

**The Committee on Health Law
And The Committee on Bioethical Issues of
The Association of the Bar of the City of New York**

A.5406-A

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An act to amend the public health law (i) to establish procedures for selecting and empowering a surrogate to make health care decisions for persons who lack capacity to do so on their own behalf and who have not otherwise appointed an agent to make such decisions under Article 29-C of the Public Health Law and (ii) to repeal certain provisions of such law relating thereto.

THIS BILL IS APPROVED

A. The Committees Strongly Endorse The Bill As Written And Urges Its Swift Passage.

The Committee on Health Law and the Committee on Bioethical Issues of the Association of the Bar of the City of New York strongly endorse the Family Health Care Decisions Act and urge swift passage of this urgently needed legislation. The Association of the Bar has submitted position statements in favor of similar legislation in 1993, 1994, 1996 and 2001.

The Association of the Bar is an organization of over 23,000 lawyers and judges dedicated to improving the administration of justice. The members of the Committees on Health Law and Bioethical Issues include attorneys, physicians, and in-house hospital counsel who grapple daily with issues involving medical decision making and end-of-life care. The Association has always taken great interest in the legal, social and public policy aspects of medical care, as well as in other public health issues, and through its various committees, regularly issues reports and policy statements, and testifies at hearings.

We live in a time when medical technology can extend life well beyond what many would want. Without the legal right to refuse treatment at some point, medical technology can impose enormous personal burden and suffering upon the very patients the technology was intended to aid. Every day vital health care and treatment decisions are being made in New York State by persons other than health care agents on behalf of incapacitated patients. These crucial decisions must be made for the patients' well-being, as they were yesterday and will be tomorrow. The central issue presented by this bill is not whether such treatment decisions should be made by a surrogate but rather who should legally be vested with the decision making authority and what criteria should be used for making those decisions.

The Family Health Care Decisions Act provides legal authority for a decision making system that effectively balances empowerment of a surrogate and adequate protections for incapacitated patients. The Act specifically establishes procedures for: (i) honoring patient wishes and values, as best they can be ascertained; (ii) involving family and loved ones in

decision making for incapacitated patients; and (iii) ensuring safeguards to prevent inappropriate decisions particularly in cases where the wishes of the incapacitated patient are unknown and there are no primary advocates involved.

Existing New York law recognizes and honors health care wishes of a competent adult. But New York law permits health care decisions to be made for an incompetent adult in only three circumstances: 1) when a health care agent has been appointed by the patient or by a court; 2) when the patient, while competent, has prepared a written directive; and 3) when the health care decision is to refuse cardiopulmonary resuscitation. In other cases New York has severely circumscribed the right to make health care decisions for an incapacitated patient by imposing an often unrealistic burden of proof on family members, friends or others who seek to act on the patient's behalf. Unless they can prove a patient's precise wishes by "clear and convincing evidence," family members and loved ones have no legal authority with respect to these crucial medical treatment decisions. The proposed bill, however, delegates such decision making authority to a close family member or a close friend, without the need to satisfy a burden of proof with respect to the patient's wishes.

B. Current Law: Competent Adults Fully Control Their Medical Treatment Decisions.

The right of a competent adult to accept or reject medical treatment is a firmly established legal principle. "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." Schloendorff v. The Society of New York Hospital, 211 N.Y. 125, 129 (1914) (Cardozo, J.). The right of a patient to refuse treatment has been expressly recognized by the New York Court of Appeals. Eichner v. Dillon (In re Storar), 52 N.Y.2d 363 (1981). Furthermore, that right is protected under the Due Process Clause of the State Constitution (see Rivers v. Katz, 67 N.Y.2d 485 (1986)). The United States Supreme Court has found that the refusal of life sustaining medical treatment implicates a liberty interest protected under the United States Constitution. Cruzan v. Missouri Department of Health, 497 U.S. 261 (1990). This body of strong case law has clearly established the right of competent adult patients to make all decisions regarding their medical treatment, even when death will result from the refusal of treatment.

