JUDGES, THE WITHDRAWAL OF TREATMENT FROM DYING OR DISABLED INFANTS, AND INEQUALITY-IN-DIGNITY: SOME REFLECTIONS ON ENGLISH LAW IN LIGHT OF THE *CHARLIE GARD* CASE

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INTRODUCTION

In 2017, the *Charlie Gard* case[1] attracted worldwide attention. Charlie was a terminally ill infant who had suffered progressive brain damage and muscle weakness from a rare genetic condition: mitochondrial DNA depletion syndrome (MDDA). He was kept alive on a ventilator in Great Ormond Street Hospital for Sick Children (GOSH), London. His doctors wished to withdraw his ventilation on the ground that it was futile. Charlie's parents, Chris Gard and Connie Yates, disagreed. They wanted to fly Charlie to New York where a doctor was willing to treat him with an experimental drug which offered the possibility, however remote, of preventing further deterioration in his condition, if not of some slight improvement. Their wishes were supported by many people who witnessed their plight through media reports, including President Trump and Pope Francis.

The hospital initiated legal proceedings in the High Court. It asked the judge, Mr. Justice Francis, to hold that Charlie's "best interests" (BI) required disconnection. Francis J, after hearing from counsel for the hospital, for the legal guardian who had been appointed to represent Charlie's interests, and for Charlie's parents, agreed. The parents' appeals to the Court of Appeal, the Supreme Court, and the European Court of Human Rights, were dismissed.

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1. Great Ormond St. Hosp. v. Yates (*Gard I*) [2017] EWHC (Fam) 972 (Eng.).

Charlie's case raised at least two important ethical questions, one concerning a child's right to life; the other the rights of his or her parents. The first is whether English judges have sometimes reasoned that life-prolonging treatment is not in a child's BI because the child's *life* is of no benefit; whether *treatment* is not worthwhile because the child's *life* is not worthwhile. The second is whether the legal criterion for overruling the wishes of parents in such cases should be whether treatment is in the BI of the child; or whether the treatment would involve a risk of "significant harm" to the child, or whether the parents' decision is (very) unreasonable. The second question has generated much scholarly analysis[2] but the first not so much.[3] The focus of this paper is, then, on the first question, though it will touch on the second. The paper argues that the English courts have indeed adopted the view that continued *life* is no longer in the BI of some dying or disabled children, and that this view is inconsistent both with their human rights and with claims by the courts to value the lives and dignity of all patients equally.

The paper comprises three parts. Part I outlines the ethical view that all children, whatever their age, disability, or life expectancy, enjoy an equal and intrinsic dignity. It will point out that their equality-in-dignity is recognized by the criminal law's prohibition on the intentional shortening of their lives, as well as by international documents on human rights that prohibit discrimination on the ground of disability. Part II shows that in the *Gard* case, and in a line of similar cases prior and subsequent to it, the English courts have repeatedly rejected children's equality-in-dignity by judging their lives to be of no benefit, or even a disbenefit, which judgment is thought to justify or help justify the discontinuation of their life-sustaining treatment. Part III offers some critical reflections including the reflection that a proposal to amend the law ("Charlie's Law") does not go far enough to ensure respect for the equal dignity of all infants or for their parents' rights. Although the paper concerns cases decided in England, its ethical and legal

2. *See* PARENTAL RIGHTS, BEST INTERESTS AND SIGNIFICANT HARMS (Imogen Goold et al. eds., 2019); DOMINIC WILKINSON & JULIAN SAVULESCU, ETHICS, CONFLICT AND MEDICAL TREATMENT FOR CHILDREN (2018); Raanan Gillon, *Why Charlie Gard's Parents Should Have Been the Decision-Makers About Their Son's Best Interests*, 44 J. MED. ETHICS 462 (2018); David Archard et al., *How Should We Decide How to Treat the Child: Harm Versus Best Interests in Cases of Disagreement*, 32 MED. L. REV. 158 (2024); Melissa Moschella, *Parental and Governmental Authority in Medical Decisions: The Tragic Case of Charlie Gard*, PUB. DISCOURSE (July 10, 2017), https://www.thepublicdiscourse.com/2017/07/19726/; *see also infra* notes 276-89 and accompanying text.

3. It is not raised, for example, in the commentary on *Gard* in a leading medico-legal journal, which concludes that the BI test was "compassionately and correctly applied." Emma Cave & Emma Nottingham, *Who Knows Best (Interests)? The Case of Charlie Gard*, 26 MED. L. REV. 500, 500 (2017).

analysis will be of relevance to other common law jurisdictions, including the United States.

PART I: OUR EQUALITY-IN-DIGNITY

1. *Equal Dignity and the Law*

The view that disability can be such as to deprive an infant's life of benefit and of his or her equality-in-dignity with nondisabled infants is inconsistent with the doctrine and principle of the sanctity or inviolability of life that has long informed the common law. The sanctity of life is regularly cited in cases like *Gard*, by counsel, medical witnesses, and judges as a key principle, but it is far more often cited than understood.

The principle of the sanctity or inviolability of life, which has historically shaped the criminal law's prohibition on intentional killing, reflects the moral view that the life of *every* human being, however sick, disabled, or close to death, has an intrinsic, ineliminable, and equal dignity or worth.[4] It is because of this dignity that it has always been, and remains, a serious crime for a doctor intentionally to administer a lethal injection to any patient. It is a crime even if the patient is seriously disabled and suffering gravely, even if the patient is on the cusp of death, and even if the patient autonomously requests a hastened death. That absolute legal prohibition reflects the moral view that we all enjoy an ineradicable dignity in view of our common humanity, a dignity that grounds our right to life, our right not to be intentionally killed.[5] That right can be breached not only by acts intended to end our life, such as lethal injections, but also by deliberate omissions, such as the discontinuation of life-sustaining treatment intended to hasten our death. Our equality-in-dignity can also be disrespected by the denial of life-sustaining treatment on the ground that our lives lack benefit or are a burden, even if withholding or withdrawal is not motivated by an intent to hasten our death.

The sanctity or inviolability of life is not, however, "vitalist": it does not hold that human life is a supreme moral value to be preserved at all costs.

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4. For an excellent analysis of dignity, see Daniel Sulmasy, *Dignity and Bioethics: History, Theory, and Selected Applications*, *in* HUMAN DIGNITY AND BIOETHICS: ESSAYS COMMISSIONED BY THE PRESIDENT'S COUNCIL ON BIOETHICS 469 (2008); *see also* CHRISTOPHER KACZOR, A DEFENSE OF DIGNITY: CREATING LIFE, DESTROYING LIFE, AND PROTECTING THE RIGHTS OF CONSCIENCE (2013).

5. *See* JOHN KEOWN, THE LAW AND ETHICS OF MEDICINE: ESSAYS ON THE INVIOLABILITY OF HUMAN LIFE, 3–22 (2012); NEIL M. GORSUCH, THE FUTURE OF ASSISTED SUICIDE AND EUTHANASIA, 181–218 (2006).

Both the law and professional medical ethics have long recognized that it is proper to withhold or withdraw "extraordinary" or "disproportionate" treatments. Treatments may be disproportionate either because they are futile - they cannot secure a therapeutic benefit - or because they are too burdensome to the patient. Futility morally permits, though it does not necessarily require, a patient (or a parent) to refuse a treatment.

There is a crucial moral distinction between withdrawing a treatment because it is futile and withdrawing a treatment because it is thought that the patient's *life* is futile. The latter judgment is inconsistent with respect for the patient's dignity.[6] All patients have a right not to have their life-sustaining treatment withdrawn because a doctor (or judge) thinks their lives are of no benefit or lack dignity, especially if treatment is withdrawn to hasten their demise. While it is ethical to assess the patient's medical condition in order to determine whether a treatment would be beneficial or would be futile, and while it is also ethical to consider any burdens that a treatment might impose, it is unethical to judge that the patient's *life* is either futile or a burden.

This distinction was clearly explained by Lord Justice Ward, the presiding judge in the *Conjoined Twins* case (a case that attracted no less national and international attention than *Gard*).[7] His Lordship affirmed: "What the sanctity of life doctrine compels me to accept is that each life has inherent value in itself and the right to life, being universal, is equal for all of us."[8] He said:

> Given the international conventions protecting "the right to life," . . . I conclude that it is impermissible to deny that every life has an equal inherent value. Life is worthwhile in itself whatever the diminution in one's capacity to enjoy it and however gravely impaired some of one's vital functions of speech, deliberation and choice may be.[9]

He quoted[10] a pertinent observation by Lord Mustill in *Bland*. Lord Mustill said that the proposition that because of incapacity or infirmity one life was intrinsically worth less than another was "the first step on a very dangerous road indeed. . . ." Ward LJ held that the trial judge in the *Conjoined Twins* case had been wrong to hold that the life of the weaker

6. *See* JOHN KEOWN, EUTHANASIA, ETHICS AND PUBLIC POLICY, 37–49 (2d ed. 2018).
7. Re A (Children) (*Conjoined Twins: Surgical Separation*) [2000] EWCA (Civ) 254.
8. *Id.* at [186].
9. *Id.* at [187]–[188].
10. *Id.* at [188].

twin, Mary, was worth nothing to her: Mary retained her ineliminable value and dignity.[11] Similarly, in the case of *Inglis*, Lord Judge, the Lord Chief Justice, affirming the conviction of a mother for murdering her son who was in a "persistent vegetative state," observed that in the eyes of the law against intentional killing "a disabled life, even a life lived at the extremes of disability, is not one jot less precious than the life of an able-bodied person."[12] The House of Lords Select Committee on Medical Ethics also emphasized the idea of our equality-in-dignity when, explaining the committee's opposition to the legalization of euthanasia and physician-assisted suicide, it described the law's prohibition on intentional killing as the "cornerstone of law and of social relationships" that "protects each one of us impartially, embodying the belief that all are equal."[13]

As we shall see below, however, the courts in cases like *Gard* have judged that life-sustaining treatment may be withdrawn because the infant's *life* is futile. Such reasoning undermines fundamental human equality. It also undermines the law's prohibition on intentional killing. If an infant's life is either of no benefit or is a burden, why should the law prohibit his or her intentional termination, whether by act or omission?[14]

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11. *Id.* (Ward LJ's judgment was cited by Francis J in *Gard*, but not on this key point. *Gard I* [2017] EWHC (Fam) 972 [36].).

12. R v. Inglis [2010] EWCA (Crim) 2637 [38], [2011] WLR 1110 [1118].

13. SELECT COMMITTEE ON MEDICAL ETHICS, REPORT, 1993-94, HL 21-I, ¶ 237 (UK).

14. The courts have failed to appreciate the extent to which cases like *Gard* seriously compromise the law of homicide. Guidance on withdrawal of treatment from children issued by the Royal College of Paediatrics and Child Health (regularly cited by judges in cases like *Gard*) states that in cases of treatment withdrawal in accordance with that guidance the "primary" intention is not the death of the child. Vic Larcher et al., *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice*, 100 ARCHIVES DISEASE CHILDHOOD (SUPP. 2) s1, s15, at 3.2.1 (2015); *see also infra* notes 70-73 and accompanying text. May hastening death, however, be a "secondary" intention? In the landmark case of *Bland*, three of the five Law Lords assumed that the withdrawal of an incapacitous adult patient's tube-feeding was motivated by an intent to bring his life to an end. As Lord Browne-Wilkinson put it: "Murder consists of causing the death of another with intent to do so. What is proposed in the present case is to adopt a course with the intention of bringing about Anthony Bland's death. As to the element of intention . . . in my judgment there can be no real doubt that it is present in this case: the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland." Airedale NHS Tr. v. Bland [1993] AC 789 [881]. It does not follow, however, that because a doctor foresees the hastening of the patient's death, even as certain, it is therefore the doctor's purpose to hasten death. (For criticism of the judgments in this leading case on the withdrawal of treatment or tube-feeding from incapacitous adults, see John Finnis, Bland: *Crossing the Rubicon?*, 109 L.Q. REV. 329 (1993); John Keown, *Restoring Moral and Intellectual Shape to the Law After* Bland 113 L.Q. REV. 481 (1997)). In relation to incapacitous adults, statute now provides that withdrawal must not be "motivated" by a "desire" to bring about death. Mental Capacity Act 2005, c. 9, § 4(5) (UK).

2. *International Human Rights Documents*

Further recognition of the inherent and equal dignity of all patients, whether dying or disabled, is evident in international human rights documents. As the Preamble to the Universal Declaration of Human Rights proclaims: "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world."[15]

The Convention on the Rights of the Child came into force in 1990 and was ratified by the UK the following year.[16] Its Preamble notes that "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth." Article 6 provides that States Parties recognize that every child has the inherent right to life and that they must ensure, to the maximum extent possible, the survival and development of the child. By Article 23 they recognize that a mentally or physically disabled child should enjoy a full and decent life in conditions that ensure dignity and the right of the disabled child to special care. Article 24 asserts the right of the child to enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health, and provides that States Parties shall strive to ensure that no child is deprived of his or her right to access such health care services.

Of particular relevance to the nontreatment of infants with disabilities is the UN Convention on the Rights of Persons with Disabilities. This Convention came into force in 2008[17] and was ratified by the UK the following year.[18] Its Preamble recalls the Human Rights Declaration's affirmation that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,[19] recognizes that discrimination on the basis of disability is a violation of the inherent dignity and worth of the human person,[20] and notes that "children with disabilities should have full

15. G.A. Res. 217 (III) A, Universal Declaration of Human Rights, at 71 (Dec. 10, 1948).

16. G.A. Res. 44/25, Convention on the Rights of the Child (Nov. 20, 1989).

17. G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Dec. 12, 2006).

18. U.N. Off. of the High Comm'r for Hum. Rts, *United Kingdom of Great Britain and Northern Ireland – IMM Situation*, (June 8, 2009), https://www.ohchr.org/en/treaty-bodies/crpd/united-kingdom-great-britain-and-northern-ireland-imm-situation (the Convention was signed by President Obama in 2009 but it has not yet been ratified by the U.S. Senate).

19. G.A. Res. 61/106, annex, *supra* note 17, ¶(b).

20. *Id.* ¶(h).

enjoyment of all human rights and fundamental freedoms on an equal basis with other children."[21]

Article 4 requires States Parties to take all appropriate measures, including legislation, to modify or abolish existing laws and practices that constitute discrimination against persons with disabilities[22] and to take all appropriate measures to eliminate discrimination on the basis of disability by any person or organization.[23] Article 5 provides that States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law,[24] and that States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.[25] Article 7 provides that States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children[26] and that in all actions concerning children with disabilities the BI of the child shall be a primary consideration.[27] Article 10 states that States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.[28] Article 25 provides that persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability[29] and requires States Parties to provide persons with disabilities with the same range, quality and standard of free or affordable health care as provided to other persons; to provide those health services needed by persons with disabilities specifically because of their disabilities,[30] and to require health professionals to provide care of the same quality to persons with disabilities as to others.[31]

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21. *Id.* ¶(r).
22. *Id.* at 5.
23. *Id.* at 6.
24. *Id.* at 6; *see also id.* at 9 (art. 12).
25. *Id.* at 7.
26. *Id.*
27. *Id.*
28. *Id.* at 9. Also worthy of mention are Article 17, which protects physical and mental integrity; Article 14, which prohibits the unlawful or arbitrary deprivation of liberty; Article 18, which protects freedom of movement; and Article 23, which requires respect for home and the family.
29. *Id.* at 15.
30. *Id.*
31. *Id.*

Other relevant human rights documents include the European Convention on Human Rights (ECHR) which came into force in 1953.[32] The Convention was incorporated into UK law by the Human Rights Act 1998. The Act, which came into force in 2000, empowered UK courts to grant remedies for breaches of Convention rights. Relevant Articles of the Convention include Article 2, protecting the right to life; Article 8, guaranteeing respect for private and family life; Article 9, protecting freedom of thought, conscience, and religion; and Article 14, prohibiting discrimination on any ground. Also worthy of note is the Equality Act 2010, which prohibits unjustified discrimination on the basis of any protected characteristic, one of which is "disability"[33]

We may now contrast the idea of human equality-in-dignity that undergirds these international documents and the common law prohibition on homicide with the reasoning of the courts in *Gard* and similar cases. *Gard* generated more media and scholarly attention than the other cases we shall mention, so we shall set it out in greater detail, but it created no new law. The law it applied was essentially the same as in cases both prior and subsequent to it.

PART II: THE COURTS' DENIAL OF EQUALITY-IN-DIGNITY

1. *Charlie Gard*

Charlie was born on August 4, 2016. After a few weeks, his parents noticed that he was less able to lift his head and support himself than other babies of his age. By 11 October he had become lethargic and his breathing shallow and on that day he was admitted to GOSH.[34] Charlie would remain there until he died on 28 July 2017, just shy of his first birthday.

32. *Convention for the Protection of Human Rights and Fundamental Freedoms*, EUR. CT. OF HUM, RTS. (Nov. 4, 1950), https://www.echr.coe.int/documents/d/echr/ convention_ENG;A useful summary of international human rights documents mentioning human dignity was provided in N.W. London Clinical Commissioning Grp. v. GU [2021] EWCOP 59 [42]-[63]; *see also infra* notes 239-42 and accompanying text.

33. On the applicability of the Act to healthcare, see the guidance issued by the Equality and Human Rights Commission. 4 EQUAL. AND HUM. RTS. COMM'N, YOUR RIGHTS TO EQUALITY FROM HEALTHCARE AND SOCIAL CARE SERVICES: EQUALITY ACT OF 2010 GUIDANCE FOR SERVICE USERS (updated October 2018).

34. *Gard I* [2017] EWHC (Fam) 972 [44]–[45] (Eng.).

(i) Charlie's Condition

Charlie had a rare genetic disease: a mitochondrial disease called MDDS.[35] Mitochondria are small structures in the fluid that surrounds the nucleus of a cell. They have been described as power stations in virtually every cell. One of their key functions is to convert energy from a person's food and oxygen into a form of energy that the cells can use. Lack of mitochondria leads to organ dysfunction and in Charlie's case his brain, muscles, and respiration were seriously affected. He also suffered from deafness and epilepsy. His heart, liver, and kidneys were also affected, but not seriously. Because of his severe and progressive muscle weakness, he could no longer move his arms and legs or breathe without assistance.[36] While Charlie was not "brain dead," there were no signs of normal brain activity such as responsiveness, interaction, or crying.[37] From mid-December, he began to suffer seizures, a sign that death was at most six to nine months away.[38]

The consensus of expert medical opinion was that Charlie's condition was grave, progressive, irreversible, and terminal. One medical expert said that Charlie's life was limited both in quality and quantity and that there was no reasonable prospect of recovery; that it was arguable that he "would derive no benefit from continued life,"[39] and that withdrawal of treatment would be in accordance with ethical guidance on the withdrawal of treatment from children issued by the Royal College of Paediatrics and Child Health (RCPCH).[40]

Charlie's doctors wanted to withdraw his ventilation. His nurse said that in over two hundred hours with him she had not seen evidence of him responding to his parents; that it was impossible to tell if he was asleep or awake and that, from a nursing viewpoint, the only real change since his admission was that he needed four different types of seizure medication.[41] No one knew for certain whether Charlie felt any pain. On the one hand his

35. *See id.* at [52]. (Charlie's condition was "infantile onset encephalomyopathic mitochondrial DNA depletion syndrome.").

