



## NEW YORK STATE TASK FORCE ON LIFE & THE LAW

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December 22, 2010

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188 State Street, Room 409  
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Honorable Dean G. Skelos  
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188 State Street, Room 907  
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Honorable Sheldon Silver  
Speaker, New York State Assembly  
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188 State Street, Room 932  
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Honorable Brian M. Kolb  
Minority Leader, New York State Assembly  
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188 State Street, Room 933  
Albany, New York 12248

Dear Senators Sampson and Skelos, and Assembly Members Silver and Kolb:

On behalf of the New York State Task Force on Life and the Law (the “Task Force”), I am pleased to submit for your consideration, *“Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice.”*

The Task Force was created by Executive Order in 1985 to develop public policy on issues arising at the interface of law, medicine, and ethics. Since then, the Task Force has issued influential reports on a variety of bioethics issues, including genetic testing, assisted reproductive technologies, allocation of ventilators in the event of a pandemic influenza outbreak, and organ donation.

The Task Force commends the Legislature on the passage of the Family Health Care Decisions Act (“FHCDA”) in March 2010, which provides New Yorkers with an invaluable tool to facilitate surrogate decision-making for health care. Prior to the FHCDA, families and close friends of patients did not have the authority to make even routine health care decisions on a patient’s behalf, and were required to satisfy an extremely high evidentiary burden when the decision concerned the withholding or withdrawing of life-sustaining treatment. The FHCDA greatly improved this situation by authorizing surrogates to make health care decisions for loved

ones in hospitals and residential health care facilities. However, it still leaves thousands of New Yorkers who receive care in other settings and who cannot speak for themselves without the benefit of a surrogate decision-maker.

The Legislature directed the Task Force to examine whether the FHCDA should be amended to apply to decisions for health care provided in settings outside of hospitals and residential health care facilities. *See* 2010 N.Y. Laws Ch. 8, § 28 (2). Over the past several months, the Task Force has deliberated over the ethical and legal issues raised by extending the FHCDA, and is prepared to make an initial recommendation that the FHCDA should be amended to provide surrogates with authority to make decisions on behalf of incapable patients for hospice care.

In order to be eligible for hospice, a patient must suffer from a terminal illness and have a life-expectancy of six months or less. These patients' conditions often affect their ability to make choices or express wishes, precisely at a time when they face many important health care decisions. Accordingly, surrogate decision-making for these vulnerable patients is crucial to ensuring that their rights and welfare are protected, and that they live the remainder of their days in dignity and with appropriate care.

As is set forth in further detail in the accompanying document, the Task Force hereby recommends that the Legislature amend the FHCDA to include decisions regarding hospice care. In the coming months, the Task Force will continue to explore the legal and ethical dimensions of extending the FHCDA's surrogate decision-making authority to other care settings and will provide additional recommendations on these issues to the Legislature.

Thank you for your attention to this matter, and for entrusting the Task Force with this important project. We look forward to working with you in the future.

Sincerely,

Beth E. Roxland, J.D., M.Bioethics  
Executive Director  
New York State Task Force on Life and the Law

Enclosure

cc: Richard F. Daines, M.D., Commissioner, New York State Department of Health  
Honorable Thomas K. Duane, Chair, New York State Senate Health Committee  
Honorable Kemp Hannon, Ranking Member, New York State Senate Health Committee  
Honorable Richard N. Gottfried, Chair, New York State Assembly Committee on Health  
Honorable James G. Bacalles, Ranking Member, New York State Assembly Committee on Health

**Recommendations Regarding the Extension of the Family  
Health Care Decisions Act to Include Hospice**

NEW YORK STATE TASK FORCE ON LIFE AND THE LAW

November 30, 2010

I. Introduction

The enactment of the Family Health Care Decisions Act (“FHCDA”) in March 2010 reflects the culmination of seventeen years of advocacy and support from the health care community in New York State, and represents a landmark legislative achievement. The law establishes a framework to allow surrogate decision-making for patients without capacity when they have not chosen a health care proxy or left other instructions to direct their care. The Task Force on Life and the Law (“Task Force”) proposed the legislation in its 1992 report titled “*When Others Must Choose: Deciding for Patients Without Capacity*” and welcomed with enthusiasm its passage.

