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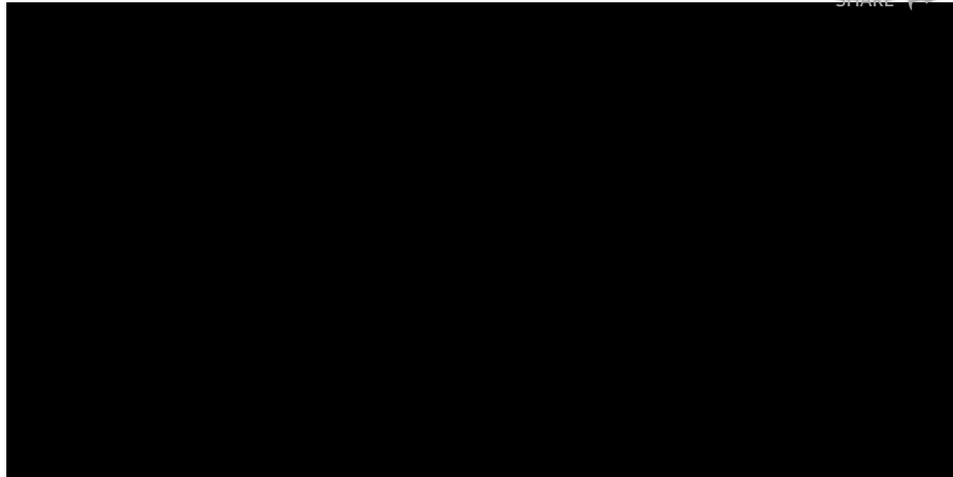
Texas law under fire after hospital moves to take Fort Worth baby off life support

BY KALEY JOHNSON AND TESSA WEINBERG

DECEMBER 02, 2019 05:00 AM



SHARE



9-month-old Tinslee Lewis at Cook Children's Hospital in Fort Worth is set to have her life-sustaining treatment ended against her family's wishes. BY TEXAS RIGHT TO LIFE

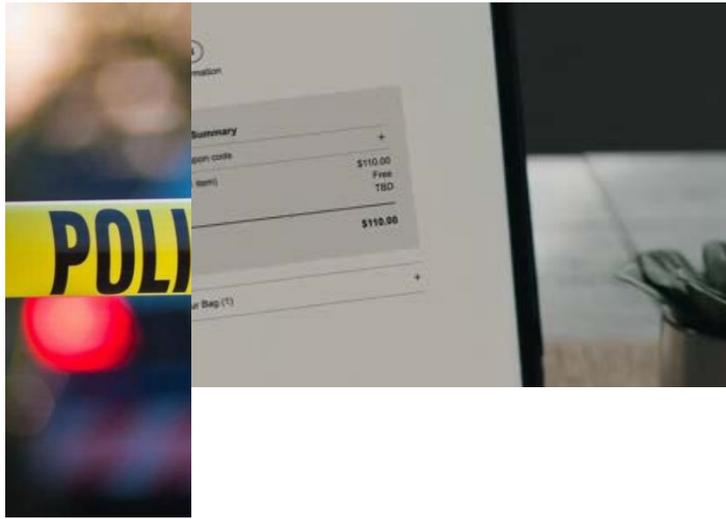
FORT WORTH

Tinslee Lewis has spent all 10 months of her life at Cook Children's Hospital, where she is on life support for several critical medical conditions. Unbeknownst to her, she has been thrust into a debate over a 20-year-old law that some argue removes a family's right to decide whether their loved ones live or die.

In late October, Tinslee's mother, Trinity Lewis, [was told the news](#) — Cook Children's Hospital determined her daughter's condition would not improve, and keeping Tinslee on life support was causing her unnecessary suffering, they said. In 10 days, doctors planned to take Tinslee off life support.

But Lewis fought back, and [a judge granted the family](#) until Dec. 10 to find a new hospital to transfer her daughter to.

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Tinslee's case [quickly gained statewide attention](#) as one of the latest instances in which physicians cited the Texas Advance Directives Act. If doctors determine care is futile or medically inappropriate, a provision in the act allows an ethics committee to choose to end treatment 10 days after a family is notified, unless the family can find another hospital to take the patient.

