

Another Voice | End-of-life care

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Long-ignored legislation would ease suffering

By JACK P. FREER

For the past 15 years, the New York State Legislature has failed to pass a bill so sensible that most New Yorkers probably believe it already to be law. The Family Health Care Decisions Act, introduced in 1993, would allow families and guardians to make medical decisions for patients who can no longer decide for themselves.

In the vast majority of states, it is the law, but not in New York. Because of that, helpless patients are suffering and dying miserable deaths.

An elderly patient I'll call "Joan" had emphysema. In failing health, Joan agreed to have a legal guardian appointed. She was hospitalized this July and placed on a ventilator. Although awake on and off, she was never again clear-

headed enough to make health care decisions for herself. And she was found to have a type of lung cancer that is known to be rapidly fatal.

A ventilator forces air into the lungs through a plastic tube that is wedged in the windpipe. This is so distressing that most will try to pull it out. To prevent this, patients are heavily sedated and/or their wrists are tied down to the bed. Despite this burden, most of us would gladly accept this treatment for a short time if it would save our lives. For Joan, it was not going to be a short time and it was not going to save her life.

Joan's doctors asked her guardian for permission to provide the only kind of treatment that could possibly benefit her: comprehensive palliative care. That would mean providing meticulous attention to her symptoms and quality

of life. It would mean no longer doing the kinds of tests that have become commonplace in hospitals — blood tests, scans and intrusive procedures — because they could no longer offer any hope of cure or a significantly longer life. It would also mean stopping the ventilator and treating her breathing problems by other means.

There is no question that she could live a little bit longer on the ventilator, but it would be just a short time until the ventilator could no longer push enough air into her cancerous lungs.

But the guardian's attorney knew that New York law would consider the breathing machine "life-sustaining treatment" that could not be stopped unless the patient herself had refused it in advance or had a health care proxy. The machine was continued, right up

until her inevitable death during the first week of this month.

Your state senators and Assembly members can change this cruel and inhumane (not to mention, embarrassing) law. Now is the time to contact them (and candidates running for those offices in November). Ask them if they support the Family Health Care Decisions Act, and if not, why not. You may also want to familiarize yourself with the details of the law and this act at www.familydecisions.org before you speak with them.

Fifteen years is long enough. This bill needs to be passed so that other dying patients will not have to endure the kind of death Joan experienced.

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