

THE DEATH OF BABY DOE

Jeff Lyon



Bloomington Hospital

Bloomington, Indiana is a peaceful and serene, tightly knit, homespun community that is both protective of traditional values and tolerant of the liberal

Jeff Lyon is a *Chicago Tribune* feature writer. This story is excerpted from his book *Playing God in the Nursery* (W. W. Norton & Co.), an examination of the ethical and social implications of decisions not to treat impaired newborns.

university population it hosts.

In the spring of 1982, however, this tranquility was disrupted by a tragic and controversial episode. A Bloomington couple allowed its infant son to die of a treatable birth defect.

The child, who succumbed while surrounded by willing rescuers, has become known to the world as Baby Doe, his identity sealed by the courts to

protect his parents. We will continue to respect their privacy by not naming them in this story.

Good Friday, April 9, 1982. The afternoon light was dying as Walter Owens hurried into the rear entrance of Bloomington Hospital where one of his patients had just gone into labor.

The mother, a petite woman with closely cropped hair, was 31 years old.

Photos by Larry Crewell/Bloomington Herald-Telephone

Her pregnancy had proceeded quite normally, and she had previously given birth to two healthy children. There was no reason to expect anything other than a routine delivery.

Uncomplicated Delivery

Scanning the medical chart, Owens noted only one indication that something might be wrong. When the woman's amniotic sac burst, 45 minutes after her admission to the hospital, she began to pass amniotic fluid of an abnormal greenish color. This "staining" of the fluid signifies that the fetus is giving off a waste product known as meconium, which is sometimes, but not always, an SOS, suggesting that it may not be getting enough oxygen.

In the absence of any other warning signals, however, Owens was not overly concerned. At about 7:30 p.m., with labor progressing nicely, he made his way to the doctors' lounge and slipped into his hospital garb. Then, after carefully scrubbing up for the birth, he joined the parents in the delivery room. The only other person in the room as Owens began to deliver the baby was a nurse, Dana Watters.

Over the next 40 minutes, everything went smoothly. Owens could not have asked for a more uncomplicated birth.

The time of delivery was logged at 8:19 p.m., and it was at that instant—as he placed the infant on its mother's abdomen—that Owens saw he had a catastrophe on his hands.

The baby was as limp as a rag doll. Blue from lack of oxygen, it lay scarcely breathing, its small heart pumping raggedly like an engine that won't turn over. Its initial Apgar score was 2.

But Owens observed something else in the small, flaccid body that lay before him, something that made his heart sink. He saw the telltale signs of Down's syndrome.

The mother, too, must have seen something in the child's face. "You look beautiful," she crooned, stroking the infant on her belly. "You look different from my other two, but I love you anyway."

But there was no time to ponder the

situation. The child needed help to breathe. Owens tried flicking his fingers against its tiny chest to stimulate respiration, but it responded weakly. He nodded to Mrs. Watters, who whisked the baby to a nearby radiant warming table, where she began feeding him oxygen via a hose from the wall. At last the infant began to breathe normally, and his color brightened. Mrs. Watters gave a thumbs-up signal to Owens, who was delivering the placenta. The veteran obstetrician relaxed somewhat.

Complicated Infant

Mrs. Watters then took up a DeLee trap and threaded it into the child's esophagus to suck amniotic fluid from the stomach. But as she slid the slender tubing down the throat, she felt it suddenly stop. She tried again.

"I can't pass the catheter, Dr. Owens," she murmured anxiously.

The two of them peered at each other over their masks. They both knew what that meant.

"Esophageal atresia," thought Owens grimly. No food would reach the infant's stomach.

Owens suspected the child had a tracheoesophageal fistula as well. The child will have trouble breathing, being unable to rid itself of mucus, and eventually its lungs will be "digested" by its own stomach juices backing up.

The mother's face seemed to cloud over as she waited for Owens to stop examining the baby. He was taking



Dr. James Schaffer advised surgery.

forever, much longer than he should. "What's wrong?" she asked, alarmed.

