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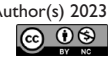
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Case commentary

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A different kind of death? Barts NHS Trust v Dance and Battersbee

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Abstract

The case of Archie Battersbee, a 12-year-old boy who suffered a catastrophic hypoxic brain injury, was the subject of several Family Division and Appeal Court hearings between April and August 2022. During the protracted legal process, appeals were made by the family to the Supreme Court, the European Court of Human Rights, and the United Nations' Committee on the Rights of Persons with Disabilities (CRPD Committee). These were unsuccessful in achieving a stay on the withdrawal of life-sustaining interventions, whose continuance the Family Division of the High Court had found not to be in Archie's best interests. This commentary focuses on two novel aspects of the proceedings: the Court of Appeal's overturning of Arbuthnot J's conclusion that Archie was brainstem dead, and the CRPD Committee's intervention in response to the family's appeal.

Keywords

Children, brain death, brainstem death, best interests, Committee on the Rights of Persons with Disabilities, withdrawal of treatment

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> 'Death is not a social construct. It is one of the inescapable biological facts that unite all life forms'.[1]

1. M. Hayden, 'Negotiating Ambiguities in Life and Death', 2016 Henry K. Beecher Prize in Medical Ethics (30 May 2016). https://bioethics.hms.harvard.edu/sites/default/files/assets/Bioethics_Images/Hayden_Beecher.pdf (accessed 17 April 2023).

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This apparently simple statement conceals the significant academic and social ambivalence that persists around equating a diagnosis of brain/brainstem death[2] with the legal death of the person, with individual disagreements entering the legal system at an apparently escalating rate.[3] The recent case of Archie Battersbee brought the issue into broader public consciousness as it wound a protracted and acrimonious course through the courts, including several hearings in the Family Division of the High Court, two judgments by the Court of Appeal, two applications for permission to appeal to the Supreme Court, and applications to both the United Nations' Committee on the Rights of Persons with Disabilities (CRPD Committee), and the European Court of Human Rights (ECtHR).[4] Despite the relative alacrity with which the UK courts responded to the various submissions and appeals, the legal process was drawn out; 110 days elapsed between the NHS Trust initiating High Court proceedings aimed at establishing whether Archie was alive, or dead on neurological criteria, and the ultimate judgment issued by the Family Division on 5 August 2022.[5] For part of this time Archie assumed a unique status in English jurisprudence, having been declared to have died on May 31 by the High Court,[6] but (in effect) not to be dead by the Court of Appeal some 5 weeks later.[7] Following the Court of Appeal decision, Hayden J undertook an analysis of Archie's welfare, leading to a declaration that continuing life-sustaining interventions was not in Archie's best interests.[8] Subsequent applications to the CRPD Committee and the ECtHR (which declined to hear the case) failed to achieve a stay, and Archie died on 7 August 2022.

Archie's case raises many issues, including the role of third party organisations; in this case the Christian Legal Centre supporting Archie's parents; and the way in which Hayden J counted, weighed, and balanced competing matters in determining Archie's best interests. However, for reasons of space, we focus on two relatively novel aspects of the case. The first is the medico–legal interaction in the diagnosis of brainstem death. The second is the role played by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).[9] However, first, we shall briefly set out the factual context of the case.

2. Brainstem death is the applicable standard in the UK and Ireland: see Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (London: RCPCH, 2008). Many other jurisdictions (including the United States) operate on a standard based on whole brain death.
3. In the UK, one pertinent case came before the courts in 1993, one in 2015, two in 2020, and four in 2022: see M. Donnelly and B. Lyons, 'Disputing Death: Brain Death in the Courts', *Legal Studies* (2023, forthcoming). For an American perspective see T. Pope, 'Brain Death Forsaken: Growing Conflict and New Legal Challenges', *Journal of Legal Medicine* 37 (2017), pp. 265–324.
4. *AB and Others v United Kingdom*, application no. 37412/22.
5. *Barts NHS Trust v Dance and Battersbee* [2022] EWHC 2098 (Fam).
6. *Barts Health NHS Trust v Dance and Battersbee* [2022] EWHC 1435 (Fam), [180].
7. *Barts Health NHS Trust v Dance and Battersbee* [2022] EWCA Civ 935.
8. *Barts Health NHS Trust v Dance and Battersbee* [2022] EWFC 80.
9. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html.

