

**LANDMARK LEGISLATION IN NEW YORK AFFIRMS BENEFITS  
OF A TWO-STEP APPROACH TO ADVANCE CARE PLANNING  
INCLUDING MOLST: A MODEL OF SHARED, INFORMED  
MEDICAL DECISION-MAKING AND HONORING PATIENT  
PREFERENCES FOR CARE AT THE END OF LIFE**

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ABSTRACT

This article reviews the development of a two-step approach to advance care planning including the Community Conversations on Compassionate Care (CCCC) and Medical Orders for Life-Sustaining Treatment (MOLST) Programs and recent landmark legislation in New York State in the context of shared, informed medical decision-making to ensure patient preferences for care are honored at the end of life. Health care professionals working with patients, families, health care agents, and surrogates in the health systems must be trained, qualified, and comfortable with the discussions needed for effective, shared, and informed medical decision-making. The key elements utilized in the development and implementation of CCCC and New York's MOLST Programs is addressed. Data from pilot studies is reported. Recommendations are made for development, implementation, and sustainability of a POLST Paradigm Program and integration with the CCCC Program.

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## I. INTRODUCTION

This article explains the development of the CCCC and MOLST Programs in New York State (NYS), integration of the Family Health Care Decisions Act and the Palliative Care Information Act, and the critical role of professional training, consumer education, and system implementation in advance care planning and end-of-life decision-making. In March 2010, a seventeen-year effort to enable legislation that would improve end-of-life decision options culminated in passage and signing of the Family Health Care Decisions Act (FHCDA), a NYS law that enables a patient's family member to make health care decisions when the patient is not able to do so.<sup>1</sup> The key provisions of the FHCDA became effective on June 1, 2010.<sup>2</sup> The New York State Department of Health (NYSDOH) also revised the MOLST form (DOH-5003) in June of 2010 to make it more user-friendly and to align the form with the procedures and decision-making standards set forth in the FHCDA.<sup>3</sup>

The FHCDA was followed by the enactment of the Palliative Care Information Act (PCIA) in NYS.<sup>4</sup> Passage of the PCIA will ensure that patients and their family members and loved ones will be provided information on the key pillars of palliative care: advance care planning, pain and symptom management, and caregiver support.<sup>5</sup>

The implementation of the MOLST Program together with family health decision making and palliative care legislation in NYS dramatically changes the landscape for both patients with advanced chronic illness and dying patients and their families, and serves as an emerging model of shared, informed medical decision-making for the nation. The critical importance of initiating advance care planning for all adults eighteen and older focuses on 1) choosing the right health care agent (also known as a durable power of attorney), 2) discussing values, beliefs, and goals for care with family, loved ones and providers and 3) putting it in writing by completing a health care proxy (also known as a durable power of attorney for health care). This article further describes a paradigm shift in advance care planning across the health-illness continuum,<sup>6</sup> using a two-step approach to advance care planning.

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1. N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2007).

2. *Id.*

3. *Medical Orders for Life-Sustaining Treatment (MOLST)*, N.Y. ST. DEP'T OF HEALTH, [http://www.nyhealth.gov/professionals/patients/patient\\_rights/molst/](http://www.nyhealth.gov/professionals/patients/patient_rights/molst/) (last visited Mar. 30, 2011).

4. *See* N.Y. PUB. HEALTH LAW § 2997-c.

5. *Id.*

6. *See also* Patricia A. Bomba & Daniel Vermilyea, *Integrating POLST into Palliative Care Guidelines: A Paradigm Shift in Advance Care Planning in Oncology*, 4 J. NAT'L COMPREHENSIVE CANCER NETWORK 819 (2006).

## II. CCCC, MOLST, AND ADVANCE CARE PLANNING

Patient preferences for care at the end of life are not consistently followed despite the presence of advance directives completed in accordance with state law.<sup>7</sup> In NYS, two types of advance directives protect a patient's right to request or refuse medical treatments if a patient loses the ability to make medical decisions: the health care proxy created by statute,<sup>8</sup> and the living will which is not a creature of statute, but is honored by the courts.<sup>9</sup>

The NYS health care proxy is a legal document that lets you name someone to make decisions about your medical care, including decisions about life support.<sup>10</sup> The health care proxy form appoints someone to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

The living will lets you state your wishes about medical care in the event that you develop an irreversible condition that prevents you from making your own medical decisions.<sup>11</sup> It becomes effective if you become terminally ill, permanently unconscious or minimally conscious due to brain damage, and will never regain the ability to make decisions. Persons who want to indicate under what set of circumstances they favor or object to receiving any specific treatments use the living will.<sup>12</sup> Increasingly, however, individuals are being counseled that appointing a health care agent is best practice due to the clear limitations of the living will as an advance care planning tool.

Unfortunately, studies have shown that most patients either do not have advance directives<sup>13</sup> or, for those patients who do, advance directives like the living will do not adequately provide health care professionals with explicit instructions for making critical decisions.<sup>14</sup> This finding is consistent with the reality that what really happens to patients in hospitals and other health care settings usually depends on medical orders. Patients' advance directives, or their spoken wishes, and their surrogates' voices often get lost in the regimented hustle and bustle of clinical convention.

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7. See generally Donna A. Casey & David M. Walker, *Clinical Realities of Advance Directives*, 17 WIDENER L. REV. 429 (2011).

8. N.Y. PUB. HEALTH LAW § 2981(2)(a).

9. See, e.g., *In re Univ. Hosp. of State Univ.*, 754 N.Y.S.2d 153, 156 (Sup. Ct. 2002).

10. N.Y. ST. DEP'T OF HEALTH, Health CARE PROXY: APPOINTING YOUR HEALTH CARE AGENT IN NEW YORK STATE 1 (2010), available at <http://www.health.state.ny.us/forms/doh-1430.pdf>.

11. N.Y. ST. DEP'T OF HEALTH, YOUR RIGHTS AS A HOSPITAL PATIENT IN NEW YORK STATE 9 (2010), available at <http://www.health.ny.gov/publications/1449.pdf>.

12. See *id.*

13. *Advance Care Planning—Professionals*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/advanced\\_care\\_planning\\_-\\_professionals](http://www.compassionandsupport.org/index.php/for_professionals/advanced_care_planning_-_professionals) (last visited Mar. 16, 2011).

14. Susan E. Hickman et al., *Hope for the Future: Achieving the Original Intent of Advance Directives*, in IMPROVING END OF LIFE CARE, WHY HAS IT BEEN SO DIFFICULT S26, S26-S27 (Bruce Jennings et al., eds., 2005).

A decade of research has shown that an emerging national model, the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program, more accurately conveys end-of-life care preferences for patients with serious, chronic, life-limiting conditions, and is followed by medical professionals because POLST contains medical orders.<sup>15</sup> Known by a different name, the NYS Medical Orders for Life-Sustaining Treatment, or “MOLST,” Program developed by the Community-wide End-of-life/Palliative Care Initiative<sup>16</sup> (2001) in Rochester, NY is among the first six programs in the country and shares common core elements with other endorsed programs.<sup>17</sup>

Like POLST, the MOLST Program is designed to improve the quality of care seriously ill patients receive at the end of life.<sup>18</sup> It is based on effective communication of patient wishes, documentation of medical orders on a brightly colored pink form, and a promise by health care professionals to honor these wishes. MOLST enables physicians and other health care professionals to discuss and convey the wishes of patients with serious life-limiting illness who have a life expectancy of less than one year, or anyone interested in further defining their end-of-life care wishes. MOLST is outcome-neutral and may be used either to limit medical interventions or to clarify a request for all medically-indicated treatments.<sup>19</sup> Qualified and trained health care professionals participate in discussions leading to completion of a MOLST in all settings, particularly along the long-term care continuum, including the nursing home.<sup>20</sup>

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15. See, e.g., Melinda A. Lee et al., *Physician Orders for Life-Sustaining Treatment (POLST): Outcomes in a PACE Program*, 48 J. AM. GERIATRICS SOC'Y 1219 (2000) (showing that POLST forms are promising tools for indicating patient preferences regarding end of life care); Judy L. Meyers et al., *Physician Orders for Life-Sustaining Treatment Form: Honoring End-of-Life Directives for Nursing Home Residents*, J. GERONTOLOGICAL NURSING, Sept. 2004, at 37 (stating that POLST forms enable patients to effectively express their life-sustaining treatment choices to physicians); Terri A. Schmidt et al., *The Physician Orders for Life-Sustaining Treatment Program: Oregon Emergency Medical Technicians' Practical Experiences and Attitudes*, 52 J. AM. GERIATRICS SOC'Y 1430, 1434 (2004) (reporting that EMTs found POLST forms useful in making treatment decisions).

