FEDERAL AND STATE AFFAIRS COMMITTEE OF THE KANSAS HOUSE OF REPRESENTATIVES
PUBLIC TESTIMONY ON House Bills 2849 and 2884
Monday, February 13, 2006
State Capitol, Room S-313
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Chairman Edmonds and members of the Committee; thank you for the opportunity to present testimony regarding HB 2849 and 2884 on behalf of the Kansas LIFE Project. My name is John Carney and I am vice president for Aging and End of Life at the Center for Practical Bioethics in Kansas City and co-chair of the LIFE Project Public Task Force as well as a founding member of the organization. I also served as a member of the HB 2307 Committee assigned in 2005 by the Kansas Judicial Council to review proposed revisions to the Kansas Guardianship Statute related to hydration and nutrition for wards of the court.

My remarks today will be limited primarily to the provisions in the House Bills under consideration dealing with the administration of nutrition and hydration for wards of the court, and the attendant responsibilities of guardians in medical end-of-life decisions for their wards.

For most of my professional career I have worked in the realm of hospice and palliative care – at the local level in south central Kansas, at the state level, within the region and nationally, having served on the boards of directors of state and national hospice and palliative care organizations, including a brief stint as the latter's chief operating officer. That professional experience notwithstanding, what I believe provides me far more meaningful perspective on this issue is the 26 years I assisted my mother in caring for my recently deceased father, who for more than a quarter of a century was disabled by stroke, facing the slow and often undetectable diminishment of his ability to care for himself. I stand before you, not so much as a career professional, but more as a son and family caregiver who knows the meaning of providing and deciding with and for a disabled person.

Secondly, in the broader context of my professional work it has been my experience that Kansas healthcare professionals are guided in their end of life care practice by the following convictions:

1. Respect for the principle of personal autonomy is pervasive, protected not only for those who can speak for themselves but equally for those who rely on others to speak for them. This conviction ensures access to safe, appropriate medical care regardless of (dis)ability. For the most part it also includes a respect to honor the wishes of patients when those desires are known regardless of whether they are expressed in writing or through a silent nod or a squeeze of the hand.
2. We respect the accrediting, credentialing and licensing processes that govern our healthcare care system to ensure competent medical practitioners. We rely in the obligations dictated by license and professional standard for those professionals to act in our best interest.
3. Healthcare decisions are first and foremost private matters between patients and their professional caregivers, naturally inclusive of those who by patient choice or legal appointment become involved.
4. Dying has changed. From this point forward, death for most of us will no longer result from a single acute event, but rather from a series of slow and often imperceptible changes – disabling over time; the result of multiple chronic diseases that ebb and flow. This process of subtle decline will be affected by new medicines and new procedures, but only rarely by new discoveries. For the majority of us the most common disability we face is dementia, the ability to make reliable decisions.
5. We cannot know, direct or predict with specific certainty today what future treatment decisions we will be asked to make for ourselves or for those we love. While we may describe our values, express our desires and discuss our intentions in healthcare directives based on today's understanding of our health status and current medical

interventions, we must trust and rely on those expressions to guide our proxies and agents in the future.

6. All medical procedures, especially those requiring surgery and the administration of anesthetics just as all medications, carry risks, burdens, side effects and benefits which must be measured, weighed and evaluated by patient, family and medical professional.
7. Dying is part of life. Death will come to all of us. Though unwelcome it does not have to be inhumane, nor must it at every turn be the enemy to be avoided at all costs.
8. Within the last 10 years, Americans have discovered that modern medicine is capable of creating "mechanical paths to death" whose impact can be more devastating and burdensome than the natural progression of some mortal diseases.

How do we balance the need to protect those who are vulnerable, whose wishes may be unknown or unknowable with the private healthcare decisions of patients and families who decline or refuse treatment?

First and foremost, overwhelming evidence suggests that relying on existing written advance directive will not achieve that end. A number of recent studies including one sponsored by the Pew Charitable Trust released in early 2006, point to the woeful progress in the Advance Care Planning arena. This is not a subject Americans approach comfortably or handle well even in conversation, let alone in writing. Many may speak with family members but do not, as a rule, write their wishes down or discuss them in detail with their physicians. Physicians also express reluctance in discussing the issues with patients. Consider the following facts:

1) Only a minority of Americans even have advance healthcare directives in place. Unfortunately in many instances they are unavailable at the time they are needed for healthcare providers and evidence points to their not being honored due to standard protocols that favor treatment.
2) Most advance healthcare care directives are not explicit, often describing values, treatment **preferences** and general conditions. Topics such as hydration and nutrition, while referenced may offer no instruction or guidance on, as proposed language requires, "current circumstances."

