

**APRIL 30, 2009
WOMEN'S CITY CLUB OF NEW YORK
ADVOCACY ACTION TO SUPPORT
THE 2009 NYS FAMILY HEALTH CARE DECISIONS ACT**

WCC supports New York State legislation entitled the **Family Health Care Decisions Act** that enables family members, domestic partners, and close friends of a person found to lack decision-making capacity, to act on his/her behalf in making medical decisions. This provides the right to engage physicians regarding treatment, including medications, surgery or other medical procedures, reviewing an individual's medical record, or selecting residential settings. It is intended to reflect the individual's wishes and protect his/her rights, including but not limited to end of life decisions.

Unknown to most people, there are no "legal rights" under current New York State law short of a signed Health Care Proxy, which ensures family members, including spouses, the right to make such decisions and safeguard the patient's wishes. If more than one person asserts that s/he should be the surrogate, an Ethics Committee at the facility would review the case. The Committee would interview family and friends and make a decision as to who the surrogate should be based on the person's best interest.

New York State Senator Tom Duane, Chair of the Senate Health Committee, has introduced S 3164 which is designed to act on this issue. Assembly Member Richard Gottfried who chairs the NYS Assembly Health Committee and has taken the lead on this issue for a great many years, soon will be introducing a similar bill. This legislation is budget neutral. It essentially extends the Health Care Proxy law which has been in place for many years but unfortunately has not been signed by most New Yorkers.

With new State leadership and a Governor who have supported this legislation in the past, there are high hopes of getting this important Family Health Care Decisions Act passed this legislative year. Please help us do so.

THE WCC URGES YOU TO PLEASE ACT NOW!

**CALL / WRITE / EMAIL THE LEGISLATIVE LEADERSHIP
AND YOUR LOCAL REPRESENTATIVES TODAY!**

Governor David Paterson
State Capitol, Albany, NY 12224
Tel: (518) 474-8390
To email the Governor, go to: <http://www.state.ny.us/governor/contact/index.html>

Speaker of the NYS Assembly Sheldon Silver
932 Legislative Office Building, Albany, NY 12248
Tel: (518) 455-3791
Email: speaker@assembly.state.ny.us

Senate Majority Leader Malcolm A. Smith
909 Legislative Office Building, Albany, NY 12247
Tel: (518) 455-2701
Email: masmith@senate.state.ny.us

State Senator Tom Duane
430 State Capitol Building, Albany, NY 12247
Tel: (518) 455-2451
Email: duane@senate.state.ny.us

State Assembly Member Richard Gottfried
822 Legislative Office Building, Albany, NY 12248
Tel: (518) 455-4941
To email, go to: <http://assembly.state.ny.us/mem/?ad=075&sh=con>

family decisions Coalition

Putting family health care decisions into the hands of families

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MEMORANDUM OF SUPPORT

Family Health Care Decisions Act

S.3164 Duane

APRIL 2009. The Family Decisions Coalition is composed of a broad group of individuals and groups from the health care, legal, and medical professions, as well as various organizations that represent nursing home residents, health care consumers, and their families. The Coalition's sole focus is to mobilize the New York State Legislature to pass the Family Health Care Decisions Act.

More than a decade ago, the New York State Task Force on Life and the Law, a nationally recognized nonpartisan commission consisting of health care providers, community representatives, attorneys, clergy, and bioethicists, issued a comprehensive set of recommendations to bring New York law on health care decision-making into line with the laws in the vast majority of other states. The Task Force's comprehensive proposal, now known as the Family Health Care Decisions Act, would give family members and others close to the patient the right to decide about treatment for patients without capacity. Decisions would have to be based on the patient's wishes or, if the patient's wishes are unknown, the patient's best interests. The Act contains numerous safeguards to promote good decisions and protect patients' rights.

Currently, New York State lags behind the rest of the nation in permitting close family members to make health care decisions for incapacitated patients. Only a court-appointed guardian or a judge is permitted to consent to treatment for patients who lack capacity to decide for themselves. This is true even when the patient has a spouse or other family member willing and able to act on the patient's behalf. This archaic rule often results in considerable delay in administering health care, as well as added expense. In some cases, patients are denied appropriate treatment because no one can afford to go to court on their behalf to obtain a guardianship.

More critically, a series of judicial decisions provide that no one, not even a judge, can decide to forego life-sustaining measures for previously competent patients who have lost decision-making capacity, unless the patient has signed a health care proxy or left "clear and convincing evidence" of his or her treatment wishes. Because most people never sign such a proxy or leave this kind of evidence, incapacitated patients are routinely at risk of receiving burdensome, extended treatments that violate their wishes, values, or religious beliefs.