Background

On 7 April 2022, Archie Battersbee, a 12-year-old boy, was found by his mother unconscious and with a dressing gown cord around his neck. Despite maternal attempts at cardiopulmonary resuscitation (CPR), when paramedics arrived they found Archie to have suffered a cardiac arrest and to be comatose. Although further resuscitation was successful in re-establishing Archie's circulation, it is likely that Archie's brain suffered from a severe lack of blood flow and oxygen for approximately 40 minutes. Archie was taken first to a local hospital and subsequently transferred to the Paediatric Intensive Care Unit at the Royal London Hospital where, for 3 weeks after the initial accident and prior to the first hearing, he remained unconscious and unresponsive, and totally dependent on mechanical ventilation for respiration. The various tests that were conducted on Archie (with parental agreement) indicated catastrophic brain damage – a diagnosis supported by specialists' second opinions. The severity of the injury, and Archie's clinical state, were such that clinicians considered that he might fulfil the criteria for brainstem death. However, Archie's parents refused permission for the hospital to perform some of the relevant tests for a diagnosis of brainstem death under the Academy of Medical Royal Colleges' *Code of Practice for the Diagnosis and Confirmation of Death* (2008) (hereafter 'the Code').[10] The Trust therefore made an application for a declaration that it was lawful and in Archie's best interests for brainstem testing to take place.

Diagnosing brainstem death

Following the hearing on 13 May 2022, Arbuthnot J gave permission for the Trust to proceed with the testing, despite the wishes of Archie's parents.[11] However, the experts charged with this assessment were unable, for technical reasons, to proceed with testing. They had used a nerve stimulator to test the integrity of Archie's peripheral nerves to be assured that if he failed to respond during brainstem testing this would be due to brainstem death rather than some other neurological reason. Therefore, when Archie showed no reaction to the peripheral nerve stimulator, the experts concluded that they could not continue with brainstem death testing.[12] When the case returned to the Family Division a month later, the Trust applied for a declaration that Archie was brainstem dead or, in the alternative, for an order that it was not in Archie's best interests to continue to receive mechanical ventilation.[13]

10. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWHC 1165 (Fam)
11. [2022] EWHC 1165 (Fam). The question of whether parental consent is required for brain death testing has been the subject of much disagreement in the US. See the debate between A. Shewmon and T. Pope, 'Point and Counterpoint: Whether Informed Consent Should Be Obtained for Apnea Testing in the Determination of Death by Neurologic Criteria?', *Chest* 161 (2022), pp. 1143–1147. In *Battersbee*, although she did not specifically comment on the matter, Arbuthnot J. clearly operated on the basis that court referral is necessary in the absence of parental consent: see Donnelly and Lyons, 'Disputing Death'.
12. The use of a nerve stimulator is not required under the Code. It is unclear why more sophisticated tests were not performed following the failure to elicit a response. Given Archie's medical history it seems improbable that he had an additional condition that would have rendered formal testing impossible.
13. [2022] EWHC 1435 (Fam), [2].

Despite the inability of clinicians to test for brainstem death in accordance with the Code, Arbuthnot J concluded that Archie had died on 31 May, shortly after the magnetic resonance imaging (MRI) scans taken on that day.[14] This declaration was a departure from existing practice in that no doctor had diagnosed Archie as brainstem dead. Instead, Arbuthnot J's decision was reached on the basis of 'anxious and careful scrutiny of all of the evidence'.[15] Arbuthnot J also found that, even if Archie were not dead, it was not in his best interests to continue with life-sustaining interventions, such as mechanical ventilation.[16]

Arbuthnot J permitted Archie's parents to appeal on a single ground – whether the making of a declaration of death was such an exceptional category of case that she should have applied the criminal, rather than the civil, standard of proof. When the matter came before the Court of Appeal, the court acceded to the parents' application to broaden the appeal to six grounds, most notably that the 'judge was wrong to make a diagnosis of death in a manner which was not compliant with' the Code.[17]

The Court of Appeal was critical both of Arbuthnot J's declaration of brainstem death and of the way that the best interests test had been conducted. The Court noted the lack of authority to support a finding of brainstem death in the absence of testing in accordance with the Code or of a medical diagnosis.[18] However, because all parties had agreed that 'it would have been better' for Arbuthnot J to have proceeded to a best interests analysis once it had become clear that brainstem testing could not happen, the Court did not find it necessary 'to go further and hold that . . . it was wrong for the judge to diagnose death on a basis which is not compliant with the Code.'[19] On the best interests evaluation, the Court rightly raised concerns about the validity and security of the evaluation in this instance, given that Arbuthnot J had already declared that Archie was dead and thus had no interests. Accordingly, the Court directed that the case be remitted to Hayden J to determine where Archie's best interests lay.[20] In turn, Hayden J was also critical of the Arbuthnot J's judgment:

> The Court of Appeal concluded that such an approach was wrong in law. It strikes me that it is also wrong, clinically. The law and good medical practice will rarely, if ever, diverge. Ascertaining death requires the application of clear clinical guidelines. Where they are not met, brain stem death cannot be identified with the certainty that such a conclusion requires.[21]

This categorical statement of Hayden J seems to imply that Arbuthnot J's judgment must be particularly flawed. However, we would suggest that two significant issues influenced Arbuthnot J's conclusions. First, Arbuthnot J's reasoning is clearly aligned with the judgement of Lieven J in *Manchester University NHS Foundation Trust v Midrar Namiq and Ors*[22]; and second, there were mitigating factors that made judgment difficult.