Mrs. Watters bit her lip. "We seem to be having some difficulty getting the tube down into his stomach," she replied.

The father, his nondescript surgical outfit concealing the apprehensive man inside, kept his wide eyes focused on the doctor.

"Is . . . he going to be all right?" he stammered.

"We're going to have to see," Owens said solemnly. Believing a second opinion to be in order, he asked the father who their family doctor was. Their general practitioner was Dr. Paul Wenzler, the man replied, but where their children were concerned, Dr. Wenzler consulted with Dr. James Schaffer, a prominent Bloomington pediatrician.

Owens told Mrs. Watters to get Schaffer on the phone immediately. By chance, Schaffer was already in the hospital making rounds. He agreed to examine the baby in the special-care nursery. Mrs. Watters bundled up the infant and set off on the trip down the hall. As she rushed out of the room, the husband looked imploringly from her to the face of his son. Then he buried his head in his hands.

James Schaffer studied the infant. There was little doubt that it had Down's syndrome.

Next, he, too, tried to pass a catheter down the baby's esophagus. Just as before, it would not go down. Schaffer was not surprised. Down's syndrome is frequently accompanied by other malformations. He ran his expert hands along the child's limp body, and soon he noticed something else amiss. There was a weak pulse in the child's leg, a symptom of a constricted main artery. Sure enough, when a chest X-ray came back, it seemed to show that the heart was abnormally enlarged.

Schaffer conferred with Owens. Joining them was Wenzler, who had just arrived at the hospital. Their discussion was brief. The facts of the child's handicaps seemed clear enough. All that remained was to outline for the parents what the treatment options were.

The three doctors filed into the recovery area, where the mother lay in silence. Her husband was pacing the floor. As gently as possible, the physicians began to explain the prognosis for the couple's newborn son.

Schaffer spoke first. In his opinion, the child needed an immediate transfer to James Whitcomb Riley Children's Hospital in Indianapolis. Riley was equipped to surgically repair the boy's esophagus and trachea; Bloomington Hospital was not. Without an operation, Schaffer explained, the child would die.

Dr. Wenzler concurred. Without the operation, the boy would not be able to eat or drink. Anything he took by mouth would cause him to suffocate.

Then it was Owens' turn to speak. "It was right at that moment," Schaffer later recalled, "that everything went to hell."

Owens could simply have joined Wenzler in seconding Schaffer's recommendation. Had he done so, a chapter in American moral politics might never have been written. But he saw things a different way. The operation, he told the parents, could indeed save the child's life. But it was a rigorous procedure, generally accompanied by a significant amount of pain, and it frequently required follow-up surgery over several years. Above all, he reminded them, it could do nothing about the Down's syndrome. The child would still be retarded for the rest of his life.

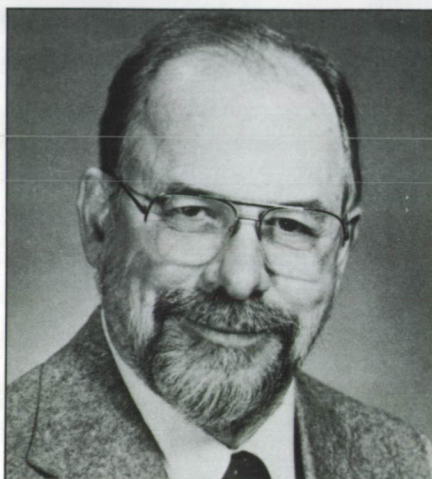
"However," he informed the parents, "you do have an alternative."

What they could do, he explained, trying to choose his words carefully, was in effect do nothing: Simply refuse consent for surgery, in which case the baby would die of pneumonia in a few days as the digestive juices attacked his lungs.

Having said his piece, Owens fell silent.

