

# Bettering the Best Interest Test: End-of-Life Treatment Decisions for Young Children

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## INTRODUCTION

*“Let the doctor tell me I shall die unless I do so-and-so;  
but whether life is worth having on those terms is no more  
a question for him than for any other man.”<sup>1</sup>*

C.S. Lewis

Recent controversial cases illuminate the global discrepancies in national standards applied for medical decision-making involving young children. This is especially true of end-of-life treatment decisions where the child is not in a position to self-advocate, due to age or disability. Countries have different answers as to whether the guardian or the state should make the ultimate treatment decision for a child, and in particular the decision to terminate treatment or withdraw life-saving measures. This underlies the broader legal issue of patient autonomy, and whether the child belongs to the state or the guardian<sup>2</sup> for purposes of medical decision-making.

Nations also have defined disability differently and have given different meanings to the subjective concept of quality of life, which leads to different patients’ rights policies. This diversity of values and circumstances clearly have an effect on the type of quality of life considered intolerable, and therefore directly influence medical decision-making, particularly at the end of life. Unsurprisingly, these treatment decisions are exceptionally important because of the life and death reality. This importance drives a heightened need to adopt a comprehensive standard that preserves the autonomy of patients and their guardians, while accounting for the level of suffering of the patients and the possibility of survival.

Currently, the “best interest” standard is widely accepted on a quasi-global level. Under this standard, courts look at various factors to determine what is in the *best interest* of the patient, even if it is contrary to the wishes of the patient or the patient’s guardians. To retain decision-making authority

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1. C.S. Lewis, *Willing Slaves of the Welfare State*, THE OBSERVER, July 20, 1958.

2. See, e.g., Rachel Bovard, *States are right to act toward preventing an Alfie Evans in the US*, THE HILL, May 9, 2018, <https://thehill.com/opinion/international/386907-states-are-right-to-act-toward-preventing-an-alfie-evans-in-the-us> [<https://perma.cc/65NW-HKYC>].

when children are concerned, guardians must establish that continuing (or discontinuing) treatment is in the best interest of the child, which often results in the guardians being pitted against the advice of medical professionals. Consequently, losing decision-making authority leads to the usurping of the paternal role. Additionally, whether the “best interest” standard does what it claims to do—act in the best interest of the child—is highly debated, particularly when the end result goes against the ethos of those who know the child best.

This Comment argues that shifting the burden of proof from the patients’ guardians to the state and adopting an “extreme suffering” test will allow guardians to exercise their autonomy while still accounting for the overall interests of the patient. Under this test, the guardians retain decision-making power and ultimately formulate a treatment plan they believe is in the best interest of the child. The state will only have the authority to step in when the treatment chosen by the parents will certainly (or as medically certainly as it can be) lead to extreme pain for the patient, with no possibility that the suffering will subside. At that point, the state will step in.

The issue of end-of-life treatment for young children has gained new traction in the United States in the weeks just prior to this writing. A tense legal battle is currently raging in Texas over the treatment of Tinslee Lewis, a baby girl with a rare heart defect.<sup>3</sup> Tinslee’s mother is petitioning the courts to keep her on life support until she can find a physician who will perform a tracheotomy on Tinslee.<sup>4</sup> Tinslee’s current healthcare providers are countering that Tinslee’s condition is irreversible and she should be removed from life support.<sup>5</sup>

The Comment will compare the laws governing end-of-life care for minors in the United Kingdom, Israel, Australia, and the United States; it will explore cases like Tinslee’s that have illustrated the disagreements between guardians and physicians over end-of-life treatment decisions for critically ill children, and it will focus on two prominent British cases. The Comment will examine the historical influences and motivations of the diverse legal schemes and how different legal systems address the relevant issues. It will conclude by proposing a model standard.

Parts I and II will explore the two pivotal concerns in determining who should make the decision for a child’s end-of-life treatment. Part I will

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3. See *infra* Section III.C. (discussing Tinslee’s case and advance directives).

4. *Id.*

5. *Id.*

explain the best interest test and will consider two cases of critically ill children and how the laws led to the results in each case. Part II will describe the role of autonomy in medical decisions generally, and how the autonomy of the guardians in cases involving minor children should remain intact except for the most extreme cases. Part III will discuss other considerations in determining end-of-life treatment, including the role of mediation and alternatives to court rulings, and legislature on experimental treatment, advance directives, and do-not-resuscitate orders. Part IV will propose a legal solution and a Model Code, which will formulate a test based on the patient's "extreme suffering" that gives deference to guardian autonomy. Part IV will also review the negative implications of the best interest test on disability rights. The Comment will culminate with an illustration of how the two cases discussed in Part I would have resulted in different outcomes had the Model Code been used; it also theorizes how an ongoing case would be decided under the Model Code.

## I. BEST INTEREST TEST

The first major prong to consider in determining how to proceed with a critically ill child's treatment is that child's "best interest."<sup>6</sup> The best interest standard is an ethical requirement calling for caregivers to provide medical treatment in good faith and by placing the caregiver's assessment of the person's best interests above their own.<sup>7</sup> This standard particularly applies to the care of dependent individuals such as infants or small children whose age prevents them from making decisions on their own.<sup>8</sup> In the more legal sense, the best interest test has emerged as a means to resolve disputes between parties over the treatment for a young patient when the parties take the dispute to court. However, while this standard may be beneficial in resolving other controversies involving children, such as custody disputes, it has not proved an overall effective means of minimizing harm when assessing whether a child should receive treatment. The cases of Charlie Gard and Alfie Evans demonstrate that while this standard is favored by courts in United Kingdom (UK),<sup>9</sup> the outcomes reached by relying on it often bring devastating consequences.

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6. THE FREE DICTIONARY, <https://medical-dictionary.thefreedictionary.com/best+interest+standard> [<https://perma.cc/VP4B-FMYJ>] (last visited Mar. 8, 2020).

7. *Id.*

8. *Id.*

9. *See infra* Section I.A. (discussing the cases of Charlie Gard and Alfie Evans).

*A. United Kingdom*

According to the Royal College of Paediatrics and Child Health, when “treatment is unable or unlikely to prolong life significantly, it may not be in the child’s *best interest* to provide it.”<sup>10</sup> Omitting treatment may also be appropriate “where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself.”<sup>11</sup> The Royal College has issued guidelines which identify three situations where medical providers can consider limiting treatment: (1) when life is limited in duration; (2) when life is limited in quality; and (3) when there is informed competent refusal of treatment.<sup>12</sup>

While UK courts now adhere to this “best interest” standard, this is a shift from the historical position of UK law. At common law, fathers possessed sole custody of and decision-making for their children.<sup>13</sup> A father could enforce his right to the custody of his child through a writ of habeas corpus,<sup>14</sup> which resulted in near-absolute paternal rights.<sup>15</sup> This absoluteness shifted in 1839 with the Custody of Infants Act<sup>16</sup> creating some maternal custody rights,<sup>17</sup> and subsequent legislature and reliance on the best interest test that have since considerably lessened parental rights.<sup>18</sup>

Specifically, in 1891, the Custody of Children Act clarified that parental rights are not absolute.<sup>19</sup> The Guardianship of Infants Act followed in 1925, later to be replaced by the Children Act 1989 (the 1989 Act), which

10. Vic Larcher et al., *Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice*, 100 ARCHIVES OF DISEASE IN CHILDHOOD s13 (2015) (emphasis added), [https://adc.bmj.com/content/archdischild/100/Suppl\\_2/s1.full.pdf](https://adc.bmj.com/content/archdischild/100/Suppl_2/s1.full.pdf) [<https://perma.cc/92RK-H85Q>].

11. *Id.* at s4.

12. *Id.*

13. See, e.g., Sarah Abramowicz, Note, *English Child Custody Law, 1660–1839: The Origins of Judicial Intervention in Parental Custody*, 99 COLUM. L. REV. 1344 (1999).

14. The Habeas Corpus Act was enacted by the Parliament in 1679 and remains in force. Habeas Corpus Act 1679, 31 Car. 2, c. 2 (Eng. and Wales). It ensures that an individual cannot be imprisoned unlawfully. Literally translated, “habeas corpus” means “you may have the body.” *Learning Timelines: Sources from History, Habeas Corpus Act 1679*, BRITISH LIBRARY, <http://www.bl.uk/learning/timeline/item104236.html> [<https://perma.cc/EDN98-37NJ>] (last visited Mar. 14, 2020).

15. Abramowicz, *supra* note 13, at 1344.

16. Custody of Infants Act 1839, 2 & 3 Vict., c. 54 (Eng.).

17. *Id.*

18. *In the matter of Alfie Evans No.2* [2018] EWHC (Fam) 308 (appeal refused by UKSC) (Eng.).

19. Custody of Children Act 1981, 54–55 Vic., c. 3 (Eng.).

established that a child's best interest is the paramount consideration when any question relating to the child comes before the courts.<sup>20</sup> The best interest test as articulated by the 1989 Act reflects the globally recognized standard,<sup>21</sup> and UK courts consistently abide by it, as shown in the case of baby Charlie Gard.<sup>22</sup>

### 1. *Charlie Gard*

Charlie Gard was born full term on August 4, 2016 in England.<sup>23</sup> At birth, he appeared "perfectly healthy,"<sup>24</sup> but within a month, his parents noticed he could not lift his head or support himself.<sup>25</sup> By October of 2016,<sup>26</sup> Charlie was admitted to Great Ormond Street Hospital (Great Ormond) in London, where physicians diagnosed him with an exceptionally rare genetic condition.<sup>27</sup> Physicians deemed his prognosis bleak,<sup>28</sup> and Charlie soon lost the ability to move his arms and legs and to open his eyes.<sup>29</sup>

After ceaseless research and consultation with physicians from across the world, Charlie's parents learned of an experimental, non-invasive treatment<sup>30</sup> that had prior success with another syndrome similar to Charlie's

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20. Section 31(2) of the 1989 Act also discusses the "significant harm" to the child as a threshold matter in determining whether a court can consider whether to make a care or supervision order. Children Act 1989, c. 41, § 31(2) (Eng.); *Significant harm*, THOMSON REUTERS, [https://uk.practicallaw.thomsonreuters.com/8-538-0246?transitionType=Default&contextData=\(sc.Default\)&firstPage=true&comp=pluk&bhcp=1](https://uk.practicallaw.thomsonreuters.com/8-538-0246?transitionType=Default&contextData=(sc.Default)&firstPage=true&comp=pluk&bhcp=1) (last visited Mar. 27, 2020) [<https://perma.cc/7GUF-93ER>].

21. Justice Committee, Operation on the Family Courts, 2011, HC 518-I ¶ 47.

22. *Id.* at 48.

23. *Timeline: Charlie Gard and his parents' legal battle to save him*, THE GUARDIAN (July 28, 2017), <https://www.theguardian.com/uk-news/2017/jul/24/timeline-charlie-gard-and-his-parents-legal-battle-to-save-him> [<https://perma.cc/4XLM-TD4Z>] [hereinafter *Charlie Gard Timeline*].

24. Cory Franklin, *The lesson everyone missed in the Charlie Gard story*, WASH. EXAMINER (Aug. 8, 2017), <https://www.washingtonexaminer.com/the-lesson-everyone-missed-in-the-charlie-gard-story> [<https://perma.cc/E7HG-KHQJ>].

25. *Charlie Gard Timeline*, *supra* note 23.

26. *Id.*

27. Charlie was diagnosed with encephalomyopathic mitochondrial DNA depletion syndrome. *Charlie Gard: The story of his parents' legal fight*, BBC (July 27, 2017), <https://www.bbc.com/news/health-40554462> [<https://perma.cc/GYL6-EYUV>] [hereinafter *Charlie Gard Story*]; Rosalyn Broad, Comment, *RECENT DEVELOPMENTS: Gard v. United Kingdom: Does the State Know Best?*, 26 TUL. J. INT'L & COMP. L. 405 (2018); *Charlie Gard Timeline*, *supra* note 23.

28. *Charlie Gard Story*, *supra* note 27.

29. *Charlie Gard Timeline*, *supra* note 23; Broad, *supra* note 27.

