

HOSPICE AT THE CROSSROADS: CAN IT SURVIVE?

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Today the United States hospice movement stands on the shoulders of those who carried it during its first twenty years. The question now confronting that movement is whether its contemporary proponents have the shoulders to permit people in the year 2019 to make the same statement.

The problem hospices face is extinction and/or irrelevancy. I believe that the American hospice movement is at a turning point, a time of great opportunity or the time of its own sunset. It can become a victim of sclerosis brought on by the very structures that fostered its rapid and vigorous growth, or it may evolve to new forms by shedding the shells and removing the barriers that would tether it from continuing to soar.

Twenty years ago, hospices emerged and have been propelled amidst the dynamics of several intertwined forces.¹ These included:

- Demographics of an aging population.²
- Technology advances in medicine - from transplantation to various forms of alimentation, intubation and intensive care.³
- The autonomy movement supporting patient control.⁴
- Ethics awareness and the birth of ethics committees.⁵
- Frequent legal/judicial dialogues and decisions supporting the right to die.⁶
- AIDS and younger deaths with complicated grief.⁷
- Health care upheaval in both delivery and financing.⁸
- Growing interest in death dating back to Kübler-Ross in 1969.⁹

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1. See generally CATHY SIEBOLD, *THE HOSPICE MOVEMENT: EASING DEATH'S PAINS* 38-42 (1992).

2. See *id.* at 40.

3. See *id.* at 38.

4. See *id.* at 43.

5. See *id.*

6. See *id.*

7. See *id.* at 164.

8. See *id.* at 50.

9. ELIZABETH KÜBLER-ROSS, *ON DEATH AND DYING* *passim* (1969).

- Recognition of inadequate pain management and futile care.¹⁰
- Opening of public debate about euthanasia and assisted suicide.¹¹

Since then, even more changes and stressors have impelled the explosion of end-of-life care. Advances in reproductive and genetic medicine, cloning, organ and tissue harvesting may well stimulate even more end-of-life endeavors. Daniel Callahan, founder of the Hastings Center, observed that today's medicine is as different from medicine of 1960, as medicine of 1960 was from that of the middle ages.¹² With these continuing advances, it should be no surprise that hospices which arose in some measure in response to these dynamics find themselves needing to recreate their structures and reproject their vision.

It is also not surprising that armed with such sophisticated technology, the most appropriate paradigm for death is that it is really a failure of medicine and technology eluding our control only because we haven't yet found the right elixir. The prevailing orientation is not just to find disease cures and life prolongation, but to do away with death altogether. There is a tangible desire for the keys to achieving immortality. After all, at this time in our history one can pay to be cryogenically preserved for later resuscitation.¹³ Evidence of this continuing tendency may also be found in the disproportionate amount of funding available for the study of diseases that can cause death rather than for diseases that reduce and/or destroy quality of life. Heart disease, cancer, diabetes and stroke are more endowed than afflictions such as deafness, blindness, osteoporosis, depression and arthritis.¹⁴ It is difficult to integrate death as an ordinary event of life into an environment so assiduously dedicated to eradicating it.

This article will assess the position of American hospices in the midst of these cultural and economic trends.

10. See SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 *passim* (1995).

11. See SIEBOLD, *supra* note 1, at 45.

12. See Daniel Callahan, *Frustrated Mastery: The Cultural Context of Death in America*, 163 THE W.J. MED. 226, 226-30 (1995).

13. See SIEBOLD, *supra* note 1, at 40.

14. See Callahan, *supra* note 12.

STRENGTHS OF HOSPICES:

1. Hospices serve a very large number of people with a primary customer base of 500,000 new patients each year and are still growing at nearly ten percent per annum.¹⁵
2. Hospice's secondary customer base, comprised of caregivers and family members of hospice patients, is conservatively estimated at nearly two million new people each year.¹⁶
3. The current funding base for American hospices is more than three billion dollars.¹⁷ Medicare is currently reimbursing hospices at an annual level of more than two billion dollars and comprises slightly more than sixty percent of all hospice reimbursement.¹⁸
4. Hospice is defined in federal law and also has legal status in most states through licensure laws.¹⁹
5. Hospices have certification, licensing and accreditation programs through federal, state and private bodies, such as the Joint Commission on Accreditation of Healthcare Organization.²⁰
6. Hospices have leadership and advocacy organizations at the state level.²¹
7. Hospice insiders and the general public see hospice as having a powerful and compelling mission.²²
8. Hospices are characterized by extraordinarily dedicated volunteers and paid staff.²³
9. A profound, refined and robust team culture permeates the operations and philosophy of hospice organizations.²⁴

15. See National Hospice Organization, Hospice Fact Sheet (visited Jan. 25, 1999) <<http://www.nho.org/facts.html>>.

16. See Marshall B. Kapp, *Family Caregiving for Older Persons in the Home*, 16 J. LEGAL MED. 1, 5 (1995).

17. See generally Jennifer G. Hickey, *A Safe Haven for the Dying?*, 15 INSIGHT 14, 14 (Jan. 25, 1999).

18. See SIEBOLD, *supra* note 1, at 134.

19. See 42 U.S.C.A. § 1395x(dd)(1) West (1998).

20. See DENICE C. SHEEHAN & WALTER B. FORMAN, *HOSPICE AND PALLIATIVE CARE* 65-69 (1996). Medicare licensure laws require quality to be measured and evidenced through surveys measuring patient satisfaction and standards compliance. See *id.* at 65. Accreditation programs through private bodies provide manuals and guidelines for hospice organizations and include quality improvement surveys and requirements. See *id.* at 65-69.

