REVIEW OF THE CASE

Guarding Charlie Gard

FR. GERALD D. COLEMAN, PSS, PhD

The heart-wrenching case of Charlie Gard is now well-known and widely assessed.[1] He was born in West London on Aug. 4, 2016, to Chris Gard and Connie Yates. He seemed at first to be developing normally, but by October was failing to put on weight. He was admitted to the neonatal intensive care unit at London's Great Ormond Street Hospital, one of the world's leading children's hospitals.

Charlie was treated for a rare genetic condition called encephalomyopathic Mitochondrial DNA Depletion Syndrome (MDDS),[2] which prevents cells from producing sufficient energy to maintain normal bodily functions. Charlie had a form called RRM2B, and most experts agree that there is no cure or treatment.

The child suffered from catastrophic and irreversible brain damage and was on life support, unable to breathe on his own.[3] Along with his muscle weakness, Charlie began to experience persistent epileptic seizures, despite being on four types of anti-seizure medications.[4]

Charlie was deaf, unable to respond to his parents and unaware of being awake or asleep. His doctors believed he experienced some significant pain because "being ventilated, being suctioned [are] all capable of causing pain." They also described Charlie as "non-responsive" and indicated that his skull had not grown in three months, an indirect measure of brain development. For these reasons, his doctors wanted to remove the ventilator.

In light of these medical facts, this article addresses four interrelated issues: mitochondrial diseases, the U.K. courts and parental rights, Catholic moral teaching, and the range of responses this case elicited.

MITOCHONDRIAL DISEASES

Charlie's diagnosis sheds light on a little-known but deadly disease that demands broader discussion. His condition of RRM2B mutation prevents the production of an enzyme that creates a building block to synthesize DNA, which in turn causes both brain damage and muscle weakness. Charlie's condition was described as "extensive, severe and irreversible."

Although Charlie's specific mutation is rare, mitochondrial diseases as a group are commonplace. Approximately 1 in 2,500-5,000 adults, teens and children are affected, meaning mitochondrial diseases are more common than childhood cancers. Medical experts concluded that there was "very little known" about any viable treatment for Charlie's mutation, which spotlights the vast need for more research into mitochondrial conditions.

THE U.K. COURTS AND PARENTAL RIGHTS

Due to Charlie's diagnosis, his doctors agreed that there was nothing they could do beyond ventilator support, and they recommended its removal. His parents objected, and the hospital asked London's High Court for an opinion, a standard procedure in cases where doctors and families disagree.

Charlie's parents wanted doctors to try an experimental treatment called nucleoside ther-

apy, which would supplement his lack of building blocks. This treatment had previously been considered by his physicians but had been ruled out as futile, because Charlie's brain damage would not be reversed. Additionally, this treatment had never been used on children with Charlie's particular type of mitochondrial depletion syndrome, nor tried in animal tests.

However, Charlie's parents anchored hope in American physician Michio Hirano, MD, of New York-Presbyterian Hospital/Columbia University Medical Center. Hirano described the proposed nucleoside treatment as "experimental" and unlicensed. To use it would require approval for a "compassionate use exception" from the U.S. Food and Drug Administration.

From more than 80,000 donors, Charlie's parents raised in excess of $1.7 million to transport the child to New York and pay for his treatment. "He is our son," they said. "We feel it should be our right to decide to give him a chance at life."[5]

In July 2017, Hirano flew to London and testified in court about Charlie's case. He later examined the child and studied the latest MRI scan. Hirano concluded that he could no longer offer the proposed therapy; the condition of Charlie's muscle tissue made it unlikely the child could benefit from the treatment. The hospital and the courts criticized Hirano for having made a diagnosis before he had examined Charlie, or reviewed the child's medical records. A dispute also arose over whether or not Hirano had relinquished a "financial interest in some of the ... compounds he proposed prescribing." Such a financial link would raise serious moral questions about conflict of interest. [6]

