

Moral Lessons from the Life of Alfie Evans: Two Ethical Perspectives

Editor's Note: Even though the Alfie Evans case has been resolved, the ethical issues that it raised are still very much alive. We present two different ethical analyses of this case. One is from Saint Louis University Professors Jason Eberl and Toby Winright, and the other is from Fr. Gerard Coleman, P.S.S. of the University of Santa Clara.

WHO WAS ALFIE EVANS?

Due to an unidentified degenerative condition, Alfie Evans (May 9, 2016 - April 28, 2018) was hospitalized continuously since December 2016 at the Alder Hey Children's Hospital in Liverpool, England. His physicians described his condition as a "semi-vegetative state," a relatively new category of disorder indicating that the patient has partial preservation of conscious awareness. This classification, also called a "minimally conscious state" (MCS), is a disorder of consciousness distinct from persistent vegetative state (PVS) which is characterized by absence of responsiveness and awareness due to overwhelming dysfunction of the cerebral hemispheres. A person in MCS sustains some interaction with the environment.¹ Alfie missed numerous developmental milestones as his condition lasted for 23 weeks. Alder Hey Children's Hospital said that Alfie had a "catastrophic and untreatable neurodegenerative condition..., his brain was corrupted by mitochondrial disease,"² and continued treatment was "futile."³

A decision by a British justice ordering that ventilation be discontinued was upheld by both the UK Court of Appeals and the Supreme Court. A three-judge panel of the European Court of Human Rights determined that there was no evident human rights violation and, thereby, ruled the case inadmissible.⁴

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Tobias Winright and Jason Eberl Respond

Here we are again. Less than a year after the plight of 11-month-old Charlie Gard and his parents generated international attention and divided opinions among Catholic ethicists,⁵ the parents of another child in the United Kingdom, 23-month-old Alfie Evans, were waging a legal battle against the physicians entrusted with his care over whether life-support should be continued.⁶ For more than a year, Alfie's respiration had been supported by mechanical ventilation, and his physicians viewed continued treatment to be "unkind and inhumane."

Alfie's parents disagreed with his physicians, contending that he was still responsive and that his condition was improving. They sought to have Alfie transferred to the Vatican's Bambino Gesù Pediatric Hospital in Rome, where the medical staff was willing to provide continued treatment. The Italian government even granted Alfie honorary citizenship to symbolize the country's willingness to receive and care for him. In the midst of their attempt to have Alfie released from Alder Hey and transferred to Bambino Gesù, his father, Thomas, traveled to Rome to appeal directly to Pope Francis for assistance and specifically asked for "asylum" for his family. Just a few days prior, the pope had publicly commented on Alfie's situation in his Sunday Angelus address but did not specify what he deemed the outcome should be. He described the case as "delicate ... very painful and complex." After meeting with Thomas Evans, Pope Francis was more specific, appealing via Twitter "that the suffering of [Alfie's] parents may be heard and that their desire to seek new forms of treatment may be granted."

Prelates in the UK also reflected different levels of moral specificity. One bishop tweeted, "If there is anything at all that can be done, may the Lord enable us by His love and grace to effect it". The Bishops' Conference of England and Wales offered a more general statement "that all those who are and have been taking the agonizing decisions regarding the care of Alfie Evans act with integrity and for Alfie's good as they see it."⁷

This moral imperative – to act with integrity for Alfie's good – is at the heart of the issue. Alfie's physicians do not appear to have been intentional violators of the Hippocratic Oath. They and the justices who supported their decision to discontinue life-support saw themselves as protecting Alfie's "best interests." Alfie's parents and their supporters viewed his continued life, no matter the degree of neurodegeneration he suffered, to be intrinsically valuable and worth safeguarding at all costs.

