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Nation

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Mom fighting ruling to end infant's life support

BY MICHAEL GRABELL The Dallas Morning News

DALLAS - Baby Daniel is nearly brain-dead. He cannot breathe without a ventilator. He cannot eat without a feeding tube.

And if his mother doesn't find another hospital, the doctors at Children's Medical Center Dallas will disconnect him from the machines and he will die. The hospital's ethics board has ruled that it would be futile and inappropriate to keep Daniel alive - despite his mother's wishes to try.

The child's fate could be settled after a judge hears the case Friday.

"Something deep down inside is telling me not to unplug my 10-month-old," said Dixie Belcher, Daniel's mother. "I know it's going to take him quite a while to pull out of this, but I know he's my little fighter, and he's got to pull through. He's got to pull through."

Part of the reason Belcher cannot bring herself to unplug her son is that she has been here before.

Fourteen years ago in a hospital room at Children's Medical Center, she says, she struggled with another doctor's recommendation to remove life support from her 5-month-daughter, Jamie, who also suffered breathing problems.

That time, Belcher consented. She can't do it again.

Daniel's situation is a poignant illustration of the complex yet delicate decisions that doctors, social workers and courts must make to determine not only when a child's life should end, but when motherhood does as well.

The case is complicated by the fact that Daniel is no longer in her custody - because of allegations of neglect - but in the care of the state.

In Texas, hospitals are not obligated to continue life support beyond 10 days after the ethics board has made its decision. The parent must find another hospital where the child can be transferred or seek a court order for more time.

That is what Belcher has done. Daniel was set to die May 21. But late on May 19, a Friday, a Dallas district judge issued a rare temporary restraining order, preventing the



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hospital from disconnecting him.

The case will be heard Friday. Children's Medical Center is not saying what it will do if the order is dismissed and no other hospital is found.

Daniel Wayne Cullen II was born in July, three months premature, weighing just 2 pounds, 6 ounces.

His lungs weren't fully developed, and he stayed in the hospital receiving oxygen treatment for his first four months. During that time, his airway narrowed, and doctors inserted a tube in his trachea to help him breathe.

Daniel - affectionately nicknamed "Fat Boy" by his mother - then lived for several months in a cramped apartment where Belcher also cares for her ailing mother.

But on April 4, Daniel somehow pulled the tube out of his neck. He stopped breathing for several minutes, causing severe and, the doctors say, irreversible brain damage.

He has been at Children's Medical Center ever since, waiting for a decision from his doctors, who say he will never recover, and his mother, who says he responds only to her.

"I feel that my son knows I'm there," said Belcher, 37. "If anyone has kids they would feel that. And I know my son hears me. I know that."

Belcher says that when she holds him and calls him "Fat Boy," he will grip her fingers. The doctors tell her it is just his muscles contracting involuntarily.

"When the nurse gave him to me, his eyes were shut. I'm talking shut," she said. "And when she put him in my arms, I called him, 'Fat Boy! You better open those eyes up, boy!' And when he did, he opened his eyes just as wide as they would go, and the nurse didn't see it."

In the case of Belcher's daughter, Jamie, the doctors gave the infant some medicine to help her go peacefully, and Belcher held her, watching her first-born die.

Belcher says she sat in the room for two more hours, holding her daughter's lifeless body. She whispered to Jamie that she was God's angel before she was hers and that she was going home.

"I sat there a while with her," Belcher recalled. "It wasn't easy. I still haven't gotten over it. I haven't seen nobody for it. No help or nothing for it. I keep it all inside."

Children's Medical Center officials declined to discuss Daniel's case, citing medical privacy laws. But a letter from the hospital says that the ethics board met May 9, ultimately siding with the doctors' contention that there was nothing more they could do.

During such meetings, doctors, nurses and ethicists ask for the parents' wishes and discuss the patient's medical problems, what has been done so far and what could be done in the future, said Tom Mayo, a Southern Methodist University bioethicist. Mayo is co-chairman of Children's Medical Center's ethics board and helped write the state's futile-care law.

"Nobody likes to see parents suffering," he said. "These are the kinds of decisions, when you find yourself in opposition to the parents, that are extremely painful for them as well as for the physicians. ... But as a member of an ethics board, as difficult as those conversations are, keeping our focus on what is in the best interest of the child helps."

In end-of-life questions involving adults - such as the fiercely debated Terri Schiavo case last year - the issue often is what the patients would have wanted.