21. See NATIONAL HOSPICE ORGANIZATION, *THE 1998-99 GUIDE TO THE NATION'S HOSPICES* (1998).

22. See DAVID CLARK, *THE FUTURE FOR PALLIATIVE CARE* 174 (1993) (The success and importance of hospice care has resulted in some assimilation back into mainstream medical care.).

23. See generally LARRY BERESFORD, *THE HOSPICE HANDBOOK* 33-46 (1993) (discussing the hospice team).

24. See ANDREA SANKAR, *DYING AT HOME* 53 (1991).

10. Hundreds of millions in good will dollars are given to hospices through the labor of volunteers.²⁵ A 1992 study conducted by the National Hospice Organization estimated that there were over 96,000 volunteers nationally who were involved with hospice programs, totaling over 5.25 million hours of service.²⁶
11. High consumer satisfaction is evident among hospice providers.²⁷
12. Excellence in the quality of services is the norm for hospices.²⁸
13. There is recognition by many that hospice is *the* treatment of choice for the terminally ill.²⁹ It is known by many as the "gold standard" of care for the terminally ill.³⁰

As positive as these qualities may sound, *there are some serious weaknesses* that hospices are only recently beginning to realize. These include:

1. The basis of the current American hospice model in a partly antiquated 1982 design which assumed a cancer disease progression and was financed accordingly.³¹
2. The significant lack of research supporting the best achievements of hospice care.³²
 - The anecdotally reported most common complaint that hospice patients are referred too late (Why didn't they tell me sooner?) is not established in journals.³³
 - What percent of the 2.2 million annual deaths in the U.S. *should* hospices be caring for? What is the target population

25. Telephone Interview with Joan Richardson, National Council of Hospice Professionals Section Manager and Technical Assistance Manager, National Hospice Organization (January 28, 1999).

26. *See id.*

27. Sheryl Gay Stolberg, *As Life Ebbs, So Does Time To Elect Comforts of Hospice*, N.Y. TIMES, March 4, 1998, at A3.

28. American Society of Clinical Oncology, *Cancer Care During the Last Phase of Life*, 16 J. CLINICAL ONCOLOGY 1986, 1987 (1998).

29. *See* Analee Wulfkuhle, *Old Colony Hospice: Providing Care for Southeastern Massachusetts*, (visited Feb. 16, 1999) <<http://www.oldcolonyhospice.org>>.

30. *See id.*; Sharon M. Steinberg & Susan D. Block, *Caring for Patients at the End of Life in an HMO*, 1 J. PALLIATIVE MED. 387, 397 (1998) (describing hospice care as the gold standard for end-of-life care).

31. Andrew A. Skolnick, *MediCaring Project to Demonstrate, Evaluate Innovative End-of-Life Program for Chronically Ill*, 279 JAMA 1511, 1511-12 (May 20, 1998).

32. *See* STEPHEN R. CONNOR, HOSPICE: PRACTICE, PITFALLS, AND PROMISE, 110-15 (1998).

33. *See* Julie Sneider, *Cold Comfort: Hospice Field Gets Competitive*, 16 BUS. J. MILWAUKEE 23 (Oct. 2, 1998) (statement of Mary Runge, director of hospice services for the Visiting Nurses Association and Aurora Health Care).

of terminally ill within the total population of those who die each year?

- How satisfied are hospice consumers?
 - There is much innuendo about why physicians don't refer or don't refer sooner. What is known about this or why they refer at all? After all, there were 500,000 referrals in the last 12 months.³⁴
3. I do not believe that hospices have particularly well mobilized their extensive consumer base for advocacy, promotion or even lobbying.
 4. I believe there is a glaring lack of physician spokespersons who are strongly identified with hospice. To be sure, important contributions have come from Drs. Ira Byock, Michael Levy, Brad Stuart and others. However, these dedicated people have given most of their time to patient care and program development.
 5. I believe there is a rigidity by many in hospice to over identify with the current model of care.
 6. I believe that there is a certain arrogance exhibited by some in hospice.

In addition to these somewhat internal challenges, there are many external challenges which have arisen during the past few years.