16. *About Us: Background and Mission*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/about\\_us](http://www.compassionandsupport.org/index.php/about_us) (last visited Feb. 21, 2011) [hereinafter *Background and Mission*].

17. See, e.g., *Medical Orders for Life-Sustaining Treatment—Professionals: Development of the MOLST Program*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/molst/development](http://www.compassionandsupport.org/index.php/for_professionals/molst/development) (last visited Mar. 30, 2011) [hereinafter *Development of the MOLST Program*].

18. See Patricia Bomba & Charles P. Sabatino, *POLST: An Emerging Model for End-of-Life Care Planning*, ELDERLAW REP., Feb. 2009, at 1.

19. See *Medical Orders for Life-Sustaining Treatment—Professionals: MOLST Form*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/molst/molst\\_form](http://www.compassionandsupport.org/index.php/for_professionals/molst/molst_form) (last visited Mar. 30, 2011) [hereinafter *MOLST Form*].

20. *Id.*

MOLST provides resuscitation instructions if the patient has no pulse and/or is not breathing.<sup>21</sup> Additionally, the medical orders provide direction about other types of life-sustaining treatment that the patient may or may not want, for example, decisions about intubation and mechanical ventilation, transport to the hospital, ICU care, artificial nutrition and hydration, and antibiotics.<sup>22</sup> Key features of the program include education, training, and a quality improvement process.

Prior to 2010, NYS had been one of the few states that did not authorize family members to make health care decisions for incapacitated loved ones, except for decisions related to cardiopulmonary resuscitation when the patient's heart and/or breathing stops. Thus, the CCCC program was developed to support the MOLST Program at a time when no one—not even a concerned family member—had the right to make decisions about medical treatment for patients who lacked capacity, unless the patient had signed a health care proxy or left "clear and convincing evidence" of his or her treatment wishes.<sup>23</sup> As a result, some incapacitated patients were denied appropriate palliative treatment that improved quality of life and reduced suffering, while others were subjected to burdensome, highly invasive treatment that potentially violated their wishes and prolonged their suffering. Further, the CCCC program focuses on preparing for a sudden unexpected illness, from which one expects to recover, as well as the dying process and ultimately death.

Advance care planning is a key pillar of palliative care and is recognized as a critical process. There is a role for both traditional advance directives, like the health care proxy, and the MOLST in a two-step approach to advance care planning, a process of planning for future medical care in case you are unable to make your own decisions is critical. Advance care planning begins with conversations among families and other trusted individuals, such as friends and doctors.<sup>24</sup> The process builds trust and establishes relationships among family, close friends, health care professionals, and others who will care for you or be with you as you approach death. Advance care planning permits peace of mind for the individual and family by reducing uncertainty and helping to avoid confusion and conflict over care.<sup>25</sup>

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21. *Id.*

22. *Id.*

23. *See In re Univ. Hosp. of State Univ.*, 754 N.Y.S.2d 153, 157 (Sup. Ct. 2002) (setting out that "[t]he patient's wishes must be established by clear and convincing evidence").

24. *MOLST Form*, *supra* note 19 (discussing the individuals with whom it is recommended to have this conversation and recommending the documentation in the medical record).

25. *See Casey & Walker*, *supra* note 7, at 429.

## III. RESEARCH ON ADVANCE CARE PLANNING AND END-OF-LIFE CARE

The Institute of Medicine, in its 1999 report *Approaching Death: Improving Care at the End of Life*, stated end-of-life care must improve on all levels.<sup>26</sup> The need for improvements in the quality of this care is growing. By 2030, twenty percent of the American population, or seventy million people, will be over the age of sixty-five.<sup>27</sup> Since seventy-five percent of individuals dying each year are over the age of sixty-five,<sup>28</sup> there is a greater need for appropriate person-centered end-of-life care that integrates shared, informed medical decision-making.

Humane care for those approaching death is a social obligation not adequately met in the communities we serve. Too often, death is viewed as a medical failure rather than the final chapter of life. As a result, many people fear a protracted, technologically-over-treated death, abandonment during a time of need, and profound suffering of self and family.<sup>29</sup> Currently, conversations about death are too frequently avoided until a crisis occurs, resulting in inadequate advance care planning and patient preferences not being known or honored. Surveys reveal more than seventy percent of surveyed Americans indicated that they wish to die at home.<sup>30</sup> Yet, only twenty-five percent of Americans die in their home and seventy-five percent die in institutions.<sup>31</sup>

Providing quality medical care is more than supplying appropriate, timely medical interventions without error. Quality medical care is person-centered and respects an individual's wishes, values, and beliefs. This is more difficult when the person requiring care is unable to communicate his or her own wishes, which is too often the case in end-of-life care.

*A. Advance Care Planning Discussions*

Since the Patient Self-Determination Act passed in 1990,<sup>32</sup> the current system of communicating end-of-life care wishes solely using traditional advance directives, such as the living will, has proven insufficient. Traditional

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26. INST. OF MED., *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 1 (1997).

27. LAST ACTS, *MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA TODAY* 39 (2002) [hereinafter *MEANS TO A BETTER END*].

28. *Id.* at 16.

29. See Emily Clough, *A Critique of Advance Directives and Advance Directives Legislation*, 11 *APPEAL: REV. CURRENT L. & L. REFORM* 16, 20-21 (2006) (discussing the fear of dying and prolonged and needless suffering).

30. *MEANS TO A BETTER END*, *supra* note 27, at 13.

31. *See id.* at 13.

32. Patient Self-Determination Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388-115, 1388-204 (codified as amended in scattered sections of 42 U.S.C.).

advance directives require individuals to recognize the importance of advance care planning, understand medical interventions, evaluate personal values and beliefs, and communicate their wishes to their agents, loved ones, physicians, and health care providers.

A study by Tierney et al.,<sup>33</sup> found that elderly patients with chronic illnesses who discussed advance directives with their primary care physicians, showed significantly greater satisfaction with their care than those who did not have advance care planning discussions.<sup>34</sup> The strongest predictor of satisfaction with care was the presence of advance care planning discussions.<sup>35</sup>

In a retrospective study of over 1,500 decedents, bereaved family member reports showed an association between completion of an advance directive and greater hospice use, as well as fewer issues with communication.<sup>36</sup> However, there were unmet pain needs and concerns about emotional support for both the patient and family.<sup>37</sup>

Unfortunately, traditional advance directives like the living will apply to future circumstances, require further interpretation by the agent and health care professionals, and do not result in actionable medical orders. The situation is further complicated by the difficulty in defining “terminal” or “irreversible” conditions and accounting for the different perspectives that physicians, agents, and loved ones bring to the situation. For example, a patient with dementia nearing the end of life eats less, has difficulty managing secretions, aspirates, and often develops pneumonia. While end-stage dementia is “terminal,” pneumonia may be potentially “reversible.” Decisions regarding care depend upon interpretations of prior conversations, physicians’ estimates of prognosis, and, possibly, the personal convictions of the physician, agent, and loved ones. The presence of the living will alone does not help clarify the patient’s wishes in the absence of antecedent conversation with the family, close friends, and the patient’s personal physician.

Traditional advance directives like the health care proxy focus on proactive discussions of personal values, beliefs, and goals of care. It is extremely important to choose the right health care agent who will make decisions in accordance with the patient’s current values and beliefs, and that the chosen health care agent is able to separate their personal values from the patient’s values. Further, it is essential that conversations ensue with family, loved ones, and providers. A study by Coppola et al. discovered that family members correctly identified the patient’s wishes more than seventy percent of

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33. William M. Tierney et al., *The Effect of Discussions About Advance Directives on Patients’ Satisfaction with Primary Care*, 16 J. GEN. INTERNAL MED. 32 (2001).

