

Carol Levine: The Family Health Care Decisions Act

What Patients and Family Members Need to Know

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New York State has been a leader in many areas of health care, but in one important area it has lagged behind nearly every other state. Family members generally assume that they will be able to make health care decisions for their dying relatives, even if the relative had not signed a health care proxy. In New York family members have been shocked and dismayed to learn that they have had no legal rights at this crucial time. Now at last the law has been changed.

On March 16, 2010, Gov. David A. Paterson signed the New York State Family Health Care Decisions Act, 17 years after it was first introduced in the Legislature. Even though the path during that time was slow and meandering, both the Assembly and Senate finally passed the bill with almost no opposition. In what can charitably be called Albany's *annus horribilus*, this achievement is a tribute to the Act's determined advocates in the Legislature and across the state.

Although the Family Health Care Decisions Act (FHCDCA) has a simple purpose—to allow family members to make end-of-life health care decisions when the patient has not signed a health care proxy or advance directive—its specific provisions are complex. The Act goes into effect on June 1, although hospitals and nursing homes that already have procedures in place to manage these situations can begin using the law immediately. How the law will be implemented depends to a large degree on the new forms and policies that hospitals, nursing homes, and their associations are now developing.

Meanwhile, what do you as a patient or family member need to know about the new rules? Here are some questions that the new law has already raised.

Do I have to Sign a New Health Care Proxy Form?

No. If you have a New York State health care proxy form, appropriately signed and witnessed, your proxy is still authorized to make decisions about treatments that you would or would not want if you become unable to express your wishes. If you have further stated your wishes in an advance directive or included them in your proxy document, these statements are still binding, although it would be a good idea to review them (and locate them if necessary) to see if you want to make any changes. Make sure you have multiple copies, readily available in case of an emergency. Your best chance of having your wishes fulfilled is still to appoint a willing and responsible proxy and have a serious discussion about what you do and don't want.

If you do not have these documents, now is a very good time to get them in order. [Information about New York State's proxy rules and the form](#) you need to fill out are available.

And if you are a family caregiver—someone who provides or manages care for a seriously or chronically ill person—you should encourage that person, if still able to express his or her wishes, to appoint a health care proxy. The Next Step in Care guide "[Advance Directives: A Family Caregiver's Guide](#)" explains why this is important.

The law fills some important gaps, but it is far better to close gaps yourself.

Does the Law Apply to All Care Settings?

No. The law applies only to patients in general hospitals or residents in nursing homes; it does not apply to people at home, in assisted living facilities, or in hospice care. There is, however, a separate section on out-of-hospital do not resuscitate (DNR) orders.

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Who Can Make Decisions under the New Law?

The FHCDA establishes a process for determining whether an adult patient without a health care proxy has decision-making capacity. If an attending physician and a consulting physician agree that the patient lacks the capacity to make health care decisions, the law establishes a priority list for choosing a person to be the surrogate decision maker. At the head of the list is a court-appointed guardian if the patient happens to have one. The FHCDA also amends the guardianship law (Article 81 of the mental hygiene law) to permit guardians to make decisions about life-sustaining treatment.

In rank order, the list then goes to a spouse, if not legally separated, or domestic partner; a son or daughter 18 years old or older; a parent; a brother or sister 18 years old or older; and finally, a close friend. The law goes to great lengths to define a domestic partner: someone who is in a formal relationship with the patient as defined by the "laws of the United States, any state, local or foreign jurisdiction or registered ...with any registry maintained by the employer of either party or any state, municipality, or foreign jurisdiction." There are other options as well, including being dependent on or mutually interdependent for support.

Anyone lower in the hierarchy (e.g., an adult child instead of a spouse) or in the same category (e.g., another sibling) can challenge the designation.

How are Patients Protected from Inappropriate Decisions?

The law sets out a series of procedural requirements intended to protect vulnerable patients and make sure that the choice of surrogate and the surrogate's decision are subject to review.

1. A decision to withhold or withdraw treatment must be based on a determination that treatment would be an "extraordinary burden to the patient" and would "involve such pain, suffering, or other burden that it would reasonably be deemed inhumane."
2. Surrogate decisions must be made "in accordance with the patient's religious and moral beliefs" or, if these are not known, "in accordance with the patient's best interests."
3. In a nursing home, an ethics committee must review the surrogate's decision to remove life-sustaining treatment. In a hospital, if a physician objects to withdrawing or withholding nutrition or hydration, an ethics committee must also review the case.

These are stringent requirements, and certainly such momentous decisions should not be made lightly. Still, while the new law is intended to remove barriers that impede decision making and cause needless suffering for patients and families, as well as prolonged nonbeneficial hospital stays, an unintended consequence may be more work for ethics committees and further delays.

Looking Back—and Ahead

New Yorkers have been held to an unrealistically high legal standard of proving that a patient would or would not have wanted certain treatments under specific circumstances. This standard was set in the 1989 *O'Connor* case, in which the New York Court of Appeals, the state's highest court, ruled that a hospital could insert a nasogastric feeding tube in Mary O'Connor over the objections of her daughters. The court ruled that there must be "clear and convincing" evidence that a patient, while competent, had made a firm and settled commitment to decline the specific medical assistance in the circumstances that now existed. Even though some of the judges recognized that this standard would be challenging for families, they said that the remedy was legislative, not judicial.

Families in New York State now have the legal authority to make health care decisions for their dying relatives. The challenge now will be to see that the law is implemented fairly and with compassion and sensitivity.

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