

*Charlie Gard and Baby Sam*HEARTBREAKING CASES TEST
ETHICS AND PUBLIC POLICY

After months of legal battling, baby Charlie Gard was moved from intensive care at the Great Ormond Street Hospital in London to a pediatric hospice, where he was removed from life support. He died shortly thereafter on July 28, 2017, just short of his first birthday.



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Charlie was born with an incurable genetic defect that progressively damaged his brain, muscles and other organs, leaving him unable to move or breathe on his own. He could not see or hear. His doctors were unsure whether he felt pain. Eventually they concluded there was no further treatment possible in Charlie's case, and they recommended palliative care.

Charlie's parents rejected that conclusion and went to court for permission to take Charlie to the United States for an experimental therapy, a plea they eventually abandoned when scans showed the child's condition had gravely deteriorated.

Just a few weeks ago, I read about another such case in an article titled, "You Should Not Have Let Your Child Die," by Gary Comstock, professor of philosophy at University of North Carolina.¹ Comstock describes the case of Baby Sam, who was born in Ames, Iowa, with a genetic disorder that usually results in serious disability and death at an early age.

There are a number of similarities in these two cases: Both infants had a debilitating, ultimately terminal genetic illness for which there is no cure; both were on ventilators and had little or no chance of a conscious life; both had parents faced with a terrible range of choices; both were in economically prosperous countries with advanced medical resources.

But the similarities stop there.

In Charlie Gard's case, the parents wanted to do everything possible, but the clinicians and the court deemed the actions and treatments to be of marginal value for Charlie's quality of life, therefore not in the child's best interest. In Baby Sam's

case, his parents apparently were free to choose any treatment they wanted, or to take their child elsewhere.

In Baby Sam's case, there was no public debate, at least in part because his condition, called trisomy 18, is better known — it occurs in about 1 of 2,500 pregnancies, according to the Trisomy 18 Foundation.² It is a tragedy of little fanfare.

Charlie's condition, called infantile onset encephalomyopathy mitochondrial DNA depletion syndrome, is so rare that only a handful of cases are known,³ and it generated enormous public interest. The Vatican offered the services of its Bambino Gesù pediatric hospital to continue Charlie's life support, and at least one American hospital and physician offered to provide experimental nucleoside bypass therapy — which has not been tested for Charlie's particular condition — until imaging indicated Charlie's muscular atrophy and brain damage had progressed too far.

Interest extended even to the U.S. Congress. Rep. Brad Wenstrup (R-Ohio) and Rep. Trent Franks (R-Arizona) introduced legislation that would help Charlie and his parents get immigration visas and U.S. residency, ostensibly to rescue them from the clutches of a socialist country and its single-payer system.⁴

In Charlie's case the parents resisted removing the child from life support as long as they could, first hoping to find something medical that could be done, then asking to be allowed to take the child home, ultimately arguing that they wanted Charlie to remain in the hospital ICU for a little longer so they could spend more private time with their son before he was moved to a hospice and the mechanical life-support measures would cease.

In Baby Sam's case, the parents made the difficult choice to let their son die.

The title of Comstock's article led me to be-

lieve that he was going to criticize the parents for not doing everything medically possible. So I was shocked to read the following advice: “You should not have let your baby die. You should have killed him.”

Comstock explains the choices: “We can leave our babies on respirators and hope for the best. Or we can watch the child die a tortured death. Shouldn’t we have another option? Shouldn’t we be allowed the swift, humane option afforded the owners of dogs?”

DILEMMAS AND PRINCIPLES

There is a textbook full of ethical dilemmas in these two cases. Although the answers in cases like these are never easy, there are several principles that stand out for us in Catholic health care.

1. Health care decision-making should remain as close to the patient as possible, and treatment choices should be made from the patient’s perspective. This is always difficult, because all of us want a say in the care of those we love. It is even more difficult with infants, who have never exercised their own moral responsibility and have never had the chance to express their wishes.

