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Meeting the Need for Clear Guidelines: Protecting Vulnerable Adults from Improper Limitation of Medical Treatment in Institutions

Jane D. Hoyt*
and James M. Davies**

Though some hospital patients and nursing home residents cannot speak or communicate clearly and may depend on nursing staff for nasogastric or gastric feedings to maintain comfort and life, they still remain able to experience life. Such patients may look up with trusting eyes and expressions as care givers enter the room. At times, for example when visitors are present, or music, or just sunshine, there may be a very pleasant feeling in the room, and these patients often seem content and happy. Some patients who recover the ability to communicate reveal that they were aware of their surroundings while too disabled to communicate.¹

Both the professional literature² and the popular press³ abound with articles on the limitation of medical treatment for institutionalized people who are very ill, very old, and/or very disabled. One article in the *New England Journal of Medicine* goes so far as to specify that certain elderly persons, whom the authors label "pleasantly senile," might be given resuscitative and intensive care only "sparingly."⁴ The reader cannot help but speculate what might be denied to those elderly individuals who wax and

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1. See generally Minneapolis Tribune, April 25, 1982, at 8A, col. 2; *The Awareness Factor*, Omni, April 1985, at 22.

2. See generally Dennis Horan & Edward Grant, *The Legal Aspects of Withdrawing Nourishment*, 5 J. Legal Med. 595 (1984); Theodore A. Stern, *Lifesaving Treatment: Ethical and Practical Guidelines*, 25 Consultant, J. Med. Consultation 133 (1985); Marshall Kapp, *Legal and Ethical Implications of Health Care Reimbursement by Diagnosis Related Groups*, 12 Law Med. & Health Care 245 (1984).

3. See generally Andrew Malcolm, *Someday I'll Tell the Children . . .*, Family Circle, Sept. 3, 1985, at 32; Charles Krauthammer, *What to do About "Baby Doe,"* The New Republic, Sept. 2, 1985, at 16.

4. Sidney H. Wanzer, S. James Adelstein, Ronald E. Cranford, Daniel D. Federman, Edward Hook, Charles G. Moertel, Peter Safar, Alan Stone, Helen B.

wane in "pleasantness" of personality. Other ethicists raise arguments for caution in the area of limiting treatment.⁵

The Nursing Home Action Group (hereafter NHAG)⁶ in Minnesota believes all people, regardless of the severity of their disabilities, should have access to food, water, and ordinary medical treatment, and should have all of their constitutional rights respected. In order to ensure that these rights are respected in institutional settings, NHAG has drafted the "Guidelines for the Provision of Medical Treatment and Nursing Care."⁷

This article will present a brief explanation of the need for clear guidelines on medical care and treatment, a review of several situations and legal cases demonstrating the need for clear guidelines, and a presentation of the actual guidelines NHAG has drafted to ensure protective decision making for vulnerable patients.

I. The Need for Clear Guidelines

Opinions and beliefs regarding limitation of treatment differ greatly, as do the definitions of basic terms used in health care decision making, such as "supportive care only," "irreversible," "competent," and "imminent."⁸ Even medical terms such as "irreversible coma," "persistent vegetative state," and "dementia"⁹ have varied meanings among physicians. This confusion ultimately has life-and-death implications. *In Re Elaine Pritchard*,¹⁰ a recent California case, demonstrates this very well. Elaine Pritchard's husband asked the court for permission to remove a feeding tube—an action which would have resulted in her death.¹¹ Physicians had reported to the court that the forty-three-year-old woman was in a permanent coma;¹² however, another consultant subsequently found Mrs. Pritchard to be neither comatose nor "vegetative," but

Taussig, Jan van Eys, *The Physician's Responsibility Toward Hopelessly Ill Patients*, 310 *New England J. of Med.* 955 (1984).

5. See generally Horan & Grant, *supra* note 2, at 631; Mark Siegler & Alan Weisbard, *Against the Emerging Stream: Should Fluids and Nutritional Support Be Discontinued?* 145 *Archives of Internal Med.* 129 (1985); Daniel Callahan, *On Feeding the Dying*, 13 *Hastings Center Rep.* 22 (1983); Gilbert Meilaender, *On Removing Food and Water: Against the Stream*, 14 *Hastings Center Rep.* 11 (1984).

6. The Nursing Home Action Group is a small organization in Minnesota which advocates improvement in nursing home care and is a member group of the United Handicapped Federation.

7. See *infra* text accompanying notes 90-99.

8. See *infra* text accompanying notes 91-93.

9. Ronald E. Cranford, *Termination of Treatment in the Persistent Vegetative State*, 4 *Seminars in Neurology* 37 (1984).

10. No. 80125 (Super. Ct. Cal., San Mateo County Ct., Dec. 19, 1985).

11. *Deny Death Request*, *Peninsula Times Tribune*, June 28, 1985, at 3A, col. 1.

12. *San Jose Mercury News*, Dec. 14, 1985, at 3B.

severely "demented."¹³ After this diagnosis, the husband withdrew his request.¹⁴

More recently, in March 1986, the American Medical Association's seven-member Judicial Council issued a "clarification and expansion" of A.M.A. Opinion 2.15,¹⁵ an official statement entitled "Terminal Illness,"¹⁶ in which the withholding of artificially supplied nutrition, hydration, and medication, is now approved (but not mandated). This is approved not only for terminally ill patients, but also for persons who are in a presumed irreversible coma, though not terminally ill.¹⁷ Although A.M.A. Opinion 2.15 states there should be "safeguards to confirm the accuracy of the diagnosis" and "concurrence of those who have responsibility for the care of the patient,"¹⁸ the opinion offers no guidelines for the protective procedures.

Without careful delineation of protective steps to be taken preceding limitation of treatment, the frail patient might be denied appropriate lifesaving or life-enhancing care and treatment. Without accompanying definitions, some common terms of medical ethics may be confusing or useless when mentioned to patient, family, or friends in a care conference, or when written on the discharge summary of a patient being transferred to another health care facility. Good efforts are being made in some communities to standardize terminology used by nursing homes, hospitals, and the emergency personnel who transport patients between facilities,¹⁹ but more intensive efforts are needed to educate both professionals and consumers.