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There was a fundamental and unbridgeable divide of principle over parental rights. Fordham University's Charles Camosy, PhD, wrote, for example, that "Charlie did not belong to his physicians. He belonged to his parents. And they to him."[7]

Catholic teaching holds that a patient is the primary decision-maker in health care decisions, and in Charlie's case this role fell to his parents. However, they were not given the final word. In the U.S., the *Ethical and Religious Directives for Catholic Health Care Services* testify that "family members and loved ones should participate in the treatment decisions for [a] person" such as Charlie.[8] The *Catechism of the Catholic Church* is very clear: "The role of parents ... is of such importance that it is almost impossible to provide an adequate substitute. The right and the duty of parents ... are primordial and inalienable."[9]

CATHOLIC MORAL TEACHING

Numerous moralists and ethical centers weighed in on the dilemmas surrounding Charlie.[10] One writer believed that allowing Charlie to die amounted to "judicial murder."[11] Another writer stated that allowing Charlie to die amounted to "selective abortion"[12] because he had a disability. Santa Clara University's Lisa Fullam rightly took issue with those who claimed that Charlie's human dignity was being disregarded because he suffered from a disability. Rather, "the staff at [Great Ormond Street Hospital] were not life-denying monsters but professionals who have devoted their lives to the care of sick children."[13]

A central question, generally overlooked in this case, concerns whether or not Charlie's ventilator offered hope of benefit proportionate to his suffering. A medical intervention is ordinary or extraordinary relative to a patient.[14] Did keeping Charlie on a ventilator promise any real benefit, or had its use become burdensome, as it did not promise any proportionate good and was only prolonging his suffering and dying?

The Catholic tradition holds that if a treatment amounts to "great or enormous effort" (*summus labor*), it is optional.[15] Remaining on a ventilator would keep Charlie alive for a while. But his condition would continue to deteriorate, his pain would continue and his dying would be prolonged.

Pope John Paul II wrote that "Euthanasia must be distinguished from the decision to forgo so-called 'aggressive medical treatment,' in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden to the patient and his family. In such situations, when death is clearly imminent and inevitable, one can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted." (*Evangelium Vitae*, 1995, no. 65)[16]

Human life must always be respected, but accepting death is also necessary. It seems that the intention of Charlie's doctors to remove his ventilator was not to murder or euthanize him, but rather to admit that further treatment was no longer of any real benefit. Seeking every possible intervention is not morally necessary. While human life is always worthy of respect, not every treatment is worth pursuing because it no longer serves its purpose, it is excessively burdensome or it promises too little benefit relative to the burdens it entails.

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A RANGE OF RESPONSES

"Guarding" or protecting Charlie summarizes the worldwide responses to this case, perhaps best framed by Catholic journalist Austen Ivereigh, who wrote that Charlie "elicited great love: not just from his extraordinary parents whose testimony moved the world, but from the hospital and the courts too, as well as public opinion. His case divided us because we cared enough to want to save him, or to want him to avoid unnecessary suffering."[17]

Similarly, Gnaegi Center for Health Care Ethics Professor Tobias Winright wrote, "In a way Charlie 'belonged' to all of us, if such a word is even apt, for we are all called to be each other's 'keepers.'"[18]

The general consensus is that Charlie's life had the same worth as anyone else's,[19] as evidenced in Pope Francis' remark that human life must be defended especially "when it is wounded by illness." A Vatican spokesman told Vatican Radio that the Pope had been following Charlie's case "with affection and sadness,"[20] desiring to "accompany" Charlie's parents through a very difficult time. Archbishop Vincenzo Paglia, president of the Pontifical Academy for Life, supported the right of Charlie's parents "to care for him right up to the end," while wisely adding that it is also necessary to "accept the limits of medicine."[21]

Charlie was baptized on July 24, 2017. He was moved to a neonatal hospice on July 27, and he died there the same day. His parents took his body home briefly for private grieving, and they have established a charity to help other children with Charlie's condition.

