



STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES
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Testimony of the office of Protection and Advocacy for Persons with Disabilities
Before the Judiciary Committee

Presented by: James D. McGaughey
Executive Director
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Good morning and thank you for this opportunity to comment on **Raised Bill No. 660, AN ACT CONCERNING LIVING WILLS.**

This proposal would significantly expand the scope of Connecticut's living will statute. The living will statute encourages people to think about and express their personal wishes for end-of-life care. It operates by conferring immunity upon physicians and health care facilities that withhold or remove life support in accordance with the provisions of a living will or other recognized written advanced directive. However, under current law, that immunity is conditioned on several things, chief among which are findings that the patient is either terminally ill or permanently unconscious. This bill would expand the scope of that statutory immunity to include situations where a patient is "critically ill" or "permanently incapacitated".

Based on our experience representing a number of individuals with various types of disabilities who have faced health care crises and life-defining medical decisions, our Office has serious concerns about this proposal. Among these are:

- The bill introduces new terms such as "critical illness" and "permanent incapacity" which refer to, but would inevitably alter the meaning of existing, well-tested legal definitions. For instance, the term "life support system" is currently defined as any medical procedure or intervention: "which, when applied to an individual, would serve only to postpone the moment of death or maintain the individual in a state of permanent unconsciousness..." This definition is intended to be applied in the context of a statutory scheme that conditions withdrawal of those life supports on a medical finding of terminal illness or permanent unconsciousness. But, if the "trigger" for withholding or withdrawing life supports is stretched to include "critical illness", which the bill defines as a "severe" medical condition where "...the withholding or withdrawing of life support systems is likely to result in death in a relatively short time...", then the definition becomes part of a circuitous, self-justifying rationale for withholding treatment in a situation where the person might well survive. Introducing these concepts in statute would add considerable complexity and uncertainty to decision

making, both at the time a living will is executed and in the event of a later medical crisis.

- From a disability rights perspective, expanding the grounds for withholding or withdrawing life support to include “permanent incapacity” is disturbing. Many people with disabilities are born with, or acquire cognitive disabilities such that they could be considered “incapacitated” as that term is defined in the underlying statute. These disabilities are generally considered to be permanent, so the people who live with them would presumably meet the criterion for “permanent incapacity”. While individuals with life-long, significant cognitive disabilities would not be likely to have living wills, many do have surrogate decision makers who look to the standards expressed in the living will statute for guidance. Medical personnel who provide treatment and who advise conservators and guardians on treatment options also look to statutory standards. Including the term “permanent incapacity” among the acceptable grounds for withholding or withdrawing treatment represents a significant expansion of what is legally permissible. Inevitably, doing so would affect the way that decisions are made about people who have significant cognitive disabilities.
- Similarly, including the term “critical illness”, which could mean any physical condition where a person becomes, even temporarily, dependent on tube feeding or mechanical ventilation, is also very disturbing. Many people with disabilities routinely rely on feeding tubes to eat or mechanical ventilators to breathe. I know a number of these people who lead quite good lives. Suggesting that, as a matter of State policy, it would be acceptable to execute a document opting to die rather than live with disabling conditions that many people do, in fact, live with crosses into new territory.
- Declaring, in statute that, absent a terminal diagnosis or a clearly identified state of permanent unconsciousness, it would be acceptable for physicians or hospitals to withhold or withdraw what would otherwise be considered medically indicated, beneficial treatment fundamentally redefines a major, traditional role of health care providers. In the long run, I believe it would also work to diminish the value that we, as a society, attach to the lives of people who live with significant disabilities.

The current living will/advanced directive statutory framework reflects a balance that has been struck between the State’s longstanding interests in protecting life, and our equally abiding respect for the individual’s right to make very personal decisions about his or her own lives. This is an area of law where it behooves us to go slowly and to be mindful of the implications of making changes.

Thank you for your attention. If there are any questions, I will try to answer them.