Charlie Gard’s case was in the courts for months; foreign interests intervened and offered to provide care for the infant. In an op-ed piece, U.S. Rep. Franks wrote, “We don’t just protect [innocent lives], we fight for the lives of every individual, even the little lambs that somehow get lost. No matter how marginalized — those with physical or mental disabilities; the one who can’t speak, the one who can’t hear, the one who can’t see; they are equal under our laws, even if they lack the very ability to understand that those laws exist.”⁵

2. Money is never the sole determinant of who receives care, but in reality, medical resources are finite, and someone has to make decisions about where health care dollars are best allocated. In the U.S., we ration by denying primary care and care for chronic illness; in Britain, the National Health Service tends to deny high cost, low benefit treatments. In Charlie’s case, I wonder whether concerns about possible costs and making exceptions were also factors.

How much we spend and who pays are the issues at stake in our ongoing political battle about U.S. health care. It seems to me that the Catholic

view would favor public health over individual rights and relatively equitable access to primary care, especially for children and other vulnerable groups, over isolated cases of high-tech intervention.

3. Catholic health care is rooted in our belief in the redemptive value of suffering, even if it defies logic. Suffering by infants pushes us into unanswerable questions about God’s providence, yet we have to believe that it has something to do with the Paschal Mystery: God suffered, died and was raised from the dead for us. Somehow our suffering is linked to our hope in the Resurrection. There is a point where we can do nothing more medically, but that does not mean we lose hope. Killing a patient to end suffering is not only an inhuman act, but an act of angry despair. Prolonging suffering with no hope of recovery can be a denial of our trust in God’s providence.

Despite the differences, the most important similarity between the two cases is that Charlie and Sam both were excellent candidates for hospice care for dying patients, or palliative care for patients who cannot be cured but who are not imminently dying, either.

Hospice care creates a circle of life and gratitude around the patient. It manages medication and other interventions in such a way that suffering is minimized, and families have a chance to say good-bye and deal with the loss that is unfolding before them.

Hospice recognizes the limits of what we can do medically, but it doesn’t give up, it doesn’t marginalize patients for whom there is no medical hope, and it doesn’t capitulate to euthanasia. Instead, it embraces them and helps them prepare for death. Hospice care creates a circle of life and gratitude around the patient. It manages medication and other interventions in such a way that suffering is minimized, and families have a chance to say good-bye and deal with the loss that is unfolding before them. Hospice blends the clinical and the spiritual in a way that was the hallmark of

our foundresses and founders.

Both cases make me wonder why there are so many situations in which patients or decision-makers cling to the extremes of “do everything possible” or “If we can’t do anything for him, put him out of his misery.” Why have we not been able to make a compelling case for hospice and palliative care, which acknowledge mortality and the limits of human medicine, but which also respect human dignity and our hope in the Resurrection?

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NOTES

1. Gary Comstock, “You Should Not Have Let Your Baby Die,” *New York Times*, July 12, 2017. www.nytimes.com/2017/07/12/opinion/you-should-not-have-let-your-baby-die.html.
2. Trisomy 18 Foundation website. The foundation says “10% or more” of babies born with the condition may survive to their first birthday. (www.trisomy18.org).
3. BBC News, “Charlie Gard: The Story of His Parents’ Legal Fight,” BBC website. www.bbc.com/news/health-40554462. (accessed Aug. 7, 2017).
4. One publication linked Britain’s National Health Service with Charlie’s death. “Yanking Life Support from UK Baby Demonstrates Dangers of Socialized Medicine,” *The Federalist* July 3, 2017. <http://thefederalist.com/2017/07/03/yanking-life-support-uk-baby-demonstrates-dangers-socialized-medicine>. (accessed July 28, 2017).
5. Trent Franks, “We Are All Charlie Gard,” *Fox News Opinion* website, July 11, 2017. www.foxnews.com/opinion/2017/07/11/are-all-charlie-gard-legislation-would-allow-infant-and-parents-to-come-to-us.html. (accessed July 12, 2017).

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