Inside an Opinion

Why would a doctor whose entire career had been devoted to bringing babies into the world now raise the option of letting one die? Owens later ascribed his behavior to an experience



Dr. Walter Owens: "You do have an alternative."

he'd had years before. His nephew's wife had given birth to a malformed baby, among whose defects was one requiring major surgery. It was performed at once, at the pediatrician's recommendation. When numerous bouts of pneumonia subsequently afflicted the infant, the same pediatrician vigorously treated them.

"But the child has never been normal," Owens explained. "It learned to walk at the age of four, and it has never learned to talk. It is, at times, aggressive and destructive. My nephew and his wife are very strong people and have handled it. But they've had no more children. She has devoted her whole life to caring for this child.

"Obviously, this has colored my thinking on the survival of such children. I believe there are things that are worse than having [such] a child die. And one of them is that it might live."

The pediatrician who had recommended surgery for Owens' grandniece and who had treated her pneumonias so vigorously was Dr. James Schaffer.

It was 9:30 in the evening. The doctors suggested the parents take some time to weigh their options. The emergency was not so critical that they had to decide on the spot. The couple nodded.

In the interim the three doctors sat drinking coffee at the nurses' station. A chill had descended upon them since Owens had suggested nontreatment. They did not speak.

At almost the stroke of 10 p.m. the father appeared in the doorway. "We've reached a decision," he announced softly. For a moment he seemed to have trouble with the words. But at last, with a glance at Owens, he said, "We have decided that we don't want the baby treated."

Physicians Tangle

Schaffer looked shocked. Immediately, he began to remonstrate with the father. Didn't they understand that the baby would die without treatment? Yes, they did understand, the man said. But they were nevertheless withholding consent.

With his colleagues looking dumbfounded, Owens leaped up to congratulate the father. "You've made a wise and courageous choice," he told the man. "Here's how I look at it. If you let the baby die, you're going to grieve a little while. But if you go ahead with this surgery, you're going to grieve for the rest of your lives."

Schaffer stalked out of the room. A few minutes later, when Owens entered the special-care nursery to check on the baby, he found Schaffer speaking by telephone with the chief physician on duty at Riley Hospital's neonatal intensive care unit.

"I want you to talk to this man," Schaffer told Owens tersely.

Owens took the receiver. Right away, as Owens remembers it, the doctor on the phone became threatening. This was infanticide, the physician said heatedly, and there were laws against such a thing. "There's going to be a court order to take control of this child," he warned Owens. "You can be sure of it."

Saturday, April 10, was the lull before the storm. Owens, in consultation with the parents, drew up the infant's treatment order. The order stipulated the following: (1) Hospital personnel might feed the child orally if they wished, but they should be advised that it was likely to result in aspiration and death; (2) intravenous feedings were positively forbidden; and (3) the child should be kept as comfortable as possible and given sedation as needed.

The treatment order was taped to the side of the baby's Isolette. That accomplished, the couple had a second unhappy piece of business to attend to: talking to an attorney. There had been threats of legal action on the night of the birth, and now the hospital management was acting strangely. An administrator had begged them to take the child home, and when they had refused, he had asked them to sign a release absolving the hospital of responsibility for the baby's death.

Judicial Decision

One can hardly blame the hospital administrators for being nervous. A child with a treatable medical condition was being allowed to die in their special-care nursery. Aside from humanitarian questions, there was the issue of legal culpability. If the baby died on the hospital's grounds, could the institution be held criminally liable?

On Saturday night the hospital's attorney, Len Bunger, came up with what appeared to be the perfect solution—a judicial hearing. A judge could order the parents to send the child to Riley. And a judge could take custody of the day-old infant away from them if they refused. At the very least, Bunger reasoned, it would take the responsibility off the hospital's shoulders. Judge John Baker, of the superior court, heard the case at 10:30 that night in the hospital.

The questions to be resolved: whether parents ever have the right to refuse life-saving treatment for their children and whether a life of handicap is so abysmal as to warrant its termination at birth.

Only rarely in American jurisprudence had such questions been raised. On the few occasions on which they had, the courts had almost invariably ruled against the parents and in favor of life. But in those instances the doctors had always been lined up *against* the parents.