GOVERNMENT SCRUTINY through Operation Restore Trust and the Office of the Inspector General have taken their toll and have tainted the alter boy image that hospices have enjoyed.³⁵ These investigatory endeavors have generated fear among referral sources and providers.³⁶ Although most of this fear has been unwarranted, the scrutiny hit hospices like a torpedo; the damage sustained requires a long recovery period.³⁷

REGULATION that may be inappropriate or overly aggressive has been leveled on hospices through Local Medical Review Policies

34. See National Hospice Organization, Hospice Fact Sheet (visited Jan. 25, 1999) <<http://www.nho.org/facts.html>>.

35. See generally Sneider, *supra* note 33. Operation Restore Trust was launched by the U.S. Department of Health and Human Services in 1995 to investigate certain health care providers' Medicare billings and combat fraud and abuse. See *id.*

36. See *id.*

37. For a brief overview of some of the findings of the Office of Inspector General with respect to hospice care within nursing facilities, see generally *Hospice in the Nursing Home Has Many Problems, But Much Promise*, 10 THE BROWN U. LONG-TERM CARE QUALITY ADVISOR, April 1, 1998. See also Laurie Dove, *Hospice "Working as Intended" Feds Withdraw Charges of Fraud*, 13 WICHITA BUS. J. 5 (MAY 8, 1998) (discussing the effects of governmental scrutiny on Kansas hospice organizations).

(LMRPs).³⁸ These assume near perfection in prognostication and extend beyond the requirements of law intended to assure reasonable access to hospice care. They are based on guidelines which the National Hospice Organization (NHO) developed to increase access for non-cancer patients.³⁹ NHO promoted them to serve as *sufficient conditions* for referral discussions, but they have been converted through the Medicare bureaucracy into *necessary screens* through which referrals will be evaluated for reimbursement.⁴⁰ NHO has called for their suspension until their measurement validity can be established.⁴¹ Hospices feel particularly stung by these policies at a time when the median length of stay is declining precipitously to less than nineteen days, and while there is not even discussion about counterbalancing measures to evaluate the appropriateness of aggressive tests and interventions such as MRIs and surgery hours before death.⁴²

Palliative care has emerged as a significant and legitimate medical endeavor with a strong academic base.⁴³ From its exponents flows significant research contributions establishing the shortcomings in traditional medicine as well as the need for extensive reshaping in our efforts to care for people at the end of life.⁴⁴ The SUPPORT Study⁴⁵ was certainly a wake-up call, but more recent studies published in 1998 document the need for more truthful dialogue with cancer patients⁴⁶ as well as the shortcomings of pain management in the elderly.⁴⁷ Spokespersons articulating this research include Drs. Kathleen Foley, Joanne Lynn, Christine Cassell and many others.⁴⁸ These academic spokespersons credibly articulate the need for a new model of end-of-life care.

38. See *Implementation Update: Report on the Medicare Hospice Benefit and End-of-Life Care*, NEWSLINE (National Hospice Organization), Aug. 1, 1998, at 4.

39. See *id.*

40. See *id.*

41. See *id.*

42. See Sneider, *supra* note 33 (describing declining lengths of stay, specifically in the Milwaukee region).

43. For a general discussion of palliative medicine, see Laurie Petrie, *New Direction: Pain Relief, Caring*, CINCINNATI POST, Sept. 23, 1998, at 1A.

44. See generally *id.*

45. See SUPPORT Principal Investigators, *supra* note 10.

46. See Jane C. Weeks et al., *Relationship Between Cancer Patients' Predictions of Prognosis and Their Treatment Preferences*, 279 JAMA 1709, 1709-14 (1998).

47. See Roberto Bernabei et al., *Management of Pain in Elderly Patients with Cancer*, 279 JAMA 1877, 1877-82 (1998).

48. See, e.g., Joanne Lynn et al., *Health Values of Hospitalized Patients 80 Years or Older*, 279 JAMA 371 (1998).

Unlike hospice, palliative care tends to be physician led and research based.⁴⁹ Its research has attracted significant funding from prestigious institutions.⁵⁰ Here are some specific challenges from proponents of palliative care to hospices.

- To say that hospices neither hasten death nor prolong life is a maxim reflecting some of the religious orientations of hospice, but it is not appropriate for defining a field of medicine.⁵¹
- The palliative care model does not forsake hospice—it applies the hospice model more sensibly than currently fostered by regulation and reimbursement.⁵²
- Many hospitals require a primary caregiver as an admission criterion, thus limiting access.⁵³
- Hospice patients may not call for assistance from emergency services.⁵⁴
- Some hospices will not provide certain comfort oriented treatments such as treatments to prevent blindness from cytomegalovirus in AIDS patients.⁵⁵
- Hospice staff often lack a sense of collegiality, thinking that hospice alone truly cares.⁵⁶
- Hospice is perceived as a “toxic” word.⁵⁷
- Access to palliative care does not require any specific prognosis.⁵⁸
- “In some hospices, physicians and other health care providers may know less about palliative care and pain relief than do physicians referring these patients.”⁵⁹

49. See generally J. Andrew Billings, *What is Palliative Care?*, 1 J. PALLIATIVE MED. 73, 73-80 (Nov. 1, 1998).

50. See *id.*

51. See *id.*

52. See *id.*

53. See, e.g., Sandra Hosking, *Horizon Health Care Begins Hospice Services Here*, J. BUSINESS-SPOKANE, Sept. 17, 1998, at B6. But see Jim Wooddell, *Letter to the Editor*, CHARLESTON GAZETTE, Dec. 31, 1998, at P12 (suggesting that having a primary caregiver is not a prerequisite for admission to some hospice programs. Mr. Wooddell is the Executive Director of Kanawha Hospice Care, Inc.).

