

On Charlie Gard

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Eleven-month-old Charlie Gard was the subject of international news through much of the summer of 2017. In addition to receiving attention from Pope Francis, President Donald Trump, and Vice President Mike Pence, a number of Catholic ethicists weighed in—with some drawing different conclusions—on what, morally, ought to be done in this truly tragic case. In what follows, I provide a “moral note” that highlights some of these analyses and the questions they raised. I also offer some of my own commentary throughout this overview and in its conclusion.

The first question for ethics, as H. Richard Niebuhr famously taught, to be asked is, “What is going on?”¹ Hence, Lisa Fullam of the Jesuit School of Theology at Berkeley

prefaced her thoughtful and nuanced article in *Commonweal*, “before the moral question can be addressed, the medical condition can use some explication.”² And in an article for *America*, Michael Redinger, who is a psychiatrist and medical ethicist at the Western Michigan University Homer Stryker MD School of Medicine, similarly wrote, “In my profession it is often said that good medical facts precede good ethics.”³

Charlie was diagnosed with encephalomyopathic mitochondrial DNA depletion syndrome (MDDS), with a mutation in his RRM2B gene. It is an extremely rare genetic condition for which there is no cure. As of 2013, fifteen infants have been diagnosed with RRM2B mutations. Severe multi-organ symptoms

are the result, and those born with this condition die, as Fullam notes, “in early childhood at the latest.” Charlie suffered persistent seizures, was deaf, had muscle weakness, and depended on a ventilator for breathing. He was in the neonatal intensive care unit at London’s Great Ormond Street Hospital (GOSH). According to his attending physicians, Charlie had suffered from irreversible brain damage, keeping him on life support to assist his breathing only prolonged and increased his pain and suffering, and he was in the “terminal stages” of the disease. Therefore, they decided it was in Charlie’s “best interest” that the ventilator should be withdrawn and that he should receive palliative care and be allowed to die.

His parents, Connie Yates and Chris Gard, upon finding out about a possible experimental treatment—a nucleoside therapy—appealed the hospital’s decision and requested permission from a High Court judge to be allowed instead to remove him from the hospital in order to take him to New York City for that treatment. However, the High Court, and then the Court of Appeal and the Supreme Court, each agreed with the GOSH physicians’ recommendation. The European Court of

Human Rights judges were also unpersuaded to intervene by his parents. Still, he had another brain scan at GOSH to help determine whether he could receive experimental therapy.⁴ Columbia University neurosurgery professor Michio Hirano, who flew to the UK hospital, studied the scan in order to determine whether Charlie could benefit from the treatment. Hirano had testified that there was approximately a 10 percent chance that Charlie would respond to this treatment. He had also been provided access to all of Charlie’s records and was given an opportunity to examine him. Hirano, another international expert, and the GOSH team caring for Charlie met for several hours, to determine whether he should be permitted to travel to the U.S. for treatment. The judge from the High Court held further hearings in order to render another decision on July 27th, wherein Charlie was to be transferred to a hospice and have life support withdrawn. On July 18th the U.S. Congress granted Charlie permanent resident status in order for him to be flown to New York to undergo a therapy trial overseen by Hirano.⁵ However, Charlie’s parents came to the realization that his condition had deteriorated to the point that the experimental treatment had no

reasonable chance of success. Charlie passed away on July 28th.

According to Fullam, “The central moral question in light of Catholic medical ethics is whether treatment offers hope of benefit that is proportionate to whatever suffering Charlie is capable of experiencing and would experience with further treatment.” None of the Catholic moralists whose pieces I consider here disagreed about this being a pivotal question. The University of Dayton’s Jana Bennett, who will part ways from Fullam regarding the answer, nevertheless similarly began her article in *America* with “the Catholic Church’s distinction between ordinary means and extraordinary means of prolong life and seeking treatment,” quoting St. John Paul II’s words in *Evangelium Vitae*: “It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death” (no. 65).⁶ So, while Catholic theological ethicists shared this as a moral framework for thinking through this case, they did differ on the conclusion to which it led them. Other moral questions, too, were

raised in a number of these moralists’ essays that are viewed as significant if not “central.”