The Family Health Care Decisions Act would remedy these problems by giving family members and others close to the patient the authority to make treatment decisions for incapacitated patients who have not signed a health care proxy or left specific oral or written treatment instructions. This legislation would only apply in general hospitals and residential care facilities, such as nursing homes. It would not cover mental hygiene facilities, the psychiatric units of general hospitals, or outpatient settings such as clinics or doctors' offices.

The surrogate decision-maker's primary function would be to consult with physicians and other professionals responsible for the care of the patient, and to advocate on the patient's behalf. The surrogate decision maker would be required to make decisions consistent with the incapacitated patients' wishes, including their religious or moral beliefs. In the event these wishes are not reasonably known, the decisions would have to be in the best interest of the incapacitated patient. Decisions to withhold or withdraw life-sustaining treatment would be authorized only if specific medical criteria are satisfied. Any disputes among family members or between family members and health care professionals would automatically trigger review by an interdisciplinary ethics committee.

An important feature of the Act is that it would give family members and other surrogate decision-makers access to incapacitated patients' medical records. Under current law, family members are denied the right to review the medical records of incapacitated patients, which makes it impossible for them to advocate effectively on the patient's behalf.

The Act also provides mechanisms for facilitating access to treatment for incapacitated patients who have no family or friends available to make decisions. In addition, it would clarify parents' authority to make decisions about life-sustaining treatment for minor patients.

While life sustaining treatment decisions are included in the umbrella of permitted decision making, this is not a right to die bill. On the contrary, in addition to allowing family members to refuse life-sustaining treatment for incapacitated patients under appropriate circumstances, the law would empower family members to advocate for aggressive life-sustaining measures for patients who would have wanted them. Moreover, the legislation affirms existing laws against assisted suicide and euthanasia.

Legislation similar to the Family Health Care Decisions Act has proved effective in numerous other states, and it undoubtedly would also work well in New York. We respectfully urge your full support of the Family Health Care Decisions Act, a proposal that would improve the quality of life and liberty of all New Yorkers.

family Decisions Coalition

Putting family health care decisions into the hands of families

Family Health Care Decisions Act

S.3164 Duane

What would the legislation do?

Enable family members and others close to the patient (a 'surrogate') to decide about treatment for incapacitated patients who have not signed a health care proxy or left specific oral or written treatment instructions. It would also cover treatment decisions for patients who have no available family or friends to decide for them.

Why is the legislation necessary?

Under current New York law, no one, not even a concerned family member, has the right to make decisions about medical treatment for previously competent patients who have lost decision-making capacity, unless the patient has signed a proxy or left 'clear and convincing evidence' of his or her treatment wishes. Most people never sign a proxy or leave this kind of evidence. As a result, some incapacitated patients are denied appropriate treatment, while others are subjected to burdensome treatments that violate their wishes, values, or religious beliefs.

Is this a right to die bill?

No. The legislation affirms existing laws against assisted suicide and euthanasia.

Under the legislation, who would make medical decisions for me if I lose the capacity to decide myself?

A surrogate decision maker can be a family member or another close to you. S/He will work with healthcare providers responsible for your care.

What type of treatment decisions would the legislation cover?

The legislation would cover all treatment decisions for adult patients, including decisions about life-sustaining measures. For minor patients, the legislation would cover only decisions about life-sustaining treatment. Other treatment decisions by parents and guardians for minor children are authorized by existing New York law.

On what basis would my family members or others decide about treatment?

Decisions must be consistent with your wishes (including your religious and moral beliefs) or, if your wishes are not reasonably known, decisions must be in your best interest.

Would the bill allow my surrogate to choose to have all available treatments provided to me?

Yes, if your surrogate determines that doing so would accord with your wishes or best interests.

Do other states have similar laws?

Yes. D.C. and 35 other states have statutes. Case law in most other states grants family members and others similar authority.

Would the legislation promote assisted suicide or euthanasia?

No. It would not permit assisted suicide or euthanasia, and affirms existing laws against these practices.

Who supports the legislation?

Over 50 civic, medical, legal and religious organizations support the legislation, and the list is growing.

Are there special safeguards for decisions to stop life-sustaining treatment?

Family members or other surrogates could refuse life-sustaining treatment only if the treatment imposes an 'excessive burden' on you and you are terminally ill or permanently unconscious, or if you have an irreversible or incurable condition and the treatment would 'involve such pain, suffering or other burden that it would reasonably be deemed inhumane or excessively burdensome under the circumstances.

When would surrogate authority begin? Can I decide as long as I am able?

Family members or others could decide about your treatment only if your attending physician and a second health care professional determine that you lack capacity to decide for yourself. You would retain the right to decide about treatment as long as you have the ability to do so.

What if there is a conflict between health care providers, family members or others close to me?

Each hospital or nursing home would be required to establish a committee to mediate disputes between health care professionals, family members and others close to the patient. The committees would be required to consider each case fully, grant access to the process to patients and surrogates, and protect patient's confidentiality.