In Minnesota, many basic rights of hospital patients and nursing home residents, including the right to courteous and respectful care, and to "[a]ppropriate care . . . designed to enable [patients] to achieve their highest level of physical and mental functioning,"²⁰ are protected by the Minnesota Hospital Patients and Nursing Home Residents Bill of Rights.²¹ The Minnesota Vulnerable

13. *Id.*

14. *New Diagnosis Ends Man's Court Battle to Let Wife Die*, Los Angeles Herald Examiner, Dec. 15, 1985, at A10.

15. "New Medicine" Raises Troubling Questions, Am. Med. News, Mar. 28, 1986, at 11, col. 4.

16. Judicial Council, American Medical Ass'n, Current Opinions of the Judicial Council of the American Medical Ass'n 11 (1984).

17. *Id.*

18. *Id.*

19. See Steven Miles & Timothy Crimmins, *Orders to Limit Emergency Treatment for an Ambulance Service in a Large Metropolitan Area*, 254 J. A.M.A. 525, 526 (1985).

20. Minn. Stat. § 626.557 (1984 & Supp. 1985).

21. Minn. Stat. §§ 144.651-652 (1984).

Adult Protection Act mandates all health care personnel and encourages all other people to report suspected physical or mental abuse and neglect.²² The Minnesota Supreme Court, while recognizing the right to refuse treatment, has also recognized a state interest in the preservation of life.²³ However, if the patients or residents, family, friends, and health care personnel are not guided by protective procedures and these persons do not have a clear understanding of terms and the possible consequences of decisions, this may ultimately mean that the patients' or residents' right to receive treatment or nourishment may be denied.

In addition to legislation, some private groups have attempted to clarify the criteria for determining whether or not a patient should receive treatment. In June of 1983, an ad hoc Task Force on Supportive Care in Minnesota drafted guidelines which were "one of the first practical attempts to deal with the issue of appropriate care for the elderly in the long-term care setting."²⁴ These guidelines recommended three categories of nursing home residents to be considered candidates for the withdrawal or noninitiation of life-maintaining medical treatment:

A. *Terminally Ill and Imminently Dying*, for example, from cancer or cardiac disease.

B. *Severe and Irreversible Mental Disability*, where the resident demonstrates a significant inability to communicate, or to interact meaningfully with the environment, and an unawareness of self and/or the environment; for example, those with pre-senile and senile dementia . . . and . . . strokes.

C. *Severe and Irreversible Physical Disability*, where there may exist normal mental functioning but, because of pain and suffering, or severe motor impairment, the resident demonstrates a significant inability to interact physically in a meaningful way with the environment; for example, those with spinal cord injury, head trauma, emphysema, and amyotrophic lateral sclerosis.²⁵

As there is documented evidence of poor decision making

22. Minn. Stat. § 626.557 (1984 & Supp. 1985).

23. *In re Conservatorship of Torres*, 357 N.W.2d 332, 339 (Minn. 1984). After discussing the constitutional bases for a patient's right to refuse life-sustaining treatment, the court in *Torres* recognized that this right is not absolute. The right to refuse life-sustaining treatment has been balanced against the state's interest in protecting its citizens. Such state interest includes: "(1) the preservation of life; (2) the prevention of suicide; (3) the protection of innocent third parties; (4) and the preservation of the ethical integrity of the medical profession." *Id.* (citing Comment, *Law at the Edge of Life: Issues of Death and Dying*, 7 Hamline L. Rev. 431, 440 (1984)).

24. Task Force on Supportive Care, *The Supportive Plan—Its Meaning and Application: Recommendations and Guidelines*, 12 Law Med. & Health Care 97, 98 (1984).

25. *Id.* at 99 (footnotes omitted).

which has caused much suffering,²⁶ there was general appreciation that an important issue was being raised for consideration by the task force. Indeed, the guidelines were being proposed to meet the important need for more careful decision making. There was great disappointment, however, that mental and physical disability would be suggested as justifiable criteria for the withdrawal or noninitiation of medical treatment. Representatives of twenty-one local disability organizations unanimously passed a resolution on September 24, 1983, opposing "the initiation of 'supportive-care-only' plans/orders, . . . on the basis of physical or mental disability."²⁷ In April of 1984 the Board of the United Handicapped Federation in Minnesota—an organization then consisting of twenty-five member groups—adopted a four-point resolution affirming the right of all persons to life-maintaining and life-enhancing care.²⁸ The focus of the Task Force guidelines on physical and mental disabilities made alternative guidelines imperative.

A recent study in Minnesota underscores the need for more thorough and protective guidelines pertaining to the limitation of treatment.²⁹ The study determined that approximately seventy-three percent of nursing homes will accept care plans which limit treatment, and sixty-six percent will accept "Do-Not-Resuscitate" orders.³⁰ However, seventy-seven percent have no administrative protocols for the implementation of limited treatment.³¹ Of twenty limited-treatment care plans reviewed, only sixty percent required periodic review, and only fifty-five percent called for co-professional involvement.³² Forty percent permitted limited treatment to be initiated with a mere notation (e.g., "supportive-care-only") by the doctor on the medical chart.³³ Not one of the twenty plans considered the need for guardianship where a patient is unable to either request or refuse a care plan which could hasten death.³⁴

26. *Id.* at 98.

27. Resolution passed by Solidarity Day Coalition, Minneapolis, Minnesota (Sept. 24, 1986) (on file with *Law & Inequality: A Journal of Theory and Practice*).

28. Resolution adopted by the United Handicapped Federation, St. Paul, Minnesota (April 12, 1984), quoted in Jane Hoyt & James Davies, *A Response to the Task Force on Supportive Care*, 12 *Law Med. & Health Care* 103, 105 (1984); Letter from the Minnesota Assn. for Retarded Citizens (July 13, 1984) (on file with *Law & Inequality: A Journal of Theory and Practice*).

29. Steven H. Miles & Muriel B. Ryden, *Limited-Treatment Policies in Long-Term Care Facilities*, 33 *J. Am. Geriatrics Soc'y* 707 (1985).