34. *Id.* at 37.

35. *Id.* at 38.

36. Joan M. Teno et al., *Association Between Advance Directives and Quality of End-of-Life Care: A National Study*, 55 J. AM. GERIATRICS SOC’Y 189, 193-94 (2007).

37. *Id.* at 193.

the time.<sup>38</sup> Additionally, family members were two to three times more likely to choose over-treating versus under-treating the patient.<sup>39</sup> Without conversation, wishes will not be known.

A study published in 2009 revealed end-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals.<sup>40</sup> Aggressive care is associated with worse patient quality of life and worse bereavement adjustment.<sup>41</sup>

Published in 2010, a randomized controlled study of 151 patients with newly diagnosed non-small cell lung cancer examined early palliative care plus standard oncologic care versus standard oncologic care alone.<sup>42</sup> Quality of life and mood were assessed at baseline and at twelve weeks.<sup>43</sup> The primary outcome was change in quality of life at twelve weeks.<sup>44</sup> The study revealed fewer patients in the early palliative care group received aggressive end-of-life care (thirty-three percent compared to fifty-four percent, P=0.05).<sup>45</sup> Further, the median survival was longer among patients receiving early palliative care (11.6 months compared with 8.9 months, P=0.02).<sup>46</sup>

### B. Completion Rates of Advance Directives

Sadly, the advance directive completion rate in our nation has not significantly increased since the passage of the Patient Self-Determination Act in 1990.<sup>47</sup> At that time, seventy-five percent of Americans approved of the notion of patient self-determination and twenty percent had completed a living will.<sup>48</sup> More than a decade later, the 2002 *Means to a Better End* report revealed only fifteen to twenty percent of Americans had completed some form of

38. Kristen M. Coppola et al., *Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives*, 161 ARCHIVES INTERNAL MED. 431, 436 tbl.2 (2001).

39. *Id.*

40. Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES INTERNAL MED. 480, 487 (2009).

41. *Id.* at 482-84.

42. Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 734, 736 (2010).

43. *Id.* at 735.

44. *Id.*

45. *Id.* at 738.

46. *Id.*

47. MEANS TO A BETTER END, *supra* note 27, at 9.

48. Vicki Joiner Bowers, Comment, *Advance Directives: Peace of Mind or False Security?*, 26 STETSON L. REV. 677, 691 (1997) (citing to a 1990 Gallup Poll and indicating that while seventy-five percent of Americans were in favor of the advance derivative concept, only twenty percent had actually executed one); Kimber P. Richter et al., *Promoting the Use of Advance Directives: An Empirical Study*, 4 ARCHIVES FAM. MED. 609, 609 (1995) (describing a 1991 Gallup Poll where seventy-five percent of respondents indicated they would like to have a living will but only fifteen percent reported having completed one).



advance directive.<sup>49</sup> It is likely that even fewer have had the open, honest conversations regarding end-of-life care wishes, the critical element of the advance care planning process. Documents cannot account for every circumstance and, therefore, the family and health care agent need to know the patient's general wishes for the end of life, knowledge that is best attained through open conversations.

Subsequent to the intense media pressure surrounding the Terry Schiavo case, a nationwide poll conducted by the Pew Research Center in 2005 found that ninety-five percent of adults were aware of the need for advance directives, but only twenty-nine percent of Americans had completed a living will (health care proxy completion rates were not assessed).<sup>50</sup>

### *C. POLST Paradigm: A Model for Ensuring Patient Preferences are Honored*

A growing body of literature supports the efficacy of the POLST approach in honoring and communicating patient's wishes.<sup>51</sup> For example, emergency medical technicians in Oregon reported that the POLST form provides clear instructions about patient preferences, and is useful when deciding which treatments to provide.<sup>52</sup> In contrast to the single intervention focus of out-of-hospital do-not-resuscitate (DNR) orders, the POLST form provides patients the opportunity to document treatment goals and preferences for interventions across a range of treatment options, thus permitting greater individualization.<sup>53</sup>

In a chart review study conducted in nursing facilities in two eastern Washington counties approximately six months after implementation of the POLST program in Washington State, POLST forms were found in twenty-one charts at these facilities.<sup>54</sup> Chart reviews and analyses of interviews with staff and residents/surrogates found evidence that the POLST form accurately

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49. MEANS TO A BETTER END, *supra* note 27, at 9.

50. News Release, Pew Research Ctr., More Americans Discussing—And Planning—End-of-Life Treatment: Strong Public Support for Right to Die 1, 2 tbl. (Jan. 5, 2006), available at <http://people-press.org/reports/pdf/266.pdf>.

51. Lee et al., *supra* note 15, at 1224 (concluding that “the POLST shows promise as a tool for promoting . . . patients’ preferences regarding end of life care are carried out.”); Susan W. Tolle et al., *A Prospective Study of the Efficacy of the Physician Order Form for Life-Sustaining Treatment*, 46 J. AM. GERIATRICS SOC’Y 1097, 1101 (1998) (stating that POLST “appears to have enhanced the clinicians’ respect for refusal of treatment and encouraged a higher degree of exploration about patient and family desires to set limits on life-sustaining treatment”); Patrick M. Dunn et al., *A Method to Communicate Patient Preferences About Medically Indicated Life-Sustaining Treatment in the Out-of-Hospital Setting*, 44 J. AM. GERIATRICS SOC’Y 785, 789 (1996) (describing the success of the Medical Treatment Coversheet, a similar document).

52. Schmidt et al., *supra* note 15, at 1432-33.

53. Susan E. Hickman et al., *Use of the Physician Orders for Life-Sustaining Treatment Program in Oregon Nursing Facilities: Beyond Resuscitation Status*, 52 J. AM. GERIATRICS SOC’Y 1424, 1425-26 (2004).

54. Meyers et al., *supra* note 15, at 41.

conveyed treatment preferences ninety percent of the time.<sup>55</sup> Most charts contained documentation regarding an informed consent process (seventy-six percent) and there was evidence that residents' wishes were honored in a majority of cases (ninety percent).<sup>56</sup> When patients had advance directives in their charts, the POLST form was congruent with the advance directives one hundred percent of the time.<sup>57</sup>

The multi-state study of POLST, published in 2010, consisted of a stratified random sample of ninety Medicaid-eligible nursing facilities and included a comprehensive review of nursing facility residents' medical records.<sup>58</sup> POLST was compared with traditional advance care planning in terms of the effect on the presence of medical orders reflecting treatment preferences, symptom management, and the use of life-sustaining treatments.<sup>59</sup> The study found that residents with POLST forms had significantly more medical orders about life-sustaining treatments than residents with traditional advance directives.<sup>60</sup> There were no differences between residents with or without POLST forms regarding symptom assessment or management measures.<sup>61</sup> POLST was more effective than traditional advance planning at limiting unwanted life-sustaining treatments.<sup>62</sup> The study suggests use of POLST offers significant advantages over traditional advance directives in the nursing facility setting.<sup>63</sup>

In summary, more than a decade of research has shown that an emerging national model, the POLST Paradigm Program, like New York's MOLST, more accurately conveys end-of-life care preferences for patients with serious, life-limiting conditions, and yields higher adherence by medical professionals.

#### *D. Cost of Care*

There are significant regional variations in the cost of care, percentage of deaths occurring in hospitals, and other measures of end-of-life care. High-spending regions reveal more inpatient-based and specialist-oriented care. However, there is scant evidence of improvement in health outcomes, including mortality rates, quality of care, access to care, and patient/family

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55. *Id.* at 44.

56. *Id.* at 43.

57. *Id.* at 42.

58. Susan E. Hickman et al., *A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program*, 58 J. AM. GERIATRICS SOC'Y 1241, 1243 (2010).

59. *Id.* at 1242-43.

60. *Id.* at 1246-47.

61. *Id.*

62. *Id.* at 1246.

