

CAUSE NO. 048-112330-19

TINSLEE BREAU	§	IN THE DISTRICT COURT OF
LEWIS, A Minor ,	§	
And Mother, TRINITY LEWIS, On Her	§	
Behalf	§	
	§	
	§	TARRANT COUNTY, TEXAS
v.	§	
	§	
COOK CIHLDREN’S MEDICAL	§	
CENTER	§	
	§	48th JUDICIAL DISTRICT

LETTER ON BEHALF OF AMICUS CURIAE

Jillian Schumacher, a practicing attorney of the Texas Bar, respectfully requests leave to file this Letter on Behalf of Amicus Curiae, not as an attorney to any party to this cause, but as counsel to amicus parties Donald Jones, Christine Long, Ebele Agu, and Sandra Hollier (“Amicus Curiae”).

Amicus Curiae were responsible for the medical decision of a family member who was receiving life-sustaining treatment at a Texas hospital when the hospital carried out the procedures prescribed by Texas Health and Safety Code section 166.046 to remove the life-sustaining treatment of their family member¹ over their objection. Amicus Curiae seek to share their experiences with this process as friends of the court to help demonstrate the way the law affected each of them. Although each of the Amicus Curiae had different experiences relating to notice of the hospital ethics committee meeting and differing opportunities to speak, the statute deprived

¹ Donald Jones was responsible for the medical decisions of his wife, Carolyn Jones. Christine Long was responsible for the medical decisions of her daughter, Breanna Amerson. Ebele Agu was responsible for the medical decisions of her mother, Patricia Ikenma. Sandra Hollier was responsible for the medical decisions of her four-year-old son, Clifton F. Tarrant, II.

each of the Amicus Curiae of the basic procedural due process rights protected by the Texas and United States constitutions. Based on their painful experiences, Amicus Curiae believe that the statute always operates unconstitutionally.

A. Experiences of Amicus Curiae with section 166.046

The stories of the Amicus Curiae below demonstrate a range of experiences with hospitals invoking section 166.046.

1. Carolyn Jones

Donald Jones's wife, Carolyn Jones, a conscious 61-year-old woman, was receiving life-sustaining treatment at Memorial Hermann Southwest Hospital in May 2019. Although Mrs. Jones was intubated and could not communicate, she was awake, responsive, reacting to pain and did not have a terminal condition.

Mrs. Jones's husband was informed on March 8, 2019, that the hospital had had a meeting of doctors and hospital staff and decided to discontinue Mrs. Jones's life-sustaining treatment after ten days. Mr. Jones was told that they decided it was time to take away her oxygen, dialysis, food, and water. Mr. Jones objected. According to Mr. Jones, a hospital employee whispered to him that he should call Texas Right to Life, and he did. Because a Texas Right to Life attorney told the hospital that she planned to file a restraining order, the hospital did not remove life-sustaining treatment on March 18.

The hospital had a second ethics committee meeting in May and decided to remove Mrs. Jones's life-sustaining treatment over the objection of her husband. After waiting the ten-day statutory period, the hospital removed Mrs. Jones's ventilator on Monday, May 13, 2019, at 2 p.m. Mrs. Jones's family was gathered by her bedside begging the hospital staff not to remove her care.

Miraculously, Mrs. Jones lived through the night. Tuesday was the day of the week Mrs. Jones normally received dialysis. Although Mrs. Jones had survived the removal of the ventilator, the hospital refused to administer dialysis. On Wednesday, Mrs. Jones was still alive and the hospital continued to refuse dialysis.

Finally, late on Wednesday night, Texas Right to Life arranged for a private ambulance to transport Mrs. Jones to the emergency room at Ben Taub Hospital. Eventually, Ben Taub Hospital secured a transfer to Lyndon B. Johnson Hospital where medical personnel provided dialysis to Mrs. Jones. Mrs. Jones then resided at a skilled nursing facility, until she passed away of natural causes on June 25, 2019.

2. Breanna Amerson

Christine Long's daughter, Breanna Amerson, is a 29-year-old woman. In 2011, Ms. Amerson was diagnosed with multiple sclerosis. In June 2016, Ms. Amerson was in a rehabilitation facility, regaining strength after recovering from pneumonia, when she stopped breathing. A nurse administered a breathing treatment, and Ms. Amerson was transferred to Texas Health in Fort Worth where she began receiving life-sustaining treatment.

