Neutral Citation Number: [2022] EWHC 2250 (Fam)

Case No: FD22F00036

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26/08/2022

Before:

THE HONOURABLE MR JUSTICE HAYDEN

- -

Between:

Guy's and St Thomas' NHS Foundation Trust

Applicant

- and -

(1) A (A Child, through his r.16.4 Guardian)
(2) F (as a Litigant in Person)
(3) M (as a Litigant in Person)
(4) A Local Authority (Intervener)

Respondents

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- -

Mr David Lawson (instructed by **Hill Dickinson**) for the **Applicant**
Miss Claire Watson QC (instructed by **Duncan Lewis**) for the **First Respondent**
Ms Yasmeen Jamil (instructed by **a Local Authority)** as the **Intervener**

Hearing dates: 25th August 2022

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN

MR JUSTICE HAYDEN:

1. This application concerns A, a boy who was born on 7th April 2022. On 10th June 2022 he sustained a profound hypoxic ischaemic brain injury following a cardiac arrest, which occurred shortly after he was found limp in his cot with abnormal breathing. An ambulance was called, and he was taken to the Accident and Emergency Department at Queen Elizabeth Hospital. A return of spontaneous circulation was not established until his arrival. It is estimated that his brain was deprived of oxygen for approximately 30 minutes. A was stabilised and transferred on the same day to the Evelina Children's Hospital ("the Hospital") where he remains intubated and ventilated on the Paediatric Intensive Care Unit (PICU).

2. On 19th and 22nd June 2022 brain stem testing was undertaken in accordance with the Code of Practice for the Diagnosis and Confirmation of Death. It was concluded that the criteria for brain-stem death were met and a medical declaration (or diagnosis) of death was made giving the date and time of death as 19th June 2022 at 13.15 hours. By an application dated 27th June 2022 the Trust sought a declaration of death and authorisation to withdraw A's mechanical ventilation, ancillary care, and treatment.

3. An initial hearing took place on 28th June 2022 before Peel J, at which Ms Gaywood, the Children's Guardian in family law proceedings, was appointed as A's Guardian in these proceedings and the court set down a directions timetable. The application was referred to me and a final hearing was listed for 13th July 2022.

4. In early July and contrary to anything seen before, A began to show some respiratory effort indicative of a degree of brain stem function. As a consequence of this unexpected development the Trust immediately rescinded the medical declaration of brain stem death and the initial application of 27th June 2022 was no longer pursued. On 12th July 2022 the Trust sought permission to amend the main application to seek a declaration that it is in A's best interests for mechanical ventilation to be withdrawn.

5. On 13th July 2022 the matter came back before me for a Directions hearing at which the application to amend was granted. It was agreed that the sole issue before the court is what medical treatment is in A's best interests. The parties were granted permission to file and serve further evidence, including second opinion reports and expert evidence from a consultant paediatric neurologist and consultant paediatric intensivist. A final hearing was listed on 25th and 26thAugust 2022. On the 13th July 2022, I gave a judgment: ***[2022] EWHC 1873 (Fam)*** setting out what had occurred and why I was requiring further expert evidence, given the extraordinary facts.

6. On 11th June 2022, A had undergone a CT head scan which was reported as follows:

> *"1. There are bilateral areas of mixed density extra axial blood, mainly subdural with smaller amounts within the subarachnoid space, lying along the convexities, falx and tentorium which are increased in extent. A small right temporal contusion appears new. No secondary complication such as hydrocephalus or compartmental/midline shift. A neurosurgical opinion is advised regarding the areas of intracranial haemorrhage, if not previously obtained.*
>
> *2. Diffuse hypodensity of the brain parenchyma is highly suspicious of diffuse ischaemia, in this given clinical context.*
>
> *3. The constellation of imaging findings, in the absence of any suitable explanation, is suggestive of traumatic head injury. Non accidental injury is a strong consideration if there is no history of accidental trauma. Note is made of the recent findings on chest radiograph, where bilateral rib fractures are demonstrated.*
>
> *Further evaluation with skeletal survey and MRI of the brain/spine, as per local protocol is advised, along with discussion at the paediatric neurology radiology clinical meeting."*

7. On 13th June 2022 A underwent the first of three EEG's which was markedly abnormal, reflecting severe encephalopathy. A later underwent x-rays and a retinal examination which revealed multiple fractures and retinal haemorrhages which were bilateral and multifocal.