54. See generally Billings, *supra* note 49.

55. See *id.*

56. See *id.*

57. See Skolnick, *supra* note 31, at 1512.

58. Cf. Lee Bowman, *Hospice Leaves a Lot of Funding to be Desired*, THE COM. APPEAL, Sept. 20, 1998, at A13 (suggesting that hospice programs require a specific prognosis).

59. Mark J. Lema, *A Compassionate Approach to Pain Management in the Terminally Ill Patient*, HOSP. MED., May 1998, at 11-12.

- “Insofar as palliative care appears to be more academic, scientific, doctor driven, inpatient based, inclusive of specialists . . . [the fear that hospice philosophy will be supplanted is] well founded.”⁶⁰

MISINFORMATION has plagued hospices from its onset twenty years ago and continues to challenge it today. Then it was that hospices only cared for cancer patients or for the affluent elderly. More recent misinformation includes the following:

“The dirty little secret about euthanasia is that it’s common in hospitals, hospices and nursing homes even in the 49 states where it’s illegal.”⁶¹

Several of the above observations are unfounded or true only in the exception. Most hospices *do* provide access to aggressive palliative care and all hospices provide emergency services.⁶² Hospice patients *do not* lose their own physician when they elect hospice care.⁶³ Many hospice benefits *relieve* financial stress; hospice is a Medicare benefit providing full prescription coverage.⁶⁴ Hospice is available in *all* settings, including hospitals and nursing facilities.⁶⁵

Some interpret the finding that sixty-two percent of all Americans die in general hospitals⁶⁶ as a sign that hospice is not working, and therefore conclude that a new model is required. This is somewhat shortsighted and misleading.

- First, a movement that has grown from no patients a short time ago to 500,000 new patients each year today is hardly a failure.
- Second, of the sixty-two percent, some would never be appropriate for hospice care in that they are not terminally ill.
- Third, some of these patients should be referred from hospital settings to more appropriate care centers. Certainly, this is one of the lessons from the SUPPORT research.⁶⁷ Conversations about end-of-life care simply don’t take place as often as they should. No good end-of-life care can occur without such communication.

60. See generally Billings, *supra* note 49, at 77.

61. Adam Cohen, *Showdown for Doctor Death: With His Latest Arrest, Kevoorkian Pushes the Euthanasia Debate a Grisly Step Further*, 152 TIME 46 (Dec. 7, 1998).

62. See 42 C.F.R. § 418.208(a) (1999).

63. See 42 C.F.R. § 418.3 (1999).

64. See 42 C.F.R. § 418.202 (1999).

65. See 42 C.F.R. § 418.98 (1999).

66. See COMMITTEE ON CARE AT THE END OF LIFE, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE*, 31-2 (Marilyn J. Field & Christine K. Cassel eds., National Academy Press 1997).

67. See *supra* note 10, for a discussion of the SUPPORT study.

- Fourth, hospices are permitted to work and offer services within acute care settings. Examples of this already exist and new models are being developed.
- Finally, there is fertile ground for new models of palliative care particularly focused on this sixty-two percent.

THE GROWTH OF GRASS ROOTS EFFORTS is not itself a challenge to hospice since many of them also promote hospice care. However, it is curious that hospices have not themselves been at the forefront of these efforts. In addition to the Hemlock Society⁶⁸ and other groups promoting assisted suicide and euthanasia, there are these:

AGING WITH DIGNITY-FIVE WISHES, founded in 1996 by Jim Towey, is a privately funded, non-profit organization seeking to safeguard human dignity as America ages and to provide more compassionate care for the seriously ill.⁶⁹ Aging with Dignity holds forums that bring together government, business and religious leaders, along with ordinary citizens to formulate solutions to avoid intergenerational conflict.⁷⁰

AMERICANS FOR BETTER CARE OF THE DYING (ABCD) is a coalition of citizens and professionals united to ensure that public policy addresses the needs of individuals and families coping with a fatal illness.⁷¹ ABCD will provide an information network, encouraging and supporting public involvement in correcting system deficiencies.⁷² ABCD seeks to harness the strength of many concerned people to speak with a shared voice.