But since babies are too young to form opinions about how their lives should end, the question is not what the patients would have wanted - or what their parents want. Instead the concern is what is in the children's best interests. Mayo said that for the treatment to be ethical, the benefit must outweigh the burden.

Daniel's case also prompts debate about how the state decides when parenthood ends.

Daniel was placed in the temporary custody of Child Protective Services after he removed his tube. Because of that, Belcher cannot sit at his bedside in what may be his final days. His caseworker decides when she can visit.

"It was found that there was reason to believe that medical neglect and neglectful supervision of the child had occurred," said Marissa Gonzales, CPS spokeswoman.

The agency does not offer opinions in life-support cases if the parent's rights haven't been terminated, she said.

The CPS file raises questions about what Belcher was doing when Daniel pulled out his tube. A police detective said she told him she had gone outside to smoke a cigarette.

Belcher says she had just woken Daniel up and was in the kitchen preparing his rice cereal. She says she took good care of Daniel and closely watched his condition.

"I would make sure his crib was beside my bed, and I would put my hand through the bars of the crib and put my hands on him so I can feel him," she said. "That way, when my hand was on him, if anything did go wrong with him and he couldn't breathe, I could get up that quick."

On the day of Daniel's accident, the detectives described a dirty apartment that reeked of smoke despite the boy's breathing problems and despite a sign on the door about his grandmother's oxygen machine.

On a nightstand to the left of the crib was an ashtray with five cigarette butts. Next to it were two packs of Marlboros. On the stove was a pot with meat and congealed grease. The sink was two-thirds full with baby bottles and nipples soaking in water that was cloudy, as if it had been there a while. Trash overflowed onto the ground.

"In the living area, I observed another filter that had been removed from the trachea that appeared to be stained the color of nicotine, leading me to believe that the child had been breathing in second-hand smoke," Detective Alan Frizzell wrote.

Belcher admits she has made mistakes. Torn between a sick child and a sick mother, she felt she had nowhere else to go.

"My mom was smoking," she said. "I always tried to go outside. I would take and have a pullover or another shirt on so the shirt I had on wouldn't smell like smoke. And I would wash my hands."

Belcher's history with CPS began in January 2004, when the agency investigated a complaint regarding an older son, James, now 8. The five referrals in Belcher's file often involved allegations of neglectful supervision but no complaints about physical abuse.

The callers accused the family of selling drugs out of the apartment. They complained that Belcher smoked cigarettes and marijuana in front of Daniel.

Belcher denies that. She said that family members were dealing once, but that she didn't know and left when she found out.

A review of police calls to the apartment since Daniel's birth shows no reports of drug dealing. And Belcher has never been charged with or convicted of a crime.

"The CPS people asked me if there's any way that I can leave (the apartment) so everything would be better for me and my kids," she said. "The baby's daddy was staying in a motel room at the time."

But the couple argued frequently, and Daniel Wayne Cullen Sr. walked out, she said. Cullen, who Belcher says is the father, did not return a call seeking his opinion on what should happen to Daniel.

Belcher also failed drug tests. On April 3, the day before Daniel removed his tube, she tested positive for cocaine. Belcher says she was stressed out and smoked some marijuana with a friend. She says she didn't know it was laced with cocaine.

Even before Daniel left Children's in November, the medical staff worried about Belcher's parenting ability.

"I have concerns that Dixie may not be able to care for Daniel to maintain his multiple medical needs," wrote Sally Adams, a pediatric nurse practitioner at the hospital's low birth weight clinic. "I consider Daniel to (be) high risk for his multiple medical problems regardless of his home and social situation or his mother's problems."

Caring for Daniel was never easy, Belcher said, but she feels she did as good a job as any mother could do.

At the apartment last week, she flipped through the daily reports of a nurse sent to help her care for Daniel during his first month home. The reports say Belcher appeared able to take care of Daniel's medical needs, such as checking and cleaning his tube.

Belcher's attorney, the hospital and CPS are looking for another hospital that will treat Daniel, so far with little luck. But under state law, Belcher would have to pay for the transfer, which she says she can't afford.

For now, she is taking down Daniel's crib, to discourage herself from standing over it at night as if the child were still there.

"It still hurts knowing he's not home," she said. "I get up every night in the middle of the night, every hour on the hour, checking on him to see if he is OK, and then when I get up to his bed, it's like, 'Mom, wake up here. He's not here. You don't have him with you right now.' It hurts. That's why I'm taking down his bed."



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