30. *Id.* at 708.

31. *Id.*

32. *Id.*

33. *Id.* at 709.

34. *Id.*

Lack of protocols or the use of simplistic protocols could cause inadequate consideration of treatment plans, insufficient documentation, lack of legal protection for health care givers, inadequate consent by the patient, and intolerable anguish for the vulnerable patient, family, and friends. Further evidence of chaos in this area of medical ethics comes from a survey of physicians at a prominent teaching hospital affiliated with Harvard Medical School.³⁵ Some decline to comply with their patients' requests for a "Do-Not-Resuscitate" order because that term, though not meant to indicate limitation of treatment until heartbeat or breathing stop, may in fact result in less care and treatment than was intended.³⁶ Of particular concern to advocates of disability rights is the current emphasis on limitation of treatment which ignores certain unfortunate realities. These realities include the facts that many patients live in substandard situations³⁷ which could cause a deterioration of physical and mental health, and that not all families can be presumed to have the best interests of the patient in mind.³⁸

In Minnesota, the immediate need for clear, protective guidelines was demonstrated in July 1985, when the Minnesota Department of Health issued three state licensing correction orders against Abbott Northwestern Hospital "relating to the lack of Supportive Care Only policies . . . the failure to provide appropriate care . . . [and] the apparent lack of any attempt to involve the VA [Vulnerable Adult] in the Supportive Care Only decision."³⁹ The subject of the report was an elderly woman who had required nursing home care after a recent broken hip.⁴⁰ She had been hav-

35. Susann E. Bedell & Thomas L. Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital*, 310 *New Eng. J. Med.* 1089 (1984).

36. *Id.* at 1092.

37. See generally National Citizens' Coalition for Nursing Home Reform (hereinafter NCCNHR), *Consumer Statement of Principles for the Nursing Home Regulatory System—State Licensure and Federal Certification Programs* 3-7, 102-104 (1983), (NCCNHR, 1309 L Street, N.W., Washington, D.C. 20005); Committee on Nursing Home Regulation, Institute of Medicine, *Improving the Quality of Care in Nursing Homes* 3 (1986); Special Committee on Aging, United States Senate, *Nursing Home Care: The Unfinished Agenda*, May 21, 1986, at 3-16 (on file with *Law & Inequality: A Journal of Theory and Practice*).

38. See generally *Domestic Abuse Against the Elderly*, Hearing Before the Subcomm. on Human Services of the House Select Comm. on Aging, 96th Cong. 1st Sess. (Apr. 28, 1980); *Abuse of Older Persons*, Hearing Before the Subcomm. on Human Services of the House Select Comm. on Aging, 97th Cong. 1st Sess. (March 23, 1981).

39. Minnesota Department of Health, Office of Health Facility Complaints, *Summary Investigation Report* (hereinafter OHFC Report), Case No. V85-299 (July 12, 1985) at 20. (Copies of cited reports on file with *Law & Inequality: A Journal of Theory and Practice*).

40. *Id.* at 1.

ing difficulty swallowing⁴¹ and was readmitted to the hospital in "satisfactory"⁴² condition for rehydration.⁴³ According to the Health Department report, the patient did not receive nutrition or hydration during the six days⁴⁴ prior to her death, despite her charted requests, which stated she had "asked for some water, . . . appears thirsty [and] pointing to mouth."⁴⁵ Other medical problems were not treated either.⁴⁶

II. Standards of Care Affecting Quality of Life

Allocating treatments on the basis of a policy or institutional assessment of "quality of life" or "active life expectancy" is ageist in design and a resurrection of the spirit of the public hygiene laws of the Nazi Germany. "Quality of life" should enter decisions to limit treatment only by individual residents exercising their autonomy, according to their personal experience of the benefits and burdens of continued treatment, after full access to the social and medical resources needed to make the most of a disabled existence.⁴⁷

A crucial factor which must be addressed when considering the ethics of "limited care" decisions is that poor conditions and low standards of care have been well documented in all too many United States nursing homes.⁴⁸ For example, at the Bryn Mawr Nursing Home in Minneapolis, complaints about poor care were substantiated in the early 1980's by the Minnesota State Department of Health. These cases included a patient with a painful bladder infection, who was not terminally ill, and was not given curative treatment or kept comfortable.⁴⁹ This patient was on a "nursing supportive care list," although there was no physician's order for the "supportive care," nor was there documentation that the patient was involved in the decision to be treated with only "supportive care" even though he appeared to respond appropriately when he understood questions.⁵⁰ Another patient with a painful, foul-smelling, draining wound was not given curative

41. *Id.* at 2, 3.

42. *Id.* at 4.

43. *Id.*

44. *Id.* at 7-9.

45. *Id.* at 7.

46. *Id.* at 5.

47. Steven H. Miles, *Nursing Home Policies to Limit Medical Treatment: Out of the Closet and into the Light*, 1 *Minn. J. of Gerontology* 9 (1985).

48. See generally NCCNHR, Institute of Medicine, Special Comm. on Aging, *supra* note 37.

49. OHFC Report, *supra* note 39, Case No. 81-0153 (Apr. 2, 1981), at 1-5, 7. (Copies of cited case reports are on file with *Law & Inequality: A Journal of Theory and Practice*).

50. *Id.* at 5.

treatment until the Health Department intervened.⁵¹ Physician's orders to ensure that specified patients received stated minimum amounts of fluids were not properly followed.⁵² Patients were awakened and put in their wheelchairs at dawn for the convenience of the institution, but in violation of the Nursing Home Residents' Bill of Rights.⁵³ Physical and verbal abuse of patients was also documented.⁵⁴ A patient under physician's orders to be restrained "night and day for safety"⁵⁵ fell several times. The last time she was found face down in a cement stairwell, calling for help. A head laceration had already clotted by the time she was found. The *Minneapolis Tribune* provides an example of a patient with a history of arson who was admitted to a health care facility. At the time of a fatal fire at Bryn Mawr, the *Minneapolis Tribune* reported that the patient who started the fire had a history of arson and entered the facility with an inadequate admission history.⁵⁶ OHFC reports indicate at the same time that an unnamed patient with a history of arson had an inadequate care plan.⁵⁷

Given the existing poor conditions in many nursing homes in the United States,⁵⁸ is it possible and fair to pass judgment on a patient's capacity to "interact meaningfully" with such an environment? Some guidelines use this ability as a criterion for denying life-maintaining care and treatment.⁵⁹ It is terribly unjust to require persons living in such an environment to demonstrate a certain "quality of life" before receiving food, water, or ordinary medicines. Many factors, including greed, mismanagement, budget constraints, and negative attitudes towards people who are elderly, ill, or have disabilities, contribute to poor conditions in some nursing homes. The proper response to the challenge presented by substandard health care conditions and the consequent human suffering is to improve the quality of services and the health of patients.

