surrogate decision-making process made by proponents of limiting that power is the arbitrary and often inappropriate standards brought to best interests calculations.²⁶⁷ Issues like dignity, quality of life, and privacy are distinctly normative and very difficult for an

256. See Welch, *supra* note 38, at 1634-35.

257. See *id.* But see Dresser, *supra* note 71, at 691-99. Dresser suggests that more can be done to ascertain the experiential reality of incompetent patients, specifically patients with dementia. "Although we must be careful and cautious, uncertainty about a patient's mental experiences should not lead to their exclusion from the treatment calculation." *Id.* at 698.

258. See Chantel Notice of Motion, *supra* note 236, at 8-10; see also *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 286-87 (1990); *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985); *In re O'Connor*, 531 N.E.2d 607, 613 (N.Y. 1988).

259. *Cruzan*, 497 U.S. at 286-87; *Rasmussen ex rel. Mitchell v. Fleming*, 741 P.2d 674, 691 (Ariz. 1987); *In re Browning*, 568 So. 2d 4, 16 (Fla. 1990); *O'Connor*, 531 N.E.2d at 613.

260. *O'Connor*, 531 N.E.2d at 613 (holding that the proponent of ending treatment must show that the preference for refusing treatment was strong enough to rebut any presumption that the person would change her mind).

261. See *Cruzan*, 497 U.S. at 283; *Conroy*, 486 A.2d at 1231.

262. *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324, 332 (Sur. Ct. N.Y. County 2004).

263. See *id.*

264. See *id.*

265. *In re R.H.*, 622 N.E.2d 1071, 1077-78 (Mass. App. Ct. 1993).

266. *Chantel R.*, 791 N.Y.S.2d at 326.

267. See *supra* Part II.B.2.

able-bodied surrogate decision maker to accurately bring to bear on the lived experience of the never competent.²⁶⁸ While surrogate and guardian statutes and case law often have clauses requiring guardians to ascertain the preferences of the ward, these preferences are often erased by simply asserting that because the preference is expressed incompetently, it should be ignored.²⁶⁹

In Part III this Note will attempt to synthesize the perspectives expressed in Part II and focus on these ideas from the perspective of the individual autonomy of the never competent.

III. GRANTING NEVER-COMPETENT PATIENTS FULL AUTONOMY THROUGH GUARDIAN DECISION MAKING

This part argues that while a strong guardian is ultimately necessary to protect the rights of never-competent persons, neither the strong guardian's duty of loyalty nor the requirements to find the ward's best interests adequately protect the fundamental autonomous rights of the never competent to have their expressed preferences considered. Instead, statutory language should require surrogates to begin their determination of a never-competent patient's best interests with an evaluation of that patient's expressed preferences. This patient-centered approach keeps the strong guardian model's protection from indecision while maintaining the safeguards for patient autonomy inherent in the weak guardian model.²⁷⁰

A. Fulfilling the Promise of Autonomy Through a Patient-Centered Approach

The analysis for determining end-of-life medical decisions for the never competent should begin with evaluating the patient's preferences. Rather than starting with a determination of the never-competent patient's best interests, the surrogate must start by seeking evidence of the never-competent patient's expressed preferences for treatment or nontreatment. The surrogate can look to both verbal and nonverbal expressions such as hostility to treatment or improved mood or activity following treatment.²⁷¹ If an expressed preference is ascertained, the surrogate can then compare that preference with a best interest analysis.²⁷² A surrogate should not be able to override that preference unless there is clear evidence that no reasonable person would choose that course of action. The surrogate nevertheless retains the authority to make any decisions necessary for the never-competent individual.²⁷³

268. See *supra* Part II.B.2.

269. See *supra* Part II.B.3.

270. Compare *supra* Part II.A with *supra* Part II.B.

271. See *supra* Part I.C.

272. See *supra* Part I.B.2.

273. See *supra* Part II.A.1.

The perspective on incompetence needs to shift. A finding of incompetence is not a mechanism to erase the autonomy of the incompetent. It is simply a finding that a person needs assistance in making critical decisions.²⁷⁴ Any expressed preference of a never-competent patient should be the starting point of the inquiry into his best interests, not just a stop along the way.²⁷⁵ If a patient's expressed preference is life affirming, it is hard to see how his best interests can be served in denying him treatment, irrespective of what a "reasonable person" would do in the same situation.²⁷⁶ If a never-competent patient expresses a preference to refuse life-sustaining treatment, then a surrogate should be able to make an inquiry into whether a competent person in his situation could reasonably make that choice. The surrogate, however, must make a serious attempt to understand the never-competent individual's specific situation and his expressed preferences.²⁷⁷