While Ms. Amerson was in the process of receiving life-sustaining treatment, the hospital informed Ms. Long that the hospital was planning to have an ethics committee meeting to discuss withdrawing Ms. Amerson's breathing assistance. The ethics committee informed Ms. Long of the meeting, scheduled for Monday morning, on Friday afternoon. Ms. Long was able to have the meeting postponed after continuing to ask questions about the meeting and learning that the committee chairman would miss the meeting due to his vacation. Because the meeting was delayed, Ms. Long was able to (1) learn her daughter was a candidate for weaning rather than full

remove of life-sustaining treatment, (2) secure counsel before the meeting, and (3) start the process to have Ms. Amerson accepted by a different hospital.

During the meeting, the attending physician's remarks, included the query, "Who would want to live with MS (multiple sclerosis)?" The remarks showed the attending physician considered Ms. Amerson's life not worth living because of her underlying condition. Ms. Amerson's counsel was able to intervene in the process and fight for Ms. Amerson to be transferred to another facility and weaned from breathing assistance. The weaning was successful and Ms. Amerson is alive today. Ms. Amerson's mother suspects that if the ethics committee meeting had not been delayed, and Ms. Amerson were prematurely removed from life-sustaining treatment, Ms. Amerson would have died.

3. Patricia Ikenma

Patricia Ikenma was a 69-year-old who became sick in August 2018 while she was in Dallas visiting her daughter Ebele Agu. Mrs. Ikenma was admitted to John Peter Smith Hospital and underwent medical procedures to address high levels of bilirubin, but the procedures were unsuccessful. Mrs. Ikenma's lungs collapsed after one of the procedures and she was provided life-sustaining treatment. She improved, leading to the removal of life-sustaining treatment and then relapsed a few days later.

Medical providers suggested another procedure and placed Mrs. Ikenma on life-sustaining treatment in preparation for the procedure. During this time period, doctors determined that Mrs. Ikenma needed a tracheotomy, but two different teams of medical providers disagreed on whether the procedure was necessary. Mrs. Ikenma's family withdrew their consent to the tracheotomy and the hospital asked the family to remove Mrs. Ikenma and place her in another facility.

Ms. Agu contacted a lawyer. At that point, the hospital gave Ms. Agu three days' notice that an ethics committee would review her mother's case. The ethics committee decided to remove life-sustaining treatment. Ms. Agu did not have enough time to process what was happening or to find another facility.

The statutory ten-day countdown began on September 26, 2018 and the hospital removed Mrs. Ikenma's ventilator on October 5, 2018. Mrs. Ikenma died following the removal of life-sustaining treatment.

4. Clifton F. Tarrant, II

Ms. Hollier is the mother of Clifton F. Tarrant, II. Clifton was a four-year-old boy who suffered a traumatic brain injury. Clifton was life-flighted to Children's Memorial Hermann Hospital in Houston, Texas, where he was placed on a ventilator to help regulate his breathing as well as a feeding tube and five different blood pressure medications. Clifton underwent surgery to help reduce the brain swelling.

Clifton began to have seizures and appeared to be unresponsive. Doctors encouraged Ms. Hollier to remove life support, but as Ms. Hollier continued to watch her son, she began to notice that he was moving. Doctors explained that the movements were symmetrical movements that were involuntary body movements. But Clifton continued to improve. He no longer needed any of the five blood pressure medications and began to move symmetrically as well as asymmetrically.

Children's Memorial Hermann Hospital called several ethics committee meetings, in which many people were present in the room who had never treated or seen Clifton. Ms. Hollier's questions and comments were dismissed. During the ethics committee meeting, a panelist told Ms. Hollier, "This is not a courtroom where people can object. This isn't up for discussion."

Claiming Clifton had poor quality of life due to his injury, the ethics committee decided to remove Clifton from life support.

Ms. Hollier was informed that she had ten days to find another facility that would be willing to provide Clifton with treatment and that Ms. Hollier could present a list of potential transfer facilities to a social worker and someone would call. But Clifton's mother was not a part of those phone calls and had no way to verify if any calls were made. After ten days of submitting countless lists to the social worker, Ms. Hollier watched as the hospital removed her son's life support.

Ms. Hollier was given the option to provide her son with a lethal dose of morphine to ease his suffering, but she did not want to hasten his death. After watching her son convulse and gasp for air for over an hour, Ms. Hollier finally could not bear it and asked that the hospital administer the morphine, ending Clifton's life.

