



the director's desk

BY PAIGE C. CUNNINGHAM, JD, PHD
EXECUTIVE DIRECTOR

“What do you think about the Charlie Gard case?”

These days, taking a measured approach to controversial cases does not earn ‘shares’ on Facebook, ‘likes’ on Instagram, or ‘retweets’ on Twitter. But it seems to be the best way to offer a credible and helpful response. All too often, highly charged issues are not amenable to sound bites. They are interlaced with powerful emotional triggers, such as the agony of a parent over a child’s incurable and painful disease or the desperate desire of parents to avoid conceiving yet another child with a lethal condition.

I learned as a law student that “hard cases make bad law.” This is due, in part, to human compassion. In the face of particularly gruesome, tragic, or outrageous facts, a judge or jury may ignore clear legal boundaries in order to achieve justice or fairness for the plaintiff (or victim). Out of sympathy for the injured party, a new principle or rule may be issued that could apply in unintended, and possibly harmful, ways.

For example, consider a young man who designs a clever logo, but fails to trademark it. The company who registers it as a trademark makes millions, while the young man struggles to pay college loans. Even though the company is in compliance with trademark laws, sympathies likely would lie with the young man. This is a hard case. Yet, a verdict for him would mean rewriting a significant body of trademark law, affecting scores, perhaps thousands, of other cases.

The “hard cases make bad law” maxim might apply to ethical dilemmas as well. Do “hard cases of deep human suffering yield poor ethical judgments?” Hastily rendered opinions might not be grounded in the facts of the situation. Our natural empathy could make it difficult to identify all the relevant ethical issues. Public outrage can be instigated by misrepresentation of research results, poor reporting, or misunderstanding of the science. It is much easier to gin up emotion than it is to patiently wade through the details and consult experts for a more accurate understanding.

These challenges were highlighted for me recently in the case of Charlie Gard, the little boy hospitalized in the UK whose parents wanted to bring him to the U.S. for treatment of a rare genetic disease. Charlie was born in August 2016 with mitochondrial DNA depletion syndrome (MDDS), a progressive disease that attacked his muscles and brain and for which there is no known cure. Two months later he was transferred to a children’s hospital in the National Health Service, Greater Ormond Street Hospital (GOSH). Meanwhile, Charlie’s parents learned of an experimental treatment they wanted Charlie to try in the United States.

That is when the difficulty began. The staff at GOSH determined that the series of seizures Charlie experienced beginning in December caused such severe damage that further treatment would only cause pain and suffering with no benefit to the baby. On January 30, the parents launched a GoFundMe campaign, which garnered worldwide attention and donations, including statements of support from a president and a pope. Connie Yates and Chris Gard, the baby’s parents, said “He’s our flesh and blood. We feel it’s our right as parents to decide if we should give him a chance at life. If he’s still fighting, we’re still fighting.”

Despite the parents’ pleas and private fundraising efforts, GOSH went to court to prevent Charlie’s transfer, based on the determination that it would prolong Charlie’s pain. The court initially sided with the hospital, then reconsidered after a group of experts raised the possibility that the treatment might help. When Dr. Hirano, the expert who would provide the treatment, examined scans of Charlie (but did not physically examine him), he concluded that it was too late for treatment to help. A few days later, the parents agreed to the withdrawal of life support. Charlie died under hospice care a few days before his first birthday.

In this situation legal proceedings obscured some of the details of the baby’s condition. This is understandable (even if frequently overlooked in sound bites or viral tweets) in America, but when combined with the hospital’s obligation to protect patient confidentiality, accurate information upon which to formulate ethical judgments was lacking. The legal complexities and distinctives of the UK legal system did not translate well to American audiences, including the lesser regard for parental rights in the UK.

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University.

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THE CENTER FOR
BIOETHICS
& HUMAN DIGNITY
TRINITY INTERNATIONAL UNIVERSITY

2065 HALF DAY ROAD | DEERFIELD, IL 60015 USA
V 847.317.8180 | F 847.317.8101
INFO@CBHD.ORG | WWW.CBHD.ORG

When asked to comment on the case, my first inclination was, “I don’t know enough about this to contribute anything useful.” The need for reflection prompted me to dig deeper and to consult others with medical and legal expertise. What I learned inhibited me from issuing a full-throated defense of Charlie’s parents or an unqualified attack on GOSH and the British courts.

My hesitations were these:

- Charlie was being cared for at the top children’s hospital, which handles the most difficult cases.
- The doctors had been vilified, but were prevented by physician-patient confidentiality from responding.
- I did not know enough about the medical facts of his condition.
- If Charlie did receive the treatment, he would have been a research subject of a highly experimental therapy which had never been tried on a human being—or even an animal. (Of course, research on rare diseases cannot be conducted in the same way as for conditions that affect large populations.)
- Charlie’s parents’ would naturally seek whatever help they could find to save their only child.
- The UK legal system is different than in the U.S. where a hospital could not keep a patient against his parents’ wishes.
- I wondered if the parents had adequate legal representation early enough in the process.
- There appeared to be a conflict of interest regarding the attorney appointed to represent Charlie’s interests; she was the board chair of Compassion in Dying.
- Social media was being exploited to demonize the various parties, to politicize the issues, and to capitalize through fundraising campaigns.

The radio host who wanted to interview me was persuasive. Prior to our on-air conversation about the case, I emailed him the following observations:

- Cases like these should not be tried in the court of public opinion.
- Some situations do not have good outcomes—no matter what happens.

- We all wish that Charlie had been able to get treatment earlier, when his parents first started requesting it—before the seizures began.
- Do not be too quick to judge. Physicians are human and should be respected as such.
- I was concerned that we are quick to defend physicians’ right of conscience when it comes to assisted suicide (and rightly so), but are equally quick to attack this right when it comes to their professional views about the wisdom of maintaining a very sick and possibly dying child on life support.
- People are generous. This story of one baby generated a huge outpouring of concern and donations. There would not be nearly as much interest if the story were about a group of patients, or about simply curing MDDS, Charlie’s disease. We respond with generosity to tragic stories.
- We have an obligation of charity toward others. Christians may disagree about the outcome of this situation, even when we agree on the underlying principles, such as respect for life and parental rights. Let us be charitable in our characterizations of others.

Responses to the case did not always follow traditional lines, illustrating its complexities. Ethicist and sometimes provocateur Julian Savulescu supported treatment. Some pro-life advocates sided with the hospital and doctors. Both sides believed they were acting in Charlie’s best interests. It is obvious that the ethical issues merit a much fuller discussion.

In my transition from years of advocacy in the pro-life movement to the world of academia and scholarly research, I have learned that the best answer to *What do you think about ...?* may be, *Let me do some investigating and get back to you.* ●●●

Editors’ Note: This thesis, “Let me withhold my judgment until I get all the facts straight,” is a central point of a recent book that we have enjoyed at the Center, The Death of Expertise: The Campaign Against Established Knowledge and Why it Matters by Tom Nichols (Oxford University Press, 2017).

1 Richard Wheatstone, “Brave Mum and Dad,” *The Sun*, August 15, 2017. <https://www.thesun.co.uk/news/3985035/charlie-gard-parents-connie-yates-chris-gard/>.

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