The reliance of House Bills 2849 and 2884 on previous explicit written instructions, when no such support or structure within the healthcare system exists, is unrealistic and problematic.

Before proceeding with further analysis of the measures under consideration, it is important to point out that the particular provision related to the withholding and withdrawal of nutrition and hydration for wards of the court was referred to the Kansas Judicial Council during the interim session last summer and fall.

The work group assigned to study the provision was named the **HB2307 Advisory Committee**. I, along with representatives from the legislative and judicial systems; healthcare ethics, legal, nursing and medical professions; long term care, hospice and disability fields met for five months to address the language. Our recommendations were forwarded to and approved by the Judicial Council in December 2005. The language recommended by Council is not part of either of these two bills.

Furthermore, the provision [59-3075 (e)(7)(C)] is still part of HB2307 in the House Judiciary Committee and Senate Bill 92. Given the uncertainty of where the Judicial Council's report will be reviewed, it seems premature to act on yet another version of the language before full consideration is given to the Judicial Council's recommendation.

As an example, new language appearing in both 2849 and 2884 references the term ***objectively futile*** as if it had some basis in ethical or medical literature. To our knowledge there is no accepted term in either field, and in fact American Medical Association ethics representatives indicate that disagreement exists on the use of the term **futile** itself, some arguing that it has

negative values associated with it, is ultimately subjective in nature and can effectively be applied only retrospectively. In this application, the reference to ***objectively futile*** may serve neither ward nor guardian.

The Center for Practical Bioethics is currently involved in an almost year-long process with member Kansas City area hospitals in developing a policy guidance document on the use of the term futility. Focus group feedback from disability and minority stakeholder groups reflect ***no consensus on the use of the term futility***. Requiring this level of evidence may not prove helpful to either the affected parties or the court. At the outset the use of the term appears problematic.

In addition, how is it that the court system is better equipped to handle these delicate, gut wrenching, emotionally charged issues than are healthcare professionals, carefully selected and legally bound guardians, and family members? Thousands of these kinds of decisions get made daily in the privacy of homes, hospitals and nursing homes in the best interest of disabled patients without incident.

No evidence of the system failing Kansans was presented during the five month review conducted by the HB2307 Committee for the Judicial Council. Despite the lack of evidence, the committee nonetheless made a number of recommendations to accommodate perceived risks. Those recommended changes deserve serious consideration.

To assume that surgical procedures performed on disabled persons would not be considered medical care if the purpose is to provide artificial hydration and nutrition appears to be contradictory. Would surgeons and physicians be exempt from liability should the procedures fail? Why do the provisions not include efforts to assist with artificial or mechanical assistance for breathing or elimination – two other equally important physical requirements for sustaining life?

The assumption that these two procedures (hydration and nutrition) are fundamentally different than others, outside the parameters of medical care, and carry no **relative** risks oversimplifies the complexity of caring for disabled persons usually affected by a multi-organ and multiple system issues.

Reducing or limiting the physician's reasonable medical judgment in addressing burden and benefits of interventions or risks (side effects) to "hastening death", "medical impossibility" or incapacity again appears to oversimplify the physician's responsibility to manage the patient's care.

Finally, the most troubling dilemma raised in these proposed measures is the provision for "presumption of life", only because the definition of what it means to sustain or preserve life is never addressed. Nearly every religious and philosophical traditions, from east to west, accepts the purpose of life as being more than the physical function of bodily organs. Humans are social animals, functioning within family systems and social units. Meaning in life, for most of us, comes not only from within but from outside of us as well – through a higher power or social construct. There is a give and take with the world.

If we follow the presumption of life argument to its natural conclusion, without definition as to what preserving and sustaining life means, then the bodily function of organs, mechanically assisted or artificially supported, wins out. How then can we stop at hydration and nutrition? Aren't we obligated to return to the question of what society in general has already resolved - the meaning of brain death; what it means to be an organ/tissue donor, and how can anyone can determine when my time has come.

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