The FHCDA was designed to fill a longstanding gap in New York law by providing an invaluable tool for surrogate decision-makers to honor the wishes of patients when they cannot speak for themselves, or to act in the best interests of these patients when their wishes are unknown. Prior to the passage of the FHCDA, families and close friends of patients did not have the authority to make even routine health care decisions on a patient’s behalf, and were required to satisfy an extremely high evidentiary burden when the decision concerned the withholding or withdrawing of life-sustaining treatment. As a result, surrogates did not have the ability to consent to ameliorative treatments or to object to procedures, regardless of the degree of invasiveness, which may have run contrary to their loved one’s previously expressed wishes or best interests.

II. FHCDA Issues for Task Force Consideration

The scope of surrogate authority under the FHCDA currently is limited to decisions about health care provided in two specific settings: hospitals and nursing homes.<sup>1</sup> The Legislature explicitly assigned<sup>2</sup> to the Task Force the project of considering whether the FHCDA should be amended to apply to decisions for health care provided in other settings, such as hospice, home care, or doctor’s offices.<sup>3</sup>

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<sup>1</sup> N.Y. Pub. Health Law Art. 29-CC § 1 (2010); *see also* N.Y. Pub. Health Law § 2994-b (applicability). More specifically, the FHCDA applies only to decisions regarding care provided in “hospitals,” which is defined to include “general hospitals” and “residential health care facilities.” *Id.*

§ 2994-a (18). A “residential health care facility” is “a nursing home or a facility providing health-related service.” *Id.* § 2801 (3). Hereinafter, the terms “nursing home” and “residential health care facility” will be used interchangeably, and “general hospital” will be referred to as “hospital.”

<sup>2</sup> 2010 N.Y. Laws Ch. 8, § 28 (2).

<sup>3</sup> The original Task Force proposal envisioned that surrogate authority would extend to all treatment decisions, without regard to where they were made, so long as appropriate safeguards were in place. However, the delivery of health care has changed significantly since the proposal was developed and it is prudent to reevaluate the effectiveness of the safeguards outside of the institutional settings of hospitals and nursing homes.

The Task Force began its deliberations by identifying: (1) the settings where surrogate health care decisions are likely to be necessary, and (2) the procedural safeguards required to ensure proper oversight of health care delivery and protection of patient rights in these additional sites. For the reasons discussed below, surrogate decision-making in hospices emerged as a priority for early legislative action. In the coming months, the Task Force intends to continue its deliberations and issue further recommendations on the extension of the FHCDA, but is making an initial recommendation that the FHCDA be amended to include surrogate decision-making in the context of hospice care.

### III. Provision of Hospice Care

#### A. *The Provision of Hospice Care in New York State*

Hospice is an interdisciplinary approach to end-of-life care that emphasizes palliative treatments and comfort care rather than curative care, while simultaneously providing comprehensive support to patients and their families. Hospice care is often provided in hospitals and nursing homes, but also is routinely provided in the home and other community-based settings. Patients are not eligible for hospice care until it is determined that their condition is incurable and that they have a life expectancy of six months or less.

In order to receive hospice care, an eligible patient must “elect” to enroll in hospice.<sup>4</sup> Once the hospice election is made, a detailed care plan is created by the hospice team and the patient, which includes preferences and directions for withholding or withdrawing care. Therefore, health care decisions must be made both to elect hospice and to direct the care of the patient once he or she is enrolled in hospice. When a patient lacks decision-making capacity, the family or other decision-maker must step in to make these decisions.

#### B. *Barriers to Surrogate Decision-Making Regarding Hospice Care*

Patients who qualify for hospice care are an extremely vulnerable population who, by definition, are at the end of their lives. Due to complications resulting from terminal illness, many of these patients lack decision-making capacity and therefore must be able to rely on surrogate decision-makers and clinicians to ensure that they live out their final days in comfort and with dignity.

The current wording of the FHCDA creates a barrier to the utilization of hospice by terminally ill individuals because the authority it bestows upon surrogates is limited to care provided in hospitals or nursing homes. The FHCDA does not permit a surrogate to elect hospice care for a loved one who is being cared for outside of a covered facility at the time of the election decision. Even when a patient is successfully enrolled in hospice, a surrogate lacks the ability to make decisions about on-going care so long as that care is to be provided outside of a covered facility, for example, where hospice care will be provided in a stand-alone hospice facility or in the home. Therefore, the ability of a patient without decision-making capacity to access hospice care will depend upon where care is currently provided or will be provided going forward. Instead, the focus should be solely on ensuring that the individual’s known preferences or best interests are honored at this crucial time.

