Neutral Citation Number: [2022] EWCA Civ 935

Appeal No: CA-2022-001239
Case No: FD22P00346

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE HIGH COURT OF JUSTICE
FAMILY DIVISION
MRS JUSTICE ARBUTHNOT

Royal Courts of Justice, Strand
London WC2A 2LL

Date: 06/07/2022

**Before:**
**SIR GEOFFREY VOS, MASTER OF THE ROLLS**
**SIR ANDREW McFARLANE, PRESIDENT OF THE FAMILY DIVISION**
and
**LADY JUSTICE KING**

**B E T W E E N**

**BARTS HEALTH NHS TRUST**

**Applicant/Respondent**

**and**

**(1) HOLLIE DANCE**
**(2) PAUL BATTERSBEE**

**Respondents/Appellants**

**(3) ARCHIE BATTERSBEE (A child by his Children's Guardian)**

**3rd Respondent**

**Edward Devereux QC, Bruno Quintavalle, and Rob George** (instructed by **Andrew Storch Solicitors**) appeared on behalf of the **appellant parents** (the parents)

**Martin Westgate QC and Fiona Paterson** (instructed by **Kennedy's Law**) **for the Respondent NHS Trust** (the Trust)

**Katie Gollop QC and Maria Stanley (instructed by Cafcass Legal), on behalf of the Guardian, for the child** (Archie)

Hearing date: 29 June 2022

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# JUDGMENT

**Sir Geoffrey Vos Master of the Rolls, Sir Andrew McFarlane President of the Family Division and Lady Justice King:**

Introduction

1. This tragic case concerns the future of 12-year old Archie. On 7 April 2022, Archie's mother found him suspended from the banisters at home with a dressing gown cord around his neck. Since then, Archie has been in hospital. The Trust applied to Mrs Justice Arbuthnot (the judge) for a declaration that Archie was brain stem dead, or in the alternative for an order that it was not in Archie's best interests to continue to receive mechanical ventilation.

2. After a 3-day hearing, the judge declared on 13 June 2022 that Archie had died at noon on 31 May 2022: "irreversible cessation of brain stem function having been conclusively established". She granted the Trust permission to cease the administration of mechanical life support and medication. The judge made no order as to Archie's best interests, but said at [196] that, had she not made the declaration of death, she would have found that it was not in Archie's best interests for him to continue medical treatment.

3. The judge granted the parents permission to appeal her order on only one ground. That ground was that the making of a declaration of death was such an exceptional category of case that the judge should have applied the criminal, rather than the civil, standard of proof.

4. Before the expedited appeal hearing on 29 June 2022, the court sent an indication of the argument it wished to hear. It asked whether, once it had become apparent on 16 May 2022 that it was not going to be possible to administer a brain stem test, it would have been more appropriate to proceed to decide Archie's best interests, rather than continuing with the attempt to determine whether a declaration of death was appropriate. The court also said that it acceded to the parents' application to add 5 additional grounds of appeal. The permitted grounds of appeal were as follows:

    i) The judge was wrong not to apply the criminal, rather than the civil, standard of proof to her determination of the declaration of death, because such an application is an exceptional category of case.

    ii) The judge was wrong to extend the common law definition of death to include brain stem death.

    iii) The judge was wrong to make a declaration of death without accommodating the religious/philosophical views of death held by Archie (and his family) thereby breaching their rights under Article 9 of the European Convention on Human Rights.

    iv) The judge was wrong to make a diagnosis of death in a manner which was not compliant with The Academy of Medical Royal Colleges' Code of Practice for the Diagnosis and Confirmation of Death 2008 (the Code).

    v) The judge was wrong to determine on the basis of the evidence, on the balance of probabilities, that Archie was dead.

vi) The judge wrongly approached the determination of what was in Archie's best interests.

