



Neutral Citation Number: [2022] EWFC 14

Case No: FD21P00855

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 04/03/2022

**Before:**

**THE HONOURABLE MR JUSTICE HAYDEN**

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**Between:**

**THE NEWCASTLE UPON TYNE HOSPITALS**  
**NHS FOUNDATION TRUST**

**Applicant**

**- and -**

- (1) H (A Child by his Cafcass Guardian)**
- (2) Mrs A (Mother)**
- (3) Mr B (Father)**

**Respondents**

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**Ms Claire Watson** (instructed by **Ward Hadaway**) for the **Applicant**  
**Mr Neil Davy** (instructed by **CAFCASS**) for the **First Respondent**  
**Ms Maggie Jones** (instructed by **Ben Hoare Bell**) for the **Second Respondent**  
**Mr B** (as a Litigant in Person)

Hearing dates: 1- 2<sup>nd</sup> and 4<sup>th</sup> March 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.

.....  
**THE HONOURABLE MR JUSTICE HAYDEN**

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 incapacitated person and members of their family 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 Hayden:

1. This application concerns H, who is now one year old. In June 2021, he sustained a profound hypoxic brain injury following a drowning incident, whilst being bathed at home by his mother. The extent of the brain injury has been characterised as ‘devastating’, consequent upon cardiac arrest and a delay of 29 minutes before circulation could be recovered. H is currently intubated and ventilated in Paediatric Intensive Care (PICU). The consensus of evidence, both independent and within the clinical team, has concluded that H’s treatment is now futile and burdensome. The applicant Trust seeks declarations that it would be lawful and in H’s best interest:
  - i) That mechanical ventilation should be withdrawn;
  - ii) That cardio-pulmonary resuscitation and resuscitation drugs including inotropes, should not be given in the event of a cardiopulmonary arrest;
  - iii) That he should be provided with such treatment, palliation and nursing care as advised by the responsible medical and nursing practitioners, whether at hospital or elsewhere, to ensure that H suffers the least pain and distress and retains the greatest dignity.
2. H has been represented by his Guardian in these proceedings. She has described this as a ‘truly tragic case’ and expresses “*the greatest of sympathy for the position that H’s mother and father find themselves in*”. With great reluctance, but nonetheless, with clarity the Guardian considers that the declarations should be granted in the terms sought. She analyses this to be in H’s best interests.
3. The Mother (MRS A) and Father (Mr B) resist the applications. Recognising the force of the medical evidence in support of the application, they contend that insufficient weight has been given to some of H’s recent behaviours and responses which they argue ought to be viewed as markers of an improving clinical situation. They ask that H “*ought to be given more time*” in order that these responses and behaviours might be more thoroughly assessed.

## Background

4. H was admitted to PICU at the end of June 2021. The history given, by the parents, was that he had suffered a drowning event at home whilst in the bath. They related that H was wearing an inflatable device. Mrs A stated that she had left the bathroom to get a towel. A short time later, Mr B entered the bathroom and found H face down in the bath with no pulse. He pulled H out of the bath, placed him on a sofa and commenced cardiopulmonary resuscitation (CPR). The parents telephoned 999 but Mr B, recognising the gravity of the situation, began the journey by car to the local hospital, which was not that far away. There was no CPR during this journey (approximately 6 minutes). The family were met, enroute, by the paramedic team. When assessed by the paramedics H was still in cardiac arrest and had no sign of electrical activity from his heart (asystole). CPR was commenced and H was transported to his local hospital where resuscitation continued in the Emergency Department. Return of spontaneous circulation finally occurred 29 minutes following the 999 call. Manifestly, this is a long period of time without any effective circulation.