B. Texas Health and Safety Code section 166.046

Texas Health and Safety Code section 166.046, entitled "Procedure If Not Effectuating a Directive or Treatment Decision," outlines the process that each hospital effectuated when it decided not to honor the health care treatment decisions made by each of the Amicus Curiae. *See* Tex. Health & Safety Code § 166.046 (West 2017). The statute provides that if a physician refuses to honor a patient's advance directive or a treatment decision made by or on behalf of the patient, "the physician's refusal shall be reviewed by an ethics or medical committee." *Id.*

Section 166.046 provides limited protections for patients and their families in situations in which physicians refuse to honor their medical treatment decisions. Under section 166.046, a patient or patient's representative has the following rights:

- (b) The patient or the person responsible for the health care decisions of the individual who has made the decision regarding the directive or treatment decision:

(1) may be given a written description of the ethics or medical committee review process and any other policies and procedures related to this section adopted by the health care facility;

(2) shall be informed of the committee review process not less than 48 hours before the meeting called to discuss the patient's directive, unless the time period is waived by mutual agreement;

(3) at the time of being so informed, shall be provided:

(A) a copy of the appropriate statement set forth in Section 166.052; and

(B) a copy of the registry list of health care providers and referral groups that have volunteered their readiness to consider accepting transfer or to assist in locating a provider willing to accept transfer that is posted on the website maintained by the department under Section 166.053; and

(4) is entitled to:

(A) attend the meeting;

(B) receive a written explanation of the decision reached during the review process;

(C) receive a copy of the portion of the patient's medical record related to the treatment received by the patient in the facility for the lesser of: (i) the period of the patient's current admission to the facility; or (ii) the preceding 30 calendar days; and

(D) receive a copy of all of the patient's reasonably available diagnostic results and reports related to the medical record provided under Paragraph (C).

Tex. Health & Safety Code Ann. §166.046 (West 2017). This statute served as the only protection available to each of the Amicus Curiae during the painful and vulnerable period in which they were

faced with the grave medical prognosis of their family members and the prospect that the hospital treating the family member would discontinue the life-sustaining treatment the family member needed to remain alive.

C. Due Process of Law under Section 166.046

1. Principles of Due Process

The Texas Constitution provides that “[n]o citizen of this State shall be deprived of life, liberty, property, privileges or immunities, or in any manner disenfranchised, except by the due course of the law of the land.” Tex. Const. art. I, § 19. The due-process clause of the Fourteenth Amendment to the United States Constitution provides that “[n]o State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; not shall any State deprive any person of life, liberty, or property, without due process of law” U.S. Const. amend. XIV § 1. Although the Fourteenth Amendment to the United States Constitution and the due-course-of-law provision of the Texas Constitution are textually different, Texas courts “have traditionally followed contemporary federal due process interpretations of procedural due process issues.” *Mosley v. Tex. Health & Human Servs. Comm’n*, No. 17-0345, 2019 WL 1977062, at *9 (Tex. May 3, 2019).

To determine whether a person has been deprived of due process, courts consider whether the party claiming that her right to due process has been violated (1) has a liberty or property interest that is entitled to procedural due process; and (2) if the party has a liberty or property interest that is entitled to procedural due process, courts determine what process is due. *Id.* An individual’s interest in life and in making his own medical decisions are liberty interests that cannot be deprived without due process of law. *See Cruzan v. Director, Mo. Dep’t of Health*, 497 U.S. 261,

269 & 281, 110 S.Ct. 2841, 111 L.Ed.2d 224 (1990). Due process at a minimum requires notice and an opportunity to be heard at a meaningful time and in a meaningful manner. *Mosley*, 2019 WL 1977062, at *9.

Courts measure what process is due under a “flexible standard” that depends on the practical requirements of the circumstances. *Id.* The flexible standard considers three factors: (1) the private interest that will be affected by the official action; (2) the risk of an erroneous deprivation of such interest through the procedures used, and probable value, if any, of additional or substitute procedural safeguards; and (3) the government’s interest, including the function involved and the fiscal and administrative burdens that the additional or substitute procedural requirement would entail. *Id.* In the case of disputes relating to section 166.046, particularly high levels of procedural due process are required because the interest in life is the most significant liberty interest a person has. Second, there is a high risk of error because determinations about medical futility involve medical judgment as well as value judgments.