Pope Francis asked for prayers that Charlie's parents find God's consolation and love.[22] Hopefully, everyone has.

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NOTES

1. Charles Bouchard, "Heartbreaking Cases Test Ethics and Public Policy," *Health Progress* 98, no. 5 (Septem-

ber-October 2017): 68-70.

2. At the time of Charlie's death, it was believed that only 16 children globally had this condition.

3. Kenan Malik, "Charlie Reveals Our Moral Muddle," *New York Times*, July 20, 2017, A23.

4. Lisa Fullam, "Updated: The Best for Charlie," *Commonweal*, July 12, 2017, www.commonwealmagazine.org/updated-best-charlie.

5. Alice Park, "When Parents and Doctors Disagree on what Futile Means," *Time Magazine*, July 24, 2017, 18.

6. www.theguardian.com/uk-news/2017/jul/25/michio-hirano-us-doctor-intervention-charlie-gard-case-raises-ethical-questions.

7. Charles C. Camosy, "Learning from Charlie Gard," *First Things*, August 3, 2017, www.firstthings.com/web-exclusives/2017/08/learning-from-charlie-gard.

8. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed., no. 25. There are many Catholic documents that support the right of parents as "primordial" in the care of their children, e.g., "Moral Reflections on Vaccines…," Pontifical Academy for Life (2005).

9. *Catechism of the Catholic Church*, no. 2221. Also, in its 2000 *Troxel v. Granville* decision, the U.S. Supreme Court stated that parents have a "fundamental right" regarding decisions about their children. See also John Paul II, *Familiaris Consortio*, (Nov. 22, 1981), no. 36.

10. Tobias Winright, "On Charlie Gard," *Health Care Ethics USA* 25, no. 3, (Summer 2017): 1-11. Winright offers an invaluable and thorough assessment of many of the moral analyses proposed.

11. Michael Sean Winters, "Let Charlie Gard Live," blog post, July 5, 2017, www.ncronline.org/print/blogs/distinctly-catholic/let-charlie-gard-live.

12. Jana Bennett, "Charlie Gard: A Story of Disability Bias," *America* 217, no. 3 (Aug. 7, 2017). https://americamagazine.org/politics-society/2017/07/07/charlie-gard-story-disability-bias.

13. Fullam, "Updated: The Best for Charlie."

14. *Ethical and Religious Directives*, nos. 56, 57.

15. John Paul II, *Evangelium Vitae*, no. 65.

16. *Evangelium Vitae*, no. 65.

17. Austen Ivereigh, "Doctors, Courts Not the Enemy in the Charlie Gard Case," *Crux*, July 6, 2017. https://cruxnow.com/commentary/2017/07/06/doctors-courts-not-enemy-charlie-gard-case/.

18. Winright, 9.

19. Bernadette Tobin, "The Fight over Charlie Gard: We Can Evaluate His Treatment, Not His Life," *ABC Religion and Ethics*, July 14, 2017. Tobin, director of the Plunkett Centre in Australia, stressed this point: Regardless of a person's age, mental ability, race, etc., the dignity of human life demands "equality" for all human beings. www.abc.net.au/religion/articles/2017/07/14/4702035.htm.

20. Ines San Martin, *Crux*, "Pope Francis Backs Parents in UK's Charlie Gard Drama," July 2, 2017. https://cruxnow.com/vatican/2017/07/02/pope-francis-backs-parents-uks-charlie-gard-drama/.

21. Vincenzo Paglia, "The Case of Charlie Gard," *Pontifical Academy for Life* website, www.academiavita.org/_articles/2019945661-comunication_case_charlie_gard.php.

22. Greg Burke, "Declaration of the Director of the Holy See Press Office," July 24, 2017. https://press.vatican.va/content/salastampa/en/bollettino/pubblico/2017/07/24/170724a.html.

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