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Notes and Comments

Hospice: An Alternative Treatment of Care for the Terminally Ill

I. Introduction

In the Middle Ages, the hospice of the monastery was a place of welcome for strangers, pilgrims, and poor travelers.¹ Refreshing the travelers in mind and spirit as well as body, the hospice became synonymous with a holistic concept of care.² The hospice of today,³ whether it is home based or institution based,

1. Institutions for the aged as well as homes for poor travelers provided medical services so that "hospice" and "hospital" eventually became synonymous terms. 6 DICTIONARY OF THE MIDDLE AGES 288 (1985). See also ENCYCLOPEDIA BRITANNICA 1114 (15th ed. 1982) ("The monasteries possessed an 'infirmitorium', a place to which their sick were taken for treatment. The monasteries had a pharmacy and frequently a garden with medicinal plants. In addition to caring for sick monks, the monasteries opened their doors to pilgrims and other travelers.").

2. "The typical medieval hospice was a blend of guest house and infirmary where all comers were given food, shelter, and care until they died or set out again, refreshed and renewed, on their journeys." A. MUNLEY, THE HOSPICE ALTERNATIVE 28 (1983).

3. There is considerable variation among the types of services provided by hospices nationwide. The Joint Commission on Accreditation of Hospitals (JCAH) survey has identified six major hospice provider types. The *acute care hospital* has a hospice unit, identifies hospice beds, or identifies hospice patients on any ward and addresses their needs by a "floating team" (the scattered bed approach). The *community home health agency* is most often a visiting nurse association whose staff is divided into teams to provide hospice care to individual hospice patients. The *independent hospice program* is not owned by any other health care institution or agency. These programs are usually licensed and receive reimbursement as home health agencies but serve hospice patients only. A *long-term care facility* has one to four identified hospice beds, may or may not have identified hospice inpatient staff, but usually provides general home care services through a contract with a home care agency. *Volunteer hospices* have an average of 1.5 full-time paid staff that can include physicians, registered nurses, social workers, and others. The *case management* hospice works with an existing home health agency and/or hospital by providing services that are hospice specific. STAFF OF HOUSE SUBCOMM. ON HEALTH, 98TH CONG., 1ST SESS., MATERIALS ON MEDICARE BENEFIT 5-6 (Comm. Print 1983). A March 1983 survey by JCAH identified the independent hospice, the hospital hospice, and the home health agency hospice as the largest types of program ownership.

also focuses on the total person. It is a program of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families.⁴ Dr. Cecily Saunders, a medical doctor dedicated to improving methods of pain control for terminally ill cancer patients, initiated the hospice movement when she opened St. Christopher's Hospice in London in 1968.⁵ In the early 1970's, this original concept formed the basis of a United States hospice movement.⁶

The first American hospice was Hospice, Inc., in New Haven, Connecticut (later renamed the Connecticut Hospice), which began serving home care patients in 1974⁷ as a demonstration project funded by the National Cancer Institute.⁸ Initial progress on the New Haven project was slow and there was concern regarding public unwillingness to accept a radically different concept of care for the terminally ill.⁹ From one program,

Id. at 7. Millhaven Hospice in Tucson, Arizona, an independent hospice, offers care in the home, day care at the hospice, 24 hour inpatient care, and bereavement services for the family. G. DAVIDSON, *THE HOSPICE* 63-64 (1978). The Permanente Medical Group in California is an example of a hospice program within an acute care hospital. The patient is admitted under his attending physician's orders and the hospice physicians serve as consultants for developing strategies for symptom control and management. M. HAMILTON & H. REID, *A HOSPICE HANDBOOK* 145-46 (1980). The home health agency program is frequently a special unit of the local public health nursing association. This type of program usually requires that there be a member of the family designated as the primary caregiver. R. BUCKINGHAM, *THE COMPLETE HOSPICE GUIDE* 31-34 (1983).

4. A. MUNLEY, *THE HOSPICE ALTERNATIVE* app. A, 320-21 (1983) (quoting the National Hospice Organization's Standards of a Hospice Program of Care).

5. *Id.* at 29. Now a model for modern hospice care, St. Christopher's program offers inpatient care, home care, and bereavement services. *Id.*

6.

The modern hospice as conceived in Great Britain is more than an attempt to revitalize the holistic focus, the sense of community, and the spirit of welcome that medieval caregivers offered. It sets before the American public an ideology that, if properly implemented, can humanize and reform existing patterns of terminal care.

Id. at 30.

7. G. DAVIDSON, *THE HOSPICE* 41 (1978). The goal of the project was to demonstrate home care for the terminally ill without aggressive rehabilitative treatment and to see if this type of care was acceptable to the American public. *Id.*

8. *Id.*

9.

There was concern at the outset that palliative home care would be unacceptable in this country. I was frequently told that 'Americans are hospital oriented; when Americans are sick they want to be in the hospital.' 'Nobody dies at home in this country. The society is not set up for it.'

Hospice, Inc., the hospice philosophy of care has grown into a nationwide health care industry with 1,568 hospices across the country.¹⁰

The hospice movement in the United States developed independent of any federal regulation until 1982.¹¹ That year, a congressional decision to include hospice care under Part A of Medicare¹² heralded a new era for the hospice program, its patients, and their families. The congressional goals in enacting this legislation were to contain health care costs and to provide compassionate care for the terminally ill.¹³ The National Hospice Study by Brown University shows an average adjusted savings of \$2,221 per patient for home care based hospices and \$585 for hospital based hospices.¹⁴ The question of cost effectiveness of hospice care and the savings to Medicare will continue to be monitored.¹⁵ It is difficult to quantify a program that provides intangible benefits of dignity and privacy for a terminally ill patient and support for his family. The entry of Medicare benefits into the hospice program, however, demands a closer watch over the cost of this type of care as well as over the cost of traditional

Id. (quoting Sylvia A. Lack, Hospice, Inc.); see also R. BUCKINGHAM, *THE COMPLETE HOSPICE GUIDE* 14 (1983).

10. Telephone interview by the author with Ira Bates, National Hospice Organization (June 18, 1986).

11. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, 96 Stat. 356 § 122 (1982) (current version at 42 U.S.C. §§ 1395b-1 to 1395h, 1395x to 1395z, 1395aa to 1395cc (1982)).

12. Social Security Act of 1965, Pub. L. No. 89-97, tit. I, § 102, 79 Stat. 286, 291-332 (1965) (current version at 42 U.S.C. § 1395 (1982)). (Medicare is a federal health insurance program for the aged and certain disabled covering hospital insurance (Part A) and physician and certain other services (Part B)). See generally 1986 *MEDICARE & MEDICAID GUIDE* (CCH) 5315-16.

13. H. R. 30773, 97th Cong., 1st Sess., 127 CONG. REC. H30826 (daily ed. Dec. 11, 1981) (remarks of Senator Leon Panetta in introducing legislation to make hospice care reimbursable under the Medicare program).

14. National Hospice Organization, *Hospice News* 5 (May 1986) (newsletter). The greatest saving is during the last month of life, and the relative savings are reduced the longer the patient is in the hospice program. *Id.*

15. *Id.* at 5. Congress has mandated three new studies to provide better information about cost effectiveness and the quality of care under the hospice benefit. Abt Associates is doing the largest study through 1988. Jack Martin and Company is doing a cost analysis of non-Medicare certified hospices to serve as a control group for the evaluation. The Joint Committee on Accreditation of Hospitals is surveying sixty Medicare certified and sixty noncertified hospices in order to determine whether Medicare participation is affecting the quality of hospice care. *Id.*

care.

Moving a volunteer-based organization into the arena of federal regulation raises important issues for attorneys,¹⁶ health care professionals,¹⁷ and hospice patients.¹⁸ This Comment will review these issues and analyze them as they apply to the future of hospice as an alternative method of care for the terminally ill.

Part II of the Comment is an analysis of the provisions of the federal legislation as well as the licensure and regulatory provisions of two states, New York and Connecticut. The role of the volunteer, central to the hospice philosophy, is discussed in Part III. The fundamental issue of the hospice's liability for the acts of those working in a volunteer capacity is examined.

The care of the terminally ill raises a number of ethical questions which are discussed in Part IV. It is a basic philosophical premise of hospice that a patient has the right to forego life-sustaining treatment. This right is inherent in the patient's right of privacy and right of self-determination. In order to make a decision to participate in the hospice program, a patient and his family must understand the nature of his illness, the prognosis, and the ramifications of his decision to elect hospice care. The physician's duty to disclose this information is also addressed in Part IV.

This Comment concludes that the future of hospice has been firmly secured through the action of Congress which brings hospice under Part A of Medicare. At the same time, professionals and volunteers alike must be sensitive to the need to retain

16. Hurzeler, Barnum & Abbott, *Hospice, The Beginning or the End?: The Impact of TEFRA on Hospice Care in the United States*, 5 U. BRIDGEPORT L. REV. 69, 73-74 (1983). Lawyers should be aware of federal involvement in a previously self-regulated area. As federal reimbursement increases the development of hospice programs, lawyers must advise providers, insurance payers, and patients. *Id.*

17. Tehan, *Has Success Spoiled Hospice?*, HASTINGS CENTER REPORT 11-12 (1985). Regulations impose restrictions raising a concern that a minimum standard of operation has been established with little incentive for improvement. Cost concerns force the hospice staff to make decisions about admission to a hospital setting which are not always in the patient's best interest. *Id.*

18. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 116-17 (1983) [hereinafter cited as PRESIDENT'S COMM'N REPORT]. The federal legislation's reimbursement programs impose restraints on the hospice providers that may limit patient choice and undermine self-determination. The reduced cost factor of hospice may also limit the patient's access to more aggressive treatment. *Id.*

the original concept and philosophy of hospice care. Attorneys must be aware of the unique quality of hospice care and must understand the regulatory process in order to provide counsel to patients.

II. Legislation

A. Federal

The hospice program was considerably strengthened when Congress voted to extend Medicare¹⁹ coverage to hospice care under the Tax Equity and Fiscal Responsibility Act (TEFRA) in 1982.²⁰ Primarily an effort to control the federal government's health care costs, TEFRA became effective on November 1, 1983, and was to terminate in 1986.²¹ On April 7, 1986, Congress enacted the Consolidated Omnibus Budget Reconciliation Act (COBRA), which eliminated the temporary status of the hospice benefit.²²

An important element in the hospice program is the use of the interdisciplinary team.²³ This approach is central to the hospice belief that because a person is a composite of physical, psychosocial, social, and spiritual components, hospice care must be provided by a team in which these various disciplines are represented.²⁴ The hospice standard of an integrated administrative structure²⁵ is followed in the federal provision for a governing body to assume responsibility for the hospice's total operation.²⁶

19. Social Security Act of 1965, 42 U.S.C. § 1395 (1982).

20. 42 U.S.C. §§ 1395b-1 to 1395h, 1395x to 1395z, 1395aa to 1395cc (1982).

21. Pub. L. No. 97-248, 96 Stat. 356, § 122(h)(1)(A) (1982).

22. Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, 100 Stat. 168, § 9123 (1986).

23. A. MUNLEY *supra* note 2, at 321 (citing National Hospice Organization's Standards of a Hospice Program of Care, 1982). The standards formulated by the National Hospice Organization state that "[h]ospice care consists of a blending of professional and nonprofessional services, provided by an interdisciplinary team, including a medical director." 42 C.F.R. § 418.68 (1986). The federal regulations require that the hospice have an interdisciplinary group which includes a doctor, a registered nurse, a social worker, and a pastoral or other counselor. *Id.*

24. NATIONAL HOSPICE ORGANIZATION, THE BASICS OF HOSPICE (1986) (brochure).

25. R. BUCKINGHAM, THE COMPLETE HOSPICE GUIDE 53 (1983) (administrator is liaison with the medical director and director of home care programs).

26. "A hospice must have a governing body that assumes full legal responsibility for determining, implementing and monitoring policies governing the hospice's total operation." 42 C.F.R. § 481.52 (1986).

Hospice standards require a quality assurance program that includes an evaluation of services.²⁷ The federal regulations also mandate "a self-assessment of the quality and appropriateness of care provided."²⁸ An essential element of the hospice program is the availability of home care services on a twenty-four hour basis.²⁹ These provisions ensure that the hospice concept of care is continued in the form and intent in which it was developed.