COMPASSION IN ACTION-TWILIGHT BRIGADE, founded in May 1997 by author Dannion Brinkley, is a group that came together to form an organization whose core mission is that no one die alone.⁷³ The group does not endorse suicide or euthanasia, but rather stands for the right of the dying to be treated with respect and dignity throughout the dying process.⁷⁴ It has mobilized a band of trained volunteers, called the Twilight Brigade who go into homes, hospitals, and hos-

68. See generally Hemlock Society, USA (visited Jan. 24, 1999) <<http://www.privatei.com/hemlock/index.html>>.

69. See Aging with Dignity-Five Wishes (visited Jan. 24, 1999) <http://www.agingwithdignity.org/awd/index_new.html>.

70. See generally *id.*

71. See Americans for Better Care of the Dying (visited Jan. 24, 1999) <<http://www.abcd-caring.com>>.

72. See *id.*

73. See Compassion in Action-Twilight Brigade (visited Jan. 24, 1999) <http://www.twilightbrigade.com/start_overview.html>.

74. See *id.*

pices—anywhere the dying need support, caring, and compassion.⁷⁵ It also provides relief to caregivers and families.

CARING FRIENDS, founded by the Hemlock Society provides information and support programs for the terminally ill members.⁷⁶ It is staffed by trained volunteers willing to be in attendance when a Hemlock member with a terminal illness chooses to end suffering by dying with as much dignity as possible.⁷⁷ Caring Friends provides end-of-life information and support to complement the phone advice and written information.⁷⁸ The service includes helping the dying person explore all reasonable alternatives, such as hospice care, and assuring that no member dies alone unless that is his or her wish.⁷⁹

In my view, the development of these organizations represents a response to needs that hospices could address if they learned to better articulate their mission in the public domain, and if their messages were developed to respond to the current interest in care at the end of life. There is no significant consumer advocacy endeavor dedicated to promoting hospice care.

THERE ARE MANY SIGNS OF HOPE for hospice in particular and end-of-life care in general. Not so long ago, hospice advocates were lamenting that too few professionals were interested in, or knowledgeable about end-of-life care. That has changed with a blossoming of many efforts and initiatives, such as:

- American Society for Clinical Oncology (ASCO):
“Hospice is the best developed model of end-of-life care in the U.S. health care delivery system.”⁸⁰
- American College of Surgeons’ statement encouraging the provision of access to appropriate palliative care and hospice care.⁸¹
- American Medical Association’s (AMA), Education for Physicians on End of Life Care (EPEC) project is to be launched in early 1999.⁸² The project will start by train-

75. *See id.*

76. *See* The Hemlock Society, *Caring Friends Program Announced* (visited Feb. 12, 1999) <<http://www2.privatei.com/hemlock/press-x.html>>.

77. *See id.*

78. *See id.*

79. *See id.*

80. American Soc’y of Clinical Oncology, *Cancer Care During the Last Phase of Life*, 16 J. CLINICAL ONCOLOGY 1986, 1986-89 (1998).

81. *See* Comm. On Ethics, American C. of Surgeons, *Statement of Principles Guiding Care at the End of Life*, 83 BULL. OF THE AM. C. OF SURGEONS 4, 46 (1998).

82. *See* American Medical Association, *The EPEC Home Page* (visited Jan. 24, 1999) <<http://www.ama-assn.org/ethic/epec>>.

ing hundreds of physician trainers whose follow-up work will extend throughout the country in both academic and practice settings.⁸³ A national, grass roots, train-the-trainer program, EPEC is aimed at giving physicians the skills needed to help patients face the end of life, when care options have been exhausted.⁸⁴

One can find evidence of growing and widespread interest in end-of-life issues by examining the explosion of associated web sites providing resources and information ranging from the sublime to the bizarre. A sample of these sites is provided as an exhibit to this article.

Other signs of hope include recognition of hospice through a postage stamp released in 1999, the inclusion of hospice in leadership in the growing number of state initiatives on end of life care.⁸⁵

THERE ARE NUMEROUS INNOVATIONS under way that demonstrate the vitality in the American hospice movement. Some hospices are adding the term 'palliative' to their name while others are dropping the hospice name altogether. Hospice of the North Shore in Chicago is now Palliative Care Center of the North Shore; Hospice Buffalo is now Hospice and Palliative Care Center of Buffalo; the New Jersey Hospice Organization is now the New Jersey Hospice and Palliative Care Organization. Both the Hospice Nurses Association and the Academy of Hospice Physicians changed their names to Hospice and Palliative Nurses Association and the American Academy of Hospice and Palliative Medicine respectively. Although a name change may be seen as superficial, it is also true that more palliative care has been provided through hospices than through any other palliative care entities. Perhaps the name change clarifies the legitimate leadership role of hospice in palliative care.

An initiative developed by the Lawrence University called *Guidelines for the Responsible Utilization of Intensive Care*⁸⁶ sets forth parameters for determining appropriateness of intensive care. The unique feature of this endeavor is that it attempts to determine who qualifies for intensive care before the care takes place. While some may see this as only a form

83. See *id.*

84. See *id.*

85. See United States Postal Service, 1999 Stamp Program, Hospice Care (visited Mar. 8, 1999) <<http://www.usps.gov/images/stamps/99/hospice.htm>>.