As with the case of Charlie Gard, Alfie's situation prompted strident responses from the pro-life community, some of whom styled themselves as "Alfie's Army," camping outside of Alder Hey and at one point attempting to storm the hospital.⁸ Both these activists and pro-life scholars viewed Alfie's plight as another example of a secular tendency to emphasize "quality of life" over the inherent dignity of each living human being, no matter their physical or cognitive status. Such is the perspective of Charles Camosy, associate professor of theology at Fordham University, who accuses physicians – and, particularly, acute care physicians such as those in charge of Alfie's care – of a "bias" towards valuing the lives of disabled patients less than disabled patients do themselves.⁹ Camosy rightly warns against a growing trend

of “systematic ableism,” particularly in Western nations, as evidenced by increasing abortion rates of fetuses diagnosed with Down Syndrome and legalized protocols for euthanizing children based on quality-of-life assessments in Belgium and the Netherlands. He calls for renewed Catholic opposition to this secular ethic analogous to the outspoken stance Clemens August von Galen of Munich and other German bishops took against the Nazi T4 euthanasia program, which led to a public outcry that contributed to the Nazis formally abolishing the program, although it still persisted in a more limited and secretive way and was a precursor to the large-scale systematic killings of the Holocaust.¹⁰

It is important to emphasize, contrary to one critic’s interpretation,¹¹ that Camosy’s reference to Catholic opposition to the Nazi euthanasia program does not necessarily support a claim that the physicians at Alder Hey promoting systematic euthanization of the disabled. Rather, it draws attention to an excessive emphasis on “quality of life” considerations and the imperative – particularly for Catholics – to witness against it. A key difference between the historical and contemporary examples is that while the Nazis were concerned about racial “purity” and ending the lives of those perceived as a “burden” upon society, those who favored discontinuing treatment for Alfie were concerned about the burden *for him*. Their primary, if not sole, concern was whether allowing his continued neurodegeneration would cause undue pain and suffering *to him*, as opposed to focusing on any putative costs of his continued support to society. Justice Anthony Hayden, whose initial judgment determined the outcome of the case, affirmed that his concern was Alfie’s “poor quality of life,” defined in terms of what

levels of pain or suffering he may have been experiencing:

It is my opinion (and that of my intensive care consultant colleagues), that Alfie has a poor quality of life. He is completely dependent on mechanical ventilation to preserve his life. He has no spontaneous movements, cannot communicate and continues to have frequent seizures. I believe that it is unlikely that Alfie feels pain or has sensation of discomfort but I cannot be completely certain of this since Alfie has no way of communicating... given Alfie’s very poor prognosis with no possible curative treatment and no prospect of recovery the continuation of active intensive care treatment is futile and may well be causing him distress and suffering. It is therefore my opinion that it is not in Alfie’s best interests to further prolong the current invasive treatment. It would, in my opinion, be appropriate to withdraw intensive care support and provide palliative care for Alfie for the remainder of his life.¹²

Justice Hayden’s assessment is a far cry from the Nazi determination of *Lebensunwertes lebens* (“life unworthy of life”).¹³ What is more, he mentions “distress and suffering” that continued treatment may have been causing Alfie, a rationale consistent with Catholic moral teaching on burdens and

benefits; he also cites Alfie’s overall disabled condition by referring to his dependence on mechanical ventilation, lack of spontaneous movements, inability to communicate, and frequent seizures.

As Udo Schuklenk, Camosy’s above-noted critic, points out, “well-meaning people could hold different views on cases like this.” For instance, one could argue that, if Alfie’s parents or other supporters were willing to pay for continued care for him, even if it offered no reasonable expectation of improving Alfie’s overall condition, then they should have been allowed to do so.

This brings us to the central point of debate among Catholic ethicists: whether continued life-support or other forms of treatment for Alfie would constitute a burden on him disproportionate to the reasonably expected benefits of such treatment. We have now moved beyond the “culture war” question of quality-of-life versus the intrinsic dignity of disabled persons to the more pragmatic question of whether continued treatment offered Alfie any hope of recovery, or at least continued life, without introducing undue pain and suffering. This is the crux of the Catholic tradition’s well-known distinction between morally obligatory (“ordinary”) and morally optional (“extraordinary”) forms of treatment.¹⁴ It is the point upon which Catholic ethicists have reasonably disagreed about both the Charlie Gard and the present case, as well as others involving the care of critically ill newborns and babies.¹⁵

For Jesuit ethicists Kevin Wildes, president of Loyola University – New Orleans, and John Paris, Michael P. Walsh Professor of Bioethics Emeritus at Boston College, the question comes down to the effectiveness of continued treatment, not only in sustaining

Alfie’s continued life, but also in securing any reasonable hope of recovery from his neurodegenerative condition.¹⁶ Noteworthy for their analysis is the fact that a February 2018 MRI scan showed “the almost total destruction of his brain.”

