Neutral Citation Number: [2020] EWCA Civ 164

Case No: B4/2020/0192

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE FAMILY DIVISION
MRS JUSTICE LIEVEN
FD19P00674

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 14/02/2020

Before :

THE PRESIDENT OF THE FAMILY DIVISION
LORD JUSTICE PATTEN
and
LADY JUSTICE KING

- -

Re M (Declaration of Death of Child)

- -
- -

Lord Brennan QC and **Bruno Quintavalle** (instructed by **Barlow Robbins**) for the **Applicant Appellant**
Neil Davy (instructed by **Hill Dickinson Solicitors**) for the **Respondent**

Hearing dates : 6th and 12th February 2020

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Approved Judgment

Sir Andrew McFarlane P :

1. This application for permission to appeal concerns the tragic consequences that have followed the difficult birth of a baby boy on 18 September 2019.

2. Following a normal, full-term pregnancy the child's mother went into labour on the way to hospital. There was, unfortunately, a prolapse of the umbilical cord, meaning that the cord dropped into the birth channel ahead of the baby and became trapped against the baby's body. The significant force of the process of birth impeded the functioning of the cord which was, prior to birth, supplying oxygen to the unborn child. As a result the flow of oxygen to the baby's brain was cut off for a significant period. At birth he had an undetectable heart rate and no respiratory output. His heart was restarted, but he was immediately placed on a ventilator in the neonatal intensive care unit (NICU).

3. In accordance with established medical procedure, and following two "death by neurological criteria" ("DNC") assessments, the treating doctors concluded that by 20:01 on 1 October 2019 irreversible brain stem death had occurred and the child was, therefore, clinically dead.

4. Despite the apparent finality of that conclusion, the child's body has remained connected to the NICU ventilator, his heart has continued to beat, and he has been fed. He has gained weight. From time to time some movement of his limbs is detected. In consequence the child's parents do not accept that their baby is dead. They therefore oppose the plan of the Manchester University NHS Foundation Trust ("the Trust"), who are responsible for the hospital, and who seek permission to turn the ventilator off and disconnect it.

5. In consequence of the dispute between the parents and the Trust, the Trust issued an application in the Family Division of the High Court on 26 November 2019 seeking a declaration in the following terms:

> "Midrar Namiq has no capacity to consent to, to refuse, or to make decisions about the medical treatment he should receive, namely the administration of mechanical ventilation.
>
> It is lawful for Manchester University Hospital NHS Foundation Trust to make arrangements for his mechanical ventilation treatment to be withdrawn to allow him a kind and dignified death."

6. The application was heard by Mrs Justice Lieven over the course of three days in January 2020. The judge's reserved judgment was given on 28 January 2020. The judge concluded that the application made by the Trust should be granted and declarations were made in the following terms:

> "1. Midrar Namiq is a child under the age of eighteen having been born on 18/9/2019 whose interests have been represented within these proceedings by his guardian.

> 2. Midrar Namiq has no capacity to consent to, to refuse or to make decisions about the medical treatment he should receive, namely the administration of mechanical ventilation.
>
> 3. It is lawful for Manchester University Hospital NHS Foundation Trust to make arrangements for Midrar Namiq's mechanical ventilation treatment to be withdrawn."

7. The judge's order was stayed to permit the parents time to consider an appeal. Notice of appeal was filed on 30 January. On 31 January Lady Justice King adjourned the application for permission to appeal to a hearing of the full court with the appeal to follow if permission is granted. That hearing was initially listed on 6 February, but was adjourned (to allow the parents' leading counsel time for preparation) to 12 February 2020.

8. In addition to the substantive order, Lieven J also imposed a Reporting Restrictions Order preventing the publication of the identity of any of the medical professionals involved in the child's care. The parents' application for permission to appeal also seeks to challenge the Reporting Restrictions Order ("RRO").

Factual Background

9. Discussion between doctors employed by the Trust and the parents about the cessation of intensive care support commenced some three days after M's birth on 21 September. At that stage, and at all subsequent stages, the parents refused to agree to the withdrawal of treatment, referring to their religious beliefs as Muslims.

10. A number of medical tests were carried out. On 23 September an EEG showed:

> "…unreactive very low amplitude diffuse poorly formed much attenuated tracing which contains mainly ECG artefact and movement artefact. No clearly appreciated cerebral activity is noted. No sub-clinical or clinical seizure activity is seen…the findings give strong support to severe diffuse hypoxic encephalopathy."

11. On 24 September, an MRI scan was carried out which found "global brain injury affecting entire cortex and deep grey nuclei which would be supportive of prolonged insult…".

12. At the end of September, further discussions were held with the parents and they are recorded as saying that their Imam had advised them not to take Midrar off the ventilator, and that as long as his heart continues to beat they are hopeful of him getting better.

13. The recognised method for the clinical assessment of death in the United Kingdom involves two doctors evaluating a range of neurological criteria on two separate occasions in order to establish whether or not a patient is "brain stem dead". The process of assessing "death by neurological criteria" ("DNC") is described in two documents. Firstly, "*A code of practice for the diagnosis and confirmation of death*", dated 2008, produced by the Academy of Medical Royal Colleges. That code expressly stated that

it did not apply to babies under the age of two months. Subsequently, in April 2015 bespoke guidance was issued by the Royal College of Paediatrics and Child Health ['RCPCH'] which focussed upon "*the diagnosis of death by neurological criteria in infants less than two months old.*"

14. The first DNC test was undertaken by Dr E (Consultant Neonatologist) and Dr B (Consultant Paediatrician at the Trust's Paediatric Intensive Care Unit) on 1 October 2019, concluding at 20:01. The second test was conducted by the same two clinicians on 2 October 2019. Each element observed by each of the two doctors during each of the two tests indicated brain stem death. In accordance with the Code of Practice and the guidance, the date and time of death were therefore fixed at the conclusion of the first DNC test as 20:01 on 1 October.