Supporters of the law say it allows physicians to make a difficult, but responsible, decision that families may not be able to accept. Those opposed say hospitals do not have the moral authority to decide who lives and dies.

State Rep. Garnet Coleman, a Democrat from Houston who was one of the original authors of the Advance Directives Act 20 years ago, says that despite pushes to change the law nearly every session, the law is sound.

"I stand by the law as I passed it," Coleman said. "It works the way it's supposed to work."

HISTORY OF LAW

Texas is one of the only states where physicians can end a patient's treatment against a family's wishes. The provision was [included in a 1997 bill](#) meant to streamline Texas law on advance directives, legal documents that allow patients to convey their wishes on end-of-life care.

While the [bill](#) made it out of both the House and Senate, it was [vetoed by then-Gov. George W. Bush](#), in part, due to concerns that sufficient checks weren't in place to review a physician's decision.

So Coleman and Sen. Mike Moncrief, a Democrat and former mayor of Fort Worth, came back the following session in 1999 and [included provisions meant to provide a layer of accountability](#). That included requiring that an ethics or medical committee review a physician's decision to end treatment, along with stipulations that the patient be informed of the committee meeting at least 48 hours in advance, be allowed to attend and receive a written explanation of the decision reached.

That year, it made it past the governor's desk and was signed into law by Gov. Bush, making Texas a leader in passing such legislation. The law had the backing of physicians associations, politicians from both sides of the aisle and anti-abortion groups.

And concessions were made, like agreeing to a 10-day window for patient transfers instead of Texas Right to Life and National Right to Life's original proposal of six months, said Dr. Robert Fine, the head of the palliative care program for Baylor Scott & White who helped write the law.

“The message was that we recognize there can be a disagreement about end-of-life care, and to bring us a law that everyone unanimously agrees to,” Fine said.

But that’s since changed, with lawmakers, anti-abortion groups and even Attorney General Ken Paxton calling for the 10-day provision to be revisited.

Doctors themselves feel like they’re walking a political tightrope if they rely on the law, resulting in hospitals rarely using it, Fine said.

“We do everything we can to stay out of this process,” Fine said.

PROCESS OF LAW

Determining what treatments to pursue and when can be difficult decisions that sometimes place patients’ families and doctors at odds.

But the decision to end someone’s care does not happen suddenly, Fine said. Usually, a physician will tell a family they feel treatment is futile and, if the family disagrees, both parties go into counseling and talk through their options.

“In most cases, families come to that decision, so it doesn’t ever even go to the ethics committee,” Coleman said. “It’s just that the family needed time.”

There are also cases in which the situation is reversed — a family may want to end their loved one’s care while doctors believe treatment could still work.

But if an agreement cannot be reached, the physician can ask an ethics committee — often made up of physicians and nurses at the hospital — to look at the case.

The law requires that the physician and hospital staff continue to offer life-sustaining treatment while making “a reasonable effort” to transfer the patient to another physician or facility willing to offer treatment or alternative care. The hospital is not obligated to continue treatment following the tenth day after the family has received the committee’s written decision.

And while [cases have gained attention out of Fort Worth](#) and [Houston](#), a lack of data on the law’s usage makes it difficult to determine how often physicians employ this process.

According to the Texas Hospital Association, a survey showed in 2011 that the process was used 21 times at 16 hospitals.

CALLS FOR CHANGE

Tinslee’s case has drawn renewed calls for reform, with Paxton, the attorney general, [weighing in](#) and [arguing that the statute is unconstitutional](#).

The 10-day provision has been fiercely opposed by Texas Right to Life, the Lewis family and some lawmakers. Tye Brown, Tinslee’s cousin, said the original 10-day deadline was not enough time to find another hospital.

In recent years, lawmakers have filed legislation to try to extend the period a hospital is obligated to provide treatment, prevent conflicts of interest, and more, but many of those bills haven’t gained traction in past sessions. Coleman said he’s open to making changes to the law, noting he’s filed bills of his own to do just that.

