July 10, 2023

The Honorable Sam Thumma
1501 W. Washington, Suite 2
Phoenix, AZ 85007

Dear Chairman Thumma,

On behalf of the Arizona Hospital and Healthcare Association (AzHHA), and the 80 hospitals and health systems we represent, thank you for the opportunity to comment on the discussion draft revisions to the Uniform Determination of Death Act (rUDDA) as prepared for the Uniform Law Commission (ULC) meeting for July 21-26. Revisiting a 40-year-old uniform law is certainly appropriate, especially one rooted in medical science that has advanced significantly since the original UDDA was drafted. However, AzHHA and our members have serious concerns that several provisions in the current draft constitute broader policy changes that would ultimately result in less uniformity around the death declaration process. Furthermore, some of these policy changes would be difficult to administer in many situations and could create confusion for patients and family members. Our detailed comment are as follows:

A. Any Change to the Determination of Death Should Be in Consultation with Key Medical Associations (Section 3: Determination of Death).

As a general matter, AzHHA is not opposed to updating the definition of death given the UDDA was adopted more than 40 years ago. However, we believe strongly that any new definition should be crafted in consultation with leading professional medical associations, such as the American College of Physicians (ACP), American Medical Association (AMA) and American Academy of Neurology. This would follow a similar path for approval of the 1980 UDDA, which was a product of joint meetings between the ULC and the AMA, as well as the American Bar Association. The original UDDA was then approved by the AMA after promulgation by the ULC. While AzHHA does not have specific recommendations regarding the two options laid out in Section 3, we have read the June 7 comments submitted by the ACP. We believe the ULC should give strong consideration to these comments if the Commission chooses to finalize the rUDDA. Ultimately, we do not believe the ULC should adopt revisions to the UDDA without support from the key professional medical associations referenced above.

B. The 'Time to Gather' Requirement May Not Be Aligned with Patient Wishes, May Not Be Practical and May Conflict with Current State Statute (Section 4: Time to Gather).

Section 4 of the draft states:

> "After an individual is determined to be dead under Section 3(a)(2) but before the discontinuation of circulatory and respiratory support of the individual, the health-care institution shall allow a reasonable time for those designated by the individual's surrogate to gather at the individual's bedside."

Having family and loved ones present at the bedside before, during and immediately after death is extremely important, and hospitals take great effort to ensure this occurs. However, the gathering as outlined in Section 4 is not always practicable. Family members may live out of state or in another country or may be unable to travel due to financial constraints or their own health conditions. Infectious disease outbreaks, such as with COVID-19, may also necessitate alternatives to bedside visitation. The size of the hospital room may also limit the number of family members who can be present at any given time. Moreover, a patient's healthcare directive may have designated who the patient wishes to have notified and present at his or her death, and this directive should not be overridden by a surrogate's decision. Doing so would violate the very principle of patient-centered care.

The Arizona Legislature grappled with many of these issues in 2021 and 2022, and as a result enacted Laws 2022, Ch. 296, which establishes state policy regarding hospital visitation, including end-of-life visitation. It is our understanding that other states have also adopted hospital visitation laws, many of which could conflict with the draft rUDDA. AzHHA is specifically concerned Section 4 of the rUDDA draft conflicts with A.R.S. 36-407.02, which permits a physician to disallow a visitation if the physician "determines based on the patient's condition that the visitation does not meet health and safety standards or is reasonably likely to harm the patient." The statute goes on to state the steps a hospital must follow if visitation is denied.

While it would be rare for the visitation exception in A.R.S 36-407.02 to be triggered in most end-of-life scenarios as outlined in Section 4 of the rUDDA draft, there are occasions when this will happen. We are very concerned that including Section 4 in the final rUDDA would undercut important state-specific policies on hospital visitation, including end-of-life visitation, that the Arizona Legislature and legislatures across the county have adopted. And this could ultimately result in litigation if competing statutes become law.

C. Notification of Surrogate May Delay Clinical Diagnosis of Patient's Condition (Section 5).

Section 5, Paragraph b of the discussion draft states:

> "Before a health-care professional begins a clinical evaluation to determine death of an individual under Section 3(a)(2), the health-care institution shall make a reasonable effort to notify the individual's surrogate that the evaluation will begin."