C. Current Law: A Competent Adult May Delegate Authority To Make Health Care Decisions In The Event Of Incapacitation By Completing A Health Care Proxy.

1. Advance Directives Are Authorized by New York Law.

Article 29-C of the Public Health Law is a powerful and extremely useful instrument in the compassionate delivery of care, allowing competent adults to express their wishes in anticipation of becoming incapacitated. Competent adults may delegate health care decision making authority to another adult, should they become unable to make such decisions themselves, by completing a health care proxy. Alternatively, competent adults may leave written instructions as to specific wishes regarding medical treatment in the form of a "living will".

Both federal and state law strongly support the use of such written advance directives to honor the wishes of patients who have lost the ability to make medical treatment decisions. The Patient Self-Determination Act of 1991, 42 U.S.C. 1395cc(a) et. seq.; In the Matter of Westchester County Med. Center (O'Connor), 72 N.Y. 2d 517, 530-531, (1988); Eichner v. Dillon (supra).

2. Yet Few People Take Advantage of Advance Directives.

Most adults in New York do not prepare advance directives. Despite vigorous efforts to educate people regarding the wisdom of executing advance planning mechanisms, only a small proportion of patients have a health care proxy or a living will. A 2001 study of New York seniors found that two out of three seniors responding had not completed advance directives despite the fact that all of the research sites had previously conducted programs to educate them about the importance of having a health care proxy. When asked whom they trust the most to make medical decisions for them, the vast majority (79%) mentioned a spouse or other family member. Only 17 percent mentioned their physician. More than half of those studied indicated they believed family decision making was legal in New York State without a designated health care proxy even after reading a statement that the law states otherwise. Results of Literacy Study Reinforce Need for the Family Health Care Decisions Act, Sarah Lawrence College, Health Advocacy Program.

D. Current Law: Where There Is No Health Care Proxy A Surrogate May Consent To A Do-Not-Resuscitate Order.

Absent a health care proxy, Public Health Law 29-B authorizes a surrogate who has a close relationship with the incapacitated patient to consent to a “do-not-resuscitate” order not to attempt cardiopulmonary resuscitation in the event the patient suffers cardiac or respiratory arrest.

E. Current Law: Without an Advance Directive, Clear And Convincing Evidence Must Be Shown To Withdraw Or Withhold Life Sustaining Measures.

The New York Court of Appeals has held that evidence of treatment wishes provides a basis for withdrawing or withholding life sustaining measures from an incapacitated patient only if it is clear and convincing. (see In re Eichner (supra))

“Every person has the right to life, and no one should be denied essential medical care unless the evidence clearly and convincingly shows that the patient intended to decline the treatment under some particular circumstances...*This is a demanding standard, the most rigorous burden or proof in civil cases.*” (emphasis added) In re O'Connor, supra at 530-531.

F. Several Burdens On Families, Health Care Providers And The Courts Are Imposed By The Current State Of The Law, While Possibly Extending The Pain And Suffering Of Incapacitated Patients Unnecessarily. The Family Health Care Decisions Act Will Alleviate Those Burdens and That Suffering.

- 1. The Clear and Convincing standard poses a formidable barrier to both families and health care providers. Surrogate decision making under the proposed bill provides a workable, timely and financially less burdensome alternative.**

(i) Clear and Convincing Evidence is a Demanding Standard: With the exception of cardiopulmonary resuscitation, in the absence of a health care proxy, medical treatments must be continued regardless of the consequences to the patient unless clear and convincing evidence can be shown as to the patient's wishes to the contrary. As the Court of Appeals stated, this is a demanding standard, the most rigorous burden of proof in civil cases. O'Connor (supra, at 531)

The "clear and convincing" evidence standard does not work. Rather than facilitate a health care provider's ability to follow patient choice about treatment, this standard poses a formidable barrier to both families and providers. A majority of courts in other states has found the "clear and convincing" evidence standard to be unworkable and overly burdensome in these cases.