On the first question—about the traditional distinction between “ordinary” and “extraordinary”—Fullam noted that these “do not refer to the degree of novelty or technological complexity of a medical intervention.” A ventilator, for example, can be either, depending on the patient’s circumstances. She wrote, “Ordinary treatments hold the reasonable prospect of proportionate benefit and are morally indicated, while extraordinary treatments hold no such promise and may be discontinued.” This distinction applies not only when deciding whether to forego a specific treatment, but also when deciding to discontinue one. Fullam added, “If continuing a medical treatment causes or prolongs suffering that is disproportionate to the benefit that the patient will likely gain from that treatment, then it is extraordinary” and may be discontinued.

Accordingly, Fullam referred to the medical team’s reports that Charlie was “essentially nonresponsive, except to painful stimuli,” and she observed that he was “not expected to recover the ability to breathe without a ventilator and will likely need tube-feeding

permanently. His apparent reaction to painful stimuli makes it likely that medical interventions such as suctioning his airway would cause him pain. The nucleoside therapy has few side effects beyond the possibility of diarrhea. While his decline might be slowed by the projected treatment, the damage to his brain is permanent.” Fullam thus concluded that “Charlie’s existence seems to consist principally of experiencing pain, even if dimly.” She added that, while most of us “are capable of interpreting pain and suffering in ways that can make it meaningful,” Charlie’s case was different in that he “cannot comprehend a greater good or reason for [his] pain, but can only experience it.” In her view, Charlie’s suffering was disproportionate to the unlikely benefits that nucleoside therapy might provide. Her answer to the question, then, was: “Continuing treatments that extend his pain without prospect of proportionate benefit also delay his entering into the next life, where mitochondria don’t matter, and where every tear will be wiped away—and don’t we all want what’s best for Charlie?”

In a press statement, the Anscombe Bioethics Centre in Oxford concurred that this conclusion is “morally defensible.”⁷ In its view, “The statements that ventilation could itself be causing suffering and that it was producing only a poor ‘quality of life’ (i.e. state of health and well-being) together constitute an argument about whether this particular treatment is worthwhile.” This mode of reasoning is “ethically defensible” from a Catholic standpoint, although argument may exist—as it has—about the conclusion.

Similarly, Redinger wrote that “the proper application of Catholic moral reasoning could be seen to ultimately support the...final decision to withdraw life support.” In his view, the likelihood of any benefit from the experimental treatment was so “remote” that it would be “futile or, more accurately, ‘nonbeneficial’....”

In the above considerations, a few ethicists also commented on two important theological points. As the statement from the Anscombe Bioethics Centre framed it, “There are two things that need to be kept in mind in end of life care: respecting life and accepting death.” On the one hand, human life is to be respected, regardless of a

person's age, mental ability, race, etc. As Bernadette Tobin, who is director of the Plunkett Centre for Ethics in Australia, observed, "Charlie's life has the same worth as does anyone else's life—that is what we mean by the *equality* of all human beings."⁸ Yet, life is not an absolute good, to be preserved at all costs. Otherwise there wouldn't be martyrs. On the other hand, death is an evil to be avoided and resisted. Yet, from a Christian perspective anchored in belief in the resurrection of the dead, it is not an absolute evil, so at some point it may be accepted. With this in mind, a number of these ethicists expressed concerns about a "technocratic paradigm" that fuels vitalists' striving to use every means possible to preserve life. Though not accusing Charlie's parents of having "that mentality," London-based Catholic journalist Austen Ivereigh at *CRUX* wrote, "Because the means exist doesn't mean we should reach for them. We must discern—in this case, what is in the best interests of a vulnerable baby."⁹

A second question that some Catholic moralists asked was whether Charlie's attending team of health care professionals and the courts viewed his life, itself, as a "burden" that's not "worthwhile." As Tobin wrote, "What doctors have to evaluate is not

Charlie's *life*, but medical *treatments* available to him." In other words, which medical treatment is in Charlie's best interests? Tobin was open to the possibility that "the burdens of a proposed treatment are likely [to] outweigh the benefits it promises," even though she was not convinced that this was the case. Fordham University's Charlie Camosy, in an article appearing at *CRUX*, believed that GOSH's "decision is a classic example of Pope Francis's now-famous image of 'the throwaway culture.'"¹⁰ In Camosy's view, if Charlie "had the right kind of mental capacities," he wouldn't "be discarded" like GOSH and the courts had decided—moreover, Camosy averred "that the UK government is aiming at his death." If so, the intent in GOSH's withdrawing of the ventilator, he opined, "is, in fact, euthanasia," which is "an act or omission which by intention causes death." As a test of whether this is the case, Camosy added, "Suppose, for instance, that when Charlie is taken off of life support he actually continues to breathe on his own and refuses to die. Will those who made the decision be pleased with this outcome? Of course not."