We agree it is extremely important for hospitals to notify patient families when a patient enters the end-of-life process. And hospitals already have policies and procedures that cover who is informed, when they are informed, and what we are permitted to share with them.

Much of this may be included in a patient's healthcare directive, so the notification can be patient specific. A.R.S. 36-3231 prescribes the steps Arizona healthcare providers must take if an adult patient is unable to communicate healthcare treatment decisions, which includes making a reasonable effort to locate and follow a healthcare directive and making a reasonable effort to consult with a surrogate. We support this Arizona law.

Our concern with Paragraph b above is the requirement that a reasonable effort be made to notify a patient's surrogate *before* a healthcare professional begins the clinical evaluation of neurological death. This mandate will delay a clinical diagnosis of a patient's medical condition, and potentially result in work-flow disruptions for clinicians. While we believe including a patient's surrogate and other loved ones is vital to all healing that occurs in a hospital setting, including the grieving that occurs at the end-of-life, this type of statutory intervention in a clinical diagnosis process imposes an unwarranted and excessive legal standard on medical decision making. For these reasons we oppose including this section in any revisions to the rUDDA approved by the ULC.

D. <u>'Objection to Death' will Create Confusion and a Legal Double Standard (Section 6).</u>

Section 6 of the draft:

- Allows an individual to object to a determination of neurological death;
- Requires the objection to be documented in the individual's medical record or through "information provided to the health-care institution by the individual's surrogate"; and
- Requires health-care institutions to make reasonable efforts to accommodate an individual's objection to a determination by neurological death, including that the institution comply with the individual's choice.

Every hospital and healthcare professional shares the goal of honoring the patient's wishes, particularly as it pertains to end-of-life care. However, allowing patients or their surrogate decision makers to object to a medical diagnosis and by their objection, invalidate the diagnosis, is baffling to say the least. If a physician diagnoses a patient with heart disease, the patient cannot simply decide they do not have heart disease. The medical fact remains, even if the patient doesn't accept it. Neurologic death has been a well-established medical diagnosis for more than 40 years. Allowing a patient to "opt-out" of this diagnosis based on the individual's beliefs related to neurological death as a concept will create confusion among the public and potentially call into question the validity of all neurological death diagnoses.

We are particularly concerned that the discussion draft would allow a surrogate to object to a neurological death diagnosis based on "information provided to the health-care institution by the individual's surrogate." What if the healthcare institution possesses a valid healthcare directive that runs counter to the "information" provided by the surrogate? These situations will likely result in some level of litigation. Finally, we are concerned that this section of the rUDDA draft creates a legal double standard by allowing patients to opt-out of a neurological death diagnosis, but not a cardiac death diagnosis.

AzHHA strongly opposes the inclusion of Section 6 in any revisions to the UDDA adopted by the ULC. The section sets a precedent that any medical diagnosis could be overridden by the patient or the patient's surrogate, and taken to the extreme, would entitle a patient to medical treatments that may be contra-indicated by medical science and evidenced-based medicine.

Conclusion

Our hospitals and their staff experience death every day and have the professional expertise to help patients and their families navigate it with dignity. The proposed changes to the UDDA in Sections 4, 5 and 6 would not improve patient care or outcomes. Instead, they would unnecessarily complicate best medical practice and create potential conflict with existing state level policy. Moreover, the controversial nature of these provisions will likely result in fewer states adopting the uniform law, which ironically would lead to less rather than more uniformity. For the above-mentioned reasons, the ULC's purpose "to bring clarity and stability to critical areas of state statutory law" will not be served by adopting the current version of UDDA.

Thank you for your consideration of these concerns. If you have any further questions or would like to connect with hospital leaders to discuss these matters, please reach out to me.

Thank you for your partnership,

Ann-Marie Alameddin
President and Chief Executive Officer

cc: Barbara Atwood, Tim Berg, Roger Henderson, Edward Lowry, Jr.

AMA/sgr

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