The "clear and convincing" standard is predicated on the notion that a person, while competent, would have clearly expressed his or her wishes regarding end-of-life decisions in some manner. However, for many people discussion of end-of-life matters is a personally uncomfortable subject, such that they refrain from expressing their wishes in this area. In addition, the cultural backgrounds of some New Yorkers make it extremely difficult, if not impossible, to even mention their own death and dying, let alone to articulate "clear and convincing" plans for it.

Under the proposed bill, there is no need for the surrogate to show clear and convincing evidence of the patient's wishes with respect to medical treatment. This is balanced by a set of workable safeguards. The proposed legislation is in line with the laws of the vast majority of other States in allowing a surrogate to make health care decisions free from the clear and convincing evidence standard.

(ii) Court Proceedings Necessitated by the "Clear and Convincing" Evidence Standard Are Costly For Families: Even if the patient's condition is terminal and hopeless and even if medical interventions are not in the patient's best interest and such interventions increase rather than

decrease the patient's immediate suffering, treatment must continue, unless clear and convincing evidence can be shown. That showing may require the expense of a court proceeding, leaving those closest to a terminally ill patient who may be unable to bear that expense helpless to prevent the initiation of further medical treatment, even though they know deep in their hearts that their loved one would never have permitted it. The proposed bill alleviates this problem.

(iii) Court Proceedings are Time Consuming and Extend Patient Suffering: Meeting the clear and convincing burden of proof in a court proceeding as may now be required by New York law may extend the pain and suffering of a patient who would otherwise have wished for the cessation of further medical treatment.

(iv) Experience with DNR Decisions Has Shown that Clear and Convincing Evidence is Not Required: New York does not require "clear and convincing" evidence of a patient's wishes in cardiopulmonary resuscitation decisions. There has been no evidence to date that the current, less burdensome statutory standard for refusing cardiopulmonary resuscitation on behalf of incapacitated patients leaves those patients unprotected or vulnerable to decisions that are not in their best interests.

2. Current New York Law denies legal decision making power to those closest to the patient. The proposed legislations vests health care decision making power in a person most likely to know the patient's wishes or act in the patient's best interests.

(i) Under Current New York Law, Families Have No Legal Decision Making Authority: While it is the practice of many health care providers to turn to the family of an incapacitated adult patient for consent to treatment, family members and close friends do not have any legal right to provide or withhold that consent. Inevitably, cases arise when those most intimate with the patient lack the authority to protect the patient from unwanted medical treatment and must stand by and endure the knowledge that further medical treatment is only prolonging suffering.

(ii) Leading Authorities Advocate Surrogate Decision Making By A Person Close To The Patient.

- i. *Task Force.* The New York State Task Force on Life and the Law, recognized as a model of sound public policy study of important issues of life and death, has addressed this issue. The Task Force has included leaders in the fields of law, medicine, nursing, philosophy and bioethics, as well as patient advocates and representatives of diverse religious communities. In 1992, the Task Force published

When Others Must Choose; Deciding for Patients Without Capacity. This report included a legislative proposal for surrogate decision making in those cases where the patient has not (or could not) execute a health care proxy.

- ii. *Presidential Commission.* The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has strongly held that decision making for patients who lack capacity is best discharged by those who know and care for the patient, rather than health care providers or courts, to whom the patient is a stranger. Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions (1983).

(iii) *Court Adjudication is Inappropriate for Many End-Of-Life Decisions.*

- i. *Courts Are Ill Equipped.* A clear consensus has evolved in both the legal and medical literature that courts of law, in most instances, are inadequate to address fundamental end-of-life decisions. Also clear is that judges are not particularly desirous of being asked to make such personal decisions for others. Given the highly nuanced, clinically oriented nature of these decisions, judges and courts of law are largely ill equipped to consider such matters competently and compassionately. Furthermore, in many situations, taking end-of-life decisions to court may unduly delay resolution and unnecessarily prolong suffering.
- ii. *The Bill Brings Decision Making Out Of The Courtroom And To The Patient's Bedside.* Under the proposed legislation courts are used as a forum of last resort. The decision making process is in the hands of a person who would most likely know the wishes of the patient or act in the patient's best interests. The surrogate's decisions are also informed by the health care providers who are taking care of the patient. In other words, the decision making process is brought out of the courtroom and to the patient's bedside where a family member or close friend makes decisions informed by knowledge of the patient as an individual and by health care providers advising that decision maker.

