Neutral Citation Number: [2022] EWHC 2422 (Fam)

Case No: FD22P04067

IN THE FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 28 September 2022

Before:

MR JUSTICE POOLE

- -

Between:

Guy's and St Thomas' NHS Foundation Trust

Applicants

- and -

(1) A (By his Children's Guardian)
(2) F
(3) M
(4) A Local Authority (Intervener)

Respondents

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- -

David Lawson (instructed by Hill Dickinson LLP) for the Applicant
Neil Davy (Instructed by Duncan Lewis) for the First Respondent
Victoria Butler-Cole KC and Arianna Kelly (instructed by Dawson Cornwell) for Second and Third Respondents
Kieran Pugh (instructed by Local Authority) for the Intervener

Hearing dates: 26-27 September 2022

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A Reporting Restriction Order has been made in this case which was heard in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the child who is the subject of the proceedings and members of their family, any individual having day-to-day care of or medical responsibility for the child and/or in the withdrawal of treatment from the child, and any clinician who has provided second opinions or advice to the Applicant Trust in the management of the child's care, treatment and/or diagnoses, must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Poole :

1. This case concerns the most sombre decision of whether life-sustaining treatment for a baby boy, A, should continue. The court is required to make that decision because his parents and those treating him cannot agree. A judge approaches a decision such as this with an open mind but is not free to apply his or her own moral views or religious beliefs. Rather, the judge is bound to apply existing legal principles.

2. A's parents, F and M, have been represented at this hearing by Victoria Butler-Cole KC and Arianna Kelly, recently assisted by Dawson Cornwell solicitors, and at earlier proceedings by Helen Mulholland and Irwin Mitchell solicitors, and in the Court of Appeal by Bruno Quintavalle, for no fees. It is no small commitment to represent parents in a case such as this and it is a testament to the legal profession that it should provide unpaid specialist services in this way.

3. A was born in April 2022. His initial progress was largely unremarkable until 10 June 2022, at the age of nine weeks, when he was found in a floppy and limp condition at home. An ambulance was called and he was transported to Queen Elizabeth Hospital, Accident and Emergency Department. He was stabilised there and then transferred to the Paediatric Intensive Care Unit (PICU) at the Evelina Children's Hospital (Evelina) in central London. The records indicate that he was in cardiac arrest when the paramedics arrived and despite resuscitation attempts his brain was starved of oxygen for approximately 32 minutes. On admission to the Evelina, A had fixed dilated pupils. He was neuro-protected for three days, meaning that he was kept cool and effectively anaesthetised. An MRI scan on 14 June 2022 showed "hypoxic ischaemic brain

injury, multiple intracranial subdural and subarachnoid haemorrhages and spinal cord abnormalities". He had therefore suffered a primary injury of intracranial bleeding and, secondary to that, severe hypoxic ischaemia.

4. Further investigations revealed multiple fractures and retinal haemorrhages.

5. Brain stem testing was performed on 17 to 19 June 2022 and death was declared at 1315 hours on 19 June 2022. A's parents would not consent to the discontinuation of mechanical ventilation and requested a second opinion. Two doctors from a different NHS Trust in London performed brain stem tests on 22 June 2022 and confirmed the declaration of death. Still the parents would not consent to the withdrawal of ventilation and so on 27 June 2022 the Trust made an application to the High Court for a declaration that A was dead. An initial directions hearing was held before Peel J on 28 June 2022 but a few days later on 1 to 3 July 2022 A was seen to attempt to breathe. The Trust, swiftly rescinded its own determination of brain stem death and applied to amend its application to seek, instead, a declaration that it was in A's best interests to withdraw treatment. At a hearing before Hayden J on 13 July 2022 permission to amend was given and a directions order made including the grant of permission to the parents and the Guardian jointly to instruct an independent expert witness – see *Guy's and St Thomas' v. A, B, C* [2022] EWHC 1873.

6. On 26 August 2022 Hayden J heard the Trust's application during which he received evidence from the instructed independent expert, Dr Brierley. The parents had had the benefit of pro bono legal representation at previous hearings but shortly before the hearing beginning on 26 August they lost that benefit and sought an adjournment. Hayden J refused the adjournment and proceeded to

conclude the hearing and make his determination. The Court of Appeal upheld the parents' appeal against the refusal to grant an adjournment - *Re: A (Withdrawal of Treatment: Legal Representation)* [2022] EWCA Civ 1221 - and remitted the Trust's application to the High Court. On 13 September 2022 I gave directions for further, updating evidence.

7. The Applicant Trust continues to apply for a declaration that it is in A's best interests to withdraw mechanical ventilation. The application is supported by A's Guardian but opposed by his parents. Notwithstanding the marked differences in their views as to what is in A's best interests, there is considerable mutual respect amongst the parties. The parents acknowledge that A has received exemplary care from healthcare professionals at the Trust. The Trust recognises the sincerity of the parents' concerns and beliefs and the care they have given to A during his time on the PICU.

8. As this brief introduction demonstrates, there are three unusual features of this case:

   i) In June 2022 A was found to have met the tests for brain stem death but in early July 2022 he started intermittently to breathe. The tests for brain stem death are no longer met but had the court determined the Trust's initial application on the evidence available before 1 July 2022, it may well have declared that A was dead.

   ii) Legal proceedings have been protracted by the amendment of the application and then the appeal. This is the second full hearing of the Trust's application for a declaration that it is in A's best interests to withdraw mechanical ventilation.

iii) Investigations into A's injuries have raised concerns that they may have been inflicted non-accidentally. The police arrested and then bailed the parents. An interim care order has been made in favour of the Local Authority which has intervened in this application.

9. In relation to those three features of the case, my approach is as follows:

i) I have to decide the application that is now before the court. The reliability of the brain stem death testing is not an issue for determination by this court. Nevertheless, the history of a clinical determination of brain stem death which has subsequently been rescinded is potentially relevant to the court's assessment of the current medical evidence and to the parents' views that the current medical consensus may also be proved to be wrong.

ii) Although Hayden J carried out a full assessment of A's best interests, the Court of Appeal has set aside his decision to refuse an adjournment. In the circumstances I hear this application afresh, uninfluenced by the determination that Hayden J made. In any event, I have received further evidence.

iii) Concerns that A's injuries are non-accidental will not affect my determination of what is in his best interests. Investigations are continuing, no admissions have been made and nothing has been proved. I cannot assume any particular outcome from those investigations. I shall assess A's best interests, including giving weight to his parents' views, as I would have done had no suspicion of non-accidental injury been

raised. Findings as to the cause of A's injuries will be for others to make in criminal or public family law proceedings.