86. See The Lawrence University GRUIC Project, *Guidelines for the Responsible Utilization of Intensive Care* (visited Mar. 8, 1999) <<http://www.execpc.com/~wapc/practj.html>>.

of rationing, it is also a possible path to prevent indignities associated with death in isolation in intensive care environments.

There are twenty-one wonderful innovative programs funded by the Robert Wood Johnson Foundation in 1998 which provide an opportunity to test new models designed to expand and extend end-of-life care to new populations and settings.⁸⁷ Some of these three year projects include:

PROJECT SAFE CONDUCT at the Ireland Cancer Center in Cleveland, Ohio, is a collaborative effort by the Ireland Cancer Center at University Hospitals of Cleveland, Hospice of the Western Reserve, and Case Western Reserve.⁸⁸ The project develops palliative care curriculum for medical and nursing schools, offers patients and families a guide to end-of-life treatments and services, and fosters integration of life-prolonging care with holistic palliative care.⁸⁹

PALLIATIVE CARE PROGRAM is a collaboration of the University of Michigan's Comprehensive Cancer Center, Hospice of Michigan, four large medical centers, and physicians' practices.⁹⁰ The collaboration is studying the benefit of introducing hospice care to people earlier in the course of an illness for a better quality of life, and aims to integrate hospice into the plan of care for patients in the advanced stages of cancer while life-prolonging treatment continues.⁹¹

PROJECT ENABLE (EDUCATE, NURTURE, ADVISE BEFORE LIFE ENDS) joins together the Norris Cotton Cancer Center of the Dartmouth-Hitchcock Medical Center, local health care providers, and hospices in Lebanon, Manchester, and Berlin, New Hampshire. The project seeks to coordinate care for cancer patients and educate families and patients with seminars on the issues of life completion and life closure.⁹²

87. See The Robert Wood Johnson Foundation's National Programs (visited Jan. 27, 1999) <<http://www.rwjf.org/nation/jnation2.htm>> (highlighting the national program and its goals); see also The Last Acts Home Page (visited Mar. 14, 1999) <<http://www.lastacts.org>> (click on 'end-of-life grants' for a description of over 80 programs, including the six programs described below).

88. See The Last Acts Home Page, *supra* note 87; see also Ireland Cancer Center & Hospice of the Western Reserve Win \$450,000 Grant to Revolutionize Care of Terminally Ill (visited Jan. 27, 1999) <<http://www.uhhs.com.toheal/hnews/news/news49.html>>. For more information on Project Safe Conduct, call (216) 844-7832.

89. See *id.*

90. See The Last Acts Home Page, *supra* note 87. For more information on Palliative Care Program, call (734) 637-3421.

91. See *id.*

92. See The Last Acts Home Page, *supra* note 87. For more information on Project ENABLE, call (603) 650-6300.

END-OF-LIFE CARE FOR PEOPLE WITH SERIOUS MENTAL ILLNESS is a partnership between the Massachusetts Department of Mental Health, the state's Medicaid Bureau, Emerson Hospital's Hospice Program, and Hospice of the South Shore.⁹³ The project will integrate end-of-life care planning into the mental health planning process, including reciprocal education, development of treatment protocols and tools for assessing patient competence in choosing health care options.⁹⁴

PROJECT PEACE (PALLIATIVE EXCELLENCE IN ALZHEIMER'S CARE) is a collaborative project between the University of Chicago and Hospice of Michigan that will address patient and family preference for end-of-life care and the possibility of earlier full hospice care for Alzheimer's patients. It will also develop advanced care planning and treatment to increase comfort and quality of life.⁹⁵

THE RENAL PALLIATIVE CARE INITIATIVE at the Baystate Medical Center in Springfield, Massachusetts, is a demonstration project to improve end-of-life care among dialysis patients in the Connecticut River Valley Region by improving knowledge of palliative care, challenging denial of death and dying, and widening community and institutional roles.⁹⁶

ROAD SIGNS FOR THE FUTURE

Road signs pointing the way to the future of hospice are clear and merit intense attention by those who wish to foster its advance. What do they say?

Hospices should *assess themselves* for barriers brought on by their own rigidity and occasionally self-righteous attitudes. It is time for this introspection. Some in hospice see themselves as victims of an uncaring medical system. Hospices need to quit whining about the oncologists. Moreover, there is a need for hospices to become educated about the myriad of end-of-life endeavors. This is particularly urgent as most of these endeavors are emerging from outside the domain of hospice care. Furthermore, development of *outcome measures* is essential to establish the true value of hospice care. National caregiver sur-

93. See The Last Acts Home Page, *supra* note 87. For more information on End-Of-Life Care for People with Serious Mental Illness, call (617) 727-9830.