3. Health care professionals feel legally vulnerable if they withdraw or withhold medical treatment. This fear of legal action can lead to over-treatment. The bill provides immunity for health care providers who honor health care decisions made in accordance with the proposed Act.

Under existing law, clinicians often feel legally vulnerable if they submit to the family's compassionate and common sense pleas. As a result, fear of legal

attack may lead to over-treatment of an incapacitated individual. This is treatment that provides neither benefit nor palliation and may even increase suffering, but is provided out of fear of liability if such interventions are withheld.

In a 2002 study, Common Good, a bi-partisan organization composed of leaders in government, education, health care, law, business and public policy, interviewed physician regarding how fear of litigation impacts the practice of medicine. The study found that when looking at patient end of life issues 61% of physicians have noticed physicians being reluctant to make what they believe to be humane choices because of concerns that a family member might bring suit. Half (50%) have noticed a physician resorting to aggressive treatments of terminally ill patients because of liability concerns. Just under half (42%) have noticed a physician or staff member going against a patient's expressed wishes concerning life-prolonging medical interventions because of concerns that a family member might bring suit. Fear Of Litigation Study, Common Good, April 11, 2002.

4. **Health Care Decisions Are Now Open To Intervention By Third Parties. The Bill Would Foreclose Intervention.** Under current law third parties unknown to the patient or the State could attempt to intervene in medical treatment decisions with respect to an incapacitated patient. Since the bill delegates the decision making authority to the surrogate, such attempted interventions would be statutorily barred. Only certain persons close to the patient may commence a special proceeding if they disagree with the surrogate's decisions.

G. Response To Opposition Of The Family Health Care Decisions Act.

While a number of concerned and respected organizations, representing a broad based constituency, have already come out in favor of this proposed legislation on numerous occasions, there are also groups that have expressed concern with or opposition to this legislation. Some of the concerns raised are: (1) The proposed legislation has an impact on reproductive rights; (2) The Act does not sufficiently protect patients against families and health care institutions that may not be willing to act consistently with the patient's best interest; and (3) Artificial nutrition and hydration should not be deemed medical treatment.

1. The Issue of Reproductive Rights

Section 2994-d (4)(a)(ii) of the proposed legislation delineates the standards by which a surrogate makes health care decisions for an incapacitated person whose wishes as to treatment and end of life issues are not reasonably known and cannot, with reasonable diligence, be ascertained. In such a case the surrogate must make health care decisions in accordance with the patient's best interests. In determining what course of action is in the patient's best interest, the

surrogate is required to take a patient-centered approach. Viewing the situation from the patient's perspective, the surrogate must take into consideration the concerns and values as a reasonable person in the patient's circumstance would wish to consider. Furthermore, the law requires that the surrogate's assessment be consistent with the values of the patient, including the patient's religious and moral beliefs, to the extent reasonably possible.

From this patient-centered viewpoint the surrogate is instructed to take into consideration concerns and values as the patient would, including, among other considerations, the impact of treatment decisions for a pregnant woman on her fetus and on the course and outcome of her pregnancy. This language has raised some concerns regarding reproductive rights.

One concern has been that this provision would create a separate, legal right for the fetus that would require a surrogate to place the fetus' interests over those of the pregnant woman. Nothing in § 2994-d(4)(a)(ii) confers any such right.