8. On 14th June 2022 a whole spine and head MRI was performed, which revealed the following:

> *"There is extensive brain parenchymal abnormality involving both cerebral and cerebellar hemispheres and parts of the brainstem with features suggestive of hypoxic ischaemic injury, multiple intracranial subdural and subarachnoid haemorrhages and spinal cord abnormalities. In the absence of a suitable medical explanation and in view of the constellation of brain and spine findings along with multiple fractures and retinal haemorrhages, the appearances would be highly suggestive of non-accidental injury."*

9. It requires to be stated that brain stem tests had been conducted on 17th, 18th and 19th and 22nd June. The tests on the 22nd had, at the parent's request, been performed by two doctors from a different Trust. Every test confirmed brain stem death. I described in my earlier judgment how it was discovered that A was beginning to breathe by a nurse on duty between Saturday night and Sunday morning between the 2nd and 3rd July 2022.

10. On 4th July 2022 an EEG was performed which revealed the following:

> *"**Factual Report:***
> *This 30-minute EEG was recorded at the bedside on PICU. He was not on medication.*
> *No identifiable physiological activity could be identified throughout the EEG. He had a nappy change during recording with no changes on the EEG. Following the bagging during recording he was triggering the ventilator from a baseline of 24 up to 40. No changes were seen on the EEG.*
> *…*
> ***Conclusion:***
> *2nd EEG. No recordable electrical activity is seen on this occasion. The subtle chest movement was not accompanied with an ictal EEG correlate."*

11. On 5th July 2022 a further MRI of A's brain and spine was performed and was reported as follows:

> *"Summary: Expected interval maturation of the prior acute hypoxic ischaemic changes in the brain and acute changes of the spinal cord, with evolution into severe multicystic encephalomalacia/myelomalacia and parenchymal volume loss, as described. There has also been some maturation of the extra-axial haemorrhages, with increase in size of some of the subdural collections but without any significant mass effect or midline shift. Interval enlargement of the ventricles and basal cisterns is in keeping with diffuse neuroparenchymal volume loss."*

12. On 11th July 2022 a third EEG was performed which was reported as follows:

> *"**Factual Report:***
>
> *This was an urgent 30-minute portable EEG performed on PICU. The patient was not on any medication. The nurse at the bedside reported that he has been consistently triggering the ventilator since around 08:00 am this morning. No movements were observed other than head movement in association with respiration - this produced associated respiration artefact. Pupils were unequal, (size 4 on the left/size 4 on the right), fixed and dilated.*
>
> *The trace shows no discernible physiological activity. Auditory, tactile and suction stimulation failed to elicit any significant changes.*
>
> *…*
>
> ***Conclusion:***

> *3rd recording. No recordable electrical activity was seen. When external stimuli were applied, no recordable electrical activity was seen. No seizures were seen.*
>
> ***Opinion:***
>
> *No seizures, clinical or electrographic, are seen.*
>
> *No recordable electrical activity is seen during the recording.*
>
> *Clinical correlation is advised."*

13. Pursuant to my order of the 13th July 2022, Dr Joe Brierley, Consultant Paediatric Intensivist, Great Ormand Street Hospital, was appointed to provide an independent expert opinion concerning A and to assist in understanding the unreliable brain stem test results. Dr Brierley visited A, his parents, and the staff of the hospital PICU on the 28th July 2022.

14. Dr Brierley found A to be deeply unconscious to no response to stimulation, no purposeful movement, and no signs of awareness of his surroundings or any interaction with the environment. A remained in a coma, with a persisting Glasgow coma score of 3 i.e., the lowest score possible. This confirmed the clinical team's own observations that there are no external signs of consciousness.

