

Euthanasia Prevention Coalition USA

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To: Members of the ULC Drafting Committee re the Uniform Determination of Death Act

I have been observing your meetings on the Uniform Determination of Death Act (UDDA) on behalf of the Euthanasia Prevention Coalition USA. We are aging and disability advocates, lawyers, doctors, nurses and politicians who support positive measures to improve the quality of the lives and well being of people instead of offering them assisted suicide and euthanasia.

I am an attorney with a varied background. Relevant to your deliberations, I was a columnist on medical decision making for a state bar publication, a pro bono member of a disability rights litigation team, specializing in disability discrimination within health care, and a member of a governor's task force on controlling health care costs.

As you consider revisions to the UDDA, I recommend you ask yourselves if they will increase or decrease trust between patients and physicians. Consider the example of Lisa Avila whose family rejected her brain death diagnosis and resulting plan to stop life supporting treatment after the same providers missed her fatal ectopic pregnancy. ["For them to push the family to do that is just unspeakable," said Lisa Avila's aunt, Jessica Jule. "Pretty much they're trying to kill her to reduce them from having to pay the bill that it would cost to keep her alive," said Avila's cousin, Yvette Townsend.](#)

Not only did their distrust affect decisions for Lisa, it will impact future decisions her family members and friends will make about their own health and that of others. It is well known that [distrust leads to a failure to engage and then once receiving health care, insistence on aggressive treatments](#), especially in communities subjected to health care disparities.

The importance of the trust that underpins medical relationships cannot be overemphasized.

Medical professional relationships have strong elements of trust and are marked by unique vulnerabilities and power disparities. These relational features arguably are greater for medical care than in any other professional arena. In addition, medical liability is seen as an important influence on health care quality and cost, which are of substantial public policy significance.

American Law Institute (ALI) Tentative Draft No. 1 of the Restatement Third of the Law of Torts: Concluding Provisions (March 2022) Ch 11 Liability of Medical Professionals and Institutions, Introductory Comments at 91. For sale at <https://www.ali.org/publications/show/torts-concluding-provisions/#drafts>

Brain death is a label applied to people thought not worth saving. Professor Thaddeus Pope says brain death "has been described as 'at once well settled and persistently unresolved.' **This is no surprise once brain death is recognized as a value judgment instead of as a scientific truth.**"¹ Harvard ethicist Robert Truog M.D. says the [central justification equating brain death with biological death is now known to be false.](#)" It is well accepted that "brain death" was legally

adopted to allow the supply of organs for transplantation. [“Donation after circulatory death determination is not preferred, as this manner of death tends to render organs unusable...”](#)

Thus, the Drafting Committee’s effort is fraught with controversy and challenges. Clever word-smithing will not change that. In this letter, I will comment on your draft language as of the end of your February 10-11 meeting.

Reversible but Permanent Due to Clinician Inaction

The Drafting Committee has changed the criteria for both circulatory/respiratory death and brain death from “irreversible” to “permanent.” This means clinicians can refuse to act to reverse patient conditions. This language would allow a clinician who has caused a potentially fatal injury to refuse to treat the patient, instead waiting for the person to die. This completely undermines trust.

Functional Impairment instead of Anatomical Location of Brain Injury

The Drafting Committee has changed the criteria from whole brain death to a list of functional impairments. The change is from “irreversible cessation of all functions of the entire brain, including the brain stem” to “permanent coma, permanent cessation of spontaneous respiratory functions, and permanent loss of brainstem reflexes...” We know that [coma can evolve to persistent vegetative state or partial consciousness and that about 50% of those in a persistent vegetative state following a traumatic injury, eventually recover consciousness.](#) This process takes a few months to a year, but brain death is often quickly determined. A quick labeling of brain death does not allow this healing process to take place.

The Committee’s draft allows for family to gather for a short time after brain death has been determined before circulatory-respiratory support is stopped. Think about what this says to the family: we’ll let you say good-bye while your loved one looks/is alive; then we’ll pull the plug because your loved one really isn’t dead until we do that. This very seriously undermines trust.

The underlying problem is that, brain death represents a value judgment. An analysis in the AMA Journal of Ethics says brain death examination [“evaluates function but cannot distinguish between a ‘stunned,’ quiescent brain and an irreversibly damaged brain;... ‘super locked-in patients’ ...could appear brain dead, despite preserved consciousness or afferent olfactory and visual pathways, analogous to vegetative patients who demonstrate subclinical awareness when carefully interrogated.”](#)

The Committee’s new language allows more false positive, i.e. incorrect, determinations that people who are alive and possibly could recover will be labeled legally dead. This seriously undermines trust.

Disability Discrimination

Reliance on functional impairments instead of biological injuries as discussed above raises a question of whether the language facially discriminates on the basis of disability. The disability community is looking at this question.

Clever Elimination of Informed Consent

The draft purports to accommodate objections to the harmful apnea test for brain death and for being determined brain dead. However, the objection(s) must be lodged before brain death tests are started. Since no notice of the right to object is required, this is a hollow right. Further, committee discussions indicated this would replace any rights to receive required disclosures for giving informed consent. Informed consent, which is recognized by the common law throughout the country, underpins the trust patients place in physicians and health care systems. Taking this right to informed consent away by ambiguity undermines that trust.

Medical Malpractice Should Not be Rewarded

The Drafting Committee's charge is in response to concerns from medical providers about increased litigation and challenges to brain death determinations.² Cases specifically cited in raising these concerns frequently involve alleged medical malpractice leading to what families see as alleged brain death.

Lisa Avila, age 36, died from an undiagnosed ectopic pregnancy, but was labeled brain dead.

Jahi McMath, age 13, lost her airway after a tonsillectomy, allegedly because of malpractice. She was declared brain dead in California but not in New Jersey.

Aden Hailu, age 20, came out of an appendectomy and exploratory surgery with severely low blood pressure and severe, catastrophic brain damage due to lack of oxygen. Her father refused to consent to brain death testing.

Professor Truog says:

Although the issues described above have generated a substantial number of legal challenges, they have not been overwhelming in either their number or their impact, and practice under the current UDDA has been generally well-accepted by the public for more than 40 years. The risk of future lawsuits could also be mitigated by providing an opt-out for patients who object to the determination of death by neurologic criteria, a concession that has been available in New Jersey for more than 3 decades.³

Holding providers accountable for malpractice, including malpractice in determining whether someone is dead, is necessary to support trust in the medical system. Those who commit malpractice should not be given an easy way out by labeling the impaired patient brain dead.

Sincerely,

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Immediate Past Chair, EPC-USA

¹ Thaddeus Mason Pope, "Brain Death Forsaken: Growing Conflict and New Legal Challenges," *Journal of Legal Medicine* 37, no. 3-4 (July-December 2017): 265-324.

² Truog RD. "The Uncertain Future of the Determination of Brain Death" *JAMA* Published online February 07, 2023.

³ *Supra* n. 2.