This proposal grants verbal never-competent patients, such as Chantel R., real autonomy and favors their preferences regarding end-of-life medical decisions rather than simply dismissing and silencing them.²⁷⁸ Courts that examine cases such as *R.H.*, where the decision to refuse treatment was made without asking the preferences of the adult patient with Down's Syndrome, should begin by asking about the patient's preferences.²⁷⁹

While this patient-centered approach would not necessarily alter the outcome of cases involving severely impaired nonverbal individuals such as Saikewicz²⁸⁰ or Storar,²⁸¹ it would force the courts to explicitly deal with patients' expressed preferences in conducting their analysis. While severely impaired individuals will often express annoyance at any medical procedure, one can look to other actions in ascertaining their preferences for or against treatment.²⁸² Courts could look to life-affirming expressions such as renewed energy following treatments and other measures of overall well-being.²⁸³

This patient-centered analysis may yield similar results to the strong guardian approach, yet the tenor of the analysis will change.²⁸⁴ The inquiry

274. See *supra* notes 34-39 and accompanying text.

275. Cf. N.Y. Surr. Ct. Proc. Act § 1750-b(2)(a) (McKinney Supp. 2006) ("The guardian shall base all advocacy and health care decision making solely and exclusively on the best interests of the mentally retarded person and, when reasonably known or ascertainable with reasonable diligence, on the mentally retarded person's wishes, including moral and religious beliefs.").

276. See *supra* Part II.B.3.

277. See Dresser, *supra* note 71, at 698.

278. See *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324, 329 (Sur. Ct. N.Y. County 2004); *supra* Part I.

279. See *In re R.H.*, 622 N.E.2d 1071, 1077 (Mass. App. Ct. 1993); *supra* Part I.

280. Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417 (Mass. 1977).

281. *In re Storar*, 420 N.E.2d 64 (N.Y. 1981).

282. *Id.* at 69; see *supra* Part I.C.1

283. See *Storar*, 420 N.E.2d at 69.

284. See *supra* Part II.A.

and the analysis centers on the expressed preferences of the patient whose life is so profoundly affected by the surrogate's decision. This analysis will offer dignity and respect to the never competent, and help their families and guardians come to terms with their treatment. It also fully realizes the principle of patient autonomy that is the basis of end-of-life medical decision making for all persons, competent or not.²⁸⁵

Legislators need to bring the principles of patient autonomy to end-of-life decision making for the never competent. This can only be done by making the inquiry into any expressed preferences of the never competent the starting point for the analysis of their best interests. The never competent and their surrogates deserve to have their decisions afforded the consistent application of legal principles.²⁸⁶ By making the never competent's wishes the starting point for end-of-life medical decision making, legislators and courts can fulfill the principle of patient autonomy for everyone.²⁸⁷

B. *The Patient-Centered Approach and the Strengths of the Weak Guardian Model*

The arguments for the weak guardian model support this proposal.²⁸⁸ By focusing on the never competent's expressed preferences, the proposal grants equal protection to never-competent persons by giving them a voice in medical decision making.²⁸⁹ When making end-of-life medical decisions for formerly competent patients, surrogates must inquire into their expressed preferences prior to incompetence.²⁹⁰ Requiring an inquiry into the preferences of the never competent grants them a similar voice in these critical decisions.