While Catholic philosophical anthropology, following St. Thomas Aquinas, holds that one’s self-conscious, intellectual functioning is inherently immaterial, the actualization of such functioning exists in the brain during one’s embodied life.¹⁷ We can thus conclude that Alfie had the capacity for such intellectual functioning because his body continued to be informed by his rational soul, but that this capacity was irreversibly precluded from further actualization in this life due to the material deficiencies of his brain.¹⁸ That Alfie remained a *human person* until he succumbed to bodily death on April 28, 2018, is unquestionable within the Catholic anthropological framework. Whether the condition leading up to his death held any hope of recovery – *spes salutis* – is open to question, and even doubtful. This is the basis of Wildes’s and Paris’s assessment that continued support for Alfie constituted *extraordinary* – i.e., morally optional – care. Furthermore, if Alfie had maintained some degree of sentient awareness – and thus potentially “could suffer increased seizures in transit [to Bambino Gesù] which have the potential to cause further brain damage, together with ... pain and discomfort” – then continued treatment could certainly have been construed as *disproportionately burdensome* to him and therefore extraordinary.

Another pertinent question is whether Alfie – if allowed to continue living at Alder Hey or to be transferred to Bambino Gesù – would potentially have benefited from *experimental*

treatments. Unlike Charlie Gard, for whose diagnosed condition there was initially an experimental treatment available -- the unknown etiology of Alfie's neurodegeneration meant that there was no available experimental treatment that might have improved his condition. Furthermore, the nature of any such possible intervention as "experimental" would render it inherently *extraordinary*. This raises questions about a document issued by Bambino Gesù entitled, "Charter for the Rights of Incurable Children" that includes, among its ten points, a right to "the best experimental cures."¹⁹ While parents and medical staff certainly have the right to attempt experimental treatments for severely disabled children, it is not morally *required* of them to do so; in other words, a child does not have a *right* to an experimental treatment that is deemed to be either medically futile, disproportionately burdensome, or inordinately expensive -- as Wildes, Paris, and Camosy all acknowledge.²⁰

Of course, a key question has to do with *who decides*. As ethicist Michael Panicola notes, parents have the most at stake and are usually motivated by love for their offspring. They want what is best for them. At the same time, they might not understand well the medical considerations, and they might be subjectively "too involved emotionally to make reasonable decisions."²¹ Medical professionals possess experience and knowledge and may be less emotionally involved and more objective, but they too are human, have feelings, and make decisions through a moral lens whether they realize it or not. No facts, including medical ones, are self-interpreting. As for the courts, although "their judgment would be, for the most part, objective and not rushed," they may be "too distant from the situation and may not be able to respond as quickly as is required for

the well-being of the newborn and others."²² As we have noted elsewhere, in cases such as Charlie Gard's, both parents and medical professionals can make mistakes.²³ Courts, too. In the end, even though it is not absolute, priority should arguably be given to the parents.

As Stanley Hauerwas notes -- the Alfie Evanses and Charlie Gards, their families and their caregivers -- need the accompaniment of a committed community of virtue, namely, the Church, as a "suffering presence" especially for the disabled children and the dying.²⁴ It might even require a *silent solidarity* and, whatever happens, definitely entails *faithful follow up* with the family.²⁵

Fr. Gerard Coleman Responds

Two recent commentaries bring sharp and contrasting focus to the case of Alfie Evans. The international Catholic weekly *The Tablet* editorialized, "Sometimes the point is reached when further medical intervention, even if it might prolong the life of the patient, becomes disproportionate to any possible benefit. There is no legal or moral obligation to keep a patient alive by extraordinary means, when all hope is gone and treatment is becoming overly burdensome. But knowing when that point has been reached sometimes requires an unbearably difficult judgment."²⁶