10. At this hearing I received oral evidence from Dr Z, Consultant Paediatric Intensivist at the Evelina, Dr Y, Consultant Paediatric Neurologist at the Evelina, from Dr Brierley, independent expert Consultant Paediatric Intensivist, from F and M, from Dr T, who provided a second opinion to the Trust, and from the Guardian, Ms Gaywood. In the late afternoon on 26 September 2022, with the agreement of his parents, I visited A in the PICU at the Evelina, accompanied by Ms Gaywood. I am grateful to her and to the parents and the staff at the Trust for enabling the visit. As they have been since his admission to the PICU, F and M were at A's bedside. A lay absolutely still, beautifully dressed in bright colours.

Background

11. F and M have friends but no extended family in the UK. As well as A they have a six year old son who attends school. They wanted to leave a gap of some years before trying for another child. M's pregnancy with A was planned. He was born by elective Caesarean section. On discharge home after his birth he fed and slept well and began to smile. On my visit to see A in hospital, F and M showed me a photograph of A taken only three days before his admission to the PICU. He looked strong and healthy. A was seen regularly by the midwife and health visitor and was noted to be "generally well". He was reviewed for his eight week check up and immunisations on 8 June 2022 with no concerns. Then, at about

midday on 10 June 2022, F found A unresponsive and A was later admitted to the PCIU at the Evelina in the circumstances set out above.

12. There has been a series of brain scans and EEGs performed on A. Dr Y, Consultant Paediatric Neurologist at the Evelina, took the court through three sets of MRI scan images in the same axial, coronal and sagittal planes on successive dates: 14 June, 5 July, and 14 September 2022. The images show evolving and extensive changes to the parenchyma, the functional brain tissue. On the sagittal plane images for example, the majority of the light grey areas showing parenchyma on 14 June 2022 give way to dark grey areas showing cerebrospinal fluid on 14 September 2022 – the fluid has filled the spaces left by necrosed brain tissue. This is known as cystic encephalomalacia. I understand that the images do not demonstrate additional injury over time but rather the increasingly manifest effects of the devastating hypoxic ischaemic insult suffered by A's brain on 10 June 2022.

13. A's brain has suffered significant volume loss as tissue has died and his head circumference has reduced. On 11 August 2022 Dr Z and Dr T measured head circumference at 39.5 cms but on 14 September Dr Z measured it at 38 cm. The range of head size for a baby of A's age is 41-45 cm.

14. EEG tests have been performed over time also. Electroencephalograms (EEGs) measure electrical brain activity. The first EEG on 13 June 2022 was reported as being "markedly abnormal". Subsequent EEGs on 4 July, 11 July and 14 September 2022 have been reported by a Consultant Neurophysiologist and each shows an absence of recordable electrical activity, no response to stimuli,

and no seizures. This means that there has been no detectable electrical activity from A's brain for over two months.

15. Ventilation is provided for A through an endotracheal tube. A does not require much oxygen - about 20% - to maintain good oxygen saturation, but he does require very high ventilatory pressures – the highest having been 30 cmH_2O, and the current pressure being 28 cmH_2O. These high pressures are required because although he has flaccid limbs he has a rigid trunk: his neck, thorax and abdomen. He does not suffer spasticity, rather his abdomen and thorax are constantly rigid. This means that greater pressure is required to move the diaphragm down against the abdominal rigidity to allow for his lungs to fill with air. The muscle rigidity in the abdomen has pushed the diaphragm up in the chest, reducing left lung volume. The right lung, protected from similar upward pressure by the liver beneath it, has compensatory hyperinflation. The very high ventilatory pressures give rise to an ongoing risk of barotrauma to the lungs – they could "pop" as Dr Z put it. However, more recently there has been some slight softening of A's abdomen and a slightly lower ventilatory pressure at 28 cmH_2O. This is still a very high pressure and the truncal rigidity continues. It prevents A from being able to be lain prone.

16. The determination in June 2022 that A was brain stem dead followed application of the Academy of Royal Medical Colleges' document "A code of practice for the diagnosis and confirmation of death." There is no dispute that the criteria for "diagnosing" A's brain stem death set out in this document were met. The correct tests were performed. The correct procedures were adopted. There were no errors made by the clinicians who followed the code of practice. On 22 June

2022 critical care consultants from another London NHS Trust reached the same conclusions as those at the Applicant Trust that A was brain stem dead. However, at the beginning of July 2022, A started breathing and the declaration of death by the Trust was immediately rescinded. A would not meet the criteria for brain stem death now. It is reassuring to know that the application of the code to young babies such as A is being actively considered. I understand there to have been a few case studies reported worldwide in which breathing followed determinations of brain stem death in adults as well as children. I also understand that the onset of breathing did not herald good recovery and that the prognoses remained bleak for all those patients. Nevertheless, it is understandable that F and M should question the reliability of confident statements about A's prognosis given that they were told that their son's brain stem had died but he later started intermittently to breathe independently.

17. Having made no respiratory effort at all from admission, on the evening of 1 July 2022 A was noted to be making a hiccough type of sound. Then, on 2 July 2022, he started breathing. This was rhythmic and sustained although insufficient to consider extubation. This must have seemed to the parents at the time to be a miracle. Very sadly however, A's breathing has since deteriorated. On 19 August 2022 Dr Z took A off the ventilator and placed A on the anaesthetic circuit ensuring he was fully oxygenated. He made three breaths in four minutes. On repeating the exercise on 14 September 2022 A took three gasps (not breaths) in five minutes. Dr Brierley conducted similar exercises. On 28 July 2022 he disconnected the ventilator and noted a sustained respiratory effort by 2.5 minutes but insufficient to sustain life and therefore to consider liberation from mechanical ventilatory support. On 23 September 2022, Dr

Brierley disconnected A again and noted only two spontaneous breaths in three minutes, "far fewer than when I saw him in July". Although Dr Z noted gasps rather than breaths, the trajectory of deterioration in breathing is common to both her and Dr Brierley's observations.

