STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Richard F. Daines, M.D.
Commissioner

James W. Clyne, Jr.
Executive Deputy Commissioner

August 31, 2010

Dear Colleague:

A New York State law that went into effect June 1, 2010, the Family Health Care Decisions Act (FHCDA), provides legal authority for surrogate consent to any type of health care decision for patients who cannot make their own decisions and have not signed health care proxies. The FHCDA applies to persons living with HIV/AIDS when they are in a general hospital or a nursing home.

Attached is an "AIDS Institute Fact Sheet: The Family Health Care Decisions Act and HIV/AIDS". This Fact Sheet provides an overview of the FHCDA and clarifies specific aspects of the FHCDA related to HIV/AIDS.

Specific questions pertaining to the FHCDA as it relates to HIV/AIDS can be directed as follows:

Clinical questions: Lyn C. Stevens, MS, NP, ACRN; New York State Department of Health AIDS Institute; at (518) 473-8815 or e-mail lcs02@health.state.ny.us

Legal questions: Jonathan Karmel; New York State Department of Health Division of Legal Affairs; at (518) 473-3303 or e-mail regsqna@health.state.ny.us

Please make the Fact Sheet available to staff and make "Deciding About Health Care: A Guide for Patients and Families" available to patients/clients with HIV/AIDS, as appropriate.

Sincerely,

Humberto Cruz
Director, AIDS Institute

Attachment

AIDS Institute Fact Sheet:
The Family Health Care Decisions Act and HIV/AIDS

Brief Overview of the Family Health Care Decisions Act

The Family Health Care Decisions Act (FHCDA) went into effect June 1, 2010.[1] It leaves in place current laws that allow for the appointment of legal guardians as well as the health care proxy law, which allows a patient to appoint a health care agent to make health care decisions in the event the patient loses the capacity to do so. However, in cases where patients cannot make their own decisions and do not have a legal guardian or health care proxy, FHCDA specifies, using a prioritized surrogate list, who has legal authority to make health care decisions.

Under the surrogate list, the spouse (if not legally separated from the patient) or the domestic partner is legally authorized to make decisions. If there is no spouse or domestic partner, an adult child may make health care decisions. Next on the list is a parent, then an adult sibling, and finally a close friend. The terms "domestic partner" and "close friend" are defined in the law. For persons with a Mental Hygiene Law Article 81 guardian authorized to decide about health care, that guardian is at the top of the surrogate list.

Surrogates can make any type of health care decision, including a decision to withhold or withdraw life-sustaining treatment. No exceptions for HIV diagnosis or treatment are noted in the law. Decisions must always be made based on the patient's wishes, or based on the patient's best interests if the patient's wishes are not known. The FHCDA specifies the clinical criteria under which decisions to withhold or withdraw life sustaining treatment may be made. It also clarifies how the legal guardian of a minor patient can consent to withholding or withdrawing life-sustaining treatment for a minor, and also allows emancipated minors to make such decisions for themselves.

In the event that no one on the surrogate list is available, the FHCDA allows (but does not mandate) physicians at facilities to make any type of health care decision without going to court. The law sets forth required procedures and clinical criteria, which vary depending on whether the treatment is routine medical treatment, major medical treatment, or a decision to withhold or withdraw life-sustaining treatment.

FHCDA changes existing law regarding Do Not Resuscitate (DNR) orders. A DNR order is an order not to attempt cardiopulmonary resuscitation (CPR) in the event a patient suffers cardiac or respiratory arrest. In the past, there was a special law for DNR orders, but now DNR orders in general hospitals and nursing homes will be issued under the provisions of FHCDA that apply to any decision to withhold or withdraw life-sustaining treatment.

How the Family Health Care Decisions Act Relates to HIV/AIDS

Applicability of the Family Health Care Decisions Act (FHCDA) FHCDA only applies in a "general hospital" or a "residential health care facility." A "general hospital" is a general hospital as defined in Public Health Law section 2801(10), excluding a ward, wing, unit or other

part of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by the Office of Mental Health. A "residential health care facility" means a residential health care facility as defined in Public Health Law section 2801(3), including a nursing home.

Consent for HIV-Related Testing for General Hospital Patients and Nursing Home Residents who Lack Medical Decision-Making Capacity and Do Not Have Health Care Proxies A surrogate from the surrogate list in the FHCDA can consent to an HIV related test in a general hospital or nursing home. The FHCDA provides for this as follows:

The surrogate must make health care decisions in accordance with the patient's wishes, including the patient's religious and moral beliefs. If the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, the surrogate makes decisions in accordance with the patient's "best interests." An assessment of the patient's best interests shall include:

- consideration of the dignity and uniqueness of every person;
- the possibility and extent of preserving the patient's life;
- the preservation, improvement or restoration of the patient's health or functioning;
- the relief of the patient's suffering; and,
- any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.

In all cases, the surrogate's assessment of the patient's wishes and best interests must be patient-centered. Health care decisions must be made on an individualized basis for each patient and must be consistent with the values of the patient, including the patient's religious and moral beliefs, to the extent reasonably possible.

An HIV-related test can also be done for a patient in a general hospital or resident of a nursing home for whom no surrogate is available (e.g., the patient has no close family or friends). An HIV-related test would be categorized as "major medical treatment" for purposes of FHCDA. FHCDA authorizes such treatment as follows:

An attending physician must recommend such treatment in consultation with general hospital or nursing home staff directly responsible for the patient's care. In a general hospital, at least one other physician designated by the hospital must independently determine that he or she concurs that the recommendation is appropriate. In a nursing home, the medical director of the facility, or a physician designated by the medical director, must independently determine that he or she concurs that the recommendation is appropriate; provided that if the medical director is the patient's attending physician, a different physician designated by the nursing home must make this independent determination.