30. The treatment was called nucleoside bypass therapy. *Charlie Gard Story*, *supra* note 27.

condition.<sup>31</sup> Charlie's parents consulted a physician from Columbia University Medical Center in the United States,<sup>32</sup> who confirmed that Charlie could be treated in the United States if his parents financed the treatment.<sup>33</sup> By January of 2017, a public crowdfunding page raised approximately 1.3 million pounds (1.68 million dollars) for Charlie's treatment.<sup>34</sup>

The British physicians opposed the idea of Charlie receiving experimental treatment in the United States and argued that Charlie's life support should be removed to allow him to die with "dignity."<sup>35</sup> As Charlie was being evaluated for this treatment option, he suffered numerous seizures which caused severe damage to his brain,<sup>36</sup> heart, liver, and kidneys.<sup>37</sup> Despite the severity of the damage, physicians at Great Ormond could not definitively ascertain whether Charlie experienced pain.<sup>38</sup>

In March of 2017, despite the objections of Charlie's parents, Great Ormond applied to the Family Division of the High Court for an order to halt Charlie's treatment.<sup>39</sup> Great Ormond presented experts who testified that there could be no reversal of Charlie's brain damage, even with treatment.<sup>40</sup> The judge agreed with the experts and granted the order on

31. Kate Samuelson, *What to Know About Charlie Gard, the Terminally Ill Baby Trump Wants to Help*, TIME (July 3, 2017), <https://time.com/4843746/president-trump-pope-francis-charlie-gard/> [https://perma.cc/V655-S8Y9].

32. Debra Goldschmidt & Richard Greene, *British baby Charlie Gard to be evaluated by US doctor*, CNN (July 17, 2017), <https://www.cnn.com/2017/07/14/health/charlie-gard-us-doctor-bn/index.html> [https://perma.cc/VA7B-EEAD].

33. *Charlie Gard Story*, *supra* note 27.

34. Charlie's parents publicly opined their strong belief that Charlie should be given the opportunity to try the medications because he has "literally nothing to lose but potentially a healthier, happier life to gain." Samuelson, *supra* note 31.

35. *Gard v. United Kingdom*, App. No. 39793/17, Eur. Ct. H.R. 2, 28 (2017); *Charlie Gard Story*, *supra* note 27.

36. *Gard v. UK*, Eur. Ct. H.R. at 2, 28; Broad, *supra* note 27; *Charlie Gard Story*, *supra* note 27.

37. *Charlie Gard Story*, *supra* note 27.

38. *Id.*

39. *Charlie Gard Timeline*, *supra* note 23.

40. *Gard v. UK*, Eur. Ct. H.R. at 2, 28; Broad, *supra* note 27; *Charlie Gard Story*, *supra* note 27.

April 11, citing *Wyatt v. Portsmouth NHS Trust*<sup>41</sup> in his decision.<sup>42</sup> Charlie's parents appealed,<sup>43</sup> but the Court of Appeal dismissed their petition less than three weeks later.<sup>44</sup> The British Supreme Court affirmed the first decision, ruling that it would be against Charlie's best interest to take him to the United States to receive treatment without a real prospect of improvement.<sup>45</sup>

Following the effective termination of parental autonomy over Charlie's treatment, Charlie's parents applied for an order to the European Court of Human Rights (ECtHR).<sup>46</sup> The parents argued that not only had state authorities violated their positive obligations to protect life, but that their own parental rights had been disproportionately affected in violation of Articles 6 and 8 of the European Convention of Human Rights (ECHR).<sup>47</sup> In particular, Charlie's parents maintained that applying a "best interest" test instead of a "significant harm" test permitted unjust interference in their parental rights, and that the High Court had erred by relying on the "best interest" test alone.<sup>48</sup>

Charlie's parents sought to distinguish between two categories of cases relating to children's treatment decisions.<sup>49</sup> The first category involved parents who opposed the treatment physicians proposed but did not have a viable alternative to present to the court, and the second category of cases involved parents who did have an alternate treatment option.<sup>50</sup> Charlie's parents' case fell into the latter category because they proposed a treatment plan and had the means to pay for it.<sup>51</sup>

Charlie's parents also advocated that parental autonomy in a child's medical decisions should only be superseded if the parents' proposed treatment is likely to cause the child "significant harm."<sup>52</sup> Great Ormond,

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41. Charlotte Wyatt was born prematurely in October of 2003, weighing only one pound, and with serious damage to her brain, lungs, and kidneys. Despite medical opinion that Charlotte had no prospect of normal development or independence, Charlotte's parents fought in court to require physicians to provide her with ventilation. *Wyatt v. Portsmouth NHS Trust and Another* [2005] EWHC (Fam) 693 (Eng.).

42. *Great Ormond Street Hospital for Children NHS Foundation v. Yates and Others*, [2017] EWHC 972 (Fam)13, [2018] 1 All ER 569 (Eng.); Broad, *supra* note 27.

43. *Charlie Gard Timeline*, *supra* note 23.

44. *Id.*

45. *In the Matter of Charlie Gard* [2017] UKSC [5], [17] (Eng.).

46. *See Gard v. United Kingdom*, App. No. 39793/17, Eur. Ct. H.R. 1 (2017).

47. *Id.* at 15.

48. *Id.* at 6–7, 15.

49. *Id.* at 6.

50. *Id.*

51. *Id.*

52. There is no statutory definition of significant harm, but the Children Act 1989 provides some guidance. Under Section 31(9), in determining whether the harm to the child's health is significant, the child's health and development must be compared to that of a

the hospital, contended that the treatment proposed by Charlie's parents was not in Charlie's best interest, even though there was no evidence that the intended treatment would have an adverse effect on Charlie.<sup>53</sup> Charlie's parents countered that Great Ormond acted outside of its power as a public authority when it initially applied to prevent treatment it did not intend to provide, and therefore the court had no jurisdiction to uphold Great Ormond's position.<sup>54</sup>

The ECtHR dismissed Charlie's parents' complaint.<sup>55</sup> It held that the UK's regulatory framework, which requires physicians to apply to the courts in uncertain cases, was compatible with Article 2 of the ECHR.<sup>56</sup> Additionally, interference with parental rights in accordance with the law was permissive as it pursued a legitimate end that protected the interests of the child.<sup>57</sup> The ECtHR agreed with Great Ormond in applying the best interest test, and clarified that the basis for that test was in broad international consensus.<sup>58</sup> After the decision, Great Ormond announced there was "no rush" to change Charlie's treatment, and there would be "careful planning and discussion," albeit without the consent of Charlie's parents.<sup>59</sup>

Charlie's parents were seemingly out of available legal avenues<sup>60</sup> to regain autonomy over Charlie's treatment plan when the case garnered international attention.<sup>61</sup> Pope Francis called for Charlie's parents to be allowed to "accompany and treat their child until the end,"<sup>62</sup> and the Vatican's children's hospital, Bambino Gesù, offered to treat Charlie.<sup>63</sup> The President of the United States, Donald Trump, tweeted his support for Charlie's family and contacted the physician at Columbia University who had previously

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"reasonable" child. Children Act 1989, c. 41, § 31(9) (Eng.), <http://www.legislation.gov.uk/ukpga/1989/41/section/31> [<https://perma.cc/NR8W-5HM7>].

53. Gard v. UK, Eur. Ct. H.R. 2, 7 (2017).

54. *Id.* at 6.

55. *Id.* at 20.

56. *Id.* at 2, 28 (2017); *Charlie Gard Timeline*, *supra* note 23; Broad, *supra* note 27, at 411.

57. Gard v. UK, Eur. Ct. H.R. 2, 15 (2017).

58. *Id.* at 25.

59. *Charlie Gard Timeline*, *supra* note 23.

60. *Id.*

61. See Emma Cave & Emma Nottingham, *Who Knows Best (Interests)? The Case of Charlie Gard*, 26 MED. L. REV. 500, 513 (2018).

62. *Charlie Gard Timeline*, *supra* note 23.

63. *Id.*

confirmed that Charlie could be treated in the United States.<sup>64</sup> The physician, along with other medical experts, co-signed a letter suggesting that unpublished data showed therapy could improve Charlie's brain condition.<sup>65</sup>

On July 10, 2017, Charlie's parents returned to the High Court requesting review of the case<sup>66</sup> in light of the new evidence relating to the potential treatment for Charlie's condition. Under the initial ruling, Charlie was prohibited from being transferred despite available medical alternatives.<sup>67</sup> The following week, a Columbia University physician traveled to London to examine Charlie and to consult with Great Ormond physicians.<sup>68</sup> On July 17, the physician testified in court that the treatment option championed by Charlie's parents had a ten percent success rate, and that Charlie's electroencephalogram (EEG)<sup>69</sup> showed "disorganization of brain activity [but] not major structural brain damage."<sup>70</sup> In response, a lawyer from Great Ormond blindsided Charlie's parents by representing the results of a new scan of Charlie's brain to the court before Charlie's parents received it.<sup>71</sup>

The legal battles wore on Charlie's family, and on July 24, one day before the High Court was expected to rule, Charlie's parents announced they were ending the legal fight over Charlie's treatment because "time ha[d] run out."<sup>72</sup> The following day, Charlie's mother returned to court to beseech the judge to allow Charlie to spend his final days at home.<sup>73</sup> Great

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64. Jessica Glenza, *How Charlie Gard Captured Trump's Attention and Animated Pro-Life Groups*, THE GUARDIAN (July 26, 2017), <https://www.theguardian.com/uk-news/2017/jul/26/charlie-gard-us-pro-life-rightwing-ethics> [<https://perma.cc/V33S-24A5>].

65. The doctor conceded that treatment would ideally be tested on mice first but there was no time for such trial in Charlie's case. *Charlie Gard has 10% chance of improvement, US doctor claims*, BBC NEWS (July 13, 2017), <https://www.bbc.com/news/uk-england-london-40593286> [<https://perma.cc/T78V-4XA5>].

66. *Charlie Gard Timeline*, *supra* note 23.

67. *Great Ormond Street Hospital for Children NHS Foundation v. Yates and Others* [2017] EWHC 1909 (Fam) 13, (Eng.).

68. *Charlie Gard Timeline*, *supra* note 23.

69. An EEG, or electroencephalogram, is a test that records the electrical signals of the brain. *What is an EEG (Electroencephalogram)?*, WEBMD, <https://www.webmd.com/epilepsy/guide/electroencephalogram-eeeg> [<https://perma.cc/2EDQ-HDC7>] (last updated July 20, 2019).

70. Haroon Siddique, *Charlie Gard's Father in Court Outburst After Scan Results Revealed*, THE GUARDIAN (July 21, 2017), <https://www.theguardian.com/uk-news/2017/jul/21/charlie-gards-father-in-court-outburst-after-scan-results-revealed> [<https://perma.cc/VP7Y-GL49>].

71. *See id.*

72. Crux Staff, *Parents of Charlie Gard Drop Legal Fight, Saying 'Time has Run Out'*, CRUX (July 24, 2017), <https://cruxnow.com/global-church/2017/07/parents-charlie-gard-drop-legal-fight-saying-time-run/> [<https://perma.cc/PR6L-4N77>].

73. Michael Edison Hayden, *Charlie Gard's Family Asks Court to Let the Boy Come Home to Die*, ABC NEWS (July 25, 2017), <https://abcnews.go.com/International/charlie-gards-family-asks-court-boy-home-die/story?id=48834464> [<https://perma.cc/H29C-2LT9>].

Ormond opposed the request.<sup>74</sup> The judge denied the request, stating the only two options for Charlie were to remain at the hospital or enter hospice.<sup>75</sup> Charlie's parents indicated they wanted to privately fund hospice treatment, and Great Ormond fought them on yet this other request.<sup>76</sup> The judge ruled that Charlie should be taken into hospice by noon of the following day if the parties could not come to an agreement.<sup>77</sup>

Charlie was transferred to hospice on July 27, 2017, as planned by the court.<sup>78</sup> The plan dictated that life support would be withdrawn shortly after the transfer so as to avoid "the risk of an unplanned and chaotic end to Charlie's life."<sup>79</sup> In an emotional statement, Charlie's mother noted that Great Ormond "denied [them] of [their] final wish."<sup>80</sup> Charlie passed away the following day, just weeks before his first birthday.<sup>81</sup>

The court in Charlie's case ruled using the "best interest" test but under the Universal Declaration of Human Rights, parents have the right to determine what is in the best interest of their child.<sup>82</sup> In its judgment, the High Court explained how the Custody of Children Act 1891<sup>83</sup> severely qualified this parental right by granting courts the right to protect minors from neglectful or abusive parents.<sup>84</sup> Subsequent Acts of Parliament<sup>85</sup> established that a child's best interest is the principal consideration for any

74. Haroon Siddique, *Charlie Gard: Judge to Decide on Parent's 'Last Wish' that Son Can Die at Home*, THE GUARDIAN (July 26, 2017), <https://www.theguardian.com/uk-news/2017/jul/25/charlie-gard-connie-yates-asks-court-die-at-home> [<https://perma.cc/66UM-NX22>].