18. A's baseline heart rate has reduced gradually over time. His heart rate would previously drop, sometimes to below 100 but that no longer happens. His heart rate is now stable at about 120 beats per minute but there is markedly reduced variability which is a poor prognostic factor.

19. A requires frequent deep suctioning of secretions. He has no cough or gag reflex and so cannot protect his airway. He undergoes deep suctioning as needed, usually at intervals of between one and four hours.

20. A has no corneal reflex and his eyelids do not close due to eyelid retraction. Nursing staff and his parents regularly apply lubricant to his eyes.

21. A has no control over his body temperature and easily becomes cold. He lies on a heated mattress and under an overhead heater and has two heated blankets.

22. A is fed through a nasogastric tube.

23. A's heart rate does not respond to interventions or handling. He shows no motor or autonomic response to central painful stimuli (elbow pressure). As noted the EEGs do not show any electrical activity in response to stimuli.

24. A is not sedated and is not administered any drugs. His extremely depressed neurological state is therefore not attributable to sedation.

25. A's parents keep a constant vigil at his bedside. Their older child is looked after by friends. He visits A on the PICU at weekends. The parents change A's nappies and clean him. They change his clothes. They keep a close eye on the monitors for signs of change. The medical personnel at the hospital speak highly of the parents' care for A. The parents speak highly of the medical, nursing and other staff at the hospital. Dr Brierley describes the care provided to A as exemplary.

Treating Clinicians

26. Dr Z is a Consultant in Paediatric Intensive Care at the Evelina. By her statements and her oral evidence at the hearing she showed great compassion for A and his family but she is clearly deeply troubled by the continuation of ventilation in this case. In that regard she spoke on behalf of the medical and nursing personnel at the Evelina who feel "moral distress" by reason of having to provide care that they consider to be unethical in the circumstances. Dr Z explained that A's case had not been referred to the Trust's ethics committee because it was not considered a borderline case requiring ethical guidance. The reasons why Dr Z and her colleagues consider that it is unethical to continue ventilation of A is because they consider that (i) it is burdensome to him to undergo interventions necessary to keep him alive such as ventilation and suctioning; and (ii) A has no prospect of any recovery – he will remain in deep unconsciousness and so whilst the interventions may prolong his life (or as Dr Z put it, prolong his death) the interventions will not benefit A.

27. Dr Z told the court that the ventilatory pressures required in A's case were so high that he could not be considered for treatment other than in the PICU. It would not be possible even to transfer him to a high dependency ward in a specialist paediatric hospital.

28. In Dr Z's opinion, A is unconscious with no awareness of the world around him and no prospect of recovery from his catastrophic brain injury. She said that she could not rule out that A could suffer pain – only he could tell us if he was able to do so. Interventions such as suctioning would be "noxious" to a baby who could feel pain. Certain features of A's case were unprecedented in her and her colleagues' experience. The MRI images from 14 September 2022 for example show brain tissue loss more extensive than they have previously seen. She was not able to give an informed explanation of A's truncal rigidity and recent slight softening because "we have never had a child like this before". It is unprecedented for her team to be treating a baby who was deemed to be brain stem dead three months ago.

29. Dr Y is a Paediatric Neurologist at the Evelina. She gave clear evidence about the MRI scans and EEGs. The MRI scan findings indicate reduced volume in many areas of the brain with injury to the cortex, brainstem, deep brain structures and the upper regions of the cervical spinal cord. She examined A on 15 September 2022: his pupils were fixed and dilated as they have been since admission to the PICU on 10 June 2022. Corneal and oculocephalic reflexes were absent. Upper and lower limbs were flaccid and reflexes were absent. Neck, chest wall and abdominal muscles were rigid. There was no response to stimuli – visual, touch or auditory – and there were no spontaneous movements.

Dr Y said that the clinical findings are entirely consistent with the EEG investigations and MRI scans: they demonstrate a catastrophic brain and brain stem injury with no possibility of repair or regrowth of the brain tissue which has been damaged and lost. Dr Y advised that there is no intervention or medication that could be offered to promote recovery. She did not think it possible that there could be any return to consciousness.

30. Dr Y was asked about A's capacity to enjoy pleasure and suffer pain. In her opinion A could not enjoy pleasure. The cortex has, as she put it, liquified, and so there could be no awareness. Awareness is, she suggested, necessary for a sensation of pleasure. In contrast, the relative sparing of the more primitive parts of the brain might allow for reflex responses to pain or discomfort which may be experienced subjectively by A. In her opinion A probably has no consciousness of pain or pleasure but experience of pain cannot be excluded.

Clinicians Giving Second Opinions

31. I heard from Dr T, a Consultant Paediatric Neurologist from an NHS Trust in the south west of England. He gave a second opinion at the request of the Applicant Trust. He assessed A at the Evelina on 26 July 2022 and has reviewed the records including the most recent MRI scan and EEG in September 2022. He was very frank in his oral evidence. The EEG investigations measure cortical activity and show that A has no neuronal activity because "his brain is dead". Dr T clarified that A still has some brain stem function but that the clinical evidence, the MRI scans, and EEG establish that "A has global injury. All his

functions - to see, to hear, to feel, to respond, to allow muscles of arms and legs to move, to achieve some sensory input - are all lost." He said further,

> " The [most recent] MRI scan supports the findings of the previous scans showing global injury affecting the entire cerebrum and shows changes which are cystic encephalomalacia reflecting the death of brain cells which the body converts into liquid and hence a cyst like structure forms. The dead part of the brain liquifies meaning there is no viable brain there."

He stated very clearly that these changes are irreversible. Neither treatment nor time will lead to recovery or regeneration of dead brain tissue.

32. Dr T said that given the extensive brain damage and tissue loss he doubts that A can experience pain but "we cannot know". A cannot give us the signs of discomfort or pain and so there are no outward indicators that A suffers pain.

33. I have also read the second opinions of two critical care consultants, one a professor, from another London NHS Trust, dated 22 June 2022, and one from a Consultant in Paediatric Intensive Care at a third London NHS Trust, dated 27 July 2022. Those written second opinions confirm the findings, assessments and opinions of the medical team at the Evelina. The critical care consultants performed brain stem testing prior to when A started to breathe, and they reached the same conclusion that had been reached by the team at the Evelina, namely that A was brain stem dead.

