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The Honorable Samuel A. Thumma
Judge, Arizona Court of Appeals, Division One
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1501 West Washington
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To the Honorable Samuel Thumma:

Thank you for allowing me to share my thoughts as an observer.
Below, I comment on the current ULC draft which I place in context of suggestions for a direction forward, newer information from Canada which I attach, and some thoughts on pausing the process.

I offer these reflections with the hope that this Uniform Law Commission will come closer to honoring its charge to promote legislation for consistent state law that supports a medical determination and declaration of death that applies uniformly to all patients.

General Comments and Suggestions for Moving Forward:
The draft of 4/21/2023 pursues a direction opposite to that suggested by the charge to the Drafting Committee. While the ULC has welcomed all opinions and voices on this issue, not all opinions are evidence-based or based in coherent philosophy. In my limited perspective as an observer, guidance on how to weigh the diverse opinions may be helped by clarification of the charges with some clarifying specifics.

In the spirit of attempting to promote movement towards its charge, I offer four suggestions as preconditions for contemplation and drafting by the Drafting Committee:

1) **Accept the validity of guidelines for the diagnosis of death by the medical profession** and opportunity for their further development. No patient diagnosed as dead by neurologic criteria within guidelines promulgated by the *American Academy of* Neurology (AAN) has recovered consciousness. Guidelines for the determination of brain death are well-vetted and continue to be scrutinized. While rare cases reach social media as individuals "awakening" from death, after review these have been found either to be mistaken reporting, or cases where the guidelines have not been followed. Flexibility in state law should be stated to allow for the continuous evolution of guidelines for medical determination of circulatory and neurologic death when based on additional medical advancement and evidence. (Wijdicks EFM, Varelas PN, Gronseth GS, Greer DM. Evidence-based guideline update: determining brain death in adults: report of the quality standards Subcommittee of the American Academy of neurology. *Neurology.* 2010;74(23):1911–1918) (Biel S, Durrant J. Controversies in Brain Death Declaration: Legal and Ethical Implications in the ICU. Curr Treat Options Neurol. 2020;22(4):12).

2) **Discussion of medical criteria for defining death**: The meetings of this ULC are not the time or place to discuss changes in the specific medical criteria for determining death or

arguing their validity. Further discussion on points such as hormone testing or changes in apnea testing should be tabled or disallowed for purposes of the ULC. The ULC should support current extant practice and procedure as uniform—no consent is required to determine death by circulatory or neurologic criteria. Continuation of that circumstance is recommended by the AAN.

3) **Legally defining death:** A legal, and not a philosophical or medical answer has been requested of the ULC with regard to legally defining death. The limiting of choices to 3 options might help to move the ULC forward. They are a,b, and c below. d. and e. are included to differentiate legal from philosophical and medical approaches.

    a. Adopt the newer definition (or similar) as proposed in earlier draft: "*A determination of death for an individual shall be made in accordance with currently accepted national medical standards by establishing either: (a) the permanent cessation of spontaneous circulatory and respiratory functions, or; (b) the permanent cessation of spontaneous respiratory functions and the permanent loss of the clinical functions of the brain and brainstem necessary for consciousness*". Similarly, adopting the wording from the Canadian Consensus opinion would suffice.
    b. Adopt the vast majority of the wording and spirit of the Nevada 2017 statute to retain the previous problematic legal definition but to place it in the proper context.
    c. Abandon a legal definition and defer to the medical definition.

    d. The philosophical debate on the definition of death is beyond the scope of the ULC. Deferring to the approach developed by The President' Council on Bioethics in 2008 may seem reasonable. The Council concluded that the devastating loss of brain functions as demonstrated in the diagnosis of death by neurologic criteria were sufficient for a legal declaration of death. They based this not so much on the loss of all functions of an organ such as the brain or the heart or the integration of functions. Instead, they said, "brain failure" ". . .can continue to serve as a criterion for declaring death—not because it necessarily indicates complete loss of integrated somatic functioning, but because it is a sign that this organism can no longer engage in the essential work that defines living things." In the case of humans, this means that death by neurologic criteria reliably demonstrates the presence of a biological condition so inconsistent with human life as to render death. While words may escape the ULC with regard to defining life, and particularly human life, the President's Council has described what it is not.

    e. Similar medical answers to the definition of death are contained in the Canadian definition, the World Health Organization definition, and the definition from the United Kingdom and need not be addressed by the ULC except to consider incorporation verbatim as in option a. above.

4) **Adopt the approach to exceptions already nearly uniform within the United States**: While a belief in a "miracle recovery" may coexist with religious faith or idiosyncratic personal belief there is no observed difference in recovery in the presence of religious faith or personal belief. Religious exceptions to the diagnosis and declaration of death remain absent from all states except New Jersey, where death can be diagnosed but not declared. Suggestions to states for a uniformity of approach should favor the condition that is present largely throughout the United States: no religious or other exceptions to the diagnosis of a medical condition. In addition, with adequate support from law, consistent with uniformity,

there should be no legal exception to the declaration of death when diagnosed within guidelines for that diagnosis and following guidelines for neurologic criteria.

For a recent state example of model legislation, please see Nevada's state law revision in 2017.

