

WHY IS AN ONLINE REGISTRY FOR ADVANCED HEALTH CARE DIRECTIVES
IMPORTANT TO THE CITIZENS OF THE STATE OF CONNECTICUT?

Submitted by Janice E. Favreau in testimony before the Public Health Committee
on March 14, 2007

Background

- A young man is involved in a car accident in the middle of the night, and is taken to an out-of-state hospital, unconscious - having suffered a traumatic brain injury.
- A middle age man who is in the last stages of cancer suffers a cardiac arrest.
- A young woman suffering from an undiagnosed medical condition suddenly slips into a coma.

Would any of these people want to be kept alive at all costs? Maybe - or maybe not. In the absence of any written directive, a hospital must do all it can to keep these people alive. Perhaps a family member is available to make a decision, but is it the decision that the patient would have wanted? What if family members disagree? What if the State decides that it has an inherent interest to step in to safeguard the rights of the patient in spite of what the family believes to be the right decision?

These questions could be answered by simply completing one or all of a set of forms, collectively known as an Advanced Health Care Directive. There are two main components to an Advanced Health Care Directive: (1) an instruction directive and (2) proxy directives. But what happens if this Directive cannot be found or the patient is hospitalized out of state? Once a patient is *hooked up* to life support, it becomes that much more difficult to *pull the plug*. What happens if such a Directive has never been completed?

Facts

According to a Hastings Center Report from 2004, approximately only 18% of Americans nationally have completed some form of a Living Will.¹

The AARP estimates that out of those who have completed this document nearly 35% **cannot find** this document when needed.

¹ Hastings Center Report 34, no. 2 (2004): Enough: The Failure of the Living Will 30-42, at 35

WHY IS AN ONLINE REGISTRY FOR ADVANCED HEALTH CARE DIRECTIVES IMPORTANT TO THE
CITIZENS OF THE STATE OF CONNECTICUT?

Submitted by Janice E. Favreau in testimony before the Public Health Committee on March 14, 2007

Page 2

Again, according the Hastings Center Report on what are common excuses for not filing out one?

- People don't know what they are.
- They think that it is difficult to execute one.
- They don't want to discuss the topic with their doctors, or their loved ones.
- They think it is something only the elderly or ill people need to worry about.
- They don't have the time, and finally
- They simply procrastinate.

Supra. at 32

Cases

Most people tend to leave such decisions to their family or their physician. However, in the three most highly publicized cases regarding end of life decisions, the iconic Karen Ann Quinlan of New Jersey (1976), Nancy Cruzan of Missouri (1990) and Terri Shiavo of Florida (2005), none of these *young* woman left written directives for their end-of-life decisions. As result, in two of these cases, (Quinlan and Cruzan), the state had interest to intervene on behalf of the patient, and to prolong their lives. In the case of Cruzan, the Missouri Supreme Court felt that it was better to “err on the side of life, because that error was correctable rather than the uncorrectable decision to withdraw her life support”. Cruzan v. Missouri, 497 U.S. 261 (1990). The Court stated that Nancy had failed to provide “clear and convincing evidence” of her wishes *Id.* at 261. In Terri Shiavo's case the battle took place between family members. How much easier it would have been on all concerned, if these women had executed an Advanced Health Care Directive.

Connecticut

Connecticut enacted its first “Life Support Systems Removal Act” which included a Living Will Form in 1985. The Act has subsequently been revised to include the Appointment of Health Care Agent, Appointment of an Attorney-in-Fact for Health Care Decisions, The Designation of

WHY IS AN ONLINE REGISTRY FOR ADVANCED HEALTH CARE DIRECTIVES IMPORTANT TO THE
CITIZENS OF THE STATE OF CONNECTICUT?

Submitted by Janice E. Favreau in testimony before the Public Health Committee on March 14, 2007
Page 3

a Conservator of the Person in the event of future incapacity and an Anatomical Gift Designation. (Conn. Gen. Stats, Chap. 368w. Secs. 191-570-570d). Connecticut has been in the forefront of enacting this type of legislation. However, in my own unofficial poll among friends, *very few* have actually completed any of these documents.

What is the Solution?

We hope that by the passage of this proposed legislation to enact a voluntary and *consumer friendly* on-line registry which will provide electronic access from anywhere to this important information, the citizens of our state will be encouraged to complete this important and life-changing document. Their decision to do this will not only provide them with autonomy in this end-of-life decision, but it will greatly relieve and reduce the burden on the family, who can then be certain that they are “doing the right thing”.

Personal Statement

The following reasons are why I feel an Online Registry for Advanced Healthcare Directives should be enacted:

- **As a citizen.** Since 1987 I have believed in and kept current My Advanced Health Care Directives. Just last June, I entered St. Francis Hospital for bilateral hip replacement. In order to protect myself against unnecessary use of life support in the event something went wrong during or following the surgery, I was required to bring an originally-signed Advanced Health Care Directive with me to the hospital. On top of all the other things I had to take care of prior to my surgery, finding this original document and remembering to bring it with me on the day of my surgery became another task added to my already overloaded list of “Things to Do.”
- **As a daughter.** When my mother was diagnosed with terminal cancer, not only did I had to make sure that she had completed this document, but I had to keep track of in the event that it became necessary to implement.
- **As a student.** In a University of Hartford Bio-Ethics class, I learned that the majority of Americans have *not* completed this important document. It simply becomes another one of those “get to one of these days” things that gets added to everyone’s over-scheduled

WHY IS AN ONLINE REGISTRY FOR ADVANCED HEALTH CARE DIRECTIVES IMPORTANT TO THE
CITIZENS OF THE STATE OF CONNECTICUT?

Submitted by Janice E. Favreau in testimony before the Public Health Committee on March 14, 2007

Page 4

days but never gets completed. However, in the course of my research, I discovered that the states of Arizona and North Carolina have instituted online registries for this document in order to facilitate the completion and accessibility of them. I have subsequently learned that the state of Montana also has initiated this process in 2005.

I urge the State Legislators to consider the passage of this Act to implement an online registry for these Advanced Health Care Directives not only to relieve family members of having to make an "on the spot" decision for their loved one, but more importantly to make those instructions quickly and easily accessible 24 hours a day to medical personnel who need to determine what treatment to provide to the patient who cannot speak for his or herself.

End of Statement

#