By requiring surrogates to begin their analysis with a never competent's expressed preference, a patient-centered approach addresses the problem of surrogates whose interests diverge from those of the patients.²⁹¹ While the problem cannot be entirely solved without stripping surrogates of the power needed to fulfill the rights of never-competent individuals,²⁹² it does focus the attention of the surrogate on the never competent's expression. This will require the surrogate to focus on the subjective experience of the never competent and discourage the imposition of the surrogate's normative views.²⁹³

Finally, by encouraging surrogates to respect any life-affirming expressions by the never competent, the proposal conforms to the presumption in favor of life found in the case law surrounding end-of-life

285. See *supra* Part I.A.

286. See *supra* Part II.B.1.

287. See *supra* Part I.A.

288. See *supra* Part II.B.

289. See *supra* Part II.B.1.

290. See *In re Conroy*, 486 A.2d 1209, 1227 (N.J. 1985); *supra* Part I.A.

291. See *supra* Part II.B.2.

292. See *supra* Part II.A.1.

293. See *supra* Part II.B.2.

medical decisions.²⁹⁴ When a never-competent individual, such as Chantel R.,²⁹⁵ makes a life-affirming statement, this proposal would shift the burden to the surrogate to argue that the preference is clearly irrational or destructive. The life-affirming statements of a never-competent individual should not be held to the standard of informed consent.²⁹⁶

C. *The Patient-Centered Approach and the Strong Guardian Model*

Requiring surrogates to begin their determination of a never-competent patient's best interests with an evaluation of that patient's expressed preferences fulfills the requirement for equal protection, patient autonomy, and the presumption in favor of life suggested by arguments for the weak guardian model.²⁹⁷ At the same time, it does not contradict the argument for a strong guardian: the fundamental need for surrogates to be empowered to make all necessary decisions for the never competent.²⁹⁸ Unlike the strong guardian model, the patient-centered approach puts the expressed preferences of a patient before an objective analysis of a patient's "best interest."²⁹⁹

1. Benefits of a Strong Guardian: Avoiding the Curse of Indecision

The fundamental principle of patient autonomy must control both the need for surrogate decision making as well as the limits of surrogates' power.³⁰⁰ Current jurisprudence regarding end-of-life medical decision making for formerly competent individuals is rooted in the idea that individuals have a basic liberty interest in controlling their medical treatment.³⁰¹ Because this liberty interest comes from bodily integrity, it is fully possessed by the never competent as well.³⁰² But in order to exercise this interest, a never-competent individual ultimately requires a surrogate to effectuate his rights.³⁰³ Therefore any statutory or common law principle which ultimately limits what decisions surrogates can make on behalf of the never competent violates their fundamental liberty interests.³⁰⁴

The tragic case of Sheila Pouliot provides a warning as to the ultimate effect of arbitrary limits on the power of surrogates to make decisions on

294. See *supra* Part II.B.3.

295. See *In re Chantel R.*, 791 N.Y.S.2d 324, 329 (Sur. Ct. N.Y. County 2004); *supra* Part II.B.1.

296. See *supra* Part II.B.3.

297. See *supra* Part II.B.

298. See *supra* Part II.A.1.

299. See *supra* Part II.A.2-4.

300. See *supra* Part I.A.

301. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278-79 (1990); *supra* Part I.A.

302. See *Cruzan*, 497 U.S. at 279; *In re Guardianship of Grant*, 747 P.2d 445, 449 (Wash. 1987).

303. See *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).

304. See *supra* Part II.A.1.

behalf of the never competent.³⁰⁵ In Pouliot's case, the New York Attorney General indicated that life-sustaining medical treatment could never be withdrawn from a never-competent patient because that patient would never have been competent to express a preference for avoiding futile care. This stance only extended the suffering of Pouliot beyond humane limits or medical necessity.³⁰⁶ This can still happen in some states where the burdens (such as requiring permanent unconsciousness) are high enough to run the risk of having similar tragedies.³⁰⁷ While courts have not gone so far as to find a constitutional right to surrogate decision making,³⁰⁸ the liberty interests of never-competent patients cannot be protected unless surrogates have the power to make any decision necessary for the well-being of their wards.³⁰⁹

2. The Strong Guardian Model's Threat to Patient Autonomy

Beyond the never competent's fundamental interest in empowered surrogate decision makers, the strong guardian model fails to adequately protect the principle of patient autonomy for the never competent.³¹⁰ Surrogate decision makers must be compelled to take the expressed preferences of the never competent as the starting point in their analysis of the never competent's best interests.³¹¹ A patient-centered approach more fully realizes the ideal of patient autonomy.³¹² Unlike the pre-HCDA scheme in New York State—where surrogates did not have the power to make end-of-life medical decisions because the wishes of the never competent could not be ascertained to a legally recognized level—here, surrogates should have that power.³¹³ However, they must still base their decisions on any expressed preferences of the never-competent patient.