15. Despite the apparent clarity of the DNC test results, the parents remained strongly opposed to turning off the ventilator. The Trust therefore sought an opinion from an independent consultant from a different hospital trust. Dr Y (Consultant Neonatologist) at Liverpool Women's Hospital was instructed. He examined Midrar and reviewed the clinical notes on 29 October and his opinion states:

> "Midrar has no prospect of recovery from his injury. He will not regain consciousness. He will not regain the ability to breathe independently or survive without mechanical ventilation. He has no perception of the world around him and this will not return.
>
> His heart and circulation continues to function only because of the mechanical ventilation he is receiving and the excellent clinical care that he continues to receive. This circulation is sustaining the function of his other organ systems, but his brain is not functioning and will not recover.
>
> Eventually, Midrar's other organ systems and his heart will also die as a consequence of this injury, even if mechanical ventilation is continued. He will eventually develop ventilator associated pneumonia. He will start to develop muscle wasting and joint contractures. It is likely that internal homeostasis will be disturbed as he no longer has central control of endocrine or autonomic functions. It may be possible to manage some of these complications by medical intervention. This is likely to require repeated reintubation of the trachea, chest physiotherapy and airway suction, repositioning and nursing care to maintain skin integrity, multiple blood tests, repeated venous cannulation and antibiotic administration, escalation of ventilator settings and oxygen administration and an increasing number of drugs to be administered.
>
> Midrar is unconscious and has no appreciation or perception of the world around him. I do not believe that he has the capacity to feel pain or distress, so this deterioration will not be distressing for him. It will however, be an undignified and unkind way to allow his death to take place. It will also place a significant burden of distress onto his family

> and onto those who are caring for him given the futility of these interventions and the associated unkindness."

16. On 4 November a third DNC test was undertaken in the presence of the parents (and at their request) by Dr B and, on this occasion, Dr M (Consultant Neonatal Intensivist). Dr G, the consultant in charge of the unit, was also present. The results of this third DNC test confirmed the findings of the earlier two tests, namely brain stem death.

17. On 5 November a further MRI scan was carried out which demonstrated "catastrophic appearances with interval brain liquefaction including brain stem supportive for brain stem death test. Complete effacement of intracranial CSF [cerebral spinal fluid] spaces including ventricles and cisterns." In other words, in contrast to the MRI scan on 24 September, some six weeks earlier, by 4 November part of the baby's brain had degraded to the extent that a significant proportion had turned to liquid.

18. In her evidence, Dr G described the physical presentation of Midrar's head as it was in early January:

> "Midrar's brain continues to deteriorate. He now has obvious overlapping of his skull bones as his brain shrinks. His head circumference measurement today [3 January 2020] is 38.1 cm; which is smaller than the first head circumference of 39.1 cm measured on 27.9.19 at 9 days of age."

The court process

19. The Trust's application was made on 26 November 2019. The matter came before Mr Justice MacDonald on 17 December on which occasion detailed directions were given for a full hearing to take place before Mrs Justice Lieven starting on 20 January 2020. In particular the child was joined as a party to the proceedings and an officer from Cafcass was appointed to act as children's guardian.

20. The order of 17 December noted that the parents were indicating an intention to identify additional experts to provide opinion evidence. MacDonald J directed that any such application must be filed and served by 9 January 2020.

21. The case came before Lieven J for directions on 14 January. It was at that hearing that the parents, through their counsel, Mr Bruno Quintavalle, applied to adjourn the main hearing so that they could instruct an independent expert. That application was refused. On the first morning of the hearing on 20 January, Mr Quintavalle renewed his application for an adjournment which was, again refused by Lieven J in a recent judgment. The parents' application for permission to appeal against that decision was promptly made and refused by Lord Justice Moylan on 21 January. The full hearing therefore went ahead and, as I have recorded, judgment was given on 28 January granting the Trust's application.

22. Pausing there, it is potentially a matter of significant concern that a case of this nature involving a baby who has been certified as dead on 1 October 2019 was not concluded before the High Court until some four months later. That is a topic to which I will return at the conclusion of this judgment.

The issue

23. Lieven J correctly identified the issue to be determined by the court as whether Midrar is dead, according to the DNC tests and the relevant clinical guidance and, if so, whether the ventilator can be removed.

24. In contrast to issues concerning the medical treatment of the living, whether they be children or adults who lack capacity, where the best interests of the individual will determine the outcome, where a person is dead, the question of best interests is, tragically, no longer relevant.

The 2008 Code

25. The Academy of Medical Royal Colleges is the coordinating body for the 24 Medical Royal Colleges and Faculties for the United Kingdom and Eire. The 2008 Code of Practice for the diagnosis and confirmation of death ("the 2008 Code") was prepared by a sixteen-strong working party following extensive consultation. The 2008 Code endorsed and built upon a 1991 "report of a working party of the British Paediatric Association on the diagnosis of brain stem death in infants and children" together with an earlier code published in 1998. On its publication the 2008 Code was welcomed and endorsed by the then Chief Medical Officer (Sir Liam Donaldson) as providing "clear, scientifically rigorous criteria for confirming death". The authors of the Code stress that it is a statement of current practice which does not (and could not) seek to provide guidance for every single clinical situation where a doctor is required to diagnose death.

26. In section 2 of the 2008 Code "death" is defined as follows:

> "Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breath. This may be secondary to a wide range of underlying problems in the body, for example, cardiac arrest."

27. Section 2 goes on to further define the two overarching categories in which death may be diagnosed:

> (1) death following the irreversible cessation of brain-stem function;
>
> (2) death following cessation of cardiorespiratory function.

28. With respect to (1), death following the irreversible cessation of brain-stem function, the Code states:

> "the irreversible cessation of brain-stem function whether induced by intra-cranial events or the result of extra-cranial phenomena, such as hypoxia, will produce this clinical state and therefore irreversible cessation of the integrative function of the brain-stem equates with the death of the individual and allows the medical practitioner to diagnose death."