1. *Election of Hospice Benefits*

Eligibility for hospice care requires that a patient be entitled to Medicare Part A benefits³⁰ and be certified as terminally ill³¹ (defined as a medical prognosis that life expectancy is six months or less).³² When a patient meets the eligibility requirements, a statement must be filed with the hospice that the patient has elected to receive hospice care.³³

After electing the hospice benefit, the patient is entitled to receive hospice care for two ninety-day periods with an additional thirty-day period after the first two periods are completed.³⁴ The hospice must continue to care for the patient, however, until he dies — even if this should extend beyond the election period.³⁵ The hospice then has the financial responsibility of supporting the patient without additional reimbursement from Medicare. This provision severely restricts hospice's ability to accept patients with terminal diseases such as AIDS and Alzheimer's because the lives of these patients may extend be-

27. "There will be a quality assurance program that includes: a. Evaluation of services. b. Regular chart audits. c. Organizational review." A. MUNLEY, *supra* note 2, at 321 (citing National Hospice Organization's Standards of a Hospice Program of Care, 1982).

28. "The findings are used by the hospice to correct identified problems and to revise hospice policies if necessary." 42 C.F.R. § 418.66 (1986).

29. 42 C.F.R. § 418.50(b)(2) (1986).

30. 42 U.S.C. § 1395c (1982). Persons qualifying for Medicare benefits are those over 65 and qualified railroad beneficiaries. See generally 1986 MEDICARE & MEDICAID GUIDE (CCH) 5315-16.

31. 42 C.F.R. § 418.20 (1986).

32. 42 C.F.R. § 418.22(b)(1) (1986).

33. 42 C.F.R. § 418.24(a) (1986).

34. 42 C.F.R. § 418.24(b) (1986). These time segments are defined as "election periods." 42 C.F.R. § 418.3 (1986).

35. 42 C.F.R. § 418.24(c) (1986). Election to receive hospice care continues as long as the patient remains in the care of a hospice. *Id.*

yond the six month prognosis.³⁶ Congress is presently considering legislation, the Medicare Catastrophic Protection Act of 1987,³⁷ which would allow an extension beyond the 210 day limit.³⁸

2. *Waiver of Other Benefits*

The statute and the regulations have provisions requiring hospice beneficiaries to waive certain other Medicare benefits. The waiver includes foregoing hospice care provided by another hospice program (unless the provider hospice makes such arrangements) and foregoing any Medicare services that are related to the patient's terminal illness.³⁹ The services of the patient's attending physician, if other than the hospice physician, are still covered by Medicare.⁴⁰ The statute includes a provision that the patient waives payments for benefits except in "such exceptional and unusual circumstances as the Secretary [of Health and Human Services] may provide."⁴¹

The regulations provide that a patient or a representative may revoke the election of hospice care at any time during the election period.⁴² The patient then resumes conventional Medicare coverage⁴³ and only loses the remaining days of that particular election period. The patient may also make a new election for another period and is entitled to change hospice programs once in each election period.⁴⁴

36. Telephone interview by the author with Andrew Parker, Director of Development, National Hospice Organization (Sept. 4, 1987).

37. H.R. 2470, 100th Cong., 1st Sess., 133 CONG. REC. H6452 (daily ed. July 22, 1987). The bill passed the House on July 22, 1987. As of this writing, the bill is still under consideration by the Senate.

38. 133 CONG. REC. H6468 (1987).

39. See STAFF OF HOUSE SUBCOMM. ON HEALTH, *supra* note 3, at 25. The treatment of illnesses, such as pneumonia, which are brought on by the underlying condition of the patient are considered a hospice service. Payment of other Medicare benefits would be waived by the hospice election. *Id.*

40. 42 C.F.R. § 418.24(e)(2)(iii) (1986).

41. 42 U.S.C. § 1395c(d)(2)(A) (1982). The circumstances that would warrant this exception are not specified in the regulations.

42. 42 C.F.R. § 418.28(a) (1986).

43. 42 C.F.R. § 418.28(c)(2) (1986).

44. 42 C.F.R. § 418.30(a) (1986).

3. Covered Services

The regulations state that hospice services, to be covered by Medicare, "must be reasonable and necessary for the palliation or management of the terminal illness as well as related conditions."⁴⁵ In addition, a written plan of care must be established by the attending physician, the hospice medical director, and the interdisciplinary team before services are provided.⁴⁶ The plan includes assessment of the patient's needs and identification of the services, including the management of discomfort and symptom relief.⁴⁷ Adherence to this provision fulfills the stated goal of the hospice concept of care "to provide symptom control through appropriate palliative therapies."⁴⁸

Included in the covered hospice services are: nursing care, medical social services, physician services, counseling services, short-term inpatient care, medical appliances and drugs, home health aide services, and physical, occupational, and speech therapy.⁴⁹ In addition, there is special coverage for periods of crisis, respite care, and bereavement counseling. Nursing care may be covered on a continuous basis for as much as twenty-four hours a day during periods of crises,⁵⁰ with crisis defined as a period in which the patient requires continuous care to achieve management of acute medical symptoms.⁵¹ Respite care is provided when necessary to relieve the family members or other persons caring for the individual.⁵² The patient is placed in an inpatient facility for periods of up to five days, but only on "an occasional basis."⁵³ This provision leaves considerable discretion to the provider in evaluating the family's need for respite care.

45. 42 C.F.R. § 418.200 (1986).

46. 42 C.F.R. § 418.58(a) (1986).

47. 42 C.F.R. § 418.58(c) (1986).

48. A. MUNLEY, *supra* note 2, at 321 (citing National Hospice Organization's Standards of a Hospice Program of Care, (1982)).

49. 42 C.F.R. § 418.202 (1986).

50. 42 C.F.R. § 418.204(a) (1986).

51. *Id.*

52. 42 C.F.R. § 418.204(b)(1) (1986).

53. 42 C.F.R. § 418.204(b)(2) (1986).

4. Bereavement Services

Since the hospice focus is on the entire family, bereavement follow-up is an important component of a hospice program. Bereavement counseling is considered to be necessary in light of the sufferings of families after a death.⁵⁴ A typical hospice bereavement team includes either a trained counselor or nurse and a highly trained volunteer. The program usually begins with a visit to the family one month after the death, with follow-up calls at three month intervals until the first anniversary of the death.⁵⁵ High risk survivors, such as adolescents or young widows with children, are identified as needing more in-depth, professional counseling.⁵⁶

Bereavement counseling is a required hospice service for Medicare coverage, but it is not reimbursable.⁵⁷ Hospice providers, therefore, depend upon volunteers to assist in fulfilling the bereavement component of the hospice program.

5. Core Services

TEFRA requires that the hospice must "routinely provide directly substantially" all of the nursing, medical, social, physician, and counseling services.⁵⁸ The regulations define "directly" to require that these "core" services be provided by hospice employees.⁵⁹ "'Routinely' and 'substantially' have been generally defined to mean that the services provided directly by the hospice should be adequate to meet the general needs of the hospice."⁶⁰ Hospice staff can use contracted staff only to supplement hospice employees during periods of peak patient loads.⁶¹ Economic factors, as well as the shortage of available personnel, make full-time nursing staffs infeasible in rural and underserved

54. G. DAVIDSON, *supra* note 7, at 49. The consequences of bereavement include increased vulnerability to illness, "increased alcoholism, reactive depression, and long term detrimental effects to children caused by the loss of a parent." *Id.*

55. R. BUCKINGHAM, *supra* note 25, at 140.

56. *Id.* at 141.

57. 42 C.F.R. § 418.204(c) (1986).

58. 42 U.S.C. § 1395x(dd)(2)(A)(ii)(I) (1982).

59. 42 C.F.R. § 418.80 (1986).

60. CONGRESSIONAL RESEARCH SERVICE, EDUCATION AND PUBLIC WELFARE DIVISION, HOSPICE CARE UNDER MEDICARE 6 (1986).

61. 42 C.F.R. § 418.80 (1986).

areas. Hospice service, therefore, can be offered only by the coalition of local health departments and home health agencies. As a result, Congress has allowed a waiver of the nursing care component of the "core services" requirements for rural hospices that were in operation on or before January 1, 1983, and which have demonstrated a good faith effort (as determined by the Secretary) to hire a sufficient number of nurses to provide nursing care directly.⁶² This legislation still does not address the same staffing constraints faced by the many hospices which work with home health agencies in nonrural areas or hospices in rural areas that have come into existence after January 1, 1983. In an effort to address this problem, Senator Robert W. Kasten introduced S.322⁶³ to amend the Deficit Reduction Act to permit a hospice in a rural or medically underserved area, incorporated before January 1, 1985, to contract for nursing care with a Medicare-certified provider. In introducing this bill, the Senator stated, "We have provided coverage for a service many people will never benefit from — not because they are ineligible, but because too few hospices will be able to meet the criteria the law mandates. In effect, we have rendered the hospice benefit virtually nonexistent in many areas."⁶⁴ The bill was referred to the Committee on Finance where it failed to receive the support necessary to enable it to go further.⁶⁵

6. *Costs*

The overwhelming benefit of the hospice program is in providing humane care for persons dying of terminal illness. Reducing the escalating health care costs of the federal government, however, is also an important consideration in the hospice legislation. The Congressional Budget Office estimated that the coverage of hospice care under TEFRA would save \$109 million during the first five years after enactment.⁶⁶ This estimate indicated that each new user of hospice services will save Medicare

62. 42 U.S.C. § 1395x(dd)(5)(A) (Supp. III 1985).

63. S. 322, 99th Cong., 1st Sess., 131 CONG. REC. S893 (daily ed. Jan. 31, 1985).

64. *Id.*

65. Telephone interview by the author with a staff person in Senator Kasten's Washington, D.C. office (Mar. 25, 1987).

66. A. MUNLEY, *supra* note 2, at 289.

\$1,100.⁶⁷

Since there is not a significant savings between hospice inpatient care and traditional hospital care, the major cost saving factor is in the use of home care services. A Blue Cross study in 1982 reported that the average costs for 681 patients under the Connecticut Hospice Program ranged from \$1,257 for home care patients to \$18,927 for patients receiving home care and up to six inpatient admissions.⁶⁸ TEFRA establishes that the amount of payment for hospice care may not exceed a "cap amount" and sets forth the method for computing that amount.⁶⁹ The cap amount is \$6,500 per beneficiary per year and is adjusted for inflationary changes by using the percentage change in the medical care expenditure category of the Consumer Price Index.⁷⁰

The Health Care Financing Administration (HCFA) has established payment amounts according to the level of care furnished to the patient.⁷¹ TEFRA requires that the hospice program provide assurances that the aggregate number of inpatient days in any twelve month period not exceed twenty percent of the aggregate number of days of care provided by the hospice.⁷² An individual patient may stay in an inpatient facility longer than twenty percent of his total number of days in the hospice program,⁷³ but the inpatient days for all patients aggregated may not exceed twenty percent of the total number of days of care given by a hospice provider.⁷⁴ This requirement insures the potential cost benefit by encouraging care in the home.

7. Coinsurance and Intermediaries

TEFRA requires some coinsurance for outpatients.⁷⁵ For palliative drugs and biological prescriptions furnished by the

67. *Id.*

68. *Id.* at 288.

69. 42 U.S.C. § 1395f(i)(2)(A) (1982).

70. 42 C.F.R. § 418.309 (1986).

71. Pub. L. No. 99-272, 100 Stat. 168, § 9123(b)(1)(B) (1986) (current version at 42 U.S.C. § 1395f(i)(1)(B) (Supp. III 1985)). Payment amounts are determined within each of the following categories: routine home care, \$63.17; continuous home care, up to \$68.67; inpatient respite care, \$65.33/day; general inpatient care, \$281.00/day. *Id.*

72. 42 U.S.C. § 1395x(dd)(2)(A)(iii) (1982).

73. Hurzeler, Barnum & Abbott, *supra* note 16, at 90.

74. 42 C.F.R. § 418.302(f) (1986).

