

QUESTIONS AND ANSWERS ON THE REVISED MODEL STATE STARVATION AND DEHYDRATION OF PERSONS WITH DISABILITIES PREVENTION ACT

Why do we need legislation to protect people with disabilities from starvation and dehydration?

The case of Terri Schindler-Schiavo, a woman with brain damage whose husband wanted to starve her but whose parents fought tenaciously to continue feeding, has horrified many Americans who are outraged that such a thing could occur in our country.

What many fail to recognize is that, far from being an isolated instance, the starvation and dehydration of Schindler-Schiavo in fact typifies the current law and common practice in most states. Since the 1980's, state statutes and court decisions have empowered third parties – often relatives or hospital committees – to choose to deny food and fluids to people with disabilities incapable of speaking for themselves so as to bring about their deaths. Tragically, in most cases in which there has been a dispute within the family, courts have sided with those seeking to deny food and fluids.

What can be done that the courts won't strike down?

In *Cruzan v. Director, MDH*, 497 U.S. 261 (1990), a majority of the U.S. Supreme Court stated that there is a constitutional right to reject artificially provided nutrition and hydration, but the Court held that a state may require clear and convincing evidence, in the case of an incompetent patient, that the rejection of nutrition and hydration conforms to the patient's wishes while competent.

In creating a presumption that an incompetent person would have wanted nutrition and hydration, the proposed bill provides that the presumption is overcome if the patient executed a valid written

declaration (such as a living will) specifically rejecting nutrition and hydration in the applicable circumstances.

In *Cruzan*, 497 U.S. at 284 (U.S. 1990) (citations omitted), the U.S. Supreme Court stated:

It is also worth noting that most, if not all, States simply forbid oral testimony entirely in determining the wishes of parties in transactions which, while important, simply do not have the consequences that a decision to terminate a person's life does. At common law and by statute in most States, the parol evidence rule prevents the variations of the terms of a written contract by oral testimony. The statute of frauds makes unenforceable oral contracts to leave property by will, and statutes regulating the making of wills universally require that those instruments be in writing. There is no doubt that statutes requiring wills to be in writing, and statutes of frauds which require that a contract to make a will be in writing, on occasion frustrate the effectuation of the intent of a particular decedent, just as Missouri's requirement of proof in this case may have frustrated the effectuation of the not-fully-expressed desires of Nancy Cruzan. But the Constitution does not require general rules to work faultlessly; no general rule can.

Clearly, it is both appropriate and constitutional to limit cases in which denial of nutrition and hydration necessary to sustain life is permitted to those in which the patient, if now incompetent, explicitly rejected them in a written advance directive.

Does the bill require nutrition and hydration in every instance in which it has not been specifically rejected by the patient?

The presumption for nutrition and hydration does not apply when the medical condition of the patient is such that the provision of nutrition or hydration would not contribute to sustaining that person's life or to providing comfort to that person (as may sometimes occur, for example, in the final stages of the dying process when death is imminent). To safeguard against abuse of these circumstances, the bill defines an objective standard for the “reasonable medical judgment” required to establish their existence.