94. See *id.*

95. See The Last Acts Home Page, *supra* note 87. For more information on Project PEACE, call (773) 702-0102.

96. See The Last Acts Home Page, *supra* note 87. For more information on The Renal Palliative Care Initiative, call (413) 784-3376.

vey feedback data is a first step in the right direction. Much more measurement is needed. Finally, extensive outreach and networking is immediately necessary for hospices at the national, state and local levels. Audience expansion is vital. Relationships need to be developed with:

- Advocacy groups dealing with diseases such as amyotrophic lateral sclerosis (ALS), chronic obstructive pulmonary disease (COPD), kidney, heart, Alzheimer's and others.
- Gerontology associations.
- Caregiver organizations, both professional and grass roots. The boomers are ready for this discussion.
- Consumer, service, and religious organizations.
- Wellness and health promotion organizations. A good death may be the ultimate wellness goal. It would be a sign of progress to see "self-determined life closure, a safe and comfortable dying and effective grieving" posted on the bulletin boards in health food stores.
- State initiatives under governors, attorney generals and health authorities.

Hospices need to talk to themselves less and significantly broaden their circle.

There is an enormous opportunity for hospices to provide leadership in the raging end-of-life arena in the United States today. Too often, hospices have been seen as begging for a seat at the table in important end-of-life explorations and programs. Perhaps this has been due to dedication at the bedside and to attending hospice organization needs. Whatever the reasons, the perspective must change if hospice is to be a part of the evolution of end-of-life care. Through its extensive experience and high quality of care, hospices should not be begging to get to the table, or worse, learning that the party already took place. Rather they should be hosting the banquet.

Hospices could develop networks of volunteer representatives or ambassadors at the national, state and local levels to officially serve as liaisons to many non-hospice organizations to extend their capacity.

ACADEMIC RESEARCH is a very serious need. Although Dr. Nicholas Cristakis and others are making important contributions, much more is required. Hospices must support and advocate for research funding. In addition, they should be aligning themselves with academic settings for collaborative studies.

PROFESSIONAL EDUCATION is a priority at all levels. Moreover, it is necessary for all disciplines, not only those associated with hospice

clinical teams, but for others as well. Attorneys, for example, have ample opportunity to contribute to issues in end-of-life care. Influencing curriculum development in academic settings, providing internship opportunities and hosting continuing education seminars are avenues that hospices should consider. Hospices have not been engaged in these endeavors to the extent that they would be welcomed. Some hospices have established institutes just for this purpose. The Hospice of the Florida Suncoast in Largo, Florida⁹⁷ and Hospice of the Western Reserve in Cleveland, Ohio⁹⁸ are two examples. NHO has published many resource materials and has participated in collaborative developments as well.⁹⁹

POLICY ADVOCACY AND PUBLIC ENGAGEMENT are perhaps the two most important priorities for hospices at this present time. NHO has recently completed an evaluation project calling for the elimination of the six month prognosis as a criterion for hospice admission.¹⁰⁰ In time, this would be replaced with an acuity based referral process essentially evaluating if the person is 'sick enough' for hospice care regardless of the time remaining.¹⁰¹ While this is a long term policy goal that would require changing Medicare law, the review also called for the promotion of maximum access to hospice under the current structure with the six month prognosis.¹⁰²

Both of these goals require aggressive and organized efforts. Both require financial resources that must be developed. Both require collaboration and networking with many organizations that do not have hospice as a primary mission. A model for such collaboration may be seen in the 1998 successful effort to prevent the Lethal Drug Abuse Prevention Act from becoming law.¹⁰³ Efforts to thwart the Hyde-Nichols proposal brought together more than fifty-five national organizations under the leadership of NHO.¹⁰⁴

97. The Hospice of the Florida Suncoast, *The Institute Mission Statement* (visited Mar. 1, 1999) <http://www.thehospice.com/index_2.htm>.

98. *See supra* note 88, for a discussion of the Hospice of the Western Reserve in Cleveland, Ohio.

99. To access resource materials, *see* National Hospice Organization, Hospice Fact Sheet (visited Jan. 25, 1999) <<http://www.nho.org/facts.html>>.

100. *See* COMMITTEE ON THE MEDICARE HOSPICE BENEFIT AND END-OF-LIFE CARE, NATIONAL HOSPICE ORGANIZATION, FINAL REPORT TO THE BOARD OF DIRECTORS 11.

101. *See id.* at 18-19, 23.

102. *See id.*

103. *See* Lee Bowman & Scripps Howard, *Medical Groups Assail Drug Bill*, ARIZ. REP., Aug. 23, 1998, at A22.

104. *See id.*

Public engagement may bring hospice care directly to the consumer through promotion, education and advertising. Both hospice patients and their family members who provide care and counsel as health declines are targets for effective and extensive campaigns. Although these efforts are most effective when coordinated at the national and state levels, all hospices and hospice advocates need to be mobilized.