15. Dr Brierley was specifically requested to help all of us, but most importantly the parents, understand A's apparent recovery from brain stem death. Dr Brierley stated as follows in his report:

> *"For, [A], his current clinical state and prognosis are far more critical than the fact he fulfilled clinical criteria for brain death as they currently stand but no longer. Most examples from the world literature regarding infants verified dead using neurological criteria (brain dead) in who the situation reversed and who were, therefore, alive, followed medical errors in the performance of the tests. The most frequent of these was complying adequately with the preconditions required before brain death testing. Essentially, this means ensuring no other cause of the clinical situation – coma and absent brain stem reflexes – is present. In infants, this can be hypothermia (as a treatment or due to exposure), sedative drugs, endocrine system abnormalities or electrolyte issues. None of these was the case in A.*
>
> *Brain death tests were performed several times by a number of senior clinicians, including from another centre, entirely in line with current UK Academy of Medical. There is a plausible explanation for [A's] recovery from a situation where his death was determined, which I suggest, and explored with his parents. I commenced by explaining that [A's] brain injury was complicated with at least two aetiologies over at least two time*

> *periods. An initial brain injury led to his collapse on the 10th of June, was associated with subdural and subarachnoid bleeding, in the setting of bilateral multilayer retinal haemorrhages and multiple fractures of different ages AND then a > forty-minute cardiac arrest led to a lack of oxygen and blood flow to an already damaged brain."*

16. In his evidence, I noted that Dr Brierley was comfortable in breaking down some complicated medical issues into relatively simple language that was easily understood by the parents. The report is written in a similarly accessible style:

> *"I explained that the brainstem, the more embryologically primitive bit at the base ofall our brains, controls the most basic functions needed to be alive such as breathing, heart rate and waking up. It is less likely to be damaged by lack of oxygen or blood flow than the more complex parts on the outside of our brains – the frontal lobes giving us personality and thought, the middle bit emotion, memoryand understanding, hearing and the back bit the understanding vision and coordination. In the most severe brain injuries caused by lack of oxygen and blood flow to the brain, the outside structures are most severely affected, whilst sometimes the brainstem is not badly affected and continues working usually. The mechanism of action by which children become 'brain dead' is not usually dueto direct damage to the brain stem but due to severe swelling of the brain above it. As the brain swells, the pressure inside the brain cavity grows, but the braincannot expand upwards as the skull acts as a close box; it can only push downwards, so the brainstem is pushed down through a small bony hole wherethe spinal cord comes off the brainstem, this can cut off the brainstem blood supply causing it to die.*
>
> *However, in infants such as A, the skull bones are not fused, so some of the swelling can be dealt with by the bones spreading apart and the skull expanding. It is possible that A's brainstem was directly affected by the lack of blood and oxygen from the cardiac arrest, and then itself became very swollen. The extent to which parts of the brainstem have become irreversibly damaged and which parts temporarily impaired due to swelling, which eventually allows function to return, only becomes apparent over time. As with any child who survives the initial phase of a severe brain injury, the fullextent of the damage can only be assessed after the initial swelling and inflammation have passed. For A, this is now very clear - he has sustained a severe level of damage to the brain, demonstrated by the clinical picture supported by imaging (MRI) andneurophysiology (EEG)."*

17. In his oral evidence, Dr Brierley was very clear that his attempt to understand the false brain stem test results was hypothesis and nothing more. It is important that this is understood. The hypothesis was shared by Dr Z, the Paediatric

Intensive Care Consultant at the treating hospital, indeed she had speculated in a similar way before Dr Brierley was instructed. Dr Z also properly emphasises that this is nothing more than a working hypothesis and should not be invested with greater significance.

18. It is important to focus on A's present situation and his prognosis. Dr Z considers that A is now dying. When Dr Brierley assessed him, he considered that A's *"brain injury [was] at the most severe end of the spectrum and will not improve".* He describes A's condition as *"grave"*. In his oral evidence, he noted the deterioration in A's condition observed recently by Dr Z. This did not surprise him indeed he had anticipated it in his report when he observed that A does not have any airway protective reflexes, the consequence of which means that *"recurrent aspiration of secretions is likely to damage his lungs progressively".* He had also foreshadowed Dr Z's concerns when he noted that *"ventilation will also be impaired by truncal dystonia"*. The deterioration was already evident to Dr Brierley at his visit:

> *"Clearly, these changes are already happening, and when I visited him, A required a peak pressure of 30 mmHg, a very high setting, having previously needed a moderately raised pressure of 23. (20/07) A setting as high as 30 mmHg usually precludes elective tracheostomy insertion in infants and is not a level usually considered suitable for the institution of long-term ventilation. Usual potential complications of continuing PICU include the risk of infection, decreased ability to develop, experience and interact, and the pain and discomfort associated with mechanical ventilation and other interventions. For A, there is no current alternative to continued ICU other than withdrawal of life-sustaining therapy and certain death. Sadly, in my opinion, issues of development, experience and interaction are not a realistic concern. Pain and discomfort are subjective, but due to the severity of his brain injury, it is impossible to assess either in A realistically."*

19. The changes that Dr Z describes are set out with great clarity in her report of the 22nd August 2022. Dr Z had been on a period of leave and returned to the unit on the 19th August 2022. She was, as she described in evidence, shocked by A's deterioration. She notes the changes, each of which she considers to be significant, which had occurred over the two weeks she was away.

> *"Ventilation is more impaired (requiring higher pressures on the manual ventilator circuit, although the set ventilator pressures are the same, but achieving less good tidal volumes).*
>
> *His breathing is less consistent or effective when taken off the ventilator onto a manual circuit.*
>
> *His heart rate is falling.*
>
> *Temperature homeostasis has been lost.*

> *Moving his limbs' during examination is resulting in involuntary mass movement of head or neck, probably due to the truncal stiffness".*

20. It had been noted within the week immediately following the return of A's breathing i.e., on 3rd July 2022, that A was becoming stiff. This began with his neck which resulted in his head moving backwards when his chest expanded. As Dr Z reminded us during the course of her evidence, babies of this age use their diaphragm to breathe. When A's chest expanded, with what Dr Z calls a *"double stacked breath",* his head would move backwards. For reasons that are all too obvious but poignant, the parents perceived this as a voluntary movement. Sadly, it was not and only occurs under these conditions.

21. All the treating clinicians led by Dr Z have expressed real professional concern at the impact on the parents of A's spontaneous recommencement of breathing after his parents had been so consistently reassured that he was dead. It is hardly surprising in these circumstances that they query the medical prognosis. During the course of F's evidence, he told me that medical science does not know everything and professional views change. He told me that he put his faith in *"my Allah"* to intervene. F and M wish their son to be ventilated in the hope that there will be some seismic change in the medical understanding, delivered through divine intervention. F spoke on behalf of the couple, though M was able to say a few words. I found F to be immensely articulate, reflective, and honest. The magnitude of his love for his son was palpable. He was dignified, strong, and resilient. His evidence was deeply moving.

22. Dr Z and Dr Brierley both recognised and articulated the need for professional humility in this most challenging situation. I pause, simply to say, that which is obvious but might get lost in the detail of the medical evidence. A had been declared dead and started, spontaneously, to breathe, not gasping but in a regular rhythm without the need for a ventilator. For this couple, committed to their faith and to the power of prayer, this must truly have seemed to be a miracle.

23. The joy of the 3rd July 2022 has, however, quickly and consistently, fallen away. In her oral evidence and in her most recent report, Dr Z told me how a little while ago, a PICU nurse had told her that they were finding it impossible to take A's temperature. In circumstances of this kind, and with a baby of this age, this is done per rectum. Dr Z told me, self-deprecatingly, how she initially thought this was unlikely and rather grandly, took the thermometer to undertake the task herself. The nurse was entirely correct, and it was impossible. Though the muscles around the chest are extremely rigid, some of A's muscles are both flaccid and areflexic, including the sphincter. This is particularly important as, in recent weeks, A has lost the capacity to control his own body temperature and requires frequent warming by the nurses. Dr Z is a senior and very experienced consultant, she became visibly distressed as she recounted how A has pyjamas on him, a number of blankets and 'all five bars' of the heating system in the cot switched on.