51. *Id.*, Case No. 81-0235 (May 28-29, 1981), at 1-4.

52. *Id.*, Case No. V81-011 (June 17, 1981), at 1.

53. *Id.*, Case No. 81-0272 (June 16, 1981), at 1, 2.

54. *See id.*, Case No. 80-0231 (March 25, 1980), at 1-2; Case No. 80-0896 (Dec. 2, 1980), at 1-2; Case No. 81-0153 (Apr. 2, 1981), at 2, 6, 7.

55. *Id.*, Case No. 80-0114 (Feb. 26, 1980), at 2.

56. *Minneapolis Tribune*, Sept. 28, 1979, at 1B, col. 1.

57. OHFC Report, *supra* note 39, Case No. 80-0696 (Oct. 2, 1980), at 1-5.

58. NCCNHR, Institute of Medicine, Special Committee on Aging, *supra* note 37.

59. Hoyt & Davies, *supra* note 28, at 103.

III. The *Conroy* and *Jobes* Cases: Legalizing Starvation in Nursing Homes

The moral and ethical dilemmas raised by limited-care requests are strikingly illustrated by a January 1985 case, *In Re Claire C. Conroy*.⁶⁰ In this case, the New Jersey Supreme Court established criteria by which a legal guardian of an elderly nursing home resident may authorize discontinuance of life-sustaining care—including nasogastric feedings.⁶¹

Although Ms. Conroy had died while the case was being appealed, the court decided to address the issues raised by her guardian's request to discontinue the nasogastric feedings. The court ruled that in certain very restricted circumstances, a legal guardian may authorize discontinuance of life-sustaining treatment—including nasogastric feeding tubes—from elderly nursing home residents who were formerly competent but who have serious and irreversible mental and physical impairments. The ruling covers those "who will probably die within approximately one year even with the treatment,"⁶² although they need not be comatose or unresponsive.⁶³ The decision must be approved by the attending physician, two independent physicians, and the state ombudsman of the Office of the Ombudsman for the Institutionalized Elderly, and must meet the criteria of a "subjective" standard or one of two theoretically more objective "best interests" tests, as summarized below:

- 1) The subjective standard: "life-sustaining treatment may be withheld or withdrawn from an incompetent patient when it is clear that the particular patient would have refused the treatment under the circumstances involved."⁶⁴

- 2) The limited-objective test: "there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him. By this 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

60. 98 N.J. 321, 486 A.2d 1209 (1985).

61. A nasogastric feeding tube is a simple, flexible tube inserted (usually by a nurse) in the nose and down the esophagus to the stomach for feeding a patient who is unable to take food by mouth. In this manner, a patient may be fed a liquid diet which provides all nutrients needed for maintaining health.

62. *In re Claire C. Conroy*, 98 N.J. at 342, 486 A.2d at 1219. See also Richard A. McCormick, *Caring or Starving? The Case of Claire Conroy*, America, April 6, 1985, at 269.

63. 98 N.J. at 358-59, 486 A.2d at 1229.

64. *Id.* at 360, 486 A.2d at 1229.

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."⁶⁵

3) The pure-objective test: There is no trustworthy evidence that the patient would have refused the treatment, and "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."⁶⁶

Under both the limited objective test and the pure objective test, certain family members as well as the guardian must agree to the discontinuation of treatment.⁶⁷ The New Jersey Supreme Court does call for extreme caution in determining the patient's intent and in evaluating medical evidence of the patient's condition.⁶⁸ It expressly declined to authorize decision making "based on assessment of the personal worth or social utility of another's life, or the value of that life to others."⁶⁹

Based on the record before it, the court found that the circumstances of Claire Conroy's situation did not meet the criteria of any of the three tests. Had she not died (with the nasogastric tube in place),⁷⁰ the court would have remanded the case for further consideration. She died from existing ailments which included arteriosclerotic heart disease, diabetes, and hypertension.⁷¹ When the litigation commenced, Claire Conroy was not comatose or considered to be suffering a terminal illness; she did react in some ways to her environment, such as by smiling.⁷²

Although the court correctly found that the circumstances of Ms. Conroy at the time the litigation commenced did not meet the criteria established for discontinuing life-sustaining treatment, the decision is nonetheless very unfortunate because, despite safeguards, the court still permits discontinuation of nourishment from elderly patients who are not terminally ill and imminently dying.

One major flaw in the court's argument is the use of pain as a

65. *Id.* at 365, 486 A.2d at 1232.

66. *Id.*

67. *Id.* at 384-85, 486 A.2d at 1242.

68. *Id.* at 368, 486 A.2d at 1233.

69. *Id.* at 367, 486 A.2d at 1232-33.

70. *Id.* at 337-38, 486 A.2d at 1217-18.

71. *Id.* at 341, 486 A.2d at 1219.

72. *Id.* at 337, 486 A.2d at 1217.

criterion for withholding treatment.⁷³ Most, if not all, pain can be alleviated.⁷⁴ Much of the pain suffered by long-term care residents, such as bedsores and contractures, can be prevented by good nursing and medical care.⁷⁵ When patients with severe disabilities are experiencing pain, the proper goal of medical and nursing care must be to alleviate this pain, rather than to terminate the life of the patient.

A serious problem with the *Conroy* subjective standard⁷⁶ is that a patient may have clearly expressed earlier that he or she would never want nasogastric or gastric feedings, but later becomes reconciled to his or her condition and enjoys the company of other people and other activities. If this patient is now unable to speak or communicate clearly, she will not be able to indicate a change of mind or heart in order to receive nourishment.