5. Initial stabilisation was carried out at the local hospital. H was intubated and ventilated. He remained unresponsive with fixed dilated pupils. A CT scan of his head was carried out, which showed no significant abnormality. H was then transferred to PICU by the regional paediatric critical care transport team.
6. When H arrived in PICU, the neuroprotective critical care measures which had been commenced at the local hospital were continued. H was kept sedated, given muscle relaxant medication, and nursed in a head up position; ventilation and blood pressure were carefully controlled; blood sugar and temperature were kept as normal as possible. These measures are constructed to maintain the patient in a stable physiological state, to help reduce secondary brain injury and to give the brain the best possible chance to recover. The practice in this PICU, is to continue with these measures for a period of at least 48 hours, after which they are stopped, and the patient can be assessed clinically. All this was followed in H's case. Later, as I will record, Dr Daniel Lumsden, Consultant Paediatric Neurologist, conducted an independent report assessing H's treatment and prognosis. Dr Lumsden, in his evidence, described these neuroprotective measures, at this early stage, as a paradigm of good practice. The hospital is well regarded nationally.
7. On the 27<sup>th</sup> June 2021, there were some concerns regarding possible seizure activity detected on a bedside 2-channel electroencephalogram (EEG). These resolved when H was treated with anti-epileptic medication. On the following day H had a more detailed formal EEG which did not show any further seizure activity. Neuroprotective measures were lifted on 29<sup>th</sup> June 2021. H's muscle relaxant was discontinued. His sedative medication was reduced more slowly, due to concerns regarding seizure activity, and was finally discontinued after a further 48 hrs. His antiepileptic medication was optimised as his sedative infusions were reduced. An MRI scan of H's brain was carried out. This was reported as having overall appearances in keeping with an extensive hypoxic ischaemic brain injury. H's parents were updated regarding the result of the scan by the responsible PICU consultant. They were informed that this result meant that H was likely to be very severely affected by his brain injury.
8. On 30<sup>th</sup> June 2021, H was assessed formally by a consultant paediatric neurologist. H was on a low dose of sedation, which would have permitted him to show response on examination. He remained deeply comatose and did not respond to painful stimulus. His Glasgow Coma Score was 3. It is important to highlight that this is the lowest possible score on the scale and reflects the extent of H's unresponsive condition. Later, in his evidence, Dr Lumsden described this as being the highest end of the spectrum of unresponsiveness.
9. H's pupils were reacting "very slightly if at all". In her report, dated 10<sup>th</sup> November 2021, Dr W, a Consultant Paediatric Intensivist, records the following:

*"Basic reflexes were not present (no cough or gag reflex; no corneal reflex). H showed some evidence of being able to take some breaths, but his breathing pattern was very abnormal and irregular. These clinical findings showed that H had suffered an extremely severe brain injury and was unlikely to survive. H's parents were again updated, on this occasion by both the intensive care and neurology consultants. They were understandably upset regarding the clinical evaluation. On*

*01/07/21 they remained upset but informed us that they were praying for a miracle to happen and that H's heart was beating, and he was alive. They asked for a letter from the hospital to support H's maternal grandfather travelling to the UK and this was provided. Over the next few days H had some seizure activity requiring medication and needed ongoing ventilation and support. Other than this his condition remained the same."*