5. When Mr Edward Devereux QC, leading counsel for the parents, opened the appeal, he submitted that the judge had been wrong to make a declaration of death where no brain stem test could be administered. He submitted that the judge ought to have moved on to a best interests evaluation. The court then asked counsel for the Trust and for the Guardian whether they were intending to contest that submission. Mr Martin Westgate QC, leading counsel for the Trust, submitted that, whilst the Trust did not say that the judge had been wrong to declare death, it would have been better to proceed straight to a best interests determination. Whilst arguing that the Guardian's approach had been justifiable, Miss Katie Gollop QC, leading counsel for the Guardian, also accepted that it would have been better had the judge proceeded to a best interests evaluation, once it became clear that a brain stem test could not be performed.

6. In the light of this agreement, the questions for this court changed. The real question was whether the Court of Appeal had the material to allow it to undertake the necessary best interests determination (or to uphold the judge's views on that point), or whether that question should be remitted to a first instance judge. The parents submitted that the case had gone wrong when the court, the evidence and the argument started to focus on whether death had occurred, rather than on Archie's best interests. Once the judge had formed the view that death had occurred, she would have found it difficult to undertake a balanced best interests assessment. As the President had said in *In re M (Declaration of Death of Child)* [2020] EWCA Civ 164 (*Re M*) at [24] "where a person is dead, the question of best interests is, tragically, no longer relevant". Mr Devereux also showed us the paragraphs in the Guardian's submissions to the judge that concerned best interests, before submitting that a new guardian needed to make a fresh best interests assessment before the issue was determined.

7. Mr Westgate argued for the Trust that the judge had had all the relevant information when she reached her best interests conclusion at [196]. Miss Gollop submitted that the Guardian would not wish to stand in the way of a renewed judicial evaluation of where Archie's best interests lay.

8. In these circumstances, this judgment now proceeds as follows to deal with:

i) The essential factual background.

ii) The reasons why the better course would have been for the judge to proceed to a best interests evaluation, once it became apparent that a brain stem test could not be performed.

iii) The issue of whether this court can uphold the judge's assessment of best interests or properly undertake a best interests evaluation on the evidence presently available.

iv) If so, where do Archie's best interests lie. If not, what further directions should now be made?

9. We announced at the end of the hearing that the appeal would be allowed and that the question of Archie's best interests would be remitted to Hayden J at a hearing fixed for

11 July 2022. We also decided that a new guardian should be appointed immediately to make a fresh best interests assessment, and that the parents should not be granted permission: (a) to appeal the judge's decision to refuse them an ethics expert, and (b) to call an expert in natural death at the hearing before Hayden J.

The essential factual background

10. On 7 April 2022, Archie was admitted to Southend Hospital with a global hypoxic brain injury consequent upon his having sustained a strangulation injury. Archie was transferred to the Paediatric Intensive Care Unit at the Royal London Hospital where he remains in a coma unable to communicate and kept alive by way of mechanical ventilation, but fortunately not in pain. Over the last 12 weeks the care that Archie has and continues to receive from both the clinicians and nursing staff has been as the judge said at [46] "exemplary". Archie's devoted mother has been with him throughout, sleeping on a sofa in his room.

11. In the period between his admission to hospital and 31 May 2022, when the most recent MRI scan was carried out, Archie's condition has steadily deteriorated. A CT scan on 10 April 2022 showed evidence that the swelling of the brain was beginning to push the brain stem against the base of the skull. By 11 April 2022, Archie had developed diabetes insipidus which is the inability of the kidneys to concentrate urine, a condition seen in very severe brain injury and indicative of a poor prognosis.

12. On 15 April 2022, further MRI and MR angiograms were carried out. This MRI showed that the cerebellar tonsils had been pushed through the foramen magnum compressing the brain stem causing "coning". No blood flow could be detected within any of the intracranial blood vessels. Dr P described this picture as presenting a "marker of no return for brain stem function". Dr E described this as a "devastating scan" which showed extreme oxygen starvation.