In America's leading conservative magazine *National Review*, Wesley J. Smith opined that Alfie was "forced off life support by doctors, bioethicists, and judges and denied the right to have care decisions made by his parents... If Alfie had been a royal baby, ...he'd still be on life support if that was what his parents wanted. It is remarkable that bioethicists and health-care honchos feel the

need to push the relatively few dissenters out of the lifeboat.”²⁷

Two critical issues are at stake: when is treatment no longer beneficial, and what rights do parents have in making treatment decisions for their children?

Involvement of The Courts

Knowing of no effective therapy for this deteriorating neurological condition, Alfie’s physicians recommended ending treatment, while accompanying him with palliative and compassionate care. In maintaining this, they followed the teaching of the treatise in the Hippocratic Corpus entitled *The Art*. There, medicine is defined as having three roles: doing away with the sufferings of the sick, lessening the violence of their diseases, and refusing to treat those who are overmastered by their disease, realizing that in such a case medicine is powerless.

For months, his parents, Thomas Evans and Kate James, both in their early twenties, had been locked in a legal battle with United Kingdom (UK) courts that ending treatment was not in Alfie’s best interest. As in the Charlie Gard case,²⁸ the family lost their appeals at all levels including the Court of Appeals, the Supreme Court, and the European Court of Human Rights.

Mr. Justice Anthony Hayden of the High Court of England and Wales endorsed an end-of-life-plan for Alfie drawn up by hospital specialists. He described Alfie as “a much-loved little boy”²⁹ but accepted the medical judgment that further treatment was not in Alfie’s best interest. Hayden wrote that his legal opinions represented “a consensus of medical expertise” that Alfie’s brain had

almost entirely eroded “leaving only water and spinal fluid.”

Alfie’s parents wanted him moved to another hospital for further diagnosis and treatment. They believed he had shown signs of improvement as they watched him stretching, coughing, swallowing, and yawning. They wanted to “maintain his life regardless of whether a cure could be found.”³⁰ Alfie’s father believed that his son’s worsening condition was due to his physicians’ decision to reduce his dosage of the anti-epileptic drug Clobazam from 14.1 mg to 11.8 mg. He saw Alfie as “my healthy young boy, who is undiagnosed [and] who is certainly not dying,” despite frequent seizures, a urine infection, and compromised lung functioning.

With the assistance of the Italian ambassador to England and Wales, Alfie was granted Italian citizenship with the hope he might be transferred to the Babino Gesù Pediatric Hospital in Rome.³¹ Mr. Justice Hayden rejected the bid to take Alfie to Italy as “there was virtually nothing left of his brain.” When his ventilator was removed on April 23, 2018,³² the hospital issued a statement that its “top priority remains in ensuring Alfie receives the care he deserves to ensure his comfort, dignity and privacy...”³³

Parental Rights

Perhaps the most agonizing element in this drama concerns Alfie’s “best interest.” Michael Dougherty argued in the Gard case that the state should “get out of the way of the parents trying to act in the best interest of the child.”³⁴ This remains a crucial point in this case.³⁵ In Britain, cases of great importance are heard in the High Court whose 108 members are appointed by the Crown from

among the most respected lawyers in England and Wales. In the Evans case, under British law, disputes between families and physicians are not to be resolved on the personal predilections of the presiding judge or the reasonableness of the arguments put forth by family or the physicians, but on “the independent and objective judgement of the court” on the best interest of the non-competent patient.