75. Great Ormond Street Hospital for Children NHS Foundation v. Yates and Others [2017] EWHC 1909 (Fam) [13], [2018] 1 All ER 569.

76. *Id.*

77. Natasha Hammond-Browning, *When Doctors and Parents Don't Agree: The Story of Charlie Gard*, 14 J. OF BIOETHICAL INQUIRY 461 (2017).

78. *Charlie Gard Timeline*, *supra* note 23.

79. Great Ormond Street Hospital for Children NHS Foundation v. Yates and Others, at [3]; *Charlie Gard Timeline*, *supra* note 23.

80. *Charlie Gard Timeline*, *supra* note 23.

81. *Id.*

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

83. Custody of Children Act 1891, 54 & 55 Vict., c. 3, § 1 (Eng.).

84. Rod Dreher, *About Alfie Evans*, THE AM. CONSERVATIVE (Apr. 28, 2018), <https://www.theamericanconservative.com/dreher/about-alfie-evans-britain-euthanasia/> [<https://perma.cc/PG9Y-6EDJ>].

85. Guardianship of Infant Acts 1925, 15 & 16 Geo.V, c. 45 (Eng.), [https://www.swarb.co.uk/acts/1925Guardianship\\_of\\_InfantsAct.shtml](https://www.swarb.co.uk/acts/1925Guardianship_of_InfantsAct.shtml) [<https://perma.cc/X5ZD-CGLS>] (Eng.); Children Act 1989, c. 41, § 41 (Eng.).

question relating to the child that comes before the courts.<sup>86</sup> The practical effect of the legal change from absolute to qualified parental rights is that the state ultimately exercises parental power over the child while leaving that right to the actual parents on a day-to-day basis.

*a. The European Convention on Human Rights*

In their appeal, Charlie's parents brought claims under Articles 2 and 8 of the European Convention on Human Rights (ECHR) to the European Court of Human Rights (ECtHR).<sup>87</sup> The ECHR and the ECtHR stem from the Council of Europe, formed after World War II,<sup>88</sup> to promote democracy in Europe.<sup>89</sup> The Council of Europe adopted the ECHR in 1950<sup>90</sup> to secure civil and political rights,<sup>91</sup> and the Council of Europe established the ECtHR to oversee the ECHR's implementation. The ECHR sets forth several fundamental rights and freedoms, including the right to life, the right to liberty and security, and the right to respect for private and family life.<sup>92</sup> At the request of the Council of Europe,<sup>93</sup> the ECtHR may give advisory opinions concerning the interpretation of the ECHR and interpret

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86. Children Act 1989, c. 41, § 41 (Eng.).

87. Hammond-Browning, *supra* note 77, at 464.

88. Convention for the Protection of Human Rights and Fundamental Freedoms, Nov. 4, 1950, E.T.S. No. 005 [*The ECHR*]; see also *The European Convention on Human Rights*, THE BRIT. INST. OF HUM. RTS., <https://www.bih.org.uk/theconvention> [<https://perma.cc/JW4F-GGMS>] (last visited Feb. 28, 2020).

89. *Do not get confused*, Council of Europe, <https://www.coe.int/en/web/about-us/do-not-get-confused?desktop=true> [<https://perma.cc/3A9D-GVT9>]; Marc Ernest Trigilio, Note, *The Convention on Human Rights and Biomedicine: Allowing Medical Treatment and Research without Consent on Persons Unable to Give Informed Consent*, 22 SUFFOLK TRANSNAT'L L. REV. 641 (1999) (noting how the European Convention of Human Rights and Fundamental Freedoms (ECHR) and its European human rights law derive in part from addressing the atrocity of the Holocaust, which increased awareness of violations of the rights and dignity of the human being, particularly in the areas of medical treatment and research); Winston Churchill, Address at the Congress of Europe in The Hague (May 7, 1948) (calling for a "Charter of Human Rights" to be "guarded by freedom and sustained by law" which ensured "people owned the government, and not the government the people" in the aftermath of World War II).

90. *The ECHR*, *supra* note 88.

91. Council of Europe, *supra* note 89.

92. *The ECHR*, *supra* note 88, at arts. 2, 5, 8.

93. Council of Europe, *supra* note 89. The two main governing bodies in Europe are the Council of Europe and the European Union. The Council of Europe is an international organization comprising of forty-seven European countries and focuses on protection of human rights and the rule of law in Europe. The European Union has twenty-eight members that have delegated some of their sovereignty so that "decisions on specific matters of joint interest can be made democratically at the European level." There is some interplay between the two authorities as no country has ever joined the European Union without first belonging to the Council of Europe. *Id.*

judgments from the courts of member states.<sup>94</sup> The ECtHR has the authority to issue binding judgments on individuals<sup>95</sup> or member states to the ECHR<sup>96</sup> and it creates law through its decisions.<sup>97</sup>

Article 34 of the ECHR allows the ECtHR to receive applications from any individual who claims to be the victim of a violation of the rights set forth in the Convention,<sup>98</sup> which is how Charlie's parents had standing to bring their claim. The ECtHR has examined general principles regarding treatment for terminally ill patients,<sup>99</sup> specifically addressing ECHR Article 2 complaints (like the one brought by Charlie's parents).<sup>100</sup> Article 2 of the ECHR provides that "everyone's right to life shall be protected by law."<sup>101</sup> The ECtHR has held that Article 2 cannot be interpreted to require access to experimental or unauthorized treatment for terminally ill individuals or that such treatment must be regulated in a particular way.<sup>102</sup>

Charlie's parents also brought a claim under Article 8, which states that "everyone has the right to respect for his private and family life, his home and his correspondence" and protects against interference by public authorities with the exercise of the right to respect for private and family life "except such as in accordance with the law and is necessary in a democratic society."<sup>103</sup> Until the passing of the Human Rights Act of 1998,<sup>104</sup> the ECtHR was the only avenue for parties in the UK to demand their human rights.

94. Guardianship of Infants Act 1925, 15 & 16 Geo. 5, c. 45 (Eng.); Children Act 1989, c. 41, § 32 (Eng.).

95. *The ECHR*, *supra* note 88, at art. 19.

96. The ECtHR is based in Strasbourg and has operated full-time since November of 1998; Council of Europe, *supra* note 89.

97. See RALPH FOLSOM, PRINCIPLES OF EUROPEAN UNION L. 69 (2017).

98. See *The ECHR*, *supra* note 88, at art. 34.

99. Broad, *supra* note 27.

100. In *Hristozov v. Bulgaria*, the ECtHR addressed a complaint regarding Bulgaria's denial of access to an experimental treatment for terminally ill patients. Bulgaria denied access because the product was not yet licensed, which was in violation of Bulgaria's regulations. The applicants' complaint was that there was no way to obtain authorized use of experimental methods once they have exhausted all conventional methods of treatment and was therefore a violation of Article 2's requirement that "everyone's right to life shall be protected by law." *Hristozov v. Bulgaria*, Eur. Ct. H.R., at 1–4 (2012).

101. *The ECHR*, *supra* note 88, at art. 92.

102. See *generally id.*, at art. 2.

103. *Id.*

104. The Human Rights Act, Equality and Human Rights Commission (Nov. 15, 2018), <https://www.equalityhumanrights.com/en/human-rights/human-rights-act> [<https://perma.cc/45WT-UXR6>].

b. *The Human Rights Act of 1998*

In 1998, the UK passed the Human Rights Act which incorporated the fundamental rights and freedoms from the ECHR into domestic British law.<sup>105</sup> The Human Rights Act has three main effects: (1) justice can be sought in a domestic court instead of before the ECtHR; (2) all public bodies and other bodies carrying out public functions must respect individuals' human rights; and (3) the Parliament and the British judiciary work to ensure legislative and interpretation are compatible with the ECHR and the ECtHR's decisions.<sup>106</sup> In Charlie's case, his parents initially sought relief in accordance with the Human Rights Act, but when they ultimately lost domestically, they turned to the ECtHR.<sup>107</sup>

The justification for the 1891 Act was that parental rights should be transferred from brutal and neglectful parents to the state, but this was not the situation in Charlie's case: his parents made immense efforts to find other physicians and hospitals who would treat their baby, and no one could seriously say that they did not want to obtain the best outcome for him. The question naturally arises as to why, then, in a situation where the parents or guardians are deemed to be seriously trying to do the best for their child, should physicians and courts step in and claim to be the paramount evaluators of a child's best interests. This question arose again in a case resulting in a similar outcome to Charlie's, just a few months later, and that involved continuing the treatment of a baby named Alfie Evans.

2. *Alfie Evans*

Alfie Evans was born a seemingly healthy baby on May 9, 2016,<sup>108</sup> in Liverpool, England. In December of 2016, he was admitted into the pediatric unit at Alder Hey Children's Hospital (Alder Hey) following a series of seizures.<sup>109</sup> Over the next year, Alfie suffered additional seizures, as well as bi-lateral pneumonia and cardiac complications.<sup>110</sup> By December of 2017, hospital officials and Alfie's parents disagreed on the appropriate

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105. *Id.*

106. *Id.*

107. *Supra* Section I.A1.

108. *Timeline: key events in the legal battle over Alfie Evans*, THE GUARDIAN (Apr. 28, 2018), <https://www.theguardian.com/society/2018/apr/28/alfie-evans-timeline-of-key-events> [<https://perma.cc/VW3K-RM43>] [hereinafter *Alfie Evans Timeline*].

109. *Id.*

110. *Alfie Evans Timeline*, *supra* note 108; Annabelle Timsit, *The life and death of Alfie Evans highlights the gap between the US and Europe on right to life*, QUARTZ, (Apr. 28, 2018), <https://qz.com/1264345/alfie-evans-life-and-death-highlights-the-vast-gap-between-the-us-and-europe-on-right-to-life/> [<https://perma.cc/R2M4-F3FV>].

course of treatment for the baby.<sup>111</sup> Officials from Alder Hey announced publicly that they were liaising directly with Alfie's family to resolve the conflict, but this claim was disputed by the family.<sup>112</sup>

When a resolution could not be reached regarding Alfie's treatment plan, Alder Hey turned to the High Court and sought a declaration stating that continued ventilator support was not in Alfie's best interest.<sup>113</sup> The hospital took an additional step and requested that the court remove all parental rights from Alfie's family.<sup>114</sup> A public hearing began on December 19, 2017, in the family division of the High Court in London.<sup>115</sup> Alder Hey argued that continuing life-saving treatment was not in Alfie's best interest.<sup>116</sup> Alfie's parents vehemently disagreed and pleaded for permission to fly Alfie to Italy for him to receive the treatment that Alder Hey refused to provide.<sup>117</sup>

Alfie's parents were finally afforded the opportunity for mediation with Alder Hey in January, about the time Alfie slipped into a coma, but the mediation ultimately proved unsuccessful.<sup>118</sup> Another hearing began at the High Court in Liverpool the following month, during which lawyers for Alder Hey argued that further treatment for Alfie was unkind and inhumane, and one physician told the judge there was no hope for Alfie.<sup>119</sup> Alfie's parents expressed to the court their feeling that Alder Hey had given up on Alfie.<sup>120</sup> On February 20, 2018, the judge ruled in favor of Alder Hey, accepting the medical evidence indicating that further treatment was futile, and that while every reasonable option should be explored, continuing treatment compromised Alfie's "future dignity" and failed to respect his autonomy.<sup>121</sup>

Alfie's parents challenged the ruling in March of 2018 and three Court of Appeal judges began analyzing the case.<sup>122</sup> Alfie's parents requested a

111. *Alfie Evans Timeline*, *supra* note 108.

112. *Id.*

113. *Evans v. Alder Hey Children's Foundation NHS Trust* [2018] EWHC 308 (Fam) [1].

114. *Alfie Evans Timeline*, *supra* note 108.

115. *Id.*

116. *Id.*

117. *Id.*

118. *Timsit*, *supra* note 110.

119. *Alfie Evans Timeline*, *supra* note 108; *Timsit*, *supra* note 110.

120. *See Alfie Evans Timeline*, *supra* note 108 (statement of Tom Evans: Alfie "looks me in the eye and wants [my] help.>").

121. *Alfie Evans Timeline*, *supra* note 108; *Evans v. Alder Hey Children's NHS Foundation Trust*; *Timsit*, *supra* note 110.

