

This op-ed appeared in the New Haven Register on March 6, 2006.

## **Knowing That A Loved One's Wishes Are Being Honored – The Benefits of an Advance Health Care Directive Registry**

*Susan Bysiewicz and Susane Grasso*

Suppose you are caring for an elderly parent who is suddenly in need of emergency medical attention. Your parent has already filled out Living Will, but now you are unable to find it or contact your parent's lawyer. You have no way of knowing what your parent's wishes are, and the document that spells them out is now missing.

What do you do now?

If a doctor treating your mother or father needs to know if they should perform extraordinary life-saving measures, or if a feeding or breathing tube should be used, how are you supposed to give them the correct answer? Your parent may have carefully outlined those wishes but may not have shared all that information with you.

Scenarios like this one have occurred before, and have often required children to make nearly impossible decisions at the most emotionally stressful times. There are times when Advance Health Care Directives, such as Living Wills or Health Care Powers of Attorney, simply cannot be located, and the person who filled them out is unable to speak for himself. The consequences of such a situation can be tragic – a person's express wishes may not be carried out.

For this reason and others, we are working together – the Office of the Secretary of the State and Connecticut Hospice, Inc. in Branford - in proposing the creation of an Advance Health Care Directive Registry, an online repository where this information can be stored safely and securely and can be accessible to health care providers and family members in a time of medical crisis. It has been accurately referred to as a "virtual filing cabinet," and would be safeguarded with a password to protect it from outside intruders.

The bill was raised by the Legislature's Public Health last week, and it is our hope that the bill will be passed and signed into law by May, allowing the Secretary of the State's office to create this registry by the late summer or early fall. It will be a service available 24 hours a day, seven days a week for any Connecticut resident who currently has a Living Will or other type of advance health care directive, and will be free of charge to all who use it.

There are three reasons why this registry is so important for Connecticut residents:

- We all need the peace of mind that comes with knowing that our critical health care information is stored safely and securely in the event that we are unable to speak for ourselves;

- Our family members should not carry the burden of having to guess what our wishes might be; and finally,
- Health providers tending to us or to our loved ones should not have the burden of having to guess what our wishes may be, particularly if they do not even know who we are prior to treating us.

This registry would be kept by the Office of the Secretary of the State, and would be easy to use. A person would bring an executed copy of a Living Will to the Secretary of the State's office. The forms would then be scanned placed in the registry, once the person filing gave final approval.

That individual would then receive a card in the mail – much like a credit card or an organ donor card – which would contain a website where their information is stored and a password. Family member, doctors, or lawyers could be given copies of this card, in case an emergency ever arose. Even at the most critical of times, such as a serious injury or accident far from home or the actual Living Will documents being lost or misplaced, emergency health care providers could find the card and access the information immediately.

This registry makes these directives instantly available to those who need them at all times, including on weekends or vacation time when the individual's lawyer's office is closed and the actual documents are unavailable. It addresses concerns such as lost or misplaced documents as well, or the unfortunate event of an accident or illness that takes place far from home. These documents would even survive natural disasters and fires.

Advocates such as the American Association of Retired Persons (AARP) and the Connecticut Commission on Aging have joined us in our support of this legislation, and registries such as this one have quite a proven track record. Two other states, North Carolina and Arizona, have already created them, and California and Vermont are working towards creating their own as well.

A Living Will or advance health care directive provides people with the security of knowing that even at times when they are unable to speak for themselves, their medical and life-care wishes can still be carried out. In those cases where the documents must be found at once with no time to waste, this registry allows for instant.

While we often have no control over health issues that may befall us or a loved one, advance directives give us a way of making our wishes and decisions known even if we cannot speak for ourselves. And knowing that those wishes will be honored if that time ever comes can provide all of us with great peace of mind.

*Susan Bysiewicz is the Secretary of the State.*

*Susane Grasso is Director of Complementary and Alternative Medicine at Connecticut Hospice, Inc.*