36. *Id.* at [53]–[54].

37. *Id.* at [58].

38. Yates v. Great Ormond St. Hosp. for Child. NHS Found. Tr. (*Gard CA*) [2017] EWCA (Civ) 410 [17].

39. *Gard I* [2017] EWHC (Fam) 972 at [60].

40. *See* Larcher et. al, *supra* note 14 (referring to the RCPCH Guidance); *see also infra* notes 70-73 (referring to the RCPCH Guidance).

41. *Gard I* [2017] EWHC (Fam) 972 at [68]–[69].

nurse said it was impossible to tell if he felt either pain or pleasure.[42] The consultant in pediatric metabolic medicine said at one point that she thought it possible he did feel pain but that it could not be demonstrated. Charlie was undergoing suctioning and other invasive treatments that would cause pain to other patients, and if he could not express feelings of pain this would reflect the severity of his brain damage. On the other hand, the same consultant later said she thought it likely he did consciously experience pain and that his medical team thought he was suffering and at more than a low level.[43] His parents Chris and Connie said Charlie reacted to things he did not like, such as a heel prick or having his nose suctioned, that he had sleep/wake cycles, and that he knew when he was awake.[44] They accepted that, without improvement, his "quality of life" was not worth sustaining. His mother said, "We would not fight for the quality of life he has now."[45] However, they thought that Charlie might benefit from a treatment called nucleoside therapy.

(ii) Nucleoside Therapy

This therapy merely involves adding a chemical compound in the form of powder to the patient's food so as to produce an alternative source of energy to be used by the patient's cells. It had been used on patients with a different and less severe mitochondrial condition than Charlie's, one that primarily affects the muscles rather than the brain, and there was limited evidence of some benefit to patients with that condition. It was not known whether the therapy could cross the blood-brain barrier so as to penetrate and be effective within the brain.[46]

Charlie's mother contacted Dr. Michio Hirano of Columbia University in New York, an expert in nucleoside therapy. He replied that the therapy had not been used on humans with Charlie's condition or even on mice, but that it might, hypothetically, be beneficial, and that it might be reasonable to try it in the light of Charlie's dire condition. Charlie's doctors, after a conversation with Dr. Hirano, and in the light of a magnetic resonance imaging (MRI) scan that appeared to show no structural damage to his brain, listed Charlie for nucleoside therapy but, after he suffered further seizures, they informed his parents that he was suffering severe epileptic encephalopathy and that the

42. *Id.* at [68].
43. *Id.* at [113]–[114].
44. *Id.* at [109].
45. *Id.* at [110].
46. *Gard CA* [2017] EWCA (Civ) 410 at [13].

treatment would therefore be futile. His medical team and the second opinions they obtained were all of the view that his condition was deteriorating, could not improve, and that he should be allowed to die. Even if nucleoside therapy were able to reach his brain, it could not reverse the damage already done. The parents sought an opinion from an independent expert, a consultant neurologist, but that expert agreed that continuing ventilation would be pointless.[47] Dr. Hirano was alone in suggesting that there might be any possible benefit to Charlie from the therapy. He agreed that Charlie's brain was so damaged that it was unlikely the therapy would work and that there was only a small chance of meaningful brain function, but he thought the therapy might improve muscle weakness and modestly increase life expectancy. If Charlie were in the United States, Dr. Hirano would treat him.

(iii) The Parents

Charlie's parents were clearly devoted to him, spending many hours by his hospital bedside. They thought he knew who they were and could sense when they were present. Connie said he enjoyed being tickled but not on his feet, preferring his head to be stroked, and that his brain function was not as bad as his doctors thought. She and Chris wanted Charlie to be given the nucleoside therapy so he would have a chance of improving, even though they knew it was not a cure. Chris said:

> He deserves his chance. We would not fight for the quality of life he has now . . . We truly believe that these medicines will work. After three months we would want to see improvement and, if there wasn't, we would let go. This is not the life we want for Charlie. A chance to keep fighting, he deserves that chance.[48]

They knew it was not a cure but thought it might slow or even stop the progress of the disease.[49] Through crowdfunding, they had raised the money to transport him.

47. *Gard I* [2017] EWHC (Fam) 972 at [83].
48. *Id.* at [110].
49. *Gard CA* [2017] EWCA (Civ) 410 at [2].

(iv) Charlie's Doctors

Charlie's doctors believed Charlie's condition was hopeless and that the proposed nucleoside therapy would be pointless. They also believed that he was suffering as a result of the intensive care he was receiving and thought it best that his ventilation be withdrawn and that he be allowed to die. The doctors and the parents were, then, at a standoff. The hospital instituted wardship proceedings.

(v) The High Court

In April of 2017, Charlie's case was heard before Francis J in the Family Division of the High Court. The hospital asked the judge to make a declaration that it would be lawful for Charlie not to undergo nucleoside therapy; for his artificial ventilation to be withdrawn, and for him to be given palliative care only. Charlie's parents opposed the granting of the declaration. Section 1 of the Children Act 1989 provides that when a court determines any question with respect to the upbringing of a child "the child's welfare shall be the court's paramount consideration." Francis J noted that although Chris and Connie had parental responsibility, overriding control was vested in the court exercising its independent and objective judgment as to what was in the child's BI.

The judge proceeded to set out the relevant legal authorities.[50] In *Wyatt v. Portsmouth NHS Trust*,[51] the Court of Appeal had laid down the "intellectual milestones" to be followed:

> The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient. There is a strong presumption in favor of a course of action which will prolong life, but that presumption is not irrebuttable. The term "best interests" encompasses medical, emotional, and all other welfare issues.

The nature of the "intellectual milestones," Francis J continued, had been explained by Holman J in *An NHS Trust v. MB*.[52] Holman J had pointed out that he was not deciding what decision he might make if he were the parent

50. *Gard I* [2017] EWHC (Fam) 972 at [35]–[43].

51. [2005] EWCA (Civ) 1181, [2006] 1 FLR 554.

52. An NHS Tr. v. MB [2006] EWHC (Fam) 507 at [16]-[17] (Eng.).

nor whether the decisions of the doctors on the one hand or the parents on the other were reasonable. The matter was to be decided by the application of an objective test and that test was the BI of the child. BI included every kind of consideration capable of impacting the decision, including the medical and emotional, as well as pleasure, pain, and suffering, and the human instinct to survive. The court had to balance all the conflicting considerations and decide where the final balance of BI lay. Considerable weight must be attached to the prolongation of life but that could be outweighed "if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great."[53] Holman J quoted[54] from the judgment of Lord Donaldson MR[55] in the leading case of *Re J*:[56]

> There is without doubt a very strong presumption in favour of a course of action which will prolong life, but[57] . . . . it is not irrebuttable . . . . Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account also has to be taken of the pain and suffering involved in the proposed treatment . . . . We know that the instinct and desire for survival is very strong.

Lord Donaldson MR continued:

> We all believe in and assert the sanctity of human life . . . Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which

53. *Gard I* [2017] EWHC (Fam) 972 at [39].

54. *Id.*

55. The author was honored to be called to the Bar in Middle Temple Hall by this distinguished judge.

56. Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam. 33 (EWCA (Civ)) at [46] (Eng.).

57. The ellipsis omitted the words "even excepting the 'cabbage' case, to which special considerations may well apply." *Id.* (Referring to patients as "cabbages" and suggesting that the presumption in favor of sustaining life may not apply to them is depersonalizing); *see infra* notes 96, 208, 214. Not only is it depersonalizing but it is also contrary to the RCPCH guidelines. *See* Larcher et al., *supra* note 14, at s12, 2.4.6 (stating that healthcare professionals should use language that is "neutral, accurate and appropriate"). Unfortunately, the RCPCH uses "persistent vegetative state" rather than "unresponsive wakefulness syndrome." *Id.* at s14, 3.1.3. There is, moreover, evidence showing that a significant proportion of individuals diagnosed with PVS are in fact conscious and able to respond to commands. *See* Neil Scolding et al., *Prolonged Disorders of Consciousness: A Critical Evaluation of the New UK Guidelines*, 144 BRAIN 1655, 1655, 1657 (2021); *see also* Karnig Kazazian et al., *Detecting Awareness After Acute Brain Injury*, 23 THE LANCET 836, 839 (2024).

> the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.

Francis J continued that Holman J had added that the court should carefully consider the views of both the doctors and the parents. Where the parents had spent a great deal of time with their child, their views may have particular value because they knew the patient so well and how he or she reacted, though the court should be mindful that parents' views may be colored by their emotions. Moreover, the parents' wishes, however understandable in human terms, were "wholly irrelevant" to a consideration of the objective best interests of the child, except to the extent that they may illuminate the quality and value to the child of the child/parent relationship.[58]

Francis J cited another case, although one involving an incapacitous adult rather than a child: the decision of the Supreme Court in *Aintree University Hospital NHS Foundation Trust v. James*.[59] The Supreme Court held that the fundamental question was whether it is lawful to give a treatment, not whether it is lawful to withhold it. The question was not whether it is in the BI of a patient to die but whether it is in the BI of a patient that his or her life should be prolonged by the continuation of treatment. If treatment were not in a patient's BI it was not lawful to give it. In considering the BI of a particular patient at a particular time, the Supreme Court continued, the decision-maker must look at his or her welfare in the widest sense, not just medical but social and psychological, considering the nature of the treatment in question, what it involved, its prospects of success, and what the outcome for the patient was likely to be. They must try to put themselves in the place of the patient and ask what his or her attitude to the treatment is or would likely to be and they must consult others who are looking after him or her or interested in his or her welfare, in particular for their view of what his or her attitude would be.

Francis J said that the above cases set out the guiding principles for him to apply in Charlie's case. He noted that Charlie's parents had clearly dedicated their lives to him since he was born and that no one could have done more to support him. He paid tribute to their love and care.[60] They knew Charlie "immeasurably better than anybody else does, professionally

58. *Gard I* [2017] EWHC (Fam) 972 at [39].

59. Aintree Univ. Hosps. NHS Found. Tr. v. James [2013] UKSC 67 [2] (on appeal from EWCA (Civ)).

60. *Gard I* [2017] EWHC (Fam) 972 at [47].

or otherwise."[61] He noted that they did not think that Charlie's condition was as bad as his doctors reported and that they wanted Charlie to have the chance of benefitting from the nucleoside therapy. In the judge's view, however, the evidence showed that the prospect of that therapy having any benefit was as close to zero as made no difference; it would be futile. Although Dr. Hirano was willing to treat Charlie in the United States no one, including Dr. Hirano, had ever treated Charlie's form of MDDS with nucleoside therapy. Dr. Hirano, who had not seen Charlie, offered the "tiniest chance of some remotely possible improvement based on a treatment which has been administered to patients with a different condition."[62] There was no evidence that the treatment could cross the blood-brain barrier so as to have any beneficial effect, though Dr. Hirano hoped it might. Moreover, expert opinion was unanimous that nucleoside therapy could not remedy Charlie's structural brain damage. Further, his doctors thought Charlie could probably experience pain but was unable to react to it in a meaningful way, and that being ventilated and suctioned were capable of causing pain. Nucleoside therapy might, or might not, subject him to pain or even to genetic mutations. If Charlie's brain damage could not be improved, as everyone seemed to agree, how could he be better off than he was now, with a "quality of life" that even his parents agreed was not worth preserving?[63] All of Charlie's doctors at Great Ormond Street were agreed that nucleoside therapy would be futile and that his ventilation should be withdrawn.

This was also the view of the guardian appointed to represent Charlie, who contended that the nucleoside therapy was not pioneering or lifesaving treatment but a purely experimental process with no real prospect of improving Charlie's condition or quality of life. There was a serious prospect, and, in the view of the hospital's expert on his condition, a likelihood, that Charlie felt pain.[64] It could not be in Charlie's BI to subject him to experimentation and the pain that this would cause when there was no prospect of benefit.

In the light of all the evidence, on April 11, 2017, Francis J granted a declaration that it would not be in Charlie's BI to undergo nucleoside therapy and that it was lawful and in his BI for his ventilation to be withdrawn and for him to be given palliative care only. The only course that was in his BI

61. *Id.* at [107]; *see id.* at [84]-[86] (noting that one of Charlie's doctors had in an email to another doctor described the parents as a "spanner in the works" which the judge interpreted as merely conveying the opinion that nucleoside therapy was not, despite the views of the parents, in Charlie's BI).

62. *Id.* at [127].

63. *Id.* at [126].

64. *Id.* at [121].

was "to let him slip away peacefully and not put him through more pain and suffering."[65] Charlie's parents appealed, first to the Court of Appeal, then to the Supreme Court and, finally, to the European Court of Human Rights.

(vi) The Court of Appeal

The parents asked the Court of Appeal to reverse the High Court judgment and declare that it would be lawful for them to transfer Charlie to a clinic willing to administer the nucleoside therapy. The Court of Appeal handed down its judgment on May 23,[66] dismissing the parents' appeal.

Delivering the judgment of the court, McFarlane LJ (as he then was) said that even Dr. Hirano, the only expert in favor of trying the nucleoside therapy, had accepted that the prospect of benefit was low and offered a vanishingly small chance of meaningful brain recovery.[67] In a letter dated the previous day, Dr. Hirano had written that he expected the treatment to be beneficial and that the best-case scenario was that Charlie's condition would stabilize, improve partially, or continue to improve with long-term therapy, and that ideally it would ameliorate the seizures and allow more normal brain function. The court did not treat this as fresh evidence, however, as it did not purport to contain anything that had not been before the judge.[68] McFarlane LJ said that all the evidence led to the sad conclusion that it would be in Charlie's BI for ventilation to be withdrawn as there was "no benefit for him in continuing to maintain his current level of existence for the remaining few months of his life." There was nothing in favor of preserving his life other than the presumption of doing so.[69]

The Court of Appeal considered two fresh legal arguments advanced by the parents' new legal team. The first ran that the BI test laid down in previous cases and followed by Francis J applied to cases where there was no alternative treatment and that the test did not apply to cases, like Charlie's, where there was a viable alternative treatment that the parents wished to pursue. In the latter sort of case, the appropriate test was whether the parents' wishes would cause "significant harm" to the child. If the parents' wishes would not cause the child significant harm, then for the state to override their wishes would infringe their right to private and family life under Article 8 of the European Convention on Human Rights.

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65. *Id.* at [128].
66. *Gard CA* [2017] EWCA (Civ) 410.
67. *Id.* at [26].
68. *Id.* at [28].
69. *Id.* at [48].

Counsel for the hospital replied that the case did engage the question of significant harm and that cases where the child could derive little or no benefit from continued life justified consideration alongside cases where significant harm might be established solely by reference to pain. She quoted the guidance issued by the RCPCH, updated in 2014, on withdrawing treatment from children with life-limiting and life-threatening conditions.[70] That guidance, endorsed by the Court of Appeal in *Re A (HR)*,[71] identified three situations when life was limited in quality. Those situations were when:

> (i) treatment imposed burdens, producing significant pain and suffering that outweighed any possible benefits;
>
> (ii) the child's underlying conditions involved burdens: the severity and impact of the child's underlying condition itself produced such pain and distress as to overcome any potential or actual benefits in sustaining life, and
>
> (iii) there was a lack of ability to benefit: the child's condition meant it was difficult or impossible for them to derive benefit from continued life.[72]

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70. *See* Larcher et al., *supra* note 14.

71. Re A (A Child) [2016] EWCA (Civ) 759 [40]-[41] (on appeal from the High Court of Justice).

72. *Gard CA* [2017] EWCA (Civ) 410 at [75]; *see also* Larcher et al., *supra* note 14, at s14, ¶¶ B-C. Paragraph B titled "Burdens of illness and/or underlying condition" states: "Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome the potential or actual overall benefits in sustaining life. Some children have such severe degrees of illness associated with pain, discomfort and distress that life is judged by them (or on their behalf if they are unable to express their wishes and views) to be intolerable. All appropriate measures to treat and relieve the child's pain and distress should be taken. If, despite these measures, it is genuinely believed that there is no overall benefit in continued life, further LST (Life Sustaining Treatment) should not be provided, for example, in advanced treatment-resistant malignancy, severe epidermolysis bullosa." Larcher et al., *supra* note 14, at s14, ¶ B. Epidermolysis bullosa is "a group of rare inherited skin disorders that cause the skin to become very fragile." *See Epidermolysis Bullosa*, NHS (June 23, 2021), https://www.nhs.uk/conditions/epidermolysis-bullosa/.

Paragraph C titled "Lack of ability to derive benefit" states: "In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them." Larcher et al., *supra* note 14, at s14, ¶ C.

The three categories, counsel suggested, carried equal weight, including (iii), even though it did not mention pain, suffering, or distress. She cited a previous case in which doctors wanted to withdraw ventilation from a brain-damaged infant against the wishes of the mother and where the trial judge, ruling that withdrawal was in the BI of the infant, had said that even if the child's life were pain-free she would conclude that "there is no measurable benefit to him to continue in his present condition and it is simply inhumane to permit it to continue."[73] Counsel added that no one knew if Charlie suffered pain "because of the ravages of Charlie's condition" but that he would suffer significant harm if the parents' wishes prevailed: "The significant harm is a condition of existence which is offering the child no benefit."[74] Counsel for Charlie's guardian also disagreed with the first new argument advanced by the parents. She said that every case involved a disagreement between the doctors and parents about which course to follow, whether or not the parents had identified an alternative treatment.

The second new legal argument ran that it was one thing for the hospital to apply for a declaration that it would be lawful for it to withdraw ventilation but quite another for it to try to prevent Charlie's parents from arranging his transfer to another hospital willing to treat him. The latter application, in the absence of evidence that a transfer would cause significant harm to Charlie, was outwith the power of the hospital as a public authority or the jurisdiction of the court. Counsel for the hospital replied that the hospital was not seeking to impose its views on the parents: it had merely brought Charlie's case to the attention of the courts so that a judge could determine where his BI lay.