For her part, Fullam took issue with those who alleged that the medical personnel

involved in this case exhibited a “disregard for the human dignity of people with disabilities...” In her view, the staff at GOSH were not “life-denying monsters” but “professionals who have devoted their lives to the care of sick children.” Again, she believed that “we all want what’s best for Charlie” even though there’s disagreement about what’s “best.” In another article at *CRUX*, Ivereigh wrote similarly about Charlie and his case:

He elicited great love: Not just from his extraordinary parents whose testimony has 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.¹¹

I would add that we should be careful about interpreting intent. In Ivereigh’s view, Camosy’s claim about the physicians’ intent is “astonishing.” I can imagine that the medical staff members who made the decision were not “pleased” one way or the other. If Charlie continued to breathe, I suspect they would have continued to provide care for him, perhaps with hope, but also probably with deep concern about

minimizing his pain and suffering. I say this even as I share Camosy’s concern about a “throwaway” mentality widespread today as evinced, for example, in the Netherlands. Still, as Ivereigh saw it, “The aim throughout this tragic case has never been the death of a child, but the defense of his best interests as a sick baby.” And, according to David Albert Jones, who is the director of the Anscombe Bioethics Centre, in an article at the *National Catholic Register*, “Note that the issue was not about whether Charlie was a human being worthy of respect. The question was, rather, what treatments would be in Charlie’s best interest, given his present condition and the likely benefits and burdens of treatment.”¹²

Similarly, Bennett worried that the “focus of the court’s documents is not on Charlie’s imminent death, but on his brain function.” If so, it would be a reflection of “our own societal failure to accept people with mental disabilities.” She noted John Paul II’s concern in *Evangelium Vitae* about prenatal diagnostic techniques that encourage selective abortion of babies who may have disabilities: “Such an attitude is shameful and utterly reprehensible, since it presumes to measure the value of a human life only within the parameters of ‘normality’ and

physical well-being, thus opening the way to legitimizing infanticide and euthanasia as well” (no. 63). Bennett believed that the current understanding of brain health and mental well-being in Western society “is limited and involves more questions than answers.” She urged Christians “to push against the subtle (and apparently well-meaning) bias perpetuated about disabilities,” and she concluded that Christians should “support Charlie and his parents in their desire to seek further treatment.”

So too did the Anscombe Centre express worry about the “opinions...also cited in court that seem to refer not to the worthwhileness of *treatment* but to the worthwhileness of Charlie’s *life*.” In its statement, the Centre conjectured that, charitably interpreted, “these are muddled ways of referring to the limited benefits of treatment relative to the burdens,” but it added that it is possible that the other interpretation of such comments, like what we’ve seen above from Camosy and Bennett, may be onto something. That is, if those words truly “express a judgement that life with some disabilities is not worth living at all,” then such a viewpoint “should be repudiated firmly.”

A third question that Catholic moralists raised had to do with who decides what ought to be done for children in a case such as Charlie’s. My colleague, the Orthodox Christian philosopher, bioethicist, and physician, Jeffrey P. Bishop, wrote: “The medical practitioners at Great Ormond Street Hospital have drawn a bright line on the floor, suggesting that they not only know what is good for Charlie, they know what is best for Charlie. He is ‘better off dead’ than alive in this condition. Whereas, for Charlie’s parents, life can be good, even while on a ventilator, and even if Charlie may only achieve a minimal of sentience or awareness of their love.”¹³ What we have here, he observed, is a “contest of goods” that problematically arises in Western political and economic liberalism and “the illusion that somehow the state is capable of setting out laws, procedures, policies and institutions that are agnostic about the good, or the good life for individuals, and that the state is neutral when it comes to goods.” Bishop rejected the bifurcation of facts and values that Camosy employed, and instead argued that medicine “is always already a moral endeavour and its knowledges and practices are always aimed at some notion of the good, even if only because the desire to

heal - to do good - guides the kind of scientific questions that are asked.” Nevertheless, Bishop seemed to side more with the parents: “What goods are possible in Charlie's case? Well, his parents think that his life is a good, even if there might be burdens for Charlie. If the experimental treatments work, and if they can treat his seizures, and if they can get him off the ventilator, he might be able to enjoy life. Each one of these facts have (sic) some possibility of success, and together could enable a myriad of other goods. Or perhaps they want to continue to show him love in just trying. After all, it is a good thing for parents to fight for their children in the face of what appears to them to be a grave injustice. Their way of being a family is a good way of being a family.”