13. The hospital, as is routinely done in these very serious cases, obtained second opinions from consultant paediatric intensivists and neurologists on 11, 14 and 15 April 2022. Their views were unanimous, namely that there was no possibility of Archie recovering.

    i) On 11 April 2022, Dr M said that it was appropriate to proceed to brain stem death testing, but that if such a test did not demonstrate brain death, continued treatment was not in any event in Archie's best interests.

    ii) On 14 April 2022, Dr X recommended involving the palliative care team and that brain stem testing be carried out. He said that, if brain stem testing could not be carried out, then an EEG and either a Brain MRI (DWI) or a further CT head and angiogram were needed to give support to a decision to withdraw life sustaining treatment.

    iii) On 15 April 2022, Dr K recommended brain stem testing but said that, if the tests did not confirm brain stem death, he would recommend stopping invasive mechanical support as being in Archie's best interests.

14. The family felt unable to agree to the recommended brain testing being carried out believing that, in itself, the test carried unacceptable risks for Archie. As it was not possible to reach agreement as to Archie's future treatment, the Trust issued these

proceedings on 26 April 2022. It sought an order that it was lawful for Archie to undergo brain stem testing in order to establish whether he was brain stem dead and, in that event, a declaration that it would be lawful to withdraw mechanical ventilation which would result in his death. On 28 April 2022, Archie was joined as a party and the Guardian was appointed to represent him.

15. At a directions hearing on 4 May 2022, the Trust was granted permission to instruct Dr Playfor, a paediatric intensivist, to prepare a report. On 9 May 2022, Dr Playfor examined Archie and met his parents. Dr Playfor was of the view that Archie would meet the criteria for brain stem death, but that, even if some residual brain stem function were demonstrated, there could be no meaningful recovery and that it was therefore appropriate to consider withdrawal of life sustaining treatment.

16. Following a contested hearing heard over two days on 12 and 13 May 2022, the judge made an order that Archie should undergo brain stem testing.

17. On 16 May 2022, Dr Q and Dr E, paediatric intensivists from hospitals in other parts of the country, attempted to conduct the brain stem test. The procedure is heavily prescribed by the Code. Prior to starting the test, the doctors perform "a train of four test" which is a peripheral nerve stimulation test to demonstrate that the patient's muscles would respond if the brain were to trigger them. The doctors were unable to elicit any response in Archie meaning that they could not be confident that he had the ability to demonstrate reactions. It was not, absent evidence of Archie's ability to respond, appropriate to proceed to the brain stem test.

18. Dr Q, in common with all the other clinicians who had had an opportunity to examine Archie and to view his scans, expressed the view that Archie had unsurvivable brain damage. He concluded by saying that "in the absence of a possibility of a reliable brain stem death test, the question of how to proceed returns to a best interests test. Brain stem testing is not required to answer this question".

19. The matter returned to the judge for further directions in the light of the inability to perform the brain stem test on 25 May 2022. The judge directed a further MRI scan as had been suggested by Dr X ([13ii] above). Permission was also given to the parents for the instruction of Dr Alan Shewmon to report on the reliability of brain stem testing as a means of declaring death. As Mr Devereux highlighted, notwithstanding the report of Dr Q, no case management directions were made at that hearing directed towards a best interests evaluation. In particular, the Guardian was not directed to prepare a further written report providing the court with a best interests analysis. Such an analysis would have involved consideration of Archie's welfare in its widest sense, not just medical but emotional, social and psychological, all balanced against the backdrop of the welfare checklist in section 1(3) Children Act 1989.

20. The MRI scan was carried out on 31 May 2022. It showed further significant deterioration. The brain displayed global shrinkage and the brain tissue was beginning to issue fluid. There were signs of necrosis in the brain stem, the medulla (which controls breathing and heartbeat), and in various parts of the spinal cord. There was no blood flow to the front and back of the brain and there was further damage to the thalamus which is responsible for vision, speech and consciousness.

21. The medical position when the matter came on for trial was, therefore, that there was overwhelming evidence that Archie would not survive. This was so, despite the fact that brain stem testing, which would potentially have led to a diagnosis of death because of cessation of brain stem function, could not be completed. A number of the doctors had expressed the view that it was likely or highly likely that Archie was in fact brain dead. They each said (albeit expressed in their individual ways) that, absent the brain stem test, a best interests assessment should determine whether life sustaining treatment should be withdrawn. No clinician, whether treating or those providing second opinions, suggested that a declaration of death could or should be made without (a) the Code being followed, and (b) a brain stem test having demonstrated brain stem death in accordance with the Code's strict protocol.