McFarlane LJ agreed with earlier judicial pronouncements that the views of devoted and reasonable parents should be treated with respect and that there was a spectrum of cases, at one end of which parental views were clearly incompatible with child welfare but at the other end of which lay highly problematic cases where there was genuine scope for disagreement between parent and judge. In the latter kind of case, it was likely (though not

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The guidance asserts that it does not make comparative judgments about the quality of life of those with disabilities or determine that some individuals are of higher worth than others, but considers the impact of treatments on a child's ability to communicate, experience awareness and pleasure, and attain goals and independence. *See* Larcher et al., *supra* note 14 at s12, 2.4.6. However, paragraphs B and C make it clear that the lives of children without such abilities lack benefit or are a burden. How is this different from a judgment that their lives are less worth preserving than the lives of children without these disabilities?

73. Re A (A Child) [2016] EWCA (Civ) 759 [58] (Eng.).

74. Damien Gayle, *Charlie Gard Doctors Can Stop Providing Life Support, Court Rules*, THE GUARDIAN (May 25, 2017, 13:03 EDT), https://www.theguardian.com/society/2017/may/25/charlie-gard-doctors-can-stop-providing-life-support-court-rules.

certain) that the court would incline to the view that the BI of a child included the expectation that difficult decisions affecting the length and quality of his or her life will be taken by the parent to whom his or her care has been entrusted by nature. In every case, however, the duty of the court was to make an objective and independent judgment, not to assess the reasonableness or otherwise of the parent's views.[75] Even if a case fell at the more favorable end of the spectrum, the court did not evaluate the reasonableness of the parents' views before embarking upon deciding what was in the best interests of the child.[76] He also bore in mind the most recent iteration of the RCPCH guidance that had been endorsed in the case of *Re A*.[77]

The Court of Appeal rejected the two new arguments raised by the parents' counsel. As to the first, the court affirmed that the legal test remained the BI test, whether or not a case involved the parents having identified a viable treatment alternative. In any event, the trial judge had concluded that nucleoside therapy was not a viable alternative. McFarlane LJ pointed out that the judge had made "clear findings that going to America for treatment would be futile, would have no benefit and would simply prolong the awful existence that he found was the current state of young Charlie's life . . . ."[78] Moreover, had the trial judge been asked to come to a conclusion as to whether Charlie was suffering significant harm, that finding would have been made: he had concluded that the nucleoside treatment would have been of no effect but might well cause pain, suffering, and distress to Charlie, and had regarded that as the principal issue raised by the case.[79]

As for the second new argument, it was also rejected. McFarlane LJ said it was wrong to cast the process about prohibiting the nucleoside therapy as being driven by the hospital. That prohibition resulted from a child-focused, court-led evaluation where the sole issue was whether it was in Charlie's BI.[80] The Court of Appeal dismissed the parents' appeal and refused permission to appeal.

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75. *Gard CA* [2017] EWCA (Civ) 410 at [89]-[92].

76. *Id*. at [94].

77. *Id*. at [93].

78. *Id*. at [97]. All of the evidence, said McFarlane LJ, led to the conclusion that treatment withdrawal was in Charlie's BI "as there was no benefit for him in continuing to maintain his current level of existence for the remaining few months of his life." *Id.* at [48].

79. *Id*. at [114]. McFarlane LJ said that the significant harm would result not from changing Charlie's nutrition but from continuing his ventilation. *Id*. at [115].

80. *Id*. at [118].

(vii) The Supreme Court and the European Court of Human Rights

The parents asked the Supreme Court for permission to appeal. On 8 June the court held that the trial judge had applied the right test and his factual findings could not be challenged. Moreover, as the appeal did not "raise an arguable point of law of general public importance," permission to appeal was refused.[81]

The parents lodged an appeal with the European Court of Human Rights on June 19. The court handed down its judgment on June 27, dismissing the appeal.[82] The court held that the parents' argument that the hospital's blocking of life-sustaining treatment for Charlie breached his right to life under Article 2 of the European Convention on Human Rights was manifestly ill-founded. There was no European consensus governing the withdrawal of life-sustaining treatment, so states were entitled to a margin of appreciation not only about whether to permit it but also as to the means of striking a balance between protecting the patient's right to life and his right to privacy and autonomy.[83] The UK had a regulatory framework in place which allowed all relevant parties to be heard and ensured that Charlie's interests were represented by an independent guardian, and it provided for access to the courts in cases of doubt about what was in his BI.[84] Also manifestly ill-founded was the vague argument under Article 5 that Charlie was being wrongly deprived of his liberty.[85]

While there had been an interference with the parents' Article 8(1) rights to private and family life, it did not amount to a violation of Article 8 because it satisfied Article 8(2): it was in accordance with law; had the legitimate aim of protecting the health, rights, and freedoms of Charlie, and was necessary in a democratic society to protect his BI. There was a broad consensus, including in international law, that in decisions concerning children their BI must be paramount. Even on the alternative test of significant harm proposed by the parents, the English courts had found that to subject Charlie to experimental treatment with no prospect of success would confer no benefit and would prolong his suffering. Moreover, the

81. *Gard CA* [2017] EWCA (Civ) 410, *permission to appeal refused*, [2017] UKSC, https://thaddeuspope.com/images/Permission_to_appeal_hearing_in_the_matter_of_Charlie_Gard_-_The_Supreme_Court.pdf.

82. Gard v. United Kingdom, App. No. 39793/17 (June 3, 2017), https://hudoc.echr.coe.int/fre?i=001-175359.

83. *Id.* at ¶¶ 83-84.

84. *Id.* at ¶¶ 80, 92.

85. *Id.* at ¶100.

English courts had been meticulous and thorough; ensured that all concerned were represented throughout; heard extensive and high quality expert evidence; accorded weight to the arguments raised; and reviewed the case at three levels. Their rulings could not amount to an arbitrary or disproportionate interference with the parents' rights. The parents' appeal was, then, manifestly ill-founded.[86] It is regrettable that the court did not appreciate the fundamentally discriminatory nature of the English courts' reasoning, denying Charlie's equality-in-dignity.

(viii) Back to the High Court

In July, the case came back before Francis J.[87] The parents' lawyers had contacted GOSH asserting there was new evidence, including the willingness of a hospital in Italy to take Charlie, and therefore a duty to refer the case back to the court. The judge made it clear that he could only change his ruling in the light of compelling new evidence. Dr. Hirano had now visited England to see Charlie and MRI scans had been conducted a week before. There was now a consensus between Charlie's parents, his doctors, and Dr. Hirano that Charlie was beyond any help even from the experimental treatment. The judge therefore confirmed the declarations he had made in April.[88]

(ix) Inequality-in-Dignity

In the *Gard* case, it is not difficult to find evidence, in the submissions of counsel, the testimony of medical experts, and in the judgments, of the opinion that the lives of some disabled infants are of no benefit or a disbenefit, and do not therefore enjoy an equality-in-dignity with other infants.

We will recall that in the Court of Appeal counsel for the hospital said that Charlie suffered significant harm from being ventilated and that the harm was "a condition of existence which is offering the child no benefit."[89] This clearly identifies the harm not in terms of suffering imposed by the treatment but in terms of the *life* that the treatment maintains. We will also recall[90] that Francis J, in setting out the "intellectual milestones," elaborated

86. *Id.* at ¶¶ 109-125.

87. Great Ormond St. Hosp. v. Yates (*Gard II*) [2017] EWHC (Fam) 1909.

88. *Id.* at [14].

89. *See* Gayle, *supra* note 74 and accompanying text.

90. *See Gard I* [2017] EWHC 972; *see also supra* note 53 and accompanying text.

by Holman J in *MB*, observed that the presumption in favor of continuing life could be outweighed "if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great." That "milestone" clearly relates to the perceived value of life, not to the benefits and burdens of treatment.

Similarly, McFarlane LJ, endorsing the trial judge's finding that taking Charlie to the United States would offer no benefit, commented that such a course "would simply prolong the awful existence that he found was the current state of young Charlie's life . . . ."[91] The words "awful existence" suggest that McFarlane LJ thought Charlie's life to be a disbenefit.[92] Lest it be thought that the judge's choice of words was merely infelicitous, and that he was not casting aspersion on the value of Charlie's life, there is no shortage of evidence confirming that the courts are engaged in precisely that form of discriminatory judgment. The evidence takes the form of their repeated reliance on the guidance of the RCPCH. That guidance, regularly cited as authoritative by the courts, clearly holds that the lives of some disabled children lack worth.

We will recall the three categories described by the guidance.[93] The first category refers, uncontroversially, to the burdens imposed by treatment, burdens which outweigh any benefits of the treatment. But the second and third categories make judgments about the value of the child's life. The second category states that the child's condition can involve burdens that can outweigh the benefit of the child's life. The third category assumes that the child's condition can make it impossible for the child to derive benefit from life.[94] Such judgments, that the disabilities affecting a child can be so severe as to deprive their life of benefit, or render their life a burden, are clearly incompatible with respect for their equality-in-dignity. Such objectionable judgments are not confined to the *Gard* case but are evident in cases both prior and subsequent.

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91. *Gard CA* [2017] EWCA (Civ) 410; *see also supra* note 78 and accompanying text.

92. In explaining his decision in *Gard*, Francis J's observation that there was a consensus that Charlie's quality of life was not one that should be sustained was immediately preceded by his citation, without demur, of a previous judgment describing the patients concerned as having "a life that is worth preserving" and "some value to their lives." *Gard I* [2017] EWHC (Fam) 972 at [125]-[126].

93. *See* Larcher et al., *supra* note 14 (referring to the RCPCH Guidance); *see also supra* notes 71-73 and accompanying text.

94. In the Court of Appeal in *Gard*, McFarlane LJ quoted a passage from the case of *Re A* in which Parker J, commenting on the third category, observed that even if the life of the child in the case before her were completely pain-free, "I would come to the conclusion that there is no measurable benefit to him to continue in his present condition and it is simply inhumane to permit it to continue." *Gard CA* [2017] EWCA (Civ) 410 at [76]; *see supra* note 73 and accompanying text.

2. *Subsequent Cases*

(i) Alfie Evans

The year after Charlie died the High Court decided the case of *Alfie Evans*, which also generated huge media coverage.[95] Like Charlie, Alfie had a progressive and ultimately fatal disease of the brain that was described as "catastrophic and untreatable,"[96] most likely caused by a mitochondrial disorder. Comatose, Alfie was fed by tube and kept alive on a ventilator in the Alder Hey Children's Hospital, Liverpool. The hospital wished to disconnect the ventilator but Alfie's parents wished to transport him to a hospital in Italy which had agreed to take him. Alder Hey initiated legal proceedings and the case came before Hayden J in February 2018. The judge agreed with the hospital that Alfie's ventilation should be withdrawn because it was not in his BI. Evidence of discriminatory ethical views in the report of the case is, as in *Gard*, not difficult to find.

One medical expert witness, acting for the parents, agreed with the hospital that withdrawal of ventilation was in Alfie's BI, even though the ventilation could sustain him for a long time. His support for withdrawal was based on "the futility of Alfie's life (i.e. the absence of any prospect of recovery)" and the uncertainty of knowing whether he was suffering.[97] The witness appeared to think that because the ventilation was futile, in being unable to improve Alfie's underlying condition, Alfie's *life* was therefore futile. Although suffering caused by a treatment is a legitimate factor to take into account in deciding whether that treatment is disproportionate, suffering caused by the patient's condition is not. Many people suffer chronically and severely; their suffering does not deprive them of their dignity.

No less concerningly, counsel for Alfie's guardian submitted that Alfie's life lacked dignity and that his BI could only be met by withdrawing ventilation.[98] The judge, correctly, disagreed that Alfie lacked dignity. The judge had visited Alfie in hospital and noted that Alfie's parents loved him; that the atmosphere around him was peaceful, dignified, and very happy, and that his doctors and nurses were caring and compassionate. "All this," said the judge, "creates an environment which inherently conveys dignity to Alfie

95. Alder Hey Child.'s NHS Found. Tr. v. Evans (*Evans*) [2018] EWHC (Fam) 308.

96. *Id.* at [19]-[20]. One may question the appropriateness of epithets like "catastrophic," "appalling," "terrible" and "awful" in relation to a patient's condition, epithets that, like "vegetative," risk prejudicing the dignity of the patient; *see supra* note 57.

97. *Evans* [2018] EWHC (Fam) 308 at [24].

98. *Id.* at [54].

himself." He added: "In my judgment his life has true dignity."[99] If, however, the judge thought that Alfie's dignity resulted from his caring environment, he risked confusing Alfie's *intrinsic dignity* with the *dignified circumstances* in which he found himself. Even if Alfie's environment had been uncaring, he would not have forfeited his innate dignity, a dignity that can never be lost. It is precisely because human beings enjoy an intrinsic and ineradicable dignity that carers ought to ensure that the circumstances in which their charges are cared for, whether in a hospital or at home, are dignified. Unfortunately, the judge ruled that discontinuance was in Alfie's BI because continued treatment "compromises Alfie's future dignity and fails to respect his autonomy."[100] This reasoning was doubly problematic: not only could Alfie's intrinsic dignity never be lost but he had no autonomy to be respected.

In one passage the judge rightly noted that, even though he accepted the medical evidence that continued treatment of Alfie was futile, it did not follow that "the futility of Alfie's situation" led to the immediate withdrawal of ventilation. He explained: "Life itself has intrinsic value, however tenuous or vestigial its hold." Both parents were Roman Catholic and, although not observant, their faith sustained them at this difficult time and it was important that their belief that Alfie was "a child of God" was considered within the broad gamut of factors relevant to the determination of his BI.[101]

The judge proceeded to cite an open letter from Pope Francis in 2017, tendered by counsel for the hospital, to the effect that there is no obligation to have recourse in all circumstances to every possible remedy and that it is proper to withhold or withdraw disproportionate measures. This was quite different from euthanasia, where the intent was to end life.[102] The judge said that this letter was a comprehensive answer to the evidence of a medical expert from Germany, the Director of the Department of Pediatric Cardiology and Intensive Care at a university hospital in Munich, who supported the transfer of Alfie to an Italian hospital. While this expert agreed with Alfie's doctors about the hopelessness of his medical condition, he supported his transfer and thought he could be safely transported internationally without any major risk. The expert criticized the objections of Alfie's doctors that transfer was risky: travelling might involve risk, but the disconnection of his ventilator spelled death. If Alfie were transferred to his

99. *Id.* at [54]-[56].
100. *Id.* at [66].
101. *Id.* at [51].
102. *Id.* at [52].

hospital in Germany, Alfie could stay in its intensive care unit with a view to his parents being trained to operate a home ventilation system.[103] The expert said:

> It is clear that in his best interest there should be a possibility for Alfie to live the possibly short rest of his life in dignity together with his family if this is the wish of his parents at home, which I believe is the best for him . . . . A dedicated neurological rehabilitation institution may be of additional benefit because there may well be other treatment and stimulation therapies I am not aware of.[104]

He added that because of the historical experience of his country, Germans had learned that there were certain ways severely disabled children should not be treated. He said:

> A society must be prepared to look after these severely handicapped children and not decide that life support has to be withdrawn against the will of the parents if there is uncertainty of the feelings of the child, as in this case.[105]

The judge criticized this evidence as "inflammatory and inappropriate" on the ground that the expert's views bore no relationship to, and did not engage with, the facts of the case, and that it was no part of an expert's function to utilize the case as a platform for his own personal beliefs.[106]

It is not easy to see why German expert's opinion should have been thought either inflammatory or inappropriate. Moreover, counsel for the hospital and Hayden J misunderstood the Papal letter which they thought provided a comprehensive rebuttal of the expert's opinion. First, Catholic moral teaching (teaching which is philosophical, not theological) *agrees* with that expert's suggestion that all infants, irrespective of disability, enjoy an intrinsic, ineliminable dignity and a worthwhile life, and that it is wrong to withhold or withdraw treatment on the basis of a judgment that their life is "futile" or "awful." Second, while the church's teaching holds that there is no obligation to consent to disproportionate treatments *it does not hold that it*

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103. *Id*. at [41]-[42].

104. *Id*. at [43].

105. *Id*. at [44].

106. *Id*.; E (A Child) [2018] EWCA (Civ) 550 [44] (Eng.). In the Court of Appeal, King LJ agreed that the Papal letter comprehensively rebutted the German expert's "tendentious views." She said that there was nothing in the expert's personal views which could or should impact the proper application of a BI evaluation.

is therefore wrong to consent to them. It makes a distinction, overlooked in cases like *Gard* and *Evans*, between a treatment being morally *obligatory* and a treatment being morally *optional.* It is one thing to say that parents and their medical advisors *need not* maintain a disproportionate treatment, quite another to say they *must not* do so. This distinction applies equally to competent patients. Take, for example, the hypothetical case of Hilda. Hilda has lung cancer and is only days from death. She finds the artificial ventilation that is sustaining her life very painful. The ventilation is, then, disproportionate for two reasons: it is futile – it cannot secure a therapeutic benefit because it cannot cure or treat her cancer – and it is very burdensome to her. Hilda may, therefore, morally request that it be discontinued for either reason or both. But the fact that she *may* request discontinuance does not mean that she *must*. She may wish the disproportionate treatment to be continued for various reasons. She may, for example, want to live a little longer so as to be able to say goodbye to her beloved son who is travelling to her bedside from a distant country.[107]

In short, properly understood, the Papal teaching quoted by Hayden J does nothing to support his judgment or to controvert the testimony of the German medical expert. On the contrary, that teaching is *inconsistent* with the judgment for Hayden J relied,[108] like the Court of Appeal in *Re A (HR)* and *Gard,* upon the guidance of the RCPCH[109] which openly assumes (contrary to Catholic moral teaching) that the lives of some infants with disabilities are of no benefit or a burden and that it is ethical for life-sustaining treatment to be withdrawn for either reason.

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107. For the Catholic Church's ethical teaching on the parental right to consent to disproportionate treatments, see Joan Desmond, *Catholic Bioethicist: Authorities 'Usurped' Role of Charlie Gard's Parents*, NAT'L CATH. REG. (July 8, 2017), https://www.ncregister.com/blog/catholic-bioethicist-authorities-usurped-role-of-charlie-gard-s-parents. On the importance of respect for parents' religious views, see David Albert Jones, et al., *Doctors, Dying Children and Religious Parents: Dialogue or Demonization?*, 8 CLINICAL ETHICS 2 (2013).