Under *Conroy*, it is not clear what age is to be considered "elderly." Regardless of the clarity, any age standard is an unacceptable form of discrimination. It is frequently not possible to predict who can be expected to die within "approximately one year." And indeed, the expectation in this context might hasten or even cause death. The court does not seem to allow for the fact that with proper care, patients may show slight or dramatic improvement despite expectations to the contrary.⁷⁷ The *Conroy* decision takes a procedurally cautious but significant step toward legalized killing, a kind of capital punishment for selected elderly nursing home residents who are experiencing pain.

Even before A.M.A. Opinion 2.15 on "Terminal Illness" was expanded, some ethicists expressed concern that involuntary euthanasia threatened persons who were mentally dysfunctional but neither terminally ill nor in pain.⁷⁸ *In re Jobes*⁷⁹ may heighten

73. Justice Handler, concurring in part and dissenting in part, criticizes the pain criterion from a very different perspective. *Id.* at 394-95, 486 A.2d at 1247-49.

74. See generally International Association for the Study of Pain, Pain (Fourth World Congress on Pain, Aug. 31-Sept. 5, 1984, Supp. 2, 1984); Judith A. Paice, *Intrathecal Morphine Sulfate for Intractable Cancer Pain*, 16 J. Neurosurgical Nursing 237 (1984); R.E. Richardson, *Intracranial Stimulation for the Control of Chronic Pain*, 31 Clinical Neurosurgery 316 (1983); Donlin M. Long, *Stimulation of the Peripheral Nervous System for Pain Control*, 31 Clinical Neurosurgery 323 (1983); Samuel Mines, *The Conquest of Pain* (1974).

75. French's Index of Differential Diagnosis (F.D. Hart ed., 11th ed. 1979).

76. 98 N.J. at 341, 486 A.2d at 1219.

77. Justina Tanhehco & Paul E. Kaplan, *Physical and Surgical Rehabilitation of Patient After 6-Year Coma*, 63 Archives of Physical Med. and Rehabilitation 36 (1982).

78. See generally Evelyn W. Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less Than Human*, 23 Mental Retardation 148 (1985); Yale Kamisar, *The Real Quinlan Question Lives On*, Minneapolis Star & Tribune, June 18, 1985, at 11A, col. 1.

such concerns. In 1980, Mrs. Jobs lost much of her mental and physical functions after medical malpractice in which her brain was deprived of oxygen. Shortly after the onset of disability, she was placed in a nursing home.⁸⁰ Mrs. Jobs' husband and family petitioned a New Jersey court in 1985 for permission to withdraw a successfully functioning feeding tube from her, which would effect her death by starvation and dehydration.⁸¹ Despite general agreement that thirty-one-year-old Mrs. Jobs was severely disabled, there was substantial and conflicting testimony in court from medical experts regarding Mrs. Jobs' capacity to feel pain and respond to stimuli.⁸² The petitioners' attorney entered the March 1986 version of A.M.A. Opinion 2.15 into evidence.⁸³ On April 23, 1986, the court ruled that Mrs. Jobs may be starved to death.⁸⁴ The case is currently being appealed.⁸⁵

At its April meeting, the Board of the United Handicapped Federation (a disability rights coalition of twenty-nine groups in Minnesota with approximately 13,000 members) discussed the implications of the Jobs case and voted to write an amicus curiae brief supporting Mrs. Jobs' right to continued nourishment.⁸⁶ Based in part on the experience of some UHF members who have recovered from presumed permanent coma, the Board also passed a Resolution in response to A.M.A. Opinion 2.15:

BE IT RESOLVED that the United Handicapped Federation considers full access to nutrition and hydration, and to ordinary medical treatment, including antibiotics, whether administered by usual physical means or by artificial or technological assistance, to be a basic right of all persons, regardless of age, whether or not they have disabilities, and whether or not they are terminally ill.

FURTHER, the United Handicapped Federation recognizes that in some rare instances of terminal cancer or other severe illness, the provision of nutrition and fluids can be hurtful due to metabolic problems, even hastening death, and thus it may be medically and ethically appropriate to limit medical treatment and/or nutrition and fluids during the terminally ill patient's final days. . . .

MOST IMPORTANT is the proper monitoring of all treatment and care during severe illness so that treatment and care are

79. *In re Jobs*, No. C-4971-85E (Super. Ct. N.J., Ch. Div.-Morris County, Apr. 23, 1986) at 2 (on file with *Law & Inequality: A Journal of Theory and Practice*).

80. *Id.* at 2-3.

81. *Id.* at 1.

82. *Id.* at 6-8.

83. *Id.* at 14.

84. *Id.* at 16-17.

85. Newark Star-Ledger, April 24, 1986, at 1.

86. St. Paul Pioneer Press & Dispatch, April 23, 1986, at 3D, col. 3.

appropriately administered.⁸⁷

IV. A Response: Protective Guidelines Proposed

Recognizing the ambiguity and difficulty of interpretation inherent in existing laws and regulations, the Nursing Home Action Group has drafted "Guidelines for the Provision of Medical Treatment and Nursing Care." These Guidelines seek to protect the vulnerable adult. The vulnerable adult is defined under Minnesota law as a person over the age of eighteen who, because of mental, physical, or emotional impairment, is "unable or unlikely to report abuse or neglect without assistance."⁸⁸ Nursing staff should not be put in the position of taking care of patients who are unnecessarily suffering pain and dying because someone, however well-intentioned, decided that these patients should die rather than receive basic nourishment and treatment.

The NHAG Guidelines define the denial of treatment and care as a violation of basic civil and human rights. NHAG has proposed these Guidelines in order that people who are elderly, disabled, or ill may live and die in comfort and dignity. International standards of human rights, moral principles respecting the value of human life, and the guarantee of equal protection of the law in the United States Constitution demand nothing less.

87. Resolution adopted by the United Handicapped Federation, St. Paul, Minnesota (April 10, 1986) (on file with *Law & Inequality: A Journal of Theory and Practice*).