14. [2022] EWHC 1435 (Fam), [180].
15. [2022] EWHC 1435 (Fam), [179].
16. [2022] EWHC 1435 (Fam), [196].
17. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1055, [4].
18. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1055, [35].
19. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1055, [35].
20. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1055, [46]-[47]. A new Guardian was also appointed to assist in this process.
21. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWFC 80, [2].
22. [2020] EWHC 180 (Fam).

These extenuating elements include as follows: (1) that Archie fell into a liminal metaphysical and legal space that has been conceptually challenging for courts dealing with similar cases; (2) that the Court was directed in a particular way by the testimony of the clinicians; and (3) that the Court was not assisted by the Code, which is insufficiently directive in difficult, though hardly unforeseeable, circumstances.

Death, metaphysics, and the courts

Brain death has been both metaphysically and biologically contentious since the diagnosis was first endorsed by an Ad Hoc Committee of Harvard Medical School in 1968.[23] In an attempt to harmonise diagnostic standards for brain death, the World Brain Death Project (WBDP) was established.[24] It identified that,

> [T]here continues to be confusion and dilemmas that arise regarding BD/DNC.[25] The wide variance in practice reflects this confusion and numerous other challenges. Inconsistencies in concept, criteria, practice, and documentation exist internationally and within countries.[26]

The extent of such inconsistencies and variability in practice is indicated by the fact that the Project sets down 108 recommendations for change and convergence. Some of the 'confusions' identified by the WBDP are also reflected in the way in which courts have conceptualised the cases that come before them.

Since 2015, in addition to *Battersbee*, at least six other applications relating to the diagnosis of brainstem death have come before UK courts.[27] Like *Battersbee*, each case

23. Report of Ad Hoc Committee of the Harvard Medical School, 'A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death', *Journal of the American Medical Association* 205 (1968), pp. 337–340. There is a substantial literature on the subject: see eg A. Capron, 'Brain Death—Well Settled Yet Persistently Unresolved', *New England Journal of Medicine* 344 (2001), pp. 1244–1246; F. Miller and R. Truog, *Death, Dying and Organ Transplantation: Reconstructing Medical Ethics at the End of Life* (New York: Oxford University Press, 2008); M. Nair-Collins, 'Death, Brain Death and the Limits of Science: Why the Whole-Brain Concept of Death Is Flawed Public Policy', *Journal of Law, Medicine & Ethics* 38 (2010), pp. 667–683; Pope, 'Brain Death Forsaken'.
24. D. Greer, S. Shemie, A. Lewis, S. Torrance, . P. Varelas, . F. Goldenberg, J. Bernat, M. Souter, M.Topcuoglu, A. Alexandrov, M. Baldisseri, T. Bleck, G. Citerio, R. Dawson, A. Hoppe, S. Jacobe, A. Manara, T. Nakagawa, T. Pope, W. Silvester, D. Thomson, H. Al Rahma, Rafael Badenes, MD, PhD22; Andrew J. Baker, MD23; Vladimir Cerny, MD, PhD24; Cherylee Chang, MD25; Tiffany R. Chang, E. Gnedovskaya, M. Han, S. Honeybul, E. Jimenez, Y. Kuroda, G. Liu, U. Mallick, V. Marquevich, J. Mejia-Mantilla, M. Piradov, S. Quayyum, G. Shrestha, Y. Su, S. Timmons, J Teitelbaum, W. Videtta, K. Zirpe, G. Sung., 'Determination of Brain Death/Death by Neurologic Criteria: The World Brain Death Project', *Journal of the American Medical Association* 324 (2020), pp. 1078–1097.
25. BD/DNC is shorthand for Brain Death/Death by Neurologic Criteria. For all relevant purposes, DNC may be regarded as synonymous with brain death.
26. Greer, 'Determination of Brain Death', p. 1078.
27. Donnelly and Lyons, 'Disputing Death'.

entailed litigants burdened by tragedy, despair, and grief.[28] In each instance, the courts have acknowledged the equivalence of brainstem death and legal death, notwithstanding that the cited basis for this derives from judicial remarks in a case that definitively was not about brain death.[29] Yet, the courts have also, frequently, inadvertently indicated that brainstem death feels somewhat different to cardiopulmonary death; that despite the stated equivalence of the two, the warm biologically persisting body of those diagnosed as brainstem dead can seem a different entity to the cold cadaver. In *Re TC (A Minor)*, a case concerning a ward of court, MacDermott LJ found that while 'death in the usual sense, of course, terminates wardship', in this case a wardship application should be brought before mechanical ventilation is discontinued.[30] Ian Kennedy was scathing about this statement, commenting that the Court seemed to think that there were different kinds of death, and that brainstem death was of a kind that 'the court in wardship had better keep an eye on'.[31] Any such equivocation, according to Kennedy, is regrettably confusing as brainstem death 'is not a variant of death. It is death.' Although there may be 'outward signs of life', these are only 'artefacts produced by machinery' whose continuance, given the diagnosis, 'has no basis in law'.[32]