There is good authority that Hilda's doctors would be under a legal duty to continue her ventilation (or at least refer her to other doctors willing to do so). Burke v. Gen. Med. Council [2005] EWCA (Civ) 1003. It appears that the duty would apply even if Hilda became incapacitous and would have wanted continued ventilation. The Mental Capacity Act 2005, c. 9, § 4(6) (Eng.), adopts a "substituted judgment" test to determine the BI of incapacitous adults. *See infra* note 270.

108. Alder Hey Child.'s NHS Found. Tr. v. Evans [2018] EWHC (Fam) 308 [46] (Eng.) ("It is necessary here to root my conclusions in the framework of the law and within the available guidance [of the Royal College of Paediatrics and Child Health].").

109. *See* Larcher et al., *supra* note 14 (referring to the RCPCH Guidance); *see also supra* notes 71-73 and accompanying text.

Third, Pope Francis lent his personal support to Alfie's parents and asked "that their desire to seek new forms of treatment may be granted."[110] He instructed the Vatican Secretariat of State to seek a diplomatic solution, which was facilitated by the grant of Italian citizenship to Alfie, and arranged for the President of the Bambino Gesù hospital to fly to England to try to persuade the English doctors to allow Alfie to be flown to Rome by Italian military helicopter. After Alfie's death, the Vatican Secretary of State, Cardinal Parolin, said that he could not understand the courts' refusal to allow Alfie to be transferred and that until Alfie's death, and in spite of the "stubbornness" of the English judges, the Pope had tried to do everything he could to help the family.[111]

As with the *Gard* case, appeals to the Court of Appeal,[112] Supreme Court[113] and European Court of Human Rights[114] failed. On 11 April 2018 Hayden J endorsed the care plan proposed by the hospital which set out arrangements for the end of Alfie's life.[115]

(ii) Tafida Raqeeb

In 2019, the High Court decided case of *Tafida Raqeeb*.[116] Tafida was five and earlier that year had suffered a ruptured arteriovenous malformation (AVM). This resulted in "catastrophic" and irreversible brain damage

110. *Pope Francis Renews Appeal for Alfie Evans*, VATICAN NEWS (Apr. 24, 2018) https://www.vaticannews.va/en/pope/news/2018-04/pope-alfie-evans-twitter-appeal.html.

111. *The Head of Vatican Diplomacy Answers Questions on Recent News Stories*, FSSPX NEWS (May 22, 2018), https://fsspx.news/en/news/head-vatican-diplomacy-answers-questions-recent-news-stories-19365.

112. E (A Child) [2018] EWCA (Civ) 550. King LJ, delivering the judgment of the court, observed that it was "inconceivable that a trust would contemplate withdrawal of treatment of a child leading inevitably to his or her death unless they were of the view that following the [RCPCH] guidelines, his life was 'futile.'" *Id.* at 115.

113. Evans v. Alder Hey Child.'s NHS Found. Tr. [2018] EWCA (Civ) 805, permission to appeal refused, [2018] UKSC, https://www.supremecourt.uk/cases/docs/alfie-evans-reasons-200318.pdf.

114. Evans v. The United Kingdom, App. No. 14238/18 (Mar. 28, 2018).

115. Alder Hey Child.'s NHS Found. Tr. v. Evans [2018] EWHC (Fam) 818. On 16 April the Court of Appeal dismissed the parents' appeal against Hayden J's rejection of their application for a writ of *habeas corpus.* Evans v. Alder Hey Child.'s NHS Found. Tr. [2018] EWCA (Civ) 805. An appeal to the European Court of Human Rights on the basis that the prevention of transfer breached Archie's rights to liberty and security under Article 5 of the European Convention was dismissed. Evans v. United Kingdom, App. No.18770/18 (Apr. 23, 2018), https://www.echr.coe.int/documents/d/echr/Decision_Evans_v_UK. The Court of Appeal dismissed a further appeal based on the facts that Alfie did not die when his ventilation was discontinued and was now an Italian citizen. Evans v. Alder Hey Child.'s Hosp. NHS Found. Tr. [2018] EWCA (Civ) 984.

116. Barts NHS Found. Tr. v. Raqeeb, [2019] EWHC (Fam) 2530 (Eng.).

rendering her dependent on a ventilator, albeit medically stable. The hospital wished to discontinue her ventilation, but her parents wanted her to be transferred to a pediatric hospital in Italy that was willing to take her. The case came before MacDonald J.

The medical evidence was that if Tafida were aware at all, she was only minimally so. There was no evidence that her everyday life involved any pain though the possibility that she could perceive pain could not be excluded.[117] The evidence also indicated that Tafida could be transported with minimum risk; that there were children in a similar condition who were being sustained long term at hospital and at home and that, even if she could not be weaned off the ventilator, there was a reasonable prospect of her being cared for at home and of living for ten to twenty years.[118] The chances of any substantial improvement in her condition were very low.[119]

The judge considered Tafida's "Medical Best Interests." He noted the hospital's submission that further treatment was not in her BI. Her treating doctor, an intensivist, thought the life-sustaining treatment was a continuing burden on her. Her neurologist thought that the proposition that because Tafida did not feel pain or distress further treatment would not cause pain or distress was an "artificial semantic construct" because if she had a "sentient" brain she *would* feel pain and distress, and that she should be allowed "the dignity of dying peacefully."[120] (What the expert thought semantically artificial about recognizing that Tafida did not feel pain or distress was left unexplained.) A consultant in pediatric neurology instructed by the hospital gave evidence that the prospect of her gaining increased awareness was negligible and with greater awareness would come awareness of the burdens of her severe neurodisability.[121] An intensivist instructed by Tafida's Litigation Friend thought that although the burdens of ventilation, if any, were modest, discontinuation was in her BI because, in line with the RCPCH guidance, it was difficult or impossible for her to derive benefit from continued life.[122] Counsel for the hospital submitted that Tafida had no hope of recovery, or only a minimal level of recovery that would be adverse to her welfare. Tafida had only "animation without experience."[123] Absence of awareness did not mean an absence of harm, given that lack of the ability to

117. *Id.* at [3]-[24].
118. *Id.* at [26]–[31].
119. *Id.* at [32]–[34].
120. *Id.* at [35].
121. *Id.* at [36].
122. *Id.* at [37].
123. *Id.* at [65].

derive benefit was a factor in assessing quality of life under the RCPCH guidance.[124] Counsel advanced the (confused) argument that, with respect to Tafida's right to life under Article 2 of the European Convention on Human Rights, the court

> should not concern itself with teleological or ontological arguments concerning the meaning of life (such as whether a life without awareness or experience is properly consistent with conceptions of being) but rather consider the quality of Tafida's current existence as measured against the principle that sanctity of life is of the highest importance.[125]

Given that Tafida derived no benefit from life, counsel submitted, the sanctity of life was outweighed by other considerations. As for dignity, the concept meant different things to different people, and it would not be dignified to transport Tafida to be kept alive in a moribund state.[126] With respect to the evidence of the medical experts that children in a similar condition to Tafida were being ventilated long-term in hospital and at home, counsel argued that it was insufficiently cogent and lacked specificity.[127]

Tafida's guardian also supported withdrawal of her ventilation. She said it was difficult to see how it could be in her BI "to have to endure the life that she currently leads devoid of any quality and beleaguered by the burden of illness and procedures that keep her alive."[128] She added: "The current regime is an inevitable burden upon Tafida, regardless of whether she experiences the pain or discomfort that would otherwise be associated with these procedures . . . ."[129] Counsel for the guardian submitted that "continued life sustaining treatment leading to a life of no suffering but no pleasure is

124. *Id.* at [66] (counsel submitted that as Tafida was either in a "vegetative" state or a minimally conscious state, compelling evidence would be required to demonstrate she would have wanted ventilation); *Id.* at [68] (counsel gave no reason to support this odd submission. No less oddly, counsel submitted that discontinuation would not breach Tafida's and her parents' freedom of religion under Article 9 of the European Convention on Human Rights since they would not, as Muslims who opposed discontinuation, be breaching a *fatwa* issued by the Muslim Council of Europe tendered in evidence against discontinuation); *Id.* at [69] (but discontinuation would offend their religious beliefs even if discontinuation were imposed on them, just like an abortion carried out on an observant but incapacitous Catholic).

125. *Id.* at [71].

126. *Id.* at [72].

127. *Id.* at [73]. This submission was strange. If those witnesses were expert in relation to Tafida's condition, why not in relation to medical practice concerning the treatment of patients in her condition?

128. *Id.* at [82].

129. *Id.*

not in Tafida's best interests."[130] How treatment could burden Tafida if she could not experience discomfort, and why pleasure was thought essential to the value of a person's life, were not explained.

By contrast, counsel for the parents submitted that in the absence of pain and suffering the question of the inability to derive benefit was a heavily value-laden factor and the best evidence as to benefit came from the family and the religious and cultural context in which they lived, rather than the narrower, medical perspective of the doctors.[131] It was the parents' position that the continuation of her life was itself inherently a good and that Tafida was growing up in a faith in which the sanctity of life was of the highest importance. Moreover, life with a severe disability was, in both domestic and international law, of equal value to other lives.[132] On the question of dignity, the parents submitted that the court should not hold that the life of a severely disabled child was undignified or of less dignity than that of a child without disability, and that there was no evidence that Tafida would consider her life undignified.[133]

MacDonald J decided the case on the basis that Tafida likely retained a minimal level of awareness and did not perceive pain in her resting state; that her condition was substantially irreversible and that she would remain profoundly neurologically disabled, and that if sustained for the next ten to twenty years, it was more than likely she would develop a range of consequential conditions including drug-resistant epilepsy, scoliosis, and renal stones.[134]

The judge took as his starting-point Tafida's assumed point of view. While recognizing the obvious difficulties of putting himself into the shoes of such a young child, he said he had to do the best he could on the available evidence.[135] He was satisfied that she would not reject out of hand a situation in which she was ventilated at home in the loving care of her dedicated family, consistent with her formative appreciation that life is precious and a non-judgmental attitude to disability, and a wish to follow her parents'

130. *Id.* at [86].

131. *Id.* at [75].

132. *Id.* at [77].

133. *Id.* at [80]. The judgment states that counsel for the parents had submitted that dignity was a subjective concept that meant different things to different people and had cautioned against the use of such a mercurial factor in the BI analysis. *Id.* at [136]. The judgment appears to confuse the submission of counsel for the parents with that of counsel for the hospital. *See id.* at [72].

134. *Id.* at [160]–[163].

135. *Id.* at [166].

religious practice.[136] Turning to the sanctity of life, the judge regarded the *fatwa* against disconnection that had been issued by the Muslim Council of Europe as a valuable restatement of the sanctity of life, a sanctity recognized by all the great religions and by those who view life through a secular prism. Tafida's life had an inherent value, and was of value to her and to her parents. She was profoundly disabled, but a life of disability was of equal value to all other lives.[137]

The key principle in the case was, said the judge, that the sanctity of life was not absolute and could give way to countervailing factors. The authorities established that it could be overborne in cases where, as the RCPCH's guidance pointed out, a child had no or minimal awareness and treatment could not provide overall benefit.[138] The judge accepted that continued treatment was medically futile.[139] However, he added, the benefits of treatment could extend beyond the merely medical and the assumption that we have no interests except in those things of which we have conscious experience did not accord with the intuitive feelings of many people, particularly those with a strong religious faith.[140] The benefits for Tafida included being at home in the care of her loving family and, insofar as she was minimally aware, gaining from her awareness of such care. A further benefit was remaining alive in accordance with the tenets of her religion for which she had begun to demonstrate a basic affinity.[141] The judge also bore in mind the evidence from the Italian specialists about the possibility of Tafida being weaned off the ventilation and that the prognosis of children with prolonged disorders of consciousness was not well-defined.[142]

As for the issue of burdens, while the hospital and guardian had submitted that the possibility that Tafida felt pain could not be excluded, the standard of proof was the balance of probabilities. Fidelity to that standard was important in every case, all the more so when the outcome being considered was so grave.[143] To the hospital's submission that continued invasive treatment would increasingly burden her dignity, the judge replied that dignity had no universal meaning. It contained a significant element of subjectivity and was influenced by the religious or cultural context in which

136. *Id.* at [168].
137. *Id.* at [169].
138. *Id.* at [170].
139. *Id.* at [171].
140. *Id.* at [172].
141. *Id.* at [173].
142. *Id.* at [174].
143. *Id.* at [175].

the question was being considered. There was innate dignity in the life of a human being who was cared for well and free from pain.[144] Being cared for by a loving family, consistently with the religious values in which she had been raised, was significantly different from continuing care in an intensive care unit.[145]

As for the medical opinions, the judge noted that while the British doctors agreed that continuing treatment was no longer in Tafida's BI, one of them thought the issue was finely balanced. Moreover, the Italian doctors thought continuing treatment appropriate. Further, the British doctors accepted that the course recommended by the Italian doctors was often adopted in Britain. While Article 2 of the European Convention on Human Rights did not extend to providing treatment which was futile and which a responsible body of medical opinion did not judge in the patient's BI, in this case there was a responsible body of medical opinion that took a contrary view.[146] As for the course of medical treatment proposed, this was not a case where transport was merely a theoretical option or for an untried experimental treatment or where the only option was an intensive care unit.[147]

MacDonald J held that although there were substantial factors supporting the hospital's case, Tafida's BI *did* warrant her transportation to Italy. He said:

> in circumstances where Tafida is not in pain, where the burden of the treatment is low, where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to her being cared for at home on ventilation by her family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction, where there is a funded care plan to this end, where Tafida can be safely transported to Italy, where the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised and having regard to the sanctity of Tafida's life, this case *does* in my judgment lie towards the end of the scale where the court should give weight to the reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of the child's life

144. *Id.* at [176].
145. *Id.* at [177].
146. *Id.* at [178].
147. *Id.* at [179].

> will be taken for the child by a parent in the exercise of their parental responsibility.[148]

He added, however, that the case was "very finely balanced."[149] The judgement closed:

> Absent the fact of pain or the awareness of suffering, the answer to the objective best interests test must be looked for in subjective or highly value laden ethical, moral or religious factors extrinsic to the child, such as futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, which factors mean different things to different people in a diverse, multicultural and multifaith society.[150]

The judge commendably arrived at the correct conclusion, and to that extent the case represents an improvement on *Gard* and *Evans*. However, the judgment, like the judgments in those cases, disclosed a failure to endorse the equal worth of all infants irrespective of disability. The opening paragraph of the judgment referred to what many saw as the child's "appalling" situation which, for some, "remains sanctified morally or as an article of religious faith" but which, seen by the doctors through the prism of medical BI, was "at best a barely wakeful shadow burdened by futile medical treatment or, at worst, mere oblivion."[151] Moreover, the judgment's understanding of dignity was confused. Instead of endorsing the objective and equal dignity of all children irrespective of their disability, it accepted that dignity was to a significant extent a subjective notion, and that "[n]ot all human life is lived in dignity," which implied that those not cared for well, or who lived in pain, lacked dignity.[152] Further, the judgment invoked the RCPCH guidance, particularly in cases where life is limited in quality due to an inability to benefit from continued life.[153] The judge failed to affirm that Tafida's life was a benefit irrespective of her level of awareness or the location of her care or her family's religion or the views of a "responsible body of medical opinion."

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148. *Id.* at [182].

149. *Id.* at [185].

150. *Id.* at [191].

151. *Id.* at [1] (the judgment here missed an early opportunity to assert the law's recognition of the fundamental equality of all children, whatever their disability).

152. *Id.* at [137].

153. *Id.* at [138], [139].

A significant factor influencing the judge in the right direction appears to have been the evidence that other children in Tafida's condition were being ventilated long-term in UK hospitals. Had he ruled that Tafida's BI did not warrant continued ventilation, the disturbing implication would have been that *their* continued ventilation was also unlawful. English judges are notoriously reluctant to question professional medical practice and opinion.

(iii) Pippa Knight

The case of *Tafida Raqeeb* can be contrasted with that of *Pippa Knight.*[154] When Pippa was two she was diagnosed with a rare and usually terminal condition called acute necrotizing encephalopathy (ANE) which resulted in severe brain damage. She was later diagnosed as being in a "persistent vegetative state" and lay, ventilator-dependent, in hospital. When she was almost five the hospital applied to court for a ruling that it would be in her BI for her ventilation to be stopped. Her mother wanted Pippa to be cared for at home and some independent doctors thought this might be feasible.[155] Poole J held it would be in Pippa's BI for her ventilation to be withdrawn, and the Court of Appeal agreed. Delivering the judgment of the Court of Appeal, Baker LJ said that Pippa's situation was factually different from Tafida's. For example, all the experts in Tafida's case had agreed that it was feasible to ventilate her at home[156] and the judicial approach to the balancing exercise was substantially the same in both cases.[157]

One may suggest that it is precisely because of their similarity that the judgment of Poole J is no less open to criticism than that of MacDonald J, if not more so. For Poole J repeatedly assumed that a life like Pippa's may be of no benefit, if not a burden. He concluded that there was "no subjective benefit to Pippa" from being kept alive in the intensive care unit[158] and he rejected a submission on behalf of her mother that medical treatment caused no physical harm to an unaware patient. The judge said: "it would be an error to allow the absence of pain or any sensation to prevent a wider consideration of welfare incorporating a consideration of physical or other harm or detriment to Pippa, from her condition, and from the treatments she needs to keep her alive."[159] He took into account "the detriment to Pippa's

154. Parfitt v. Guy's & St. Thomas' Child.'s NHS Found. Tr., [2021] EWCA (Civ) 362 (Eng.).
155. *Id.* at [1]-[6].
156. *Id.* at [61], [85].
157. *Id.* at [72].
158. *Id.* at [44].
159. *Id.* at [45].

welfare caused by her condition and the treatment for it, even though she is unaware of that detriment." He added:

> It is insufficient to view her condition as depriving her of benefit. Her condition and the treatment it necessitates are significant burdens. Even if one discounted these factors in the welfare assessment, on the grounds that Pippa has no conscious awareness of them, they ought to be taken into account in the broad assessment of her interests. It must be relevant to any assessment of her interests that she has such grave loss of function and requires such intensive and intrusive treatment to preserve her life.[160]

He also said:

> The losses of freedom, function, and ability to enjoy childhood, that severe disability, including severe brain damage, cause someone such as Pippa, are a form of harm which should be considered in assessing her welfare, whether or not they can feel pain and whether or not they have any conscious awareness.[161]

Like MacDonald J, Poole J had little time for the concept of dignity, which he thought "problematic" and involving "a high degree of subjectivity." He said: "given the very different ideas expressed to the court about what would constitute dignity for Pippa in life and in her dying, I shall not presume to adopt some supposedly objective concept of dignity to determine her best interests."[162] Pippa's guardian made extensive submissions about dignity but, unfortunately, the wrong ones. He submitted that there was an "innate indignity" and burden associated with the intensive and intrusive treatment required to keep Pippa alive, and her grave loss of function, and he submitted it was in her BI for her ventilation to be discontinued.[163]

As regards any benefits to Pippa from continued life, Poole J could not find "any palpable or impalpable benefit" to Pippa from prolonging her life

160. *Id.* at [45].
161. *Id.* at [57].
162. *Id.* at [49].
163. *Id.* at [98].

in the intensive care unit. "The profound loss of function and the daily invasion of her bodily integrity necessary to prolong her life constitute objectively identifiable burdens on Pippa's person."[164] He added: "She has no conscious awareness of and she gains no benefit from life but she daily bears the dual burdens of her profoundly disabling condition and the intensive treatment she requires to prevent it from ending her life. . . ."[165]

It could scarcely be clearer that the judge thought Pippa's life not only of no benefit but also a harm to her. And although the harm was her condition of unawareness, the fact that she was unaware of her unawareness was not thought to prevent the harm. No less problematic is how Pippa was thought to be burdened by her treatment. Labelling treatment as invasive of bodily integrity does not make it a burden (especially if the patient is unaware of it) unless, surely, it is the life that the treatment maintains that is thought burdensome. Would intensive care for an unconscious young accident victim be described as an invasion of her bodily integrity if she were expected to regain consciousness? Such treatment would surely be regarded as the conferral of a benefit, not the imposition of a burden.