75. 42 U.S.C. § 1395e(a)(4)(A)(i), (ii) (1982).

hospice, the patient is liable for five percent of the cost of each prescription.⁷⁶ This amount is not to exceed five dollars per prescription.⁷⁷ Respite care also has a coinsurance requirement equal to five percent of the estimated payments to the hospice program.⁷⁸

Under TEFRA,⁷⁹ the Secretary designates the intermediaries⁸⁰ to service hospice. Hospices may not nominate or change an intermediary.⁸¹ Freestanding hospices receive payment for covered hospice services through an intermediary designated by HCFA. Hospices that are part of other Medicare providers receive payment from the same intermediary that serves the parent provider.⁸²

B. *State Licensure*

TEFRA states that hospice programs must be licensed according to state law in order to be Medicare certified.⁸³ This requirement effectively allows the state to control the quality of care and to protect the consumer. The National Hospice Organization regards the licensing procedure as a means of protecting the hospice name and providing a legal basis for the hospice program.⁸⁴ Laws regarding licensure of hospice have been passed in twenty-six states.⁸⁵

76. 42 C.F.R. § 418.400(a) (1986).

77. *Id.*

78. 42 C.F.R. § 418.400(b) (1986).

79. 42 U.S.C. § 1395h(e)(5) (1982).

80. 42 C.F.R. § 418.3 (1986) (defining intermediary as an organization that has a contract with the Secretary to administer the benefits covered by Medicare's hospital insurance program).

81. 42 C.F.R. §§ 421.104, 421.106 (1986).

82. 42 C.F.R. § 421.117(c) (1986).

83. 42 U.S.C. § 1395x(dd)(2)(F) (1982).

84. NATIONAL HOSPICE ORGANIZATION, HOSPICE LICENSURE AND REGULATIONS: ISSUES AND GUIDELINES 2 (Jan. 1986).

85. The states with hospice licensure requirements are: Arkansas, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Iowa, Kentucky, Maryland, Massachusetts, Michigan, Montana, Nevada, New Mexico, New York, North Carolina, Ohio, Rhode Island, South Carolina, Texas, Virginia, Washington, and West Virginia. Telephone interview by the author with Andrew Parker, Director of Development, National Hospice Organization (Sept. 4, 1987).

1. *Connecticut*

Connecticut developed separate licensure regulations as part of its Public Health Code in 1979.⁸⁶ The regulations are highly specific as to the physical plant of a freestanding hospice. The emphasis on design serves to implement the hospice philosophy by creating a setting that is as homelike as possible in order to provide for the comfort, privacy, and dignity of the patients. Following the hospice concept that the patient and family are a unit of care, the regulations provide for the comfort of the family as well. The statute has a minimum space per bed requirement to provide ample room for patients, families, and visitors.⁸⁷ There are provisions for kitchens where families can prepare food, laundry facilities for family caregivers to launder the patient's personal laundry, a private consultation room, a chapel, and a separate room for viewing the deceased patient's body.⁸⁸

Another unique feature of the Connecticut hospice licensure statute is the mandate that the hospice provide "extensive opportunities for experiences in the arts to patient/family."⁸⁹ The art director must have a graduate degree, clinical experience in a hospital based setting in the arts, and a minimum of five years supervisory experience in the arts and education.⁹⁰ The art director is a member of the interdisciplinary team.⁹¹ The mandate for an art director expresses a state concern for the spiritual and emotional needs of the patient and his family. The state thus goes beyond the federal standards and provides the hospice beneficiary with an even higher standard of care.

2. *New York*

New York State began to develop the hospice concept with the enactment of Chapter 718 of the laws of 1978.⁹² This legislation amended the Public Health Law by defining hospice as a

86. CONN. GEN. STAT. ANN. § 19a-36 (West 1986).

87. CONN. AGENCIES REGS. § 19-13-D4b(a)(6)(B)(3) (1979).

88. CONN. AGENCIES REGS. § 19-13-D4b(a)(7)(E), (J), (T), (U), (CC)(3) (1979).

89. CONN. AGENCIES REGS. § 19-13-D4b(i)(1) (1979).

90. CONN. AGENCIES REGS. § 19-13-D4b(i)(2) (1979).

91. CONN. AGENCIES REGS. § 19-13-D4b(i)(3) (1979).

92. N.Y. PUB. HEALTH LAW §§ 4000-4012 (McKinney 1985).

separate provider entity within the health care system. Chapter 718 also established a hospice demonstration program to evaluate the use of hospices within the health care system of the state.⁹³ The program became effective on January 1, 1980, and terminated on July 1, 1983.⁹⁴

In 1983, the New York State Legislature enacted legislation concerning the establishment and certification of hospices in Article 40 of the Public Health Law.⁹⁵ Under this law, a proposed hospice must obtain a certificate of approval from the Public Health Council. Each hospice must also be approved by the State Hospital Review and Planning Agency and the local health systems agency. The Public Health Council will approve an application only if it is satisfied as to the public need for the existence of the hospice, as well as the competence and financial resources of the proposed hospice.⁹⁶ The Act provides that the Commissioner and the State Hospital Review and Planning Council establish and supervise the standards of services and medical care.⁹⁷ While the statute also allows for contractual agreements between a hospice and providers of other care and services, the hospice must maintain full responsibility for the planning, coordination, and quality of the services.⁹⁸ As of September 1987, seventeen hospice programs had been approved under Article 40 of the Public Health Law.⁹⁹

The Consolidated Omnibus Budget Act of 1985 (COBRA)¹⁰⁰ mandates federal financial participation under Medicaid for hospice services. The New York Legislature enacted S. 9094 to ensure that Medicaid recipients receive hospice services and that hospice providers are reimbursed for these services.¹⁰¹ These state and federal initiatives supporting the hospice program in-

93. NEW YORK STATE SENATE COMMITTEE ON AGING, HOSPICE, ITS CONCEPT AND DEVELOPMENT 14-15 (1982).

94. N.Y. PUB. HEALTH LAW § 4008 (McKinney 1985) extended the program from March 1, 1983 to July 1, 1983.

95. N.Y. PUB. HEALTH LAW §§ 4000-4012 (McKinney 1985).

96. N.Y. PUB. HEALTH LAW § 4004 (McKinney 1985).

97. N.Y. PUB. HEALTH LAW § 4010 (McKinney 1985).

98. N.Y. PUB. HEALTH LAW § 4008(3) (McKinney 1985).

99. Telephone interview by the author with Teresa Scilipote, New York State Department of Health (Sept. 8, 1987).

100. 42 U.S.C. § 1395c (1982).

101. N.Y. SOC. SERV. LAW § 365-a(2)(m) (McKinney 1986).

dicates that the program clearly fills a need in the existing health care system. The philosophy of hospice has been fully accepted and is now supported financially by the federal government, making it a realistic choice of care for the terminally ill.

3. *Private Health Insurance*

Major insurance providers have been supportive of the hospice concept with thirty-nine major carriers offering hospice benefits under their medical insurance plans.¹⁰² Blue Cross and Blue Shield's criteria for supporting hospice care is that there be a community need for hospice and assurance of the quality and cost effectiveness of the hospice program of care.¹⁰³ The insurance companies see hospice as a viable alternative to traditional hospital care and a means of containing the high costs of that care. For example, "Blue Cross of Northeast Ohio reported that the average insurance payment during the last two weeks of life with community hospice was \$699, compared to \$2,140 for traditional hospital care."¹⁰⁴

Hospice is additionally supported by major employers who include a hospice benefit in health insurance plans for their employees. General Electric, RCA, Westinghouse, and the United Auto Workers in New York State are four major organizations that have developed hospice benefit plans.¹⁰⁵

The legislatures of both New York and Connecticut have enacted laws mandating insurance coverage for hospice care. The Connecticut law requires that every individual or group hospital or medical insurance policy provides coverage for home health care,¹⁰⁶ which is defined as the continued care and treatment at home of a person under the care of a physician. Under the statute, this includes hospice patients.¹⁰⁷ Care must be provided by an agency federally certified as a home health agency and licensed by the state.¹⁰⁸

102. Telephone interview by the author with Ira Bates, National Hospice Organization (June 18, 1986).

103. R. BUCKINGHAM, *supra* note 25, at 79.

104. NASSIF, *THE HOME HEALTH CARE SOLUTION* 282 (1985).

105. NEW YORK STATE SENATE COMMITTEE ON AGING, *supra* note 93, at 20.

106. CONN. GEN. STAT. ANN. § 38-174k(a) (West 1986).

107. CONN. GEN. STAT. ANN. § 38-174k(b) (West 1986).

108. CONN. GEN. STAT. ANN. § 38-174k(c) (West 1986).

New York's amendment to the Insurance Law, which became effective January 1, 1986, also requires commercial insurers to provide coverage for hospice care to group policy holders.¹⁰⁹ This legislation adheres to the federal guidelines for Medicare benefits. Hospice care coverage of at least 210 days and five visits for bereavement counseling services must be provided.¹¹⁰

Legislation of this type strongly supports the hospice movement, enhancing the availability of hospices to all who are in need. Since cancer is a disease for which prognostication of death within a few months can be made with acceptable reliability, cancer patients make up most of the hospice patient population.¹¹¹ In 1983, 442,986 people in the United States died of cancer. Of that number, more than half, 282,926, were sixty-five years and older and therefore entitled to Medicare benefits.¹¹² However, the movement toward commercial insurance coverage for hospice care is significant for the remaining population who might be in need of hospice care and without recourse to federal funding.

III. Volunteers

Voluntarism is central to the hospice concept.¹¹³ The roots of hospice lie in the theory of caregivers who, of their own voli-

109. N.Y. INS. LAW § 3221(1) (10)(A) (McKinney 1987).

110. N.Y. INS. LAW § 3221(1) (10)(C) (McKinney 1987).

111. PRESIDENT'S COMM'N REPORT, *supra* note 18, at 112 (approximately 95% of hospice patients have cancer).

112. Telephone interview by the author with Joyce Schull, National Center for Health Statistics (June 18, 1986).

113. H. HAMILTON & H. REID, A HOSPICE HANDBOOK 157-72 (1980) (citing M. Cox, THE CONNECTICUT HOSPICE VOLUNTEER PROGRAM). The Connecticut Hospice is a good example of an organized hospice volunteer program and the role of the volunteer. The program policies state that volunteer services are an integral component of the hospice program, that volunteers do not replace paid positions, and that all applicants must be interviewed by the director and participate in an orientation course. The purpose of these policies is to ensure that volunteers understand the hospice program and are placed in jobs that best utilize their skills. *Id.* at 162-63. The orientation course provides an opportunity for the Director to evaluate the volunteer's suitability for direct patient/family care and helps the volunteer understand the degree of involvement in patient care. *Id.* at 166-70. Volunteers who choose to work directly with patients travel with experienced caregivers for a practical training process. *Id.* at 167. The Connecticut Hospice has successfully shown that trained volunteers are an integral component of hospice care and are vitally important in supporting the program, the patients and their families.

tion, help others in need. By doing so, the hospice volunteer relieves the professional staff and provides support to patients and their families.

A. *TEFRA Requirement*

To be Medicare certified, a hospice must document and maintain a volunteer staff sufficient to provide the equivalent of at least five percent of the total patient care hours provided by the entire staff.¹¹⁴ The hospice must adequately train the volunteers, who may either work in administration or give direct patient care.¹¹⁵ Finally, the hospice must document the cost saving achieved through the use of the volunteers.¹¹⁶

B. *Hospital Liability for Volunteers*

The integral and unique role that volunteers play in the hospice organization suggests that consideration should be given to the tort liability of both the volunteer and the organization. While there have been no reported cases involving hospice, the existing potential for tort action requires that providers and volunteers be aware of the legal ramifications of this issue.

1. *Basis of Liability*

Any consideration of the hospice's liability for negligence of its volunteers must begin with an examination of the hospital's responsibility to those whom it serves. The common-law doctrine of charitable immunity which prevailed for many years in American courts has been abolished in almost all jurisdictions.¹¹⁷ An important decision abrogating charitable immunity is found in *Georgetown College v. Hughes*.¹¹⁸ The *Hughes* court held that charitable corporations are responsible for the negligence of

Id. at 172.

114. 42 C.F.R. § 418.70(e) (1986).

115. 42 C.F.R. § 418.70(a)(b) (1986).

116. 42 C.F.R. § 418.70(d) (1986).

117. Comment, *Toward a More Realistic and Consistent Use of Respondeat Superior in the Hospital*, 29 St. Louis U.L.J. 601, 603 (1985).