122. *Alfie Evans Timeline*, *supra* note 108.

temporary stay in the appeal process for time to consult with lawyers, but the judges denied the request.<sup>123</sup> On March 6 of 2018, the judges upheld the lower court decision.<sup>124</sup> Alfie’s parents filed an appeal request with the Supreme Court of the United Kingdom,<sup>125</sup> and argued that Alder Hey deprived Alfie of his liberty contrary to Article 5 of the ECHR.<sup>126</sup> In deciding the request, the Supreme Court questioned whether a baby who could not stay alive without artificial ventilation, nutrition, and hydration was deprived of his liberty and it reasoned that such treatment could only be provided when in the “best interest” of the baby.<sup>127</sup> The “deprivation of liberty,” or the withdrawal of such treatment, was only lawful if it was in the child’s best interest.<sup>128</sup> The Supreme Court ultimately found that a person unable to move because of intensive care treatment to keep him alive is not deprived of his liberty within Article 5 of the ECHR.<sup>129</sup> Consequently, on March 20, the Supreme Court decided the case was not worth arguing and it denied the appeal.<sup>130</sup>

After exhausting all legal options in the UK, Alfie’s parents brought their case to the European Court of Human Rights (ECtHR) in Strasburg.<sup>131</sup> Alfie’s parents implored the Court to recognize that they were being unjustifiably discriminated against in their right to respect for family life under Article 8 of the ECHR.<sup>132</sup> The ECtHR refused to examine any of the issues related to Alfie’s future treatment and found no indication of a human rights violation.<sup>133</sup>

On April 11, the British High Court judge endorsed an end-of-life care plan for Alfie, which was agreed to by Alder Hey, who would also administer it.<sup>134</sup> Alfie’s father maintained he had a right to take his baby home.<sup>135</sup> By the following day, protestors gathered outside of Alder Hey in support of

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123. *Id.*

124. *Id.*

125. Alder Hey Children’s NHS Foundation Trust v. Evans [2018] EWHC 308 (Fam) FD17P00694 [ 26]; Timsit, *supra* note 110.

126. *In re Alfie Evans No.2* [2018] EWHC (Fam) 308 (appeal refused by UKSC) (Eng.).

127. *Id.*

128. *Id.*

129. *Id.*

130. *Alfie Evans Timeline*, *supra* note 108.

131. Timsit, *supra* note 110.

132. *In re Alfie Evans No.2* [2018] EWHC (Fam) 308 (appeal refused by UKSC.) (Eng.).

133. *Alfie Evans Timeline*, *supra* note 108.

134. *Id.*

135. *Id.*

Alfie and his family.<sup>136</sup> On April 16, Alfie's parents, still fighting to take their son to Italy for treatment, filed a habeas corpus application, arguing that Alfie was being wrongly detained at Alder Hey.<sup>137</sup> The Court of Appeal in London ruled against them for the second time.<sup>138</sup> The next day, Alfie's parents again asked the Supreme Court to consider their case.<sup>139</sup>

In the meantime, international efforts commenced to save Alfie's life.<sup>140</sup> The Italian government granted citizenship to Alfie to facilitate the treatment he could receive at Bambino Gesù Hospital in Rome.<sup>141</sup> The Italian Ministry of Foreign Affairs explained that "the Italian government hopes that in this way, being an Italian citizen will enable the immediate transfer of the child to Italy."<sup>142</sup> The Italian government went so far as to arrange for a specially equipped plane from the Italian Defense Ministry to be on reserve for Alfie and his parents to travel to Rome.<sup>143</sup> On April 18, Alfie's father met with Pope Francis, who issued a personal appeal to British authorities to allow Alfie's family to take him to Italy to seek further treatment; however, the Italian efforts were ultimately in vain.<sup>144</sup>

On April 20, 2018, the British Supreme Court again ruled against Alfie's parents and found that current law disallowed parents from using the writ of habeas corpus "to acquire the custody of their child if this will not be in his best interest."<sup>145</sup> The Supreme Court opined that there was no evidence to find that the UK law differed from the laws of the ECHR

136. *Id.*; *Hundreds in Alfie Evans Alder Hey Hospital Protest*, BBC (Apr. 13, 2018), <https://www.bbc.com/news/uk-england-merseyside-43746174> [<https://perma.cc/M9MV-AUTJ>].

137. "The writ of habeas corpus issues as a right and requires the person having custody of the body of the subject person either to produce the body or to show good legal cause why the body should not be produced or released." In the matter of Alfie Evans No.2 [2018] EWHC (Fam) 308 (appeal refused by UKSC) (Eng.).

138. *Alfie Evans Timeline*, *supra* note 108.

139. *Id.*

140. John Daniel Davidson, *Alfie Evans' Death Illustrates The Monstrous Logic Of The Welfare State*, THE FEDERALIST (Apr. 30, 2018), <http://thefederalist.com/2018/04/30/alfie-evans-death-illustrates-monstrous-logic-welfare-state/> [<https://perma.cc/43QU-2B8Z>].

141. Sean O'Grady, *Americans are using the Alfie Evans case to criticize the NHS are deluded about the realities of the US's healthcare system*, THE GUARDIAN (Apr. 25, 2018), <https://www.independent.co.uk/voices/alfie-evans-nhs-healthcare-mike-huckabee-usa-republicans-a8321601.html> [<https://perma.cc/T5K2-2YC5>]; Timsit, *supra* note 110.

142. *Alfie Evans Timeline*, *supra* note 108.

143. O'Grady, *supra* note 141; Timsit, *supra* note 110.

144. Davidson, *supra* note 140.

145. In the matter of Alfie Evans No.2 [2018] EWHC (Fam) 308 (appeal refused by UKSC) (Eng.).

or the EU in that respect.<sup>146</sup> Once again, Alfie’s parents petitioned to the ECtHR for permission to take Alfie to Rome, but the ECtHR denied the application.<sup>147</sup>

In yet another effort to regain decision-making power for their baby before it was too late, Alfie’s parents submitted new requests privately via telephone to the High Court.<sup>148</sup> The judge noted that while the Italian government’s grant of citizenship was “well-meaning,” it was “equally . . . misconceived,”<sup>149</sup> and there was no basis to find that the Italian jurisdiction should supersede that of the High Court.<sup>150</sup> The High Court dismissed the final requests and Alfie’s parents were prohibited from taking him to Italy.<sup>151</sup> Police were stationed at Alder Hey to prevent Alfie from being rescued.<sup>152</sup> One commentator noted that while the death penalty and euthanasia were both illegal in Britain, thirty law enforcement officers stood guard outside of Alfie’s room to ensure his court-ordered death could proceed uninterrupted.<sup>153</sup>

On April 23, Alfie’s father publicly announced that Alder Hey physicians removed Alfie’s life support.<sup>154</sup> Although physicians indicated that he would suffocate within fifteen minutes without ventilation, Alfie continued to breathe unaided.<sup>155</sup> Two days later, the judicial system denied Alfie’s family’s final attempt to take Alfie to treatment abroad,<sup>156</sup> citing concerns that movement would make Alfie vulnerable to possible infection.<sup>157</sup> The following day, after months of conflict, Alfie’s parents pledged to work with physicians to give Alfie “the dignity and comfort he needs.”<sup>158</sup> Five days after physicians removed life support, Alfie passed away.<sup>159</sup> Alfie’s parents revealed their grief in a statement: “Our baby boy grew his wings tonight . . . We are heartbroken.”<sup>160</sup>

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146. *Id.*

147. *Alfie Evans Timeline*, *supra* note 108.

148. *Id.*

149. *Evans v. Alder Hey Children’s Foundation NHS Trust* [2018] EWHC 308 (Fam).

150. Mr. Justice Hayden further noted that the Italian application was disrespectful to principles of international comity, particularly in the context of vulnerable children. *Id.*

151. O’Grady, *supra* note 141.

152. *Id.*

153. Ramesh Ponnuru, *Why Aren’t U.S. Liberals Outraged About Alfie Evans? A British baby’s right to life should be clear to everyone*, BLOOMBERG (Apr. 26, 2018), <https://www.bloomberg.com/view/articles/2018-04-26/alfie-evans-case-should-provoke-outrage-of-u-s-liberals>.

154. *Alfie Evans Timeline*, *supra* note 108.

155. *Id.*

156. *Id.*

157. Timsit, *supra* note 110.

158. *Alfie Evans Timeline*, *supra* note 108.

159. *Id.*

160. *Id.*

*B. Best Interest Discussion*

The best interest test has developed as a widely recognized standard for making end-of-life treatment decisions for minors, as evidenced by the laws of the UK and Australia.<sup>161</sup> A best interest determination varies by nation.<sup>162</sup> Australian courts consider: (1) the express wishes of the child at the beginning of the analysis; (2) medical opinions; (3) the child's quality of life; and (4) the impairments and benefits of treatment.<sup>163</sup> British courts similarly examine medical evidence, the parents or guardians' wishes, and the legal framework, which includes the human rights entrenched in British law.<sup>164</sup> Australia does not have a set policy but instead decides cases on a case-by-case basis.<sup>165</sup> Like the UK, parents' wishes in Australia are considered but are not decisive.<sup>166</sup>

One critique of the best interest principle is that it lacks certainty. As shown by the analyses comparing the test application in the UK and in Australia, there is no international consensus as to the appropriate hierarchy of decisive values. Therefore, the question arises as to whether the courts should be primarily concerned with the child's happiness, spiritual and religious training, or future economic productivity.<sup>167</sup> Determining what is best for a child seems to be the equivalent of essentially deciding the value of the child's life. If so, this may be a more appropriate determination for the parent or guardian to make. Even where legislation provides guidance regarding factors to consider in making a decision about a child's best interest, that guidance seems to remain normative rather than objective.

Alfie Evan's case illustrates this point: While the court opined it was saving Alfie in acting in his best interest, what it was saving Alfie from remains unclear, given that he did not appear to be in pain. Additionally, moving Alfie to an Italian hospital would have not deprived other young patients at Alder Hey from benefitting from the medical treatment Alfie

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161. See discussion, *infra* Section III.A.

162. Marit Skivenes & Line M. Sorsdal, *The Child's Best Interest Principle across Child Protection Jurisdiction*, HUM. RTS. IN CHILD. PROTECTION 59, 61, 71 (2018).

163. *Id.* at 71–72, 75–76.

164. *Id.*; see also generally *Best Interests*, WIKIPEDIA (Feb. 10, 2020), [https://en.wikipedia.org/wiki/Best\\_interests](https://en.wikipedia.org/wiki/Best_interests) [<https://perma.cc/2BQ2-5V2Z>].

165. Skivenes & Sorsdal, *supra* note 162, at 72.

166. *Id.* at 75–76.

167. *Id.* at 64–65.

was receiving at the time.<sup>168</sup> Both the court and the doctors felt that he could never recover or live without the constant aid of medical assistance, and therefore death was in his best interest: this seemed to be the sole reason for refusing his moving to Italy.

Charlie Gard's and Alfie Evans's cases show the horrifying reality of a state applying the best interest test to unilaterally decide a sick child's future, including whether that sick child should die, even though she is not in pain and her parents have made arrangements for her to be cared for in another country at no expense to the state.

Unlike the UK and Australia, neither the United States nor Israel absolutely abide by the best interest standard.<sup>169</sup> Israeli law balances patient's autonomy and sanctity of life but does not prioritize the best interest of the child.<sup>170</sup> In the United States, there is no single standard of treatment; ultimately, although parents may sometimes override medical judgment to pursue experimental treatment, parental wishes and the child's best interest are not always the guiding principles.<sup>171</sup>

## II. AUTONOMY

The second major prong in determining how to proceed with treatment for a critically ill child is the notion of patient autonomy.<sup>172</sup> Patient autonomy is the right of patients to make decision about their treatment without medical providers trying to influence their decision.<sup>173</sup> Patient autonomy is vital because it does not allow for physicians or medical staff to make any decision for the patient<sup>174</sup> and instead leaves the decision to the patient and their families or guardians. This is important, namely because it allows the patient

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168. John O'Sullivan, *The State-Ordered Killing of Young Alfie Evans*, NAT. REV. (Apr. 23, 2018), <https://www.nationalreview.com/corner/the-state-ordered-killing-of-young-alfie-evans/> [<https://perma.cc/Y6FW-2459>].

169. See generally Yehiel S. Kaplan, *The Right of a Minor in Israel to Participate in the Decision-Making Process Concerning His or Her Medical Treatment*, 25 FORDHAM INT'L L. J. 1085 (2001).

170. *Id.*

171. See *End-of-Life Decision Making for Unborn and Newborn Infants*, CARLTON FIELDS (Sept. 1, 2014), <https://www.carltonfields.com/insights/publications/2014/end-of-life-decision-making-for-unborn-and-newborn> [<https://perma.cc/74TV-B3BC>].

172. Nancy Lau, PhD & Randall Curtis, MD, *Identifying the Best Approach to Patient-Centered Decisions About Serious Illness Care*, JAMA NETWORK (Jan. 25, 2019), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2722569> [<https://perma.cc/85K8-966B>].