63. *Id.* at 1247.

satisfaction.<sup>64</sup> Dollars are wasted on unwanted, unnecessary and futile treatments. Reducing the amount spent on ineffective treatments will help reduce the total cost of end-of-life care. The cost savings estimate is 3.3% of total end-of-life care costs, or 3.3% of \$1.4 trillion estimated at \$59 billion in potential savings.<sup>65</sup>

A study published in 2009 showed that only thirty-one percent of patients with advanced cancer near the end of life had discussions with physicians about end-of-life care.<sup>66</sup> Patients who had end-of-life conversations had significantly lower costs in their final week of life, over \$1,000 less.<sup>67</sup> Further, higher costs were associated with worse quality of death.<sup>68</sup>

The MOLST Program may remove some of the financial burden of traditional end-of-life care from families and the health care system by reducing the number of unnecessary or unwanted procedures, referrals, or visits to the intensive care unit. A study comparing high cost medical care regions to low-cost care regions in the United States found that additional spending on more intense medical care at the end-of-life, such as additional referrals to specialists or additional testing, did not materially impact life expectancy.<sup>69</sup> Many individuals face altered quality of life and unpleasant burdens as a result of this additional medical care, which has little to no benefit. Honoring preferences regarding end-of-life care will reduce the propensity to follow this unproven “more is better” approach. Advance care planning, when coupled with hospice, is estimated to save up to ten percent of the cost of the final year of life, ten to seventeen percent of the last six months of life, and twenty-five to forty percent of the final month of life compared to traditional end-of-life care.<sup>70</sup>

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64. JOHN E. WENBERG ET AL., TRACKING THE CARE OF PATIENTS WITH SEVERE CHRONIC ILLNESS: THE DARTMOUTH ATLAS OF HEALTH CARE 2008 12-13 (2008).

65. *The Case for Advance Care Planning Throughout Life and Comfort Care at the End-of-life – Why it is Important* (June 26, 2009), [http://www.villagecare.org/uploads/File/Bomba\\_Casefor\\_AdvanceCarePlanning.pdf](http://www.villagecare.org/uploads/File/Bomba_Casefor_AdvanceCarePlanning.pdf) (slideshow presentation from the Rivington House Conference).

66. Zhang et al., *supra* note 40, at 480.

67. *Id.* at 482.

68. *Id.* at 484.

69. WENBERG ET AL., *supra* note 64, at 12.

70. MEANS TO A BETTER END, *supra* note 27, at 16-17.

#### IV. DEVELOPMENT OF THE MOLST PROGRAM AND A TWO-STEP APPROACH TO ADVANCE CARE PLANNING

##### *A. Community-wide End-of-life/Palliative Care Initiative*

The two-step approach to advance care planning originated in 2001<sup>71</sup> as projects of the Community-wide End-of-life/Palliative Care Initiative (the Initiative). The Initiative is a healthcare and community collaborative based in Rochester, New York, that focuses on implementation of a broad set of end-of-life/palliative care projects that result in quality improvements in the lives of those facing death.<sup>72</sup>

From the outset, the Initiative was effectively designed to ensure inclusive coalition membership, including broad representation from the community and consumers. Effective leadership was established and the Advisory Group defined the vision, mission and values. Initiative leaders and members consistently demonstrated a strong commitment to purpose. Consensus was reached on initial goals and value was placed on the development and implementation of concrete projects. The Initiative consistently employs a results-oriented approach and is committed to monitoring performance over time. Partnerships with the NYSDOH, statewide professional associations, particularly the Medical Society of the State of New York (MSSNY) and New York State Bar Association (NYSBA), and healthcare and community collaboratives throughout NYS have contributed to the success of the CCCC and MOLST Programs developed by the Initiative. Sustainability is attributable to the leadership and support provided by Excellus BlueCross BlueShield, a not-for-profit health plan in upstate New York.

In the absence of surrogate decision-making laws in NYS prior to FHCD, this innovative two-step approach to advance care planning has been successful in increasing completion rates for health care proxies across upstate New York, and in development and implementation of the MOLST Program.

The two-step approach to advance care planning encourages all persons eighteen years of age and older to complete a health care proxy when healthy and update this advance directive across the health-illness continuum from wellness until end of life. Seriously ill individuals with advanced chronic illness who may die in the next year and those interested in further defining their wishes are encouraged to have more intensive conversations on goals for care as part of the MOLST Program. Community Conversations on

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71. *Advance Care Planning—Patients & Families*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_patients\\_families/advance\\_care\\_planning](http://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning) (last visited Mar. 28, 2011).

72. *Background and Mission*, *supra* note 16.

Compassionate Care (CCCC), an award-winning, nationally-recognized<sup>73</sup> program developed by the CCCC Workgroup<sup>74</sup> helps individuals over eighteen years of age complete health care proxies. The CCCC program focuses on Five Easy Steps to complete a health care proxy, as outlined in the CCCC Advance Care Planning booklet,<sup>75</sup> the CCCC videos,<sup>76</sup> and the “Five Easy Steps” web page,<sup>77</sup> and other web pages on [www.CompassionAndSupport.org](http://www.CompassionAndSupport.org),<sup>78</sup> the community website designed by the Initiative. The CCCC videos, housed on the website, are based on successful CCCC workshops conducted with patients and families across Upstate New York and with employees at Excellus BlueCross BlueShield. Medical Orders for Life-Sustaining Treatment (MOLST), a program designed to improve the quality of care people receive at the end of life based on effective communication of patient wishes, documentation of medical orders on a brightly colored pink form and a promise by health care professionals to honor these wishes.<sup>79</sup>

### *B. Community Conversations on Compassionate Care (CCCC) Program*

In January 2001, the Rochester (NY) Community End-of-life Report, based on a response rate of fifty percent, revealed that only thirty-eight percent of hospital patients, forty percent of clients in one home care agency, and seventy-two percent of residents in our communities’ skilled nursing facilities had advance directives in place.<sup>80</sup> “Home care agencies reported that advance

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73. *Advance Care Planning—Patients & Families*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_patients\\_families/advance\\_care\\_planning](http://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning) (last visited Mar. 28, 2011).

74. *Community Conversations on Compassionate Care Creation Workgroup*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/about\\_us/workgroups\\_and\\_epec\\_faculty/community\\_conversations\\_workgroup](http://www.compassionandsupport.org/index.php/about_us/workgroups_and_epec_faculty/community_conversations_workgroup) (last visited Mar. 30, 2011).

75. Cmty. Conversations on Compassionate Care, Advance Care Planning (2010), available at [http://www.compassionandsupport.org/pdfs/about/B-1576\\_Excellus\\_2010\\_Complete.pdf](http://www.compassionandsupport.org/pdfs/about/B-1576_Excellus_2010_Complete.pdf).

76. *Community Conversations on Compassionate Care Videos*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/resource\\_directory/compassion\\_and\\_support\\_video\\_library/community\\_conversations\\_on\\_compassionate\\_care\\_videos#id=cccc&num=0](http://www.compassionandsupport.org/index.php/resource_directory/compassion_and_support_video_library/community_conversations_on_compassionate_care_videos#id=cccc&num=0) (last visited Mar. 28, 2011).

77. *Five Easy Steps Video*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/resource\\_directory/compassion\\_and\\_support\\_video\\_library/five\\_easy\\_steps\\_video#id=five-steps&num=0](http://www.compassionandsupport.org/index.php/resource_directory/compassion_and_support_video_library/five_easy_steps_video#id=five-steps&num=0) (last visited Mar. 30, 2011).

78. See, e.g., *Public Service Announcements Videos*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/resource\\_directory/compassion\\_and\\_support\\_video\\_library/public\\_service\\_announcement\\_videos#id=psa&num=0](http://www.compassionandsupport.org/index.php/resource_directory/compassion_and_support_video_library/public_service_announcement_videos#id=psa&num=0) (last visited Mar. 28, 2011).