10. At the end of his first week of admission, H had a raised temperature and the secretions from his chest were described as "*thick*". An infection was suspected. As I have been told, this is not at all unusual for ventilated children in PICU. It is important to bear this in mind because it becomes one of the factors when evaluating H's best interests at this hearing. Respiratory and blood cultures were both positive for infection and H was treated with appropriate intravenous antibiotics.
11. Over the next week H continued to be treated for infection. Whilst his seizures had settled, there was no other significant change in his condition. He continued to show no spontaneous movements. His breathing pattern remained very abnormal but over a number of days became more regular. On clinical assessment it was considered to be reasonable to conduct a trial of extubation, i.e., removing the breathing tube to see if it was possible for H to manage without it. This was discussed with H's parents and they agreed to the investigation. It is important to record that they were both very clear that should H not be able to breathe independently, either at this trial or at a later point, they would always wish him to be supported with a breathing tube and ventilator.
12. H was extubated on 9<sup>th</sup> July 2021. Failure was absolute. He was clearly unable to breathe effectively, and his oxygen saturation level dropped rapidly. Whilst he had "*good respiratory effort*" at the time, the pattern of his breathing suggested that his airway was obstructed. This was considered by Dr W and the team to be "*most likely due to his inability to hold the muscular part of his upper airway open.*" This was later confirmed on examination in theatre. H was supported with bag and mask ventilation and was re-intubated. Naturally, both parents were devastated.
13. On the following day, H had an acute cardiovascular event: he became bradycardic (a very slow heart rate) and had a further cardiac arrest. Mrs A, as she told me in evidence, was particularly distressed by this. However, H was immediately resuscitated and there was a return of circulation after 10 seconds. It is difficult to be clear about what triggered this event. H did not require any cardiovascular medication and responded very quickly to intervention. Following this episode, there was a conversation with the parents which confronted the severity of H's brain damage and his very poor prognosis. Both parents felt that it would be in his best interests to be resuscitated if he suffered a further cardiac arrest.
14. H remained intubated and ventilated with "*an irregular breathing pattern and poor respiratory drive*". He showed no clear response to any interventions and no voluntary movements. His pupils were still not responding to light and he had no other reflexes. Approximately two and half weeks after his admission, H showed some evidence of pain response when examined by the neurology consultant. There was also some evidence of what is termed, 'spasticity' i.e., increased tone or stiffness, developing in his lower limbs, for which he was commenced on medication.

15. The parents were, in my judgement, sensitively but clearly, told of the clinical opinion regarding the severity of H's brain injury. Having listened to their evidence and the way each of them articulate their case before me, I was left with the impression that they had intellectually absorbed the terrible news. Mrs A particularly has revealed a grasp of the medical issues. She is an intelligent, articulate postgraduate student. In stark and simple terms, it requires to be identified that H had suffered a devastating brain injury due to deprivation of oxygen. He is unable to breathe successfully for himself because of a combination of airway obstruction and compromised respiratory drive. His parents were told that if he survived, he would be "*very severely affected*" and was likely to have seizures. Again, both parents were clear that they would not wish extubation to take place. The concern expressed by the PICU consultant team was that H's brain injury was so severe that ongoing intensive care would not increase H's chances of recovery nor lead to, his going home with his family. Given this concern, a multi-disciplinary team discussion (MDT) was organised.
16. On the 15<sup>th</sup> July 2021, H's clinical course and current status was reviewed and options for his management were discussed. It was decided that an examination under anaesthesia would be reasonable, to ensure there was no anatomical reason for H's airway obstruction (which might be amenable to treatment) and to assess his breathing in a controlled way. Given the neurological presentation, it struck me that the decision to investigate under general anaesthesia was a courageous one. It signals to me the determination of the team to explore every avenue to achieve an outcome that embraced the parents' hopes. There was a further discussion evaluating the potential for longer term support for H, by way of non-invasive ventilation, using a mask, or invasive ventilation using a tracheostomy tube. This was forlorn, H's inability to cough and clear secretions meant that he would not be clinically stable enough even to progress to a ward on a portable ventilator. Again, this requires to be emphasised as a marker of the severity of his condition and, regrettably, as an indicator of the limited options for the future. Explicitly, the parents have had to accept that it discounts the possibility of long-term ventilation at home. Indeed, as a long-term option, it discounts even a removal to the ward away from PICU.
17. It was also decided that if the airway assessment confirmed the working clinical diagnosis, i.e., no reason other than the severity of H's brain injury to cause his inability to breathe effectively, second opinions would be sought, and H's case discussed with the hospital's Clinical Ethics Advisory Group (CEAG). In the days that followed, H showed some further signs of respiratory infection (thicker secretions and very slight increase in oxygen requirement) although there was no rise in inflammatory markers consistent with significant infection. H was treated with intravenous antibiotics and was not taken to theatre for assessment until his condition optimised. H underwent his examination under anaesthesia on 21<sup>st</sup> July 2021. There was no anatomical abnormality of his airway. Severe pharyngeal hypotonia (very floppy muscular portion of the upper airway) was noted, confirming H's inability to keep his airway open. H's breathing was also assessed. He took very few breaths when extubated in theatre and only some "*abnormal gasps*" were seen over a period approximately 30 minutes.
18. H's parents were informed of the results of his examination. They were told, unambiguously, that these findings reflected the severity of H's brain injury. His parents did not agree with the clinical assessment of his condition. They considered that he was improving and getting stronger. They thought they detected some behaviours