118. 130 F.2d 810 (D.C. Cir. 1942) (involving an action brought by a special nurse against a charity hospital for injuries resulting when a swinging door was violently pushed open by a student nurse).

their servants in suits by "strangers."¹¹⁹ Judge Rutledge's majority opinion stated that "charitable corporations should respond as others do for the wrongs inflicted by persons who act in their behalf about their business and within the course of their duties, actual or apparent."¹²⁰ Subsequent decisions abrogating charitable immunity were controlled by public policy considerations such as the increased availability of affordable insurance,¹²¹ the increased solvency of charitable organizations,¹²² the emphasis on liability instead of immunity,¹²³ and the inconsistency of the position that a group which purports to act charitably should be exempt from negligence because of its organizational status.¹²⁴

The principle of "respondeat superior,"¹²⁵ or vicarious liability, has emerged in situations where an employee negligently injures someone while working for the employer organization. This doctrine is based on the theory of risk allocation and a policy determination that employers (and not innocent plaintiffs) should be responsible for an employee's negligence.¹²⁶ In *Bing v. Thunig*,¹²⁷ the court held that respondeat superior applies to sal-

119. *Id.* at 826 (court defined stranger to include all who "carry on the work of the institution" as well as "the relative, friend or stranger who visits the sick").

120. *Id.* at 825.

121. See *O'Connor v. Boulder Colorado Sanitarium Ass'n*, 105 Colo. 259, 96 P.2d 835 (1939) (charity hospital was protected by liability insurance, and enforcement of any judgment recovered would not affect hospital's trust fund or property; paying patient could enforce liability of hospital for negligence in care and medical treatment).

122. "The hospital of today has grown into an enormous business. They own and hold large assets, much of it tax free by statute, and employ many persons." See *Haynes v. Presbyterian Hosp. Ass'n*, 241 Iowa 1269, 1274, 45 N.W.2d 151, 154 (1950). See also Comment, *Patient Recovery—A Poor Prognosis for Hospitals? The Expanding Scope of Hospital Liability*, 10 OHIO N.U.L. Rev. 519, 524 (1983).

123. "The law's emphasis generally is on liability, rather than immunity, for wrongdoing. Charity is generally no defense." *Haynes v. Presbyterian Hosp. Ass'n*, 241 Iowa 1269, 1274, 45 N.W.2d 151, 154 (1950).

124. "It is not too much to expect that those who serve and minister to members of the public should do so, as do all others, subject to that principle and within the obligation not to injure through carelessness." See, e.g., *Bing v. Thunig*, 2 N.Y.2d 656, 666, 143 N.E.2d 3, 8, 163 N.Y.S.2d 3, 10 (1957).

See also *Sessions v. Thomas D. Dee Memorial Hosp. Ass'n*, 94 Utah 460, 78 P.2d 645 (1938) (holding that the mere alleged character of the hospital did not excuse it from liability for negligence as to a paying patient).

125. BLACK'S LAW DICTIONARY 1179 (5th ed. 1979) ("This maxim means that a master is liable in certain cases for the wrongful acts of his servant, and a principal for those of his agent.").

126. S. MACKAUF, *HOSPITAL LIABILITY* 45 (1986).

127. 2 N.Y.2d 656, 143 N.E.2d 3, 163 N.Y.S.2d 3 (1957). In *Bing*, a patient whose

aried physicians employed by hospitals.¹²⁸

Respondeat superior has been applied to situations beyond the scope of the formal employer/employee relationship. In *Mduba v. Benedictine Hospital*,¹²⁹ the court held that the hospital was liable for the negligence of an independent contractor physician in the hospital's emergency room. The court's test for applying vicarious liability was "one of control in respect to the manner in which the work is to be done."¹³⁰

Decisions in cases involving an alleged injury caused by a volunteer while working for a charitable organization¹³¹ have also relied on the doctrine of respondeat superior. Vicarious liability is a negligence¹³² theory which has been applied, in a master-servant relationship, to all tortious conduct of the servant acting within the scope of employment.¹³³ The hospice's potential liability for the acts of its volunteers can be hypothesized by reviewing the relationship of the volunteer to the hospice and the scope of the hospice volunteer's employment.

2. *Volunteer's Relationship to the Hospice*

In establishing a master-servant relationship, the key element is the extent of control¹³⁴ the employer exercises over the

back had been treated with an inflammable and potentially dangerous antiseptic, was severely burned during the course of an operation because of the doctor's alleged negligence in applying an electric cautery to the patient's back. *Id.*

128. "The test should be, for these institutions, whether charitable or profit-making, as it is for every other employer, was the person who committed the negligent injury-producing act one of its employees, and if he was, was he acting within the scope of his employment." *Id.* at 666, 143 N.E.2d at 8, 163 N.Y.S.2d at 11.

129. 52 A.D.2d 450, 384 N.Y.S.2d 527 (1976).

130. *Id.* at 452, 384 N.Y.S.2d at 529 (hospital's control over way doctor managed emergency made doctor an employee rather than an independent contractor). See *Smock v. Brantley*, 76 N.C. App. 73, 331 S.E.2d 714 (1985) (court, relying on fact that hospital did not supervise or control doctor's activities, held that hospital was not liable for alleged negligence of doctors who were assigned to hospital on a rotating basis).

131. *Malloy v. Fong*, 37 Cal. 2d 356, 232 P.2d 241 (1951) (church held liable for volunteer's negligence in causing auto accident); *Leno v. Y.M.C.A.*, 17 Cal. App. 3d 651, 95 Cal. Rptr. 96 (1971) (jury question presented regarding Y.M.C.A.'s liability when volunteer's alleged negligence resulted in student drowning).

132. PROSSER AND KEETON ON TORTS 499-500 (W. Keeton 5th ed. 1984).

133. *Id.* at 501-02.

134. *Id.* at 501 (defining servant as person whose physical conduct in the performance of services is controlled or subject to a right of control).

employee.¹³⁵ Monetary reimbursement is not necessary to establish control.¹³⁶ Rather, control is defined by the extent to which the employer may determine the details of the work.¹³⁷ Indicia of control over the volunteer are also found in the actions of the organization after the alleged tort has occurred. In *Garcia v. Herald Tribune Fresh Air Fund, Inc.*,¹³⁸ a child drowned while staying at the home of a volunteer. After reporting the tragedy, the volunteer was advised by the organization that it would take care of all legal matters, that it provided liability insurance coverage to volunteers, and that it would take over control of the defense of any law suit. The court found these actions to be more than sufficient evidence in support of a finding of a master-servant relationship.¹³⁹

A second element of the master-servant relationship is the master's consent to receive services and his expectation of a benefit from the service.¹⁴⁰ By the nature of their position in the organization, hospice volunteers are performing a service which bestows a benefit on the organization.¹⁴¹ In *Trinity Lutheran Church Inc. v. Miller*,¹⁴² the organization was found to have received a benefit because the volunteer was driving a car for the church program. Benefits can be substantiated in terms of ser-

135. See generally Comment, *Organization's Liability for Torts of Volunteers*, 133 U. PA. L. REV. 1433 (1985).

136. "One volunteering services without an agreement or expectation of reward may be a servant of the one accepting such services." RESTATEMENT (SECOND) OF AGENCY § 225 (1958). See also *Baxter v. Morningside*, 10 Wash. App. 893, 521 P.2d 946 (1974).

[W]here one volunteers or agrees to assist another, to do something for the other's benefit, or to submit himself to the control of the other, even without an agreement for or expectation of reward, if the one for whom the service is rendered consents to its being performed under his direction and control, then the service may be rendered within the scope of a master-servant relationship.

Id. at 896, 521 P.2d at 948.

137. PROSSER, *supra* note 132, at 501. See also *Baxter*, 10 Wash. App. at 898, 521 P.2d at 949. There "was a mutual agreement between [a volunteer and an organization] controlling the time, destination, purpose and especially the means of [the volunteer's] undertaking." For a summary of the hospice control over volunteers' work, see *supra* note 118.

138. 51 A.D.2d 897, 898, 380 N.Y.S.2d 676, 679 (1976).

139. *Id.* at 897-98, 380 N.Y.S.2d at 679.

140. RESTATEMENT (SECOND) OF AGENCY § 221 (1958).

141. See *supra* note 113 and accompanying text.

142. 451 N.E.2d 1099 (Ind. Ct. App. 1983) (church found liable when volunteer's car struck motorcycle).

vices performed for the organization. Volunteer work in the form of instruction,¹⁴³ leadership,¹⁴⁴ ministry,¹⁴⁵ and food service¹⁴⁶ bestows a benefit upon the organization by filling a position in the organizational work force.

3. *Scope of the Hospice Volunteer's Employment*

Determining whether a volunteer's negligent conduct is within the scope of his employment requires an analysis which examines a number of factors.¹⁴⁷ In general, if the volunteer is performing an assigned duty, on the organization's time and authorized premises, and with a purpose to serve the organization, his conduct is considered within the scope of employment.¹⁴⁸ In *Scottsdale Jaycees v. Superior Court*,¹⁴⁹ for example, the court held that the volunteers traveling to a state board meeting were not within the scope of the organization's employment because they were not on the organization's time and authorized premises.¹⁵⁰ On the other hand, evidence that a volunteer divinity student was performing duties subject to ministerial supervision and control supported a conclusion that the student was acting within the scope of his agency while transporting children to a recreational center.¹⁵¹

Hospice is an organization with a unique philosophical orientation.¹⁵² The central concept of hospice is one of caring for

143. *Leno v. Y.M.C.A.*, 17 Cal. App. 3d 651, 95 Cal. Rptr. 96 (1971) (scuba instructor's negligent supervision led to student drowning).

144. *Riker v. Boy Scouts of Am.*, 8 A.D.2d 565, 183 N.Y.S.2d 484 (1959) (Boy Scouts held liable for cubmaster's negligence in supervising exhibition).

145. *Vind v. Asamblea Apostolica de la Feen [sic] Christo Jesus*, 148 Cal. App. 2d 597, 307 P.2d 85 (1957) (both church and volunteer minister held liable for minister's negligent operation of a motor vehicle).

146. *Sokolow v. City of Hope*, 41 Cal. 2d 668, 262 P.2d 841 (1953) (volunteer injured while serving food at a town fair).

147. PROSSER, *supra* note 132, at 502. Relevant considerations include: time, place, and purpose; routine nature of conduct; and master's expectations. *Id.*

148. *Id.*

149. 17 Ariz. App. 571, 499 P.2d 185 (1972).

150. *Id.* at 575, 499 P.2d at 188-90.

151. *Malloy v. Fong*, 37 Cal. 2d 356, 232 P.2d 241 (1951) (thirteen-year-old boy was severely disabled as a result of an automobile accident).

152. A. MUNLEY, *supra* note 2, at 311. "[B]ecause the philosophy demands extensive involvement of volunteers, hospice has always had to rely on members of the community in order to continue This immersion into the community projects a message that hospice is a way of giving care rather than a place for caregiving." *Id.*

and assisting a patient at a very critical time in the life of the patient and his family. Imposing liability on hospice for the torts of its volunteers could be construed as the antithesis to the essence of hospice as a program of caregivers selflessly sharing their time and talents with people in need. Nonetheless, the imposition of liability is a mechanism which encourages organizations to develop good volunteer management practices as hospice has done with its excellent training program. The well qualified and trained hospice volunteer is less likely to cause injuries.¹⁵³ The high degree of control and supervision inherent in the hospice volunteer program creates a goal oriented working environment in which the volunteer feels respected.¹⁵⁴ In assuming responsibility for the volunteer's actions, hospice effectively utilizes the volunteer as a trained member of the work force.

C. *Protective Measures to Reduce Hospice Liability for a Volunteer's Actions*

Certainly the most effective, albeit costly, means of protection for the hospice is full and complete insurance coverage. In recognition of its potential liability, the National Hospice Organization has developed an insurance plan, "Hospice Pak," with Frank B. Hall and Company of Massachusetts, Inc., as program administrator and St. Paul Fire and Marine Insurance Company as program underwriter.¹⁵⁵ The professional liability portion includes up to one million dollars coverage "for errors, omissions, mistakes or negligence of employees and volunteers"¹⁵⁶ Hospice organizations throughout the country are protected by participating in this plan.¹⁵⁷

A dichotomy is created by the fact that exposure to liability can also be reduced by maximizing the supervision and control over the volunteer.¹⁵⁸ While evidence of control increases the potential of liability under respondeat superior, control itself de-

153. Comment, *supra* note 135, at 1450.

154. *Id.* at 1451.

155. NATIONAL HOSPICE ORGANIZATION, NHO HOSPICE PAK (brochure).

156. *Id.* at 2.