79. MOLST Form, *supra* note 19.

80. RIPA/BLUE CROSS END-OF-LIFE/PALLIATIVE CARE PROFESSIONAL ADVISORY COMMITTEE, ROCHESTER COMMUNITY END-OF-LIFE SURVEY REPORT 3 (2001), available at

directives are in place for only [twenty-three percent] of patients with COPD/emphysema, [nine percent] of cancer patients, [eight percent] of patients with heart failure, and [six percent] of dementia patients.”<sup>81</sup> Thus, prior to the initiation of the Community Conversations on Compassionate Care Program, statistics for the communities in upstate New York mirrored national statistics on end-of-life care.<sup>82</sup>

In developing the CCCC Program, it was recognized that education is the first step in behavioral change and an important step in overcoming functional health illiteracy regarding advance care planning. Since behavior is too complex to systematically and consistently respond to one type of intervention over another, solely measuring completion rates of health care proxies may not adequately measure the effectiveness of the CCCC Workshop. Thus, the Health Care Proxy Readiness Form<sup>83</sup> was designed by Dr. Patricia Bomba, Dr. Andrew Doniger, and Dan Vermilyea.

To assess the effectiveness of the CCCC workshop, Dr. Bomba piloted the workshop in 2002-2004, in the community and with employees, and measured effectiveness using the Health Care Proxy Readiness Form. Each attendee completed and returned the form before beginning the workshop and six to eight weeks afterwards. This form establishes a baseline and follow-up by asking the individual to select one of five responses regarding their readiness to complete a health care proxy form. The five choices are:

- I see no need to fill out a Health Care Proxy form.
- I see the need to fill out my Health Care Proxy form, but I have barriers or other reasons why I have not done it.
- I am ready to fill out a Health Care Proxy form or I have already started.
- I already filled out my Health Care Proxy form and it reflects my wishes.
- I already filled out my Health Care Proxy form but it needs to be [updated to reflect my current wishes].<sup>84</sup>

The Community Conversations on Compassionate Care (CCCC) Pilot Study Results, 2002-2004, shows that the workshop format motivates individuals to complete an advance directive.<sup>85</sup> For those who attend a CCCC Workshop, forty-eight percent of those in attendance had an advance

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<http://www.compassionandsupport.org/pdfs/about/Rochester%20Community%20End%20of%20life%20Report%20012901.pdf>.

81. *Id.*

82. *See supra* text accompanying notes 47-49.

83. PATRICIA BOMBA ET AL., STAGING QUESTIONS: HEALTH CARE PROXY READINESS (2004), *available at* [http://www.compassionandsupport.org/pdfs/professionals/training/HCP\\_Readiness\\_Form\\_Updated\\_021810.pbomba\\_.pdf](http://www.compassionandsupport.org/pdfs/professionals/training/HCP_Readiness_Form_Updated_021810.pbomba_.pdf).

84. *Id.*

85. Cmty. Conversations on Compassionate Care, Workshop Attendee Responses (2004), *available at* [http://www.compassionandsupport.org/pdfs/research/Community\\_Conversations\\_on\\_Compassionate\\_Care\\_Pilot\\_Results.pdf](http://www.compassionandsupport.org/pdfs/research/Community_Conversations_on_Compassionate_Care_Pilot_Results.pdf) (last visited Mar. 30, 2011).

directive; fifty-five percent had an advance directive six to eight weeks later. The difference is statistically significant (p-value = 0.01).

The CCCC Program was shared across upstate New York. The End-of-Life-Care Survey of Upstate New Yorkers: Advance Care Planning Values and Actions, Summary Report describes results of the most comprehensive survey ever done in upstate New York to assess consumer attitudes and actions regarding two advance directives (health care proxy and living will) to assess impact of the CCCC Program.<sup>86</sup> A random sample of 2,000 adults, eighteen and older, living in a thirty-nine county area of upstate New York were selected for phone interview using the random digit dialing sample.<sup>87</sup> Nearly ninety percent surveyed signified “it is very/fairly important that they have someone who could make medical decisions on their behalf if they had an irreversible terminal condition and were no longer able to make medical decisions on their own. Yet, only [forty-two percent] indicated they have actually designated a Health Care Proxy.”<sup>88</sup> Further, “[s]ignificant regional variations were observed in completion rates for Health Care Proxy forms, from a low of [thirty-five percent] in Utica to a high of [forty-seven percent] in Rochester.<sup>89</sup> It was noted that “attitudes toward Health Care Proxies, on the other hand, showed little variation across regions ([eighty-five percent] to [ninety percent] saying it was very/fairly important).”<sup>90</sup> Evidence suggests that the difference is driven, in part, by physician communications with patients as the highest rate of discussion with doctors occurred in Rochester (forty-seven percent) compared to Utica (twenty-seven percent).<sup>91</sup> “Studies in the medical literature have demonstrated that physician counseling markedly increases the completion rate of advance directives.”<sup>92</sup> Additionally, community education plays a role as the highest rates occurred where the CCCC Program was initiated.<sup>93</sup> A nationwide poll conducted by the *AARP Bulletin* in 2007 found that more than ninety percent of adults thirty-five or older are aware of health care proxies and living wills, but less than forty percent have actually completed these forms.<sup>94</sup>

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86. EXCELLUS BLUE CROSS BLUE SHIELD, END-OF-LIFE CARE SURVEY OF UPSTATE NEW YORKERS: ADVANCE CARE PLANNING VALUES AND ACTIONS (2008), *available at* [http://www.compassionandsupport.org/pdfs/research/End\\_of\\_Life\\_survey-EX.pdf](http://www.compassionandsupport.org/pdfs/research/End_of_Life_survey-EX.pdf).

87. *Id.* at i.

88. *Id.*

89. *Id.* at ii.

90. *Id.*

91. *Id.* at ii-iii.

92. EXCELLUS BLUE CROSS BLUE SHIELD, *supra* note 86, at iii.

93. Patricia Bomba, Three (3)-Part Community Education Series: Advance Care Planning and Palliative Care, *available at* [http://www.compassionandsupport.org/pdfs/homepage/3\\_Part\\_Series\\_CCCC.MOLST\\_and\\_web\\_site\\_Community\\_Education\\_.pdf](http://www.compassionandsupport.org/pdfs/homepage/3_Part_Series_CCCC.MOLST_and_web_site_Community_Education_.pdf).

94. See AARP, AARP BULLETIN POLL “GETTING READY TO GO”: EXECUTIVE SUMMARY 1, 2, 6 (2008), *available at* [http://assets.aarp.org/rgcenter/il/getting\\_ready.pdf](http://assets.aarp.org/rgcenter/il/getting_ready.pdf).

*C. Medical Orders for Life-Sustaining Treatment (MOLST) Program*

The MOLST Program began with creation of the original MOLST form by the MOLST Creation Workgroup,<sup>95</sup> as a project of the Community-wide Initiative in Fall 2001.<sup>96</sup> The form was completed in November 2003. MOLST was adapted from Oregon's POLST and integrates NYS Public Health Law.<sup>97</sup> Implementation began on a voluntary basis in Rochester health care facilities shortly thereafter. A broader regional launch in January 2004 resulted in expansion to surrounding counties.

As regional adoption ensued, simultaneous collaboration with the NYSDOH began in March 2004. As a result, a revised form consistent with NYS law was approved by the NYSDOH for use as an institutional DNR in *all* health care facilities throughout NYS in October 2005. NYSDOH sent a letter on January 17, 2006, confirming its approval.<sup>98</sup> This approval did not require legislative action, but achieved significant growth in the MOLST Program across the state. Implementation of the MOLST Program began in health care facilities, including hospitals and nursing homes, and has spread to assisted living facilities, enriched housing, and the community.

With passage of the MOLST Pilot Project Legislation<sup>99</sup> and the Chapter Amendment (2006),<sup>100</sup> NYSDOH approved the MOLST for use in the community as a Nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) in Monroe & Onondaga counties. The Monroe & Onondaga Counties MOLST Community Implementation Team (Team) was formed in 2006 to oversee a three-year pilot project.<sup>101</sup> In addition to collaboration with the NYSDOH, the Team partnered with the MSSNY, NYSBA, the Healthcare Association of New York State (HCANYS), New York State Health Facilities Association (NYSHFA), the New York Association of Homes and Services for the Aging (NYAHS), the Hospice and Palliative Care Association of New York State (HCPCANYS), New York State Office for the Aging

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95. See, e.g., *Development of the MOLST Program*, *supra* note 17.