Judge Baker's opinion: Since there were two divergent medical opinions, he said, it was his conviction that the Does had every right to select one of the two. It was not for the court to decide which



Judge John Baker: "I think Indiana law is clear."

they should choose. The child would be permitted to die.

Nurses Protest

Easter Sunday, April 11. The special-care nurses revolted, threatening to walk off the job if the baby wasn't removed from the nursery. His presence among women whose every professional and human instinct was to nurture him was like an open wound.

Linda McCabe, head nurse in the unit, vividly recalls coming to work that weekend and seeing the child lying in its incubator with a "Do not feed" order taped to the side. "I felt like they had a lot of gall asking me to do that. I thought, 'Over my dead body.'"

To quell the uprising, the hospital hastily transferred the child to a private room on the fourth floor. The Does found themselves forced to hire private nurses who could watch the child around the clock and comfort him. But they were not allowed, under hospital rules, to give him drugs. Only the fourth-floor nurses could administer the morphine shots and phenobarbital prescribed to keep the baby calm and pain-free as his life slipped away.

One of them, Teleatha McIntosh, says she found the task emotionally devastating. "Without a doubt, it was the most inhumane thing I've ever been involved in," she recalls. "I had all this guilt, just standing by, giving him injections and doing nothing for him."

But even nurses who raged at the

parents for their decision had to admit they were attentive and loving to their child, frequently visiting the bedside and cradling him in their arms.

Early on Monday morning the Does, who are Catholic, had the child baptized. The sacrament was performed by their parish priest, who had indicated support for their decision. They named the child Walter, after Dr. Walter Owens.

Time Runs Out

By Tuesday, the infant lay dying in his incubator. His body weight had dropped from lack of nourishment. He was crying from hunger, and his lips were parched from dehydration. His ribs were sticking out, the result of respiratory strain. That afternoon, when the stomach acid started corroding his lungs, he had begun to spit blood.

The nurses did what they could. They turned him over, gave him back rubs, and put glycerin-soaked swabs into his mouth to ease the dryness. They also diligently suctioned the blood from his throat. Despite their best efforts, however, it was clear he had less than 48 hours to live.

Local right-to-life organizers, the county prosecutor, a local attorney, and a National Right-to-Life Association lawyer all tried different tactics to save the infant. Each effort failed.

Thursday began as Lawrence Brodeur, assistant county prosecutor, was about to play his final card. Accompanied by a constitutional expert from Indiana University, Brodeur booked a flight to Washington, D.C., where he planned to file an emergency appeal with the U.S. Supreme Court.

But time was running out for Baby Doe, as the press had christened him. He had begun to hemorrhage freely, the blood oozing from his nose and mouth. Three times Thursday afternoon and evening he had stopped breathing, only to fight his way back.

Nurse Bonnie Stuart, who was working the 3-11 shift that day, recalls seeing Mrs. Doe looking troubled. "I never saw the lady cry, but she looked like she hadn't slept much. She'd ask me if I thought it would be much longer, like

Photo by Bloomington Herald-Telephone

she was hoping it would be over soon. I never replied. It was not a friendly conversation. I wish I'd never seen the woman."

Stuart says the mother left early in the shift, which particularly upsets her. "I feel the parents could have been there for the death," she says bitterly. "I'm angry at them for involving me and then backing out, making me take care of him."

At exactly 10:01 p.m., six days after his birth, Baby Doe died with the two doctors looking on. Cause of death: chemical pneumonia, due to the regurgitation of his own stomach acid.

An autopsy was conducted by John Pless, the Monroe County coroner. Dr. Pless discovered that there had been no enlarged heart; the X-rays had been misleading. Nor could he find any direct evidence of brain damage caused by oxygen deprivation. But the child did indeed have a tracheoesophageal fistula.

On the night of Baby Doe's death, Lawrence Brodeur was in the Atlanta airport, awaiting a connecting flight to Washington. He had to turn around and come home.