As for Fullam on this question, “Ordinarily, parents are the surrogates for their children, making medical decisions for them in light of the child’s best interest.” Tobin agreed that, “[g]enerally speaking, parents bear the often-onerous responsibility of making decisions about the welfare of their children and, in particular, of authorizing medical treatment.” So, too, Camosy wrote that “Catholic moral theology generally lets those closest to the goods in question decide how

to weigh them,... [and in] this case, those closest to the goods involved are obviously the parents.” Of course, his qualifier “generally” is significant. Usually parents and medical practitioners agree; however, occasionally hospital staff may think that parents are wrong, as in this heart-rending case. As Tobin put it, “But if doctors think that parents are making a serious mistake, seeking either over-treatment or under-treatment, then they have a responsibility sensitively to try to convince the parents of that, and, if necessary, to involve a court.” In the view of the Anscombe Centre, the UK courts may have “treated Charlie as if he had not parents or as if his parents had already been shown to be acting in a very unreasonable, albeit well-meaning way.” The Centre’s director, Jones, devoted more attention to this concern, and added, “Regrettably, the Court of Appeal did not consider the reasonableness of the parents’ decision, but made its own independent assessment on the balance of the advantages and disadvantages of the medical steps under consideration,” thereby treating “Charlie as if he had no parents and Charlie’s parents as though they had no natural authority to speak for their own child.”

In another article, appearing in *The Washington Post*, Camosy warned that physicians “regularly make profound mistakes,” noting that “the third-leading cause of death in the United States is medical error.”¹⁴ Not only do they commit errors when making a diagnosis or a prognosis, physicians “rarely have serious training in ethics.” When rating the quality of life of their disabled patients, physicians give them lower marks than what the patients themselves do. Given all of this, Camosy held that the ones who are “qualified—indeed, entitled—to make decisions for a person such as Charlie” were the parents. Still, I would note that while this should be the presumption, it is also the case that parents make mistakes and often lack “serious training in ethics.”

As one of my teachers, Stanley Hauerwas, has asked in his important book, *Suffering Presence*, “Why do we think the family should have such high moral status or why should parents make the basic decisions concerning the care of their children?”¹⁵ Hauerwas thinks such questions lack “rigorous investigation,” and he opines that what is important is not that the parents conceived the child, nor that they possess the material resources to raise it, but rather

“whether they have the moral resources for such a task.”¹⁶ And he is hesitant to assume that this is the case.

For Hauerwas, what is needed is a community of virtue, namely, the church, which consists of many parents and physicians and others, but which can train them (and us) to be, as the title of this particular book by him has it, a “suffering presence” for one another, especially those who are vulnerable and in need, including mentally disabled children and the dying. Ivereigh and others rightly highlighted Pope Francis’ (and Archbishop Peter Smith’s and the Pontifical Academy for Life’s) emphasis to Charlie’s parents that the church is “with them, praying for them, and insisting they had the right to care for him right up to the end.”¹⁷

In his *First Things* reflection following Charlie’s death, Camosy wrote, “Charlie does not belong to his physicians. He belongs to his parents. And they to him.” While true, 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,” a “responsibility which every person has towards others,” as Saint John Paul II wrote in *Evangelium Vitae* (no. 8). Charlie’s baptism into the family that we call church

committed us all to care for him, and it reminds us that he ultimately belongs to God. May Charlie Gard rest in peace.

¹ H. Richard Niebuhr, *The Responsible Self: An Essay in Christian Moral Philosophy* (New York: Harper and Row, 1963), 60.

² Lisa Fullam, “Updated: The Best for Charlie, What the Catholic Moral Tradition Has to Say,” *Commonweal* (July 12, 2017), <https://www.commonwealmagazine.org/updated-best-charlie>.

³ Michael Redinger, “What Some Pro-lifers Have Overlooked in the Case of Charlie Gard,” *America* (July 5, 2017): <https://www.americamagazine.org/politics-society/2017/07/05/what-some-pro-lifers-have-overlooked-case-charlie-gard>.