24. In her helpful position statement, on behalf of A, Ms Watson QC has summarised the progressive deterioration of A's condition. For precision, it is

important to say that the brain injury is not itself progressive, but the impact of that initial injury is. I draw on Ms Watson's summary but with additional matters arising from the evidence.

25. The evolving stiffness in A's neck, abdomen and trunk, to which I have already referred, has led to the need for increased ventilation pressures to allow sufficient chest movement and gas exchange of O_2 and CO_2. Despite the maximum pressure that a PICU unit would ordinarily employ in the context of a severe lung disease or significant airway obstruction, this level of ventilation is described as *"just adequate"*. Moreover, the stress to the lungs due to pressure of this degree, has led to two-thirds of the left lung losing volume and thus putting more pressure on the right lung. That raises the real possibility of what Dr Z termed *"a popping"* of the right lung, with risk of cardiac collapse.

26. One of the consequences of the stiffness of the chest muscles, is the degree to which that compromises ventilation and oxygenation. On her return from her leave, Dr Z was struck by how stiff A's chest felt to ventilate manually and she noted, that he only took 3 breathes over 4 minutes during the spontaneous breathing test. She described these breaths as *"more like agonal, single gasps, than rhythmic breathing"*. By this she meant, those breaths which characterise respiratory compromise at the end of life. That observation, from such an experienced doctor, is plainly an important one. It signals the extent of A's deterioration.

27. Due to his truncal stiffness, it has not been possible to turn A prone, to try to improve ventilation and oxygenation and when attempting to do this, reduced anal tone and pressure on his abdomen has resulted in stool leaking out. His eyelids are also beginning to retract due to muscle stiffness, resulting in difficulty maintaining corneal hydration and his head circumference has begun to diminish. Despite the best efforts of his treating clinicians, A is now at risk of pneumothorax (collapsing of the lung) and iatrogenic pressure related lung injury (i.e., caused by the treatment itself) due to the need for high pressure ventilation. A's heart rate has also fallen from 140-190 beats per minute in July 2022 to 100 to 140 in August. This is considered to be further evidence of general and significant decline. It is impossible to escape the conclusion that treatment is futile, it protracts death rather than promotes life. Objectively, it now causes harm rather than alleviates suffering. All the doctors respect this couples' obvious faith and the care and love that they hold for their son. Dr Brierley was open and clear with the father in his discussions, *"I explained that whilst I respect their thoughts based on their devout faith, my opinion must be based on my medical expertise derived from my experience and the worldwide literature"*.

28. On the question of whether A can feel pain, pleasure or comfort, Dr Brierley said this:

> *"All these feelings are subjective, meaning only the person affected can determine what is experienced. A did not display any response to pain when I assessed him, nor any external signs of experience such as pleasure or comfort. However, with*

> *disorders of consciousness, a single examination is inadequate. More useful are the accumulated observations of the medical and nursing team and of A's dedicated parents, who spend considerable time with him. The nursing and medical staff do not describe or record any purposeful movements or reactions to pain. In addition, they do not see any signs of interaction or comfort from stimuli such as touch or voice, and there was no response to external noise/stimuli described on the concurrent EEG trace. A's parents, whilst understanding the clinical diagnosis of severe irreversible brain injury, consider some of the changes in 1 above to indicate he is 'there' and can experience and respond to the external environment. We spent time discussing these signs and their possible implications."*

29. Dr Brierley also addressed a number of the parents' specific concerns. The one that struck me most poignantly was F's interest in the significance of a family trait he had noticed in his son. He told me that both he and his father experienced a hot and red right ear in childhood when they were embarrassed or had other strong emotions. He had seen this in A and was perplexed as to what signal that might be sending as to the severity of brain injury. Dr Brierley told him that this cutaneous flushing is well described in children and is an essentially benign physiological response in some children with vasodilation to the earlobes, leading to increased blood flow. F interpreted the presence of this as indicating a capacity to feel emotion. I found F's observations and analysis to be subtle and intriguing. They also reflected his intimacy with his son. The simple truth is that Dr Brierley can offer no explanation other than to suggest that the autonomic nervous system also mediates vascular tone.