22. The final hearing took place on 6 June 2022. The Trust's position statement of 24 May 2022 said unequivocally that it would not apply for a declaration of death in the absence of a full clinical assessment of Archie's brain stem function conducted in accordance with the Code. Rather, the Trust said it would seek a declaration that it was in the best interests of Archie that mechanical ventilation should be withdrawn. The Guardian was, however, strongly of the view that there was cogent evidence for the Court to conclude that Archie had already died. She relied on the overall medical picture and, notwithstanding the absence of a brain stem test, urged the Trust to seek a declaration to that effect. The Guardian proposed that the date of the scan of 31 May 2022 would be the appropriate date for such a declaration. The parents expressed their concern at the position that the Guardian was taking.

23. The Trust's further position statement agreed "with considerable reluctance" that, on the basis of the evidence currently before the court, there was an arguable basis that Archie had, on the balance of probabilities, died. If the court was not satisfied of that, it was asked to make a declaration in Archie's best interests. Accordingly, the Trust's position statement for the trial refers to best interests in only 5 paragraphs at the end of a 22-page document.

24. At [20]-[21] of the Guardian's position statement dated 5 June 2022, she said this:

> *The Best Interests Issue*
>
> 20. As to best interests, the Guardian considers that the medical factors, including global shrinkage of the brain, severe damage to the deep centres of the brain, severe coning, and necrosis of the medulla and the spinal cord, are compelling.
>
> 21.A factor that could militate in favour of it being in [Archie's] best interests to receive further mechanical ventilation is the family's belief that life continues for as long as the heart beats. Whether that was [Archie's] belief is uncertain and if it was, whether his belief was faith based is also uncertain. Even taking that view into consideration, it is likely that the price to be paid for continued ventilation would be further necrosis of the brain and spinal cord with, perhaps, damage to other tissues and bodily functions. In these circumstances, the Guardian does not consider that it is in the best interests of [Archie] to receive further mechanical ventilation.

25. At [16]-[17] of the Guardian's final written submissions to the judge, she said this:

> *Lack of Awareness and Best Interests*
>
> > 16. The evidence of [Dr P], in particular, is that the damage to [Archie's] brain stem and spinal cord is such that [Archie] has no consciousness or awareness and his ability to feel pain is irreversibly gone. In their Position Statement … , [Archie's] parents suggested that a consequence of inability to feel pain is that the issue of best interests moves into the realm of subjective, value-laden, ethical, moral and religious factors.
> >
> > 17. The Guardian agrees that that is a potential consequence but the consequence does not necessarily follow. Physical harm remains of significant concern to the Guardian, even though C feels no pain. She would draw the Court's attention to the Court of Appeal's decision in *Parfitt v Guys and St Thomas' Childrens' NHSFT* [2021] EWCA Civ 362 at paragraphs 57 to 62 where the Court of Appeal held that the judge determining Pippa's best interests was entitled to conclude that she could experience physical harm from her condition and medical treatment, even though she had no capacity to feel pain and no conscious awareness.

26. The Guardian did not give oral evidence at the trial. The judge at the conclusion of her lengthy judgement found that Archie had died at noon on 31 May 2022. She went on to say that "in deference to his parents' views I go on to consider his best interests as if I had not made that finding".

27. The judge's treatment of best interests was brief. She said that, whilst she took into account the views of the parents and the clinicians, Archie's interests were her paramount consideration. She had in mind that "his burgeoning religious views" were significant to Archie and that, although he did not go to church, he wore a cross and a St Christopher's ring. The judge put in the balance that Archie had told his mother that, if something happened to him, he would want to remain on life support as he would not want to leave her. She also noted that his instinct to survive would have been strong. The judge thought, however, that Archie's opinion was not based on the reality of the medical intervention he was receiving, and "tragically" that Archie did not know his mother was there.

