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THOMAS A. WILDER
DISTRICT CLERK

December 20, 2019

Chief Justice Sandee B. Marion
48th District Court, Tarrant County
Tom Vandergriff Civil Courts Building - 4th Floor
100 North Calhoun Street
Fort Worth, TX 76196

Re: Cause No. 048-112330-19; T.B.L., A Minor, and Mother, Trinity Lewis, on Her Behalf v. Cook Children's Medical Center

Chief Justice Marion:

The Texas Hospital Association ("THA"), as a representative of over 450 Texas hospitals, submits this letter brief to the Court as an *amicus* and in support of Cook Children's Medical Center's position in the above-referenced Cause. The issues before the Court are of interest to THA and its member hospitals, as they affect the delivery of care and operations of Texas hospitals. In particular, the availability of the dispute resolution process in the Texas Advance Directives Act ("TADA") is of major concern. We appreciate the Court's consideration of any information herein, which we believe provides necessary context. THA has paid all fees associated with the preparation of this letter.

Texas hospitals, and those working within them, are incredibly privileged to provide care to Texans at the beginning, during, and end of lives. While THA believes the TADA serves an important function in navigating difficult end-of-life issues, others will debate the TADA's legal merits before this Court – we simply highlight the burden placed on providers when a patient receives unnecessary medical interventions at the end of life.

During the December 12, 2019 hearing before this Court, testimony set forth the intense level of medical intervention required to keep T.B.L. alive, the ethical concerns created for providers and staff, and the rationale for the determination that such intervention was medically inappropriate given the relevant prognoses. The Court heard that Cook Children's allows providers to decline shifts with T.B.L. over concerns they could be asked to act against their moral and/or ethical beliefs, as

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many "are not comfortable inflicting that kind of pain on her." We ask the Court to strongly consider this burden before ruling.

A provider's ethical responsibility to "do no harm," which may, and often does, conform with his or her moral beliefs, must be contemplated in these situations. Decisions regarding end-of-life care are taken extremely seriously, and a determination that interventions are medically inappropriate should result from lengthy discussion and deliberation between a patient (or their family or surrogate), their treatment team, and the facility. Indeed, this occurred in the instant case, as the family was well-informed prior to the ethics review committee meeting – at which the family was present and provided opportunity to engage, and which resulted in a unanimous decision to withdraw medical interventions.

THA believes the decision to terminate interventions should be left to medical professionals working closely with the patient and their families. Those professionals' education and experience provide unique insight during these deliberations, and such expertise should be respected. Continued intervention may result in disproportionate and unnecessary pain and suffering for the patient, as testimony indicates is occurring in the instant case. A decision to terminate interventions is a decision to free a patient from pain and suffering deemed unwarranted and, ultimately, to act in the patient's best interests and well-being.

Enclosed are affidavits provided by medical professionals, setting forth stories similar to the issues presented in the instant case.[1] Specifically, this testimony highlights the efforts taken by providers to ensure the patient's best interest and wellbeing are paramount, to personally interact with the patients (at times when the patient's family or surrogates do not), and a lack of understanding or awareness by the family or surrogate of the patient's desires or actual condition – which is often the root cause of disagreement in end-of-life issues.

THA believes the TADA is serving its intended purpose: to require patients, families, surrogates, providers, and facilities to engage in meaningful discussion about care and interventions provided at the end of a viable life. That conversation is ongoing in the instant case and occurred in the examples provided. We ask the Court to defer to the expertise of the treatment team in such cases and weigh the

[1] General information (e.g., ages and facility names) was redacted.

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well-being and best interests of the patient and those providers who spend the majority of the time with and caring for the patient in these situations.

THA respectfully submits this information for the Court's consideration. We thank you for your time and attention, and make ourselves available in the event the Court desires any additional information. Please contact me should the need arise.

Respectfully,

Cesar J. Lopez
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CERTIFICATE OF COMPLIANCE

I certify that I have reviewed this Amicus on behalf of the Texas Hospital Association, and I have concluded that every factual statement herein is supported by competent evidence. I further certify, according to my word processor's word-count function, there are 690 words.

By: _/s/ Cesar J. Lopez_____
Cesar J. Lopez

STATE OF TEXAS)
)
COUNTY OF Hays)

Heidi Kook-Willis, being duly sworn, states as follows:

"My name is Heidi Kook-Willis. I am a palliative care nurse practitioner who specializes in the care of adult and geriatric patients, often in the end stages of their life. All the patients I see are very sick, with chronic, life-limiting or terminal illness. Although we are not always able to heal or save the lives of our patients, we can alleviate their pain and suffering and allow for peaceful death when life prolonging measures are not effective or appropriate. Ultimately, the goal is to treat each individual with dignity and compassion. While each patient's story is special, one gentleman's stands out.