“As long as I’m there, I’m defending it and also trying to fix it,” Coleman said. “I don’t think that 10 days is magic. The idea of extending it so many more days is not a problem — it’s just finding out the number of days.”

But others want to see the 10-day provision struck in its entirety.

“I’d like to eliminate the 10-day period,” said Rep. Steve Toth, a Republican from The Woodlands who [authored legislation this past session](#) to tweak the law. “I’d like to eliminate any kind of period and move the onus over truly to the hospital.”

But Fine said it actually only takes around three days for a hospital to identify and reach out to other facilities that may be able to take the patient. The 10-day time period was the result of a compromise between opposing groups when the law was created, he said.

Brown, Tinslee's cousin, said she wants to see the Texas Advance Directives Act repealed.

'It violates a human's constitutional right to life,' Brown wrote in an email. "It literally puts an expiration date on human life. The decision to continue life is taken away from the patient, parents, or their medical power of attorney."



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And while groups like Texas Right to Life, which has provided legal assistance to Tinslee's family, argue the law should be done away with from a moral perspective, other anti-abortion groups, like Texas Alliance for Life, support the law. In a statement on Tinslee's case, the group said the act was "good public policy and constitutional."

While Texas Right to Life backed the original law, it has now become one of its fiercest opponents.

John Seago, legislative director at Texas Right to Life, said the organization thought safeguards put into the law would protect patients' rights but "it didn't take long to find out that wasn't true."

He said amendments to the law in 2003 and 2017 provided more protections, but the group still believes the 10-day provision — which he called unprecedented, unethical and unconstitutional — should be repealed.

Seago also said an immunity clause in the law leaves families without legal recourse. The provision grants doctors and hospitals protection from legal action, such as lawsuits.

"I don't think they'll ever be satisfied," Coleman said of Texas Right to Life's calls for change. "As a matter of fact, I don't believe that they want the issue to go away, because it's a very good issue to raise money off of."

Seago called that accusation "laughable," saying Texas Right to Life actually loses money by fighting the law because the group pays out of pocket to help transfer patients when possible.

Rep. Matt Krause, a Republican from Fort Worth who supported Toth's bill, said Tinslee's case shouldn't be dismissed as "political theater" if it helps highlight areas where the long-standing law can be improved.

"I don't think it's just about politics or fundraising," Krause said. "I think it's about saving lives. And making sure that Texas has a policy framework that values life, and that creates a culture of life."

Dr. Robert Truog, a bioethicist and pediatrician at Boston Children's Hospital, said he supports the law overall for its ability to allow physicians to end care when a patient is being harmed rather than helped, but pointed to ways it could be improved.

Truog said hospital ethics committees should be more diverse and not only include hospital employees so that their members represent those they are making decisions for. It's a point that Paxton raised [in an amicus brief filed in support of Tinslee's case](#), noting that while the law doesn't designate who serves on the committee, it's likely to be hospital employees.

"These coworkers may have any number of perceived or actual biases in favor of the original decision of their colleague, rendering the committee far from a neutral arbiter," the amicus brief read.

But bills [proposed by Republican](#) and [Democratic lawmakers that would have](#) required policies to prevent financial or professional conflicts of interests failed to pass this session.

And Fine said the law could use a better reporting system to track its usage, but each time the law is up for changes, “Texas Right to Life has tried to completely kill it.”

Toth said he feels like he would be “settling for a tenth of a loaf,” if a reporting system was implemented without nixing the 10-day provision. Krause said that while he would have to hear arguments both for and against a system, he would be open to measures that would add transparency to when and how the law is used.

Ultimately, Coleman encouraged patients to discuss end-of-life options sooner rather than later, so families won’t be left to navigate gray areas on their own.

“That’s why these are tough decisions, because statute doesn’t always deal well with ethics,” he said.

For Tinslee’s family, the law is not a political debate — it’s their reality. Brown said as of last week, they are still trying to find a hospital that will take the 10-month-old girl.

The family is awaiting a hearing where a judge will decide whether to extend their deadline again or to allow Cook Children’s to move forward with ending Tinslee’s treatment.

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