⁴ <https://www.thesun.co.uk/news/4041768/charlie-gard-latest-news-parents-talks-experts-great-ormond-street-hospital/>

⁵ <http://www.telegraph.co.uk/news/2017/07/19/charlie-gard-granted-permanent-resident-status-us-can-get-medical/>

⁶ Jana Bennett, “Charlie Gard: A Story of Disability Bias,” *America* (July 7, 2017): <https://www.americamagazine.org/politics-society/2017/07/07/charlie-gard-story-disability-bias>.

⁷ <http://www.bioethics.org.uk/images/user/charliegardstatement.pdf>

⁸ Bernadette Tobin, “The Fight over Charlie Gard: We Can Evaluate His Treatment, Not His Life,” *ABC Religion and Ethics* (July 14, 2017): <http://www.abc.net.au/religion/articles/2017/07/14/4702035.htm>.

⁹ 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/>.

¹⁰ Charlie Camosy, “On the Charlie Gard Case, the Church Needs to be Clear and Prophetic,” *CRUX* (July 3, 2017):

<https://cruxnow.com/commentary/2017/07/03/charlie-gard-case-church-needs-clear-prophetic/>. Camosy makes the same points in Charles C. Camosy, “Learning from Charlie Gard,” *First Things* (August 3, 2017): <https://www.firstthings.com/web-exclusives/2017/08/learning-from-charlie-gard>.

In agreement with Camosy, see Michael Sean Winters, “Let Charlie Gard Live!” *National Catholic Reporter* (July 5, 2017):

<https://www.ncronline.org/blogs/distinctly-catholic/let-charlie-gard-live>.

¹¹ Austen Ivereigh, “Is British or American view of Charlie Gard Tragedy More Catholic?” *CRUX* (July 25, 2017):

<https://cruxnow.com/commentary/2017/07/25/british-american-view-charlie-gard-tragedy-catholic/>.

¹² David Albert Jones, “Who Guards the Gards?” *National Catholic Register* (July 11, 2017):

<http://www.ncregister.com/daily-news/who-guards-the-gards>.

¹³ Jeffrey P. Bishop, “Charlie Gard and the Goods of Medicine,” *ABC Religion and Ethics* (July 17, 2017): <http://www.abc.net.au/religion/articles/2017/07/17/4703291.htm>.

¹⁴ Charlie Camosy, “Who Gets to Decide if Charlie Gard’s Life Is Worth Living? It Shouldn’t Be His doctors,” *The Washington Post* (July 13, 2017): https://www.washingtonpost.com/news/posteverything/wp/2017/07/13/who-gets-to-decide-if-charlie-gards-life-is-worth-living-it-shouldnt-be-his-doctors/?utm_term=.958ae0aa73bb. Camosy raises this concern again in his *First Things* piece,

“Learning from Charlie Gard.” On this question, Wesley J. Smith goes to the extreme in claiming, “The refusal to allow Charlie’s parents to remove their baby boy from the hospital is an act of bioethical aggression that will extend futile-care controversies, creating a duty to die at the time and place of doctors’ choosing.” Wesley J. Smith, “Whose Baby Is Charlie Gard, Anyway?” *First Things* (July 4, 2017): <https://www.firstthings.com/web-exclusives/2017/07/whose-baby-is-charlie-gard-anyway>.

¹⁵ Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame, IN: University of Notre Dame Press, 1986), 190.

¹⁶ Ibid.

¹⁷ Ivereigh, “Doctors, courts not the enemy in the Charlie Gard case.” For the statement from the Vatican’s Pontifical Academy for Life, see http://en.radiovaticana.va/news/2017/06/29/vaticans_academy_for_life_issues_statement_on_charlie_gard/1322138. A report on Pope Francis’s tweet about Charlie Gard is available at <https://cruxnow.com/vatican/2017/07/02/pope-francis-backs-parents-uks-charlie-gard-drama/>. The statement by Archbishop Peter Smith is available at <http://www.catholicnews.org.uk/Home/News/Charlie-Gard>. Another brief overview of the Charlie Gard case is provided by Catherine Pepinster, “Charlie Gard Dies After Sparking a Global Debate on the Ethics of Life and Death,” *Religion News Service* (July 28, 2017): <http://religionnews.com/2017/07/28/charlie-gard-dies-after-sparking-a-global-debate-on-the-ethics-of-life-and-death/>.