

Testimony of Dr. Constantine Aristedes Manthous,
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Senate Judiciary Committee, State of Connecticut
March 14, 2008

I apologize that, given only 72 hours prior to this hearing, I was unable to arrange for coverage of my critically ill patients to attend and testify here in person.

Dr. Allan Brandt and I requested this hearing, because Connecticut lags behind many other States in its end-of-life statutes. Despite viewing ourselves as a progressive, perhaps even liberal State, we have amongst the most restrictive advance directives statutes in the country. In Connecticut, directives are only binding for “terminal or permanently unconscious conditions.” We assert that all citizens are granted far broader rights of self-determination guaranteed by the U.S. Constitution. Accordingly, in addition to “terminal and permanently unconscious conditions, we propose that citizens, who choose, should have the right to direct their medical care if they come to “permanently lack legal decisional capacity” and/or become “acutely incapacitated with critical, but not definitively terminal illness.” In published medical studies, Connecticut’s citizens voice their strong preference to direct their own end-of-life medical therapies (Upadya, Am J Respir Crit Care Med 2002; Nicolosora, J Hosp Med 2006; Thorevska, J Crit Care 2005; DeGirolamo, Conn Med 2004; Thorevska, Conn Med 2004; Manthous, Chest 2003). These rights are guaranteed in many other states (Manthous, Conn Med 2005), but NOT in Connecticut. I have provided Senator McDonald with the advance directives of the other 49 states to support that Connecticut restricts citizens’ end-of-life rights relative to many or most other states. Therefore our request today is NOT extraordinary but rather brings Connecticut code “up-to-date” to reflect:

1. The will of citizens (as published in the medical literature cited above),
2. Rights to liberty, privacy and self-determination guaranteed in the Constitution and upheld in case law,
3. Statutes of a majority of other States in the union,
4. Current standards of medical practice, and,
5. Compassionate common sense.

My view (and experience) as a doctor:

Countless times each day in Connecticut healthcare institutions, loved ones of patients, who have lost capacity due to acute or chronic illness, are required to make end-of-life decisions about their patient-family members with only their knowledge of the person, when they could have been guided by the patients’ own written directives. The goal of our amendment is to remedy this paradox and to allow our patient-citizens the Constitution-guaranteed right to choose or decline life- or death-prolonging therapies; to speak for him- or herself through a Connecticut advance directive. Note that this modification will not change the current standard of medical care. Rather it protects doctors and healthcare institutions that practice ethical care on behalf of patients. It also

unburdens families who struggle mightily with these decisions, allowing our citizens to direct care when they cannot speak for themselves. Note that these transactions occur thousands of times each year in Connecticut. The burden it places on families – to speak on behalf of what the patient would really want, when they are suffering and only want the patient restored to them - is inappropriate and unnecessary. (And, strangely, surrogates, who may not know for sure what the patient would want, are given greater latitude than the patient whose wishes could have been delineated in an advance directive).

Importantly, doctors are “held harmless” only when they honor advance directives when patients are deemed “terminal or permanently unconscious.” Unfortunately, the word “terminal” is not defined. Does it mean “death within a year?” Within a month? Weeks? Days? Hours? It’s a nearly useless threshold if one considers that, without an explicit definition and taken to extreme, we are all “terminal.” Moreover, patients rarely present to hospital with acute illness that can be rapidly deemed terminal (days or weeks). We doctors and modern medicine can’t provide that level of certainty/prognostication. And chronic progressive illnesses that rob patients of their faculties (permanently) do not meet criteria of “terminal or permanently unconscious.” Accordingly, Connecticut precludes binding directives for the two most common general situations in which an advance directive would be useful. This leaves doctors and family members to hope that they are acting in accordance with what a patient would want rather than simply allowing the patient to stipulate in a directive when they are of sound mind. (We allow such directives i.e. “last will and testament,” for their estates. Why for money and inanimate objects, but not for medical care?)

Just as importantly, these statutes are so antiquated that they do not reflect “facts on the ground” and leave doctors who are simply practicing the standard of medical care open to prosecution. Likely hundreds of times each day, doctors and family members come to the conclusion that “Mom definitely would not have wanted this; let’s remove restorative therapies and provide only palliative treatments to ensure that she dies comfortably.” In perhaps a majority of such cases, Mom is not definitively “terminal.” Rather she would not have wanted invasive treatments and/or to continue with the quality of life that would be expected. Doctors honor those wishes, expressed by surrogates, as the current standard of care. Yet we are NOT protected by statutes when we do so in good faith. Allowing (and encouraging) Mom to create a written summary of her directives would be one additional protection of her rights and of the doctors who are working strenuously to do diligence for her personhood.

My view as a medical researcher:

Our research demonstrates convincingly, that an overwhelming majority of inpatients, sampled in the Greater Bridgeport area, wish complete control over the medical therapies they receive. To the extent that they are denied the opportunity to “direct” those therapies – that are and aren’t acceptable to them – at the greatest times of crisis, our advance directives statutes are clearly discordant with our citizens’ wishes. While there are likely to be some very vocal special interests who seek to assert their values on a majority of their fellow citizens, such “tyranny” is inappropriate and anathema to the

America envisioned by the framers. While our research only reflects views of a small fraction of our citizenry, the Greater Bridgeport community is a reasonable cross-section whose views are unlikely to differ significantly from citizens in other parts of the State.

My view as a citizen, son and future patient:

I have instructed my parents to complete an advance directive in the State of Florida, which allows greater explicit control of the medical treatments they will/won't accept. If actuation of their directives is required in the State of Connecticut, I will ensure through the Courts that their wishes, guaranteed in Florida and under the Constitution (and *Cruzan v. Director* 497 U.S, 261, 1990; and other case law) are respected in Connecticut.

Similarly I believe the State of Connecticut has no competing "interest" in imposing restrictions on my liberty to medical self-determination. If I become medically ill and incapable of making my own medical decisions, I have instructed that restorative therapies be withheld if I am most likely to be permanently institutionalized and incapacitated. The State has no appropriate reason to intervene to block my wishes. Moreover, if I should develop a slowly inexorably progressive dementia that robs me of my faculties (i.e. "capacity" to make my own medical decisions), I absolutely reject all restorative therapies and wish only care for a comfortable death. This is not assisted suicide. Nothing will be done to hasten my death. Rather it is a clear, rational prohibition of therapies against my will, because I would have ended in a state that is NOT acceptable to me. No other human or group of humans has the right to dictate what is acceptable to me if it has absolutely no impact on them. Nor do they have the right to prolong the suffering of my loved ones. Nor do they have the right to rob me of my estate (as such institutionalization insists) against my will. I have instructed my loved ones to use my estate to ensure that my rights of self-determination are secured, if this State refuses to act before I come to that end.

Conclusion

Drs. Brandt and I have drafted an advance directive that uses the current legislation as the starting point – modifying it only slightly to achieve greater liberty that meets the FIVE goals listed above. We are NOT wedded to the language of the legislation or the directive. In fact, many other States in the U.S. have excellent sample templates that could be adopted for use here. We simply request the same rights and protections enjoyed by most other U.S. citizens.

Some special interests may argue today that extension of Connecticut citizens' rights will engender a "slippery slope." This is a specious argument. Those without advance directives will in NO way be affected. A vocal minority or even majority has no right to constrain the rights of fellow citizens. I am sorry to say that many legislators have already or some day will have to circumnavigate the waters described above. I ask that you consider doing what is right and compassionate, for your own sakes as well, and resist the temptation to do what is, instead, politically expedient.