In the United States, there is no such uniform norm. As seen in the well-documented case of Jahi McMath,³⁶ American courts are unwilling to order cessation of life-sustaining treatment over the protests of a caring family. The UK’s approach is different, vesting overriding control in the court exercising its independent and objective judgment in a child’s best interest. This approach is designed to safeguard infants and children from the possibility that parents regarded their children as possessions, or when sentimentality overshadowing objectivity.³⁷

Respected bioethicist John Paris, S.J. notes that in the United States “it is the best interests of the patient, not the desires of the family or the personal predilections of the physician, which ought to prevail... Infants ... are patients in their own right [and] it is the child’s best interests, and those alone, that are to be the focus and goal of medical treatment decisions made on behalf of children.”³⁸ This judgment respects the role of parents in making critical decisions about a medically compromised child, while insisting that their decisions, based on the physician’s diagnosis and prognosis, be based on the best interest of their child as a sacred and inviolable human being.³⁹

Ashley and O’Rourke reach the same conclusion: “...only in cases of conflict where one of the parties believes that the rights of the [incompetent] patient are imperiled should there be recourse to the courts. Ordinarily ... the physician should counsel [the parents] by giving a medical opinion as to risks and benefits, and the [parents] should make the decision on the basis of the patient’s best interest, that is, to decide what is beneficial for the patient, given the circumstances that prevail.”⁴⁰

Disproportionate Means of Treatment

The *Declaration on Euthanasia* presents the church’s authoritative statement on care of the dying: “For such a decision to be made, account will have to be taken of the *reasonable* wishes of the patient and the patient’s family, *and also the advice of doctors who are specially competent in the matter* [italics added]. The latter may in particular judge that the investment in instruments and personnel is disproportionate to the results foreseen; they may also judge that techniques applied impose on the patient strain or suffering out of proportion with the benefits which he or she gains from the techniques.”⁴¹

This is a summary of centuries of consistent Catholic moral analysis on the care of the sick and dying, and finds reiteration in St. John Paul II’s *Evangelium Vitae*: “To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia.”⁴² When Pope Francis met with Alfie’s father on April 18, 2018, he expressed “admiration” and “courage” for Mr. Evans and likened him to “the love that God has for human beings in that he never gives them up for lost.” The Pope’s pastoral expression is not a redirection of the church’s traditional

teaching on the appropriate medical treatment of the dying, but a prayer for Alfie and those who at the hour of death are in need of God's compassionate mercy, and an expression of support for parents treated as bystanders by the law. This should not be confused with doctrinal teaching.

The *Catechism of the Catholic Church* provides helpful guidelines: "Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, *whose reasonable will and legitimate interest must always be respected.*" (no. 2278, italics added)⁴³ Clearly, Catholic teaching highlights the limits on what medical treatments must be provided to patients for whom there is no realistic medical expectation of benefit.⁴⁴

Renowned Jesuit moralist Gerald Kelly thoroughly surveyed the church's long-standing teachings on care for the dying. Kelly found that approved authors held that "no remedy is obligatory unless it offers a reasonable hope of checking or curing a medical condition." He concluded that "no one is obliged to use any means if it does not offer a reasonable hope of success in overcoming that person's condition."⁴⁵ This same conclusion is reiterated by Benedict Ashley and Kevin O'Rourke.⁴⁶

In light of this moral tradition, the Conference of Catholic Bishops of England and Wales wrote in the Gard case, "We do, sometimes, however, have to recognize the

limitations of what can be done."⁴⁷ This judgment was repeated in the official statement issued by Archbishop Paglia for the Vatican's Academy for Life: "The proper question raised in this and any other unfortunate similar case is this: What are the best interests of the patient? We must do what advances the health of the patient, but we must also accept the limits of medicine and ... avoid aggressive medical procedures that are disproportionate to any accepted results or excessively burdensome to the patient or family."⁴⁸ These statements are also applicable to the Alfie Evans case.

Adverse Responses

One commentator claims that Alfie's case caused a "sense of outrage." This sentiment needs necessary contextualization. In mid-April, Alfie's father encouraged supporters to gather at the hospital for a protest, suggesting that they call themselves "Alfie's Army." This wave of protests in and around the hospital caused the hospital to restrict the number of visitors due to the hostile atmosphere created. The Chief Nurse claimed that they "caused significant disruption, stress and anxiety to other families and the staff." This disruption included people entering the Pediatric Intensive Care Unit (PICU) without permission, shouting, filming patients and visitors without their consent and generally creating a "threatening, intimidating, and unsafe environment." The hospital restricted visitors mainly to Alfie's parents. The hospital's Trust Chair Sir Henry Henshaw said in an open letter that the "staff had been the subject of unprecedented personal abuse that has been hard to bear."⁴⁹ The Conference of Catholic Bishops of England and Wales released a statement fully supporting Alder Hey Children's Hospital

and “those who are and have been taking the agonizing decisions regarding the care of Alfie Evans.”⁵⁰