Proponents of the strong guardian model argue that this is already the case because guardians' duties to their wards require them to take into account any expressions of the ward.³¹⁴ But in practice, the never-competent ward's expressed interests are ignored because his expressions do not rise to the level of competence needed for informed consent.³¹⁵ Statutes and practice instead seek to separate out the never competent's

305. See *supra* notes 168-74 and accompanying text.

306. See *Blouin v. Spitzer*, 213 F. Supp. 2d 184, 186 (N.D.N.Y. 2002), *aff'd* 356 F.3d 348, 359 (2d Cir. 2004); Ouellette, *supra* note 17, at 13-21.

307. See Ouellette, *supra* note 17, at 21-29; *supra* Part I.D.

308. *Blouin*, 356 F.3d at 359.

309. See *supra* Part II.A.1.

310. See *supra* Part II.B.

311. See *supra* Part II.B.

312. See *supra* Part II.B.

313. See Ouellette, *supra* note 17, at 13-21; *supra* Part II.B.

314. See *supra* Part II.A.2.

315. See *In re Guardianship of Chantel R.*, 791 N.Y.S.2d 324, 329 (Sur. Ct. N.Y. County 2004); *supra* Part II.B.1.

expressed interests from their best interests, thereby silencing the expressions of the never-competent individual.³¹⁶

While the strong guardian model suggests that the best outcome can be achieved by providing the medically preferred treatment, this is simply another example of placing the best interest analysis before a patient's expressed preferences.³¹⁷ The best interests of the never-competent person cannot be the starting point of analysis for situations involving end-of-life medical decisions. The best interest analysis works better in decisions involving a financial impact or some readily measurable outcome.³¹⁸ End-of-life medical decisions are typically emotional and normative in character, weighing imponderable factors like the quality versus length of life.³¹⁹ The question of whether or not to terminate life-sustaining treatment when one is permanently unconscious, as in the *Chantel R.* case,³²⁰ is not, ultimately, a rational decision. Whether a permanently unconscious state is inherently undignified is a normative question that is resistant to any kind of rational analysis.³²¹ The only solution that comports with the principle of patient autonomy in end-of-life medical decisions is to begin the analysis with the expressed preferences of the never-competent patient and only turn to the best interest analysis as a corrective for destructive decisions.

The strong guardian model also asserts that favoring the expressed preferences of never-competent patients opens them up to the threat of manipulation.³²² While that remains a possibility, the proposal seeks to focus the attention of the surrogate on the subjective experience of the never competent.³²³ Even though the proposal gives substantial weight to the expressions of the never competent, it does not, ultimately, require the surrogate to follow them.³²⁴

CONCLUSION

The state's power over incompetent individuals, and particularly never-competent individuals, is ultimately for the incompetents' protection. Merely being incompetent does not remove an individual's personhood or legal rights. The difficulty lies in determining how to protect those rights, particularly in the difficult decisions involved in end-of-life medical decision making. The fundamental principle of personal autonomy underlying doctrines surrounding medical decisions requires us to ask the never competent for his preferences regarding treatment, even when those

316. See *Chantel R.*, 791 N.Y.S.2d at 329; *supra* Part II.B.2.

317. See *supra* Part II.A.3.

318. See Welch, *supra* note 38, at 1634-35.

319. See *supra* Part II.B.2.

320. 791 N.Y.S.2d 324.

321. See *supra* Part II.B.2. But see Cantor, *supra* note 63 at 118-25 (arguing that permanent unconsciousness is an intrinsically undignified state for any human being and therefore individuals should have to actively choose to be maintained in that state).

322. See *supra* Part II.A.4.

323. See Dresser, *supra* note 71, at 698.

324. See *supra* Part II.A.1.

preferences do not rise to the level of informed consent. Surrogate decision makers may ultimately reject those preferences because they are totally unreasonable, but by starting their analysis with those preferences we recognize and affirm the status of never-competent persons as equal citizens under the law.

Notes & Observations