173. William C. Shiel Jr., *Medical Definition of Patient Autonomy*, MEDICINE NET, <https://www.medicinenet.com/script/main/art.asp?articlekey=13551> [<https://perma.cc/7R3Y-CJDY>].

174. *Id.*

and their families and guardians to proceed with a treatment that best aligns with their values and circumstances.

For purposes of this Comment, patient autonomy in the context of guardians making decisions for their minor children is referred to as “guardian autonomy.” That is because patient autonomy in the context of a minor patient, specifically a patient under the age of two years, is virtually nonexistent. Because a child that age has not developed enough to make coherent decisions regarding his or her medical care, it is impossible to know what the child wants. Therefore, the autonomy of the guardian is the only relevant concern, which is problematic as the best interest of the child may differ from the best interests of the parents. Because it is impossible to assume that the interests of the child and the parent are aligned, the objection to treatment may still exist and thus relying on autonomy alone cannot provide a satisfactory resolution.

#### *A. Israel*

Israel is a country that places high value on patient autonomy.<sup>175</sup> Israel historically focused on sanctity of life as the guiding principle for decisions relating to end-of-life care,<sup>176</sup> which could be attributed to the influence of Jewish tradition on legislature. As a result, physicians seemingly had the authority to disregard the wishes of patients and guardians in favor of preserving life, even when there was evidence that the patient was suffering and without hope for a cure.<sup>177</sup> The case of Yael Schefer is one such case where the physician continued to provide treatment even when the guardian wished to stop treatment.<sup>178</sup>

#### *1. Yael Shefer*

Yael Shefer was born with Tay Sachs disease<sup>179</sup> in Israel in 1986. Physicians told her mother that Yael’s condition would inevitably worsen, and so when Yael was two years old, her mother applied to the District

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175. See PATIENT’S BILL OF RIGHTS, MINISTRY OF HEALTH (ISR.), [https://www.health.gov.il/English/Topics/RightsInsured/Pages/patient\\_rights.aspx](https://www.health.gov.il/English/Topics/RightsInsured/Pages/patient_rights.aspx) [https://perma.cc/manage/create?folder=24392-63677-78948].

176. Carmel Shalev, *End-of-Life Care in Israel—The Dying Patient Law, 2005*, 42 ISR. L. REV. 279, 279 (2009).

177. *Id.* at 287.

178. CA 506/88 Yael Shefer v. State of Israel 48(1) PD 78 (1993) (Isr.).

179. *Id.*

Court for a declaratory judgment asking that Yael not be forced to accept further treatment, as her mother believed it would be futile.<sup>180</sup> The District Court denied the application, and in 1988, the Supreme Court affirmed the denial.<sup>181</sup> The Court ruled that the supreme principle of sanctity of life adopted by Israel as a Jewish and democratic state did not permit intervention in Yael's treatment.<sup>182</sup> The Court explained that there was no evidence that Yael was suffering as a result of her illness; thus, withdrawing treatment was not a legally permissible option.<sup>183</sup>

Yael's case is an example of how religious culture and tradition, specifically Judaism, influences Israeli legislature. For instance, Judaism does not distinguish between religious and secular existence, and thus *Halacha*,<sup>184</sup> the collective body of Jewish law, guides not only religious practice but most aspects of its followers' lives.<sup>185</sup> Jewish teachings instruct that the value and sanctity of human life is immeasurable, and thus any act that hastens death, including the withdrawal of life-sustaining treatment, is akin to murder.<sup>186</sup> Therefore, as a general rule, omitting life-sustaining treatment (considered passive euthanasia) is permitted while terminating life-sustaining treatment (considered active euthanasia) is prohibited.<sup>187</sup><sup>188</sup> This was the case for Yael, where the Court refused to issue a judgment that would allow Yael's mother to terminate her treatment.

The decision in Yael's case seemingly contradicted a previously offered viewpoint by an Israeli Supreme Court Justice, Menachem Elon.<sup>189</sup> Prior to the decision in Yael's case, Justice Elon authored an instructive treatise where he compared the law in common law jurisdictions with Jewish Halakhic sources.<sup>190</sup> He concluded that there was a distinction between active and passive euthanasia but did not clarify which category the discontinuation of life support in accordance with the patient's wish fell

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180. *Id.*

181. *Id.*

182. *Id.*

183. *Id.*

184. Halacha includes Tanach (biblical law), Talmudic, and rabbinic law, and customs. Charles L. Sprung, *The Israeli Terminally Ill Law*, DEP'T OF ANESTHESIOLOGY AND CRITICAL CARE MED. HADASSAH MED. CTR, <https://www.chabad.org/media/pdf/652/ktdM6528108.pdf> [<https://perma.cc/BW4H-XM8D>].

185. *Id.*

186. *Id.*

187. Terminating treatment is to cease ongoing interventions. Omitting treatment is to decline to intervene in the first place.

188. *Id.*

189. Justice Elon has since passed away, but during his tenure as Justice, he was a prolific writer and he was at one point a presidential candidate.

190. MENACHEM ELON, *PRINCIPLES OF JEWISH LAW* (1975).

into.<sup>191</sup> Yael's case did little to clarify this distinction, and it also failed to address the legal effect of advance directives.<sup>192</sup>

In the aftermath of cases like Yael's, patients and guardians began to voice concern over their lack of independence in formulating their own treatment plans and the passage of new legislature, beginning with the Patient Right Act and culminating with the Dying Patient Law, struck a balance between the more traditional principle of sanctity of life and the individual desire for patient autonomy.

*a. Patient Rights Law*

The Patient's Rights Law (PRL) was enacted in 1996, primarily to remedy what was perceived as an imbalance of authority between physicians and patients.<sup>193</sup> Prior to the passage of the PRL, citizens voiced their desire for more patient autonomy,<sup>194</sup> in particular for the recognition of patient independence in making medical decisions, specifically regarding end-of-life treatment. The PRL gave patients more rights, framed as protection against potential abuse of power by medical professionals.<sup>195</sup>

As a result of the PRL's enactment, medical professionals generally took a cautious approach to treatment in favor of prolonging life, which led to a number of patients petitioning the courts for declaratory relief to manage their own treatment plans.<sup>196</sup> The courts explored the extent of the autonomy rights and the distinction between the rights to withhold and to withdraw treatment, whether by express wish or advance directive.<sup>197</sup> In contrast to the traditional Jewish distinction,<sup>198</sup> the courts largely held there was no legal difference between the rights of withholding and withdrawing treatment.<sup>199</sup> Accordingly, based on the principle of patient autonomy,

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191. CA 506/88 Yael Shefer (a minor) by her mother and natural guardian Talila Shefer v. State of Israel OM 779/88 (1993) (Isr.).

192. *Id.*; see also Section III.C. (discussing advance directives).

193. Shalev, *supra* note 176.

194. *Id.*

195. *Id.*

196. *Id.* at 283.

197. *Id.* at 283–84.

198. See Sprung, *supra* note 184.

199. Shalev, *supra* note 176, at 283.

treatment could be discontinued lawfully,<sup>200</sup> resulting in a stark divergence from Jewish tradition.<sup>201</sup>

However, in two cases heard by the Supreme Court, both of which involved young children suffering from severe congenital disorders, the Court dismissed the petitions of the parents requesting the withholding of treatment.<sup>202</sup> In 1999, the Israeli Supreme Court issued two rulings in the case of a young child suffering from cerebral palsy and an acute kidney condition.<sup>203</sup> First, the Court held that the patient's quality of life is not a legitimate consideration in judicial rulings,<sup>204</sup> and second, that individuals should err in favor of preserving life when doubt exists as to whether the patient should be treated.<sup>205</sup> The Supreme Court ruled that the parents did not have the right to refuse treatment on behalf of the child, who was subsequently subjected to fourteen surgical interventions before he passed away two years later.<sup>206</sup>

### *b. Dying Patient Law*

The period following the passage of the PRL brought years of political impasse on legislature involving end-of-life treatment.<sup>207</sup> However, in 2005, following calls to address issues of legal standing for family of patients and a lack of sufficient guidelines for physicians,<sup>208</sup> Israel enacted the Dying Patient Law (DPL),<sup>209</sup> the first law globally to regulate end-of-life treatment.<sup>210</sup> The DPL was presented as a balance between patient autonomy and sanctity of life,<sup>211</sup> paralleling the balance between Israeli culture and Jewish tradition.<sup>212</sup>

Although Israeli courts had increasingly developed the concept of patient autonomy as early as the 1960s, the DPL represented the most legislative deference given to patients in choosing their treatment to date. Israeli courts previously understood patient autonomy to stem from the

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200. *Id.*

201. *Id.*

202. *Id.* at 284. The two cases were: CA 506/88 Yael Shefer v. State of Israel 48(1) PD 78 (1993) (Isr.); LCA 5587/97 Attorney-General v. Ben-Ikar 51(4) PD 830 (1997) (Isr.).

203. Shalev, *supra* note 176, at 285.

204. *Id.*

205. *Id.*

206. *Id.*

207. *Id.* at 279, 283.

208. Sprung, *supra* note 184.

209. Dying Patient Law, 5765-2005, SH No. 330 (Isr.).

210. Y. Michael Barilan, *The New Israeli Law on the Care of the Terminally Ill*, 50 PERSPECTIVES IN BIOLOGY AND MED. 557 (2007); Sprung, *supra* note 184.

211. Shalev, *supra* note 176.

212. For example, it lays down a duty on physicians to make proactive efforts to inquire into the desired course of treatment of their patients. *Id.*

fundamental Israeli constitutional rights to dignity, liberty, and privacy<sup>213</sup> and to signify the “positive concept of liberty.”<sup>214</sup> The Israeli Supreme Court held that patient autonomy is violated when medical treatment is administered without a patient’s consent and therefore is a violation of human dignity,<sup>215</sup> which is consistent with the Jewish principle that omission of treatment is permissible. The DPL took into consideration this construal and those of the past, which focused on sanctity of life,<sup>216</sup> and ultimately reflected orthodox interpretations of Halakha on public values and bioethics.

The DPL addressed patient autonomy concerns by recognizing the legal effect of advance directives and the appointment of proxy decision makers.<sup>217</sup> When disagreements relating to treatment arise between physicians and the patient or family, the parties are instructed to resolve it through a local and national ethics committee instead of going before a court.<sup>218</sup> The DPL addressed communication concerns between physicians and patients’ and sought to provide effective mechanisms to resolve disputes, including when the patient did not desire treatment.<sup>219</sup>

### *B. Autonomy Discussion*

Guardian autonomy commands a high level of respect because of the unique and close relationship between a parent or guardian and a child. The guardian’s position to better understand the needs of the child should lead to deference toward the guardian’s decisions regarding treatment. This autonomy matters because the guardian is respected regardless of whether the public opines that the guardian is wrong. This deference raises important points. First, the guardian is empirically more likely to be right because of the epistemic privilege inherent in guardianship. The insight and understanding into the child’s life and the values and experiences the guardian wants the child to have lends to a fundamental parental advantage in deciding the course of medical treatment for the child. Second, there is

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213. *Basic Law: Human Dignity and Liberty*, THE KNESSET, [https://www.knesset.gov.il/laws/special/eng/basic3\\_eng.htm](https://www.knesset.gov.il/laws/special/eng/basic3_eng.htm) (last visited Mar. 18, 2019).

214. Isaiah Berlin termed the “positive concept of liberty,” which derives from the wish of the individual to be his own master. ISALAH BERLIN, *FOUR ESSAYS ON LIBERTY* 125 (Oxford U. Press 1969).

215. CA 2781/193 Ali Da’aka v. Carmel Hospital 53(4) PD 526 (1999) (Isr.).

216. Shalev, *supra* note 176.

217. Dying Patient Law, 5765-2005, SH No. 330. (Isr.).

218. *Id.*

219. *Id.*

the question of whether this life or death situation is the same or different in the context of parental decisions. One argument is that this is an extension of the decisions that society defers to guardians and is no different than whether the child learns religion or is homeschooled. The counterargument is that this decision is different because of the life and death implications, the potential for extreme suffering, and the possible cost to the public system.

The notion of guardian autonomy in the context of treatment decisions raises several other issues including the government's role and the amount of intervention it should be allowed; financial implications and who pays for the treatment; and religious values, which are unique and innate to the individual holding them.