157. Telephone interview by the author with Thomas L. O'Hara, Jr., Frank B. Hall & Co. (Mar. 25, 1987).

158. Comment, *supra* note 135, at 1445 (organization's time in training volunteers results in higher level of performance and volunteers who are more careful).

creases the likelihood that the volunteer will perform in a careless manner. The pro-active approach of utilizing high standards in the selection and training of the volunteer is a more positive and productive means of achieving the same desired result.

Hospice volunteers are an integral part of the organization,¹⁵⁹ well prepared,¹⁶⁰ and highly respected. The twin safeguards of insurance coverage and a high degree of control over the volunteers should minimize the potential for hospice liability.

IV. Ethical Considerations

A. *The Decision to Forego Life-Sustaining Treatment*

The hospice philosophy is one of providing support for persons in the last phases of an incurable disease. The philosophy is directed toward maintaining the individual as comfortably as possible and preparing the patient and his family for the impending death. Since hospice is not a curative treatment of care, the patient and his family must be prepared to make the decision to forego life-sustaining treatment.

A patient's right to make decisions about his own body was firmly established in *Schloendorff v. New York Hospital*¹⁶¹ when Justice Cardozo wrote, "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body."¹⁶² The doctrine of informed consent developed as the legal theory that a person has a right to protect his bodily integrity.¹⁶³ Kansas Supreme Court Justice Schroeder set the standard for informed consent when he stated, "Anglo-American law starts with the premise of thoroughgoing self-determination. It follows that each man is considered to be master of his own

159. 42 U.S.C. § 1395x(dd)(E)(i) (1982) (mandating volunteer utilization in provision of care and services and standards which ensure a continuing level of effort to utilize volunteers).

160. "Volunteers . . . are carefully trained and screened before their placement in the most appropriate situation." R. BUCKINGHAM, *supra* note 25, at 45.

161. 211 N.Y. 125, 105 N.E. 92 (1914) (surgery was performed on a female patient who had consented only to being examined).

162. *Id.* at 129, 105 N.E. at 93.

163. "The informed consent doctrine is based on principles of individual autonomy, and specifically on the premise that every person has the right to determine what shall be done to his own body." PROSSER AND KEETON ON TORTS 190 (W. Keeton 5th ed. 1984).

body, and he may, if he be of sound mind, expressly prohibit the performance of lifesaving surgery, or other medical treatment."¹⁶⁴ The hospice philosophy incorporates this doctrine of informed consent when the patient files the election statement acknowledging that he has been given a "full understanding of the palliative rather than the curative nature of hospice care."¹⁶⁵

The doctrine of informed consent has a constitutional basis in the right of privacy established in *Griswold v. Connecticut*.¹⁶⁶ In this landmark decision, Justice Douglas' opinion considered this right to be included within the "penumbra" of the specific guarantees of the Bill of Rights.¹⁶⁷ The *Griswold* Court found two Connecticut statutes forbidding anyone to use contraceptives and forbidding anyone to aid or counsel another in the use of contraceptives, to be in violation of the fourteenth amendment.¹⁶⁸ In *Roe v. Wade*,¹⁶⁹ this constitutional guarantee was found to protect the freedom of a woman to terminate her pregnancy under certain conditions.¹⁷⁰ Subsequently, the constitutional right of privacy of the terminally ill patient was addressed by the seminal decision of the Supreme Court of New Jersey in *In re Quinlan*.¹⁷¹ The court noted that the right of privacy guaranteed under the Constitution is "[p]resumably . . . broad enough to encompass a patient's decision to decline medical treatment . . . in much the same way as it is broad enough to . . .

164. *Natanson v. Kline*, 186 Kan. 393, 406-07, 350 P.2d 1093, 1104 (1960) *clarified* 187 Kan. 186, 354 P.2d 670 (1960) (action by patient against hospital and physician in charge of its radiology department for injuries sustained as a result of an excessive dose of radioactive cobalt during radiation therapy).

165. 42 C.F.R. § 418.26 (1986).

166. 381 U.S. 479 (1965).

167. *Id.* at 484. The *Griswold* court held: "Various guarantees create zones of privacy." *Id.* These guarantees are: first amendment, right of association; third and fourth amendments, right to privacy and security in one's home; fifth amendment, right to be free from self-incrimination; ninth amendment, enumerated rights not to disparage other rights. *Id.*

168. *Id.* at 485.

169. 410 U.S. 113 (1973). A Texas law making abortion a crime except to save the mother's life was found to be violative of the fourteenth amendment. *Id.* at 153.

170. *Id.* at 154 (subject only to the triggering of state interests in protecting potential life).

171. 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976) (court authorized removal of life-sustaining equipment that was maintaining the existence of an irreversibly comatose patient who was not brain dead).

terminate pregnancy under certain conditions."¹⁷²

A New York court in *Eichner v. Dillon*¹⁷³ also concluded that the right to privacy includes the decision by the incurably ill to forego medical treatment.¹⁷⁴ The court recognized that a right to have life-sustaining treatment withheld has also been premised on a common law right to be free from invasion of one's own bodily integrity.¹⁷⁵ The *Eichner* court further noted that although the common-law and the constitutional theories have the same result, there is a difference between them; while common-law rights can be abrogated by statute, constitutional rights cannot.¹⁷⁶ The court concluded that the rights function together to give "the incurably ill the right to determine at what point aggressive therapy should cease."¹⁷⁷ The hospice patient who is capable of making a decision about his medical treatment therefore, has a constitutionally protected right to refuse aggressive therapy and elect hospice care.¹⁷⁸

B. *When a Hospice Patient Lacks Decision-Making Capacity*

1. *The Patient's Interests*

The prospective hospice patient who is competent clearly has a right to refuse aggressive medical treatment.¹⁷⁹ The patient may, however, be unable to make a decision about his med-

172. *Id.* at 40, 355 A.2d at 663.

173. 73 A.D.2d 431, 426 N.Y.S.2d 517 (1980), *modified sub nom. In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981) (Catholic priest petitioned to terminate the respirator assisting an 83-year-old Brother in the same church order).

174. 73 A.D.2d at 459, 426 N.Y.S.2d at 539. The court stated, "as a matter of constitutional law, a competent adult who is incurably and terminally ill has the right, if he so chooses, not to resist death and to die with dignity." *Id.*

175. "Accordingly we conclude that, were Brother Fox competent, he could refuse medical treatment not only as an exercise of his common-law right to bodily self-determination, but also pursuant to his constitutional right to privacy." *Id.* at 461, 426 N.Y.S.2d at 540.

176. *Id.* at 461-62, 426 N.Y.S.2d at 540-41.

177. *Id.* at 462, N.Y.S.2d at 541.

178. See *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980) (court permitted removal of an artificial life-sustaining device from a competent but terminally ill adult). See also PRESIDENT'S COMM'N REPORT, *supra* note 18, at 123; Comment, *In re Conroy: A Limited Right to Withhold or Withdraw Artificial Nourishment*, 6 PACE L. REV. 219, 227 (1986) [hereinafter *In re Conroy: A Limited Right*].

179. See *supra* notes 161-178 and accompanying text.

ical treatment. Many factors, such as the debilitating effects of disease, senility, or trauma, can contribute to the hospice patient's incapacity. While there is no single definition of incompetency,¹⁸⁰ "a person who is unable to understand a situation and make a choice accordingly" is generally deemed to be incapable of making a decision to forego life-sustaining treatment.¹⁸¹

The right to refuse medical treatment as discussed in this Comment refers to the patient's right of privacy and choice which exists even though the incompetent patient is unable to cognitively exercise that right.¹⁸² An incompetent's right to refuse treatment should be equal to a competent's right to do so.¹⁸³ As the *Quinlan* court stated, "[h]er right of privacy . . . should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice."¹⁸⁴

In *Superintendent of Belchertown State School v. Saikewicz*,¹⁸⁵ the right of an incompetent to refuse life-prolong-

180. UNIFORM GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 1-201 (West 1983). A guardian may be appointed by a court to care for an "incapacitated person," defined as "any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, or other cause (except minority) to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions." *Id.*

181. PRESIDENT'S COMM'N REPORT, *supra* note 18, at 45. To be capable of making choices about health care treatment, the individual must have sufficiently stable and developed personal values and goals, an ability to communicate and understand information adequately, and an ability to reason and deliberate sufficiently well about the choices. See Meisel, *The Exception to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 439-53 (1979). "If the patient 'knows,' 'appreciates,' or 'comprehends' the requisite 'elements of disclosure,' he is competent." *Id.* at 446.

182. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664 (irreversibly comatose 21-year-old woman's right to refuse medical treatment could be exercised on her behalf by her guardian). See also *Rasmussen v. Fleming*, No. CV-86-0450-PR (Ariz. July 23, 1987) (available Sept. 8, 1987, on LEXIS, States library, Omni file). The incompetent patient's right to refuse medical treatment still existed despite her incompetency and her failure to articulate her medical treatment desires prior to becoming incompetent. "Because she was incapable of exercising that right, however, we must determine who could exercise that right for her." *Id.*

183. *In re Colyer*, 99 Wash. 2d 114, 124, 660 P.2d 738, 744 (1983) (husband of incompetent in chronic vegetative state sought and received court permission to discontinue life-sustaining treatment). See *Eichner*, 73 A.D.2d at 464, 426 N.Y.S.2d at 542. "We further conclude that by standards of logic, morality and medicine the terminally ill should be treated equally whether competent or incompetent." *Id.*

184. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664.

185. 373 Mass. 728, 370 N.E.2d 417 (1977) (guardian of a profoundly mentally re-

ing treatment was considered. The court recognized a general right in all persons to refuse medical treatment in appropriate circumstances.¹⁸⁶ For the incompetent hospice patient with a prognosis of six months or less of life, the decision to forego life-sustaining treatment is clearly appropriate when the alternative is prolonged suffering and loss of autonomy.¹⁸⁷ The *Saikewicz* decision recognized that because the law tends to treat incompetents the same as competents it may be appropriate in certain circumstances "for a court to consent to the withholding of treatment from an incompetent individual."¹⁸⁸

2. State's Interest

The individual rights of the incompetent patient to refuse medical treatment do not stand in unqualified isolation. Rather, the legitimate state interest in protecting the health and safety of the people must be balanced against the rights of the individual.¹⁸⁹ The right of a patient to refuse life-sustaining medical

tarded patient in a state home could make the decision to withhold chemotherapy treatment for leukemia).

186. *Id.* at 745, 370 N.E.2d at 427.

187. *Id.* at 753-54, 370 N.E.2d at 432. The court accepted the factors identified by the lower court as weighing against administering chemotherapy: the patient's age, the side effects of treatment, unlikely chances of remission, suffering caused by treatment, the patient's inability to cooperate with the treatment, and the quality of his life. The latter was understood by the Massachusetts Supreme Judicial Court as "a reference to the continuing state of pain and disorientation precipitated by the chemotherapy treatment." *Id.* See also *Quinlan*, 70 N.J. at 39, 355 A.2d at 663. In speaking of withdrawing Karen Quinlan's respirator the court stated:

We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case, could be made by a competent patient terminally ill, riddled by cancer and suffering great pain; such a patient would not be resuscitated or put on a respirator in the example described by Dr. Korein, and *a fortiori* would not be kept *against his will* on a respirator.

Id.

188. *Saikewicz*, 373 Mass. at 747, 370 N.E.2d at 428.

189. *Id.* at 740-41, 370 N.E.2d at 424-25. The court formulated these countervailing state interests from a survey of decisions involving the right of an individual to refuse medical treatment. In particular, the court relied on *Application of Pres. and Directors of Georgetown College, Inc.*, 331 F.2d 1000, *cert. denied*, 377 U.S. 978 (1964).

[A] hospital sought [and was granted] permission to perform a blood transfusion necessary to save the patient's life where the person was unwilling to consent due to religious beliefs. . . . The court justified its decision by reasoning that its purpose was to protect three State interests . . . viewed as having greater import than

treatment affects the sanctity of life itself and must therefore be weighed against the state's conflicting interest in preserving life.¹⁹⁰

In the context of medical decisions, the state has a claimed interest in: 1) the preservation of life, 2) the protection of the interests of innocent third parties, 3) the prevention of suicide, and 4) maintaining the ethical integrity of the medical profession.¹⁹¹ The paramount interest is the preservation of human life.¹⁹² There must, however, be a balance struck between the state interest in prolonging life and the interest of an individual in rejecting the traumatic cost of that prolongation.¹⁹³ When the cost to the individual is so great in terms of invasion of bodily integrity and loss of privacy, it has been held to prevail over the state interest in preserving life.¹⁹⁴

The state interest in protecting innocent third parties is centered in the theory that minor children must be protected when a competent adult refuses life-prolonging treatment for himself.¹⁹⁵ A parent who decides to refuse life-sustaining medical

the individual right: (1) the State interest in preventing suicide, (2) a *parens patriae* interest in protecting . . . minor children . . . and (3) the protection of [the] medical profession's desire to act affirmatively to save life without fear of civil liability.