Independent Expert

34. Dr Brierley is a Consultant Paediatric Intensivist at the Great Ormond Street Hospital for Children. He has twice seen A at the Evelina PICU, on 28 July and 23 September 2022, producing written reports after each visit. He gave oral evidence in person at the hearing. Dr Brierley was instructed jointly by the Guardian and the parents.

35. I was impressed by Dr Brierley's expertise, sensitivity, and candour. He readily accepted the limits of his knowledge and of medical science. He explained the technical aspects of his evidence in plain language. He was very mindful of the parents' views and their painful position. He accepted that in two respects the parents had been given medical advice about A which had turned out to be in error:

    i) The determination that A was brain stem dead in June 2022 which was rescinded when A started to breathe.

    ii) His own expectation following his first visit to A, that in the absence of improvement, ventilation would progressively worsen, leading to death from organ system failure. In fact, A's condition and his ventilation requirement has, in Dr Brierley's opinion, effectively remained the same and he told the court in oral evidence that he could not now predict how long A might be kept alive on ventilation, although his life is limited.

36. Dr Brierley posited two hypotheses as to how brain stem testing could have "confirmed" neurological death when, a fortnight or so later, A was able intermittently to breathe. The first was that whereas in a person with a closed

skull severe brain swelling will cause the brain to be pushed downwards into the hole at the base of the skull (brain herniation or "coning"), for a baby who has open fontanelles (or for an adult who has undergone a craniectomy) the swelling can expand the brain in different directions. Thus, when the swelling subsides, damage to structures such as the medulla (which controls breathing) may not be total or permanent such that breathing may re-start. The second hypothesis was that damage to A's spinal cord may somehow have caused reversible damage which temporarily prevented all breathing. As I understand it brain stem death testing for adults would require spinal cord injury to be excluded. These are merely hypotheses. Dr Brierley told the court that he has been in discussion about this case with the President of the Royal College of Paediatrics and Child Health, the Chair of the Paediatric Critical Care Society, and the Academy of Medical Royal Colleges via colleagues and that a working group has been established to clarify the "pre-conditions" before a determination of death using neurological criteria is made in a child of A's age.

37. As for the relative stability in A's condition over the past month, Dr Brierley said that whilst he had wrongly expected a deterioration, the fact remained that A was not capable of recovery. It does not seem conceivable that he will regain consciousness. For as long as he lives he will remain in intensive care.

38. Dr Brierley gave the same answers as Dr Y as to A's capacity to sense pain and pleasure. Although there are no signs that A does experience pain, he could not exclude the possibility of sensation of pain by way of some form of vestigial reflex response, but the capacity to experience pleasure could effectively be ruled out because of the complete absence of cortical activity.

39. Dr Brierley commended the exemplary care afforded to A at the Evelina. In his opinion everything that could have been done for A had been done. The time when treatment or interventions might make a difference will be in the early days after a severe brain injury. At this stage, after fifteen weeks in the PICU, there are no further interventions and there is no further treatment that will help A. However, Dr Brierley would not now be as confident as he was a few weeks ago that A will be likely to die within a relatively short time if ventilation were to be continued. A's life expectancy is limited but Dr Brierley would be cautious about putting any time on how long A might survive on continued mechanical ventilation. A had not suffered barotrauma despite the very high ventilator pressures. Hospital acquired infection would be likely to affect him at some stage - notwithstanding the exceptional nursing care he is given - but he could not say when or whether A would succumb to it.

40. Dr Brierley refers in his written evidence to the Royal College of Paediatrics and Child Health document: "A framework for practice: Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice" (Vic Larcher et al, March 2015), This "framework" states, inter alia:

> "3.1.3 Situations in which it is appropriate to limit treatment
>
> The underlying ethical justification for all decisions to withhold or withdraw LST is that such treatment is not in the child's best interests. There are three sets of circumstances where it may be appropriate to consider limitation of treatment.
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> …
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> Limited quality of life: where there is no overall qualitative benefit

Considering quality rather than quantity of life is more problematic because of potential or actual differences in views of the healthcare team and children and families as to what constitutes quality of life and the values that should be applied to define it.

In some children, continuing treatment may prolong life significantly. Yet it may be in their best interests to consider limiting it if there is no overall benefit in prolonging life because of the adverse impact entailed. In entering discussions about treatment limitation it is important to acknowledge the importance of the value that the child and his/her parents place upon their life and their view of its quality for that child, regardless of disability. These discussions may arise in the context of the burdens imposed by a child's illness and/or the treatments that the child is already receiving or that are proposed, their inability to benefit from treatments, or a combination of all three.

A. Burdens of treatments

Some forms of medical treatments in themselves cause pain and distress, which may be physical, psychological and emotional. If a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease.

…

C. Lack of ability to derive benefit

In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation."

41. In Dr Brierley's opinion there is no benefit at all to A from continuing mechanical ventilation. He will not improve with time alone and there is no treatment to give him that will improve his condition. He will remain in intensive care for the rest of his life. He will not recover consciousness because the brain tissue loss is so extensive and irreversible. Upon extubation he would not be likely to live more than minutes rather than hours. His life will be extended by continuing ventilation, but it is an extended life that would have no benefit to him.

The Parents

42. F and M stood in the witness box together, holding hands in support of each other. F told the court that there could be no certainties – A had already defied expectations. F said that however probable an outcome might be thought to be, there was always a margin for error. Men and women had to be humble before nature. Only Allah could decide when it is time for a person to die. Time with A was precious. He and his brother were all of F and M's world. They feel his presence and beg for time to be given to see whether he can recover. There is no need to rush to end his life now.

43. In the first of their three, jointly written statements, F and M said, "As parents, watching our son lying like this is unimaginable and the pain is beyond expressible… we have been praying and crying every second to almighty Allah for the wellness of A. We strongly trust and believe that he will wake up any moment…" It was an emotional experience for many in court to listen to F and M speak. They did so articulately, courteously and movingly. I was struck by

the strength of their faith and the power of their hope. I saw at the hospital that a copy of the Quran lay beside A in his small bed. The parents spoke to me about him animatedly.