88. Minn. Stat. § 626.557(2)(b)(3) (1985).

**GUIDELINES FOR THE PROVISION OF MEDICAL
TREATMENT AND NURSING CARE⁸⁹**

IN ACCORDANCE WITH THE MINNESOTA VULNERABLE
ADULT PROTECTION ACT, MINNESOTA NURSING HOME
RESIDENTS' BILL OF RIGHTS, AND UNITED STATES CON-
STITUTIONAL STANDARDS OF DUE PROCESS

PREAMBLE

The purpose of these guidelines is to ensure that the criteria for making decisions about technology and ordinary and "extraordinary" treatment will be the same for all persons, regardless of physical or mental disability. This purpose is in accord with public policy of the state of Minnesota: "to protect adults who, because of physical or mental disability or dependency on institutional services, are particularly vulnerable to abuse or neglect."⁹⁰

All levels of staff in health care facilities should be encouraged to consider that "where there is life, there is hope." Research gives reason to expect increasing improvement from many disabilities, including Alzheimer's disease, stroke, diabetes, and spinal cord injury. Health care givers should be instructed that patients who may not be capable of normal speech usually understand more than they can express; that adult patients must be treated as adults; and that active encouragement is a significant factor in rehabilitation. A patient may be incapable of ordinarily articulate, physical communication yet able to have meaningful, emotional, mental, and aesthetic experiences and to communicate with receptive persons.

It is acknowledged that no set of guidelines can resolve all questions raised by rapidly changing medical technology and by conflicting ethical values and medical opinions.

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⁸⁹. These guidelines were drafted by Jane D. Hoyt, James M. Davies, and Jeanette McDougal on behalf of the Nursing Home Action Group in Minnesota.

⁹⁰. Minn. Stat. § 626.557(1) (1985).

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I. PRINCIPLES

A. The life of a person with mental or physical disabilities has the same intrinsic value as that of a person described as normal or healthy or able-bodied.

B. The primary goal of health care givers (physicians, nursing staff, social workers, therapists) shall always be to encourage and promote the best physical, mental, emotional, social, and spiritual health of which each patient is capable. Both competent and incompetent patients shall be encouraged to participate in making decisions about their own care.

C. Orders for the withdrawal of treatment or non-initiation of treatment shall never be written on the basis of physical or mental disability. Nursing and medical personnel shall never suggest such orders to a patient, a family, or a guardian because of the patient's disability.

D. Denial of essential, life-maintaining care and life-enhancing care because of mental or physical disabilities is a violation of basic civil and human rights.

E. Food and water, or comparable nourishment, shall always be offered to all patients; however, it is acknowledged that for a person who is irreversibly, irreparably, and terminally ill and for whom death is imminent, the goal of nourishment may be comfort rather than prolonging life.

F. A medical care plan which does not prolong life may be determined to be appropriate for a person who is irreversibly, irreparably, and terminally ill, and for whom death is imminent.

G. No person in our society should be forced to choose between quality of life and length of life. Considerations of economic policy shall not be used as a justification for denying high-quality

medical and nursing care to persons who are elderly, infirm, disabled, or poor.

H. A legally and clearly competent patient has the right to refuse specific treatments, as protected in the Minnesota Nursing Home Residents'/Patients' Bill of Rights and as developed in common law.

I. Whenever the facility and/or physician plays a role in a decision concerning a patient, it shall be the responsibility of the institution and/or physician to ensure that the patient's rights are fully protected.

J. The best interests of the patient are paramount. Though family involvement in decision making may be very helpful, health care givers and physicians should be cautioned that the traditional presumption of family concern for the welfare of its members must be balanced with growing awareness of the extent of family violence and neglect in the United States.

K. After disability has occurred, an individual's new, positive opinion of self-worth, and of the value of life after disability, shall take precedence over any earlier decision, such as a "living will" or similar statement, to decline or discontinue treatment if disability occurs.

II. DEFINITIONS

A. "Caregiver" means any person (such as nursing staff, physician, social worker, therapist) or health care facility having responsibility for the care of a patient.

B. "Essential, life-maintaining care" means care, including food and water, and curative treatments, which will sustain and/or save life.

C. "Irreversible" illness means that "no known therapeutic measures can be effective in reversing the course of the illness."⁹¹

D. "Irreparable" condition of the body means "the course of illness has progressed beyond the capacity of existing knowledge and technic to stem the process."⁹²

E. "Imminent" death means that "in the ordinary course of events, death probably will occur within a period not exceeding two weeks."⁹³

F. "Supportive-care-only" means a "death-allowing care goal," that is, care which does not afford the patient curative treat-

91. Mitchell T. Rabkin, Gerald Gillerman, & Nancy R. Rice, *Orders Not to Resuscitate*, 295 *New Eng. J. of Med.* 364, 365 (1976).

92. *Id.*

93. *Id.*

ments, such as antibiotics or surgery, for the purpose of preserving life. Treatment is offered for comfort only, but not for the purpose of maintaining life. Sometimes the terms, "comfort-care-only" or "limited-care-only" are used.

G. "Do-Not-Resuscitate" means a medical order, written with documentation in a patient's medical record, providing that resuscitative measures will not be used in the event of cardiac or respiratory arrest. The "D.N.R." may be written as a specific order in a medical chart. The "D.N.R." order properly applies *only* in the event of cardiac or respiratory arrest, and the "D.N.R." may be consistent with aggressive, curative treatment of illness. The "D.N.R." order is a very different concept from "supportive-care-only," "comfort-care-only," or a "death-allowing care goal." The common element of "D.N.R." and "supportive-care-only"/"death-allowing care goal" is that resuscitation is not attempted in the event of cardiac or respiratory arrest; however, the goal of care before such an event may be very different.

H. "Legally and clearly competent" means that the person is not only "competent" in the sense of not being under guardianship or conservatorship, but also that he/she can obviously and fully understand the meaning and consequences of available treatments.

I. "Legally or clearly incompetent" means that the person, whether or not adjudicated incompetent, cannot fully understand the meaning and consequences of available treatments. A "questionably competent" person is considered incompetent within these guidelines and receives the protections and rights of an incompetent person.