30. For completeness, I should also record two other issues the parents raised and Dr Brierley's response:

> ***"Movement of his head, including movement from side-to-side;***
>
> *Both As team and his parents have seen several spinal reflexes, well described in the most severely brain injured children. However, the clinical team do not recognise the side-to-side movements as purposeful but consider them secondary head movements – though more up and down – due to A's very pronounced truncal hypertonia and the effects of the mechanical ventilator. No such movements happened during my examination; however, I have not seen such minimal head movements in children indicate neurological improvement in severe brain injury. In this context, it is essential to reflect that no medications are suppressing A's consciousness or ability to move at this stage.*
>
> ***Variation of his heart rate;***
>
> *Whilst a decrease in heart rate variation can occur in severe brain injury and is frequent in patients diagnosed with brain*

> *death, the presence of a small degree of variability is not a favourable prognostic sign in my experience. The bottom of A's brain, the brain stem, has some function left, as demonstrated by his respiratory effort (see 3). Autonomic nervous system activity is also a brain stem activity, so some heart rate variation may be present without indicating consciousness or emotion. I understand that there are no described heart rate changes to stimuli, such as suctioning. If changes in heart rate could be demonstrated to correlate with interaction such as parent voice or touch, this could support the existence of a level of awareness".*

31. This case has taken a great toll, most obviously on the parents but also on the treating clinical team. It is an indicator, ultimately of the strength and character of both, that they retain such obvious sympathy and respect each for the other. There is a recognition, by both, that when all else is paired down in this case, I am asked to balance concepts which are at very least difficult to reconcile, some might say, impossible. Dr Brierley is correct when he identifies the central tension in this case as being that between faith and medicine.

The framework of the law

32. *In North London Clinical Commissioning Group v GU,* ***[2021] EWCOP 59***, I observed the following:

> *"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. Firstly, 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."*

33. The leading and clearest iteration of the law remains that in *Aintree University Hospital NHS Trust v James [2013] UKSC 67*:

> *"[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.*
>
> *"[45] Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests' test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."* (per Baroness Hale)

34. A's rights, protected by the European Convention on Human Rights, are engaged. In the present context, the relevant rights are established by Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment)

and Article 8 (the right to respect for a private and family life). As the ECtHR recognised in *Burke v UK [2006] (App 19807/06)*, ***[2006] ECHR 1212***:

> *"the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (see also its findings as to the compatibility of domestic law with Article 2 in Glass v. the United Kingdom, no. 61827/00, § 75, ECHR 2004-II)."*

35. In this context in *Aintree University Hospitals NHS Foundation Trust v James* (supra) at [22], per Baroness Hale highlighted the following, which seems to me to be particularly apposite in this case:

> *"Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on 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 that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."*

36. These sentiments were re-stated in *An NHS Trust v Y [2018] UKSC 46* at [92], Lady Black delivering the judgment of the court stated:

> *"Permeating the determination of the issue that arises in this case must be a full recognition of the value of human life, and of the respect in which it must be held. No life is to be relinquished easily."*

37. I have once again considered the cases of *Fixsler v Manchester University NHS Trust* ***[2021] EWCA Civ 1018*** and *Barts NHS Foundation Trust v Raqeeb & Ors* ***[2019] EWHC 2530 (Fam).*** I have given much thought to McDonald J's judgment in *Raqeeb*. The following passage, in that judgment, is significant:

> *"The court must face head on the question of whether it can be said that the continuation of life sustaining treatment is in Tafida's best interests. 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. In this context, I do not discount the grave matters prayed in aid by the Trust. However, the law that I must apply is clear and requires that the best interests decision be arrived at by a careful and balanced evaluation of all of the factors that I have discussed in the foregoing paragraphs.*

> *Having undertaken that balance, in circumstances where, whilst minimally aware, moribund and totally reliant on others, Tafida is not in pain and medically stable; where the burden of the treatment required to keep her in a minimally conscious state is low; where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to placing her in a position where she can be cared for at home on ventilation by a loving and dedicated family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction; where there is a fully detailed and funded care plan to this end; where Tafida can be safely transported to Italy with little or no impact on her welfare; where in this context the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised; where, in the foregoing context, transfer for treatment to Italy is the choice of her parents in the exercise of their parental responsibility and having regard to the sanctity of Tafida's life being of the highest importance, I am satisfied, on a fine balance, that it is in Tafida's best interests for life sustaining treatment to continue.*
>
> *It follows from this conclusion that I am also satisfied, the court having determined the dispute regarding best interests in favour of the treatment being offered to Tafida in Italy, there can be no justification for further interference in Tafida's EU right to receive services pursuant to Art 56."*