28. The judge went on to say that, whilst Archie feels no pain, the medical procedures keeping his body functioning are a burden and there was the risk of a sudden and catastrophic cardiac arrest. The judge concluded by observing that Archie has no pleasure in life, that his brain damage is irrecoverable and that the downside of an unplanned death was the "inability of his loving and beloved family to say goodbye".

29. In those circumstances, the judge said that she would have found that it was in Archie's best interests for ventilation to be withdrawn. On balance, the burdens of treatment coupled with the lack of a prospect of recovery outweighed his Christian beliefs and the benefits of continuing life on a ventilator.

The reasons why the better course would have been for the judge to proceed to a best interests evaluation, once it became apparent that a brain stem test could not be performed

30. As can be seen from the factual history we have described, the case proceeded in an orthodox manner until it became clear on 16 May 2022 that it was not possible to undertake the brain stem test that the judge had ordered.

31. At that stage, whilst there was clinical evidence that it was likely that death had occurred, it was clear that it was not going to be possible to establish whether or not death had occurred under the principles established in the Code. Those principles require a brain stem test. As the introduction to the Code confirms: "[w]hen a patient is comatose, apnoeic and receiving artificial ventilation of their lungs, the criteria for determining irreversible cessation of brain-stem function will be the irreversible loss of brain-stem reflexes, diagnosed by clinical neurological testing".

32. Dr X, a consultant in neuro-intensive care medicine and anaesthesia, who was instructed to give a second opinion at the request of the parents, advised that, if they were unable to perform brain stem testing, that brain MRI and CT head and angiogram should be considered "to give support to a withdrawal decision". Neither he nor the other doctors involved said that death could be diagnosed under the Code using the other tests referred to as ancillary investigations in Appendix 3 to the Code.

33. The Code, as its title firmly indicates, governs the "practice for the diagnosis and confirmation of death". It is wide ranging and aims to cover the diagnosis of death in all situations. Whilst the Code contains an early caveat that "it does not (and could not) seek to provide guidance for every single clinical situation where a doctor is required to diagnose death", it does contain detailed guidance on the specific task of "the diagnosis of death following irreversible cessation of brain-stem function". That guidance requires a six-stage test sequence to be followed to establish "absence of brain-stem reflexes". A submission made by Miss Gollop that the caveat we have quoted contemplates diagnosing death in the context of irreversible cessation of brain stem function in circumstances where the six-stage test cannot be undertaken was not tested during the hearing. It is a submission which must, at least, be open to question. 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".

34. In any event, it is clear that, in circumstances where the brain stem function test could not be undertaken, none of the medical witnesses before the judge diagnosed death in this case. It is of note that, when the six-stage test has been conducted, the Code requires the diagnosis of death to be made by two medical practitioners of sufficient expertise.

35. No authority has been produced in which previous judges have declared that death has occurred in an individual whose bodily functioning is being mechanically maintained by a ventilator and where death is said to be established on evidence other than testing undertaken in accordance with the Code, or where the judge does not have any medical witness who has diagnosed death. The course that the judge was invited to follow in the present case was, it seems, unprecedented.

36. Before the judge, the Guardian was understandably concerned as to her position. If, as the available evidence indicated, it was probable that Archie had died then she would have no continuing status as his children's guardian and there was no basis for her to offer advice and analysis on best interests. On the instructions of the Guardian appointed to act on behalf of Archie, Miss Gollop persuaded the Trust to continue to pursue its application for a declaration of death and that is the course that was then followed by the judge.

37. In the light of the agreement between all three parties during the appeal hearing that it would have been better for the judge to have proceeded to consider best interests once it was clear that a brain stem test could not be undertaken, it is not necessary for this court to go further and hold that the parents' fourth ground is established and that it was wrong for the judge to diagnose death on a basis which is not compliant with the Code. We do, however, strongly caution judges in future cases of this kind from being drawn into attempting to declare death on a basis outside the Code where none of the medical witnesses has themselves made a diagnosis of death.