which supported this. It is important that I record what I assess as the absolute sincerity of their beliefs both as to what they were seeing and in their impression of its significance. Due to the ongoing difference in opinion, it was decided to put H's case to the (CEAG). Clinical second opinions were also sought from experts in the fields of paediatric intensive care and paediatric neurology. In their evidence before me, both parents have construed this meeting as indicating a premature leap, by the clinical team, to the serious conclusions that I have set out. Each parent suggests, in their very different styles, that this premature conclusion has influenced the thinking of the doctors and led them to disregard what they perceive to be continual signs of improvement.

19. It is for this reason that I have set out this chronology in such detail. It reveals a very different picture to that asserted by the parents. Rather than rushing to a premature conclusion, it strikes me that the clinical team went to quite extraordinary lengths to explore the possibility of a more positive outcome, even in the face of compelling medical evidence to the contrary. It was not that they reached a premature conclusion, the reality from this early stage was that this was a brain injury of such devastating consequence that there was a vanishingly small prospect of survival. Even a prospect characterised in these terms however, would be enough for many parents to cling onto. It certainly was for Mrs A and Mr B in this case. The investigations, in my judgement, were extensive and might properly be described as exhaustive.
20. The CEAG met to consider H's case on 4<sup>th</sup> August 2021. In her report, Dr W has stated that members of the group had an opportunity to speak with the family in advance of the meeting. She reports a thorough discussion, at the meeting, of all aspects of H's case. The consensus of the group was to seek second opinions and possibly to trigger a mediation process which would allow some time for the parents to come to terms with the medical conclusions. Thought was given to family support and the support of an Imam, whom the parents had been introduced to, by the hospital. There can be very little, if indeed anything, more painful for an adult human being than being told that it is in the best interest of their child that life support be discontinued. It is a situation which defies human empathy. The instinctive reaction is to recoil from pain of that magnitude. It also has to be recognised that it is incredibly challenging for the clinical team. Their instinct is to save life, to promote health, and to minimise pain. Their ethical obligation is to do no harm.
21. The team concluded that continuing to support H, when they had identified no prospect of recovery, would be unethical. By this, was meant that the treatment was futile and, given the intrusive nature of it, the balance had shifted between treatment which was desirable and treatment which had become harmful. A great deal of effort was dedicated to achieving space and time for the parents to absorb the medical realities. These dreadful dilemmas are more commonly confronted by parents whose babies have been born with a life limiting or seriously degenerative condition. It has to be remembered, this was not the case here. Prior to the drowning incident, H had been a healthy, happy little boy. His mother showed me videos of him filmed shortly before the tragic events of 26<sup>th</sup> June 2021. It is clear that the particular circumstances that led to this devastating, irreversible, hypoxic brain injury generated a real recognition by the treating team of the enormous emotional challenges faced by the parents in any acceptance of the prognosis. H is the couple's first child. He was much wanted and much loved by them

and by the wider family. What occurred was a tragedy of almost immeasurable dimension.