The Court of Appeal, in affirming Poole J's judgment, endorsed his citation of King LJ in *Re A*. In that case King LJ (who also happened to be a member of appellate bench in *Knight*) had agreed with the trial judge's finding that ventilation should be withdrawn from a brain-damaged two-year-old because, even if his life were pain-free, there was no measurable benefit in his continued life and it would be inhumane to allow it to continue.[166] The Court of Appeal also rejected a submission by counsel for Pippa's mother that Poole J had been wrong to hold that Pippa suffered harm from continued treatment. Baker LJ observed that in the criminal law an unconscious person could suffer actual or grievous bodily harm.[167] This is true, but it begs the question whether Pippa's treatment, and even more so her very life, constituted a harm to her. The Court of Appeal distinguished *Raqeeb*, but not all will find the court's reasoning persuasive. The court pointed out that Tafida was minimally aware and that her condition and treatments did not cause physical harm on the scale endured by Pippa.[168] But as Pippa was completely unaware how could the harm be greater, unless it was thought that her total unawareness was the greater harm? And if one is

164. *Id.* at [50].
165. *Id.* at [51], [54].
166. *Id.* at [58]; *see also supra* notes 71, 73, 94.
167. *Parfitt* [2021] EWCA (Civ) 362 at [60].
168. *Id.* at [61], [85].

prepared to judge that certain lives are harms, why is life with minimal awareness not thought an even greater harm than life with none? Finally, if it was in Tafida's BI to be ventilated at home, why was it not in Pippa's BI to remain ventilated in hospital, as her mother wanted?

(iv) Other Cases

There are a number of other cases subsequent to *Gard* in which medical witnesses, guardians, and judges have taken into account the lack of benefit, or burden, of the infant's life in concluding that withdrawal of treatment was in his or her BI.

In *Alta Fixsler*,[169] MacDonald J held it was in the BI of a two-year-old girl with severe brain damage and life expectancy of up to two years to have her ventilation withdrawn rather than to be transferred to Israel for continued treatment, as her Ultra-Orthodox Jewish parents wished. The medical experts unanimously agreed it would be in her BI for her ventilation to be withdrawn, one pointing out[170] that "the burden of her underlying condition" was a relevant factor mentioned in the RCPCH guidance. Alta's guardian also favored discontinuance, submitting that "Alta has no quality of life. The burdens of Alta's life outweigh any benefits . . . ."[171] The judge observed that Alta's life had inherent value and that a life of disability was equal value to other lives.[172] However, having referred to the relevant passages from the guidance of the RCPCH,[173] he concluded: "I am satisfied that the burden of Alta's underlying condition, generating as it does an experience of consistent pain for Alta and leaving her as it does in a state of perpetual darkness and silence, acts to overcome the benefits in sustaining her life."[174] The Court of Appeal dismissed an appeal by Alta's parents.[175]

169. Manchester Univ. NHS Found. Tr. v. Fixsler [2021] EWHC (Fam) 1426, [38]-[39], [116].

170. *Id.* at [46].

171. *Id.* at [47].

172. *Id.* at [97].

173. *Id.* at [73]-[75].

174. *Id.* at [109]. Mr. Justice MacDonald said the fact that she was in consistent pain was "a very heavy counterweight" to the presumption in favor of preserving life. *Id.* at [99]. He attached significant weight to the burdens that would be imposed by continuous treatment. *Id.* at [100]; *see also* Dominic Lawson, *Our Courts Are Wrong. Let This Little Girl Leave*, THE SUNDAY TIMES (Aug. 8, 2021) https://www.thetimes.com/business-money/economics/article/our-courts-are-wrong-let-this-little-girl-leave-bjxmrtl0s (questioning whether Alta was in fact suffering or in pain).

175. Fixsler v. Manchester Univ. NHS Found. Tr. [2021] EWCA (Civ) 1018, [93]-[94].

In *Guy's and St Thomas' NHS Foundation Trust v. A, F and M*,[176] Poole J granted an application by the hospital for a declaration that continued ventilation was not in the BI of a five-month-old brain-damaged infant, Baby A, despite his parents' wishes.[177] Although his life was limited, the doctors could not predict how long he might live on ventilation.[178] This was yet another case in which the medical experts, the guardian for the child, and the judge seemed to think that lack of benefit from living was a key factor in deciding that continued treatment would not be in the child's BI. The baby's consultant pediatric intensivist opined that continued ventilation was unethical because it imposed burdens on the baby and provided no benefit: it served only to "prolong his death."[179] An independent medical witness, who cited the RCPCH guidance, submitted that ventilation would preserve the baby's life, but it would be "an extended life that would have no benefit to him."[180] The baby's guardian supported the hospital's application, submitting that if the baby could not experience pleasure or pain then, balancing the benefits and burdens, his BI lay in disconnection.[181]

The judge found that the baby probably had no conscious experience of pain or discomfort but that some vestigial response could not be ruled out, and that possibilities as well as probabilities could be fed into the BI assessment.[182] The baby underwent frequent deep suctioning, was ventilated and fed by nasogastric tube. The judge said: "These constitute burdens upon him even though he is not conscious of them."[183] There was, however, benefit to the baby in that he was the object of love and devotion from his family, though the benefit of being cared for was limited by the fact that the care was provided in the setting of an intensive care unit, not a family home.[184] The judge concluded: "Weighing all the burdens and benefits to A from his current life, I have little hesitation in concluding that the burdens

176. Guy's & St. Thomas' NHS Found. Tr. v. A [2022] EWHC (Fam) 2422.

177. *See id.* at [5] (previously the baby had, following the standard protocols, been diagnosed as "brain-stem dead," but a few days later he was seen attempting to breathe. The hospital then amended its application for a declaration that the baby was dead to a declaration that continued treatment was not in his BI); *see also* D. Alan Shewmon & Noriko Salamon, *The Extraordinary Case of Jahi McMath*, 64 PERSPS. BIOLOGY & MED. 457 (2021).

178. *Guy's & St. Thomas' NHS Found. Tr*. [2022] EWHC (Fam) 2422 at [35].

179. *Id.* at [26].

180. *Id.* at [41].

181. *Id.* at [56].

182. *Id.* at [64]-[65].

183. *Id.* at [66].

184. *Id.* at [67].

outweigh the benefits."[185] He added: "He is trapped in an intensive care unit and deprived by his condition of all the opportunities for interaction, development, and family life that a baby might otherwise enjoy."[186] His quality of life was "extremely poor" and he would "only continue to suffer more burdens than benefits from living."[187] So long as he was kept alive, he would suffer more burdens than benefits "from being alive."[188]

3. *Prior Cases*

Despite the enormous public and academic attention the *Gard* case attracted, it was by no means the first in which the courts had endorsed such controversial moral views as those laid down in the RCPCH guidance. There were a number of prior cases which merited, but did not receive, comparable media and scholarly attention.

(i) Re B

In this case, decided almost forty years before *Gard*, a High Court judge held that it would be in the BI of a baby with Down syndrome to die rather than undergo a routine, life-saving operation to remove an intestinal blockage. The judgment was reversed on appeal by two judges of the Divisional Court, but even they suggested that some children with disabilities would be better off dead. One described the legal test to be applied as whether the life of the child was "demonstrably going to be so awful that in effect the child must be condemned to die . . . ."[189] The other judge described the test as whether the child's life was likely to be "intolerable."[190] Their

185. *Id.* at [68].

186. *Id.*

187. *Id.* at [75].

188. *Id.* at [76]. Re NR (A Child: Withdrawal of Life Sustaining Treatment) v. King's Coll. Hosp. NHS Found. Tr. [2024] EWHC (Fam) 910 [46]-[48]. (the same judge held the burdens of the disabled child's conditions, as well as of the treatments keeping him alive, were many and heavy; that his case fell clearly within the RCPCH guidance on when life lacked benefit and involved burdens, and he authorized withdrawal. The child defied the medical experts' prognoses by surviving withdrawal. His condition improved and months later was being cared for at home by his loving parents.); Michelle Roberts, "*Remarkable" Boy Survived Life-Support Switch-Off, Judge Says*, BBC NEWS (Sept. 24, 2024); https://www.bbc.com/news/articles/c5y3r7klxeyo. Paul Gallagher, *Charlie Gard case: Whatever Happened to Baby Charlotte Who Was Also Expected to Die?*, THE I PAPER (July 21, 2017) https://inews.co.uk/news/health/charlie-gard-case-charlotte-wyatt-high-court-80088 (illustrating medical fallibility concerning the infant's prognosis in the leading case of *Wyatt v. Portsmouth NHS Hosp. Tr.*).

189. Re B (A Minor) [1981] 1 WLR 1421 (EWCA (Civ)) (Templeman LJ).

190. *Id.* (Dunn LJ).

judgments were extempore, but nonetheless revealing in spite of (if not because of) that.

(ii) Re J

In the leading case of *Re J*[191] (cited by Francis J in *Gard*) Lord Donaldson MR said that the words "demonstrably so awful" or "intolerable" should not be regarded as laying down a quasi-statutory yardstick.[192] Similarly, Balcombe LJ did not think that either Templeman or Dunn LJJ had intended to lay down a test applicable to all circumstances, and he deprecated any attempt to lay down such an all-embracing test as the circumstances of these tragic cases were so various.[193] However, the third judge, Taylor LJ (as he then was), did endorse the "intolerability" test. He said: "the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child."[194] In the later important case of *Wyatt v. Portsmouth Hospital NHS Trust*[195] (also cited by Francis J in *Gard*) the Court of Appeal observed that although the criterion of "intolerability" should not be seen as a gloss on BI, much less a supplementary test to it, it nevertheless provided a "valuable guide" in the search for BI in such cases.[196] As Holman J wryly remarked in the later case of *Re MB* (the next case we shall consider): "I doubt my own intellectual capacity on the one hand to exclude it even as a 'gloss on,' much less supplementary test to, best interests; and yet on the other hand treat it as a 'valuable guide.'"[197]

(iii) An NHS Trust v. MB

In this case (cited by Francis J in *Gard* as explaining the "intellectual milestones" to be followed[198]) an NHS Trust applied for a declaration that continued ventilation of an eighteen-month infant with a very severe case of spinal muscular atrophy (SMA) was not in his BI. SMA is a degenerative

191. Re J (A Minor) [1991] Fam. 33 (EWCA (Civ)).
192. *Id.* at [46].
193. *Id.* at [52].
194. *Id.* at [55].
195. Wyatt v. Portsmouth NHS Tr. [2005] EWCA (Civ) 1181.
196. *Id.* at [76], [91].
197. An NHS Tr. v. MB [2006] EWHC (Fam) 507 [17] (Eng.).
198. *See supra* notes 50-58 and accompanying text.

condition in which the voluntary muscles, including the respiratory muscles, become progressively weaker until they cease to function. Impairment of the brain is not normally, however, a feature of the condition.[199] Although death was inevitable, MB might live for a few years.[200] The infant's parents wished his ventilation to be continued.

Holman J noted: "The NHS Trust, in reality the treating doctors, consider that the quality of life for M is now so low that the burdens of living are now so great that it is unethical (the word 'cruel' has been used) to continue artificially to keep him alive . . . ."[201] The two key consultants caring for MB, plus six other consultants who were part of the clinical team caring for him, agreed that MB had an "intolerably poor quality of life" that would only get worse.[202] In the view of one of the two key consultants the "worst possible scenario" was if MB had normal cognitive function and was aware of all the discomforting medical procedures (such as deep suctioning) that he was undergoing.[203] Four expert witnesses of consultant status agreed that withdrawal was in MB's BI.[204] There was, then, as the judge pointed out "a very formidable body of medical evidence of very high quality" that was unanimous that ventilation should be withdrawn.[205]

The judge invited counsel to draw up lists of the benefits and burdens of continued ventilation. The list tendered by counsel for the hospital listed only one benefit: the preservation of life. The judge preferred the more extensive list drawn up by counsel for the guardian, which contained six benefits (including the sensation of gentle strokes and listening to music) though many more burdens (such as MB's inability to move his body or to swallow).[206] The guardian was "very strongly" of the view that the burdens outweighed the benefits.[207]

The judge observed that no court had as yet been invited to approve, against the wishes of the parents, the withdrawal of treatment that would result in the immediate death of a conscious child with sensory awareness,

199. An NHS Tr., [2006] EWHC (Fam) 507 at [5]-[8].
200. *Id.* at [31].
201. *Id.* at [10].
202. *Id.* at [25]-[26].
203. *Id.* at [31].
204. *Id.* at [29].
205. *Id.* at [30].
206. *Id.* at [58]-[61].
207. *Id.* at [87].

normal cognition, and no significant brain damage.[208] He was not persuaded, even taking into account MB's predicted deterioration, that withdrawal was in his BI. Indeed, he considered it positively in his BI that ventilation be continued.[209] While accepting that MB was daily subjected to various burdens, such as the short episodes of pain caused by deep suctioning, MB nevertheless enjoyed cognition, pleasurable sensations, and a relationship of value with his family, benefits that were both precious and real.[210] Although a vast range of early childhood experiences and pleasures, such as crawling and exploring, were not available to him, he was still left with a core of pleasure, "including what is probably the single most important source of pleasure and emotion to a small child, his relationship with his parents and family."[211] In conclusion, the judge stressed that, critically, MB had survived on ventilation for eighteen months; was assumed not to have brain damage; was in a close relationship with his family who were able to spend considerable time with him; and had sufficient cognition to derive pleasure from his experiences.[212]

MB is, like *Raqueeb*, a case in which a judge, unusually, rejected the submissions of the hospital and the guardian that discontinuation of treatment would be in the BI of the child. Like MacDonald J in *Raqueeb*, Holman J is to be commended for arriving at the right decision. However, his judgment, like the submissions of the hospital and guardian, and the unanimous testimony of the medical witnesses, crucially confuses the burdens of the infant's treatment with the perceived burdens of the infant's life. Moreover, MB's life would have been of inestimable value even if it had been completely unaware of the devoted care of his loving parents. Their loving care for him, like that of the parents in the other cases we have considered, remains a considerable benefit to their child irrespective of the child's awareness of it. The provision of care to a loved one, whether an insensate child or a parent with dementia, is of benefit irrespective of the recipient's awareness of being cared for, or knowing who is providing the care, as is the loving relationship that generates the care. It is, indeed, remarkable that what should be regarded as one of the most important factors

208. *Id.* at [11]; *see also id.* at [12] (distinguishing the case of Re C (A Baby) [1996] 2 FLR 43 in which the baby had suffered serious brain damage resulting in what the judge, Sir Stephen Brown P, described as "almost a living death").

209. *Id.* at [90].

210. *Id.* at [100]-[02]; *see also id.* at [63]-[69].

211. *Id.* at [69].

212. *Id.* at [106].

in these cases, the deep and sacrificial love shown by parents for their children, truly a benefit beyond measure, seems so easily eclipsed.

(iv) Re AA[213]

In *Re J* Taylor LJ emphasized that the court "never sanctions steps to terminate life" as that would be unlawful. He added: "There is no question of approving, even in a case of the most horrendous disability, a course aimed at terminating life or accelerating death."[214] Some observers of the cases we have considered may wonder whether, even if the courts do not in terms approve courses of conduct aimed at hastening death, they nevertheless sometimes seem to come close to it. Any such concerns will not have been assuaged by a final case prior to *Gard* that we shall consider: *Re AA.*

In August 2014, GOSH applied for a declaration that it would be lawful to withdraw tube-hydration from a twelve-year-old patient, Nancy Fitzmaurice, who had been admitted the previous month. Born with a serious brain malformation, Nancy had hydrocephalus, severe epilepsy, and visual impairment. She functioned at the cognitive level of a six-week-old baby with the mobility of a six-month-old baby. She had always been fed by tube and had been cared for at home, with occasional periods in hospital.[215] She was, however, "reaching the end of her life."[216] In the eighteen months prior to the court hearing, Nancy had become increasingly intolerant of her feeds, the intolerance manifesting itself through screaming.

The judge, King J (as she then was), noted that the screaming resulted not from Nancy's resistance to being fed, or because she did not wish to be fed, but simply because she was in pain. Her doctors and nurses had tried various ways of dealing with this distressing phase of Nancy's deterioration, including stopping her feeds and gradually restarting them. That approach was, however, no longer proving an effective means of ameliorating her pain and distress.[217] Nancy now screamed in pain for hours on end and her doctors were unable to control it. Morphine and ketamine were not fully effective,

213. Re AA (A Child) [2014] EWHC (Fam) 4861 (Eng.).

214. Re J (A Minor) [1991] Fam. 33 (EWCA (Civ)) (one may note his unfortunate use of language in describing disability as "horrendous." He also described the baby's plight as "appalling" and the parent's dilemma as "hideous.").

215. Re AA (A Child) [2014] EWHC (Fam) 4681 at [1]-[5] (Eng.).

216. *Id.* at [4].