We can see similar 'equivocation' in other cases across common law jurisdictions. Francis J, following a diagnosis of brainstem death in *Oxford University Hospital Trust v AB and Anor*,[33] issued a declaration that it was in AB's best interests for all care and treatment to be withdrawn.[34] McFarlane P in *Re M (Declaration of Death of Child)* was critical of this stating that 'where a person is dead, the question of best interests is, tragically, no longer relevant.'[35] However, the President's view is not universal. In the Irish case of *PP v Health Service Executive (HSE)*, which concerned a young woman (NP) diagnosed as brainstem dead while 15 weeks pregnant, the High Court was clear that NP was a bearer of constitutional rights, recognising her 'right to retain in death her dignity with proper respect for her autonomy'.[36] A similar ascription of rights to those diagnosed brain dead was recognised in *McKitty v Hayani*, the Court of Appeal of Ontario holding that the correct approach in such cases was to presume that the

28. See *Re A (A child)* [2015] EWHC 443 (Fam); *Oxford University Hospital Trust v AB and Anor* [2019] EWHC 3516 (Fam); *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164; *North West Anglia NHS Foundation Trust v BN* [2022] EWHC 663 (Fam); *A Health and Social Care Trust v RL* [2022] NI Fam 17; *In the Matter of A (A Child)* [2022] EWHC 1873 (Fam).
29. *Airedale NHS Trust v Bland* [1993] AC 789, 878-80.
30. Unreported High Court of Justice in Northern Ireland (Family Division); MacDemott J; 30 November 1993; I. Kennedy, 'Case Commentary', *Medical Law Review* 2 (1994), pp. 353–380, p. 376.
31. *Ibid.*
32. *Ibid.*
33. [2019] EWHC 3516 (Fam).
34. [2020] EWCA Civ 164, [49].
35. [2020] EWCA Civ 164, [24].
36. [2014] IEHC 622.

applicant fell within the category of rights holders under the Canadian Charter of Rights and Freedoms.[37]

Despite his robust assertions around legal certainty in *Battersbee*, even Hayden J has dipped a toe into the metaphysical sea. In *Re A (A child)*, Hayden J questioned the legal authority of the Senior Coroner for Manchester to assume jurisdiction over the body of Child A who had been declared brainstem dead. Hayden J recognised that 'in a multi-cultural society . . . [I]t is hardly difficult to understand why the still breathing body is regarded as alive, even though "breath" may be entirely delivered by machine'.[38] Displaying a cultural sensitivity that he regarded as distinctly lacking in the approach of Senior Coroner (who had ordered the removal of the body), Hayden J continued that while coronial authority existed: 'an insistence on a legally precise definition of death to trigger the involvement of the Coroner, in such challenging circumstances is, in my judgment, so obviously wrong as to be redundant of any contrary argument.'[39] Instead, these were matters to be resolved by the courts. Here, Hayden J seems to come perilously close to the position of MacDermott LJ. Indeed, the court in *Re A* adds to rather than detracts from the conceptual fog surrounding brain death, citing from both *Jervis on Coroners* (13th Edition), referred to by the Court as 'the standard textbook', and *Thurston's Coronership* (3rd Edition). Jervis sets out the applicable point as follows:

> The coroner may also be faced with the difficult task of deciding whether a body in his area is actually dead . . . it appears that once a person has suffered brain stem death which no medical treatment is able to reverse, the person is 'dead' for the purposes of the coroner acquiring jurisdiction even whilst a machine ventilates the body.[40]

Thurston provides an opposing view, and one that is fully endorsed by Hayden J: 'while the heart beats and the blood circulates, there is no "dead" body, that is, for the purposes of establishing the Coroner's jurisdiction.'[41] In *Re M*, McFarlane P, while censorious of Francis J's approach in *AB*, approved of the approach of Hayden J in *Re A*,[42] even though it also appears to identify the brainstem dead as somehow differently dead, ethereally suspended in some space between the intensive care unit and the mortuary.

Medical testimony and the role of the code

It was into this clinically, metaphysically and legally opaque space that Arbuthnot J stepped when adjudicating on whether Archie should be declared dead. The clinical test as set out by the Code is a six-stage procedure.[43] It is neither especially technical nor

37. *McKitty v Hayani* [2019] ONCA 805, [47].
38. [2015] EWHC 443 (Fam), [24].
39. [2015] EWHC 443 (Fam), [24].
40. As quoted [2015] EWHC 443 (Fam), [21].
41. [2015] EWHC 443 (Fam), [22].
42. *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164.
43. The Code outlines the stages of the test in paras 6.1.1 – 6.1.6. The Court erroneously refers to a seven-stage test.