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<sup>4</sup> 42 C.F.R. § 418.24 (a) (2010); *see also* N. Y. Comp. Codes R. & Regs. tit. 10, § 793.6 (3) (2010).

#### IV. Task Force Conclusions

The limited applicability of the FHCDA maintains the status quo prior to its passage for hospice care outside of hospitals and nursing homes, which creates confusion and inequity. Without extending the authority bestowed by the FHCDA, would-be surrogates will continue to face the obstacles to decision-making historically inherent in New York State, especially with respect to end-of-life care. Accordingly, the FHCDA should be amended to provide surrogates with authority to make health care decisions for hospice care outside of hospitals and nursing homes.

Promoting access to hospice, as well as supporting family participation in hospice care, is consistent with the intent of the legislature and overall regulatory approach to hospice care in New York State. The legislative declaration accompanying Article 40 of the Public Health Law, which governs hospice, states in pertinent part:

In recognition of the value of hospice and consistent with state policy to encourage the expansion of health care service options available to New York state residents, it is the intention of the legislature that hospice be available to all who seek such care and that it becomes a permanent component of the state's health care system.<sup>5</sup>

Furthermore, the regulations governing hospice care envision family involvement and surrogate consent, stating, "if a patient is not capable of giving informed consent, written informed consent must be obtained from any individual who is legally authorized to give such consent on behalf of the patient."<sup>6</sup> The regulations also regard the patient and family as a unit, repeatedly referring to the "patient/family" when describing patient rights, the plan of care, and recordkeeping.<sup>7</sup> Extending the surrogate authority in the FHCDA to hospice care outside hospitals and nursing homes will help to ensure consistency in the application of associated laws and regulations.

The addition of hospice also fits well into the structure of the FHCDA as it currently stands, without requiring extensive changes. Hospices are federally certified and highly regulated at the state level. The safeguards and oversight mechanisms in the FHCDA, including the procedures for determining capacity, the procedures for end-of-life decision-making, and the requirements of ethics review committees will translate into hospice settings. Hospices have physicians and other interdisciplinary professionals on staff to fulfill the statutory requirements in these areas, and most hospices have their own ethics committee, or have access to an ethics committee (*e.g.*, through an affiliated institution or other agreement).

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<sup>5</sup> N.Y. Pub. Health Law § 4000.

<sup>6</sup> N.Y. Comp. Codes R. & Regs. tit. 10, § 793.6 (3).

<sup>7</sup> *See, e.g., id.* §§ 794.1-4.

## V. Recommendations

Because the needs of hospice-eligible patients are immediate and compelling, and because hospice programs are regulated and structured in ways that generally would allow application of the FHCDA's standards and procedures, the Task Force recommends that the FHCDA should be amended to:

- Allow patients who meet the criteria for hospice, but cannot make decisions on their own, the ability to have a surrogate appointed for them pursuant to the FHCDA for decisions relating to hospice care.
  - When patients have no surrogate reasonably available, willing or competent, decisions should be made on a patient's behalf in accordance with standards and mechanisms already set forth in the FHCDA.<sup>8</sup>
- Apply similar presumptions and procedures currently in the FHCDA to the determination of whether a potential hospice patient lacks capacity, and to the selection of the individual who will serve as surrogate.
- Enable surrogates to elect hospice care on behalf of patients, regardless of where the patients reside at the time of the election.
- Authorize surrogate decision-making for all care while in hospice, including creation of the hospice plan of care and decisions to withholding and withdrawing life-sustaining treatment, using similar standards for decision-making and oversight mechanisms that the FHCDA currently requires in hospital and nursing home settings.

Beth E. Roxland, J.D., M.Bioethics  
Executive Director

On Behalf of the New York State  
Task Force on Life and the Law

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<sup>8</sup> Patients who do not have an individual available to act as a surrogate similarly stand to benefit from hospice care as their counterparts with surrogates, and therefore should have equal access to such care. While there are legitimate concerns about the vulnerability of these individuals, the safeguards required by the FHCDA, such as oversight by an Ethics Review Committee, will ensure that only patients who are eligible—and for whom such care is in their best interests—will have decisions regarding hospice care made on their behalf.