44. F and M started and finished their evidence by thanking all those involved in A's care. This is a case in which although there are deeply felt differences as to whether life-sustaining treatment should continue, there is no animosity expressed towards the professionals who have devoted themselves to caring for A.

45. F and M are able sometimes to pick A up and hold him. They change his nappies and keep him clean. They change his clothes. For hours on end they will watch over A and note the readings on the monitors beside A's bed looking for any signs of change. They know that he is gravely brain damaged. They understand the medical evidence but their faith and hope prevent them from making a decision to let go of their baby son.

46. The parents have not disputed the evidence of Dr Z that A's heart rate does not change when he is handled but they queried the significance of a change in the required ventilation readings when he is placed on M's lap. Dr Z explained that the ventilator is sensitive to a change of position of that kind. A was completely still when I saw him but he has at times shown some small movements. Dr Z and Dr Brierley explained that twitching movements are known to occur in severely brain damaged patients. F recalls that when he was a child his own ear would become hot and red whenever he was embarrassed or felt a strong emotion. His father had the same trait. He has noticed A's ear turning red. Dr Brierley has explained this as a known physiological response in some children

with vasodilation to the earlobes leading to increased blood flow. The reddening of A's ear is not due to inner emotion but is a product of the autonomic nervous system which mediates vascular tone. Although A's head circumference has reduced – an exceptional finding in a young baby – his body has grown which the parents have taken as a positive sign. However, this is to be expected since he is receiving nutrition through his nasogastric tube. The parents have also noted some variation in the size of A's pupils. In fact, his pupils do not react to light but slight changes over time are well known to occur – it is called anisocoria – and are not an indication of recovery from severe brain injury.

Legal Principles

47. The law applicable to decisions of the kind this court is required to make in respect of a young child, has been set out in numerous cases. Relying heavily on *Re J (a Minor) (Wardship: Medical Treatment)* [1991] Fam 33 and *Re A (Male Sterilisation)* [2000] 1 FLR, the Court of Appeal in *Portsmouth Hospitals NHS Trust v Wyatt and Anor* [2005] EWCA Civ 1181 set out the core legal principles as follows:

> "In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (Re J). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (Re J). The term 'best interests' encompasses medical, emotional, and all other welfare issues (Re A). The court must conduct a balancing exercise in which all the relevant factors are weighed (Re J) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A)."

48. The Court of Appeal in *Re A (A Child)* [2016] EWCA Civ 759 noted at [31]:

> "Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 22:-
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> "Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."
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> And from paragraph 39:-
>
> "The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

49. I cannot improve on MacDonald J's summary of the principles as they apply to a decision whether to continue life sustaining treatment to a young child, in *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) at [116]:

"As regards the application by the court of [the] best interests principle in the context of medical treatment to children who are not 'Gillick' competent, this is well settled. The following key principles can be drawn from the authorities, in particular Re J (A Minor)(Wardship: Medical Treatment) [1991] Fam 33, R (Burke) v The General Medical Council [2005] EWCA 1003, An NHS Trust v MB [2006] 2 FLR 319, Wyatt v Portsmouth NHS Trust [2006] 1 FLR 554, Re Ashya King [2014] 2 FLR 855, Kirklees Council v RE and others [2015] 1 FLR 1316 and Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410:

i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.

ii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies…

iii) Each case is fact specific and will turn entirely on the facts of the particular case.

iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.

v) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be. Within this context, the views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

vi) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient (see Airedale NHS Trust v Bland [1993] ACR 789 at 825). The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great…

> vii) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests…
>
> viii) The court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
>
> ix) Regard must be paid to the rights of the child, in particular her right to life under Art 2 and her right to respect for private and family life under Art 8. Regard must also be paid to the parents' rights, in particular their right to respect for private and family life under Art 8. In this case, the right of Tafida and her parents to freedom of thought, conscience and religion under Art 9 of the ECHR is also engaged and must be considered.
>
> x) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive"

50. In a case where the child concerned may very well have no awareness and be unable to experience either pleasure or pain, Baker LJ observed in *Parfitt v (1) Guy's and St Thomas' Children's NHS FT (2) Knight* [2021] EWCA Civ 362 at [60]:

> "The proposition that no physical harm can be caused to a person with no conscious awareness seems to me to be plainly wrong. As I observed during the hearing, the law clearly recognises that physical harm can be caused to an unconscious person. In the criminal law, for example, an unconscious person can suffer actual or grievous bodily harm and it would be no defence to a charge under the Offences against the Person Act 1861 that the victim was unconscious. The judge was in my view entirely justified in citing examples from the law of tort in which it has been recognised that physical harm can be caused to an insensate person. As Mr Mylonas observed, if the proposition advanced on

> behalf of the appellant was correct, there would be no limit on a doctor's ability to perform any surgery upon any insensate patient. For my part, I fully endorse the judge's reasoning for rejecting the appellant's proposition at paragraph 76 of his judgment."

Similarly, the court should take into account benefits of which A is unaware, such as the devoted care given to him by his parents in the PICU.

51. In *An NHS Trust v MB* [2006] EWHC 507 at [16] Holman J said this about the wishes of parents of a child who is the subject of a case such as the present,

> "Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

In fact, the European Court of Human Rights has indicated that regard should be had to parental wishes, not just their views about what is in their child's best interests. In *Gard and Others v the United Kingdom* - 39793/17 (Decision [2017] ECHR 605 (27 June 2017) the ECtHR identified the requirements that the state has to meet to satisfy its positive obligations under Art 2 of the European Convention on Human Rights in a case where life sustaining treatment is to be withdrawn:

> "[80] In addressing the question of the administering or withdrawal of medical treatment … the Court has taken into account the following elements:
>
> - the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2;

> - whether account had been taken of the applicant's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel;
>
> - the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests."