22. An Imam who works with the Trust, was already known to the family by the time of the CEAG meeting and had introduced them to the local mosque. He was present at the meeting and made himself available to provide support for the family. He remains available. The parent's faith is important to them. Mrs A dresses traditionally. The couple has known each other for many years. They are cousins. Their marriage was arranged. They have a strong and obviously supportive relationship. Mr B is very protective of Mrs A. He respects her and obviously admires her academic commitments. Mrs A refers to Mr B as her 'partner', not as she told me, out of any disrespect but because she admired the way the term is used in the West. Both parents were equally resistant to the medical advice. Mrs A has expended great energy trying to undermine the medical consensus. Mr B exhibits anger with some of the professionals. Mrs A tries to temper his excesses. She has no need to, I sense that the nurses and the medical staff, who are all greatly experienced, recognise Mr B's anger as a facet of his grief.
23. Accordingly, second opinions were sought from Dr Joe Brierley, a Consultant Paediatric Intensivist at Great Ormond Street Hospital and Dr Daniel Lumsden, a Consultant Paediatric Neurologist from Evelina London Children's Hospital. Dr Brierley has met with H and his parents on 16<sup>th</sup> July 2021, reviewed H, again with his parents, on 28<sup>th</sup> August 2021.
24. I have little doubt that Mrs A and Mr B invested great hope in this process and that they were devastated by the fact that both experts ultimately confirmed agreement with the clinical opinion of the intensive care and neurology teams the treating hospital. Dr Lumsden advised that a repeat MRI scan of H's brain might be helpful in demonstrating to the parents the sequelae of severe brain injury, although it would not provide any new prognostic information. Conducting an MRI scan, where it is not medically required is uncommon. Here however, a repeat MRI scan was undertaken entirely to help the parents try to understand the evolution of the cerebral atrophy, consistent with maturing global hypoxic ischaemic injury. As I have said, I have no doubt, that on an intellectual level, both understand what has happened to their son, but on an emotional level, they simply cannot absorb it. Mrs A told me in evidence that even if H remained on the ventilator, which of necessity would have to be in an intensive care unit: *"this would be more than enough to devote my life to him"*. Dr Lumsden told me that it is unlikely that H even knows his parents are there. He has little sensory perception and no hearing.
25. Advice was sought from the Medical Mediation Foundation. The aim was to facilitate open conversations with H's family and to try to ensure that views were exchanged clearly and without hindrance. This process began on 2<sup>nd</sup> August 2021 and continued until 5<sup>th</sup> October 2021. I note that the mediation ranged over an 8-week period. It is entirely confidential. I have noticed that Mrs A, in particular, has a sophisticated understanding of the medical issues. I cannot know, but I suspect that part of this derives from the time and effort put into the mediation process. The availability of such a service strikes me as having invaluable potential, even where it doesn't achieve its stated objectives. It may for example, establish a greater respect for and understanding of different views. This in turn may defuse some distress and anger and benefit the parties in the court process that follows. Without intending any criticism at all, I



nonetheless find it important to reinforce the fact that the timescales of such mediation must be guided by those of the child/patient, taking care to identify the point where they might diverge from the timescales of the parents or family. When there is a plan to discontinue treatment, on the basis that it is both futile and burdensome, it is ordinarily likely to be in the best interests of a child for there to be agreement as to the way forward, on the part of all concerned. That is most likely to protect the child's dignity at the end of life. The lodestar, however, must always be the needs of the child.

