

THE NETWORK IN AGING
of Western New York
Town Hall Meeting on Aging-Related Issues
February 20, 2009

- Assemblyman Jeffrey Dinowitz, Chairman, NYS Assembly Committee on Aging
- Senator Reverend Ruben Diaz, Chairman, NYS Senate Committee on Aging
- Michael Burgess, Director, NYS Office for the Aging

I'm Dr. Jack Freer. I am an internist and geriatrician. I've spent my entire medical career in New York State (since graduating from UB medical school in 1975). In those 34 years, I've seen too many elderly patients suffer. Unfortunately, a lot of that suffering was needless and the direct result of New York law. New York case law does **not** permit family members to make medical decisions for incapacitated patients (except for DNR) if there is no Health Care Proxy. The NY Task Force on Life and the Law designed the Family Health Care Decisions Act to remedy this situation but it has consistently failed to pass in the legislature. Today, I'm asking you to do all you can to make that bill law this year.

If NY law is causing so much suffering, one would assume legislators are getting inundated with calls and e-mail. But you're not, are you?
Why not? There are a few reasons.

Fortunately, many people go years without a loved one suffering an incapacitating illness. And a growing number of those family members now have health care proxies. But I think there's a more important reason that the public hasn't risen up in anger, demanding a change in the law. They simply are not aware of the details of the law. They assume the law **IS** what it **SHOULD BE**. Most people believe family members actually have the authority to make decisions (even life and death decisions) for incapacitated loved ones.

After all:

- It makes sense that families decide
- Families CAN decide in other states
- Families **SOMETIMES DO** get to make decisions in NY--usually when doctors and nurses are unfamiliar with the law, and usually for less serious decisions.

So most New Yorkers don't even know there's a problem until it's too late. Too often it happens like this:

An elderly patient, maybe your mother or sister, suffers a catastrophic illness-- let's say a severe stroke. She can't communicate. We can keep her alive, but can never restore her function. She is frightened, unable to speak or even understand what we say to her. She may be agitated. She'll have to be physically restrained or sedated in order to deliver life-sustaining treatment. You and other family members who know and love her learn about hospice care. You want to bring her home or to a home-like environment. Take out the feeding tube and get rid of the restraints. You tell the doctors that's what you want for her, and you believe that's what she'd want for herself.

- You **believe** that's what she'd want for herself.
- Did she ever actually **say** that?
- **When** did she say it?
- **How** did she say it?
- **Who else** heard her say it?

That's the kind of grilling family members get all over New York these days. And if the answers don't satisfy the hospital or nursing home's ethics committee, administrators or lawyers, then those patient will never get the treatment that most people think appropriate: comprehensive palliative care.

Please, make this the year that New York joins almost every other state in providing decent humane care for patients who can't speak for themselves.

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