96. *Background and Mission*, *supra* note 16.

97. Judith D. Grimaldi & Tammy Lawlor, *MOLST: New York State's Medical Orders to Honor the Wishes of a Seriously Ill Patient*, N.Y. ST. B.A. ELDER LAW ATT'Y, Spring 2009, at 15, 16; see CTR. FOR ETHICS IN HEALTH CARE, OR. HEALTH & SCIS. UNIV., PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST) (2009), available at <http://www.ohsu.edu/polst/programs/documents/POLST.JUNE.2009sample.pdf>.

98. Letter from Martin J. Conroy, Director, Bureau of Hosp. and Primary Care Servs. et al., to Chief Exec. Officer (Jan. 17, 2006), available at <http://www.compassionandsupport.org/pdfs/legislation/MOLSTDOHapprovalletter.pdf>.

99. *Legislation*, COMPASSION AND SUPPORT AT THE END OF LIFE, <http://www.compassionandsupport.org/index.php/legislation> (last visited Mar. 30, 2011).

100. Grimaldi & Lawlor, *supra* note 97, at 15.

101. *Contributor Showcase*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/contribute/contributor\\_showcase](http://www.compassionandsupport.org/index.php/contribute/contributor_showcase) (last visited Mar. 30, 2011).



(NYSOFA), New York State Society on Aging (NYSSA), the Greater New York Hospital Association (GNYHA), and other professional associations, health care facilities, systems and agencies across NYS.

A successful MOLST Pilot Project resulted in Governor David Paterson signing into law a bill that made MOLST permanent and statewide, thereby changing the scope of practice for EMS across NYS.<sup>102</sup> MOLST was consistent with NY Public Health Law section 2977(13), authorizing the use of MOLST, at the time the Public Health Law was amended. Since then, it has been repealed and a new NY Public Health Law, Article 29-CCC, was created to govern Nonhospital DNR Orders.<sup>103</sup> The new article is now consistent with the new FHCDA law and cannot be altered. MOLST has been reviewed annually since 2005, complies with NYS Public Health Law, and has been adapted to meet clinical needs.

The NYSDOH updated the MOLST form (DOH-5003) in June of 2010 to make it more user-friendly and to conform to the procedures and decision-making standards set forth in the FHCDA.<sup>104</sup> The MOLST Statewide Implementation Team was launched in May 2010 to oversee effective statewide implementation of the MOLST Program and to support NYSDOH implementation of the FHCDA and revision of the MOLST form.<sup>105</sup> This statewide team replaced the bi-county team that was in place from 2005-2010.

#### *D. Functional Health Literacy*

The Initiative recognized the importance of functional health literacy as an essential element in the advance care planning process as well as improving end-of-life care. Functional health literacy is based simply on a “need to know” and a “need to do” with respect to being informed about medical information. With a lack of knowledge about medical care and medical conditions, functional health illiteracy results in a decreased comprehension of medical information and a lack of understanding and use of appropriate services, from preventive to end-of-life services, like palliative care and hospice. Patients experience poorer health status, poorer self-reported health, and poorer compliance rates. As a consequence, increased hospitalizations and increased health care costs result.

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102. Grimaldi & Lawlor, *supra* note 97, at 15.

103. N.Y. PUB. HEALTH LAW § 2994-dd(6) (McKinney 2011).

104. *Medical Orders for Life-Sustaining Treatment (MOLST)*, N.Y. ST. DEP'T OF HEALTH, [http://www.health.state.ny.us/professionals/patients/patient\\_rights/molst/](http://www.health.state.ny.us/professionals/patients/patient_rights/molst/) (last visited Mar. 30, 2011).

105. *MOLST Statewide Implementation Team—Professionals*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/molst/statewide\\_implementation\\_team](http://www.compassionandsupport.org/index.php/for_professionals/molst/statewide_implementation_team) (last visited Mar. 30, 2011).

The community website, [www.CompassionAndSupport.org](http://www.CompassionAndSupport.org) is another project of the Initiative.<sup>106</sup> Initially developed as a resource for patients and families, the website is dedicated to educating and empowering patients, families, and professionals on advance care planning, MOLST, palliative care, pain management and hospice care, and related topics. A key goal of the website is to provide community education that aims to overcome functional health illiteracy and ensure shared, informed medical decision-making.<sup>107</sup> The website houses information on both the CCCC and MOLST Programs.

#### *E. Shared, Informed Medical Decision-Making*

In a study of advance care planning in the Program of All Inclusive Care for Elderly, researchers reported that program effect including local provider practice styles accounted for substantial variation in end-of life treatment choices.<sup>108</sup> This evidence is consistent with research done by Wennberg and colleagues on the relationship between regional health care spending, practice patterns, and outcomes.<sup>109</sup>

Health care professionals, working as an interdisciplinary team, play a key role in educating individuals about advance care planning and shared, informed medical decision-making, as well as in resolving conflict. To be effective, shared medical decision-making must be well-informed. The decision-maker (patient, health care agent, or surrogate) must weigh the following questions:

- Will treatment make a difference?
- Do burdens of treatment outweigh benefits?
- Is there hope of recovery? If so, what will life be like afterward?
- What does the patient value? What is the patient's goal of care?

It is exactly this kind of in depth discussion with patients, family members, and surrogates that is needed. Patients, family members, and surrogates are often reluctant to ask these questions and afraid to discuss the dying process. Even if they are informed of a diagnosis and prognosis, they do not know what they mean in terms of their everyday experience and future. This is why an interdisciplinary approach to advance care planning is effective.

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106. See *Community Web Site Creation Workgroup*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/about\\_us/collaborators](http://www.compassionandsupport.org/index.php/about_us/collaborators) (last visited Mar. 30, 2011).

107. See Cmty. Conversations on Compassionate Care, *supra* note 75.

108. See Helena Temkin-Greener et al., *Advance Care Planning in a Frail Older Population: Patient Versus Program Influences*, 27 *RES. ON AGING* 659, 685-86.

109. WENNBERG ET AL., *supra* note 64, at 28-29.

The trained and qualified health care professional has completed his/her own health care proxy (in some states, known as durable power of attorney for health care). As a result, the health care professional is better equipped to manage an in-depth discussion and is comfortable in educating on advance care planning in the community, as well as in the professional workplace. In all settings, advance care planning education is provided to patients, families, and loved ones and all are encouraged to complete a health care proxy, as anyone may face a sudden and unexpected acute illness or injury and risks becoming incapacitated and unable to make your own medical decisions. In NYS, decision standards are higher for surrogate decision-making.<sup>110</sup> FHCDA is a law of last resorts and encourages everyone eighteen years and older to engage in advance care planning discussions early and engage in dialogue with family and loved ones.<sup>111</sup> In the end, it is the conversations that sustain us when we lose our own loved ones.

Antecedent conversation reduces the potential for conflict. Nonetheless, losing a loved one is a difficult, emotion-laden experience. When conflict arises, trained and qualified health care professionals can assist in resolving conflict by identifying and managing misunderstanding that may occur if the diagnosis is unknown or uncertain, too much jargon is used, contradictory information is provided, or an overoptimistic prognosis was previously rendered. Further, the provider can provide support to the decision-maker who is often emotionally distressed, sleep-deprived, and psychologically unprepared when decisions are made in the midst of a crisis. The provider may identify and deal with distrust in the health care professionals or the system, guilt, grief, interfamily issues, and explore potential secondary gain. A team of professionals can assist with negotiating values conflict that results in disagreement about the goals of care and relative benefit of treatment. If unresolved, referral to the ethics committee can assist with resolution of the values conflict.