### *I. Government Intervention*

The interplay between guardian autonomy and state action in making end-of-life treatment decisions differs by nation.<sup>220</sup> As the cases of Charlie and Alfie demonstrate, if a public body in the UK decides that a parent's choices risk harming a child, it can challenge the parent in court; doctors and social workers can request a judicial order to override the legal state of parental responsibility.<sup>221</sup> These cases show a shift in British caselaw to allowing states to supersede the autonomy of the child's guardian. As recently as 2005, a judge characterized an application that would give doctors the "last word" on her treatment as "wholly novel,"<sup>222</sup> but just over ten years later, this application has become ostensibly routine. It appears that over the past decade, the notion that doctors have the final judgment in end-of-life cases for minors has become increasingly and unquestioningly conventional.<sup>223</sup> Cases like Alfie and Charlie seem to confirm the policy, at least in the UK, that children belong to the state.<sup>224</sup>

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220. ANDREW WEBB ET AL., *OXFORD TEXTBOOK OF CRITICAL CARE 1856* (Andrew Webb et al. eds., 2d ed. 2016).

221. Holly Christodoulou, *RIGHT TO DECIDE: What are Charlie's Law and Alfie's Law, what rights would they give parents over their children's care and who has backed them?*, *THE SUN* (Sept. 3, 2018), <https://www.thesun.co.uk/news/6156576/alfies-law-charlies-law-rights-parents-care-alfie-evans-charlie-gard/> [<https://perma.cc/2YU5-2DMY>].

222. *Wyatt v. Portsmouth NHS Trust and Another* [2005] EWHC 693 (Fam) (Eng.).

223. See Susan Scutti, *Could Charlie Gard's Case Happen in the United States?*, *CNN* (July 6, 2017), <https://www.cnn.com/2017/07/06/health/charlie-gard-us-laws/index.html> [<https://perma.cc/FTF2-BJY8>].

224. However, recent legislation in the UK calls for Members of Parliament to legislate to give parents more rights over their child's hospital treatment. The campaign recognizes the dedication of medical professionals treating sick children, but also that parents have "moral rights." Christodoulou, *supra* note 221.

Similarly, on a continental level, the European court has assumed a paternalistic role by upholding the UK court's overriding the guardians' wishes in the cases discussed.<sup>225</sup> As a result of these European legal and political systems that are based on the primacy of the state's authority, disputes over a child's medical care inevitably result in a limitation of parental authority.<sup>226</sup>

This European approach can be contrasted to that in the United States, where the U.S. Constitution provides for privacy rights.<sup>227</sup> American case law makes clear that the basis for parental decision-making is the constitutional right to privacy.<sup>228</sup> This includes decisions relating to a child's medical treatment. Both state and the federal constitutions protect parents' rights to make important decisions for and on behalf of their minor children.<sup>229</sup> The constitutionally protected privacy interest in making important decisions on behalf of their children includes the right to assert their child's right to life.<sup>230</sup>

## 2. Financial Implications

Patient and guardian autonomy are seemingly dependent on who bears the cost of continuing treatment. In the UK, the National Health Service (NHS) offers health care funded by general taxation,<sup>231</sup> which allows the state to assert moral leadership over every aspect of its citizens' lives, including what treatment is administered to hospitalized children.<sup>232</sup> Because the NHS assumes the cost of treatment, the decisions lies with the state.

225. Broad, *supra* note 27.

226. *See id.*

227. Compare Emeline L.K. Diener, *Feature: Who's Your Daddy?*, 40 PA. LAWYER 38, 43 (2018) with Broad, *supra* note 27.

228. Diener, *supra* note 227.

229. In *Rideout v. Hershey Medical Center*, 30 Pa. D. & C. 4th 57 (1995), a physician unilaterally turned off the respirator of a young girl with a malignant brain tumor, in spite of her parents' protests. After the child's death, her parents brought suit claiming the hospital had deprived them of parental rights and free exercise of religion. The hospital demurred to these claims, and the court held that while the parents had a constitutionally protected privacy interest in making decisions on behalf of their child, they had no right of action under federal law.

230. *See* Diener, *supra* note 227, at 44.

231. O'Grady, *supra* note 141.

232. Ted Bromund, *Britain's National Health Service Isn't A World Beater*, FORBES (Oct. 30, 2016), <https://www.forbes.com/sites/tedbromund/2016/10/30/britains-national-health-service-isnt-a-world-beater/#1f0c925a45f9> [<https://perma.cc/XGV6-W8M9>].

The inexorable issue that arises in a system such as the NHS is sustainability. Because the public is unwilling to pay higher taxes, the UK spends less on health services than other nations with similar systems. As a result, the NHS is required to ration the treatment it provides.<sup>233</sup> This has led to record numbers of patients traveling abroad to receive medical treatment as the NHS struggles to cope with demand,<sup>234</sup> which contrasts with the court's explicit refusal to allow terminally ill minors to leave hospitals to seek treatment. The lack of funds and unavailability of medical care seems inextricably intertwined with treatment decisions and therefore presents a fundamental conflict. Minimizing the state's involvement in treatment decisions is a possible solution.

The case of Alfie Evans raises the counterargument that because the family did not ask the British government to pay for the expensive treatment, cost was clearly not a factor in the court's decision.<sup>235</sup> However, it is possible, and likely, that the court was still concerned with equitable administration of treatment. If the court allowed Alfie to be treated without the financial aid of the NHS, the backlash of disallowing a different child to be treated because of the guardian's inability to pay without assistance from the NHS would be severe.

Issues of cost also arise in Israel, as providing intensive care for children on life support can cost thousands of dollars a day. Some health professionals argue that such care, while seeming compassionate, can jeopardize the health of other critically ill children who could benefit from those resources.<sup>236</sup> One possible negative effect of the Israeli law is the large number of patients spending years on life support, often unconscious, because of laws against removing artificial ventilation.<sup>237</sup>

The role of government in healthcare in Australia is similar to that of the UK and Europe generally, in that it usurps the function of patient and

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233. *Id.*

234. The timing of the number of patients leaving Britain for overseas treatment was contemporaneous with a suppression on "health tourism" within the UK. Under EU reciprocal arrangements, British citizens are entitled to receive treatment elsewhere in Europe, with costs covered by the health service, provided it is treatment the NHS typically funds. Laura Donnelly & Katie Morley, *Soaring numbers flying abroad for medical care as NHS lists lengthen*, THE TELEGRAPH (Oct. 22, 2017), <https://www.telegraph.co.uk/news/2017/10/22/soaring-numbers-flying-abroad-medical-care-nhs-lists-lengthen/> [<https://perma.cc/UY5J-7XKW>].

235. *Supra* Section I.A.2.

236. *See generally, supra* Section II.A.1. (providing an example of a terminal patient who was nonetheless forced to receive medical treatment when medical resources could have been spent on a patient who could have recovered to live a full life).

237. Sprung, *supra* note 184.

guardian autonomy.<sup>238</sup> Australia justifies government involvement by theorizing that private markets alone provide too little of the public goods crucial for health, and government action may be needed to compensate for problems generated by uncertainty and insurance market failure.<sup>239</sup> These justifications can be countered by comparing the Australian system to the NHS. Not only does the NHS experience a shortage of public goods relating to healthcare, but the problems stemming from the NHS have palpably caused patients to go abroad for treatment. In contrast, the United States has thus far avoided moving to a nationalized healthcare system.

### 3. Religious Implications

One similarity between the legislative motivations of Israel and the United States is the fundamental religious influence, which lends to patient and guardian autonomy. One of the central elements to the founding of the United States was a desire for religious freedom and limited governmental intervention in all aspects of life, including medical treatment.<sup>240</sup> Under the Free Exercise Clause of the United States Constitution,<sup>241</sup> parents have the right to freely exercise their religion on behalf of their children.<sup>242</sup> Because of the way the United States Supreme Court has interpreted, or rather refused to interpret, “religion,” any sincere and meaningful belief, even if not logical or comprehensible to others, and even if the individual cannot articulate it, is protected under the First Amendment.<sup>243</sup> This protection extends to medical treatment decisions made on the basis of religious

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238. Rebecca Bailey-Harris, *The Family Law Reform Act 1995 (CTH): A New Approach to the Parent/Child Relationship*, 8 ADEL. L. REV. 83, 86 (1996).

239. Philip Hagan & Andrew Podger, *Reforming the Australian Health Care System: The Role of Government*, 2-3 Commonwealth Dep’t of Health and Aged Care (Mar. 1999), [http://www.health.gov.au/internet/main/publishing.nsf/Content/4FC61B6C2C9937CDC-A257BF0001D3BA7/\\$File/ocpanew1.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/4FC61B6C2C9937CDC-A257BF0001D3BA7/$File/ocpanew1.pdf) [<https://perma.cc/AT97-GBPD>].

240. *Founders’ Quotes on Founding Principles*, BILL OF RIGHTS INST., <https://billofrightsinstitute.org/founding-documents/founders-quotes/> [<https://perma.cc/V66M-D5CQ>] (last visited Mar. 14, 2020).

241. U.S. CONST. Amend. I.

242. States also provide additional protection for free exercise of religion. In *Rideout*, the court quoted the Pennsylvania Constitution, Art. I, sec. 3, which states that “no human authority can, in any case whatever, control or interfere with the rights of conscience.” The hospital demurred on the grounds that a belief that a life is sacred, standing alone, is not a “religious belief.” The court also refused to dismiss that claim. *Rideout v. Hershey Medical Center*, 30 Pa. D. & C. 4th 57, 84–84 (1995).

243. *Wisconsin v. Yoder*, 406 U.S. 205, 234–35 (1972) (holding a law mandating school attendance unduly burdened the Free Exercise Clause of the U.S. Constitution).

beliefs.<sup>244</sup> However, some cases<sup>245</sup> indicate a slow but steady trend in American medicine, mirroring that of Europe's, in allowing doctors to overrule or even ignore parental decision-making with judicial approval.<sup>246</sup> Comparably, Israel implemented Jewish principles relating to autonomy and sanctity into legislature: a patient is entitled to formulate his or her own treatment plan.<sup>247</sup> Sanctity of life overrules autonomy by prohibiting any action that intentionally and actively shortens life; autonomy overrules the sanctity of life by permitting the withholding of treatments directly related to the dying process in accordance with the patient's wishes.<sup>248</sup>

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244. See Diener, *supra* note 227, at 44.

245. In 2016, two-year-old Israel Stinson was declared brain-dead after a severe asthma attack led to cardiac arrest and limited oxygen flow to his brain. Doctors advised that he be removed from life support, but Israel's parents fought in court to keep him on life support, hoping to eventually care for him at home. Before they could take him from the medical center, Israel required operations to insert feeding and breathing tubes, which the medical center refused to perform. After a federal judge rejected the family's lawsuit in May of 2016, Israel's parents flew him to a private hospital in Guatemala, where doctors were willing to give him a feeding and breathing tubes. Until that point, Israel had been surviving on a diet of dextrose. In Guatemala, doctors reported that Israel's condition was improving, and tests showed Israel had brain activity. Doctors performed electroencephalogram (EEG) tests and detected slight electrical activity in Israel's brain, and movement in his pupils. After about three months, Israel was accepted as a patient at Children's Hospital in Los Angeles. The family returned to the United States, but shortly thereafter, the hospital determined that Israel should be removed from life support. This was shocking because just a week prior, the court issued a temporary order to stop the hospital from removing the ventilator until they could get an opinion from another neurologist. Israel's parents sought an injunction to prevent Children's Hospital from taking action while they arranged to put him in home care. On Tuesday, August 23, the hospital informed Israel's mother that it would file a motion to oppose the injunction, which was filed on the following Thursday. The struggle to save Israel ended when a Los Angeles Superior Judge ruled in favor of the hospital's decision. Immediately following the ruling, Israel's ventilator was removed, and he passed away. CBS LOS ANGELES, *Family Shocked After Brain-Dead Boy Removed From Life Support* (Aug. 25, 2016), <https://losangeles.cbslocal.com/2016/08/25/family-shocked-after-brain-dead-boy-removed-from-life-support/> [<https://perma.cc/HP27-5Y58>] [hereinafter *Family Shocked*]; Erica Evans, *After court rules against parents, toddler is taken off life support*, L.A. TIMES (Aug. 26, 2016), <http://www.latimes.com/local/lanow/la-me-ln-toddler-life-support-20160826-snap-story.html> [<https://perma.cc/46RW-HSCH>]; Claudia Buck, *Court documents reveal final details behind brain-dead toddler case*, THE SACRAMENTO BEE (Sept. 11, 2018), <https://www.sacbee.com/news/local/health-and-medicine/article100885077.html> [<https://perma.cc/T8RN-BQ7J>]; *Fonseca v. Kaiser Permanente Med. Ctr. Roseville*, 222 F. Supp. 3d 850 (E.D. Cal. May, 13 2016). Compare with Israel's policy in Sprung, *supra* note 184 (describing that it is unlawful to end treatment, regardless of parents' decisions).