29. The Code draws attention to three aspects which should be noted:

> "First, the irreversible loss of the capacity for consciousness does not by itself entail individual death. Patients in the vegetative state (VS) have also lost this capacity (see section 6.9). The difference between them and patients who are declared dead by virtue of irreversible cessation of brain-stem function is that the latter cannot continue to breathe unaided without respiratory support, along with other life-sustaining biological interventions. This also means that even if the body of the deceased remains on respiratory support, the loss of integrated biological function will inevitably lead to deterioration and organ necrosis within a short time.
>
> Second, the diagnosis of death because of cessation of brain-stem function does not entail the cessation of all neurological activity in the brain. What does follow from such a diagnosis is that none of these potential activities indicates any form of consciousness associated with human life, particularly the ability to feel, to be aware of, or to do, anything. Where such residual activity exists, it will not do so for long due to the rapid breakdown of other bodily functions.
>
> Third, there may also be some residual reflex movement of the limbs after such a diagnosis. However, as this movement is independent of the brain and is controlled through the spinal cord, it is neither indicative of the ability to feel, be aware of, or to respond to, any stimulus, nor to sustain respiration or allow other bodily functions to continue.
>
> In short, while there are some ways in which parts of the body may continue to show signs of biological activity after a diagnosis of irreversible cessation of brain-stem function, these have no moral relevance to the declaration of death for the purpose of the immediate withdrawal of all forms of supportive therapy. It is for this reason that patients with such activity can no longer benefit from supportive treatment and legal certification of their death is appropriate."

30. With respect to (2) death following cessation of cardiorespiratory function, the Code states:

> "**2.2 Death following cessation of cardiorespiratory function**
>
> For people suffering cardiorespiratory arrest (including failed resuscitation), death can be diagnosed when a registered medical practitioner, or other appropriately trained and qualified individual, confirms the irreversible cessation of neurological (pupillary), cardiac and respiratory activity. Diagnosing death in this situation requires confirmation that there has been irreversible damage to the vital centres in the brain-stem, due to the length of time in which the circulation to the brain has been absent."

31. Appendix 1 of the 2008 Code establishes a template form that is to be completed by two appropriately qualified doctors. It is headed "Procedure for the diagnosis and confirmation of cessation of brain-stem function by neurological testing of brain-stem reflexes". On the form each of the two doctors is to answer each of the following eight questions:

- Do the pupils react to light?

- Are there corneal reflexes?
- Is there eye movement on caloric testing?
- Are there motor responses in the cranial nerve distribution in response to stimulation of face, limbs or trunk?
- Is the gag reflex present?
- Is there a cough reflex?
- Have the recommendations concerning testing for apnoea been followed?
- Were there any respiratory movements seen?

32. At paragraph 6.1.6 the Code is plain to stress that "the process for testing the respiratory response to hypercarbia (apnoea test) should be the last brain-stem reflex to be tested and should not be performed if any of the preceding tests confirm the presence of brain-stem reflexes". The test involves optimising the oxygen saturation in the patient's blood before disconnecting the ventilator and attaching an oxygen flow. The patient's condition is then observed for five minutes. If, after that time, there has been no spontaneous respiratory response, a presumption of no respiratory centre activity will be documented on the form together with a further confirmatory arterial blood gas sample to ensure that there has been an increase in the partial pressure of carbon dioxide in the blood from the starting level established prior to the test.

33. The 2008 Code is explicit (at paragraph 6.2) that it does not apply to children under the age of two months.

34. The 2008 Code is clear that death can be diagnosed by establishing the cessation of brain-stem function through the observation of the eight physical elements itemised at paragraph 31 above. No additional tests are required:

> "**6.7 Investigations**
>
> The accuracy of the clinical criteria for the diagnosis of death as a result of cessation of brain-stem reflexes over the past thirty years provides justification for not including the results of neurophysiological or imaging investigations as part of these criteria. However, death cannot be diagnosed by the testing of brain-stem reflexes alone in instances where a comprehensive neurological examination is not possible (e.g., extensive facio-maxillary injuries, residual sedation and some cases of paediatric hypoxic brain injury). … In such cases a confirmatory test may reduce any element of uncertainty and possibly foreshorten any period of observation prior to formal testing of brain-stem reflexes.
>
> The various tests available, together with an assessment of their relative benefit and complexity, are listed in Appendix 3."

35. Appendix 3 lists a number of specific tests designed to establish blood flow in the larger cerebral arteries, brain tissue perfusion or aspects of neurophysiology. In this latter category testing by an electroencephalogram ("EEG") is included; its "reliability-accuracy" is listed as "mixed".

36. Finally, the 2008 Code advises that problems related to the diagnosis and management of the vegetative state (VS) must not be confused with those relating to death:

> "Brain-stem death is not part of the VS, which has been defined as a clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and opening which may simulate sleep and waking."

The 2015 guidance

37. The lacuna left open by the 2008 Code, which expressly does not relate to babies under the age of two months, was filled by the publication of guidance by the UK Royal College of Paediatrics and Child Health in 2015. The 2015 guidance states that the method of diagnosis endorsed in the 2008 Code "can be confidently used in infants from 37 weeks corrected gestation (post menstrual) to two months post term." However, in view of the immaturity of the new-born infant's respiratory system a further precautionary measure is advised regarding the apnoea test so that a stronger hyper-carbic stimulus is used to establish respiratory unresponsiveness. Finally, the 2015 guidance is, in common with the 2008 Code, explicit in stating that "ancillary tests are not required to make a diagnosis of DNC in infants from 37 weeks corrected gestation (post menstrual) to two months post term."

The legal context

38. In the United Kingdom, there is no statutory definition of death. In the few reported cases in which the issue has been raised, the courts have, from at least 1992 onwards, accepted the validity of the medical diagnosis arising from an irreversible absence of brain stem function.

39. In the House of Lords decision in *Airedale NHS v Bland* [1993] AC 789 the medical consensus that death was to be diagnosed by an absence of brain stem function was expressly endorsed. Firstly, in the speech of Lord Keith (page 856):

> "In the eyes of the medical world and of the law a person is not clinically dead so long as the brain stem retains its function."

And in the speech of Lord Goff (page 863):

> "I start from the simple fact that, in law, Anthony is still alive. It is true that his condition is such that it can be described as a living death; but he is nevertheless still alive. This is because, as a result of developments in modern medical technology, doctors no longer associate death exclusively with breathing and heartbeat, but it has come to be accepted that death occurs when the brain, and in particular the brain stem, has been destroyed.

> …There has been no dispute on this point in the present case, and it is unnecessary for me to consider it further. The evidence is that Anthony's brain stem is still alive and functioning and it follows that, in the present state of medical science, he is still alive and should be so regarded as a matter of law."