In any event the parents have Article 8 rights and their wishes have to be taken into account in that context. Nevertheless, parental views and wishes do not take precedence – A's best interests prevail. In *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ observed:

> "As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

52. The Court of Appeal has recently addressed the relevance of religion and culture to the assessment of a child's best interests in *Fixsler v (1) Manchester University NHS Foundation Trust* [2021] EWCA Civ 1062. Baker LJ stated at [81]:

> "The family's religion and culture are fundamental aspects of this child's background. The fact that she has been born into a devout religious family in which children are brought up to follow the tenets of their faith is plainly a highly relevant characteristic of hers. Under s.1(3)(d), the court is required to have regard to the fact that Alta is from a devout Hasidic family which has very clear beliefs and practices by which they lead their lives and that, if she had sufficient understanding, she too would very probably choose to follow the tenets of the family religion. I agree with Mr Simblet that this is a central part of her identity – of "who she is". It is unquestionably an important factor to be taken into

> consideration. But it does not carry pre-eminent weight. It must be balanced against all the other relevant factors."

Not all adherents to a particular religion share the same beliefs and it cannot be assumed that A would have developed the same or similar religious views as his parents. Nevertheless, I should take into account the parents' particular convictions and that A has been born into a family that hold to those convictions.

53. M and F contend that the language of "dignity" does not assist the court's analysis of what is in A's best interests. It is, they contend, a vague concept which, quoting from a 2020 Medical Law Review article, '*The Discourse of Dignity in the Charlie Gard, Alfie Evans and Isaiah Haastrup Cases'*, by Monique Jonas and Samantha Ryan, "serves to compel acceptance of, rather than providing reasons to support, a best interests judgment." For some, dignity would be found in ensuring that A's life has a peaceful end but, as Ms Butler-Cole KC and Ms Kelly state in their position statement,

> "From the perspective of A's parents and the faith and culture in which he was being raised, his greatest dignity will be found in continuing to live, even if that is with the assistance of very significant medical interventions, with his death occurring at a time of Allah's choosing, not that of a health professional or a court. It is contrary to A's innate human dignity to withdraw treatment from him."

54. In *North West London CCG v GU* [2021] EWCOP 59, Hayden J provided a comprehensive history of the central position of the concept of "dignity" in international texts, instruments, and documents in order to evaluate its application to a decision in the Court of Protection concerning the provision of

clinically assisted nutrition and hydration and to similarly challenging decisions that the courts are required to make. Hayden J noted that the concept of dignity is,

> "… mentioned in the Universal Declaration of Human Rights of 10 December 1948, the Preamble to which states that "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world", and Article 1 of which provides that "all human beings are born free and equal in dignity and rights"."

Hayden J set out many other international conventions and documents that refer to the "inherent dignity of all human beings" or similarly to the requirement to prevent the violation of "respect for human dignity". He then concluded at [63] and [64]:

> "Though it is an ambitious objective to seek to draw from the above texts, drafted in differing jurisdictions and in a variety of contexts, unifying principles underpinning the concept of human dignity, there is a striking thematic consistency. The following is a non-exhaustive summary of what emerges:
>
> i. human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;
>
> ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;
>
> iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;
>
> iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;
>
> v. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity,

> fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;
>
> vi. compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.
>
> Thus, whilst there is and can be no defining characteristic of human dignity, it is clear that respect for personal autonomy is afforded pre-eminence. Each case will be both situational and person specific. In this respect there is a striking resonance both with the framework of the Mental Capacity Act 2005 and the jurisprudence which underpins it. The forensic approach is 'subjective', in the sense that it requires all involved, family members, treating clinicians, the Courts to conduct an intense focus on the individual at the centre of the process. Frequently, it will involve drilling down into the person's life, considering what he or she may have said or written and a more general evaluation of the code and values by which they have lived their life."

55. In the case of A, a baby who was barely two months old when he suffered his catastrophic brain injuries, his own wishes and feelings cannot be ascertained and respect for his autonomy will have a very different character than were he an adult or older child who had developed their personality, views and beliefs. Nevertheless, as Hayden J powerfully articulates, respect of A's innate human dignity requires the court to apply an intense focus on A. Having regard to the authorities set out above, it seems to me that the court recognises and respects A's dignity by conscientiously applying the legal principles that have been laid down, not by making a decision that accords with the court's own concept of dignity. Those principles require the court to consider A's best interests in the widest sense, including burdens and benefits of which A is, and will remain, unaware. It would be wrong to assume that human beings, including babies as young as A, have "no interests except in those things of which we have

conscious experience." – Lord Hoffmann in *Airedale NHS Trust v Bland* [1993] AC 789 at 829. An assessment of A's best interests will therefore take into account the care and devotion given to him by his family, the importance of his family's religious beliefs and culture, and the circumstances in which he is and could be cared for and treated. The anxious assessment of A's best interests in the widest sense accords respect to his innate human dignity. The court does not apply a separate test of dignity – there is no objective concept of dignity on which the court can rely to help it determine what is in A's best interests. Rather, the intense focus on A and the application of the established legal principles, recognises and respects his innate dignity as a human being.

The Guardian's Position

56. Ms Gaywood has visited A in hospital on five occasions. She has spoken with the parents and with staff. With deep sadness she agrees with the Trust's application. She told the court that she has sought to consider the case from A's point of view and that the balance of his interests lies in withdrawing ventilation. In relation to the question of whether A can feel pain, Ms Gaywood said that she considered that the evidence was that he did not feel pain but that a definitive position could not be taken.: "If he does not experience pain or pleasure my recommendation remains the same, balancing the benefits and burdens. If there is a possibility of him feeling pain, it would reinforce my recommendation."

The Court's Decision

57. The court is asked to make this sombre decision and has a duty to do so. All attempts to find an agreed way forward have failed. I have to assess what is in A's best interests in the light of all the evidence and the views that I have received and applying the legal principles set out above. The medical evidence presented to the court is consistent and clear: A has suffered a catastrophic brain injury which has resulted in an irreversible loss of a significant amount of brain tissue. There is no detectable electrical activity in his brain. MRI scans show the devastating extent of his brain damage. It is virtually certain that he will not recover consciousness. I accept the evidence that he will never leave an intensive care unit setting. The parents do not want to accept this evidence but the evidence is compelling.

58. Accordingly, the evidence drives me to conclude that treatment is futile in the sense that it will not bring about any improvement in A's condition. Indeed, it will not bring about a return to consciousness. Continued ventilation and intensive care support will be likely to prolong A's life whereas he would be unlikely to survive more than minutes following extubation, but the only difference such continued intervention would make would be to the quantity not the quality of A's life.