26. H remains intubated and ventilated in PICU. He is ventilated on low settings (low pressure and oxygen requirements) reflecting the fact that he does not have any significant lung problems. His heart rate and blood pressure are stable. He has pupil reactions which vary. His eye movements were originally mostly horizontal from side to side (described as roving movements) but that has changed in recent months. Sometimes H's pupils are still, though he does not show signs of being able to fix his gaze on an object.
27. Crucially, when evaluating the seriousness of H's situation, it is important to emphasise that he has no cough or gag reflex. He is unable to swallow or to clear his own secretions and his bedside nurses have to clear his secretions by suctioning on a regular basis. Mrs A and Mr B spend a huge amount of their day dedicating themselves to H's care, bathing him, changing him and when there is a suitably experienced nurse available, cuddling him. They do not undertake the suctioning though Mrs A has told me she would like to. Mrs A believes that when she cuddles H, this soothes him. Dr Lumsden thought this unlikely. He considered that it is "*unlikely that H experiences either pain or pleasure*". He was pressed on this in cross examination and was ready to accept that "*on some primitive level*" H might react or recoil from irritating intervention e.g., suctioning or cold water. I found MRS A's account that H is sometimes soothed by being cuddled for a short time to be convincing. It did not strike me as being inconsistent with what Dr Lumsden had said. It may be that this too, is a simple, primal, or primitive reaction. Certainly, it is everything for Mrs A. She told me "*it is a big position of pleasure for me when he is in my arms, so chilled out, so relaxed*". I am prepared to contemplate that something of her own calm pleasure communicates itself in some way to her son.
28. I heard in evidence from Dr Brierley and Dr Lumsden. Both attended Court. I also heard Dr W, Dr R and Nurse A. Their evidence was taken together by way of the procedure known as 'hot tubbing'. This option for expert witnesses, in all civil proceedings, to give their evidence concurrently was introduced by CPR PD 35, para 11 under the April 2013 Jackson Reforms. It worked particularly well here. The thrust of Ms Jones' cross examination, on behalf of Mrs A, was to investigate the nature, extent, and significance of H's current presentation. Inevitably, these 3 witnesses were differently placed to answer the different facets of the enquiry. They responded to the questions when they each had something to say, and it fell within the area of their particular discipline.
29. Dr Lumsden articulates the consensus that H suffers from a persistent disorder of consciousness. He told me in evidence and, again, I noted in Mrs A's evidence that she had understood this carefully, that the most severe disorder of consciousness is "*coma*", a state of unarousable unresponsiveness. H was in this condition immediately following his cardiac arrest. Dr Lumsden reported having described H to his parents as being in "*a vegetative state*". He told them, and they understood this to be, a state of wakefulness without awareness. It permits of a vestigial capacity for spontaneous or

stimulus induced arousal, but it does not encompass any self or environmental awareness. Dr Lumsden is clear that H continues to exhibit this degree of disorder of consciousness. In his most recent report, dated 20<sup>th</sup> February 2022, he describes how he discussed with the parents that “*consciousness*” is a difficult term to define but incorporates both “*wakefulness and awareness*”. ‘Awareness’ is the ability to have experience of any kind, and ‘wakefulness’ is a state in which the eyes are open and “*there is a degree of motor arousal; it contrasts with sleep-state of eye closure and motor quiescence*”. Those definitions were taken from the Royal College of Physicians 2020 document: “**Prolonged disorders of consciousness following sudden onset of brain injury – National Guidelines**”. Dr Lumsden applies them by parity of analysis, there are no separate guidelines for PDOC in children. The following extracts from Dr Lumsden’s report of the 20<sup>th</sup> February 2021, require to be set out:

*“With regards to [H]:*

- 1) The cause of his brain injury is clear, and relates to the cardiac arrest he has experienced;*
- 2) I believe reversible contributors can be excluded. I do not believe [H’s] current medications are causing sedation to the extent that interferes with his assessment. There is no evidence of a metabolic disturbance, and throughout my 2 assessments is carbon dioxide levels have remained within normal levels. There is no evidence to suggest [H] may be experiencing sub-clinical seizures (his parents agreeing that seizures of any type have not been witnessed for some time, with an agreement made with his local paediatric neurology team to being to reduce his anti-epileptic medications).*
- 3) I have undertaken assessments on 2 occasions now – 28<sup>th</sup> August 2021 and 16<sup>th</sup> February 2022. During both assessment [H] was well positioned in an appropriate environment, and there have been no factors (e.g. intercurrent illness) which I believe would confound the assessment.*