And, finally, by Lord Browne-Wilkinson (page 878E):

> "Recent developments in medical science have fundamentally affected these previous certainties. In medicine, the cessation of breathing or of heartbeat is no longer death. By the use of a ventilator, lungs which in the unaided course of nature would have stopped breathing can be made to breath, thereby sustaining the heartbeat. Those, like Anthony Bland, who would previously have died through inability to swallow food can be kept alive by artificial feeding. This has led the medical profession to redefine death in terms of brain stem death, i.e., then death of that part of the brain without which the body cannot function at all without assistance. In some cases it is now apparently possible, with the use of the ventilator, to sustain a beating heart even though the brain stem, and therefore in medical terms the patient, is dead; "the ventilated corpse"."

40. In *Re A* [1992] 3 Med LR 303 Mr Justice Johnson, sitting in the High Court Family Division, made a declaration that a 19 month old child was "dead for all legal, as well as medical, purposes." In doing so, Johnson J held that, in consequence of the conclusion as to the child's death, it was not possible for the court to exercise the inherent jurisdiction that it would have over a live child either as a ward of court or otherwise. He did, however, hold that the court retained jurisdiction to make a declaration as to death and to declare that it would not be unlawful for the ventilator to be disconnected.

41. In more recent times there have been two cases in which judges of the Family Division have been called upon to make a declaration of death. Firstly, Mr Justice Hayden in *Re A (A Child)* [2015] EWHC 443 (Fam) and, secondly, Mr Justice Francis in *Oxford University NHS Trust v AB and others* [2019] EWHC 3516 (Fam).

42. The judgment of Hayden J in *Re A* merits close scrutiny as it establishes, in my view, the correct structure for dealing with sensitive applications of this nature.

43. The case involved a 19 month old healthy boy who choked on a tiny piece of fruit that became lodged in his throat. He became unconscious and, thereafter, suffered catastrophic brain damage through a lack of oxygen which, in turn, led to cardiac arrest. In accordance with the practice under the 2008 Code brain stem death was established as at 10 February 2015. It is of note that judgment was given by Hayden J two days later on 12 February.

44. Hayden J was impressed by the evidence of Dr Stephen Playfor, a Consultant Paediatric Intensivist, who explained the significance of brain stem death in clear non-technical

terms which are usefully and succinctly summarised by Hayden J in paragraph 11 of his judgment:

> "Dr Playfor…told me brain stem death does not equate to the death of the whole brain. There are studies that demonstrate that you can have electrical activity in some areas of the brain after brain stem death is established. The key point, he said, is that no patient has ever regained consciousness or awareness following brain stem death. Dr Playfor went on to explain the reason for that in language which I found to be simple and accessible. The nerves which generate the breathing mechanism and maintain the integrity of the heartrate are all connected to the brain stem. In simple terms, when the brain stem dies, it is impossible for a patient to breath unassisted."

45. The importance of that description in the context of the application that is at present before this court, is that Lord Brennan QC, for the parents, has drawn attention to the fact that the diagnosis of death in America, Canada, Australia and elsewhere is not based upon brain stem death, as it is in the UK, but relates to the wider concept of "whole brain death".

46. Hayden J held that the High Court, Family Division under its parens patriae and/or inherent jurisdictional powers had jurisdiction over the child's body and could exercise that jurisdiction to make declaratory relief both as to the state of death and any consequential matters, such as the removal of the body from a ventilator.

47. In concluding his judgment, and after expressing his profound respect for the father's opposing views, Hayden J stated "the time has now come to permit the ventilator to be turned off and to allow Child A, who died on 10 February, dignity in death."

48. This court is grateful to Hayden J who has provided a copy of the declarations made by the court in *Re A* which are as follows:

> "It is declared that:
>
> 1. [The child] died at 10.10 hrs on the 10 February 2015, irreversible cessation of brain stem function having been conclusively established; he having lost the essential characteristics necessary to the existence of a living human person namely (i) the irreversible loss of the capacity for consciousness (i.e. a permanent absence of consciousness), along with the (ii) irreversible loss of the capacity to breath; thus the inevitable and rapid deterioration of integrated biological function.
>
> 2. Permission to a consultant or other medical professional at [the hospital] to (1) cease to mechanically ventilate and/or to support the respiration of [the child] and (2) extubate [the child] (3) cease the administration of [medication] to [the child] and (4) not attempt any cardio or pulmonary

> resuscitation upon [the child] when cardiac output ceases or respiratory effort ceases.
>
> The action(s) and/or inaction(s) of the clinicians employed by the [hospital], as described in paragraph 2 above, are lawful."

49. In *Oxford University NHS Trust v AB* a fourteen year old girl, AB, had been found hanging following an apparent suicide attempt in the family home on 17 October 2019. She was declared dead in accordance with the DNC criteria at 10.26 on 22 October. Francis J gave judgment on 25 October. In doing so he relied upon the approach taken by Hayden J in *Re A*. The judge was fully satisfied by the medical evidence submitted by the treating clinician. He declared that the criteria for death had been established and "that it is lawful and in AB's best interests for all care and treatment to be withdrawn." By referring to "best interests" in the course of what was obviously an ex tempore judgment given in the most fraught circumstances, I consider that Francis J inadvertently fell into error. Once death has been established, then the concept of "best interests" no longer has any legal relevance.

The Judge's Judgment

50. Despite the wording of the declaration set out in the Trust's application which sought authority for "treatment to be withdrawn to allow him a kind and dignified death", Lieven J correctly identified that "the issue I have to decide is whether Midrar is dead, according to DNC as set out in the relevant clinical guidance, and therefore the ventilator can be removed".

51. In the early stages of her judgment Lieven J summarised the factual background, including each of the clinical tests that had been undertaken, the relevant guidance and the law represented by the two recent decisions of *Re A* and *Oxford University NHS Trust v AB* before turning to the respective positions of the parties. The Trust's position was straightforward, relying upon the Code and the case law to hold that a declaration of death was the inevitable conclusion of the legal process. The Trust's position was supported by Cafcass who represented the interests of the child. The primary submission in law of Mr Bruno Quintavalle, junior counsel who acted for the parents before the judge and also before this court, was that Hayden J had been in error when deciding *Re A*. His submission was that in medically complex cases such as these it was inappropriate for the court to deal with the case on a fact-finding basis, but, instead, the court should apply a best interests analysis.