Can this court uphold the judge's assessment of best interests or properly undertake a best interests evaluation on the evidence presently available?

38. We conclude that it would not be appropriate either to uphold the best interests assessment made by the judge or to undertake that exercise afresh ourselves.

39. The judge's focus was entirely upon the medical and legal question of whether she should make a declaration of death. The Guardian likewise focused on that question allocating very little space in her statements to the question of best interests. If, as we think, the proper procedure should have entailed a consideration of the best interests question alone, one can imagine that the debate would have been undertaken from a different angle. The judge would have mentioned the welfare criteria listed in section 1(3) of the Children Act 1989 and would perhaps also have referred to [119] of MacDonald J's decision in *Tafida Raqeeb v. Barts NHS Foundation Turst* [2019] EWHC 2531 (Admin), [2019] EWHC 2530 (Fam) as to the importance of the future welfare of the child.

40. Moreover, the judge did not ask for a dedicated assessment of Archie's best interests from the Guardian and, unusually in cases of this kind, did not hear oral evidence from the Guardian.

41. In our judgment, the judge correctly placed significant weight on the medical evidence in saying how she would have determined Archie's best interests. It is not, however, reasonable to expect the parents to have confidence in that decision when the judge had just explained in some detail why she had concluded that Archie was in fact dead. The procedural mis-step taken by the judge means, in our view, that in the circumstances of this case, the decision as to best interests must be decided afresh.

42. There are two reasons why we do not think it would be appropriate for us to take that decision. First, the Guardian started from the same premise as the judge, namely that Archie was dead. With that starting point, it was hard to see how it could ever be concluded that continued treatment was in his best interests. Secondly, however, and perhaps more importantly, we do not have a complete best interests evaluation by a

children's guardian, and we think the court deciding best interests should have the benefit of such an evaluation.

43. Whilst understanding the difficult professional position that the Guardian was placed in, having herself concluded that Archie was "dead beyond doubt", it was, ultimately, for the court to determine whether or not to make a declaration of death. At all stages prior to a declaration of death being made, Archie remained a party to the proceedings and his children's guardian retained the duties placed upon her by [7.6] and [7.7] of PD16A of the Family Procedure Rules 2010. As a CAFCASS officer, the Guardian was, in addition, subject to the duties contained in Part 3 of PD16A, which include a requirement at [6.6(e)] to advise the court on "the options available to [the court] with respect to the child and the suitability of each such option including what order should be made in determining the application". Unless the court otherwise directs, the children's guardian must "file a written report advising on the interests of the child" ([6.8(a)] of PD 16A).

44. In future cases, even where a children's guardian apprehends that the medical evidence may establish that the represented child has died, the guardian should discharge their continuing duty to advise the court on best interests unless and until a declaration of death has been made.

<u>If so, where do Archie's best interests lie? If not, what further directions should now be made?</u>

45. As we have explained, therefore, we do not believe that we can properly undertake the best interests assessment that ought to have been the focus of the judge's decision-making after 16 May 2022.

46. The case will now be remitted to Hayden J to determine where Archie's best interests lie.

47. We made three directions at the end of the hearing. We ordered that a new guardian be appointed to provide Hayden J with a best interests evaluation. The Guardian had said that she would be willing to provide that evaluation, if, but only if, the parents wanted her to do so. They did not, so their wishes concluded that question.

48. We refused permission for either an ethics expert or an expert in natural death. In our view, such experts could not add anything to the huge experience of Family Division judges in general and Hayden J in particular.

<u>Conclusions</u>

49. For the reasons we have given, we will allow the appeal on the sixth ground, namely that the judge adopted the wrong approach to the determination of what was in Archie's best interests. Once it had been established that a brain stem test could not be undertaken so as to enable a diagnosis of death to be made in accordance with the Code, the judge ought, as a matter of good practice, to have progressed to decide Archie's best interests alone. The judge was, of course, entitled to order further medical tests so as to inform

her best interests decision, but the two-pronged course she adopted was not appropriate in the circumstances of this case.