Saikewicz, 373 Mass. at 741, 370 N.E.2d at 425.

190. *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984) (parents seeking to terminate use of their terminally ill child's life support system). "While we agree that the state has a definite interest in preserving life, we must balance that right against the rights of an individual." *Id.* at 370.

191. *Saikewicz*, 373 Mass. at 741, 370 N.E.2d at 425.

192.

There is a substantial distinction in the State's insistence that human life be saved where the affliction is curable, as opposed to the State interest where, as here, the issue is not whether, but when, for how long, and at what cost to the individual that life may be briefly extended.

Id. at 741-42, 370 N.E.2d at 425-26.

193. *Quinlan*, 70 N.J. at 41, 355 A.2d at 664. The court weighed the degree of bodily invasion (respirator, intravenous feeding, catheter) and concluded that Karen's privacy right outweighed the state interest. "[T]he State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest." *Id.*

194. *Saikewicz*, 373 Mass. at 744-45, 370 N.E.2d at 427. The court viewed the state interest in preserving life with "regard to the heavy physical and emotional burdens on the patient" in prolonging life and found that any person, competent or incompetent, has a right to be "spared the deleterious consequences of life-prolonging treatment." *Id.*

195. *Id.* at 742-43, 370 N.E.2d at 426 (discussing state interest in "protecting third

treatment is, in effect, abandoning the minor child whose interests must be protected.¹⁹⁶ Since a parent's death deprives a child of vital care and support, the state has a valid interest in sanctioning medical procedures in an effort to preserve the parent's life.

The third state interest, the prevention of suicide, is based on the common law concept of suicide as a voluntary act of intentional self-destruction.¹⁹⁷ The decision to refuse life-prolonging treatment, however, is merely an intent to allow the disease to take its natural course, with the eventual death coming as a result of the underlying disease.¹⁹⁸ Furthermore, in refusing medical treatment the patient may not have the specific intent to die but rather a wish to live free of the invasive techniques of medical intervention.¹⁹⁹

The final state interest is the maintenance of the ethical in-

parties, particularly minor children, from the emotional and financial damage which may occur as a result of the decision of a competent adult to refuse life-saving or life-prolonging treatment").

196. *See, e.g.*, Application of Pres. & Directors of Georgetown College, Inc., 331 F.2d 1000, *cert. denied*, 377 U.S. 978 (1964) (mother of a seven-month-old child not permitted to refuse life-sustaining blood transfusion).

The state, as *parens patriae*, will not allow a parent to abandon a child, and so it should not allow this most ultimate of voluntary abandonments. The patient had a responsibility to the community to care for her infant. Thus the people had an interest in preserving the life of this mother.

Id. at 1008.

197. R. PERKINS & R. BOYCE, *CRIMINAL LAW* 120 (3d ed. 1982).

198. "A death which occurs after the removal of life-sustaining systems is from natural causes, neither set in motion nor intended by the patient." *In re Colyer*, 99 Wash. 2d at 123, 660 P.2d at 743. *See also Saikewicz*, 373 Mass. at 743 n.11, 370 N.E.2d at 426 n.11 ("The interest in protecting against suicide seems to require little if any discussion." The court noted that a competent's decision to refuse medical treatment is not necessarily considered suicide.). *See also Eichner*, 73 A.D.2d at 467, 426 N.Y.S.2d at 544.

The current Penal Law provides for criminal liability solely as to a third party who aids or promotes the suicide attempt; it does not impose liability against the *individual* himself. . . . Hence, there seems to be no public policy against permitting a terminally ill patient to choose not to delay the inevitable and imminent termination of his life — at least insofar as public policy is reflected in the current Penal Law.

Id.

199. *Satz v. Perlmutter*, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), *aff'd*, 379 So. 2d 359 (Fla. 1980). A competent adult patient in a terminal condition from amyotrophic lateral sclerosis (Lou Gehrig's disease) was being totally sustained by artificial means. His desire to forego treatment was not classified as suicide because of his basic wish to live and the fact that he did not self-induce his disease. *Id.*

tegrity of the medical profession.²⁰⁰ Since medical ethics do not require medical intervention in disease at all costs, this interest is not particularly threatened by permitting competent patients to refuse life-sustaining medical treatment.²⁰¹ In addition, "recent surveys have suggested that a majority of doctors now approve of passive euthanasia and believe that it is being practiced by members of the profession."²⁰²

The strong and legitimate state interest in preserving life is usually outweighed by the patient's right of free choice and self-determination.²⁰³ State intervention may be necessary to protect the health and welfare of innocent third parties.²⁰⁴ The right of a competent adult, however, to decide on the course of his own medical treatment has been found to be paramount to the other three enumerated state interests — preservation of life, prevention of suicide, and maintenance of the integrity of the medical

200. *Saikewicz*, 373 Mass. at 743-44, 370 N.E.2d at 426-27. The court considered this interest as well as the need to allow hospitals the full opportunity to care for people under their control. In concluding that the right to refuse necessary treatment in appropriate circumstances is consistent with existing medical mores, the court stated that "it is not necessary to deny a right of self-determination to a patient in order to recognize the interests of doctors, hospitals, and medical personnel in attendance on the patient." *Id.*

201. *In re Conroy*, 98 N.J. 321, 351-52, 486 A.2d 1209, 1224-25 (1985). A guardian of an incompetent 84-year-old patient with serious and irreversible physical and mental impairments and a limited life expectancy was granted permission to have her life-sustaining treatment withdrawn. The *Conroy* court also noted its finding in *Quinlan*: "[P]hysicians distinguish between curing the ill and comforting and easing the dying; they refuse to treat the curable as if they were dying or ought to die, and . . . they have sometimes refused to treat the hopeless and dying as if they were curable." *Id.* at 352, 486 A.2d 1225 (quoting *In re Quinlan*, 70 N.J. at 47, 350 A.2d at 667).

202. *In re Conroy*, 98 N.J. at 352, 486 A.2d at 1225. See also *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981) (consolidation of *In re Storar* and *Eichner v. Dillon*). In reviewing the *Eichner* case, the dissent stated: "There is reliable information that for many years physicians and members of patients' families, often in consultation with religious counselors, have in actuality been making decisions to withhold or to withdraw life support procedures from incurably ill patients incapable of making the critical decision for themselves." *Id.* at 385, 420 N.E.2d at 75, 438 N.Y.S.2d at 277 (Jones, J., dissenting).

203. "On balance, the right to self-determination ordinarily outweighs any countervailing state interests, and competent persons generally are permitted to refuse medical treatment, even at the risk of death." *In re Conroy*, 98 N.J. at 353, 486 A.2d at 1225.

204. *Holmes v. Silver Cross Hosp.*, 340 F.Supp. 125, 130 (N.D. Ill. 1972). Because the patient had a minor child, a balancing of relevant state interests may have justified the authorization of a blood transfusion against patient's wishes in order to save his life. *Id.*

profession.²⁰⁵

C. *Decisionmaking for the Incapacitated Hospice Patient*

The federal regulations for a Medicare-certified hospice program allow a representative²⁰⁶ of the patient to sign the elective statement for the patient.²⁰⁷ The legal authority for this decisionmaking capacity has been developed by the courts in doctrines of substitute decisionmaking.²⁰⁸ Although the courts have not consistently followed a standard,²⁰⁹ most of the decisions regarding surrogate decisionmaking have focused on one of two standards, the substituted judgment standard²¹⁰ and the best interest standard.²¹¹

205. *In re Conroy*, 98 N.J. at 355, 486 A.2d at 1226.

206. 42 C.F.R. § 418.3 (1986) ("defining representative as a person who is, because of the individual's mental or physical incapacity, authorized in accordance with State law to execute or revoke an election for hospice care or terminate medical care on behalf of the terminally ill individual").

207. 42 C.F.R. § 418.26 (1986) (requiring election statement to include the "individual's or representative's acknowledgement that he or she has been given a full understanding of the palliative rather than curative nature of hospice care, as it relates to the individual's terminal illness").

208. *See generally In re Conroy: A Limited Right*, *supra* note 178, at 229-34.

209. *See, e.g., In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981). The court declined to apply the substituted judgment standard where the profoundly retarded, terminally ill patient had never been competent at any time during his life. In refusing to grant the patient's mother the right to decide whether the patient would want life-prolonging treatment ceased, the court reasoned that it is "unrealistic to attempt to determine" how a person who was never competent to make a decision would choose were he competent. *Id.* at 380, 420 N.E.2d at 72, 438 N.Y.S.2d at 275.

210. *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. Ct. App. 1969) (kidney removed from incompetent to save the life of his normal brother). "The right to act for the incompetent in all cases has become recognized in this country as the doctrine of substituted judgment and is broad enough not only to cover property but also to cover all matters touching on the well-being of the ward." *Id.* at 148.

211. PRESIDENT'S COMM'N REPORT, *supra* note 18, at 135. The best interests standard rests solely on protection of the patient's welfare. Factors to be taken into account include the relief of suffering, the preservation or restoration of functioning, and the quality, as well as the extent, of the life sustained. For a relevant discussion of standards in substitute decision-making, see Comment, *In re Conroy, A Limited Right*, *supra* note 178, at 228-41.

1. *The Quinlan Approach*

The substituted judgment standard, adopted by the court in *Quinlan*,²¹² allowed an incompetent patient's father to give his best judgment as to whether his daughter would have exercised her right to withdraw life-sustaining treatment if she were able.²¹³ By expressing his daughter's intent, Karen Quinlan's father was able to exercise her right of privacy and right to preserve her bodily integrity.²¹⁴

2. *The Saikewicz Approach*

The court in *Saikewicz* acknowledged the benefit of the substituted judgment standard in that the standard respects the integrity and autonomy of the individual.²¹⁵ In this case, however, the incompetent patient was a profoundly retarded man who was never able to express his intent as to the medical treatment.²¹⁶ In formulating its version of the substituted judgment doctrine, the court looked to the history of the doctrine,²¹⁷ and stated that the court must ask the decisionmaker to step into the incompetent's shoes, to include the factor of his permanent incompetency, and then to choose as if he were competent.²¹⁸

3. *The Conroy Approach*

In an important New Jersey Supreme Court decision, *In re Conroy*,²¹⁹ the rights of an elderly, incompetent woman to refuse life-sustaining treatment were at issue. The subjective standard of substituted judgment as formulated by the *Conroy* court is dependent on a clear expression by the patient that she would

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

213. *Id.* at 41, 355 A.2d at 664.

214. *Id.* at 41-42, 355 A.2d at 664. A decision to refuse medical treatment is a valuable incident of the patient's right to privacy. The family's best judgment prevents the destruction of this right. *Id.*

215. *Saikewicz*, 373 Mass. at 751, 370 N.E.2d at 431.

216. *Id.* at 729, 370 N.E.2d at 419.

217. "The English Court accomplished this purpose by substituting itself as nearly as possible for the incompetent, and acting on the same motives and considerations as would have moved him." *Id.* at 752, 370 N.E.2d at 431.

218. *Id.* at 752-53, 370 N.E.2d at 431.

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

have refused the treatment under the circumstances involved.²²⁰ The *Conroy* court enumerated several items which might indicate a patient's intent to refuse treatment, including: a "living will";²²¹ an oral directive to a family member, friend, or health care provider;²²² durable power of attorney;²²³ the patient's articulated reaction to medical treatment administered to others;²²⁴ a person's religious beliefs;²²⁵ and the patient's consistent pattern of conduct as to prior decisions about his own medical care.²²⁶ If however, it is impossible to ascertain the incompetent's wishes, the courts have looked to a best interest standard.²²⁷

On the theory that an incompetent is a ward of the state, the state's *parens patriae*²²⁸ power supports the authority of its courts to allow decisions to be made for an incompetent that serve the incompetent's best interest. The court in *In re Conroy* formulated two best interest tests, a limited objective and a pure

220. "The standard we are enunciating is a subjective one, consistent with the notion that the right that we are seeking to effectuate is a very personal right to control one's own life." *Id.* at 360, 486 A.2d at 1229. See *John F. Kennedy Memorial Hosp. v. Bludworth*, 452 So. 2d 921 (Fla. 1984) (court applied the substituted judgment doctrine in finding a living will persuasive evidence of incompetent patient's intention).