#### V. NEW YORK RECOGNIZES FAMILY HEALTH DECISION MAKING

The FHCDA marks a major shift in health policy in NYS by formally recognizing family health decision-making in the state statutory scheme. In essence, the FHCDA gives health care decision making authority to surrogates for patients who have lost decision making capacity and did not leave prior

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110. Jonathan D. Moreno, *Who's to Choose? Surrogate Decisionmaking in New York State*, HASTINGS CTR. REP., Jan.-Feb. 1993, at 5, 6.

111. See NANCY BLASCHAK ET AL., WHEN WE HAVE NO VOICE: THE FAMILY HEALTH CARE DECISIONS ACT (FHCDA) 12 (2009), available at [http://www.compassionandsupport.org/pdfs/professionals/molst/TOTAL\\_Web\\_Version\\_of\\_Full\\_Report.pdf](http://www.compassionandsupport.org/pdfs/professionals/molst/TOTAL_Web_Version_of_Full_Report.pdf) (“The [FHCDA] recognizes the significance of discussions and expressed desires regarding health care preferences that individuals have with one another and that such conversations have a worthy place in determining a course of intervention.”).

instructions or appoint a health care agent.<sup>112</sup> This authority extends to all health care decisions including the withholding or withdrawal of life-sustaining treatment, subject to certain standards and restrictions.<sup>113</sup> Currently, the law only applies to decisions for patients in hospitals or nursing homes.<sup>114</sup> However, it is likely to be amended to include community settings such as a patient's home, clinic, or physician's office.

The FHCDA is a critically important law for numerous reasons. First, prior to its enactment, unless a health care agent had been appointed or prior instructions had been left (by a living will or the completion of a MOLST form, or orally in a hospital), it was almost impossible for family members to make health care decisions for patients without capacity. This was a result of court decisions in NYS which required "clear and convincing" evidence of a patient's wishes, a very difficult legal standard to meet.<sup>115</sup> And since in NYS, as elsewhere, the vast majority of patients had not taken steps to make their health care wishes known, decisions to forgo or stop treatment, even when such treatment was clearly burdensome and not beneficial, could not be made by loved ones. Even decisions to consent to treatment that may have been beneficial and likely to improve the quality of life of a patient had little legal support.

#### *A. Surrogates*

Under the FHCDA, once a decision has been made that a patient lacks decisional capacity, that person's decisions can be made by a person highest in the following priority list: Mental Hygiene Law Article 81 court appointed guardian; spouse or domestic partner; adult son or daughter; parent; adult sibling; or close friend (who could be another relative).<sup>116</sup> The responsibility to notify at least one person on the surrogate list in order of priority rests with the hospital or nursing home.<sup>117</sup> It is assumed that if there is more than one eligible person in a category highest on the priority list and the eligible persons cannot reach agreement themselves, the hospital or nursing home will generally be able to determine which one is better suited to be the surrogate. In cases in which conflicts may arise among family members or eligible persons who are surrogates, the provider can play a key role in resolving such conflicts informally, even at this early stage of the process. Likewise, if the

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112. Robert N. Swidler, *The Family Health Care Decisions Act: A Summary of Key Provisions*, N.Y. ST. B.A. HEALTH L.J., Spring 2010, at 32, 32.

113. *Id.* at 32-33.

114. *Id.* at 32.

115. Moreno, *supra* note 110, at 6.

116. N.Y. PUB. HEALTH LAW § 2994-d (McKinney 2011).

117. *Id.* at § 2994-c(4)(b).

conflict needs to be referred to the ethics committee,<sup>118</sup> the provider can play a key role in the deliberations of the ethics committee. The provider may or may not be a member of the ethics committee. A provider who is not involved in the case would need to be part of the ethics committee review.

### *B. Capacity Determinations*

The attending physician makes capacity determinations.<sup>119</sup> In a hospital, an initial decision that a patient lacks capacity must be supported by a concurring determination by a health or social services practitioner prior to making any decisions to withhold or withdraw life-sustaining treatment.<sup>120</sup> The concurring practitioner can be a registered nurse, nurse practitioner, physician assistant, another physician, psychologist, or licensed clinical social worker. In nursing homes there must also be a concurring decision independently made by “a health or social services practitioner employed by or otherwise formally affiliated with the facility.”<sup>121</sup> The only exception, at this time, applies when a health care agent makes medical decisions for the incapacitated patient; two physicians must determine capacity.<sup>122</sup> Expanding the work of capacity determination to other trained and qualified professionals is especially important in nursing home settings in which large populations of frail, elderly residents suffer from various cognitive impairments and dementias, and physicians are not consistently present in the nursing home at the time of admission.

### *C. Decisions for Patients Who Lack Capacity*

The law is very broad in allowing the surrogate to make all health care decisions. However, there are certain criteria that must be followed and, for some decisions, there are stringent limitations. The surrogate is required to make treatment decisions “in accordance with the patient’s wishes, including the patient’s religious and moral beliefs”, or, if the patient’s wishes are not reasonably known and cannot be ascertained, “in accordance with the patient’s best interests.”<sup>123</sup> An assessment of the patient’s best interests must include the following subjective and objective considerations: i) “dignity and uniqueness of every person;” ii) “possibility and extent of preserving the patient’s life;” iii) “preservation, improvement or restoration of the patient’s

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118. *See Medical Orders for Life-Sustaining Treatment—Professionals: Ethics Review Committee*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/molst\\_training\\_center/ethics\\_review\\_committee](http://www.compassionandsupport.org/index.php/for_professionals/molst_training_center/ethics_review_committee) (last visited Mar. 30, 2011).

119. N.Y. PUB. HEALTH LAW § 2994-c(2).

120. *Id.* § 2994-c(3).

121. *Id.* § 2994-c(3)(b)(i).

122. *See id.* § 2994-c(3)(a), (c)(i).

123. *Id.* § 2994-d(4)(a)(i)-(ii).

health or functioning;” iv) “relief of the patient’s suffering;” and v) other values that a “reasonable person in the patient’s circumstances would wish to consider.”<sup>124</sup>

While relief of pain and suffering is broadly the goal of palliative care, the express language written into the FHCDA on relief of patient suffering provides a new legal basis for assessment of patient suffering as integral to the surrogate decision making process.<sup>125</sup>

#### *D. Decisions to Withhold or Withdraw Life Sustaining Treatment*

Although the standard for decisions based on a patient’s wishes or best interests might reasonably be considered sufficient for all health care decisions, other standards must be met in certain situations. Decisions to withhold or withdraw life-sustaining treatment, including DNR orders, must meet one of the following standards: (1) “treatment would be an extraordinary burden to the patient” and determinations are made by an attending physician with the concurrence of a second physician to a reasonable degree of medical certainty that the patient is terminally ill (expected to die within six months) or the patient is permanently unconscious; or (2) the provision of treatment would cause such “pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome” and determinations are made by an attending physician with the concurrence of a second physician to a reasonable degree of medical certainty that the patient has an incurable or irreversible condition.<sup>126</sup> The first part of the above assessment of burden to the patient is subjective and non-clinical in nature and would be made by the surrogate, in consultation with the physician; the second part of the determination is clinical and is made by the physician and concurring physician.

In a nursing home, the surrogate may make a decision to refuse life-sustaining treatment for a patient with an irreversible or incurable condition only if the ethics review committee or a court reviews the decision and determines that the standards set forth above are met.<sup>127</sup> This requirement does not apply to a decision to withhold CPR. If an attending physician in a hospital objects to a surrogate’s decision to withhold or withdraw artificial nutrition and hydration for a patient with an irreversible or incurable condition, the decision cannot be implemented until the ethics review

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124. *Id.* § 2994-d(4)(a)(ii).

125. N.Y. PUB. HEALTH LAW § 2994-d(4)(a)(ii).

126. *Id.* § 2994-d(5)(a)(i)-(ii).

127. N.Y. ST. DEP’T OF HEALTH, DECIDING ABOUT HEALTH CARE: A GUIDE FOR PATIENTS AND FAMILIES 5 (2010), available at <http://www.health.state.ny.us/publications/1503.pdf>.

committee or a court reviews the decision and determines that the standards set forth above are met.