38. MacDonald J's findings in that case i.e., minimal awareness, low burden of treatment and a positive finding that T was not in pain, provide a factual substratum different from that which arises here. A, I accept, is dying. The evidence of it is beyond any coherent contrary analysis. The parents recognise this. I give great weight to their faith and beliefs, which are deeply held and sustain them. During the course of this hearing, I declared that, with immediate effect, and prior to the delivery of this judgment, notice should be given to the clinical team that the Court had had declared that CPR should not be undertaken. The evidence was that it would have no prospect of success and would be compromising to the dignity of all involved were it to occur. I invited the parents to think carefully about it because it was a decision that I preferred to come from them as parents and not me as a Judge. Within a very short period, they were able to agree and, I was entirely satisfied, that they were comfortable with it.

39. For reasons which I entirely understand, they make a distinction, in their faith, between that which is the will of Allah, which they would perceive cardiac arrest to be, and the obligation in their faith to promote life at all costs.

40. My unwavering focus must be fixed on that which I assess to be in A's best interests. I have taken time to survey the broad canvas of the evidence in this case, as I am obliged to do, and not merely the medical evidence. The spectrum here, given A's short life, is narrower and more circumscribed than in some cases. Nonetheless, the culture and faith into which A has been born is an

important factor, however difficult it might be to calibrate the weight to be afforded to it. Ultimately, the severity of A's brain injury, the complete absence of any ability to benefit from treatment, the impossibility of excluding potential for residual pain and the burden of the treatment itself illuminate mechanical ventilation as contrary to A's best interests.

41. There is unique value in human life, frequently referred to as the 'sanctity of life'. That does not dissipate where awareness diminishes, or the capacity of the brain becomes so corroded that all autonomy is lost. It is perhaps in these circumstances that it requires the most vigilant protection. The evidence is clear that A is now dying and will die, at some indeterminate point, whether ventilated or not. To continue ventilation will serve here only to protract death. In simple terms, it would confer harm without conveying benefit. That cannot be reconciled with the ethical obligations of the treating clinical team nor can it be in A's best interests. For this reason, the ventilation should be withdrawn, and palliative care provided.

42. This case has raised real and important questions as to the confidence that can be placed in the **Code of Practice for the Diagnosis and Confirmation of Death** in cases involving infants. The identified conditions necessary for the prognosis and confirmation of death (para 5) may need to be reviewed, as Dr Brierley suggests, particularly in the context of babies under 6 months of age and those with open fontanelles (as here). I have been told that the Royal Academy of Medical Colleges are considering their guidelines and that these are being reviewed, both at a national and international level. In other countries, for example, the USA and Australia, a test of whole brain death is applied. I should record that I have been told, that the application of this test here, would have yielded the same results. Dr Z has told me that the advice and guidelines are anticipated relatively quickly. Though I do not want to be prescriptive, I record that it strikes me that the appropriate application in most cases concerning infants, or at least until further guidance is received, is to make an application predicated on the patient's best interests rather than to seek a certification of brain stem death.

Postscript

43. On the 25th July 2022, a Fatwa was ordered decreeing that A *"cannot be taken off life support in any way and pushed to the lap of death".* It was issued in Bangladesh. It is important to record that the identified sanctions focus upon the *"permanent anger of Allah"* and do not contain any express threats to life. This case has been heard in open court where this matter has been discussed in the context of the implementation of the palliative care plan, it is therefore necessary for me to mention it in this judgment. The focus of the care plan is to afford A peace, privacy and the intimate comfort of his parents at the very end of his life. The hospital has made sensitive and family focused plans to continue to promote this. I entirely agree with their approach whilst recognising that some sensitive accommodation might have to be made to protect the identity of some of the treating clinicians.