

ISSUES IN PERSPECTIVE

Dr. James P. Eckman, President Emeritus
Grace University, Omaha, Nebraska
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Thinking Biblically about Charlie Gard

The case of 11-month old Charlie Gard of the United Kingdom has been heart-wrenching. It also raises a number of profound ethical questions. Charlie was born with a pair of genetic mutations that depleted his body of mitochondria, the minute structures that produce energy molecules that the body's cells need to live. As a result, he has suffered — according to the hospital — “catastrophic and irreversible brain damage.” He cannot breathe, he essentially cannot move, and he cannot hear. He has been kept alive by life support systems. His parents, Chris Gard and Connie Yates, have pinned their hopes on an experimental treatment called nucleoside therapy. An American neurologist, Michio Hirano, of Columbia University Medical Center, had offered to treat Charlie and his parents had raised about \$1.7 million to fly him to America and pay for his treatment. After his parents learned of the results of an MRI done in mid-July, this hope ended: It was “too late” for the experimental therapy that had been offered in the United States.

Charlie's case raises an important and fundamental issue about medical care in 2017. *Time* magazine capably summarizes the difference between the American model of care and the UK model: “In the US, such conflicts are generally resolved in favor of the parents. When doctors don't feel medically and ethically able to continue futile treatment of a child, they offer parents the opportunity to find other hospitals that would. ‘In the US we have created a culture where everybody should get whatever health care they want,’ says David Magnus, director of the Center for Biomedical Ethics at Stanford University. ‘As long as neither neglect nor abuse is involved, we give parents tremendous latitude in making decisions for their children.’ That's not the case in the UK, in large part because of the country's single-payer national health system. It's more routine for the medical community, and the courts, to make decisions about what's acceptable care, what's excessive care and even, as in Charlie's case, when care should stop.” Therefore, Charlie's case in the UK ended up in the courts. Judges, both in the UK and at the European Court of Human Rights, had sided with the doctors at the Great Ormond Street Hospital, who have argued that the life-support systems keeping Charlie alive should be turned off. The courts have decided that it is not in Charlie's “best interests” to receive further treatment and that he should be permitted to “die with dignity.” Dr. Hirano had maintained that there was a 10% chance of the treatment he offered succeeding in giving Charlie increased muscle strength and brain function. There is no evidence that Charlie is in pain nor that the treatment would have caused pain for Charlie. Since the court first heard the case, it has been six months, and, as mentioned above, it is now “too late” for any such experimental therapy for Charlie. Therefore, Charlie's parents have ended the fight for Charlie's life and desire to take him home, where he will die.

Ethicist Kenan Malik has written that “When it comes to considering the child’s ‘best interests,’ the choice in Charlie’s case is between a possible future and a definite non-future . . . in cases in which a person is unable to exercise autonomy, the state should acknowledge the difficulties in defining his best interest. It should also be particularly cautious about sanctioning death, especially when experts are divided and parents are opposed. It is a measure of our moral confusion that in Britain lawmakers and the courts have decided the very opposite.” Charlie’s case does indeed raise profoundly important ethical questions, which need to be surfaced and addressed:

- First of all, as Adam Gaffney of the Harvard Medical School and a pulmonary and critical care physician at the Cambridge Health Alliance clarifies, “The core principle around which so many of our bioethics debates revolve is autonomy, which is to say the sovereignty of the individual over his or her own body, the right to be at the center of all medical decisions. Paradoxically, however, the principle of autonomy is often of limited applicability in critical care, as during a moment of an overwhelming illness, many people are unable to engage in the complex, necessary discussions (in Charlie’s case, he is obviously also too young).” And therein rests the crux of the Charlie case: There was no consensus between family and physicians. His physicians have firmly and consistently held that his condition makes discontinuing life support the appropriate medical decision, and they have been supported in this by multiple court decisions. Frankly, the wishes and desires of his parents are irrelevant.
- Second, Ross Douthat is certainly correct when he argues that “The rights of parents are essential to a free society’s architecture, and fathers and mothers are far more likely than any other party to have their child’s best interest close to heart. To intervene on behalf of experts against family is sometimes necessary but always dangerous, fraught with totalitarian temptations to which the modern West is not immune.” With the acceleration of medical technology and the growing assumption of medical costs by the government, situations similar to Charlie’s will grow. This harsh reality will produce two “temptations,” to use Douthat’s words:
 1. “To regard illness as a costly problem to be solved, not just by the limiting of possible treatments, but by the active hastening of death. That way lies assisted suicide and not-exactly-voluntary euthanasia, which are becoming mainstream in some of Britain’s nearest neighbors, and whose long shadow darkens the Charlie Gard debate.”
 2. “The second institutional temptation is not toward active wickedness but toward sclerosis, groupthink and stagnation. Establish an iron triangle of doctors, insurers and government boards, tell them they must establish predictable standards for what treatments will be covered, and they will inevitably resist many of the experiments through which medical progress advances.” Charles Krauthammer correctly warns that “In countries where taxpayers bear the burden of expensive treatments, the state has an inherent incentive (of which Britain’s National Health Service has produced notorious cases) to deny treatment for reasons of economy rather than mercy.”