Source Patient Testing to Inform Post-Exposure Prophylaxis (PEP) Following Occupational Exposure AIDS Institute clinical guidelines specify that post-exposure prophylaxis **(**PEP) should be initiated as soon as possible, ideally within 2 hours and generally no later than 36 hours post-exposure.[2] A source patient who does not have a health care agent, who is under anesthesia and who is likely to be able to directly consent within this time frame should be

provided the opportunity to directly consent to an HIV test. In situations in which the source patient does not have a health care agent and is unlikely to be able to directly consent for HIV testing within this time frame (e.g. patient on a ventilator), surrogate consent may be considered.

Decisions regarding source patient testing should recognize that a patient is tested following a needle-stick, for example, to make sure that the health care worker has not been exposed. Such testing is in the best interest of both the health care worker and patient. For the exposed health care worker, source patient testing provides valuable information necessary to guide PEP.

HIV testing is also in accordance with the source patient's best interests as that term is defined in the FHCDA. The FHCDA specifies that decisions be based on the concerns and values a reasonable person in the patient's circumstances would wish to consider. Health care decisions are made consistent with the values of the patient, including the patient's religious and moral beliefs. Based on this, the Department's perspective is that it is in the patient's "best interests" to be tested for HIV following an occupational exposure. Such testing may also provide important information to guide the medical care of the source patient.

Please note that a separate 2010 law amended Public Health Law section 2781(6). Chapter 308 of the Laws of 2010, effective September 1, 2010, authorizes durable consents for HIV related testing as well as HIV related testing without consent in certain cases involving occupational exposures, with results disclosed only to the health care provider of the exposed person. Public Health Law section 2781(6) applies when no person is available or reasonably likely to become available to consent in time for the exposed person to receive appropriate medical care.[3]

Disclosure Under the FHCDA, surrogates have the right to be fully informed by a doctor about the patient's medical condition and the doctor's proposed treatment, even if this means disclosure of the patient's HIV status. In some cases, the surrogate may not be aware that the patient has HIV/AIDS. While surrogates are not legally prohibited from sharing confidential HIV-related information, health care providers should caution surrogates about inappropriate disclosure and the need for discretion to protect the patient's best interests.

Authorization for Release of Confidential HIV-Related Information Any person authorized pursuant to law to consent to health care for the patient may also sign a release of confidential HIV related information. A "HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV Related Information" is available in English and Spanish on the Department's public web site.[4]

Life-Sustaining Treatment The FHCDA has specific provisions for "decisions to withhold or withdraw life-sustaining treatment." The term "life-sustaining treatment" means that the attending physician believes that the patient will die within a relatively short time if the patient does not get the medical treatment or procedures.

These provisions apply to all patients, including individuals with HIV/AIDS. Decisions to withhold or withdraw life-sustaining treatment would be made based on specific criteria, including, for example, whether treatment would be an extraordinary burden to the patient and the patient can be expected to die within six months or the patient is permanently unconscious; or

the provision of treatment would involve such burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition.

Additional Information

"Deciding About Health Care: A Guide for Patients and Families"[5] was developed by the New York State Department of Health to provide answers to frequently asked questions about how health care decisions can be made and by whom.

Information and resources related to the Family Health Care Decisions Act, including Frequently Asked Questions, have been developed and continue to be updated by the New York State Bar Association's FHCDA Information Center. The FHCDA Information Center is on-line at the New York State Bar Association web site.[6]

References

1. New York State Public Health Law, Article 29-CC

2. NYSDOH, AIDS Institute. *HIV Prophylaxis Following Occupational Exposure*. May, 2010. Available at: http://www.hivguidelines.org/clinical-guidelines/post-exposure-prophylaxis/hiv-prophylaxis-following-occupational-exposure/

3. The new Public Health Law section 2781(6)(e) applies:

"in situations involving occupational exposures which create a significant risk of contracting or transmitting HIV infection, as defined in regulations of the department and pursuant to protocols adopted by the department,

(i) provided that:
  (A) the person who is the source of the occupational exposure is deceased, comatose or is determined by his or her attending health care professional to lack mental capacity to consent to an HIV related test and is not reasonably expected to recover in time for the exposed person to receive appropriate medical treatment, as determined by the exposed person's attending health care professional who would order or provide such treatment;
  (B) there is no person available or reasonably likely to become available who has the legal authority to consent to the HIV related test on behalf of the source person in time for the exposed person to receive appropriate medical treatment; and
  (C) the exposed person will benefit medically by knowing the source person's HIV test results, as determined by the exposed person's health care professional and documented in the exposed person's medical record;
(ii) in which case
  (A) a provider shall order an anonymous HIV test of the source person; and
  (B) the results of such anonymous test, but not the identity of the source person, shall be disclosed only to the attending health care professional of the exposed person solely

for the purpose of assisting the exposed person in making appropriate decisions regarding post-exposure medical treatment; and

(C) the results of the test shall not be disclosed to the source person or placed in the source person's medical record."

4. NYSDOH, AIDS Institute. "HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV Related Information" (DOH-2557). Available at: http://www.nyhealth.gov/diseases/aids/forms/informedconsent.htm

5. NYSDOH. *Deciding About Health Care: A Guide for Patients and Families*. May, 2010. Available at: http://www.nyhealth.gov/publications/1503.pdf

6. New York State Bar Association. Family Heath Care Decisions Act Information Center. Available at: http://www.NYSBA.org/FHCDA