59. In reaching those conclusions I acknowledge that some humility is required. At the end of June 2022 I would have received evidence that A was brain stem dead whereas within two days he was, for a while at least, breathing unassisted. In a different context Dame Elizabeth Butler-Sloss President said *in Re U, Re B* [2004] EWCA Civ. 567, "The judge in care proceedings must never forget that

today's medical certainty may be discarded by the next generation of experts or that scientific research may throw a light into corners that are at present dark". Similar caution should be exercised in the present case, in particular given the striking fact that A was declared to be brain stem dead three months ago and later started breathing. It was clear to me that Dr Brierley, Dr Z and Dr Y in particular accepted that predictions about A needed to be made with humility. However, even allowing for proper caution, I find that it is virtually certain that A will make no form of recovery from his extensive brain damage that would allow him to become aware of his surroundings or to experience pleasure. Furthermore, he will always require ventilation in an intensive care unit.

60. The parties addressed me on a difficult issue which is whether the court should approach a finding about A's experience of pain applying a balance of probabilities test. In *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) at [175] MacDonald J held,

> "I have given careful consideration to the submission of the Trust and the Children's Guardian that the possibility that Tafida feels pain cannot be completely excluded and that, accordingly, Tafida will be increasingly burdened by pain consequent upon the other physical disabilities she will develop in the future, as she would be were she to develop a greater level of awareness, can likewise not be excluded as a possibility. However, some caution must be exercised in respect of this submission. The standard of proof applicable in these proceedings is the balance of probabilities. Whilst it is tempting to say simply that the possibility that Tafida feels pain cannot be entirely ruled out and therefore the court must proceed on the basis that it is better to err on the side of caution, this does not maintain fidelity to the applicable standard of proof. Such fidelity is important in every case, but all the more so when the outcome being considered is so grave."

61. At paragraph [82] of my judgment in *Guy's and St Thomas' v Knight* [2021] EWHC 25, I applied that approach in relation to a finding that Pippa had no

conscious awareness because it was important to draw a distinction between a minimally conscious state and a state of no awareness at all. In the later judgment of Hayden J in *Newcastle Upon Tyne Hospitals NHS Foundation Trust v H* [2022] EWFC 14, the court was faced with opinion evidence that it was unlikely, but not impossible, that H experienced discomfort, pain or pleasure at some level. Hayden J held,

> "I do not consider that civil test has application in this situation. I would go further, I consider it would be quite wrong, when balancing the difficult and sensitive issues raised here, not to take account of the fact that treatment might be causing H pain. In this case, as I have set out above, the situation is further complicated by the fact that Dr Lumsden agrees that it is likely that H periodically experiences some kind of "primitive pain" reaction and discomfort. Dr Lumsden states that this is not to be equated with the pain that a sentient adult might experience. The civil standard of proof test i.e., the balance of probabilities, certainly requires to be applied in particular, and prescribed circumstances. In this context, however, i.e., in an investigative, non-adversarial, sui generis process, such a constricted approach lacks the necessary nuance. It is medically impossible to exclude the possibility of pain in H's case. There is no test, there can be, in the case of a young child, no formal assessment. The conclusions reached are based on observations alone to establish a negative i.e., what is thought not to be there. It is trite to say that this is a delicate and sensitive process. The Court's finding should reflect nothing more and nothing less than that reality when it is evaluating those factors that illuminate H's best interests. Where the doctors cannot exclude the possibility of pain, neither should the Judge."

62. Mr Davy for the Guardian presented the judgments of MacDonald J and Hayden J as setting out two conflicting approaches to findings in cases of this kind. The first approach reflects the dicta of Lord Hoffmann in *In Re B (A Child)* [2008] UKHL 35,

> "If a legal rule requires a fact to be proved (a "fact in issue"), a judge or jury must decide whether or not it happened. There is

> no room for a finding that it might have happened. The law operates a binary system in which the only values are 0 and 1. The fact either happened or it did not."

Hence, if I were to find that A probably does not feel pain then the possibility that he does feel pain is excluded when the best interests assessment is made. The second approach is to avoid a binary determination and to carry forward both the probability that A does not feel pain and the possibility that he does feel pain into the best interests assessment.

63. I am not sure that the choice between the two approaches is as stark as Mr Davy suggests. The binary approach articulated by Lord Hoffmann applies if a fact has to be proved. In *Re A (A child)* [2016] EWCA Civ 759, the first ground of appeal was that, "the judge was plainly wrong to make a finding of fact that A was in pain and/or felt pain." The Court of Appeal reviewed the evidence on which the judge had had to decide that issue and noted at [49],

> "The judge, having seen and heard the evidence had to resolve this difficult issue and in doing so had to choose between what was (given the level of expertise and experience of the experts before her) undoubtedly a 'reasonable range of professional opinion'.

The Court of Appeal held at [50],

> "… it cannot be said that the judge was plainly wrong in preferring the interpretation of Drs Manna and Thomas that the physical signs which they had observed, and which are the commonplace signs associated with pain and/or discomfort, are evidence of precisely that."

Hence, the Court of Appeal approved the making of a finding of fact, which must have been made on the balance of probabilities, as to whether the individual concerned could feel pain. In that case there was disputed expert evidence as to whether pain was experienced. It would have been impermissible for the court to have made a finding that expert A was correct, and then to proceed to a best interests assessment on the basis that the expert B might have been right. A determination was necessary and the decision is a binary one. However, in the present case the situation is different.

64. I find that the weight of the evidence is that A probably does not consciously experience pain – he has no awareness of pain or discomfort - but that some vestigial reflex responses to pain or discomfort, for example, when suctioning takes place, cannot be excluded. The evidence on the issue of pain appears to have some similarities with the evidence in *Newcastle upon Tyne Hospitals NHS Foundation Trust v H* (above). If A does "suffer" pain or discomfort, I am satisfied that given the death of cortical brain tissue, it is without awareness and only as a reflex response. Even that level of experience of pain is unlikely - his heart rate and blood pressure have not responded to stimuli and his EEG is unresponsive to stimuli, but it cannot be excluded and need not be excluded for a meaningful determination of best interests to be made.