217. *Id.* at [6].

despite being given in extremely high doses. It was thought that the management of her pain would become more difficult and less effective.[218]

The hospital ethics committee had convened at the end of July to consider Nancy's case. It decided, with the agreement of Nancy's doctors and her mother, that because of Nancy's pain her tube-feeding should be stopped.[219] Although Nancy's hydration was continued, her condition continued to deteriorate and she was in constant, unmanageable pain. Her doctors and mother concluded that even hydration was no longer in Nancy's BI.[220] However, while Nancy was "terminally ill" and would die "soon," she was "in no immediate danger of dying." The consequence of a refusal of the declaration would be that she would continue to be in "appalling pain" for as long as it took for her either to get a chest infection and die from pneumonia or for her vital organs to break down.[221] Over the previous twenty-four hours, her breathing had become more difficult, her secretions were now thick and mucous and it might well be that she was succumbing to a chest infection that would rapidly cause her death.[222]

King J granted the application. Her Ladyship thought that Nancy's case undoubtedly came within the "no chance" situation described by the RCPCH guidance[223] where "Treatments delay death but neither improve[] life's quality nor potential. Needlessly prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient; hence there is no legal obligation for a doctor to provide it."[224] The guidance gave as an example chemotherapy for a child with progressive metastatic malignant disease.[225] It was hard to see, the judge commented, how the continuation of Nancy's treatment was other than "burdensome" given her unremitting pain.[226] King J added that extending Nancy's life to some "modest extent" would be of no overall benefit to her but would subject her

218. *Id.* at [7]-[8].

219. *Id.* at [11].

220. *Id.* at [12].

221. *Id.* at [13].

222. *Id.* at [14].

223. Re AA (A Child) [2014] EWHC (Fam) 4861 [5] (Eng.) (referring to paragraph 3.3.1 of the second edition of the guidance, published in 2004).

224. *Id.* at [18].

225. *Id.*

226. *Id.*

to the continuation of the unremitting and unmanageable pain she suffered.[227] Nancy died two weeks later.[228]

The case raises several disturbing questions. First, given that Nancy's death was not imminent, why did the judge regard the case as one of "extreme urgency" and deliver an extempore and short (five page) judgment at the conclusion of the submissions?[229] Second, why was a guardian not appointed to represent Nancy's interests, even if need be at short notice? The judge arrived at her decision in the light of witness statements from Nancy's consultant pediatric neurologist; from the consultant in pediatric palliative medicine at GOSH and from the manager of Nancy's ward, together with a second opinion from a pediatric palliative care consultant from another hospital that had been prepared for the Ethics Committee at GOSH.[230] Given the gravity of the case, would it not have been appropriate for those experts to have been examined in court, and cross-examined by a guardian for Nancy, who could also have sought further expert opinions? Third, can providing water by tube sensibly be categorized as a "treatment"? What is it thought to be treating? It is not obviously comparable to chemotherapy for a progressive metastatic malignant disease, which is undoubtedly a treatment. Fourth, even if the hydration were a "treatment," why did the judge think it "burdensome"? The judge appeared to conflate the burden of being given water by tube (a burden that was nowhere explained) with the burden of living with pain. Fifth, was this a case not only one in which Nancy's life was regarded as a burden, but one in which she was in effect "condemned to die" and in which the court approved "a course aimed at terminating life or accelerating death"? Is this impression not fortified by the fact that, even though Nancy might have been succumbing to a chest infection, it was nevertheless thought proper to withhold her fluids? Was the problem thought to be not that Nancy was dying but that she was not dying quickly enough, even after her food had been stopped? Indeed, why did GOSH make an application at all, given that doctors and mother were agreed on withdrawing hydration, unless it was appreciated that the proposed course pushed the limits of established law (however permissive the law already was)? The judge said she considered the case in the light of the evidence, including

227. *Id*. at [20].

228. Paisley Gilmour, *Why I Begged Judge To End My Sick Daughter's Life: 'Nancy is no longer my girl, she's a shell'*, DAILY MIRROR (Oct. 25, 2014, 10:58 PM), https://www.mirror.co.uk/news/real-life-stories/begged-judge-end-sick-daughters-4509235.

229. Re AA [2014] EWHC (Fam) 4861 [Introduction] (Eng.) (her judgment did not even mention the sanctity of life or the presumption in favor of life-prolonging treatment).

230. *Id*. at [9].

Nancy's mother's views as to her daughter's BI. The judge quoted from a letter written to her by the mother two days beforehand. The letter stated:

> [T]he fact that I have to watch my angelic child endure such an horrific existence for a possible ten-plus weeks or, even, months, is too much to bear. My daughter is no longer my daughter; she is now merely just a shell. The light from her eyes is now gone and is replaced with fear and longing to be at peace.[231]

It added: "removing fluids is what is best for my child to stop the pain and suffering and for her to be finally at peace, as I do not want the rest of her time here fraught with tears and sadness." The judge noted that the court therefore had the "benefit" of the mother's views as to Nancy's BI.[232] But of what benefit were those views, views which, describing Nancy as a "shell", who was no longer a daughter, and whose life was "horrific", arguably served to depersonalize Nancy?[233] The courts consistently distinguish between the BI of the child and the wishes of the parent or parents, which they regard as "wholly irrelevant" to the determination of BI. Was that distinction clearly maintained in this deeply unsettling case?

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231. *Id*. at [15].

232. *Id*. at [19].

233. Another disturbing pre-*Gard* case concerned infant Ronnie Bickell. Ronnie had Congenital Myasthenic Syndrome (CMS) which left him paralyzed and ventilator-dependent. Counsel for the hospital said that although his brain function was unaffected and he could bang on a drum and paint with his hands and feet and show pleasure when being bathed, his normal cognition would, in the view of his doctors, simply make his plight all the more unbearable because as he got older he would see glimpses of what other people could do. They also thought that even if a tracheostomy were performed with a view to his being ventilated at home, he would lead a "miserable, sad and pitiful existence". Beth Hale, *Let My Little Boy Die: Heartbroken Mother Fights Father for Right To Switch Off Disabled Baby's Life Support*, DAILY MAIL (Nov. 3, 2009, 5:37 AM), https://www.dailymail.co.uk/news/article-1224486/Baby-RB-Tug-love-babys-mother-says-life-support-turned-father-goes-court-stop-it.html. McFarlane J (as he then was) said:

> It is sufficient to say that as each day has gone on the picture of RB and the life, if that is the right word, that he could experience on home ventilation has become clearer. Undertaking a tracheostomy and connecting him to a portable ventilator, rather than being a panacea, would simply open up the potential for him to have to endure a further range of procedures and operations. The very living of life itself, day by day, hour by hour, is likely to be at best uncomfortable for him and, more probably, regularly painful for him. Re RB (A Child) [2009] EWHC (Fam) 3269 [7] (Eng.).

Gard, and the cases we have considered both prior and subsequent to it, show the extent to which medical experts, counsel for hospitals and for children's guardians, and judges have engaged, and continue to engage, in judgments that the lives of dying or disabled infants are of no benefit or are a burden. Further cases could also be cited,[234] but the authorities we have discussed suffice to make the point.

PART III: SOME CRITICAL REFLECTIONS

1. *Discriminatory Ethical Judgments*

We will recall that at the end of his judgment in *Raqeeb*, MacDonald J recognized the essentially moral nature of the inquiry into BI.[235] The judges are indeed, behind the legal curtain of BI, making judgments freighted with ethical evaluations of the lives of dying and disabled children. As this paper has argued those judgments are, moreover, ethically flawed, endorsing the objectionable notion that the lives of disabled children lack benefit or are a burden. Such judgments are contrary both to the foundational moral and legal principle of the sanctity of life, according to which all patients are equal in dignity and, it is submitted, to international human rights documents that explicitly and implicitly reject discrimination on the ground of disability, not least when that discrimination ends the patient's life. In *In King's College Hospital NHS Foundation Trust v. R*, Poole J said that the law applied equally to all children whatever the extent of their disability, but that in considering a child's BI the court must have regard to their particular circumstances.[236] However, when those circumstances include disability, such as brain damage, and when that disability is thought, either by itself or

234. For example, see Kings Coll. Hosp. NHS Found. Tr. v. Thomas [2018] EWHC (Fam) 127 [30], [36], [43], [67], [74], [106]-[110] (Eng.); and Barts Health NHS Tr. v. Dance et. al. [2022] EWHC 1435 (Fam) [192], [195].

235. *See supra* note 150 and accompanying text. In *An NHS Trust v MB*, by contrast, Holman J stressed that he was not concerned with any ethical issues that surrounded the case but only with where the objective balance of the infant's BI lay, and that if he declared that continued ventilation was not in the infant's BI then the ethical decision whether to withdraw it was for the doctors concerned. He added: "Judges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions." [2006] EWHC 507 (Fam) [24]. As we have seen, however, judges in these cases are making what are profoundly ethical decisions, regularly adopting the ethical views of (some though by no means all) medical professionals. Moreover, if a judge declared treatment not to be in a child's BI, why would a doctor who continued it not be acting unlawfully? And if a judge declared treatment was in a child's BI, why would a doctor not be legally required, if he or she did not wish to provide the treatment, to refer the child to a physician who was willing to do so?

236. King's Coll. Hosp. NHS Found. Tr. v. R [2014] EWHC (Fam) 910 [45] (Eng.).

in combination with other factors, to render the child's life not worth living, there is surely no escaping the reality that the courts *are* discriminating on the basis of disability.

The courts have turned into this ethical dead end in no small measure because their understanding of key ethical concepts, including the sanctity of life and equality-in-dignity, has been mistaken.[237] The sanctity of life may well mean different things to different people, but the courts need to give it an objective meaning in law. In law, its core meaning has long been, as Ward LJ explained in the *Conjoined Twins* case, that all human lives, irrespective of disability or projected lifespan, enjoy an equal and ineliminable dignity and a right not to be intentionally killed or abandoned. Crucially, the courts in our baby cases have failed to grasp the key moral distinction between a judgment that a *treatment* is not worthwhile because it is futile or too burdensome, and a judgment that the patient's *life* is not worthwhile because it is thought to be of no benefit or to be a burden. It is regrettable that this key distinction was not unmistakably marked out and entrenched by Lord Donaldson MR in the leading case of *Re J.* [238]

2. *Misunderstanding Dignity*

Nor is dignity, properly understood, a subjective or redundant concept. Its central and most important meaning, as reflected in the Preamble to the UN Declaration of Human Rights, is the ineliminable, equal worth we enjoy in virtue of our common humanity. In that sense, it provides the very foundation of human rights, however multicultural and multifaith a society may be. It is remarkable that the courts have consistently declined to recognize and affirm the key role that this conception of dignity should play in the law. To the extent that the judges have discussed dignity in the baby cases the discussion has been cursory if not evasive or even dismissive. We

237. It is difficult to agree that the UK court system in its "timeliness, consistency and attention to what matters most (the interests of the child)" provides "a model of how the judicial system should respond to family-physician conflicts over treatments for seriously ill children." JJ Paris et al., *The Charlie Gard Case: British and American Approaches to Court Resolution of Disputes Over Medical Decisions*, 37 J. PERINATOLOGY 1268, 1271 (2017).

238. *See* Re J (A Minor) [1991] Fam. 33 (EWCA (Civ)); *see also supra* notes 55-58 and accompanying text. His Lordship should also have appreciated that the value of life does not flow from the human "instinct" or "desire" to survive (some people lack the desire to go on and others desire not to) but from our shared human nature, which includes our radical capacity for free will, moral agency and reason; *see also* ALFONSO GÓMEZ-LOBO WITH JOHN KEOWN, BIOETHICS AND THE HUMAN GOODS 30 (2015) (although we lack to the *ability* to reason when we are infants we nevertheless all possess the radical *capacity* to reason. Similarly, although I do not have the ability to speak Swahili I have the capacity to do so).

will recall that, unusually, Hayden J in *North West Clinical Commissioning Group v. GU* canvassed the many international documents that mention human dignity.[239] He accurately noted that they affirmed dignity's foundational basis for human rights; that dignity is predicated on a universal understanding that human beings possess a unique and intrinsic value; that human beings have an inviolable right to be valued, respected and treated solely in virtue of their humanity; that the protection of human dignity is an indispensable priority, and that it imposes on the state a duty to protect everyone's dignity, which involves guaranteeing respect for their dignity and, axiomatically, avoiding discrimination.[240] So far, so good. Strangely, he then concluded:[241] "Thus, whilst there is and can be no defining characteristic of human dignity, it is clear that respect for personal autonomy is afforded pre-eminence." He arrived at this conclusion despite having noted[242] that the texts he quoted did *not* define dignity in terms of autonomy, let alone accord autonomy pre-eminence.

The true position is that our radical capacity for autonomous choice helps to account for our human dignity but that human beings enjoy dignity whether or not they are able to exercise autonomy. We all lack autonomy at some stage or stages of our lives (some of us for all of our lives) but we nevertheless retain dignity throughout. Moreover, an autonomous choice may be flatly inconsistent with dignity: the mere fact that a choice is autonomous tells us nothing about whether it respects human dignity, whether one's own dignity or that of another. Of what moral value is a choice to undermine dignity? Where they conflict, dignity morally trumps autonomy. Indeed, much of the law, particularly the criminal law, involves limitations on our autonomy, such as its prohibitions on murder and female genital mutilation (in both cases whether or not consensual) in order to safeguard human dignity. Nor did Hayden J seem to appreciate, despite having noted that the documents recognize the universal and intrinsic dignity of all human beings and prohibit discrimination, that respect for dignity rules out any judgment that some people's lives lack benefit or are a burden. Judging that the lives of some human beings are not worth living because of their disability is, quite simply, a discriminatory and unjust denial of their equality-in-dignity.

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239. N.W. Clinical Commissioning Grp. v. GU [2021] EWCOP 59 [42]-[63] (Eng.); *see supra* note 32.

240. *N.W. Clinical Commissioning Grp.* [2021] EWCOP 59 at [63].

241. *Id.* at [64].

242. *Id.* at [48].

In *Guy's and St Thomas' v. A, F&M*, counsel for the parents submitted that the language of "dignity" did not assist the court's assessment of their baby's BI.[243] Counsel was correct if the word is used carelessly, as it often is, to conflate the patient's innate worth with the circumstances that may surround the patient. Properly understood, however, the concept is critical to the protecting of the BI of patients, particularly the most vulnerable. In that case, Poole J, having quoted extensively from Hayden J's analysis of dignity in *North West Clinical Commissioning Group*, concluded:

> The court does not apply a separate test of dignity – there is no objective concept of dignity on which the court can rely to help it determine what is in A's best interests. Rather, the intense focus on A and the application of established legal principles, recognises and respects his innate dignity as a human being.[244]

This is confusing. How can one talk about respecting a patient's innate dignity, and of established legal principles doing so, if there is no objective concept of dignity? And how do judgments respect innate dignity if they accept, as the judgments we have considered do (including Poole J's in that case), that the lives of certain patients are not worth living because they are a burden or lack benefit? In *Knight*, Baker LJ said that in a future case it may be necessary for the Court of Appeal to address the meaning of dignity.[245] It has long been necessary, and it is regrettable that the courts have consistently skirted the issue. The courts should, consistent with the international human rights documents cited by Hayden J, and the dicta of Ward LJ in *Re A* and of Judge LCJ in *Inglis*, urgently reaffirm the equal dignity of all human beings, including those with serious disabilities.

In an article published in 2019, Sir James Munby, the former President of the Family Division of the High Court, suggested that the few references by English judges to "dignity" could be explained by the fact that the word does not appear in the European Convention of Human Rights; that the common law had developed pragmatically and traded in "hard-edged facts" rather than "soft-edged concepts"; that the courts had long found the BI test sufficient without resorting to the relatively unfamiliar concept of dignity, and that to the limited extent that English lawyers had any interest in philosophy, it tended to be in Benthamite utilitarianism rather than in Kant's

243. Guy's & St Thomas' NHS Found. Tr. v. A [2022] EWHC (Fam) 2422 [53] (Eng.).

244. *Id.* at [55].

245. Parfitt v. Guy's & St. Thomas' Child.'s NHS Found. Tr., [2021] EWCA (Civ) 362 [100].

emphasis on the dignity of the individual.[246] However, he rightly observed (quoting one of his own judgments):

> The recognition and protection of human dignity is one of the core values – in truth the core value – of our society and, indeed, of all the societies which are part of the European family of nations and which have embraced the principles of the Convention. It is a core value of the common law, long pre-dating the Convention and the Charter. The invocation of the dignity of the patient in the form of declaration habitually used when the court is exercising its inherent declaratory jurisdiction in relation to the gravely ill or dying is not some meaningless incantation designed to comfort the living or to assuage the consciences of those involved in making life and death decisions: it is a solemn affirmation of the law's and of society's recognition of our humanity and of human dignity as something fundamental.[247]

Moreover, whereas dignity was a meaningful concept that identified a goal to which we should strive (to do as we would be done by and act toward each other in a spirit of brotherhood[248]), BI was not. English judges, he added, seemed immune to a painful truth: to assert that something was in someone's BI was merely to record the result of a process in what may be a complex moral and social question was transformed into a question of fact. The BI approach did no more than identify the person whose interests were in question. It did not assist in identifying the relevant factors and offered no hierarchy of values, much less any general principle that might direct the difficult decisions to be made.[249] He continued:

> It may be an unfair parody, but too often one was left with the feeling that determining where a child's best interests truly lay amounted to little more than a process of selecting those factors which, amongst the mass of materials rehearsed

246. James Munby, *Why Do We Ignore Dignity? Some Comments*, 2 EUR. HUM. RTS. L. REV. 119, 119-21 (2019).

247. *Id.* at 120.

248. *Id.*

249. *Id.* at 123.

> by the judge, were fastened upon as justifying the outcome.[250]

Dignity, by contrast, identified a principle of universal application which was, indeed, the ultimate legal value, and the identification of dignity as the ultimate legal value provided the rationale for the BI test and a benchmark for the BI evaluation. There was no conflict between dignity and BI: the one complemented and gave content to the other.[251] Dignity was no mere rhetoric or empty slogan: it was a vitally important principle not merely ethically but legally and it provided the courts with a powerful tool for the heaviest lifting.[252] Sir James concluded his paper by noting the significance of the way cases were argued by advocates. His remarks on dignity will hopefully encourage counsel representing children like Charlie Gard, and their parents, confidently and robustly to articulate and advocate for the equality-in-dignity of all children.