EMS transported a frail, elderly, [redacted] nursing home resident to our hospital. His vitals were poor, and he was minimally responsive, suffering from a host of maladies, including severe pneumonia, septic shock, and advanced dementia.

We aggressively treated him with antibiotics, fluids, and medications to support his blood pressure. Eventually, we had to intubate him.

The man was fighting for his life, but our medical interventions were not helping. Days passed, and his condition was not improving. In fact, it was only worsening. His organs were shutting down, and his body was not tolerating the fluids we were giving. Our treatments were clearly providing no benefit. We were all very concerned this man would suffer cardiac arrest, and we would have to perform CPR, which we knew would be futile and cause undue suffering

to this very frail man. We came to realize we were only artificially prolonging this man's suffering. Our best efforts were not honoring his dignity, and this was clearly causing moral distress among care team members, from physicians to nurses.

This man did not have a Do Not Resuscitate (DNR) order or a Directive to Physicians outlining his wishes. Furthermore, despite every effort by medical staff, social workers and nursing home staff, no one could reach his designated emergency contact.

We knew the correct moral and ethical decision was to withdraw care and let him die peacefully. We consulted with the hospital Chaplain, and ultimately presented this man's case--and our moral dilemma-- to the hospital's ethics committee. After due consideration and collaboration among medical, legal, and ethics experts, the committee approved changing his code status to DNR and removing life-sustaining care. Soon after that, we extubated him, and several minutes later, he passed peacefully.

I took an oath to care for my patients – to do them no harm. Thankfully, the medical care team and ethics committee recognized that the right and compassionate decision was to relieve this man of needless suffering and allow him a dignified, peaceful death."

Heidi Kook-Willis, APRN, AGNP-C

SWORN TO AND SUBSCRIBED before me on December 17th, 2019.

Stephanie Martinez

Notary Public, State of Texas

STEPHANIE MARTINEZ
Notary Public, State of Texas
Comm. Expires 04-08-2023
Notary ID 131963721

STATE OF TEXAS)
)
COUNTY OF Travis)

Dieter Martin, being duly sworn, states as follows:

"My name is Dieter Martin. I am an Internal Medicine physician who is board certified in Internal Medicine as well as Palliative care. I have practiced in the hospital setting my entire career. I have been asked to provide testimony regarding my experience with futile care.

One case that sticks in my head among many took place early in my career. This was a tragic case of a man [redacted] who was found down by his family and sent to the hospital. He was down for an unclear amount of time but clearly had suffered a lethal hypoxic brain injury. He was in the intensive care unit for over a week. I counseled the family daily on his poor prognosis. The other physicians agreed that he was futile given the extent of his injury. Meaningful recovery was not a possibility and his likelihood of surviving the hospital stay was daily approaching zero. Even with all the resources in the world, this man was going to die.

The family was holding out for a miracle. They prayed and adorned him with various religious artifacts. Our chaplain services were engaged and trying to help alleviate their spiritual suffering. It came to pass that the family's pastor was in the background assuring them a miracle would occur. A miracle was not in the works and he most undoubtedly suffered during his last days on this planet. The day that I got them to withdraw care was when the overwhelming odor of his necrotic brain tissue became evident. I extubated the patient and he passed quickly and peacefully. This family suffered watching their loved one die over the course of over a week

needlessly. I fear their grief was worsened by their experience and that the memory of their father will forever be dominated by what they had to endure.

After that experience I felt that I had failed. I failed in that I was not able to teach the family about his dying process and get them to acceptance. It is at that point that I began studying palliative care and pursued my board certification in Palliative Care. Since then, I have had more few and far between episodes like this. However, I can tell you that it is typically external interference in the family's progress toward acceptance of the cruel fact of life that we are all frail and all destined to pass that drives this outcome. Clergy are powerful leaders in the dying process. They can be equally damaging if they carry an agenda. Thankfully, most clergy tend their flock remembering God's mercy.

Having any legislation that further interferes with our God given right to die with dignity would be catastrophic. Physicians are trained for years and licensed to give the best medical care that we can. When laymen interfere with that management, people get hurt. After all, I cannot board a commercial airliner and insist that I fly the plane! Why would we expect a different outcome when laymen take the yoke of medical care? In my training I was taught that my duty to my patients was to ease suffering, avoid debility and prolong life, IN THAT ORDER. The capstone of my training was an oath to do no harm. I know that I take that responsibility very seriously. When I am asked to prolong suffering and thereby harm my patient with no good outcome, I am in violation of that philosophy. I am in support of obstetricians who refuse to perform abortions due to conscientious objections and am puzzled why I may be asked to actively cause suffering for my patients.