65. That is the finding that I take forward in my assessment of best interests. It is not necessary to make a finding on the balance of probabilities as to whether A has a reflex response to pain. I proceed on the basis that it is possible that he does so. The court is able to feed possibilities as well as probabilities into a best interests assessment. In some instances it is necessary for the court to make a

finding to resolve disputed evidence or to determine a crucial issue. If so then the court will have to make those determinations on the balance of probabilities. In *Knight*, the court needed to make a determination as to whether Pippa was in a minimally conscious state or was wholly unaware. That was a decision to be made on the balance of probabilities in the light of all the evidence. Once the finding had been made on the balance of probabilities, the alternative finding no longer fell to be considered as part of the best interests assessment. The situation appears to me to be quite different in the present case where a best interests assessment can be done on the basis that A has no conscious awareness of pain (on the balance of probabilities) but may have a vestigial reflex response to pain. Those two conclusions are not mutually exclusive. In this case, as in *Newcastle v H*, the court is able to make findings that allow for possibilities and uncertainties and to take those into account in an assessment of best interests.

66. Applying the legal principles set out above, I proceed on the basis that the burdens of treatment should be taken into account even though they probably do not cause pain or discomfort to A of which he is aware. He undergoes frequent deep suctioning, he is ventilated, he is fed through a nasogastric tube. These constitute burdens upon him even though he is not conscious of them. The interventions are not as burdensome as they are in many cases but they are burdens nonetheless.

67. The overwhelming weight of the evidence is that A does not and will never experience pleasure. It is distressing for his parents to contemplate this, but A will not be aware of their presence. However, just as there can be harm without

awareness of pain, so there can be benefit without consciousness of pleasure. In considering A's interests in the widest sense I should consider the circumstances in which he is being cared for and his place within a loving family. A is the object of love and devotion from his parents. His life has meaning to them, to his brother, and to those who are caring for him at the Evelina. It is of benefit to A to be cared for in such circumstances. However, the benefit to him is limited. The family care is provided for him in the setting of a PICU. It is right to note that his care has been de-medicalised so far as is possible. He is not administered any drugs for sedation or otherwise. He is not on a drip and has no intravenous lines. However, he is subject to the interventions already noted and the unanimous evidence of the clinicians and expert was that A will never live outside an intensive care unit. That is not a family home. He will not develop as a child within the family and be able to interact with them. He will not be able to form relationships with his caring family.

68. Weighing all the burdens and benefits to A from his current life, I have little hesitation in concluding that the burdens outweigh the benefits. He experiences no pleasure and no comfort. He has the benefit of loving care from his parents but he also suffers the burdens of interventions required to keep him alive. He has no awareness of either. He is trapped in an intensive care unit and deprived by his condition of all the opportunities for interaction, development, and family life that a baby might otherwise enjoy.

69. There is a stark choice in this case. There are only two possible outcomes. The first is that ventilation is continued. A would remain in the PICU. His life expectancy would be uncertain but limited. He would be subjected to the same

or similar interventions as at present. He would be at risk of suffering infection or barotrauma. The alternative is to withdraw ventilation. The parties have agreed a care plan in the event of a decision by this court that continued ventilation is not in A's best interests. It involves a plan for ceilings of care and then extubation. On extubation it is likely that A would survive for a short time only. The care plan would allow him to be made as comfortable as possible and to be with his family when he died.

70. The evidence establishes that it is virtually certain that prolonging A's life by continued ventilation and intensive care will not lead to any form of recovery. His existence will continue in the same way. The sole benefit of continued ventilation is therefore to prolong life. It cannot be known for how long life can be prolonged but it would be for longer than were ventilation to be withdrawn. Dr Z said that it is A's death that would be prolonged but whilst A's condition could be described as "dying", he is in fact living – he has life and the law which I must apply is that there is a rebuttable presumption that steps should be taken to preserve life.

71. A's parents' faith and hope impel them to believe that A will recover. I take their views about recovery into account but they are heavily outweighed by the medical evidence in this case.

72. For the parents, Allah, not man, must decide when A will die. That has been made clear to them by their Imam and in a fatwa (a ruling on a point of Islamic law) from a Madrasah. I take into account the parents' strong religious convictions and that A is a member of a family in which those convictions play such an important role but I cannot be bound by them, any more than I can be

bound by the different religious convictions or secular beliefs of any other parent or party in other cases. I have to make a decision applying the legal principles set out above by which I am bound, not by adhering to the principles of a particular religion.

73. I acknowledge the parents' hope that by preserving A's life for now, some medical breakthrough or chance event might bring about an improvement in A's condition and quality of life. The power of hope is very strong but some realism is also required. Given the devastating nature of A's brain injuries there can be no realistic hope of an improvement or a medical breakthrough in the next few weeks or months that will change for the better the balance of benefits and burdens that now characterise A's life.

74. I take into account F and M's wishes and their deeply held views as to A's best interests. I also take into account the strong views of those caring for A at the Evelina as to his best interests.

75. A has extremely severe brain damage. His quality of life is extremely poor. He cannot see or hear, he cannot move, he has no awareness. He undergoes invasive interventions to keep him alive. He has now been in intensive care for over fifteen weeks and has shown no signs of consciousness, no voluntary or purposeful movement, no awareness of the world around him, no responses to stimuli, he has EEGs which are the equivalent of a flat-lining heart monitor, and MRI scans which show a devastating loss of brain tissue. Sufficient time has now passed since his admission to the Evelina to conclude with confidence that he has no hope of any form of recovery and will never leave intensive care. Continued treatment is to that extent futile. Continued ventilation and intensive

care would allow A to remain alive for longer than were they to cease but, whilst there is a presumption that life should be preserved, that presumption is rebutted in this case where A will only to continue to suffer more burdens that benefits from living.

76. A's current quality of life is extremely poor. The burdens suffered by him in order to keep him alive outweigh the benefits to him of being kept alive by a significant margin. Treatment is futile in the sense that it cannot bring about any improvement in A's condition or the quality of his life. So long as he is kept alive he will suffer more burdens than benefits from being alive. There are no other options than to keep him alive by continued ventilation in an intensive care unit so prolonging the burdens to him of being kept alive, or to withdraw mechanical ventilation which will then bring an end to his burdens.

77. When assessing A's best interests from his point of view and applying the legal principles set out above to the evidence in this case I have come to the sad conclusion that it is not in A's best interests to continue to receive mechanical ventilation. Accordingly, I shall make the declarations sought by the Applicant Trust and approve the agreed palliative care plan.