246. Bovard, *supra* note 2.

247. Sprung, *supra* note 184.

248. *Id.*

## III. OTHER CONSIDERATIONS

While best interest and autonomy are the two pivotal considerations in resolving disputes over a child's end-of-life treatment, there are other possible means and guidelines to resolve disputes. Mediation is one way to prevent litigation over disputes, and legislative measures on experimental treatment, "Do Not Resuscitate" orders, and advance directives may provide further guidance in resolving disputes over treatment.

*A. Mediation*

Another consideration in the medical decision-making process is the role of mediation: in the context of treatment decisions, mediation is a private process where a neutral third person (the mediator) aids the parties, usually the guardians of the child and the medical staff, in discussing and resolving the dispute.<sup>249</sup> During mediation, the parties have the opportunity to discuss the issues, explain their interests and feelings, provide each other with information, and explore possible resolutions to the dispute.<sup>250</sup> This often leads to a more favorable alternative than a court order, although clearly mediation does not resolve all disputes.

Current legislature is proposed in the UK to require the involvement of independent medical mediators as early as possible<sup>251</sup> in the process so that physicians and the patient's family can come to an agreed-upon course of action.<sup>252</sup> Similarly, Israel's DPL requirement that parties in conflict should resolve their issues through a local and national ethics committee keeps them from resorting to the courts. However, although mediation is widely viewed as an initial method of dispute resolution, there seems to be questions about its actual effectiveness given what is at stake.

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249. See *Mediation, Dispute Resolution Process*, ABA [<https://perma.cc/9H2W-L3G6>].

250. *Id.*

251. Great Ormond Street Hospital has previously stated that "mediation is one of the important ways in which we work with families to reach agreements, in the best interests of the child." Catherine Burns, *Charlie Gard's parents want 'Charlie's Law'*, BBC News, (June 20, 2018) [<https://perma.cc/4WJU-MYTW>].

252. Charlie's parents claimed they asked for mediation months prior to his death, but the hospital refused to facilitate it until the final few days of his life. Charlie's father noted that "[i]f mediation had taken place with an independent mediator, we would have felt our voices were being listened to." Instead, Charlie's parents were forced to engage in a long legal battle. *Id.*

## 1. Australia

In recent years, Australia has legislated to increase the focus on mediation and primary dispute resolution.<sup>253</sup> In 1990, Australia became a signatory state to the United Nations Convention on the Rights of the Child, and as a result adopted the Australia's Family Law Reform Act (FLRA) of 1995.<sup>254</sup> The FLRA represented a shift away from lengthy and expensive litigation and enabled parties to reach optimal resolutions while minimizing the psychological and emotional impact.<sup>255</sup>

## B. Experimental Treatment

Another consideration in end-of-life care is the availability of experimental treatment. "Right to Try" laws allow patients with life-threatening conditions<sup>256</sup> to bypass drug regulations to gain access to experimental treatment.<sup>257</sup> These laws provide one way for patients to get non-traditional treatment.

### 1. United States

In 2018, President Donald Trump signed Bill S.204,<sup>258</sup> which created a uniform system for terminal patients seeking access to investigational treatments in states that did not have a Right to Try law.<sup>259</sup> The legislation allows gravely ill patients to request medicines that have cleared initial phases of testing, but that have not yet been approved by the Food and Drug Administration ("FDA").<sup>260</sup> This bill provides a new pathway for terminally ill patients who have exhausted government-approved options and cannot get into a clinical trial to access treatments<sup>261</sup> and allows patients

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253. Bailey-Harris, *supra* note 238, at 84.

254. *Id.*

255. Clare Decena, *The History of the Family Law Act & its Amendments*, Family Law Express (May 16, 2014), [<https://perma.cc/G6NX-V38F>].

256. Federal law defines a life-threatening disease or condition as: "Diseases or conditions where the likelihood of death is high unless the course of the disease is interrupted." 21 CFR 312.81(a)(1).

257. Angelica LaVito, *Trump signs 'right-to-try' allowing gravely ill patients to bypass FDA for experimental treatments*, CNBC (May 30, 2018) [<https://perma.cc/KCU2-8NN7>].

258. Trickett Wendler, Frank Mongiello, Jordan McLinn, and Matthew Bellina, Right to Try Act of 2017, Pub. L. No. 115-176, § 2. Donald Trump signed this bill into law on May 30, 2018; *see also Federal Right To Try: Questions and Answers*, RIGHTTOTRY, <http://righttotry.org/rtt-faq/> (last visited Mar. 19, 2019).

259. Forty states previously had versions of right to try legislation. Right to Try, *supra* note 258.

260. LaVito, *supra* note 257.

261. Right to Try Act of 2017, Pub. L. No. 115-176, § 2.

to circumvent a system where testing and approval by the FDA may take several years.<sup>262</sup>

To be eligible for Right to Try in the United States, an individual must: (1) be diagnosed with a life-threatening disease or condition;<sup>263</sup> (2) have exhausted approved treatment options, including participation in a clinical trial; and (3) provide written consent regarding the risks associated with taking the investigational treatment.<sup>264</sup>

However, under Right to Try laws, doctors are not obligated to request treatment if they do not professionally opine that such treatment could help the patient.<sup>265</sup> Similarly, drug companies are not required to provide treatment<sup>266</sup> and are permitted to develop their own policy and procedures for approving Right to Try requests.<sup>267</sup> Federal laws allow the company to recover costs directly related to providing an individual treatment, but prohibits making a profit on any drug or treatment not approved by the FDA.<sup>268</sup>

Right to Try legislation allows guardians to elect a course of experimental treatment that has not yet met national standards. In the United States, courts give weight to medical opinions but provide guardians with wide latitude regarding experimental treatment.<sup>269</sup> In contrast, the ECtHR has held that Article 2 of the ECHR cannot be interpreted to require access to experimental treatment, or to require the adoption of particular regulation for experimental treatment, meaning patients do not have access to non-government approved treatment.<sup>270</sup>

262. LaVito, *supra* note 257.

263. American federal law defines a life-threatening disease or condition as: "Diseases or conditions where the likelihood of death is high unless the course of the disease is interrupted."

264. Right to Try Act of 2017, Pub. L. No. 115-176, § 2.

265. *Id.*

266. Right to Try Act of 2017, Pub. L. No. 115-176, § 2; Right to Try, *supra* note 258; Thaddeus Mason Pope, *Why Oncologists Should Decline to Participate in the Right to Try Act*, THE ASCO POST (Aug. 10, 2018), <http://www.ascopost.com/issues/august-10-2018/declining-to-participate-in-the-right-to-try-act/>.

267. Right to Try Act of 2017, Pub. L. No. 115-176, § 2; Right to Try, *supra* note 258.

268. *Id.*

269. See *McMath v. State of Cal.*, No. 15-CV-06042-HSG, 2016 WL 7188019, 7 (N.D.C.A. Dec. 12, 2016).

270. See *supra* Section I.A.

### C. Advance Directives

Patients may also consider the use of advance directives in determining end-of-life treatment. An advance directive is a legal document that tells the patient's physician and family what type of medical care the patient desires for when the patient will be incapable of doing so.<sup>271</sup> Texas is one of several U.S. states with an advance directives law. Section 166.046 of the Texas Advance Directives Act (TADA) gives physicians and hospitals the ability to discontinue life-sustaining care even when a patient's guardian desires to continue treatment.<sup>272</sup> Section 166.046 of TADA mandates what happens when a patient's physician does not want to abide by a patient's advance directive or by the direct wishes of the patient's family.<sup>273</sup> This typically occurs when the physician wants to deny a request for life-sustaining treatment and means that, under the TADA, medical workers are allowed to withdraw life-sustaining treatment.

The TADA has been in U.S. news recently because of its effect on the case of baby Tinslee Lewis.<sup>274</sup> Tinslee is currently at the Cook Children's Medical Center in Fort Worth, Texas.<sup>275</sup> She has been hospitalized with lung and heart problems since her birth.<sup>276</sup> Tinslee's mother has said that she wants to be the person who makes the decision for her child. Her physicians counter that their care is causing Tinslee pain without hope for a cure, and thus the care should be halted.<sup>277</sup> A trial court ruled that her

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271. *Advance Directives and Do Not Resuscitate Orders*, FAMILYDOCTOR.ORG, <https://familydoctor.org/advance-directives-and-do-not-resuscitate-orders/> [https://perma.cc/K4EZ-LUF2] (last visited Apr. 6, 2020).

272. Advance Directives Act, TEX. HEALTH & SAFETY § 166.046 (1999); Rachael Thompson, Comment, *Searching for Fairness: Examining the Texas Advance Directives Act in Light of the Clear and Convincing Evidence Standard*, 56 HOUS. L. REV. (2019).

273. TEX. HEALTH & SAFETY § 166.046 (1999).

274. *See generally* Raga Justin, *Texas anti-abortion activists take on baby Tinslee's life support case, attempting to strike down a law that protects doctors*, TEXAS TRIB. (Feb. 20, 2020), <https://www.texastribune.org/2020/02/20/baby-tinslee-lewis-case-attracts-attention-anti-abortion-groups/> [https://perma.cc/Q9KE-4KMJ]; Wade Goodwyn, *Legal Battle Over Terminally Ill Child Raises Sanctity of Life Questions*, NPR (Jan. 17, 2020), <https://www.npr.org/2020/01/17/797220652/legal-battle-over-terminally-ill-child-raises-sanctity-of-life-questions> [https://perma.cc/2LD9-QGCG].

275. Rebecca Flores, *Gov. Abbott backing Fort Worth baby Tinslee Lewis as doctors try to take her off life support*, KVUE (Jan. 20, 2020), <https://www.kvue.com/article/news/local/texas/fort-worth-baby-tinslee-lewis-gov-abbott-support/269-d8aaac76-03b6-4621-88c6-4b3e7e0e36b9> [https://perma.cc/25F3-A2VG].

276. *Id.*

277. *Id.*

doctors could terminate treatment, but the court of appeals stayed that ruling pending appeal.<sup>278 279</sup> As of this writing, the case is still under appeal.

#### *D. Do-Not-Resuscitate Orders*

Do-not-resuscitate (DNR) orders may be part of an advance directive. A DNR is a request not to have cardiopulmonary resuscitation (CPR) should the patient's heart stop or should the patient stop breathing.<sup>280</sup>

The primary issue regarding DNR orders arises when there is a unilateral entry of the DNR in the patient's medical file, which is becoming increasingly frequent, as demonstrated in the United States, where approximately half of the responding physicians revealed in a survey that they endorsed unilateral DNR orders as "appropriate."<sup>281</sup> In the same survey, twenty percent of responding pulmonary critical-care physicians reported they implemented unilateral DNR orders in the previous year.<sup>282</sup>

In response to this uptick in unilateral DNR entry, several U.S. states have legislated to provide guardians with additional safeguards in making treatment decisions for their children.<sup>283</sup> Simon's Law,<sup>284</sup> a state law passed in Kansas in 2017, ends the practice of physicians placing DNR orders on

278. Alexandria Hein, *Texas judge rules hospital can remove baby Tinslee Lewis from life support, family has week to appeal*, FOX NEWS (Jan. 2, 2020), <https://www.foxnews.com/health/texas-judge-rules-hospital-can-remove-tinslee-lewis-life-support-family-week-to-appeal> [https://perma.cc/6E89-FGEM].

279. Texas Governor Greg Abbott and Attorney General Ken Paxton filed a "friend of the court brief" in support of Tinslee and her family requesting reversal of the recent trial court ruling that physicians can remove baby Tinslee from life support if they get approval from the hospital's board. *See Flores, supra* note 275.

280. FAMILYDOCTOR.ORG, *supra* note 271.

281. Michael S. Putman, *Unilateral Do Not Resuscitate Orders*, 152 CHEST J. 224–25 (2017).

282. *Id.*

283. *See Bovard, supra* note 2.