When Alfie’s ventilator was removed, acrimonious reaction ensued. Alfie’s father called it an “execution,” saying that “doctors hate us and treat us like criminals,”⁵¹ the Italian ambassador named it “murder,” a prolife advocate described it as “legalized killing, euthanizing Alfie as one would a pet dog,” and Priests for Life issued a prayer saying that Alfie’s doctors are “blind, “pretend to be God,” and are “misguided.” The prayer made the astonishing statement that “death could [never] be in the best interest of a child,” a clear contradiction to the church’s moral tradition about disproportionate and futile treatment. The President of *LifeSiteNews* charged that the hospital with “murder of an innocent child” and claimed that their statements about Alfie were “diabolical,” and likened to a “lunatic.”⁵²

These reactions demonstrate a remarkable ignorance of the Church’s moral tradition about disproportionate treatment.

Conclusions

On April 25, 2018, a dramatic change occurred when Mr. Evans, after a meeting with Alfie’s doctors, read a message on behalf of himself and his wife, “We are very grateful and we appreciate all the support we have received from around the world... We would now ask you to return back to your everyday lives and allow myself, Kate and Alder Hey to form a relationship, build a bridge and walk across it... In Alfie’s interests we will work with his treatment team on a plan that provides our boy with the dignity and comfort he needs.”⁵³ The statement thanks the staff of the hospital “for their

professionalism and dignity” and expresses gratitude to “Alfie’s Army,” but asks them now “to go home.” Sadly, some interpreted this statement as written by the hospital and amounted to nothing more than a “hostage note.”

A positive note was sounded by Steven Woolfe, British Member of the European Parliament, and the group “Parliament Street” that plan to initiate changes in UK law to help children and their parents in the future in the hope of preventing parents from being “sidelined” in government-funded hospitals. “We demand a change in the law to restore the rights of parents in such decisions... Now is the time to act. We cannot have another baby, another family ... go through the struggle and torment the Evans family have. It’s time for Alfie’s Law.”⁵⁴

¹ <https://merckmanuals.com-vegetativestate>

² See Gerald D. Coleman, “Guarding Charlie Gard,” *Health Progress* November-December 2017, 54-58.

³ <https://www.liverpoolecho.co.uk.alfie-evans>

⁴ For an overview of Alfie’s case, see “Who Was Alfie Evans and What Was the Row over His Treatment?” *BBC News* (28 April 2018):

<http://www.bbc.com/news/uk-england-merseyside-43754949>.

⁵ Tobias Winright, “On Charlie Gard,” *Health Care Ethics USA* 25, no. 3 (Summer 2017): 1-11.

⁶ For an overview of Alfie’s case, see “Who Was Alfie Evans and What Was the Row over His Treatment?” *BBC News* (28 April 2018):

<http://www.bbc.com/news/uk-england-merseyside-43754949>.

⁷ Charles Collins, “Pope Francis Asks that Alfie Evans Be Allowed to ‘Seek New Forms of Treatment,’” *CRUX* (23 April 2018): <https://cruxnow.com/church-in-uk-and-ireland/2018/04/23/pope-francis-asks-that-alfie-evans-be-allowed-to-seek-new-forms-of-treatment/>.

⁸ “Alfie Evans: Claims Protest Makes Hospital Visits ‘Scary,’” *BBC News* (16 April 2018):

<http://www.bbc.com/news/uk-england-merseyside-43781041>; “Alfie Evans: Protesters Try to Storm Alder Hey Hospital,” *BBC News* (23 April 2018):

<http://www.bbc.com/news/uk-england-merseyside-43867132>.