Prospect and Retrospect

It is likely to be years before the issues that were raised that night in Bloomington, Indiana, are settled to society's satisfaction. In response to the episode, the Reagan administration issued a series of federal fiat's designed to ensure that virtually all handicapped babies, no matter how severe their disabilities, receive the medically indicated life-saving treatments. The quality of a child's future life was not to enter into the equation. These "Baby Doe" regulations, as they came to be called, were vigorously opposed by the medical community, which considered them an infringement on parental rights and doctors' discretion. A federal court ultimately ruled them invalid.

But Congress thereupon passed legislation defining nontreatment as a form of child abuse. The new law, signed by President Reagan last October, insists on treatment of all handicapped children regardless of parental wishes—save

where the child is chronically and irreversibly comatose or where the treatment would merely prolong dying. It is expected that the law will be challenged in court, most likely by the American Medical Association.

What do those who lived with the Bloomington case for six terrible days have to say about it in retrospect?

Lawrence Brodeur, the assistant prosecutor, continues to bristle over Judge Baker's use of quality-of-life criteria as justification for not treating the Doe child. "Who," asks Brodeur, "can make a decision as to what is minimal quality of life? Very simply, no one can. Nobody is qualified to do that. Maybe the child will be happy. Maybe it won't. How can you know? So you have to go back to your basic tenets of law."

Judge John Baker also says he has not changed his mind. "I've never had second thoughts," he says. "I've thought about it from every angle, but I've never come to another conclusion."

Baker explains: "I think Indiana law is clear. When there are two medical opinions, each in conflict, which to choose is up to the parents. There were two sides here. One side said let's do a full-court press, let's do everything medically possible. The other side said the child's opportunity to bring joy and be healthy was very limited and that once they opened the baby up, there was no pulling back. They'd have to correct all the abnormalities, and in so doing they might cause the child to be strapped to the bed forever. I couldn't subject the child to this."

The judge says he's received a huge volume of mail. "Some say they wish they'd been allowed the same alternative with their children. Others say they wish I'd been hanged with the rest of Hitler's exterminators."

Afterpains

As for the Does, Judge Baker says: "They've resented comments about their moral character. They had a tragedy on their hands. It was their baby son who died, after all."

Teleatha McIntosh, one of the nurses who watched the Doe child die, found

the whole affair extremely traumatic. "I feel that a terrible injustice was done," she says. "I couldn't sleep for a long time afterwards. Every time I closed my eyes, I'd see that baby lying there bleeding and fighting for breath. It was hard to get it out of my mind."

Bonnie Stuart, who also worked the fourth floor that week, says she too had insomnia. "It still seems like a nightmare to me. I still can't believe it happened in today's society. I said, 'This is wrong,' fifty times a night as I was taking care of him. He wasn't limp like they said. When I'd give him a shot of Demerol, he'd flinch. He'd open his eyes when I stroked his head. He looked like a perfectly normal little boy. Yes, he did have the eyes of a Down's child, but other than that he looked normal."

In the more than two years that have passed since the Doe child died, a number of things have happened to the people who fought over his fate.

Lawrence Brodeur took the case to the U.S. Supreme Court, arguing that although the child was dead, the issue of whether his life should have been ended needed to be resolved because it would come up again and again. In the autumn of 1983 the Supreme Court declared it a moot case and refused to hear it.

The nurses McIntosh and Stuart required several months of psychiatric counseling following the episode. The hospital provided it free of charge.

Judge Baker has a re-election campaign coming up in 1986. He believes his decision in the Doe case may harm him at the polls. He and Dr. Owens have become very good friends, to the extent that he recently brought his children over to Owens' house for a hayride.

Dr. Owens has also become quite close to the Does. When his own son died tragically many months ago, they were the first people to come by to console him.

The Does have continued to be very private people. Thus far they have not publicly revealed their feelings to anyone about what they went through. In April, 1984, Mrs. Doe gave birth to another child. It was a healthy baby girl. ■