The language of the statute is clearly patient centered, with the concern being the determination of the woman's best interests. The law does not require or permit the surrogate to give greater consideration to the impact of treatment decisions on the fetus than to their impact on the pregnant woman, unless the surrogate determines that such course of action would have corresponded with the wishes of the pregnant woman. Thus, the bill makes ascertaining the woman's best interests, based on her values and beliefs, the focus of the surrogate's decision making process. The Committees believe that the primary focus of the bill is the identification of a surrogate for an incapacitated individual and the criteria by which that surrogate must make decisions.

2. The Bill Safeguards The Rights And Interests Of The Patient.

A concern raised by those who would oppose the bill is that it does not sufficiently protect patients against families and health care institutions that may not be willing to act consistently with the patient's best interests. The Family Health Care Decisions Act, however, imposes numerous substantive and procedural safeguards intended to ensure that the rights and interests of vulnerable patients are appropriately considered and weighed in the decision making process.

The safeguards afforded by the Act are wide-ranging. They include, among others, the following: (1) In the determination of incapacitation, at least one other health care professional must concur with the attending physician's determination; (2) Notwithstanding a determination of incapacity in an adult patient, the patient's objection prevails over the surrogate's health care decision or the determination of incapacity, absent a court finding; (3) Before a surrogate's decision to withdraw or withhold life sustaining treatment may be carried out,

specific medical criteria must be met and confirmed by two physician; (4) Decisions to withhold or withdraw life-sustaining treatment when the patient is not suffering from a terminal condition or permanent unconsciousness require review and approval by an attending physician and the institution's Ethics Review Committee, which must include at least one physician not directly responsible for the patient's care; (5) A physician may object to a surrogate's decision to withdraw or withhold life sustaining treatment, resulting in the delay of such action until reviewed by either the Ethics Review Committee or a court of competent jurisdiction; (6) The bill authorizes persons with a close relationship to a patient to commence a special proceeding if they object to the surrogate's decision; and (7) If the decision is contrary to a hospital's policy based on religious or moral convictions central to that facility's operating principle and that policy was communicated to the patient, family or surrogate before admission, if reasonably possible, the bill provides for a prompt transfer of the patient to another facility. If the family is unable or unwilling to make the transfer the hospital may facilitate such transfer, seek judicial relief or honor the surrogate's decisions.

3. Artificial Nutrition And Hydration Are Medical Treatment.

There is a minority that has sought to distinguish between the provision of artificial nutrition and hydration and the provision other life prolonging medical treatments. While religious or moral beliefs may lead one to hold such a position for oneself or one's loved ones, as a matter of law and medical ethics, artificial feeding is considered medical treatment. Were the Legislature to accept that distinction, and limit surrogate decision making in this area, such action would stand squarely in contrast to clear legal pronouncements from both the Supreme Court in Cruzan and the New York Court of Appeals in O'Connor which clearly recognize artificial food and hydration as medical treatment. The bill correctly carves out only "[p]roviding nutrition and hydration orally, without reliance on medical treatment" from the definition of health care. (see Section 2994-a (11)).

H. The Committees Urge Swift Passage of the Family Health Care Decisions Act.

New York law honors the prior written expression of patients' wishes through living wills and health care proxies. New York is one of only two states, however, that currently have no effective mechanism to follow the wishes of the majority of incapacitated patients who have left no advance directive. The clear and convincing standard required under current law is a demanding standard and is burdensome on families and health care providers who wish to aid a suffering patient. The need for legislative action on this issue is indisputable and urgent.

The Family Health Care Decisions Act is a comprehensive and thoughtful approach to health care decision making for the incapacitated patient without a health care proxy. The proposed legislation would establish a system sensitive to the clinical reality in which decisions are being made. It balances the vesting of decision making authority with several safeguard provisions. Most important, it is a patient centered bill which will simultaneously provide for the best interests of the patient and the reduction of stress families face in an already painful and difficult time by giving them decision making authority and by blocking the intervention of third parties unknown to the patient in such decisions.

The need to take up the plight of incapacitated patients for whom health care decisions must be made is genuine and imperative. The Committees urge the swift passage of this bill.

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