⁹ Charles C. Camosy, “Alfie Evans and Our Moral Crossroads,” *First Things* (25 April 2018):

<https://www.firstthings.com/web-exclusives/2018/04/alfie-evans-and-our-moral-crossroads>.

¹⁰ For further information on the Nazi euthanasia program, see Michael S. Bryant, *Confronting the “Good Death”: Nazi Euthanasia on Trial, 1945-1953* (Boulder: University Press of Colorado, 2005), ch. 1.

¹¹ Udo Schuklenk, “Bioethics Culture Wars – 2018 Edition: Alfie Evans,” *Bioethics* 32 (2018): 270-1.

¹² <https://www.judiciary.gov.uk/wp-content/uploads/2018/02/alder-hey-v-evans.pdf>.

¹³ Pace the assessment proffered by Matthew Shadle, “The Fatal Flaw in the Alfie Evans Decision,” *Catholic Moral Theology* (27 April 2018):

<https://catholicmoraltheology.com/the-fatal-flaw-in-the-alfie-evans-decision/>.

¹⁴ For elucidation of this distinction, see Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (5 May 1980), §IV:

http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html.

¹⁵ See Michael Panicola, “Care of Critically Ill Newborns,” in *Health Care Ethics: Theological Foundations, Contemporary Issues, and Controversial Cases*, rev. ed. (Winona, MN: Anselm Academic, 2011), 124-155, at 138-143.

¹⁶ Kevin Clarke, “The Case of Alfie Evans: What Does Catholic Tradition Say?” *America* (26 April 2018):

<https://www.americamagazine.org/politics-society/2018/04/26/case-alfie-evans-what-does-catholic-tradition-say>.

¹⁷ See Jason T. Eberl, “Aquinas on the Nature of Human Beings” *Review of Metaphysics* 58, no. 2 (2004): 333-65.

¹⁸ For further elaboration of this argument in the context of patients in a properly-diagnosed persistent vegetative state, see Jason T. Eberl, “Extraordinary Care and the Spiritual Goal of Life: A Defense of the View of Kevin O’Rourke, O.P.” *The National Catholic Bioethics Quarterly* 5:3 (2005): 491-501.

¹⁹ Claire Giangravé, “Losers in Charlie Gard, Alfie Evans Cases Look to the Future,” *CRUX* (29 May 2018): <https://cruxnow.com/global-church/2018/05/29/losers-in-charlie-gard-alfie-evans-cases-look-to-the-future/>.

²⁰ See Charles C. Camosy, *Too Expensive to Treat? Finitude, Tragedy, and the Neonatal ICU* (Grand Rapids: Eerdmans, 2010).

²¹ Panicola, “Care of Critically Ill Newborns,” 136.

²² *Ibid.*, 137.

²³ Winright, “On Charlie Gard.”

²⁴ Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame, IN: University of Notre Dame Press, 1986), 190. See also Hauerwas, “Salvation and Health: Why Medicine Needs the Church,” in *Theology and Bioethics: Exploring Foundations and Frontiers*, Earl Schelp, ed. (Dordrecht: D. Riedel Publications, 1985) 205-225.

²⁵ In a recent presentation for my (Tobias Winright’s) students at Saint Patrick’s College in Maynooth Ireland, Catholic priest and ethicist Michael Shortall spoke about Hauerwas’s notion of “suffering presence” in connection with the initial seven days and nights of silence from Job’s friends, “for they saw that his suffering was very great” (Job 2:11-13), that is, before they ruined it by subsequently trying to explain why and attribute blame.

²⁶ “Parents’ Rights Must be Recognized,” *The Tablet*, April 28, 2018, 2.

²⁷ <https://www.nationalreview.com/corner/alfie-evans-case-medical-authoritarianism>

²⁸ See Coleman, “My Name if Charlie Gard,” *Ethics and Medics* 42:11 (2017), 1-4.

²⁹ *LifeSiteNews*, April 11 and 12, 2018.

³⁰ <https://www.nationalreview.com/alfie-evans>.