221. D. MEYER, *MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING* 502-03 n.78 (1981). A living will is a written document which advises the physician of the patient's wishes for terminal care. *Id.*

222. PRESIDENT'S COMM'N REPORT, *supra* note 18, at 136-37. An oral directive is an instruction given verbally which specifies the type of care a person wants or does not want to receive. *Id.*

223. *Id.* at 137. A durable power of attorney provides legal authority for an advance directive regarding the type of health care a person wants in the event that he is unable to make decisions for himself. *Id.*

224. See *Eichner*, 73 A.D.2d at 439-40, 426 N.Y.S.2d at 526. During a discussion about the *Quinlan* case, the patient stated that he "would not want any of this extraordinary business . . . to be done for him." *Id.*

225. A. MEYER, *supra* note 221, at 588. All religions except Orthodox Judaism "accept that the withdrawal of extraordinary medical care in cases where death is clinically certain and treatment will only prolong the process of dying is morally proper and does not constitute euthanasia." *Id.*

226. See *In re Lydia E. Hall Hosp.*, 116 Misc. 2d 477, 455 N.Y.S.2d 706 (1982). The completely expressed and repeated views against continued life-sustaining dialysis treatment were honored despite the onset of incompetence due to disease induced coma. *Id.*

227. *In re Conroy*, 98 N.J. 321, 361-62, 486 A.2d 1209, 1229-30 (1985).

228. "[L]iterally 'parent of the country', [*parens patriae*] refers traditionally to [the] role of [the] state as sovereign and guardian of persons under legal disability." BLACK'S LAW DICTIONARY 1003 (5th ed. 1979).

objective test.²²⁹ Under the limited objective test, treatment may be withheld or withdrawn “when there is some trustworthy evidence that the patient would have refused the treatment.”²³⁰ The test also requires that it must be clear to the decisionmaker that the pain and suffering of the treatment outweigh the benefits of continued life.²³¹ This test can be applied in the absence of the clear and concrete evidence of intent necessary to satisfy the substituted judgment test.

In the absence of any evidence of the patient’s wishes, treatment may still be withheld or withdrawn under a pure objective test.²³² This higher standard adds the requirement that the “recurring, unavoidable, and severe pain of the patient’s life with the treatment” renders that life-sustaining treatment inhumane.²³³ The court refused to “authorize decision-making based on assessments of the personal worth or social utility of another’s life, or the value of the life to others.”²³⁴

4. *The Colyer Approach*

In *In re Colyer*,²³⁵ an action to disconnect life support systems, there was “no evidence that Bertha Colyer explicitly expressed her desire to refuse life sustaining treatment.”²³⁶ Yet, evidence that the patient was an independent woman who disliked going to doctors, allowed the court to find that her guardian “was exercising his best judgment as to Bertha’s personal choice when he requested the removal of the life support system.”²³⁷

The family and the physicians of the hospice patient can

229. *In re Conroy*, 98 N.J. at 365, 486 A.2d at 1232. See also Comment, *In re Conroy*, *A Limited Right*, *supra* note 178, at 250-51.

230. *In re Conroy*, 98 N.J. at 365, 486 A.2d at 1232.

231. *Id.*

232. *Id.* at 366, 486 A.2d at 1232.

233. *Id.*

234. *Id.* at 367, 486 A.2d at 1232-33 (court holding that it was inappropriate to allow a surrogate to determine on the basis of the incompetent’s value to society that his life was not worth living).

235. 99 Wash. 2d 114, 660 P.2d 738 (1983).

236. *Id.* at 132, 660 P.2d at 748.

237. *Id.* Evidence that she would have requested withdrawal of treatment as well as absence of any evidence of bad motives convinced the court that Bertha Colyer’s husband was acting in her best interest. *Id.*

utilize these judicial guidelines²³⁸ in making a determination of whether to elect the hospice treatment of care and forego life-sustaining treatment. If an incompetent has previously expressed his wishes, the representative's role is clearly to abide by those wishes. In the absence of such a directive, however, the representative must balance the burden of pain against the benefit of withholding aggressive treatment and choose a course that will promote the patient's well-being.

D. *Choosing the Decisionmaker*

Designating the appropriate surrogate for the incompetent patient is a matter of making a careful evaluation of the person who can best represent the patient's interest. For hospice care, the representative is usually a family member who must make the decision to provide the physical and emotional support of the palliative program.²³⁹ The President's Commission believes that a family member is best designated as surrogate.²⁴⁰ The family is generally most concerned with what is best for the patient and most knowledgeable about the patient's goals and values.²⁴¹ Case law supports the concept that the family, physician, and patient are best qualified to make the decision to forego life-sustaining treatment.²⁴²

The closeness of the family relationship has been emphasized in court decisions with a sensitivity to the family's natural role as surrogate. The *Quinlan* court spoke of the "character and general suitability" of Karen's father and "the high degree of familial love."²⁴³ The *Eichner* court emphasized the length of the relationship and considered a member of the patient's reli-

238. See *supra* text accompanying notes 178, 209-237.

239. R. BUCKINGHAM, *supra* note 25, at 4.

240. PRESIDENT'S COMM'N REPORT, *supra* note 18, at 126-30.

241. *Id.* at 128.

242. See *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984) (parents of terminally ill infant); *John F. Kennedy Memorial Hosp., Inc. v. Blutworth*, 452 So. 2d 921 (Fla. 1984) (wife); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976) (father); *In re Colyer*, 99 Wash. 2d 114, 660 P.2d 738 (1983) (husband); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980) (wife and son).

243. *In re Quinlan*, 70 N.J. at 29-30, 53, 355 A.2d at 657, 660. The *Quinlan* court imposed an additional requirement of approval by a hospital ethics committee. 70 N.J. at 54, 355 A.2d at 671.

gious community to be a member of the patient's family.²⁴⁴

Although courts acknowledge the important role of the family, there have been cases requiring judicial intervention in choosing a surrogate.²⁴⁵ The close family member is the most appropriate representative for the hospice patient.²⁴⁶ Care must be taken, however, to be certain that the representative is not motivated by conflicting interests.²⁴⁷ A son, daughter, or spouse may wish to hasten death and be relieved of the financial and emotional burden of care. Conversely, these same family members may unduly prolong the suffering of the terminally ill patient in a selfish effort to extend the patient's life. Finally, the physician's role in hospice is critical to provide the necessary balance of medical values to the family's emotional concern for the patient.²⁴⁸

244. *Eichner*, 73 A.D.2d at 473, 426 N.Y.S.2d at 548 ("Such an individual who has known and loved the patient personally, presumably for years, can best determine what that patient would have wanted under the circumstances."). The court concluded, however, that there was also a need for a final decision by the judiciary. *Id.* at 550, 355 A.D.2d at 477, *modified sub nom. In re Storar*, 52 N.Y.2d at 382, 420 N.E.2d at 74, 438 N.Y.S.2d at 276. The Court of Appeals held that the family may apply for a judicial ruling but that it is not mandatory. *Id.*

245. *See Saikewicz*, 373 Mass. at 759, 370 N.E.2d at 435. Resolution of the question of whether potentially life-prolonging treatment should be withheld from an incompetent person is the sole responsibility of the judiciary. *In re Hamlin*, 102 Wash. 2d 810, 689 P.2d 1372 (1984) (no family to represent interests of patient who had always been incompetent).

246. Greer & Mor, *How Medicare is Altering the Hospice Movement*, HASTINGS CENTER REPORT (Oct. 1985). In the home health hospice and the independent hospice, during the last weeks of the patient's life, the families provide an average of sixteen hours per day of direct patient care. *Id.*

247.

There is no guarantee that a family member or friend will have only the patient's interest at heart. . . . [A]n heir . . . [may be] motivated more by self-interest . . . [or] [a]t the other extreme, a family member . . . motivated more by guilt than . . . concern for the patient, might consent to treatment which the patient himself would have refused.

Meisel, *The Exceptions to the Informed Consent Doctrine, Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 479-80 (1979).

248. *John F. Kennedy Memorial Hosp., Inc. v. Blutworth*, 452 So. 2d 921, 926 (Fla. 1984). A close family member may exercise the patient's right, but certification is required from the primary treating physician and from two other physicians. *Id.*

V. The Patient's Right to Make an Informed Choice

The basic rights of the terminally ill patient must be preserved by giving him the necessary information to make an informed therapeutic decision.²⁴⁹ The fact that the patient is facing death heightens the need for full disclosure.²⁵⁰ Under the doctrine of informed consent, the physician has a duty both to disclose risks and to obtain consent.²⁵¹ In order to make a decision that respects the patient's right to self-determination, the prospective hospice patient needs information in three areas. The first area is the patient's basic need to be told that his illness is terminal.²⁵² Secondly, the patient must be informed as to the meaning of hospice care and the ramifications of a palliative treatment.²⁵³ Finally, the patient has a right to be informed about the traditional treatment that would be available to him.²⁵⁴

A. *The Patient's Right to Know About His Terminal Illness*

The patient's terminal illness is a material fact about his body. The court in *Gates v. Jensen*²⁵⁵ determined that the physician's knowledge of a glaucoma condition in the patient's body

249. Comment, *Informed Consent and the Dying Patient*, 83 YALE L.J. 1658 (1974). The terminal patient has a right to self-determination through informational consent. "[D]ignity of the patient, informed consent, and the opportunity to arrange one's affairs dictate that the patient should be told of his condition." *Id.* at 1658.

250. LeBlang & King, *Tort Liability for Nondisclosure: The Physician's Legal Obligation to Disclose Patient Illness and Injury*, 89 DICK. L. REV. 1, 22-23 (1984). Full disclosure of a fatal illness such as cancer is required in order that the individual be able to make final life and death decisions. *Id.* at 18-23.

251. "The 'information' element of informed consent concerns the scope of the physician's duty to disclose collateral risks." Waltz & Scheuneman, *Informed Consent to Therapy*, 64 NW. U.L. REV. 628, 630 (1970).

252. Kuzma, *Hospice, the Legal Ramifications of a Place to Die*, 56 IND. L.J. 680 (1980-1981). The reasoning that informed consent is based on the premise of self-determination applies to terminally ill as well as curable patients. *Id.*

253. The physician has a duty to disclose a material risk. "A risk is thus material when a reasonable person, in what the physician knows or should know to be the patient's position, would be likely to attach significance to the risk . . . in deciding whether or not to undergo the proposed therapy." Waltz & Scheuneman, *supra* note 251, at 640.

254. Tietz, *Informed Consent In the Prescription Drug Context: The Special Case*, 61 WASH. L. REV. 367, 372 (1986) (to assist patient in making informed choice, physician must disclose all treatment alternatives and risks associated with them).

255. 92 Wash. 2d 246, 595 P.2d 919 (1979).

created a duty to inform the patient.²⁵⁶ The patient was deprived of her right to choose whether or not to treat for glaucoma because the physician failed to inform her of the test results.²⁵⁷

The Supreme Court of California required disclosure to assist the patient's informed choice in *Truman v. Thomas*.²⁵⁸ The court relied on its previous holding in *Cobbs v. Grant*²⁵⁹ that effective consent must be informed consent.²⁶⁰ The *Truman* court found that the doctor breached his duty to the patient by failing to inform her of the risks inherent in allowing cervical cancer to develop undetected by a pap smear.²⁶¹ The court noted that "the duty to disclose was imposed in *Cobbs* so that the patients might meaningfully exercise their right to make decisions about their own bodies."²⁶² The terminally ill patient must also make choices regarding options for treatment — aggressive intervention or palliative care.²⁶³ Even though death is inevitable, the

256. *Id.* at 251, 595 P.2d at 923.

The existence of an abnormal condition in one's body, the presence of a high risk of disease, and the existence of alternative diagnostic procedures to conclusively determine the presence or absence of that disease are all facts which a patient must know in order to make an informed decision on the course which future medical care will take.

Id.