Procedural due process protections prohibit actions that fairly may be said to be that of the one of the states. *Blum v. Yaretsky*, 457 U.S. 991, 1003, 102 S.Ct. 2777, 2785, 73 L.Ed.2d 534 (1982). An action is fairly attributable to a state if there is sufficiently close nexus between the state and the challenged action so that the action may be treated as an action of the state. *Jackson v. Metro. Edison Co.*, 419 U.S. 345, 95 S.Ct. 449, 453, 42 L.Ed.2d 477 (1974). The application of state rules of law in state courts state is sufficient state action to trigger due process protections. *See Cohen v. Cowles Media Co.*, 501 U.S. 663, 668, 111 S.Ct. 2513, 2518, 115 L.Ed.2d 586 (1991). Section 166.046 insulates hospitals from liability in courts of law and therefore any legal determinations

relating to the statute that are enforced by the courts are state action that entitles parties before the courts to procedural due process protections. *See id.*

2. Insufficiency of Process Afforded Amicus Curiae

Section 166.046 did not guarantee Amicus Curiae sufficient procedural-due process protections. First, the statute does not require the ethics committee to allow the patient to speak. Failing to allow the patient or patient representative the right to speak means that the patient does not have an opportunity to be heard. *See Mosley*, 2019 WL 1977062, at *9. Having a voice in the process is imperative. *See id.*

The experiences of Donald Jones, Christine Long, Ebele Agu, and Sandra Hollier are heart-wrenching. They are heart-wrenching simply because of the medical trauma. But, beyond the medical trauma, is the helplessness that comes when a hospital invokes section 166.046 and patients have no right to be heard in the process. Clifton Tarrant II's mother's concerns or questions were dismissed at the ethics committee meeting. She was essentially told that her voice did not matter. Part of the reason for procedural due process protections is the simple recognition that a person's voice matters. Section 166.046 is at odds with that American value.

Second, the ability to be heard in a meaningful manner requires the ability to be heard before a neutral decisionmaker. *See Caperton v. A.T. Massey Coal Co.*, 556 U.S. 868, 887, 129 S.Ct. 2252, 173 L.Ed.2d 1208 (2009). Section 166.046 does not contain any requirements regarding the make up of the ethics committee aside from the requirement that the treating physician may not be a member of the committee. Beyond that, there are no requirements regarding the number of individuals on the committee or the neutrality of any member. This issue means that the

individuals involved in the decision may have roles requiring them to safeguard hospital resources and may have biases relating to their role in hospital management.

None of the Amicus Curiae had the right to have a neutral body determine the fate of their family member.

Third, the forty-eight hour notice provision does not give patients or the individual making health care decisions on the patient's behalf enough notice to process what is happening and make their voices heard in the decision regarding whether or not to remove care. The length of time does not provide patients with enough time to obtain medical records, consult with attorneys or experts, and meaningfully prepare for the ethics committee meeting.

Christine Long believes her daughter is alive only because of the lucky coincidence of the committee chairman's vacation and her quick thinking in requesting postponement. The extra time allowed her to consult with others regarding her daughter's medical records and allowed her to advocate for a different process. Christine Long and her daughter were protected by luck. They should have been protected by Texas law. *See Mosley*, 2019 WL 1977062, at *9.

Fourth, if the ethics committee determines that life-sustaining treatment should be removed, patients and patient representatives should be given enough time to access the court system to obtain meaningful review of the decision. Ebele Agu did not have enough time to process what was happening to her mother, let alone respond to it either by attempting to access the courts or by securing transfer. Ebele Agu's mother died.

CONCLUSION

A hospital can decide to provide a patient with more process than section 166.046 requires—and in some cases a hospital does. But the experiences of Amicus Curiae are that when the hospital

implemented the procedures outlined in section 166.046, they found themselves in tenuous situations as a result of inadequate due process protections.

One of the Amicus Curiae has a daughter who is alive today because she was lucky enough to find a way to postpone the ethics committee meeting long enough to obtain counsel who could advocate for her. But others of the Amicus Curiae were not as fortunate. A different mother did not have a voice at the ethics committee meeting.

One of the Amicus Curiae, a husband, managed with the support of a non-profit organization, to transfer his wife to a facility where she lived for another month. But another of the Amicus Curiae, a daughter, was overwhelmed, unable to process what was happening, and did not have sufficient time to transfer her mother to another facility.

Although each of the Amicus Curiae had a different experience when the hospital invoked section 166.046, the statute did not protect any of them for deprivation of process.

Respectfully submitted,

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CERTIFICATE OF SERVICE

I certify that on the 19th day of December, 2019, a true and correct copy of the above and foregoing letter was forwarded to all counsel of record, via efilng, as follows:

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