³¹ Hospitals in Milan, Munich and Poland also offered to take Alfie. His father made a personal plea to Pope Francis who named Bishop Francesco Cavina of Carfi as his intermediary with the family. Subsequently, Vatican-linked Bambino Gesù Pediatric Hospital in Rome stated its willingness to receive the baby. Cavina stated that Alfie’s move to the hospital in Rome “should not be impeded” and Italian newspaper *La Nuova Busola Quotidiana* reported that the Pope opened diplomatic channels for Alfie’s transfer. Alfie’s father met personally with Pope Francis on April 18, 2018 and told him that the courts had called his son’s life futile. In fact, however, the courts, following the hospital’s assessments, judged his ongoing treatment futile, not his life.

³² Before the ventilator was removed, Alfie was given two drugs, Midazolam (and anxiolytic) and Fentanyl (an analgesic).

³³ Professor Dominic Wilkinson, consultant neonatologist at the John Radcliffe Hospital and director of medical ethics at the Oxford Uehiro Centre for Practical Ethics at the University of Oxford, supported the hospital’s decision: “Given the nature of Alfie’s condition, the doctors have wanted to provide him with palliative care, focused on his comfort, and

focused on making his remaining time as good as possible.”

³⁴ <http://www.nationalreview.com/article/449159/vaticans-charlie-gard-statement-sides-statve-over-family>.

³⁵ See J Paris, J Ahluwalia, B Cummings, M Moreland, D Wilkinson, “The Charlie Gard Case: British and American Approaches to Court Resolution Over Medical Decisions,” *Journal of Perinatology* 37 (2017), 1268-1271.

³⁶ *Winkfield v Children’s Hospital Oakland et al.* US District Court for Northern California, December 30, 2013.

³⁷ <https://publications.parliament.uk/pa/cm198889/cmhasnsrd.1989-11-16/Debate-1.html>.

³⁸ Paris, 1270.

³⁹ B Ashley, J Deblois, and K O’Rourke, *Health Care Ethics*, Washington: Georgetown University Press, 5th ed., 2006, 191-192.

⁴⁰ Benedict M. Ashley and Kevin D. O’Rourke, *Health Care Ethics*, Washington, D.C.: Georgetown University Press, 4th ed., 1997, 429.

⁴¹ Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 1980, section 4.

⁴² John Paul II, *Evangelium Vitae*, March 25, 1995, no. 65

⁴³ This same teaching appears in the *Ethical and Religious Directives for Catholic Health Care Services*, nos. 56 and 57.

⁴⁴ See J Paris, M Moreland, B Cummings, “The Catholic Tradition on the Due Use of Medical Remedies: The Charley Gard Case,” *Theological Studies* 79:1 (2018), 165-181.

⁴⁵ Gerald Kelly, “The Duty of Using Artificial Means of Preserving Life,” *Theological Studies* 11 (1950), 203-220.

⁴⁶ Benedict M. Ashley and Kevin D. O’Rourke, 417-431.

⁴⁷ <https://www.catholic-ew.org.uk/Home/News/Baby-Charlie-Gard-Final-Ruling>. A large number of Brazilian Bishops released a video and letter on April 21, 2018: “Life is sacred and inviolable, such that it may not, on any pretext, be vilified or suppressed.” The United States Conference of Catholic Bishops asked for prayers that Alfie’s family be allowed “to seek new forms of treatment” and that “the dignity of Alfie’s life and all human life, especially those who are most vulnerable, be respected and upheld.”

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http://en.radiovaticana.va/news/2017/06/29/vaticans_academy_for_life_issues_statement_on_charley_gard/1322138.

⁴⁹ <http://www.bbx.com/news/uk-england-merseyside-4391259>.

⁵⁰ *LifeSiteNews*online, April 12, 2018.

⁵¹ <https://www.mirror.co.uk/news/live-updates-toddlers-alfie-evans-12416526>.

⁵² *LifeSiteNews*online, April 25, 2018.

⁵³ <http://www.bbc/news/uk-england-merseyside-43914259>.

⁵⁴ <https://www.express.co.uk/news/uk/9516890/Alfie-Evans-update-news-baby-release-free-Adler-Hey-Hospital-Liverpool>.