The case of Charlie Gard brings us back to two essential biblical principles:

1. First, humans are created in the image of God. That basic proposition is the beginning point for thinking about Charlie. That is what gives Charlie meaning and value—he bears God’s image. It is always proper and ethically right to fight for life, because men and women are created in the image and likeness of God (Genesis 1:26-27). Human life is sacred (Genesis 9:1-6) and no one should be demeaned or cursed (James 3:9-10). To treat a human, who bears God’s image, in an undignified manner, to wantonly destroy life or to assume the position of authority over the life and death of another human, is to step outside of God’s revelation. The Bible affirms the intrinsic worth and equal value of every human life regardless of its stage or condition.
2. Second, there is nothing more devastating than a miscarriage, the death of a newborn, or the tragedy of an infant death. Over the years of my academic and church ministry, I have been frequently asked, “What happened to my child who died so young? Is my child with Jesus?” Part of the challenge in responding is that the Scriptures give us no direct answer. To provide an answer to such heart-wrenching questions, let’s review the character of God, the finished work of Jesus and the condition of lost humanity. Many expositors and theologians have attempted to provide the needed framework for giving comfort to grieving parents and family members, but none is more helpful than John MacArthur. He provides four biblical truths:
 - All children are conceived and born as sinners. Every human being inherits the guilt and corruption of Adam. When Adam sinned all humanity sinned (Romans 5:1-19; especially v. 12). Even King David affirms that he was “brought forth in iniquity, and in sin did my mother conceive me” (Psalm 51:5). Sin is not only what we do; it is what we are!
 - The salvation of humanity is a matter of God’s grace, not human works. The salvation of every person is initiated by God and is His sovereign choice, through grace, based upon no merit whatsoever in the individual sinner. MacArthur argues that “Salvation is all by grace. There is no clearer manifestation of this truth than the gift of eternal life to a helpless, lost infant. The saving grace given to an infant who has no part whatsoever in his salvation is a perfect example of salvation, which is always wrought sovereignly by God through grace.”
 - Salvation is through the sacrificial work of Jesus Christ on the cross—the supreme manifestation of God’s grace. Infants have no merit by which anyone could ever claim they deserve heaven, but the infant’s salvation is paid for by the substitutionary sacrifice of Christ on the cross.
 - Scripture teaches that salvation is by grace, but judgment and damnation are by works. Willful, rebellious sin is the basis for God’s judgment. This is clear in the passage describing the Great White Throne judgment (Revelation 20:11-15): Eternal condemnation is connected with willful sin. But,

1. Little children have no willful rebellion or unbelief.
2. Little children are incapable of suppressing the truth about God as Paul details in Romans 1:18. God's clear revelation to lost humanity is through His creation, through conscience and through His moral law (see Romans 1:18—3:20). Small infants are simply incapable of understanding, let alone suppressing such revelation.
3. Little children cannot understand sin's impact or its consequences. Young children disobey, but children have "no understanding that rebellion, lying, stealing [etc.] are in violation of God's law and that such actions have any form of eternal consequence. Young children are incapable of understanding God in this way."
4. Little children have no ability to choose salvation. The Bible is crystal clear that the human being must appropriate by faith the finished work of Jesus Christ. An infant cannot possibly make such a conscious, willful decision of faith. Free moral agency does not characterize infant children.

MacArthur concludes that, "In no place does Scripture teach infant damnation. Rather, every biblical reference—whether oblique or direct—to the issue of infants and children who die gives us reason to believe they go immediately into the eternal presence of God."

God reveals Himself throughout Scripture as a God of grace. Indeed, Scripture speaks of God's common grace (toward all humanity), His saving grace in salvation (justification), and His sustaining grace in sanctification. The epitome of His grace is of course the cross and that grace covers the heart-wrenching questions associated with the death of an infant. That truth is a source of great comfort in the case of Charlie Gard.

See *Time* (24 July 2017), p. 18; Charles Krauthammer in the *Washington Post* (24 July 2017); Ross Douthat in the *New York Times* (23 July 2017); Adam Gaffney in the *Washington Post* (25 July 2017); Kenan Malik in the *New York Times* (20 July 2017); John MacArthur, *Safe in the Arms of God: Truth from Heaven about the Death of a Child*; and Robert P. Lightner, *Heaven for Those Who Can't Believe*.