difficult to perform. The final stage is the 'apnoea test'.[44] Archie's family initially provided permission for the first five steps to be undertaken but declined to consent to the apnoea test on the grounds that it could further damage his brain. They were apparently willing for him to undergo any of the list of technical ancillary examinations included in the Code[45] rather than the apnoea test. However, the expert witness was clear in his testimony that:

> it was in Archie's best interests to have formal brain stem testing, there was no reason to do anything other than that. . . no other tests would be acceptable, the national guidance was clear that the brain stem test including for apnoea should be conducted.[46]

While conceding that 'in certain unusual cases', ancillary investigations could be useful, the expert was of the opinion that 'Archie's case was not one of those'.[47] The Court of Appeal appears to have gone further, seemingly ignoring paragraph 6.7 of the Code entirely, and potentially disregarding the possibility of using ancillary tests in any circumstances:

> The Code does not state that there is any alternative basis for diagnosing death on the basis of cessation of brain stem function other than by conducting the test. It provides for only one basis of diagnosis which is, as we have said, for 'irreversible loss of brain- stem reflexes [to be] diagnosed by clinical neurological testing'.[48]

In fact, while the Code does assert the accuracy of the clinical tests for the diagnosis of death as justification for not requiring neurophysiological or imaging investigations as part of standard assessment,[49] it also identifies that certain forms of injury,[50] the presence of certain sedative or paralysing medications, or particular metabolic derangements, may render testing to be incomplete or unreliable. In such cases, 'ancillary investigations may supplement a limited form of clinical testing'.[51] For example, in the already mentioned Irish case of *PP v HSE*, there were concerns that the apnoea test could potentially harm the foetus and so it was not carried out. In its place, a four-vessel cerebral angiogram was

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44. During the apnoea test the patient is disconnected from the ventilator, passively supplied with oxygen, and observed to ascertain whether they make any independent efforts at breathing. While there is no respiration, the blood levels of carbon dioxide rise and the blood becomes more acidic. This should trigger the respiratory centre in the brainstem to fire, causing the patient to breathe spontaneously. In situations where there has been no response to the first steps, a positive apnoea test confirms the diagnosis of brainstem death.
45. Referred to in para 6.7 of the Code, and listed in Appendix 3 to the Code.
46. *Barts Health NHS Trust v Dance and Battersbee* [2022] EWHC 1165, [64].
47. [2022] EWHC 1165, [52].
48. [2022] EWCA 935, [33].
49. This is not a universal position. Many countries require clinical testing AND neurophysiological or radiological tests for the diagnosis of brain death to be made. See A. Lewis, A. Bakkar, E. Kreiger-Benson, A. Kumpfbeck, J. Liebman, S. Shemie, G. Sung, S. Torrance, D. Greer, 'Determination of Death by Neurologic Criteria Around the World', *Neurology* 95 (2020), p. e299.
50. Feasibility is diminished where, for example, there is severe trauma to the head and face.
51. Code, p19.

performed which indicated that there was no blood flow into the brain. This confirmed the diagnosis of brainstem death.[52]

While the Code sets down a list of conditions where alternative forms of testing might obtain,[53] it is unclear whether the cited examples are intended to be exhaustive. We suggest that this interpretation is improbable; it would seem more reasonable to hold that those drafting the Code were not setting out a limited range of possibilities but rather identifying that if full clinical testing was not possible then ancillary tests could be applied. The question remains as to whether Archie's was the type of case where an ancillary examination could or could not be used as a confirmatory investigation in the place of the apnoea test. The view that Archie's was 'not one of those cases' would seem to depend on a particular reading of the Code, one undertaken by the expert and uncontradicted (and indeed unexplored) by the Court of Appeal.

However, ancillary investigations either provide sufficient reassurance of the diagnosis of death when used in place of the apnoea test (where this is either not feasible or unduly hazardous) or not. If they do not, then in cases such as *PP v HSE*, the diagnosis of brainstem death is not secure and any declaration of death is unsafe. This would obviously be problematic but would also negate the need for any mention of ancillary tests in the Code. If, however, a safe declaration of death could be made on the basis of the first five steps plus a technical investigation, then it is unclear why this was not a reasonable course of action in Archie's case. Implementing this process could have led to an early diagnosis of brainstem death, and precluded the need for the subsequent extensive litigation.