Regrettably, as Jonas and Ryan have shown in their analysis of *Gard* and *Evans*, although the judges invoked the concept of dignity they used it in quite different senses: rank-dignity; virtue-dignity; species-dignity; agency-dignity and relational-dignity.[253] Although Charlie and Alfie were thought to have species-dignity and to some extent relational-dignity, they lacked the other forms of dignity that were thought to make a life worth living, especially (because of their profound brain damage) agency-dignity.[254] The judgments, Jonas and Ryan concluded, used dignity as a "smokescreen" to obscure "the judicial sleight of hand wherein consideration of best interests moves from an analysis of dignity in life to one of dignity in death."[255] A finding that withdrawal of treatment allows for dignity in death "effectively compels acceptance of the judgements" rather than providing clearly articulated reasons to support them, and the judges' discourse of dignity enables them to recognize the value of the infants' lives while also serving as a justification for ending them.[256] Talk of dignity communicated, without

250. *Id.* at 124.

251. *Id.* at 124 n.30. ("Although those who are physically or mentally disabled may not be able to aspire to what you or I would think of [as] the good life, that is no reason why, as their dignity surely demands, we – society – should not strive to help them achieve the best possible life.").

252. *Id.* at 125-26.

253. Monique Jonas & Samantha Ryan, *The Discourse of Dignity in the Charlie Gard, Alfie Evans and Isaiah Haastrup Cases*, 29 MED. L. REV. 24, 24, 26-28 (2021).

254. *Id.* at 46-47.

255. *Id.* at 41, 46.

256. *Id.* at 44.

directly expressing, the idea that Charlie and Alfie lacked full moral standing.[257] The discourse of dignity also served to privilege the views of medical professionals (at least those from the UK) who were characterized as eminent, and to downgrade those of parents, who were categorized as emotional.[258]

As for MacDonald J's observation above that the awareness of pain or suffering provides an *objective* basis for determining that continued treatment is not in a child's BI, pain is an unfortunate feature of many if not most people's lives. Does that make their lives any the less worth living?[259] And what degree, duration or experience of pain do the courts think renders an infant's life not worth living? Although MacDonald J opined that if suffering is unlikely then its existence has not been made out on the balance of probabilities, the mere possibility of suffering, even if little attempt is made to calibrate its likelihood or degree, appears sometimes to be regarded by the courts as sufficiently weighty to displace, or help displace, the supposedly strong presumption in favor of preserving life.[260] That

257. *Id.* at 46.

258. *Id.* at 40, 46.

259. Kevin De Sabbata & Abigail Pearson, *Indi Gregory: A Wider Perspective on Children's Best Interests at the End-of-Life*, 32 MED. L. REV. 255, 258-59 (2024) (De Sabbata and Pearson observe that avoiding pain and curing illness are not the only significant issues at stake in these kinds of cases, and that an extremely important issue is the parent-child relationship. They add that medical research on emotional attachment and reactivity in the first months of life highlights the centrality of subconscious, touch-based and non-cognitive mechanisms in the mother-child relationship, and that prolonging even a painful situation, to enable a continued relationship with the parents, could still be meaningful to the child. From the infant's point of view the continuation of that relationship may be more crucial than the pain she is experiencing.).

260. Guy's & St Thomas' NHS Found. Tr. v. A [2022] EWHC (Fam) 2422 [65] (Eng.) (Poole J. observed that it was not necessary in that case to make a finding on the balance of probabilities as to whether Baby A had a reflex response to pain and that the court was able to feed possibilities as well as probabilities into its assessment of BI); *see supra* note 182 and accompanying text.

In *Barts Health NHS Tr. v. Dance* [2022] EWCA (Civ) 935 [22], [35], the Court of Appeal held the judge had been wrong to conclude that Archie (a twelve-year-old brain damaged and unaware boy on a ventilator) was dead when none of the medical witnesses had diagnosed death and it had not been possible to conduct the standard neurological tests for brain-stem death. Interestingly, Sir Geoffrey Vos MR pointed out that it was Archie's guardian, not the hospital trust, who had been strongly of the view that the judge should declare Archie dead on the balance of probabilities, *id.* at [22], and that inviting the judge to take such a course was, in the circumstances, unprecedented, *id.* at [35]. The case was remitted to Hayden J in *Barts Health NHS Tr. v. Dance* [2022] EWFC 80. *See infra* notes 264-68 and accompanying text. For discussion of two other controversial cases involving judicial approval of the diagnosis of a child's death (one in the UK the second in the US), see also Kartina A. Choong & Mohamed Y. Rady, Re A (A Child) *and the United Kingdom Code of Practice for the Diagnosis and Confirmation of Death*, 30(1) HEC FORUM 71, 71, 74, 83 (2016) (UK); D. Alan Shewmon & Noriko Salamon, *The Extraordinary Case of Jahi McMath*, 64 PERSPS. BIOLOGY & MED. 457 (2021).

presumption seems quickly to yield before evidence of pain, lack of pleasure, and limited or absent awareness.

Moreover, any judicial suggestion that a child's BI are compromised by being cared for in a hospital rather than at home, or by health care professionals rather than parents,[261] should be resisted. The circumstances in which we are cared for or the quality of that care can never displace, though they can disrespect, our dignity. Indeed, it is our innate dignity that requires us to be cared for well, whatever our location and whoever our carer. Many are the people who, like those with serious intellectual disabilities or the elderly, are warehoused in institutional settings and lack loving families to help care for, or even visit, them. This does not, and should never be allowed to, detract from their inherent worth. Nor should the fact of dependence, whether on carers or medical technology. Paul Alexander was paralyzed by polio at the age of six and spent seventy-two years in an "iron lung."[262] Did that mean his life was not worth living or was less worth living than anyone else's? There is no indignity in dependence, whether in an assisted living facility or in an intensive care unit.

3. *The BI "Balancing" Exercise*

Further, it is quite unclear how judges go about "balancing" the various factors they regard as significant. How much weight do they attach to the child's views, actual or imputed; to the supposed burdensomeness of their condition and of their treatment, and how much to the (supposedly) strong presumption in favor of preserving life? The weighing of such incommensurable factors would appear to be a largely subjective if not arbitrary exercise, and one impervious to objective evaluation by appellate courts.[263] In *Archie Battersbee*, Hayden J ruled that a twelve-year-old brain

261. *See, e.g., Guy's & St Thomas' NHS Found. Tr.* [2022] EWHC (Fam) 2422 at [67]; *see also supra* note 186 and accompanying text.

262. Jesus Jiménez, *Lawyer, Author and TikTok Star Spent 72 Years in an Iron Lung*, N.Y. TIMES, (Mar. 13, 2024), https://www.nytimes.com/2024/03/13/us/paul-alexander-iron-lung-dead.html.

263. Rob Heywood, *Parents and Medical Professionals: Conflict, Cooperation and Best Interests*, 20 MED. L. REV. 29, 36, 38 (2012) ("The reality is that many of the factors are actually impossible to measure or compare. How can a child's pain be weighed in the same scale as their parents' wishes?"). He also writes that "no matter how hard the courts try to give the impression that they are willing to consider a wide range of social and emotional factors . . . they find it incredibly difficult to distance themselves from medical opinion." *Id.* at 38. (One may add that the medical opinion is often moral opinion parading in a white coat. And one may wonder whether the courts have indeed tried to distance themselves from medical opinion or whether they tend all too eagerly to fall into its misleadingly reassuring embrace.). Heywood rightly asks (citing Professor Margaret Brazier) whether the non-medical factors recounted by

damaged boy's ventilation was not in his BI.[264] On appeal, the primary ground was that the judge had been driven by Archie's medical interests rather than his BI in the widest sense and that he did not indicate the weight he attached to each element.[265] Counsel submitted that from the parents' viewpoint the most important factors were Archie's previously stated wish that he would not want to be disconnected from a ventilator as he would not want to be separated by death from his mother, and his Christian beliefs.[266] The appeal was dismissed, the Court of Appeal holding that while the medical evidence had ultimately determined the outcome of the BI determination, the judge had taken full account of the countervailing factors.[267] The court did not question Hayden J's conclusion that treatment was not in Archie's BI because it was burdensome and deprived him of his autonomy.[268] How could the treatment have burdened an insensate patient or deprived him of autonomy, especially when his previously expressed wish had been to stay alive with his mother?

In short, whether a child lives or dies appears to turn largely on which judge happens to hear the case and the weight that judge happens to attach to each factor, including the judge's view of the worthwhileness of the child's life. In *Guy's and St Thomas'*, Poole J started his judgment with the observation that judges approached such cases with an open mind but were not free to apply their own moral views and were bound to apply existing legal principles.[269] However, what are those legal principles if not to a considerable extent the ethical views formulated, endorsed, and imposed by the judges on children and parents? And, to the limited extent that such judgments are reviewable, appellate courts seem very ready to affirm them.

4. *The Baby's Views*

Nor is the objectionable judgment that the life of a baby is not worthwhile disguised by the device of purporting to adopt the baby's viewpoint. While the exercise may reflect a well-intentioned attempt to guard against devaluing the lives of those with serious disabilities, the value of

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the courts are not merely a "smokescreen" for what is fundamentally a judgment grounded on medical tenets. *Id.* at 36.

264. *Barts Health NHS Tr*. [2022] EWFC 80 at [46].

265. *Barts Health NHS Tr*. [2022] EWCA (Civ) 1055 at [23].

266. *Id.* at [45].

267. *Id.* at [71].

268. *Barts Health NHS Tr*. [2022] EWFC 80 at [46].

269. Guy's & St Thomas' NHS Found. Tr. V. A [2022] EWHC (Fam) 2422 [1] (Eng.).

babies' lives lies not in what judges *think* the babies might *think* (a typically artificial if not entirely fanciful exercise that is no guarantee against discrimination) but in who they *are*. Indeed, patients retain their dignity even if they think, or probably would think, their lives undignified. Substituted judgments may disrespect a patient's dignity no less than BI judgments, and those that do should be excluded from decisions about treatment withdrawal.[270] If the courts insist on trying to figure out what the babies would want, why do they not presume *that the babies would strongly prefer that decisions be made by their loving parents rather than by strangers* (however professionally dedicated) like doctors and lawyers? Why is this not standardly held to be an important consideration in the application of the BI test? Would it be unfair to suggest that when judges try to imagine what a baby would want but overlook both what babies naturally would want and what their loving parents reasonably do want, they are straining at a gnat while swallowing a camel?

5. *Medical or Moral Guidance?*

Excessive judicial deference to medical opinion has a long and unfortunate history.[271] In reasoning that the lives of certain patients lack worth, it seems clear that the courts are significantly influenced by the opinions of medical professionals. It is one thing for a medical expert to give evidence that a treatment is medically futile (though even judgments about "futility" may often involve a moral judgment) but quite another that the patient's life is futile. *Medical* witnesses are being allowed to make expansive judgments about the BI of children[272] including *moral* judgments

270. This concern is even more apt in relation to the law governing incapacitous adults. Instead of defining an adult's BI in terms of their objective dignity and goods of life and health, the Mental Capacity Act of 2005 adopts an essentially "substituted judgment" test. *See* § 4(6). Such an approach potentially accommodates the view of the patient and others that the patient's life lacks dignity. Respecting people does not necessarily mean respecting their preferences, actual or assumed. *See* John Keown & Luke Gormally, *Human Dignity, Autonomy and Mentally Incapacitated Patients: A Critique of* Who Decides*?*, 4 WEB J. OF CURRENT LEGAL ISSUES, (1999); John Keown, *In Their 'Best Interests'? Respecting Patients or Their Preferences?*, 21 NAT'L CATH. BIOETHICS Q., 397 (2021); Hayden J's comment (in *North West Clinical Commissioning Group v GU* [2021 EWCOP 59 at [64]) that there is a 'striking resonance' between the subjectivist philosophy of the Act and the understanding of human dignity affirmed by the international human rights texts he cited seems wide of the mark.

271. John Keown, *Doctor Knows Best?: The Rise and Rise of the* Bolam *Test*, SING. J. OF LEGAL STUD. 342, 345 (1995); Margaret Brazier & Jose Miola, *Bye Bye* Bolam*: A Medical Litigation Revolution?* 8 MED. L. REV. 85, 92, 112-13 (2000).

272. Richard David William Hain, *Voices of Moral Authority: Parents, Doctors, and What Will Actually Help*, 44 J. MED. ETHICS, 458, 461 (2018) (pointing out not only that doctors are sometimes

about the worth of their lives. This is particularly evident in the weight the courts consistently attach to the moral guidance published by the RCPCH.[273] And what is to prevent that professional medical guidance from being expanded to embrace children with decreasingly serious disabilities?[274] If the guidance expands, will the courts follow? Judicial deference to medical opinion on the moral question of the value of a patient with disabilities is no more justified here than it was in the disturbing case of *Bland.*[275]

6. *The Parents' Views*

Given that these cases involve the making of controversial moral judgments, what makes the moral opinion of judges or doctors superior to those of the parents, not least unquestionably loving and dedicated parents like Connie Yates and Chris Gard? It is submitted that the courts should not interfere with parental decision-making unless the parents are, objectively, acting (very) unreasonably.[276] Indeed in *Re J* Balcombe LJ said (in a passage

influenced by concerns such as resource allocation but that doctors on their own do not usually know enough about a child's interests to judge what would cause them more harm than benefit).

273. Anthony Fisher O.P., *On Not Starving the Unconscious*, 74 NEW BLACKFRIARS 130, 138 (1993) (Commenting on the *Bland* case, Fisher notes that the worth of an unconscious life, the degree and significance of suffering and indignity and costs to the community are all value judgments which are no part of medical or juridical science or skill: "[t]hey are crucially different to diagnosis, prognosis, and therapeutic assessment of treatment options, and to assessing evidence and declaring on the law.").

274. *Id.* at 140 ("And if humanity *per se* is no longer sufficient, then not only consciousness but other qualities such as a certain I.Q. or a certain quality of social relationships, may in the future be regarded as necessary by doctors and courts.").

275. Airedale NHS Trust v. Bland [1993] AC 789 [861] (Eng.). *See supra* note 14. The Law Lords held that a doctor was under no duty to continue tube-feeding a patient who was in a "persistent vegetative state." In the words of Lord Keith (at 858-859):

> a medical practitioner is under no duty to continue to treat such a patient where a large body of informed and responsible medical opinion is to the effect that no benefit at all would be conferred by continuance.

He added:

> Existence in a vegetative state with no prospect of recovery is by that opinion regarded as not being a benefit, and that, if not unarguably correct, at least forms a proper basis for the decision to discontinue treatment and care: Bolam v. Friern Hosp. Mgmt. Comm. [1957] All ER 118 (QB).

In short, if some doctors thought that the patient's disability meant that his life was not worth living, that provided a legal justification for not feeding him (even, a majority of the Law Lords appeared to think, with intent to end his life).

276. ANSCOMBE BIOETHICS CTR., *Charlie Gard: Doing the Right Thing for the Right Reasons* (July 5, 2017), https://bioethics.org.uk/media/k3un05g3/charlie-gard-doing-the-right-thing-for-the-right-reasons.pdf; *see also* Moschella, *supra* note 2.

quoted by the Court of Appeal in *Wyatt*) that the BI of the ward are the first and paramount consideration "subject to the gloss on that test which I suggest, that in determining where those interests lie *the court adopts the standpoint of the reasonable and responsible parent who has his or her child's best interests at heart*."[277]

It is open to the courts, given the inherent ability of the common law to self-correct, to adopt this eminently sensible gloss. If, however, they are disinclined to do so then the legislature should replace or reconfigure the BI test so that it provides that BI are to be determined from the standpoint of the reasonable parent, with the proviso that no reasonable parent would judge their child's life to be not worth living. It is surely wrong not only that the courts should overrule the wishes of loving parents *even when they are entirely reasonable* but, adding insult to injury, regard their wishes as "wholly irrelevant" to the BI of their children.[278] Leading health lawyer Professor Margaret Brazier, having asked whether the BI test is ever more than an "empty mantra," has rightly written in her commentary on *Wyatt v. Portsmouth*: "Courts should intervene only when the evidence establishes that the parents' wishes militate *against the interests* of the child."[279]

7. *One Right Answer?*

The BI test could also be criticized for positing that there is only one "right" option. As Lady Hale noted of the test in *Aintree v. James*: "there can

277. Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam. 33 (EWCA (Civ)) at 52 (emphasis added).

278. Professor Sir Ian Kennedy criticized calls (by whom?) to keep the courts out of these sorts of decisions, opining that, rather than "let passion prevail," society should look to the courts to provide reasoned judgment. Ian Kennedy, *Despite Charlie Gard's Tragic Story, We Must Respect the Process of Our Courts*, THE GUARDIAN (July 24, 2017), https://www.theguardian.com/commentisfree/2017/jul/24/charlie-gard-tragic-respect-courts. He ignored the criticism that it is precisely the courts' reasoning that is the problem.

279. Margaret Brazier, Commentary, *An Intractable Dispute: When Parents and Professionals Disagree*, 13 MED. L. REV. 412, 415 (2005) (emphasis added). She added: "The hidden spectre in all such tragic conflicts between parents and professionals is resources. No hint is given in the judgment that either party contemplated the presence of that spectre. Both parties must have done so." *Id.* at 418. To the extent that a hospital trust may be challenging a parent's wishes in order, wholly or partly, to reallocate resources, its submission that continued treatment is no longer in the child's BI merits even more anxious scrutiny. And how is launching protracted legal proceedings that may last several months, as in *Gard*, a better use of resources than allowing the parents to take their child abroad for continued treatment? This is not to mention the considerable personal stress such proceedings will impose on hospital staff and parents (and judges) alike.

only logically be one best option."[280] Yet this simplistically fails to appreciate the often complex moral and social reality. There may in any given situation be several options that could reasonably be described as being in a child's BI. Professor Raanan Gillon, an eminent physician-philosopher from the "principlist" school of ethics, has argued that, in a pluralist society encompassing a range of moral perspectives, it is particularly important to recognize the existence of moral dilemmas and, wherever possible, to accept that both morally and legally people should be allowed to reach their own resolution of those dilemmas, provided no substantial harm or substantial injustice results. Charlie Gard's discomfort was, he notes, not so substantial a harm as to warrant depriving his parents of their normal right and responsibility to make decisions as to his BI.[281] Moreover, the degree of Charlie's discomfort was, given that his brain damage prevented expression of discomfort, conjectural; no evidence was tendered that it was any greater than that routinely experienced by the thousands of children kept alive by ventilators worldwide, and it could be minimized by palliative care.[282] Whether the tiny chance of benefit offered by the nucleoside therapy was worth that discomfort was a value judgment about which reasonable people would differ.[283] The judge claimed to be making an "objective" judgment, but where the determination of BI involved choosing one or other horn of a moral dilemma it was simply not possible to make an objective judgment.[284] He also noted that the judge inadequately addressed the question of the benefit of Charlie's continuing life. He added that a disturbing implication of the case was that those who (unlike Gillon) saw benefit in continued life as such might be legally prohibited from keeping patients like Charlie alive, even if the treatment made no claim on public resources. This would be a "highly undesirable form of 'moral imperialism' by the courts."[285]

It is noteworthy that Gillon's concern about the courts overruling the parents in *Gard* is shared by thinkers from other major ethical perspectives. Professor Melissa Moschella, a prominent critic of the ruling in *Gard*, has argued from a natural law perspective that the family has the right to

280. Aintree Univ. Hosps. NHS Found. Tr. v. James [2013] UKSC 67 [24] (on appeal from EWCA (Civ)).

281. Gillon, *supra* note 2, at 465.

282. *Id.* at 463.