Newer Information and Direction:
As the ULC continues discussion, Canadian general consensus guidelines, published in May, 2023, support the approach in the four guiding principles immediately above. As stated in the article, "This Clinical Practice Guideline was funded by HealthCanada and was developed as a partnership between the Canadian Critical Care Society, Canadian Blood Services, and the Canadian Medical Association. The project's objectives were to develop a unified brain-based definition of death and update the criteria for its determination after devastating brain injury or circulatory arrest. The definition of death should apply to all persons in all circumstances."

These guidelines may serve as a model for further drafting by the ULC with similar goals of establishing a uniformity of approach and are attached.

Comments on the current draft:
In my perspective as a physician, neurologist, and ethics consultant, the ULC draft of 4/21/2023 has opportunities for improvement. Three are problematic:

1) The draft provides for changes in the law that are present in no state in the United States—or in any other country. A single state, New Jersey (NJ) offers a unique, conservative policy that is philosophically, medically, and legally inconsistent. The NJ policy permits the diagnosis of death by neurologic criteria. However, NJ disallows the *declaration* of that death despite a medical diagnosis of death when some member of the family claims the patient, on the basis of religious conviction would not have accepted the presence of death diagnosed by neurologic criteria. All other states consider death by neurologic criteria to be both diagnosed as death and declared as such with some variation in procedure in New York without significant change in practice. In contrast to the unique NJ approach, this ULC draft disallows physicians from *diagnosing* death, a perspective without precedent. The current draft proposal amounts to a "gag rule" preventing physicians from confirming an obvious working diagnosis of death by neurologic criteria. This approach should be abandoned as it violates the ULC charges to:
    a. "Build on the structure of the current UDDA": Rather than building on it, the draft undermines the UDDA.
    b. "Help enhance uniformity": Rather than enhancing uniformity, if adopted, it creates multiple areas for uncertainty and inconsistency. The draft propels us along an untested, direction that splinters and confuses the approach through vague exceptionalism. The exceptions create a policy that is the opposite of uniform and in its extreme flexibility—disallowing the diagnosis of death—suits no one. States are unlikely to adopt this policy uniformly as it is likely to be rejected by medical organizations. There is no other law like it and, without precedent. Hence, an appeal to uniformity cannot be referenced in promoting this approach.
    c. "Avoiding conflict and litigation": This draft conflicts with medical guidelines for the diagnosis of death, erodes the practice of medicine, and is anti-science in nature. This draft likely will increase litigation when physicians attempting to comply with standard medical guidelines find themselves in violation of a misdirected law.
    d. "Accounting for innovative advancement in medicine": This proposal is opposite to the direction of innovative advancement in medicine. The original proposal to amend the UDDA remains an option and should be the proper focus of wordsmith efforts. Rather than innovative, this current draft is an antiquarian move for law, medicine, and society. Contained in it seems to be permission to return to inadequate guidelines for determining

death: isolating the diagnosis to circulatory criteria. A movement forward would include accepting the definition of death to include permanent loss of the capacity for consciousness and the procedures consequent in that approach.

2) In addition to violating the charges given to the Drafting Committee, this draft coerces medical practice away from best medical practice aligned with standard guidelines for the diagnosis of death. Guidelines for diagnosing death by neurologic criteria—the state of insensate, permanent loss of the capacity for consciousness also known as permanent coma are present throughout all states and internationally. The proposed ULC revision violates guidelines for best medical practice. This draft from this ULC steps well beyond regulating medicine and into an area of law that corrupts medical practice.

3) The section on leaving "reasonable" time for accommodation invites additional litigation. What is reasonable for some is not for others. The previous wording, a brief period of time for the family to gather at the bedside before discontinuing the ventilator is proper and demonstrated to work well for patients, families, and medical professionals in California. In this novel draft, the notion that family members can require the ventilator to be continued until someone who lives far away be present at the bedside, a process that predictably may take weeks, months or not to occur is unacceptable. This concern is not hypothetical. Families and physicians are confused by current law and turn to hospital policy for clarification. Most hospital polices may offer 8-48 hours and rarely 72 hours for accommodation. That brief period of time should be justified in suggestions for current law and offer a foundation for hospitals to determine policy in this regard. Lack of time specificity or clearer descriptor invites chaos and litigation to address the individual situation. These changes also open the door to uncertainty as to the motivation behind allowing an open-ended period of time for accommodation.

The questions of pausing activity of the Drafting Committee:
The memorandum of 5/30/3023 concludes with important observations:

> "6) The Study Committee recommended taking a "hard look" at its efforts to decide whether to proceed. Given our current progress, by what criteria should we assess the merits of proceeding with an rUDDA at this point?
>
> 7) Are there other options the Drafting Committee should consider, including whether it might make sense to "pause" the project to see if additional developments (medical, legal or otherwise) could better advance possible uniformity?"

Herein lies a question of whether the ULC should proceed further in its deliberations. If this 4/21/2023 draft portends the direction of future approach, I believe it would be reasonable to pause activities of this ULC. I recommend consideration of the 4 items of consensus offered above as a requirement to continue work as they are consistent with the charge of the Drafting Committee. If there is an inability to accept that basis for further suggestions for uniform legislation, or if these 4 items already have been considered and rejected, I agree that pausing the process would be reasonable as the Drafting Committee may be unable to come to a consensus that is consistent with its charge.

Malcolm