In the initial hearing to consider whether to override parental refusal of the apnoea test, the expert considered alternatives to this test to be inappropriate in this case. When pressed by counsel, the expert stated that one reason for not proceeding with ancillary investigations was that they were inherently more risky:

> When it came to the balance of harm, in evidence, he was clear that wheeling Archie, in what would be a mobile intensive care unit, to a testing department in a different part of the hospital was when human errors could occur. Archie would be more at risk in those circumstances. It was a relatively small risk when moving Archie but it could have catastrophic consequences. He said the risk of an apnoea test was not comparable to the risk of a move within the hospital. There was not the same array of complications with the former which was a relatively simple procedure.[54]

However, it appears that the expert did not provide, nor did it ask for, empirical data on the relative risk. This seems odd as this decision would seem to fall squarely within the standard rubric of risk, benefit, parental consent, and best interests. Counsel for the

52. [2014] IEHC 622. The same criteria for brainstem death testing apply in Ireland and the UK, although the Irish Code has been more recently updated: see R. Dwyer, D. Phelan, F. Colreavy, B. Marsh, C. Motherway, *Diagnosis of Brain Death in Adults; Guidelines* (Intensive Care Society of Ireland, 2020).
53. See Code, para 6.7.
54. [2022] EWHC 1165, [63].

family asked questions on the risk posed by the apnoea test citing studies from the United States, but these were dismissed as not pertinent by the expert.[55] Interestingly, sandwiching the expert's opinion (9 May), it would seem that Archie was safely transported for radiographic imaging on 7, 8, and 15 April, and 11 and 31 May.

These images, along with electrophysiological tests that were conducted,[56] appear to have been important factors in persuading Arbuthnot J that Archie was brainstem dead despite the absence of formal testing.[57] The imaging on 15 April showed no blood flow within the skull and tonsillar herniation[58]; the EEG on 20 April indicated that 'there was no brain activity detected'; the CT angiogram on 11 May again indicated a 'complete lack of blood flow to the brain'; the MRI on 31 May provided the kind of images that Dr P said 'were ones he usually saw at perimortem or postmortem'. In addition, to these findings, the opinions of Dr P, Dr F. and Dr Z (25 May) were in agreement with all saying that 'Archie was either likely or very likely to be brain dead'.[59] Dr F, Archie's treating Consultant Paediatric Intensivist, confirmed that 'it was likely that Archie's brain stem had died between 8th and 26th April 2022'.[60] The absence of a formal set of tests did not, in the opinion of Arbuthnot J, 'preclude her from anxiously considering the abundant clinical evidence' ('including from clinicians with different specialisms from five separate hospitals') and coming to a conclusion.[61] Following this anxious consideration, Arbuthnot J decided that the medical evidence pointed in a single direction, leading to the declaration by the Court 'that tragically on the balance of probabilities, Archie is dead.'[62]

On the balance of probabilities, Arbuthnot J may well have been correct in her finding but, although apparently logically founded on the opinions offered by the involved clinicians, it, nonetheless, was a medically unconfirmed diagnosis. The Court of Appeal was, entirely reasonably, concerned about the judicial assumption of clinical responsibility and thus 'strongly caution[ed] judges in future cases of this kind from being drawn into attempting to declare death on a basis outside of the Code where none of the medical witnesses has themselves made a diagnosis of death.'[63]

Clinicians making the diagnosis of brainstem death are reliant on the Code, yet the Code is not particularly directive where clinical testing for brainstem death cannot be

55. [2022] EWHC 1165 [45]-[50].
56. Electroencephalograms (EEGs) were performed on 10/11 April, and 20 April.
57. The list of tests is set out in *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWHC 143, [53ff].
58. The radiologist Dr P described tonsillar herniation as 'a very reliable marker for a point-of-no-return for brain stem function'; absence of blood flow correlates highly with a diagnosis of brain death: see G. Plourdeet et al, 'Flow Is Not Perfusion, and Perfusion Is Not Function: Ancillary Testing for the Diagnosis of Brain Death', *Canadian Journal of Anesthesia/Journal canadien d'anesthésie* 68 (2021), pp. 953–961.
59. [2022] EWHC 1435, [81].
60. [2022] EWHC 1435, [82].
61. [2022] EWHC 1435, [173].
62. [2022] EWHC 1435, [179].
63. *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1055, [35].

carried out to completion, stating that '(I)n such cases a confirmatory test may reduce any element of uncertainty'. This is not language that provides definitive assurance, nor is what follows, which is to point out that the 'various tests available . . . are prone to artifice and each has attracted its own literature defining false positive and negative rates'.[64] The Code fails to provide a directive hierarchy of merit, or indicate where and when each test might be useful (or not). This may be a factor of the age of the Code (14 years), and thus it perhaps lags behind technological progress. However, if the Code is to assist clinicians and the Courts in respect of something as important as the diagnosis of death, it must be definitive and action-guiding. Had there been a clearly defined diagnostic pathway in this instance, then the legal overstep of Arbuthnot J, and much subsequent litigation, could have been avoided.