52. The submission in law made by Mr Quintavalle was rejected by the judge. She held (paragraph 31):

> "The test for whether a patient is dead is in the first instance one for medical professionals. When the patient is in the tragic situation of someone like Midrar the relevant clinical tests are those set out in the 2008 Code, in particular section 6. This was the approach of Hayden J in *Re A (A Child)* and followed by Francis J in *Re AB*. I do not think that Francis J was differing from Hayden J, and he plainly did not think so.

> That the legal question is one of the application of the DNC criteria follows from previous authority and the terms of the Code. It also makes complete sense. If a patient is brain stem dead then there is no best interests to consider. Once those criteria are met the patient has irreversibly lost whatever one might define as life; and any other functions (such as the heart continuing to beat) have "no moral relevance", as the Code says at paragraph 2.1."

53. There is no application to appeal the judge's decision on this point.

54. Lieven J went on to analyse the medical evidence and the evidence that the father had presented describing various movements that had been observed, and on occasion filmed, in the child's body after the medical diagnosis of death.

55. The judge made it clear "that all four of the medical witnesses were in my view eminently well qualified to give the evidence they did. Their evidence was entirely clear and consistent, and none of them had any doubt that Midrar was brain stem dead and that he was not capable of breathing."

56. The judge rejected two specific submissions made by Mr Quintavalle which are not pursued on appeal before turning to a third, which is:

> "45. The third issue is that Mr Quintavalle argues that the DNC tests could only be carried out if the parents had given fully informed consent. He relies on *Glass v UK* [2004] ECHR 103 to argue that the tests would be invalid without such consent. In my view this argument is wrong for a number of reasons. Firstly, the parents were aware that the tests were going to be carried out probably that day, as is shown by the transcript of the conversation with Dr E, and the Father did ultimately accept this. The transcript does not suggest that the Father or Mother said the tests should not go ahead. Further, the parents were fully informed as to the purpose of the tests, so in my view the issue about "informed" consent goes nowhere on the facts of the case. Secondly, I do not think there is any requirement for written consent from the parents, or for the information to be written down. There is no such requirement in the Code. *Glass* is dealing with a very different situation, where the issue was the withdrawal of certain treatment. It is not clear to me that consent would necessarily have to be given for a test at all. But, I do not have to decide that issue because the parents undoubtedly knew that the test was to be carried out, and knew what the test was about. Therefore they were given the appropriate information, and on the facts of the case their consent can be inferred from their conduct. Thirdly, and in any event, even if the tests should not have taken place because of lack of consent that does not mean that the outputs of the test would not be admissible before me. I am being asked to decide a factual question as to whether Midrar is dead, and lack of consent would not vitiate the evidence that goes to that issue."

57. The judge then turned to the final issue arising from the undisputed evidence that movements were seen in the limbs and eyes of the child's body from time to time. She records that the medical evidence was clear that these were no more than reflexes generated in the spinal cord and, secondly, did not relate to any attempt by the child to breath.

58. Having reviewed the medical evidence the judge observed (paragraph 56):

> "Midrar's body will continue to grow as long as he remains on the ventilator and is fed. However, Dr G explained that his head is shrinking because his brain is contracting. She was entirely clear that in a baby who had suffered a serious brain injury, but was not brain stem dead, the brain would continue to grow, albeit potentially more slowly than would normally be the case."

59. Lieven J therefore concluded that she had no doubt that Midrar was brain stem dead and met the DNC criteria which had been applied in accordance with the law established in *Re A* and in accordance with the 2008 Code and the 2015 guidance. The judge therefore made the declarations that were sought.

60. Pausing there, it is informative to compare the declarations made in this case with those made by Hayden J in *Re A*. For my part, I consider that the form of words used in *Re A* is to be preferred. The declaration made by a court in cases such as this should (where the evidence establishes the case) expressly declare that the individual has died at a particular time and date before going on to give permission and declare that it is lawful for ventilation and other clinical interventions to be withdrawn. Further, I regard the formulation adopted by Hayden J at paragraph 26 of his judgment to be particularly apt in identifying the purpose of the declarations which are to allow the individual who has died "dignity in death".

The application for permission to appeal

61. This court is grateful for, and impressed by, the clarity of the submissions prepared by Mr Quintavalle, who was responsible for the presentation of the Appellant's application for permission to appeal prior to the late grant of legal aid allowing for the instruction of leading counsel. Mr Quintavalle's skeleton argument identifies five Grounds of Appeal as follows:

> 1. The learned judge erred as a matter of fact and law in concluding that Midrar is legally dead and that therefore there was no need to conduct a best interests assessment.
>
> 2. The learned judge erred as a matter of fact and law in holding that consent had been given for the first two DNC assessments and therefore failed to exclude those DNC assessments as evidence.
>
> 3. The trial considered in its entirety did not satisfy the requirements of ECHR, Article 6.1. The learned judge unjustly denied the parents the opportunity to instruct their own expert evidence.
>
> Re: Reporting Restrictions Order
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> 4. The learned judge erred in law in conducting a balancing exercise in the absence of evidence.
>
> 5. If the learned judge was entitled in the absence of evidence to proceed to conduct a balancing exercise, she nonetheless

erred in law in placing incorrect weight on the following factors:

1. Article 8 Rights of clinicians and witnesses
2. Article 6 and Article 6 and Article 10 Rights of the public
3. Article 10 Rights of the parents
4. Article 10 rights of persons affected.

62. In presenting the parents' case at the oral hearing, Lord Brennan, whilst not abandoning the pleaded grounds, understandably focussed his submissions on Ground 1. In doing so he made the following two overarching submissions relating to the underlying principles.

63. Firstly, Lord Brennan submitted (at paragraph 7 of his skeleton argument) that:

> "The appropriate judicial approach is to determine whether the medical practice relied upon is accepted by a responsible body of relevant medical opinion; and then whether it is reasoned and logical; and then whether it reasonably and reliably reflects an acceptable risk/benefit for the child namely in a death case where the loss of consciousness and breathing are irreversible, i.e. not reversible nor alterable in time to come, so that the decision to stop mechanical ventilation must be based on a secure, safe and firm based conclusion of irreversibility due to brain stem death such that there is no alternative but an order to stop mechanical ventilation. That requires careful, detailed and objective assessment of the medical practice relied upon."