These standards impose limitations upon decisions to withdraw or withhold life-sustaining treatment to which other health care decisions made by surrogates are not subject. For surrogate decisions under the inhumane/extraordinary burden standard for patients with incurable or irreversible conditions, there is language of pain and suffering written into the clinical criteria that must be operationalized in facilities in order to make a determination about treatment.

In NYS, a health care agent appointed under the health care proxy law is subject only to the limitation that the agent needs to know the patient's wishes, including those about artificial nutrition and hydration, either expressed orally or in writing.<sup>128</sup> Therefore, there is still a strong incentive for individuals to appoint a health care agent whom they trust under NYS law.

#### *E. Decisions for Minors and Unbefriended Adults Without Capacity*

The FHCDA authorizes parents of minor children to forgo life-sustaining measures in accord with the same standards that apply to surrogate decisions for adults, but only with the minor's consent if the minor has capacity.<sup>129</sup> Emancipated minors can make life-sustaining treatment decisions under the statute without parental consent subject, to ethics committee approval.<sup>130</sup> The statute also wisely sets forth a procedure for making health care decisions for adult patients without capacity who have no available persons to serve as a surrogate.<sup>131</sup>

#### *F. Ethics Review Committees*

Ethics review committees must be established to provide advice upon request or in the event of disputes, and review certain sensitive decisions by surrogates to withdraw or withhold life-sustaining treatment.<sup>132</sup> At least three of the committee members must be health or social service practitioners.<sup>133</sup>

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128. ERIC T. SCHNEIDERMAN, PLANNING YOUR HEALTH CARE IN ADVANCE: HOW TO MAKE YOUR WISHES KNOWN AND HONORED 5-6 (2011), available at [http://www.ag.ny.gov/publications/2011/Publications/Planning\\_Your\\_Health\\_Care\\_2011.pdf](http://www.ag.ny.gov/publications/2011/Publications/Planning_Your_Health_Care_2011.pdf).

129. Robert N. Swidler, *New York's Family Health Care Decisions Act: The Legal and Political Background, Key Provisions and Emerging Issues*, N.Y. ST. B.A. J., June 2010, at 18, 23.

130. *Id.*

131. *Id.* at 23-24.

132. N.Y. PUB. HEALTH LAW § 2994-m (McKinney 2011).

133. *Id.* § 2994-m(3).

VI. PALLIATIVE CARE INFORMATION ACT IS NEW LAW IN  
NEW YORK STATE

The Palliative Care Information Act (PCIA)<sup>134</sup> is a significant new law in NYS that will serve as “a model for the nation.”<sup>135</sup> Its goals are to ensure quality clinical practice and empower dying patients appropriately.<sup>136</sup> Patients are given the opportunity to receive information and counseling about their palliative care and end-of-life options, including hospice, so that they can make informed decisions about their treatment and care.<sup>137</sup> The law states, in pertinent part:

If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including but not limited to: the range of options appropriate to the patient; the prognosis, risks and benefits of the various options; and the patient's legal rights to comprehensive pain and symptom management at the end of life.<sup>138</sup>

The law also provides that the obligation to provide such information and counseling can be fulfilled by the attending physician or nurse practitioner or by referral or transfer to another appropriate health care practitioner.<sup>139</sup> Information can be provided verbally, or in a written document that the Department of Health is authorized to produce.<sup>140</sup> Practitioners can also create their own written documents. Information and counseling does not have to be provided to a patient who does not want it, but information and counseling shall be provided to a person with authority to make health care decisions for the patient if the patient lacks decision making capacity.<sup>141</sup>

The PCIA, which became effective February 2011,<sup>142</sup> was needed for many critically important reasons. The patient's right to receive information and counseling under this new law expands the well established right of patients to have information sufficient for them to make informed decisions about their treatment under existing NYS laws including the FHCDA<sup>143</sup> and the Health

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134. *Id.* § 2997-c.

135. *New York Palliative Care Information Act: Model for the Nation*, AM. PUB. HEALTH ASS'N, <http://www.apha.org/membergroups/newsletters/sectionnewsletters/aph/fall10/default.htm> (last visited Mar. 30, 2011).

136. *Id.*

137. N.Y. PUB. HEALTH LAW § 2997-c(2).

138. *Id.*

139. *Id.* § 2007-c(3).

140. *See id.* § 2007-c(2).

141. *Id.* § 2997-c(2).

142. *Id.* § 2997-c.

143. N.Y. PUB. HEALTH LAW § 2994-d(3)(c).



Care Proxy Law.<sup>144</sup> In addition, at the end of life, physicians have sometimes been reluctant to discuss with, or make full disclosure to, their patients about their diagnosis, prognosis, and end-of-life treatment options. In a retrospective study of bereaved hospice caregivers, Csikai and Martin found that caregivers expressed a desire for more information about disease course and the dying process much earlier in the decision-making process.<sup>145</sup>

Provider education on the Palliative Care Information Act is critically important for effective implementation. The NYSDOH has offered educational information on PCIA<sup>146</sup> and the CompassionAndSupport.org website offers information on PCIA in the broader framework of palliative care.<sup>147</sup>

The SUPPORT study of physicians in five United States hospitals reported that physicians did not have a high level of involvement with their patients concerning patients' end-of-life decision-making, even with the support of a specially trained nurse who had multiple contacts with the patient and family.<sup>148</sup> The investigators concluded that greater individual and societal commitment and stronger incentives were needed to improve the experience of seriously ill and dying patients.<sup>149</sup>

Effective communication is viewed as critical to hospice referrals, which frequently occur so near death or not at all. While the timing of hospice referrals involves a constellation of factors influencing hospice care at the end of life, the variability in hospice lengths of stay by nursing home hospice users and hospice users generally calls for better communication between physicians and patients to document and support patient evaluations and Medicare Hospice Benefit eligibility decisions.<sup>150</sup>

## VII. CONCLUSION

Caring for patients and families at the end of life is the ultimate in professionalism. Shared, informed medical decision-making is a patient-

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144. *Id.* at § 2982(3).

145. Ellen L. Csikai & Shadi S. Martin, *Bereaved Hospice Caregivers' Views of the Transition to Hospice*, 49 SOC. WORK HEALTH CARE 387, 395 (2010).

146. See *Palliative Care*, N.Y. ST. DEP'T OF HEALTH, [http://www.health.ny.gov/professionals/patients/patient\\_rights/palliative\\_care/](http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/) (last visited Mar. 29, 2011).

147. *Palliative Care—Professionals*, COMPASSION AND SUPPORT AT THE END OF LIFE, [http://www.compassionandsupport.org/index.php/for\\_professionals/palliative\\_care](http://www.compassionandsupport.org/index.php/for_professionals/palliative_care) (last visited Mar. 29, 2011).

148. Alfred F. Connors et al., *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, 1595-96 (1995).

149. *Id.* at 1597.

150. See generally Gail Gazelle, *Understanding Hospice—An Underutilized Option for Life's Final Chapter*, 357 NEW ENG. J. MED. 321 (2007).

centered process that is critical to ensuring patient preferences for care are honored at the end of life. Providers must be trained, qualified, and comfortable with the discussions needed for effective shared, informed medical decision-making. Health care professionals will find the two-step approach to advance care planning, including the Community Conversations on Compassionate Care (CCCC) and Medical Orders for Life-Sustaining Treatment (MOLST) Programs, is helpful in engaging all adults eighteen years of age and older to complete a health care proxy (also known as a durable power of attorney for health care) and in initiating discussions with seriously ill patients about the MOLST. For all adults, the discussion should focus on choosing the right health care agent and sharing values, beliefs, and what is important to the individual. For seriously ill patients appropriate for the MOLST, these discussions should focus on understanding the patient's goals for care, in light of the patient's health status and prognosis, and ensuring a clear understanding of the benefits and burdens of life-sustaining treatment. Functional health literacy regarding advance care planning, a key pillar of palliative care, must be achieved by patients, families, health care agents, and surrogates to assure shared, informed medical decisions. Community data and recent landmark legislation in NYS support the value of implementation of the CCCC and New York's MOLST. Development, implementation, and sustainability of the CCCC and MOLST Program highlights the success of healthcare and community collaborative initiative focused on improving care at the end of life.