CONCLUSION

- For hospices to survive well, bold initiatives such as those comprising NHO's strategic plan are required.
- Models of hospice encompassing and overlapping with curative care must be tested and studied.
- That which has permitted hospice to move with nearly relentless growth from a volunteer movement to a Medicare covered benefit, poses the threat of becoming a stifling shackle. That is the six month prognosis requirement. It is time for hospices to move beyond this barrier.
- In all these endeavors, hospice should remain the highest standard of end-of-life care. It should be the choice of excellence, comfort, and quality when other choices are suffering, abandonment, or suicide.
- Hospices can move boldly forward from serving 500,000 Americans annually to serving one million people.
- There must be a concomitant goal of increasing the average length of stay to one hundred days.

The hospice movement may end up as an irrelevant but interesting branch on the evolutionary tree by the analysis of those who look back from the vantage point of the year 2019. Or, it can work to remain the central trunk on the tree of end-of-life care in the United States. The future of hospice depends on retaining its core values of team over the individual, of presence over abandonment, of comfort over pain, of life quality and growth over indignity and meaninglessness, and of healing care when cure eludes us. Its future is in its own hands.

A SAMPLING OF WEB SITES AND
PROJECTS CONCERNING END-OF-LIFE ISSUES

Prepared by David Simpson

*I will gladly receive additional site names at
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AgeNet

<http://www.caregivers.com>

Aging With Dignity (Five Wishes)

http://www.agingwithdignity.org/awd/index_new.html

Alliance for Aging Research

<http://www.agingresearch.com>

American Academy of Hospice and Palliative Medicine

<http://www.aahpm.org>

American Board of Internal Medicine

www.ama-assn.org

Project to Improve End-of-Life Patient Care

American College of Physicians-American Society of Internal Medicine

<http://www.acponline.org>

Go to their internal search engine, <http://acponline.org/home/findit.htm>, and enter "hospice".

American Medical Association

www.ama.org

Education for Physicians in End of Life Care.

American Society of Clinical Oncology

www.asco.org

Americans for Better Care of the Dying (ABCD)

<http://www.abcd-caring.com>

Before I Die

www.wnet.org/bid/index.html

Caregiver Chat Room

<http://www.caregiver.com/chat2html>

Center to Improve Care of the Dying (CICD) at George Washington Univ.

<http://www.gwu.edu/~cidc/>

Cultural Guides to Dying, Death and the Afterlife

<http://www.indranet.com/bardo/cultural.html>

Growth House

www.growthhouse.org

The Hastings Center-The Goals of Medicine

http://fount.journalism.wisc.edu/cpn/sections/affiliates/hastings_center.html

Hospice A Photographic Inquiry

http://www.pathfinder.com/@@pdsx2A7AR@o**SGO/twep/artslink/exhibitions/hospice/

Hospice Cares

www.Hospice-cares.com/cons.html

Hospice Hands We Bring

www.growthhouse.org/rings.html

Institute of Medicine: Report of the Committee on Care at the End-of-Life

<http://www2.nas.edu/hcs/21da.html>

International Hospice Institute

<http://www.hospicecare.com/>

Institute for Health Care Improvement

<http://www.ihc.org/collaboratives/underway/bts%2Dendoflife.asp>

Last Acts

http://www.lastacts.org/default_home.html

Medicare Rights Center

<http://www.medicarerights.org/main.html>

Missoula Demonstration Project, Inc.

<http://www.dyingwell.com/MDP.htm>

National Family Caregivers Association

<http://katesdrm.home.mindspring.com/NFCA.htm>

National Hospice Organization

www.nho.org

(Karen Davie, President; Washington, D.C.)

National Public Radio

www.npr.org/programs/death/

Open Society Institute

www.soros.org/death.html

(Julie McCrady, Project Officer; New York, N.Y.)

Project on Death in America

<http://www.soros.org/death/pdiaprojects.html>

The Palliative Page

<http://dialspace.dial.pipex.com/tpwn/avenue/faa48/>

Partners Against Pain

<http://www.partnersagainstpain.com/index.html>

Robert Wood Johnson Foundation

<http://www.rwjf.org/nation/jnation.htm>

Senior Law: Elder Law & Legal Resources on the Web

<http://www.seniorlaw.com/resource.htm>

Sociology of Death and dying

www.trinity.edu/~mkearl/death.html

Supportive Care of the Dying

<http://www.chausa.org/MISSSVCS/EXECSUM.ASP>

Toolkit of Instruments to Measure End of Life Care

<http://www.gwu.edu/~cidc/toolkit/toolkit/htm>

Twilight Brigade

<http://twilightbrigade.com>

United Hospital Fund

<http://www.ahsr.aa.psiweb.com/publications/hsrreports/1996/notes2.htm>

Palliative Care Initiative

University of Chicago-End of Life Resources

<http://ccme-mac4.bsd.uchicago.edu/CCMEDocs/Death>

WEBster's Death, Dying and Grief Guide

www.Katsden.com/

Midwest Bioethics Center, Kansas City, CEO = Myra Christopher