64. Secondly Lord Brennan submits that, for that approach to be both responsible and reasonable, regard should be had to the medical practice in relation to brain stem injury and death in other countries. In seeking to make good that submission, the court was taken to detail relating to the approach adopted in the USA which differs from the UK 2008 Code in at least two significant respects. Firstly, rather than relying on a diagnosis of brain stem death, in America clinicians are required to identify the death of the "whole brain". Secondly, the authoritative document in the USA on this issue, mirroring the status of the 2008 Code in the UK, is a White Paper by the President's Council on Bioethics "Controversies in the determination of death" published in December 2008. As well as advocating diagnosis by "whole brain death", rather than brain stem death, the White Paper requires the administration of "confirmatory tests" which "go beyond the bedside checks for apnoea and brain stem reflexes" represented by the UK DNC Code. Lord Brennan has assisted the court by referring to various articles in the medical literature and we have been provided with a copy of the 2008 US White Paper.

65. In addition to the overarching submissions, Lord Brennan made a number of discrete points. Firstly, in relation to additional tests that might have been undertaken over and above the bedside DNC assessment required by the 2008 Code, Lord Brennan referred to Appendix C of the Code which lists some nine additional tests. In the present case Midrar had in fact undergone two MRI scans and an EEG and Lord Brennan submitted that if the doctors thought it was alright to undertake an MRI, why was it not reasonable

to do all of the other tests. The issue before the court is whether the child's condition is irreversible. Given the consequences of the decision surely, it is submitted, the court has a duty to be satisfied that every reasonable test has been undertaken.

66. Secondly, Lord Brennan submitted that the DNC test for apnoea was seen as controversial in the medical literature and it was therefore necessary to determine the degree of brain tissue perfusion by administering one or more of the three relevant mechanical tests listed in Appendix 3 of the Code. Lord Brennan asked, rhetorically, "why not?" undertake these tests for brain perfusion.

67. In so far as the three previously decided High Court authorities had relied upon a diagnosis based upon brain stem death, those cases were to be distinguished on the facts from the present case as, in each case, the evidence indicated that the child would be diagnosed as dead on a more widely based definition.

68. Lord Brennan took Ground 2 relating to an asserted absence of consent to the two DNC tests, shortly. He was right to do so, and it is convenient to deal with the application for permission to appeal on this Ground now. For the reasons given by Lieven J, there is no merit in this point. In addition, for the benefit of the parents, a second opinion was sought by Dr Y who, while he did not conduct her own specific DNC tests, confirmed the validity of those undertaken in early October. Finally, at the parents' express request, a third DNC test was undertaken in their presence on 4 November. The parents plainly consented to these further tests. In the circumstances, I would, therefore, refuse permission to appeal on Ground 2.

69. Ground 3, relating to the assertion that the parents were "unjustly denied…the opportunity to instruct their own expert evidence" was similarly taken shortly by Lord Brennan and can be determined at this point.

70. On one basis, this Ground cannot proceed as it has already been the subject of a targeted application for permission to appeal made during the course of the trial and refused by Moylan LJ on 21 January. However, the Ground now has even less merit in the light of the fact that, after the conclusion of the hearing before Lieven J, and in yet a further attempt by the Trust to meet the parents concern, the parents' chosen expert, Professor Wilkinson, attended Midrar and conducted a thorough assessment on 30 January. Professor Wilkinson's report, of the same date, indicates that it was prepared for the purposes of a possible appeal and provided at the request of the parents' legal team.

71. Professor Wilkinson is a Consultant Neonatologist based at the John Radcliffe Hospital Neonatal Unit in Oxford. He is the clinical lead for bereavement and palliative care in the newborn care unit at that hospital. He is also a Professor of Medical Ethics at the University of Oxford. He has written a textbook on the topic of prognosis and decision-making for critically ill children published in 2013. He was a member of the RCPCH working group behind the 2015 guidance. It is plain that he has a high level of professional expertise and experience which is of direct relevance to the issue in these proceedings.

72. In his report, Professor Wilkinson states that his own neurological assessment conducted on 30 January was consistent with the previous DNC assessments. He did not formally conduct a DNC assessment himself, however, he reported that Midrar had absent pupillary light response, corneal reflex, cough/gag reflex or response to pain.

During his visit the ventilator set rate was reduced to twelve breaths per minute. No spontaneous breaths were observed in between the set ventilator breaths. Professor Wilkinson concluded:

> "It is my opinion that Midrar's assessments for DNC were conducted in accordance with the 2015 guidelines on the diagnosis of death by neurological criteria, that he met those criteria and that therefore the Trust were justified in diagnosing him with brain death. I could find no clinical evidence that cast a doubt on that diagnosis."

73. Moving on, Professor Wilkinson concluded that there was no reasonable role for any further brain imaging or testing and he noted the relatively recent EEG carried out on 7 January which failed to detect any cortical electrical activity over a period of one hour.

74. Responding to a request to advise upon any further available treatment Professor Wilkinson stated:

> "Given the profound structural changes in Midrar's brain with liquefaction of large areas of his brain, it seems vanishingly unlikely to me that any treatment that might be developed within the short to medium term could benefit him."

75. Professor Wilkinson took time to watch videos of Midrar that had been recorded by the father demonstrating periods of partial eye opening and other movement. He concluded that "having carefully reviewed these events and Midrar in person, my opinion is that these events represent spinal or sympathetic reflex activity."

76. Professor Wilkinson set out his conclusions in two final paragraphs:

> "In summary, my expert assessment leads me to believe that baby Midrar's diagnosis of death on the basis of neurological criteria was conducted in accordance with current UK guidance, and that he continues to meet those criteria.
>
> I was not asked to make an assessment of Midrar's best interests. However, given that he meets criteria for death on the basis of neurological criteria, that he has irreversibly lost the capacity for consciousness and respiration, it is clear that he cannot benefit from continuing mechanical ventilation. Consequently it is not in his best interests to receive such treatment."