284. Simon Crosier was born with a condition called Trisomy 18, a serious congenital illness which requires life-sustaining medical treatment but is not necessarily fatal. Unbeknownst to Simon's parents, the doctors had placed a "Do Not Resuscitate" (DNR) order on Simon's medical chart, which directly conflicted with his parents' hopes that he would grow strong for corrective heart surgery. Simon's parents watched doctors stand by as their three-month old baby struggled to breathe and eventually pass away, just three days before his scheduled surgical consultation. Following Simon's death, his parents uncovered not only the non-authorized, clandestine DNR, but also that Simon's medical providers had only authorized "comfort feeds"—drops of sugar water designed to starve a patient to death—despite Simon's mother's pleas to feed him breastmilk. Simon's case compelled states to act to protect parental decision-making. *Bovard, supra* note 2.

a minor patient's chart without the informed consent of the child's guardians<sup>285</sup> and requires written parental consent for a minor to receive the order.<sup>286</sup> Under Simon's Law, parents are given the security to make medical decisions for their child that parallel the advice of their doctors, their values, and their faith.<sup>287</sup> Other U.S. states such as Missouri and Texas have followed Kansas by introducing their own versions of Simon's Law.<sup>288</sup>

#### IV. PROPOSED SOLUTION

A standard that better takes into account both the best interest and the autonomy of the patient is clearly needed. This section will discuss the objectives of a new code and the previously proposed UK legislation, and it will conclude with the formulation of a novel comprehensive model solution. The solution will focus on an "extreme suffering" test that encompasses the consideration of patient and guardian autonomy, the potential significant harm to the child, mediation, and implementation of the right to try legislation.

One of the primary objectives of this proposed solution is to reduce the time spent on litigation. In the cases discussed above, the parents of the children spent an exorbitant amount of time and resources to navigate the judicial system and were deprived of precious time with their children. As a general policy goal, parents of dying children should not be placed in the position where their only option is litigation. While deference to the state may be appropriate in some instances, government intervention leads to potential overreach and severe infringement on guardian autonomy in other cases; therefore, parental protections should be established. The final and ultimate aim is to consider alternatives to the best interest standard, which has been proven time and again to be a flawed standard.

Under new proposed UK laws, parents or guardians—working with lawyers and medical experts—will be involved in formulating a treatment plan for their child.<sup>289</sup> These laws are intended to address problems around the best interest test used by courts and to increase transparency to resolve cases before they reach the courts.<sup>290</sup> A key part of the legislation would be altering the way judges reach their decisions: the law proposes moving

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285. *Id.*

286. According to the American College of Pediatricians, the doctor-patient relationship should proceed with the physician offering medical facts coupled with hope, and if hope for survival becomes unwarranted, then physicians should discuss and reach understandings with the family regarding prognosis and interventions, which is what Simon's Law codifies. *Simon's Law*, AMERICAN COLLEGE OF PEDIATRICIANS, <https://www.acped.org/the-college-speaks/for-policy-makers/sanctity-of-life/simons-law> (last visited Mar. 19, 2019).

287. *Id.*

288. Bovard, *supra* note 2.

289. Christodoulou, *supra* note 221.

290. *Id.*

from a framework where the judge must assess only what is in the best interest of the child to one where the judge asks if the parent's choice of treatment would cause significant harm to the child.<sup>291</sup> If the judge finds that it would not, families will be permitted to try their proposed treatment.

The ECHR provides the requisite European law for a shift from the best interest standard to an "extreme suffering" test.<sup>292</sup> Specifically, Article 8 of the ECHR provides that individuals have the right to private and family life and the right to be protected against interference by public authorities.<sup>293</sup> The right against government intervention as highlighted in Article 8 offers the foundation for a transition from courts deciding what is in the child's best interest to deciding whether the child is experiencing extreme suffering. Thus, the burden of proof should be viewed through the lens of guardian autonomy. The proposed code should not focus on the best interest of the child, but rather on whether prolonged treatment would lead to extreme suffering for the child.

#### *A. Disability Rights*

A new solution is important because the best interest test may unintentionally harm disability rights. The dispute regarding end-of-life decision-making prompts issues regarding the rights of those deemed physically incapacitated because it raises the question of what types of condition are considered unbearable in saving a life.

The decisions in the cases of Charlie Gard, Alfie Evans, and others reflect a profound and literally lethal intolerance of dependence and disability. In each case, a hospital's policy against children with seemingly permanent disabilities ended with a totalitarian intervention by the state. Universally, legislature should be revised to create a space for the profoundly disabled, as well as the loved ones who wish to care for them, regardless of judgement from those who deem an existence of radical dependence not worthy of life.

Specifically, in Alfie Evans's case, the court decided that Alfie's life was no longer beneficial because he was too incapacitated to live a

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291. *Id.*

292. *See The ECHR*, art. 8.

293. *Id.*

traditionally desirable life.<sup>294</sup> Even though there was no evidence that Alfie was suffering or in pain, and there was a medical consensus that “the high quality of care that Alfie [wa]s receiving at Alder Hey could ‘sustain him for a long time,’”<sup>295</sup> the court interpreted the 1989 Children Act to rule that a life of permanent dependency and disability was not worth living.<sup>296</sup> In the end, the court sided with the physicians who contested that Alfie derived no benefit from efforts to keep him alive, even over the protests of his parents.<sup>297</sup>

When such decisions become conventional, the family and guardians of the child are entirely shut out from the process. This is problematic because different individuals have diverse value systems and place different levels of worth on life with disabilities. Therefore, when courts do get involved, they should not rely on the detached opinions of physicians to place a value on the life of a disabled patient.

Additionally, physicians could be wrong and so reliance on detached opinions could be flawed from the outset. For instance, in 2014, the parents of a young child disagreed with the hospital and social workers over the best course of treatment for the child’s brain tumor.<sup>298</sup> The family breached a court order and fled with the child from the UK to France and Spain.<sup>299</sup> The child eventually received experimental treatment in the Czech Republic and is currently living cancer-free.<sup>300</sup> Had the family adhered to the court order issued relying upon the hospital’s expertise, the hospital would have withdrawn treatment and the child almost certainly would have perished.

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294. The state came to this conclusion via judicial proceedings that because Alfie’s disability was so severe as to “render his life so poor and bereft of meaningful benefits, it [was] in his best interests” for him to die.

295. *Evans v. Alder Hey Children’s Foundation NHS Trust* [2018] EWHC 308 (Fam) (Eng.).

296. O. Carter Snead, *The Alfie Evans case is straight out of a dystopia*, CNN (Apr. 29, 2018), <https://www.cnn.com/2018/04/29/opinions/alfie-evans-opinion-snead/index.html> [<https://perma.cc/4FSF-CLFC>]. The Court found additional ethical guidance from the Royal College of Paediatrics and Child Health in that “it is no longer in the child’s best interests to continue [living]” in those cases “where the severity of the child’s condition is such that it is difficult or impossible for them to derive benefit from continued life.” *Evans v. Alder Hey Children’s Foundation NHS Trust* [2018] EWHC 308 (Fam).

297. Ponnuru, *supra* note 153.

298. Even a critique of the American response to the Alfie Evans story culminates in the author admitting that he would have allowed the parents to take Alfie to Rome. Christodoulou, *supra* note 221.

299. Joel Adams, *Ashya King cleared of cancer three years after his parents abducted him from hospital for treatment abroad*, THE TELEGRAPH (Mar. 3, 2018), <https://www.telegraph.co.uk/news/2018/03/03/ashya-king-cleared-cancer-three-years-parents-abducted-hospital/> [<https://perma.cc/7Y6W-5EJC>].

300. *Id.*

Like with all state involvement, there is an inherent risk of abuse when the test for life is left to the government. Where a judiciary has the power to deem what disabilities are worth living with, the inherent subjectivity of the standard will inevitably lead to inequitable results. The decision of whether to pursue treatment, even when it furthers a life of severe physical incapacitation, should lie with the guardians of the child in all but extreme cases.

Therefore, an alternate to the best interest test should consider first, the level of suffering the patient is experiencing, and second, the autonomy of the guardian. The proposed model health code that follows takes into consideration these two prongs.

*B. Model Health Code: End-of-Life Decisions for Minors*

Courts do not have the authority to supersede the wishes of legal guardians to sustain treatment for a minor unless a caregiver requesting to withdraw treatment has established with clear and convincing evidence that:

- (a) The patient has been proven to be in extreme pain; *and*
- (b) The treatment is not reasonably expected to lead to a positive outcome;  
*and*
- (c) The guardian has been given an opportunity to arrange for alternate care;  
*and*
- (d) No physician or facility has expressed a willingness to provide treatment to the minor.

In all other cases, the guardian retains the right to decide the course of treatment for the minor.

In the case where joint guardians disagree on a course of treatment, the guardian wishing to sustain care should prevail unless the above prongs are satisfied.

For purposes of this standard, extreme pain refers to physical pain. As such, paralysis and other conditions that do not traditionally result in severe physical pain will not meet the requisite standard. A positive outcome refers to any potential for improvement, regardless of magnitude.

When a minor, deemed competent and mature of age, expresses an unwillingness to continue with treatment, that should weigh in favor of the

court's interceding. In all other cases, the wishes of the minor patient will not supersede that of the guardian.

Had this standard been applied to either the Charlie Gard or the Alfie Evans case, the party requesting court intercession surely would not have met the burden of proof. In both Charlie's and Alfie's cases, physicians admitted that they could not definitively say that either baby was even experiencing pain at all, which means the party requesting court intervention would have failed on the first prong. This differs from Baby Tinslee's case, because medical staff have opined that she is experiencing pain, particularly when her medication wears. Under the model code presented, Tinslee's guardian would have lost on this prong unless Tinslee's guardian could present evidence to rebut that presented by medical staff. In the case of a dispute between medical professionals over whether the patient is experiencing pain, there would be a thumb on the scale for the evidence presented on behalf of the family or guardians.

In applying the second prong of the model code to Alfie and Charlie's cases, it is clear that the burden of the caregiver requesting withdrawal would not be met here either. In both cases, the alternate medical facilities who volunteered to treat the children would not have done so had those medical facilities thought further treatment was futile.

The third prong is intended to keep the burden of proof on the caregiver wishing to withdraw treatment instead of shifting it to the parent. This prong allows the guardians reasonable time to arrange for alternate care after the current caregiver has expressed an unwillingness to continue it. The amount of time deemed "reasonable" will be decided on a case-by-case basis.

In terms of the last prong of the Model Code, the guardians of both Alfie and Charlie had secured places at other medical facilities willing to treat them. In Alfie's case, not only had the Italian government granted him citizenship<sup>301</sup> to facilitate his entry into the country for treatment, it had also arranged for a Defense Ministry specially equipped plane to take him to the Bambino Gesù. The Bambino Gesù also offered to provide care to Charlie. It was further made clear that other facilities would be willing to take Charlie when the Columbia physician and other medical experts co-signed a letter opining that treatment could improve Charlie's brain condition. It is unclear whether Tinslee has been offered treatment at another facility;

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301. One way to gain access to treatment abroad may be to renounce the citizenship of a country refusing treatment in favor of obtaining citizenship in a country willing to offer medical treatment. Both Alfie and Charlie were granted new citizenship to expedite their receiving of treatment in other countries. However, this grant of citizenship ultimately proved futile because the British courts refused to recognize it. Thus, as a result of the inherent uncertainty in this method, change in citizenship does not appear to be a viable option to receive treatment from another country.

the staff at her current hospital is claiming she has not, while the family and their supporters are claiming she has.

Another case to consider is the situation where the guardian wishes to cease treatment against the recommendation of the treating physician. This is similar to the case of Yael Shaefer discussed above. This is a rare scenario, and not addressed by the proposed solution in this Comment.

Because the opposition parties in both Alfie and Charlie's case would have failed on all prongs, under the Model Code, the court would have disallowed itself from interceding and instead it would have deferred to the guardians to decide to either withdraw treatment in accordance with the recommendations of their current caretakers, or move their child to a facility that would treat him. Although it remains to be seen what will come out in Tinslee's appeal, at present, it does not appear that the opposing party could necessarily prove each prong with clear and convincing evidence, and thus, the decision should be left with her guardian to decide whether to stop life-sustaining measures or move her to a different facility.

#### CONCLUSION

Relying on this standard, only when the child is provably suffering from extreme pain, additional treatment offers no hope for a positive outcome, the guardian has been given opportunity to search for alternate care, and no medical facility is willing to provide treatment to the child, should the court intervene on behalf of the opposing party. As long as any one of these conditions is not met, courts should give deference to the guardian.

In addition to implementing this standard, mediation should be prioritized before resorting to judicial action, and legislation on experimental treatment, advance directives, and do-not-resuscitate orders should be drafted with a focus on the autonomy of the guardian.

The ultimate goals are to give parents across the globe the freedom to care for disabled or critically ill children and to turn away from the traditional concept of "best interest" in its current application, which is inimical to the goal of providing care and comfort to these children. This shifts the outcome away from withholding treatment from those who are neither suffering nor imminently dying merely because their lives have been deemed not worth living. By transitioning to a test that better reflects the views of the guardian, the chances of that treatment helping a physically dependent child will increase.

