

Dec. 19, 2019

Re: Case at Cook Children's Hospital

Dear Gov. Greg Abbott:

Texas hospitals are privileged to provide health care to Texans at the beginning of life and at the end. Both events are emotional and involve families at their most vulnerable time. Through the Texas Advance Directives Act, the state has established a compassionate and carefully balanced process to guide decision making around end-of-life care. The Texas Hospital Association and the Catholic Health Association of Texas seek to correct several misconceptions that exist among certain groups that are pursuing political action and changes to current law. The recent attention has been prompted by the Tinslee Lewis case in Fort Worth.

There has been significant coverage regarding the case of 10-month-old Tinslee, who has been hospitalized at Cook Children's Medical Center her entire life and is currently surviving due to full mechanical ventilator support. Tinslee's condition requires aggressive medical intervention daily, and her treatment team has determined her condition will never improve. In fact, teams of medical experts, both inside and outside Texas, as well as a formal ethics committee, believe continued intervention is medically inappropriate and will contribute to Tinslee's ongoing pain and suffering. However, recent court decisions – including a decision Dec. 12 by the District Court in Fort Worth – have required the hospital to continue medical intervention.

In rare cases of disagreement between a treatment team and a patient or family about ending medical treatments, Texas law requires a review by an ethics committee before treatment ends. If the committee determines additional intervention is medically inappropriate, the law provides additional time to identify a facility willing to accept transfer of the patient. In the case of Tinslee, an ongoing lawsuit has succeeded in extending this 10-day timeframe.

There are several areas of focus and clarification we'd like to highlight:

- The central mission of hospitals is to heal the sick and alleviate suffering. Hospitals treasure their sacred role in bringing new life into the world. Hospitals also have the difficult role of accepting prognoses and easing pain through compassionate end-of-life care.
- Requiring doctors and nurses to perform potentially unethical medical interventions on a patient who is irreversibly ill, and who may needlessly suffer pain from such interventions, violates providers' consciences and strongly held ethical beliefs. Testimony in the current case reveals that many of Tinslee's providers believe these interventions are inappropriate.
- Discussions with the family occur long before the dispute resolution process begins. In practice, care providers work closely with families for weeks and sometimes months leading up to the start of any 10-day provision initiated by the hospital. Cook Children's

- has worked with Tinslee's family since September to locate a facility willing to accept a transfer.
- When there is disagreement, Texas law requires an ethics committee review before treatment ends. The committee consists of a diverse group of experts, including physicians, specialty providers, medical ethicists, members of the clergy, social workers, parents of former patients, and other community members. The review, which occurred in Tinslee's case, considers relevant medical and ethical criteria and the patient's condition and prognosis. The patient's attending physician cannot serve as a committee member; Tinslee's family participated in this discussion. Of the 22 people who served on the committee, all voted in favor of discontinuing the medical interventions.
 - In Tinslee's case, Cook Children's reached out to numerous other facilities to see if any would be willing to accept Tinslee as a patient; all declined and agreed that Tinslee's condition will not improve with continued medical intervention. As part of standard practice, Cook Children's undertook the meticulous effort to locate other care.
 - It is extremely rare for a hospital to initiate the dispute resolution process; it is rare for a medical team and a family to disagree about medical interventions in a situation of this kind. The dispute resolution process and timeframes are necessary to resolve these rare situations and honor the ethical boundaries of all concerned.

In every case, the patient must come first. Cook Children's has provided the best, most compassionate care to Tinslee. We stand by the medical team's efforts to lessen her pain and the ultimate recommendation to end her ongoing suffering. Doctors and nurses have a moral obligation to first do no harm. Health care providers should not be required to use their skills and technologies if not in the best interest of the patient or if medically inappropriate.

A hospital's central mission is always to heal and act in the best interest of the patient. For all parties, it's extremely difficult to be in a situation in which the standard medical care is to cease treatment. We appreciate Cook Children's medical team and the collective experts who have been by Tinslee's side and cared for her since birth.

Respectfully,



Stephen G. Wohleb
Senior Vice President and General Counsel
Texas Hospital Association

Additional Background on TADA and the Dispute Resolution Process

Attention on Tinslee's case has prompted scrutiny of the dispute resolution process, an aspect of the Texas Advance Directives Act. TADA has been in statute since 1999 and has been modified by Texas



1108 Lavaca Street, Suite 700
Austin, Texas 78701
512/465-1000
www.tha.org



lawmakers over the years in response to feedback from families, health care professionals, religious organizations and other stakeholders. Understandably with end-of-life decision making, disagreements can arise between health care providers and families, and stress and grief are very real factors that come into play. When there is a disagreement between an attending physician and a family about ending life-sustaining treatments for a patient, a formal review and dispute resolution process is initiated to offer additional time to transfer the patient to another hospital before treatment ends. The law balances the decision-making rights of the patient and family with a doctor's duty not to order medically inappropriate or unethical treatment or interventions that would cause unnecessary suffering.