283. *Id.*

284. *Id.* at 464. Gillon ventured that the enormous range of people's views about risks and benefits should factor into "every kind of consideration" capable of impacting a BI decision; *see also supra* notes 52-53 and accompanying text.

285. Gillon, *supra* note 2, at 465.

"autonomy over its internal affairs," a right widely accepted as a matter of moral principle and in law, and that the same moral right that applies to the direction of the education and upbringing of one's children applies to deciding their medical treatment.[286] Again, Professor Julian Savulescu, a utilitarian, advancing "a secular ethical argument about the extreme complexity of judging someone's life to be not worth living," concluded that Charlie should have been allowed to travel straight away, saving the state the hundreds of thousands of pounds that his continued intensive care cost.[287]

The BI test can also be criticized for holding parents to a standard that can be too demanding. Parents often make entirely reasonable decisions for their children, whether in relation to healthcare, diet, education, or lifestyle, that may not be regarded by others as the "best" decision, but which the state should nevertheless respect as within the rightful ambit of reasonable parental choice. If there is only one right answer in relation to children like Charlie, and the courts purport to know what it is, how many other entirely reasonable treatment decisions made, day in and day out, by loving parents are liable to be arrogated by the state? In short, the BI test, even if it were not being regularly applied in a discriminatory fashion, fails to respect parents' rights to make reasonable decisions about their children's treatment.[288]

8. *US Law*

Finally, while an overview of the relevant law and practice across the United States is well beyond the scope of this paper, it would appear that US courts tend to attach greater weight to parents' wishes. Professor Pope has written that US courts do not infringe on the parental prerogative just

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286. Moschella, *supra* note 2.

287. Nick Triggle, *Charlie Gard: A Case that Changed Everything?*, BBC (July 29, 2017), https://www.bbc.com/news/health-40644896; *see also* Julian Savluescu, Comment, *Is it in Charlie Gard's Best Interests to Die?*, 389 LANCET 1868 (2017); Dominic Wilkinson & Julian Savulescu, *Hard Lessons: Learning from the Charlie Gard Case*, 44 J. MED. ETHICS 438 (2018); Julian Savulescu & Peter Singer, *Unpicking What We Mean by Best Interests in Light of Charlie Gard*, BMJ (Aug. 2, 2017), https://blogs.bmj.com/bmj/2017/08/02/unpicking-what-we-mean-by-best-interests-in-light-of-charlie-gard/.

288. Close et al. defend the BI test and conclude that the law applying to cases like *Gard* is sound. But even they propose that doctors should not be allowed to withhold treatment against the wishes of the parents without court authorization, and that the courts need to be clearer about the factors that influence their BI determinations and how they balance those factors. Elina Close et al., *Charlie Gard: In Defence of the Law*, 44 J. MED. ETHICS 476, 476-78 (2018). They claim (at 478) that their proposals promote the value of life but those proposals would not appear to prevent courts from holding it is in a child's BI to die. *Id.* at 478.

because they think they could make a better decision. They grant parents a zone of discretion and intervene only when parents abuse their discretion.[289]

In sum, English law in relation to the nontreatment of dying or disabled children is in urgent need of major reform, whether by the courts or the legislature.

9. *"Charlie's Law"*

Would "Charlie's Law" have remedied the law's discriminatory treatment of dying and disabled infants? The proposal, put forward in 2022 as an amendment to the *Health and Care Bill* by palliative care expert Baroness Ilora Finlay, would have required a hospital in cases of a dispute between doctors and parents "to demonstrate the reasons why significant harm would be likely to be caused" by an alternative treatment proposed by the parents, and to allow for mediation where the parties were unable to resolve their disagreement.[290] It was supported by the Charlie Gard

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289. Thaddeus Mason Pope, Guest Editorial, *Charlie Gard's Five Months in Court: Better Dispute Resolution Mechanisms for Medical Futility Disputes*, 44 J. MED. ETHICS, 436, 437 (2018). In *Baby K* the US Court of Appeals affirmed a District Court ruling that doctors were obliged by statute to continue the ventilation of a baby at the mother's request, even though the baby had anencephaly, a condition where the brain stem is present but the cerebral cortex is rudimentary or absent. *In re* Baby "K," 16 F.3d 590 (4th Cir. 1994), *cert. denied*, 513 U.S. 825 (1994). *See also* Shewman & Salamon, *supra* note 260.

The Federal Child Abuse Amendments of 1984 extended the law relating to child abuse to include the withholding of medically indicated treatment, and food and fluids, from children with disabilities. The *Baby Doe* Amendment mandated states receiving federal funds for child abuse programs to develop procedures to report medical neglect. Assessments of a child's quality of life were not valid reasons for withholding treatment. U.S. DEP'T OF HEALTH AND HUM. SERVS., CHILD.S BUREAU, THE CHILD ABUSE PREVENTION AND TREATMENT ACT: 40 YEARS OF SAFEGUARDING AMERICA'S CHILDREN 30 (2014).

The CAPTA regulations were promulgated in the Federal Register in two stages, Child Abuse and Neglect Prevention and Treatment Program, 49 Fed. Reg. 48160 (proposed Dec. 10, 1984) and Child Abuse and Neglect Prevention and Treatment Program, 50 Fed. Reg. 14878 (Apr. 15, 1985). In the Final Rule, the "Supplementary Information" states that allowance for "reasonable medical judgment" does not "sanction decisions based on subjective opinions about the future 'quality of life' of a retarded or disabled person." 50 Fed. Reg. at 14880. This is repeated in "Interpretive Guidelines" that are appended to the Final Rule, 50 Fed. Reg. at 14889. The NPRM had similar language at 49 Fed. Reg. 48163, 48164. The applicability of the non-discrimination principles in s504 of the Rehabilitation Act 1973 should also be considered. *See* 45 C.F.R. § 84.1 (2024). (I am grateful to Mr Edward Grant for this information.)

For an argument that the *Baby Doe* rules should be replaced by a BI standard, see Loretta M. Kopelman, *Why the Capta's* Baby Doe *Rules Should be Rejected in Favor of the Best Interests Standard*, 25 GA. STATE UNIV. L. REV., 909 (Mar. 2012). She explains, however, that choices made in someone's BI would need only be "reasonable (or not unreasonable)," a test which would accommodate differences of opinion: "Some families may decide to pursue highly experimental treatment to extend their infant's life briefly while others prefer comfort care at home." *Id.* at 922.

290. Health and Care Bill 2022-23, HL Bill [114] cl. 172. *See* Dominic Wilkinson & Julian Savulescu, *Alfie Evans and Charlie Gard – Should the Law Change?*, 361 BMJ 1891, 1891 (2018), who

Foundation, set up to support children, adults, and their families affected by mitochondrial disease. The Foundation said the test "would replicate the legal test already used by social services considering whether to remove a child from their parents' care and would sit before, rather than replacing, the current 'best interests' test which is very broad and can be subject to a number of different interpretations."[291] The government agreed instead to commission an independent report into the causes of disputes between doctors and parents concerning the care of critically ill children.[292] It invited the Nuffield Council on Bioethics to produce the report.

Lady Finlay's amendment might well have improved the present unacceptable situation. It would have shown greater respect for parental rights in that hospitals would have had to show that parental treatment preferences would have risked causing significant harm to their child. The amendment's promotion of mediation would also have helped minimize protracted, distressing, and costly court proceedings. However, it remains doubtful whether the amendment would have made much if any difference to the outcome of cases like *Gard* that did reach the courts. The amendment provided that it did not affect the BI test,[293] and as McFarlane LJ said in *Gard*: "It is clear, in my view, that if the judge had been invited to form a

note the strong ethical arguments that courts should only override parental wishes if they risk substantial harm to the child. Auckland and Goold advocate a threshold test of significant harm for court involvement: *See* Cressida Auckland & Imogen Goold, *Parental Rights, Best Interests and Significant Harms: Who Should Have the Final Say over a Child's Medical Care?*, 78 CAMBRIDGE L.J. 287, 288 (2019) (Their study of almost thirty jurisdictions concludes that recourse to the courts in these cases is much more frequent in England and that many jurisdictions—including Ireland—adopt some form of harm threshold. Cressida Auckland & Imogen Goold, *Resolving Disagreement: A Multi-Jurisdictional Comparative Analysis of Disputes About Children's Medical Care*, 28 MED. L. REV. 643, 644-51 (2020). They also note that in England medical teams generally defer to parental wishes unless the child is likely to be harmed. *Id.* at 653. A change from BI to "significant harm" would not, then, seem to impose a major change on current standards of medical practice. The authors' conclusion that the involvement of courts in England has facilitated "open and robust debate on questions as fundamental as when a child's life ought to be brought to an end" and has served to promote pluralism and tolerance and to accommodate reasonable disagreement on matters of value (*id.* at 674) is questionable. Have the courts not tended to *suppress* reasonable disagreement, while paying lip-service to the legal presumption in favor of prolonging life, by adopting a discriminatory perspective on disabled infants' lives consistently advanced by (UK) medical professionals and by counsel for trusts and legal guardians? *See supra* notes 280-88 and accompanying text.

291. Dominic Aeissame, WRITTEN EVIDENCE FROM THE CHARLIE GARD FOUNDATION (HCS 0026), (Jan. 11, 2021) https://committees.parliament.uk/writtenevidence/40604/pdf/; *see also* Catherine Burns, *Charlie's Parents Want 'Charlie's Law'*, BBC (June 20, 2018), https://www.bbc.co.uk/news/health-44334306.

292. Health and Care Act 2022, c. 31, § 177 (UK).

293. Health and Care Bill 2022-23, HL Bill [114] cl. 172 (an attempt to repeal the BI criterion might well have met resistance from the government, the medical profession and the judiciary).

conclusion on whether Charlie was or was not suffering significant harm currently, that finding would have been made."[294] It is therefore difficult to see how "Charlie's Law" would have *greatly* improved the position of either dying and disabled children or their parents. No test, new or old, will ensure justice if it permits the making of discriminatory judgments.

Regrettably, the report by the Nuffield Council, published in 2023, did not recommend either the replacement or the qualification of the BI test.[295] The report very largely concerned itself with practical ways of preventing and resolving disagreements. Even though it notes that differing values and beliefs are seen by healthcare professionals as a particularly significant source of disagreement,[296] the document reads more like the report of a council on social work than a council on bioethics. The report's response to fundamental criticisms of the BI test—its discriminatory application by the courts and its denial of parental rights—was strikingly superficial.[297] This was despite the fact that those objections had been clearly flagged in the evidence it received.[298] The report even committed the elementary error of caricaturing the sanctity of life, which it described as the idea that "human life should be preserved at all costs."[299] If the report could not even demonstrate a sound grasp of the basics of bioethics, how could it possibly hope to identify and analyze the differing ethical values that so often prompt disagreements between doctors and patients, and which lead to such confused and controversial judicial responses to those disagreements? The report was a missed opportunity and did little to enhance the reputation of the Nuffield as a council on bioethics.[300]

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294. *Gard CA* [2017] EWCA (Civ) 410 [114], (2018) 1 All ER 569; *see also* E (A Child) [2018] EWCA (Civ) 550 at [116]-[119] (King LJ).

295. NUFFIELD COUNCIL ON BIOETHICS, DISAGREEMENTS IN THE CARE OF CRITICALLY ILL CHILDREN 7 (2023), https://cdn.nuffieldbioethics.org/wp-content/uploads/NCOB-Disagreements-Critical-Care-Indepdent-Review-FINAL.pdf.

296. *Id.* at 31.

297. *Id.* at 47-48 (The report merely recounts, in the space of a few paragraphs, some points that have been made for and against the tests of BI and of significant harm.).

298. *Id.* at 45-50.

299. *Id.* at 14; *but see The Tragic Death of a Young Woman and an Exercise in 'Ethics Washing' by the Nuffield Council on Bioethics*, ANSCOMBE BIOETHICS CTR. 3 (Sept. 17, 2023), https://www.bioethics.org.uk/news-events/news-from-the-centre/anscombe-statement-the-tragic-death-of-a-young-woman-and-an-exercise-in-ethics-washing-by-the-nuffield-council-on-bioethics/; Ben Griffiths, *Charlie Gard Parents 'Betrayed' After Hopes Dashed of Law Change on Critically Ill Kids*, MIRROR (Sept. 18, 2023), https://www.mirror.co.uk/news/uk-news/charlie-gard-parents-betrayed-after-30969481 (Charlie's parents felt "betrayed" by the report's failure to recommend the enactment of "Charlie's Law").

300. NUFFIELD COUNCIL ON BIOETHICS, CITIZEN'S JURY: EXPLORING PUBLIC VIEWS ON ASSISTED DYING IN ENGLAND 12 (2024), https://www.nuffieldbioethics.org/publication/interim-report-citizens-jury-

10. *An Interim Judicial Work-Around?*

Even without legislative change to the BI test, there may be room for hospitals and courts to adopt a more parent-friendly approach. MacDonald J in *Raqeeb* held that the case lay toward the end of the scale at which there was an expectation that "difficult" decisions about BI should be taken by the parents. Why could not *all* the cases we have considered be reasonably described as "difficult" cases? Moreover, the guidance of the RCPCH, which emphasizes that it sets out circumstances in which it *might* be ethical to withhold or withdraw treatment, not circumstances in which it *must* be withheld or withdrawn,[301] recognizes:

> Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue [life sustaining treatments]. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation.[302]

It also states:

> There may be legitimate differences between individual families in their judgements about the benefits of treatment and of continued life. Where parents have an understanding about the likely benefits of treatment and the interests of the child, their views should be given considerable weight in the decision-making process . . . .[303]

Why should "due account" not amount to affording much greater weight to parents' views than the hospitals and courts in our cases have? The guidance also observes that the parents' special relationship with their child and the value that society places on preserving family relationships gives them a unique role in evaluating the child's BI.[304] Where parents do express

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on-assisted-dying/ (As part of its consideration of the ethics of 'assisted dying', the Council convened a 'Citizens' Jury'. Leaving aside the criticisms that have rightly been levelled at such exercises, not least the stacking of the jury with people who favor legalization to reflect public opinion polls, it is noteworthy that the Council did not convene a jury of citizens or parents, also reflective of public opinion, to respond to the moral and legal questions raised by cases like *Gard*.).

301. Larcher et al., supra note 14, at s3.

302. *Id.* at s14; *see also id.* at s4 (It also states that the guiding principle of the guidance is the child's best interests "albeit with greater consideration of the interests of families and of their rights.").

303. *Id.* at s15.

304. *Id.* at s10.

views, it adds, and these are reasonable, their values should carry great weight in decision-making.[305] It notes that an approach that considers family welfare rather than purely the child's BI is a model used by the majority of pediatricians, though the BI of the child should remain the primary factor, and referral to the courts should be considered when parental decisions would pose a significant risk of serious harm to the child.[306] Importantly, the guidance states that before declining parental requests for treatment, parents should, where possible, be given an opportunity to find an alternative provider who is willing and able to provide treatment.[307] Why, then, have hospitals repeatedly sought to prevent parents from having their children treated by alternative providers, even to the extent of launching costly, protracted, legal proceedings?[308]

CONCLUSION

The view endorsed by the courts in cases like *Gard*, that the lives of certain disabled infants lack benefit or dignity, or are a burden, is vulnerable to the criticism of being discriminatory and ableist. Ableist discrimination is, regrettably, not uncommon.[309] It is difficult to avoid the sad conclusion that the courts have, to a large extent, failed both infants and parents. Even when, exceptionally, the parents of patients like Tafida Raqueeb have been allowed to take their child abroad, the judgment has been "very finely balanced," not to mention ethically confused. The fact that the judges are doing their best to arrive at a just and humane conclusion, and are clearly taking great pains to do so, does not meet the criticism that their ethical reasoning has proved consistently flawed, failing to recognize the equality-in-dignity of the children concerned, and their parents' moral right to make medical treatment decisions on their behalf. The law should be amended, either by the judges or

305. *Id.* at s11.

306. *Id.*

307. *Id.* at s18-s19 ("The family should be at liberty to change clinician and move to another consultant if this is possible.").

308. As King LJ noted in *Evans*, such cases can only be profoundly damaging to the relationship between the hospital and parents, are distressing, time-consuming, and expensive, and take clinical staff and scarce resources away from the care of other children. E (A Child) [2018] EWCA (Civ) 550 [114].

309. *See* William F. Sullivan et al., *Ethics Framework and Recommendations to Support Capabilities of People with Intellectual and Developmental Disabilities During Pandemics*, 19 J. POL'Y & PRAC. INTELL. DISABILITIES 116, 118 (2022) (such discrimination is particularly well documented in relation to people with intellectual disabilities).

by the legislature, to ensure due respect for parental decisions unless they are (very) unreasonable.[310]

A final, and ominous, note. By judging the lives of disabled infants to be of no benefit or a harm, the law forfeits any principled reason for opposing the intentional shortening of their lives, whether by the withholding or withdrawal of treatment or even by lethal injection. Many ethicists will logically ask why, if a child's life is thought to be of no benefit or a burden, he or she should not be dispatched swiftly by lethal injection rather than be allowed to linger until death after withdrawal of treatment (not least as withdrawal may not even bring about death, as in the case of *NR*)? What sensible answer could the judges give? They would find it difficult to hide behind the artificial distinction between acts and omissions, for two reasons. First, the distinction can be blurry. Is disconnecting a patient from a ventilator an act or an omission? Second, what is the moral difference between withholding ventilation or hydration and administering a lethal substance, at least if the intention is equally to hasten the child's demise?

310. In a welcome victory for parental freedom of expression over doctors' privacy, the UK Supreme Court recently held that medical staff involved in two controversial cases of the kind we have considered did not have a right to lifelong anonymity to protect them from public criticism by the parents. Abbasi v Newcastle upon Tyne Hosp. NHS Found. Tr. [2025] UKSC 15; Haastrup v King's College Hosp. NHS Found. Tr. [2025] UKSC 15.