I am very sensitive to my patients and their family's belief systems and try to navigate care with that in mind. I think that with support from men of the cloth who have not abandoned

the core duty of easing bereavement we can make life's tragedies less traumatic. I understand that Christ suffered on the cross for our sins. There is no parallel for having a loved one suffer during their passing. Restrained in bed in the sign of the crucifix with the stigmata of central lines, endotracheal tubes and catheters serves no higher purpose. Christ died for a reason and did so with dignity. This is robbed from patients forced to endure the unnatural death driven by best intentions. It amounts to torture not only for the patient but also the family. In Texas, we do not tolerate torture.

I don't know what kind of people would advocate for this. Decoupling the experts from the medical decision making, compelling the system to drive up the net suffering on this planet, robbing families of their loved one's memories. Whoever it is needs to take a step back and commit themselves to deep contemplation on what harm they are going to do if this comes to pass."

Dieter Martin, MD

SWORN TO AND SUBSCRIBED before me on December 19, 2019.

Notary Public, State of Texas

STATE OF TEXAS)
)
COUNTY OF Taylor)

Tommie Farrell, being duly sworn, states as follows:

"My name is Tommie Farrell. I am Family Physician with board certification in Hospice and Palliative Medicine as well as certification as a Hospice Medical Director. I have been practicing in the field of Hospice and Palliative Medicine for 16 years.

[redacted] I became involved with the care of a [redacted] woman who had a previous stroke and lost the ability to swallow. She also had a history of lung disease, frequent UTIs and aspiration pneumonias. She was unable to swallow and so a feeding tube was placed in the past. Despite this intervention she has had decline to a physical state of being bed bound, dependent for all activities to sustain her life and not being able to communicate her needs directly.

She was in [redacted] with tube feeding failure in that she could not tolerate any level of tube feedings without aspiration and respiratory distress. The decision was made by her primary care physician to discontinue interventions except for those of comfort. We had several conversations recorded in our medical record where the patient had told her primary care physician and various social workers that she did not want to be kept alive when she became bed bound. Despite this, her medical power of attorney (MPOA), kept insisting on all efforts to keep her alive. The primary physician kept advocating to allow a more natural dying process but feeling the constraint of the political environment of Texas felt obligated to keep listening to the wishes of this MPOA.

Eventually all options were exhausted in that no gastroenterologist would replace or attempt to change the positioning of her feeding tube due to her severely debilitated state. The MPOA reluctantly agreed to allow the patient to be sent to the [redacted] Hospice in-patient unit but insisted that iv fluids remain in place. This is against standard practice of comfort due to the possibility of third spacing of fluids into the tissues and lungs which causes increased suffering of the patient. But the attending physician kept the order due to the strong legal language used by the MPOA.

I cared for the patient in the hospice unit. The MPOA came to see the patient only once in the 8 days she was there and this for less than an hour. In his near complete absence, the nurses caring for her kept in distress on the prolonged suffering they saw in watching a woman with no ability to verbalize her needs required medications to control the ongoing struggling respirations which she had. Eventually it became obvious that indeed the iv fluids were third spacing into her lungs and she went into severe respiratory distress. Higher doses of iv medications were given to relieve this suffering the best we could. As the woman was left completely alone by the very persons asking for these interventions our hospice team took turns sitting in her room to ensure she was not alone at the time of her death.

I took my own turn in doing this. I sat there for the initial hours that we stopped the fluids and increased her medications. As I watched her gasping for every single breath, her eyes were open wide and the struggle she was going through was apparent. I felt helpless as I titrated up the medications knowing that I needed to do so in a manner that was attempting to aggressively control her symptoms but would also be done responsibly to ensure I did not end her life prematurely.

While doing this I continuously remember all the chants from Right to Life that doctors like myself "euthanize patients." I felt the anger that those who accuse me of killing others are not there to witness me sitting at the bedside of the patient holding her hand, saying prayers and reading words of scripture all in attempt to relieve the suffering of a patient that our very medical intervention placed into this period of distress and suffering and while attempting to relieve those symptoms while preserving and honoring life despite the constant allegations made by political action groups that my purpose as a hospice physician is to kill innocent and frail persons.

This lady eventually gained some comfort and I left her to the care of the nurses. She died 5 hours later. The MPOA did not come during any of these last moments despite our calls letting him know this woman was dying."

Tommie W. Farrell, MD FAAHPM HMDC

SWORN TO AND SUBSCRIBED before me on December 17, 2019.

Notary Public, State of Texas

PAM LIGHT
Notary Public, State of Texas
Comm. Expires 06-11-2022
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