Role of the CRPD

A second novel element of the *Battersbee* litigation was the role played by the CRPD, and in particular, Archie's parents' communication to the CRPD Committee.[65] According to the Court of Appeal, the CRPD was first raised before Hayden J in the best interests hearing.[66] These submissions are not referred to in Hayden J's judgment (although he does address Archie's personality and perspectives in some detail). On appeal, Archie's parents identified as relevant articles 10[67] and 12[68] of the CRPD, arguing that Hayden J had failed to take these into account in approving the withdrawal of life-sustaining treatment.[69] They argued that 'a decision to remove [life-sustaining treatment] from someone who previously had capacity, can only be made on the basis of the person's will and preferences and failing this then according to "the best interpretation of their will and preferences"'.[70] There is absolutely no authority for this proposition in the law of England and Wales.[71] Unsurprisingly, the argument was firmly rejected by the Court of Appeal which found that '[t]hese submissions, in the context of a person who is so disabled that they have no free-standing capacity for life without artificial and intensive medical

64. Code, p19.
65. Although the CRPD does not formally establish any new rights, it sets out obligations and duties on States Parties to ensure non-discrimination and the equal enjoyment of human rights by all persons with disabilities: see R. Kayess and P. French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities', *Human Rights Law Review* 8 (2008), pp. 1–34; L. Series, 'Disability and Human Rights', in N. Watson and S. Vehmas, eds., *Routledge Handbook of Disability Studies* (London: Routledge, 2019), pp. 72–88.
66. *Barts Health NHS Trust v Dance and Battersbee* [2022] EWFC 80.
67. Art. 10 provides for the equal right to life of persons with disabilities and requires States Parties to take all necessary measures to ensure its effective enjoyment.
68. Art. 12 recognises the equal right to legal capacity of persons with disabilities.
69. *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1055, [21].
70. [2022] EWCA Civ 1055, [26].
71. The language used draws on General Comment No. 1 of Committee on the Rights of Persons with Disabilities, '*Article 12: Equal Recognition Before the Law'*, (19 May 2014), CRPD/C/GC/1 (although this is specifically directed towards adults).

intervention, appear to stretch the parameters of this convention beyond its intended boundaries'.[72]

Engagement with the CRPD was expanded when, on 28 July 2022 following the expiration of the stay on withdrawal imposed by the Court of Appeal, Archie's parents lodged a 'communication' with the CRPD Committee. This individual right to communicate an alleged violation of the CRPD arises under the Optional Protocol to the CRPD (which the United Kingdom has ratified alongside the Convention).[73] If the CRPD Committee finds the communication to be admissible, it may consider the communication at a closed meeting and then forward its suggestions and recommendations, if any, to the State Party.[74] The CRPD Committee is also empowered to send a request that the State Party take interim measures to avoid possible irreparable damage to the victim(s) of the violation.[75] Such a request does not imply a determination by the CRPD Committee on the admissibility or the merits of the communication.[76]

The CRPD Committee communication process had previously been used in the case of Vincent Lambert, a 42-year old French citizen who had been diagnosed as being in a vegetative state. Mr Lambert's wife, who was his legal guardian, approved the removal of life-sustaining treatment but this was opposed by his parents who had strong Catholic religious beliefs. The case gave rise to a protracted legal dispute,[77] which at the latter stages included a communication to the CRPD Committee. As it had with the Lambert case, in *Battersbee*, the CRPD Committee sent a request to the UK Government that it refrain from withdrawing life-sustaining treatment until the CRPD Committee had considered the issue. It also invited the United Kingdom to respond on the question of admissibility within a 2-month period.[78]

Archie's parents argued that a stay on withdrawal of life-sustaining treatment should be granted pending further engagement with the Committee. In evaluating this argument, it is important to remember that all parties had acknowledged that Archie's death was inevitable, and that this was most likely to occur within weeks.[79] However, Archie's parents had advocated that 'Archie's death should be as 'natural' as possible, and the exact timing of his death should be determined only by God'.[80] Had a stay been granted, it is highly likely that Archie would have died on the ventilator before his case was considered by the CRPD Committee.

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72. [2022] EWCA Civ 1055, [26].
73. Optional Protocol, art. 1.
74. Optional Protocol, art. 5.
75. Optional Protocol, art. 4.1.
76. Optional Protocol, art. 4.2.
77. D. Wilkinson and J. Savulescu, 'Current Controversies and Irresolvable Disagreement: The Case of Vincent Lambert and the Role of "Dissensus"', *Journal of Medical Ethics* 45 (2019), pp. 631–635.
78. *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1106, [8]. There are also lengthy delays in the rest of the process: see the procedure outlined in art. 6 of the Optional Protocol.
79. *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1055, [15].
80. *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1055, [15].