77. It is surprising that, despite that very clear report, supplied to the parents' legal team for the purpose of the proposed appeal, legal aid was granted and extended to leading counsel.

78. It is clear that any basis for complaint that might have provided some merit for Ground 3 evaporated once the parents' chosen expert was permitted full access to the medical files and given the facility of conducting a full examination of Midrar. I would therefore refuse permission to appeal on this Ground.

79. Grounds 4 and 5 relate to the Reporting Restrictions Order and I will deal with those separately at the conclusion of this judgment.

80. In response to the Appellants case on Ground 1, Mr Davy for the Hospital Trust drew attention to the fact that the apnoea tests were conducted in accordance not only with

the DNC Code, but with the 2015 guidance which for infants of this age require higher oxygen levels which are, in fact, equivalent to those required in the USA.

81. Mr Davy drew attention to paragraph 6.7 of the 2008 Code (set out at paragraph 34 above) which is clear in holding that no additional tests are required, save where the patient's circumstances prevent a full DNC analysis being undertaken. Further, the Code advises that the various tests listed in Appendix 3 are all prone to artifice and are described in the relevant literature as producing false positive and negative results. In any event, in this case, Midrar has undergone two MRI scans and one EEG. He submitted that there was no basis for holding that additional tests were therefore required.

82. Turning to Lord Brennan's submission based upon the need to test brain tissue perfusion, Mr Davy explained that perfusion refers to the tissue of the brain being perfused with blood and oxygen. In this case the MRI scan demonstrates that significant parts of the brain have liquified and are no longer comprised of tissue making the measurement of perfusion either irrelevant or impossible. Mr Davy took the court to the second statement of Dr G who advised that further imaging was not clinically indicated and would not add anything to that which is already known from the earlier imaging and tests. She advised that the MRI scan undertaken in early November, which showed liquefaction, demonstrated

> "disintegration of normal brain structures and no brain metabolite activity…indicating that the brain is no longer active or alive. It is not possible for the brain to regenerate itself once there has been liquefaction, disintegration of the normal brain structures and indications that the brain is no longer active or alive."

Strikingly, Dr G concluded in these terms:

> "The parents have stated that they would like to find out what part of the brain is working. I've explained to the parents that the brain structures are no longer recognisable as they have disintegrated/liquified and the brain stem is dead."

83. Mr Davy submitted that those short passages from Dr G's statement provide the answer to Lord Brennan's rhetorical question "why not" undertake further tests.

84. Mr Davy submitted that the test drawn up by Lord Brennan at paragraph 7 of his skeleton argument is based upon the test for establishing clinical negligence. Mr Davy questions the relevance of such an approach when the issue before the court was one of fact-finding and applying those facts to the medical expert evidence before the court. There was, he submitted, no room in the context of proceedings of this nature for a test based upon establishing negligence.

85. The Appellant's case is that the proper approach of a court in these cases is not to declare that the patient is dead, but, rather assume for legal purposes that the patient remains alive so that the court must conduct a best interests analysis. Whilst Mr Davy firmly argues against that approach, he invited the court to consider the position if a best interests analysis was required. In circumstances where the clinical diagnosis of brain stem death is not challenged by any of the grounds of appeal, and where the child has irreversibly lost consciousness and irreversibly lost the capacity to breathe, there could only be one outcome to any best interests assessment. In circumstances where

there is no challenge made to the judge's findings on these three essential elements, any suggestion that a best interests test might achieve a different outcome is unsustainable.

86. Mr Davy asserts that there is no basis for this court to hold that a different basis for the diagnosis of death other than brain stem death must now apply. The House of Lord's decision in *Bland* firmly established brain stem death as the necessary medical yardstick, and this court is bound by the authority in *Bland*.

87. In any event, in this case the evidence of the disintegration of Midrar's brain goes further than the DNC criteria. The extent to which the brain tissue has turned to liquid as demonstrated in the second MRI scan demonstrates whole brain death. If there are cases that lie in a grey area between the UK criteria and the diagnostic basis adopted by the USA and other countries, this case is, sadly, not one of them.

88. In reply Lord Brennan submitted that it was obvious that a duty of care arises where doctors are engaged in diagnosing death, hence his formulation based upon the law of negligence is entirely appropriate.

89. Lord Brennan was plain in response that he was not conceding that brain stem death had been established, as additional tests have not been undertaken.

Ground 1: Discussion and conclusion

90. Out of respect for the great importance of the issue in this case to the parents, I have set out the proposed Appellant's case under Ground 1 at length. Having done so, however, it is clear that the Ground is unarguable.

91. Firstly, as a matter of law, it is the case that brain stem death is established as the legal criteria in the United Kingdom by the House of Lord's decision in *Bland*. It is not, therefore, open to this court to contemplate a different test.

92. Secondly, as, I think, Lord Brennan accepted, it is, in reality, impossible for this court now to embark upon an assessment of whether a different test, namely that adopted in the USA, should replace the long established UK criteria represented, in modern times, by the 2008 Code and the 2015 guidance.

93. Thirdly, for the reasons given by Mr Davy, tragically the medical evidence demonstrates that this is not a case in which such difference as there is between "brain stem death" and "whole brain death" is relevant. It is not necessary to repeat the graphic descriptions of Dr G and Professor Wilkinson that have been given on the basis of the November MRI scan and the January EEG. The position is that, awfully, Midrar's body no longer has a brain that is recognisable as such.

94. Fourthly, there is no basis for contemplating that any further tests would result in a different outcome. The 2008 Code is plain that, medically, no further tests are normally required. In this case, further tests have, indeed, been undertaken and they not only confirm the DNC diagnosis but, as I have described, they take matters further by providing clarity as to the disintegration of the brain tissue.

95. Fifthly, the factual and medical evidence before the judge was more than sufficient to justify her findings. Indeed, no other conclusion was open to Lieven J on that evidence. Even if there had been room for doubt, that must surely now have been removed

following Professor Wilkinson's intervention on 30 January. Given his great expertise on this particular issue and his role as an expert instructed by the parents for the purpose of considering a potential appeal, his opinion, which is 100% on all fours with that of each of the other doctors and with the conclusion of the judge, must remove any basis upon which the diagnosis of death can be challenged.