257. *Id.*

258. 27 Cal. 3d 285, 611 P.2d 902, 165 Cal. Rptr. 308 (1980), *rev'g* 93 Cal. App. 3d 304, 155 Cal. Rptr. 752 (1979) (wrongful death action in doctor's alleged negligent failure to inform patient of the risks of refusing a pap smear test which would have disclosed the presence of cervical cancer, the cause of plaintiff's death).

259. 8 Cal. 3d 229, 502 P.2d 1, 104 Cal. Rptr. 505 (1972) (medical malpractice action against physician for failure to inform patient of risks inherent in surgery for duodenal ulcer).

260.

[T]he patient's consent to treatment, to be effective, must be an informed consent. . . . Therefore, we hold, as an integral part of physician's overall obligation to the patient there is a duty of reasonable disclosure of the available choices with respect to proposed therapy and of the dangers inherently and potentially involved in each.

Id. at 242-43, 502 P.2d at 9-10, 104 Cal. Rptr. at 513-14.

261. *Truman*, 27 Cal. 3d at 292, 611 P.2d at 906, 165 Cal. Rptr. at 312 (patient's refusal to undergo risk-free test does not lessen doctor's duty to disclose material risks attendant to failure to proceed with the test).

262. *Id.* at 292, 611 P.2d at 906, 165 Cal. Rptr. at 312 (court holding that physician was obligated to provide patient with all information material to her decision).

263. LeBlang & King, *supra* note 250, at 5-6 (physician's duty to disclose illness has been expanded in recent years reflecting an emphasis on personal right).

patient has an inherent right to know the nature of his illness and to choose the course of treatment.²⁶⁴

The doctrine of informed consent has two elements: duty to disclose and breach of that duty.²⁶⁵ Failure to disclose all the options available to a terminally ill patient is a breach of the physician's duty.²⁶⁶ Proving negligence under the standard definition of harm²⁶⁷ may, however, be difficult when the protected interest is choice, not physical well-being.²⁶⁸

B. *Patient's Right to Know the Meaning of Palliative Treatment*

The hospice regulations mandate that an informed consent must be obtained from the patient or the patient's representative.²⁶⁹ Under the analysis of informed consent,²⁷⁰ the physician has an affirmative duty to obtain consent and to make disclosures. The unique nature of the hospice program of palliative care²⁷¹ must be carefully explained to the patient to ensure that

264. *Truman*, 27 Cal. 3d 285, 611 P.2d 902, 165 Cal. Rptr. 308 (patient's right to know of risk in foregoing a diagnostic test). See also *Gates*, 92 Wash. 2d 246, 595 P.2d 919 (patient's right to know about presence of disease).

265. Tietz, *supra* note 254, at 372 (patient must prove that failure to inform was proximate cause of injuries).

266. Shultz, *From Informed Consent to Patient Choice: A New Protected Interest*, 95 YALE L.J. 219 at 252 (1985-1986). See also *id.* 250-53.

267. PROSSER, *supra* note 132, at 165 (elements of a cause of action in negligence include actual damage or harm and proof of damage).

268. "[T]he patient with a desire to go home or to a hospice to die, who is instead maintained alive by hospital machinery, might have difficulty establishing 'injury' under definitions of an interest in physical well-being rather than choice." Shultz, *supra* note 266, at 252.

269.

A hospice must demonstrate respect for an individual's rights by ensuring that an informed consent form that specifies the type of care and services that may be provided as hospice care during the course of the illness has been obtained for every individual, either from the individual or the representative.

42 C.F.R. § 418.62 (1983).

270. "The patient must be informed about the treatment before his consent is valid; he must be informed of the nature and purpose of the proposed procedure, the likelihood of success, the hazards of the procedure, and any alternative forms of treatment." Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413, 420 (1979).

271.

Because they recognize that their orientation differs from the norm in health care today, most hospices discuss their philosophy and approach with potential pa-

the consent obtained is an informed consent.²⁷²

The court in *Sard v. Hardy*²⁷³ determined that the scope of a physician's duty to disclose therapeutic risks and alternatives should be governed by the amount of information the patient needs to make an informed decision.²⁷⁴ The physician has a duty to communicate the risks and alternatives to the patient, so as to give that patient the right to weigh the alternatives against his expectations.²⁷⁵ The hospice patient also has a need for information. Although the palliative program may not involve risks, the patient cannot make an informed choice without factual knowledge.

Controlling and alleviating pain is a major focus of the hospice program.²⁷⁶ The hospice approach is to consider all the sources of pain, whether they be psychological, spiritual, social, or physical.²⁷⁷ "Anticipation of extended episodes of pain leads to anxiety, depression, and insomnia for the terminal patient, and these in turn aggravate the physical component of the pain."²⁷⁸ The hospice approach is to break this cycle by treating

tients and their families in order to enhance patient self-determination. . . . Nonetheless, some patients do not realize that hospice admission amounts to a decision to forego . . . resuscitation, continuous cardiovascular monitoring or chemotherapy.

PRESIDENT'S COMMISSION REPORT, *supra* note 18, at 113-14.

272. Waltz & Scheuneman, *supra* note 251, at 637. "Since the patient's interest in making an informed decision is paramount, the first principle is that all material risks should be disclosed to him." *Id.*

273. 281 Md. 432, 379 A.2d 1014 (1977) (action against physician on theory that he negligently performed a tubal ligation on plaintiff and failed to inform her that the procedure was not absolute).

274. *Id.* at 442, 379 A.2d at 1021 (court stated that appropriate test of physician's duty to disclose should focus "on what data the patient requires to make an intelligent decision").

275. *Id.* at 443, 379 A.2d at 1021-22. The court noted that the general standard protects the patient from "a possible general conspiracy of silence, whenever it may exist among physicians." *Id.*

276. "One of the greatest contributions of the first modern hospice, St. Christopher's in England, has been its focus on pain and symptom control." A. MUNLEY, *supra* note 2, at 20.

277. R. BUCKINGHAM, *supra* note 25, at 24 (emphasis on the work of multidisciplinary team in meeting all patient needs). *See also id.* at 21 (use of diversionary activities such as occupational and physical therapy).

278. *Id.* at 20 (discussing the multidimensional task of relieving the terminal patient's discomfort).

all its components.²⁷⁹ The facts of this primary method of treatment should be communicated to the patient to enable him to understand and analyze his options.

Physical pain is treated with narcotics: codeine for moderate pain and morphine for severe pain.²⁸⁰ Patients in the terminal stages of cancer sometimes experience intense pain that can only be relieved by administering such large doses of morphine that the patient suffers from respiratory depression.²⁸¹ There have been no cases of liability attaching to the physician in this situation.²⁸² Nonetheless, the doctor must obtain the consent of the patient or the representative before administering morphine.²⁸³

The innovative nature of hospice may present an even stronger need to familiarize the patient with the components of hospice care. The common expectation is for treatment under the traditional model of aggressive medical intervention. Patients must, therefore, be informed of the nature of the hospice treatment of care, of symptom control, and of the expected manifestations of their illnesses.²⁸⁴

C. *Patient's Right to Seek Traditional Treatment*

The informational needs of a patient suffering from an incurable disease also include the right to know all of the options for treatment that are available to him.²⁸⁵ The patient needs to

279. *Id.* at 20-21 (ascertaining patient needs, educating the patient and family in nursing care, mitigating symptoms of malignant disease).

280. M. HAMILTON & H. REID, *supra* note 113, at 80, 84. See generally PRESIDENT'S COMMISSION REPORT, *supra* note 18, at 277-97 (discussing symptom control for the terminally ill).

281. PRESIDENT'S COMMISSION REPORT, *supra* note 18, at 77 n.100. See also *id.* at 295 ("[S]evere dyspnea . . . can again be treated with morphine. Although this approach is far from perfect, it does allow the physician to improve upon what is otherwise a singularly terrifying and agonizing final few hours.").

282. "[A]lthough medication is commonly used to relieve the suffering of dying patients (even when it causes or risks causing death), physicians are not held to have violated the law." *Id.* at 78.

283. *Id.* at 80. In using morphine or other pain related medicine that can lead to death, the physician must have the consent of the patient or surrogate. *Id.*

284. "[H]ospices risk pressuring patients to accept death too readily and to forego potentially life-sustaining therapies too quickly." *Id.* at 115.

285. Comment, *Informed Consent and the Dying Patient*, 83 YALE L.J. 1632, 1658. The terminal patient has a right to self-determination through informational consent. "[D]ignity of the patient, informed consent and the opportunity to arrange one's affairs dictate that the patient should be told of his condition." *Id.* See also D. HUMPHREY & A.

know the likelihood of remission of the disease and the stages of degeneration that the disease will take.²⁸⁶ The patient must be aware that it is sometimes difficult to prognosticate a life expectancy and that aggressive treatment may be appropriate if the patient lives longer than predicted.²⁸⁷ Recognizing these informational needs, a court, in the landmark decision of *Canterbury v. Spence*,²⁸⁸ held that the physician has a duty to warn of inherent dangers in the proposed treatment and to impart information.²⁸⁹ In this way, the autonomy of the terminally ill patient can be carefully guarded and his right of self-determination can be ensured.²⁹⁰

VI. Conclusion

In less than twenty years, hospice has grown from a grass-roots movement supported by a few dedicated visionaries to a federally subsidized program under the nation's health care system. An innovative approach to the care of the terminally ill, the hospice development significantly impacts the entire health care system.

Congressional support of hospice has been expressed by including hospice under TEFRA,²⁹¹ the Medicare benefit program. As the public responds in increased numbers of Medicare-certified hospice programs, Congress must make a careful assessment

WICKETT, RIGHT TO DIE, 184 (1986) (oncologists would prefer patients to seek anti-cancer therapy before care based on symptom control).

286. Comment, *Voluntary Active Euthanasia for the Terminally Ill and the Constitutional Right to Privacy*, 69 CORNELL L. REV. 363, 381 ("A candid exchange of information about alternative means of dying, particularly between a doctor and the terminal patient, will ensure that the patient's decision is fully informed as well as voluntary.").

287. "Over the past 40 years I have seen the treatment of many disseminated cancers improve to the point at which palliative therapy has evolved into curative therapy. . . . To avoid patient abuse and premature demise I would suggest a 'second opinion' for all patients being considered for hospice terminal care." N.Y. Times, Mar. 26, 1985, at A26, col. 1 (letter to the editor of The New York Times from Dr. Ezra M. Green-span, medical director of the Chemotherapy Foundation).

288. 464 F.2d 772 (1972). The appellant sought damages for personal injuries allegedly sustained as a result of an operation negligently performed by the physician. *Id.*

289. "We now find, as part of the physician's overall obligation to the patient, a similar duty of reasonable disclosure of the choices with respect to proposed therapy and the dangers inherently and potentially involved." *Id.* at 782.

290. See *supra* text accompanying notes 161-78.

291. 42 U.S.C. §§ 1395b-1 to 1395h, 1395x to 1395z, 1395aa to 1395cc (1982).

to ascertain if the intended benefits, better and more cost effective care for the terminally ill, are being realized.

State legislatures have also responded to hospice by enacting licensure laws to provide further protection for the consumer. All states without licensing statutes for hospice should consider enacting such legislation to assure a high standard of hospice care and to extend the benefit of hospice to all its citizens.²⁹²

The philosophy of hospice raises an issue of patient's rights which has legal significance for all concerned in the delivery of hospice care — provider and consumer alike. Hospice sustains the patient's right to choose to end his life naturally without aggressive medical intervention. The element of choice must always be paramount.

As an accepted and supported program of health care, hospice is entering the second phase of its growth. In the next decade, the hospice program will face the challenges of greater participation which will create increased demands on the hospice principles in the delivery of quality care. One significant challenge is meeting the needs of AIDS victims, many of whom do not have primary caregivers, a requisite of the home health model of care.²⁹³ Further legislative action may be needed to provide access to the benefits of hospice care to a greater portion of the population. In this legislative process, however, hospice must be vigilant to preserve its unique focus on the patient and his family.

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292. *Hospice Licensure and Regulations: Issues and Guidelines* (Jan. 1986). The National Hospice Organization outlines five primary reasons for licensing hospices: "protection of terminally ill patients and their families," "protection of the public," "provision of a sound legal basis for practice as part of the health system," "establishment of a mechanism to ensure reimbursement from third party payers," and "protection of the 'hospice' name." *Id.*

293. Telephone interview by the author with Ira Bates, National Hospice Organization (Mar. 23, 1987).