J. A "disability" means a physical and/or mental dysfunction which may be either chronic or acute and which may or may not involve current physical illness.

III. GUIDELINES

A. *Primary goal of caregivers.* The primary goal of health care givers shall always be to encourage the best physical, mental, emotional, social, and spiritual health of which each patient is capable.

B. *Information about rights and treatment.*

1. As required by the Minnesota Patient's Bill of Rights, "[p]atients and residents shall, at admission, be told that there are legal rights for their protection during their stay at the facility and that these are described in an accompanying written state-

ment. . . ."⁹⁴ Further, "section 144.651 shall be posted conspicuously in a public place in all facilities licensed under [these laws]."⁹⁵

2. As required by the Patients' Bill of Rights, "[p]atients and residents shall be given by their physicians complete and current information concerning their diagnosis, treatment, alternatives, risks, and prognosis as required by the physician's legal duty to disclose."⁹⁶

C. *Denial of treatment.*

1. Denial of essential, life-maintaining and life-enhancing care because of mental or physical disabilities is a violation of basic civil and human rights and shall never be suggested to a patient, a family, or a guardian.

2. Food and water, or comparable nourishment, will always be offered to all patients; however, it is acknowledged that for a person who is irreversibly, irreparably, and terminally ill, and death is imminent, the goal of nourishment may be comfort rather than prolonging life.

3. Denial of treatment to persons with mental or physical disabilities is a violation of basic rights and is required to be reported by care givers under the Vulnerable Adult Protection Act in Minnesota.⁹⁷ This Act encourages anyone else having knowledge or suspicion of abuse or neglect of a vulnerable adult to report to authorities.

D. *Decision making by the patient who is legally and clearly competent.*

1. The legally *and* clearly competent patient shall be encouraged to participate in decision making to the fullest extent possible.

2. The right of a competent patient to refuse specific treatments, as protected in the Minnesota Patients' or Residents' Bill of Rights and as developed in common law, shall be respected.

3. Medical and nursing staff shall not assist in suicide.

4. Before a facility may comply with a patient's refusal of a life-maintaining treatment, there shall be a detailed documentation in the medical record:

a. that the patient is legally *and* clearly competent,

94. Minn. Stat. § 144.651(4) (1985).

95. Minn. Stat. § 144.652(1) (1985).

96. Minn. Stat. § 144.651(9) (1985).

97. Minn. Stat. § 626.557 (1985).

- b. that the patient made the decision freely and without duress,
 - c. that the patient's intentions have been clearly interpreted,
 - d. that, as ascertained by clinical evaluation, the patient is not suffering from psychological depression or the effects of chemical use,
 - e. that the patient was, before refusing a treatment, fully informed of the range of available treatments and their consequences, as well as the consequences of nontreatment,
 - f. that the patient was encouraged to, and given agreed-upon time to, reconsider the decision,
 - g. that possible extenuating environmental factors⁹⁸ have been considered as potentially influencing the patient's decision, and
 - h. that the patient was given the opportunity to summon relatives, friends, advocates, or professionals for alternative counseling in the matter.
5. If a patient refuses a treatment, the physician or the facility may request the patient to sign a statement, acknowledging that the refusal was an informed decision.

E. *Decision making for the patient who is legally or clearly incompetent or who is "questionably competent."*

1. The legally or clearly incompetent or "questionably competent" patient shall be encouraged to participate in decision making to the fullest extent possible. Staff shall attend especially carefully to the aphasic patient, who may say "no" when meaning to say "yes," or may make similar speech errors.

2. When a major medical or life-and-death decision involves an incompetent or "questionably competent" person, a sincerely interested family member or friend should assume the responsibility of guardianship, or a guardian ad litem should be appointed. (See exception at 3. below.)

3. It is not always necessary that a guardian be appointed for a patient who is *irreversibly, irreparably, and terminally ill*, and for whom death is imminent, in order for the goal of health care to be the support of emotional and physical comfort and security of the person throughout the dying process.

4. If a decision involves limitation of medical care, it shall be documented in detail that the guardian fully understands the deci-

98. See *infra* p. 375.

sion and its consequences, and that the decision does not violate guardianship law.

5. The decisions of a legal guardian may be challenged in accordance with guardianship law.

6. The best interests of the patient are paramount. The wishes of family and friends should be considered, but only insofar as they clearly reflect a sincere commitment to *and* understanding of the best interests of the patient. The wishes of family and friends to *preserve* the life of the patient should be respected unless there is no beneficial medical way to do this.

7. Decisions about patients who are:

- a. severely disabled in any way,
- b. poor,
- c. leaving an inheritance, or
- d. without close friends or relatives, shall be particularly carefully monitored.

F. *Provision of emergency medical treatment.*

1. Emergency medical treatment (from fire department paramedics, "Code" team, or "Dr. Blue" team) shall be given to any patient in the event of injury or accident, such as choking on food.

2. Terminally ill patients shall receive emergency treatment for accident or injury not related to terminal illness.

G. *Treatment when there is irreversible, irreparable, terminal illness, and death is imminent.*

1. When it becomes clear that a person is irreversibly and irreparably and terminally ill, and death is imminent, it then may become appropriate for the goal of health care to be the assurance of the patient's physical and emotional comfort and security throughout the dying process.

a. As with all other medical judgments, this goal shall be open to re-evaluation at all times.

b. All medical and nursing treatments and care which are necessary for the physical and psychological comfort of the patient shall be provided.

c. "Heroic measures," or "extraordinary" care/treatment, may sometimes be considered of no benefit to the individual. It should be acknowledged that the meaning of "extraordinary care/treatment" changes as rapidly as the state of the art of medicine. Whatever "extraordinary" care/treatment is taken to mean, the

meaning of it is the same for all patients, whether terminally ill or not.

d. A medical plan that includes a "death-allowing care goal" must be reviewed weekly by the doctor and renewed if still appropriate.

e. If such a medical and nursing care plan is renewed two times, or if there is any other reason to question the diagnosis or prognosis, an independent second medical opinion must be obtained.

f. It is improper to write "supportive-care-only," "comfort-care-only," or "death-allowing care goal" as a specific order; however, this concept of care may be included in a medical and nursing care plan if appropriate.

g. The "Do-Not-Resuscitate" order may be appropriate when there is irreversible, irreparable illness, and death is imminent.