The Court of Appeal strongly rejected this argument, finding that the submissions by the family's counsel had 'no foundation whatsoever'.[81] McFarlane P, for the Court, noted that the CRPD had not been incorporated into the UK law and affirmed that it was 'not appropriate for this Court to apply an unincorporated international treaty into its decision making process'. The Court referred to the extensive consideration of the status of unincorporated treaties by Lord Reed in *R (SC, CB and 8 children) v Secretary of State for Work and Pensions and others*.[82] Lord Reed had concluded that the obligations that unincorporated treaties impose lie at international level, there being 'no basis . . . for any departure from the rule that our domestic courts cannot determine whether this country has violated its obligations under unincorporated international treaties'.[83] McFarlane P also rejected the argument for a stay on normative grounds, concluding that,

> if this court were to accede to the parents' application, the court would be acting contrary to what it has determined to be in Archie's best interests, it would be sanctioning a step, namely postponing the implementation of the order, which would be contrary to his best interests . . .. That seems to me to be plainly wrong.[84]

While the Court of Appeal decision would seem to have decisively closed the door to the use of the CRPD Committee as a delaying mechanism, broader questions arise as to the role of the CRPD (and the CRPD Committee) in cases where the person is in a permanent disorder of consciousness. In addition to its role under the Optional Protocol, the CRPD Committee can make its views known either through Concluding Observations on Reports by States Parties or through General Comments. Alexander Ruck Keene and Annabel Lee point to the apparently 'vitalist'[85] position set out in the CRPD Committee's Concluding Observations on the initial report of Spain.[86] Here, the Committee observed with regret 'that guardians representing persons with disabilities deemed "legally incapacitated" may validly consent to termination or withdrawal of medical treatment, nutrition or other life support for those persons', stating that 'the right to life is absolute, and that substitute decision-making in regard to the termination or withdrawal of life-sustaining treatment is inconsistent with this right.'[87] It continued,

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81. *Dance and Battersbee v Barts Health NHS Trust* [2022] EWCA Civ 1106, [36].
82. [2021] UKSC 26.
83. [2021] UKSC 26, [84].
84. *Dance & Ors* [2022] EWCA Civ 1106, [37]-[38].
85. A. Ruck Keene and A. Lee, 'Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position', *Journal of Medical Ethics* 45 (2019), pp. 794–799. As described by Keown, 'Vitalism holds the human life is an absolute moral value and that it is wrong either to shorten the life of an individual human being or to fail to strive to lengthen it': J. Keown, 'The Legal Revolution: From "Sanctity of Life" to "Quality of Life" and "Autonomy"', *Journal of Contemporary Health Law and Policy* 14 (1998), pp. 253–286.
86. Committee on the Rights of Persons with Disabilities, '*Concluding observations of the Committee on the Rights of Persons with Disabilities: Spain*' (19–23 September 2011), https://extranet.who.int/mindbank/item/1372 (accessed 11 January 2023).
87. *Ibid.*, para 29.

> The Committee requests the State party to ensure that the informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support.[88]

Ruck Keene and Lee also note that this appears to have been the only example of overt vitalism in CRPD Committee communications to date and that a broader analysis of the CRPD Committee's position suggests that it does not support an absolute right to life 'if this is to mean that all steps can and must be taken at all times to keep a disabled person alive'.[89]

This is a difficult and dangerous territory for the CRPD Committee to negotiate. Clearly, the Committee has an essential role in identifying and countering discriminatory end-of-life practices for people with disabilities, such as the inappropriate use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices for people with learning disabilities during Covid-19.[90] However, recasting the dying as disabled brings the CRPD Committee into a space in which it is ill-equipped to provide plausible pronouncements. The more circumspect approach, which Ruck Keene and Lee identify as more typical of the CRPD Committee, has a great deal to recommend it.

Conclusion

Archie Battersbee's tragic accident and the legal maelstrom which followed raises challenging questions about how we deal with the end of life where there is significant brain damage. In this casenote, we have focussed on two such questions: the way in which brainstem death is determined, and the role of the CRPD.

On the first question, the Court of Appeal has made it clear that the role of the Court is essentially to oversee the operation of the Code and not to go beyond this. Thus, legal death is essentially a clinical matter. This requires that the Code provides adequate and comprehensive direction for those who apply it in practice. We have argued here that there are unanswered questions in the *Battersbee* litigation about whether the level of guidance provided by the Code is sufficient, particularly in respect of the use of ancillary testing. It may well be the case that the choices made in this instance can be justified; however, there does not appear to have been a close interrogation of these choices. We argue that it is essential for a more rigorous kind of analysis to be conducted by the courts, especially given the apparent ceding of the determination of life or death to the medical profession.

On the second question, the Court of Appeal has decisively rejected the possibility of using a communication with the CRPD Committee as a method for delaying treatment withdrawal. This is a reasonable position to adopt in cases like this which are not suited to the CRPD Committee's lengthy processes, or falling within the specific expertise of the Committee. This, however, is not to deny the importance of human rights in decisions

88. *Ibid.*, para 30 (original emphasis).
89. Ruck Keene and Lee, 'Withdrawing Life-Sustaining Treatment', p. 797.
90. H. Bows and J. Herring, 'DNACPR Decisions during Covid-19: An Empirical and Analytical Study', *Medical Law Review* 30 (2022), pp. 60–80.

of this kind, nor indeed the role of the CRPD Committee in ensuring that end-of-life care is delivered in a way which does not discriminate against a person on the basis of an underlying disability.

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