96. Lastly, the judge said at [32] that "If a patient is brain stem dead then there are no best interests to consider. Once those criteria are met the patient has irreversibly lost whatever one might define as life…" I agree. Once a court is satisfied on the balance of probabilities that, on the proper application of the 2008 Code (and where appropriate the 2015 Guidance), there has been brain stem death there is no basis for a best interests analysis, nor is one appropriate. The court is not saying that it is in the best interests for the child to die but, rather that the child it already dead. The appropriate declaration is that the patient died at a particular time and on a particular date without more.

97. In so far however that the parents argue that this case should have been determined on a "best interests" basis, Mr Davy is right that the outcome of a best interests analysis could not produce any other outcome but approval for the removal of the ventilator. There is no evidential basis for Lord Brennan's submission that the matter should be remitted to the High Court for a 'best interests' hearing where expert evidence would be called.

98. I therefore conclude that the parents' case on Ground 1 is unarguable and has no reasonable prospect of success. Permission to appeal on that Ground is therefore refused.

Reporting Restrictions Order

99. Lieven J granted a Reporting Restrictions Order preventing the identification of any of the medical staff or other NHS Trust employees providing care to Midrar, or their families until further order. It is said that this encompasses some 370 individuals.

100. The judge found at [38], that a number of allegations made by the father at trial in relation to Midrar's care were untrue. In addition evidence in support of the making of a RRO came from Dr G who listed some six specific allegations that Midrar's father had made against the treating clinicians, or the hospital team more generally, which were said to be, and on the judge's findings were, untrue and which Dr G said were hurtful and, if repeated publicly, would be likely to cause the individual employees great distress and place them under further significant psychological pressure over and above that which has been experienced on the ward by those treating Midrar for the past four months.

101. Grounds 4 and 5 (set out at paragraph 61 above) relate to the RRO. It is submitted that, in so far as the judge made the order by identifying a class of professionals who should be protected, her decision was at odds with the approach described by Sir James Munby P in *A v Ward* [2010] EWHC 16 (Fam) and *Re J (A Child)* [2013] EWHC 2694 (Fam).

102. It is not necessary to descend to detail on this point in a judgment which is already overly lengthy when dealing with permission to appeal. In short terms, in the decade since Sir James Munby considered this matter the world has changed. The manner in which social media may now be deployed to name and pillory an individual is well

established and the experience of the clinicians treating child patients in cases which achieve publicity, such as those of Charlie Gard and Alfie Evans, demonstrate the highly adverse impact becoming the focus of a media storm may have on treating clinicians. The need for openness and transparency in these difficult, important and, often, controversial cases is critical but can, in the judgment of the court, be more than adequately met through the court's judgments without the need for identifying those who have cared for Midrar with devotion since September 2019.

103. Moving from the general to the specific, here the judge had evidence from Dr G of six specific untrue allegations that the father had made with respect to the hospital's care of his child. Parents no doubt say and do all manner of things in the tragic and difficult circumstances in which they find themselves in such cases. But the judge was entitled to be satisfied that there was a basis for this application being made in this particular case. The point that only one witness gave evidence, and that the court should have heard from the 369 other employees, only has to be stated for it to be seen to be devoid of merit.

104. In any event, the Respondent Trust has taken the view that it is likely that the potential for any adverse publicity will have significantly diminished once the ventilator has been disconnected and a short time has passed. They therefore would agree to a time limit being placed upon the RRO so that it would expire, subject to any further application, twenty eight days after the date upon which the ventilator is disconnected.

105. In the circumstances the proposed challenge with respect to the RRO has no reasonable prospect of success on appeal and permission to appeal on Grounds 4 and 5 is therefore refused.

Delay

106. At the beginning of this judgment I drew attention to the fact that some four months or more have expired since the diagnosis of death in early October. The court has now been given a detailed explanation for this passage of time. It is in part due to the Trust taking a number of steps, one after the other, aimed at engaging with the parents and achieving their consent, in order to avoid the need for court proceedings. Once the proceedings were issued, MacDonald J gave directions by email within twenty-four hours. He expressly took the view that this case should not come on for hearing urgently. In contrast to *Re A* and *Oxfordshire NHS Trust v AB*, where the parents were unrepresented in each of those two cases, MacDonald J gave time for an application for legal aid to be made, for the child to be joined, for Cafcass to become involved and, should they wish, for the parents to identify and seek leave to instruct an expert. Thereafter, the case was set down for hearing on the first available date following the Christmas vacation before Lieven J. It was heard in the North West in order to limit, at least to a degree, the practical difficulties for the parents.

107. In the circumstances, and certainly without any further investigation, it is not appropriate for this court to express criticism. Indeed, in a case which is not pressingly urgent, and, confirmation of a diagnosis of death is unlikely to be pressingly urgent, there is indeed merit in allowing a short but reasonable time for the parents to assemble a legal team and, if required, apply to instruct an expert.

108. In so far as the Trust chose to exhaust options one-by-one before issuing proceedings, including attempts at mediation, they are not to be criticised. However, in future cases, it should not be thought that the mere issue of an application to the court is such a negative step as to compromise other attempts to resolve the matter by way of second opinion, further tests or mediation. Indeed, in a proper case, where an early application is made, as well as adjourning to allow the parents to obtain legal representation, the court itself might direct and facilitate reasonable further testing and may encourage mediation.

109. I should be plain that the observations that I have made in the preceding paragraph are intended to be helpful, rather than directional. These are highly sensitive cases and each will turn not only on the facts of the case, but upon the personalities of the key family members involved.

Overall Conclusion

110. For the reasons that I have given, I would refuse permission to appeal on all 5 Grounds.

111. If My Lord and My Lady agree, the declaration made by Lieven J should be amended so that it accords with that given by the court in *Re A*.

112. The RRO is to be amended in accordance with the concession made by the Trust, so that it will expire twenty-eight days after the date upon which ventilation is removed, subject to either party having liberty to apply in the meantime.

113. Finally, although this is a judgment which concludes that permission to appeal should be refused, I direct that it be made available for reporting and wider dissemination given the importance of the issues raised and the fact that this is the first occasion that these matters have been ventilated at Court of Appeal level.

Lord Justice Patten

114. I agree.

Lady Justice King

115. I also agree.