2. It shall be the responsibility of the primary physician to document that all parties involved in the decision-making process understand that such a health care goal may hasten death.

3. Medical orders and nursing care and medical plans must reflect the specific needs of each individual patient. This applies to *all* patients, including those who are terminally ill.

4. When doubts about diagnosis or prognosis cannot be clearly resolved by medical professionals, full curative treatment shall be provided to the patient.

5. While the goal of care may, if appropriate, no longer be to prolong the life of a patient who is irreversibly, irreparably, and terminally ill, and imminently dying, the standards of nursing and medical care may *not* be lessened.

6. Experience with improper "Supportive-Care-Only" orders and "Do-Not-Resuscitate" orders gives evidence that environmental factors must always be considered whenever evaluating the health status of institutionalized persons because the health of nursing home residents may deteriorate due to environmental factors which could and should be improved. Considerations shall include, but not be limited to, the following as they affect the individual patient:

a. Do the facility's nursing and medical care, and social services, meet standards defined by state and federal rules and regulations?

b. Does the environment encourage meaningful, supportive interaction between residents and others?

c. Are meaningful, life-enriching activities avail-

able for all residents at the facility, and are residents encouraged to participate?

d. Are all patients' civil and human rights fully protected? Are patients and guardians encouraged to exercise these rights?

e. Is the patient free of medications which may cause:

—diminished activity and/or

—diminished motivation and/or

—other debilitating side effects (such as lack of communication)?

H. *Decision making in advance.*

1. When there is evidence of pre-disability decision making such as "living wills" or similar statements made by patients while able-bodied, medical and nursing staff must be alert to the fact that some persons may change their minds after disability occurs.

2. Staff shall look for and document any indications that the patient (whether competent or incompetent) has a changed outlook on life, because a person's new, positive opinion of self-worth, and of the value of life after disability, shall take precedence over any earlier decision to decline or discontinue treatment if disability occurs.

I. *Access to advocacy resources.* It is the responsibility of the facility to inform or remind each patient, and patients' guardians, of the availability of independent advocates (such as the Ombudsman Program, Legal Services, other advocates, or friends of the patient's choice) and to assist the patient in contacting an independent advocate.

J. *Terminology.*

1. The use of terms like "supportive care" and "supportive-care-only" shall be avoided because such terms are misleading.

2. If what is meant by "supportive-care-only" is that treatment will be ordered only to maintain comfort—not to maintain life—then a more accurate, descriptive term, such as "death-allowing care goal" or "limited care only" shall be used, but such terms shall never be written by themselves as medical orders.

3. It shall be documented in the medical record that all parties involved in a decision-making process about the goal of health care understand the meaning of the terms used and the probable consequences of the health care goals.

IV. FURTHER RECOMMENDATIONS

The welfare of nursing home residents will be better protected by:

A. A brochure for consumers and health care professionals in every acute and long-term care facility, clearly explaining the spectrum of care which patients or residents may request or be offered, from aggressive/curative care to a death-allowing care goal.

B. A written statement, at each health care facility, of philosophy and policy with respect to the kinds of care available.

C. Explanations of available kinds of care, presented along with other orientation materials when a patient enters a facility and again whenever the health status of the patient warrants a re-consideration of major health care goals.

D. Support groups and referral services enabling patients, relatives, and friends who are coping with life-and-death decisions to discuss their experiences and options with persons who have faced similar difficulties.

E. A regular, external review process in nursing homes, done by professionals and experienced consumers who are completely independent of the institution, to monitor the appropriateness of care plans with death-allowing care goals and "Do-Not-Resuscitate" orders.

F. The formation in nursing homes of human rights committees composed of persons not employed by the facility. The purpose of these committees will be to help ensure protection of civil rights to every nursing home resident, for example, to help ensure that no resident is denied medical, nursing, habilitative, or rehabilitative care on the discriminatory basis of mental or physical disability. Examples of specific concerns might be:

— A resident has expressed the desire to be taken outdoors occasionally but is never given the opportunity.

— A resident has expressed a desire for normal meals and has demonstrated the ability to feed him/herself. The physician, however, has ordered naso-gastric tube feedings for breakfast and dinner.

— Residents are awakened at 5:30 a.m. but are given nothing to do until breakfast is served several hours later.

It may be appropriate for nursing home staff also to form a human rights committee; however, a staff committee would not take the place of the more independent, non-employee human rights committee. A model for the latter is presented below.

PROPOSAL FOR A NURSING HOME HUMAN RIGHTS COMMITTEE

The human rights committee could be developed as part of the friends and relatives group or "family and friends council" of each nursing home. This committee would be distinct from the residents' advisory council, which Minnesota law clearly allows residents and their family the right to participate in and organize.⁹⁹

The committee shall function independent of the administration and staff of the facility. Its membership shall not include administrators, staff, part-time employees, or consultants retained by the facility.

The purpose of the human rights committee shall be to advocate for the civil and human rights and quality of services due all residents. Should adversary conditions develop between the administration and/or staff and one or more residents, the committee shall represent what it believes to be the best interests of the resident(s). The human rights committee shall not, however, take the place of other advocacy resources.

The human rights committee shall have seven to nine members, including at least two persons from categories "a" and "b" and one person from the remaining categories:

- a) family members or guardians who visit at least once a week,
- b) significant friends who visit at least once a week,
- c) representatives of the religious community,
- d) interested citizens from the community,
- e) non-staff professionals with experience in rehabilitation.

If possible, a resident of the facility should also be on the committee.

The committee shall solicit information, advice, and concerns from the administration and staff of the facility, as well as from residents and their families and friends. In turn, the committee shall provide consultation to the facility director, board of directors, and staff.

The committee shall meet at least quarterly. Membership shall not be more than three years' duration.

99. Minn. Stat. § 144.651(27) (1985). The statute provides that "[r]esident and family councils shall be encouraged to make recommendations regarding facility policies."