*The movements I have observed [H] make during both of my assessments I do not believe to be deliberate or purposeful. He has exhibited spontaneous movements and reflexive movements/responses which I would consider to be typical behaviours known to occur in VS. This includes roving eye movements, purposeless turning of the head, shedding of tears along with the facial grimacing which accompanies suctioning (as I have witnessed) and painful procedures such as cannulation (which I have not witnessed, but has been described by [Mrs A] and [Mr B], with confirmation by the nurse by his bed side on 16<sup>th</sup> August 2022).*

*I have seen no evidence on either of my assessments that [H] demonstrates any self or environmental awareness. I do not believe it is possible to exclude that [H] might experience*

*discomfort, pain or pleasure at some level, but on the balance of probabilities I believe this is unlikely. I have discussed with [Mrs A] and [Mr B] that I do not believe there is hope for a significant neurological recovery. [H] has shown no signs of neurological recovery between my two assessments, having been in my opinion in a VS on 28<sup>th</sup> August 2021, and remaining in VS at my assessment on 16<sup>th</sup> February 2022. I do not believe his conscious level will improve, and I do not believe further spontaneous improvement in his brainstem dysfunction is likely to occur. I do not believe there are any viable treatments that would result in an improvement in his neurological condition.”*

30. In his evidence and in his very recent statement, Dr Lumsden engaged in detail and respectfully, with the parent’s perception that they have seen signs of improvement. Some of these are very basic e.g., Mrs A interprets the fact that H has continued to grow, as a cause for more general optimism. She showed me 2 caps that he has, the second being larger than the first. Mrs A saw head growth as opening the potential for brain growth or recovery. There is no link between the two. I note that, H’s head is on the 6<sup>th</sup> centile. Dr Lumsden was very clear that on the basis of his assessment on the 16<sup>th</sup> February 2022, and the review of the clinical records, that there was no reason for believing H had shown signs of improvement that were clinically significant. In particular, he was clear that there was no movement from a vegetative state.
31. It is very important here to recognise that these are not parents who have convinced themselves of behaviours which could not have occurred. On the contrary, what they are reporting appears largely based in the facts. Dr Lumsden illustrates this when he signals that there has been some improvement in H’s motor disorder. It does not require any imagination to see how parents in this situation would latch on to such a remark, but there is, all agree, no connection between that and any further significant neurological recovery. To understand what the parents are seeing, it is necessary to consider the views of both Dr Lumsden and Dr R who analyse the increasing plasticity in the developing brain which permits potentially, for other regions of the brain to compensate for areas of injury when damage has occurred. In H’s case however, the injury is simply too extensive and severe for there to be compensation.
32. H has a generalised, predominantly dystonic motor disorder and brain stem dysfunction. This is indicative of a severe bilateral brain insult. Dr Lumsden further rationalises that the pattern of injury on initial and subsequent MRI imaging, and the failure of significant improvement all indicates the severity of the damage. Dr Lumsden also reviewed the published data regarding the clinical evolution of children experiencing severe hypoxic brain injury in infancy, resulting in a vegetative state. He properly signalled that there is relatively limited research, the main focus of which appears to have been on unilateral lesions, whereas we are here concerned with a bilateral injury. He cites a broader review of plasticity after early brain injury written by V Anderson, M Spencer Smith, A Wood: Do Children Really recover better? Neural behavioural plasticity after early brain insult. *Brain*, 2011: 134 (8): 2197-227. The authors of that review note that following an acute hypoxic ischemic insult affecting both sides of the brain, “*little healthy brain tissue is available to support reorganisation. As a consequence, the brain is unable to reorganise or recruit healthy*

*brain regions and functional outcomes commonly include speech and language delay or global developmental delay”.*

33. The signs recognised by the family included H’s apparent medical stability, his physical growth, his eye opening, visual behaviour, head turning, response to touch, response to temperature and pleasure on being cuddled. Dr Lumsden recognised two main changes, he catalogues them in his report as follows:

*“The 2 main changes I have observed are:*

- 1) There has been some improvement in [H’s] motor disorder. His tone at rest by the bed side was less elevated. There was less spontaneous dystonic posturing. Touch to either upper or lower limb did not as consistently result in dystonic posturing in that limb or a distal body part. When dystonic posturing was produced, the affected body part relaxed more rapidly than during my review of 28th August 2021, and the initial dystonic posturing was less pronounced. In addition to this, there has been a reduction in the spinal clonus in his left lower limb (spinal clonus in his right lower limb remaining unchanged). I have explained to [H’s] parents that in my experience the natural history of the motor disorder experienced after an acute acquired brain injury is for a period of low tone followed by the emergence of high tone (dystonia and spasticity) which can decrease over a period of weeks/months. [H] still demonstrates both dystonia and spasticity, but this does not at present appear to be causing pain/discomfort in and of itself or interfering with the delivery of daily cares. I did not on the basis of my assessment on 16th February 2022 see any signs of the emergence of deliberate, purposeful movement which would suggest recovery of his motor system or consciousness.*
- 2) Whilst [H] continues to demonstrate ongoing roving eye movements, largely in the horizontal plain, there are more frequent periods when his eyes are still. [H’s] parents describe him as “staring” when his eyes still, but I could see no evidence that his eyes were focussing at these times. I did not see any evidence of [H’s] eyes fixing on any object or face they were presented with. There was no response to visual stimulation, barring a constriction of his pupils to the light of a pen torch. I do not believe that the more frequent stilling of his eyes represents any improvement in either his visual responses or conscious level in general. I did not observe any signs during my assessment incompatible with the vegetative state, or suggestive of a minimally conscious state which would suggest an improvement in conscious level.”*

34. From the key perspective of paediatric neurology, neither Dr Lumsden nor Dr R, saw any possibility that H had or could develop any deliberate or purposeful response. The

damage to his brain is simply too extensive and there has been no sign, at all, of neurological recovery. The behaviours that the parents cling on to, both doctors are clear, are part of the small changes in his clinical evolution. In my judgement, they are understandably misinterpreted as indicators of recovery by parents, suffused with inexhaustible hope. The signs they concentrate upon are objectively, to the lay person, barely noticeable. It is a reflection of the enormous devotion of these two parents and the length of time they have spent with their son, that they have spotted every minute change in him.

35. Though Dr Brierley was called to give evidence, the focus of enquiry at this hearing has centred upon the neurology. I record that Dr Brierley concluded that H had suffered a severe, irreversible hypoxic ischemic brain injury which led him to the following conclusion:

*“No treatments can improve the brain situation, which is at the most severe end of, children who have survived at this stage. Further time on mechanical support will not improve the state of [H’s] brain but will be associated with the continuing burdens of mechanical ventilation such as suctioning. Evolving dystonia is also likely to be distressing for [H]. There is no objective sign of benefit from time with his parents at this stage, although [H] parents do think he responds to them. There are no validated scores or guidelines for assessing prolonged disorders of consciousness in infants, unlike in adults. Despite this, [H] is sadly at the severest end of the spectrum encountered in children on any score.*

***Future management:***

- *Tracheostomy and long-term ventilation are impractical due to the lack of cough and gag, and overall the lack of benefits to [H] from continuing ventilation, in the presence of significant ongoing burdens.*
  - *In my opinion, a one wean of mechanical ventilation and provision of expert palliative care is in [H’s] best interests.”*
36. Nurse A, Senior Nursing Sister, told me that nursing care in PICU involves constant nursing observation throughout the day, including suctioning, tube-feeding, nappy changing etc. Whilst their attention may not be as intense as the parents, it is “intensive” and their observations reflect their training and experience. They do not consider that H has shown any sign of awareness or response in any way. The Guardian observes that they reported to her that they are finding it increasingly distressing to care for H because they know that their interventions cannot have any impact. In these circumstances, the ventilation, the irritation of the secretion suctioning, the vulnerability to the development of infection on the PICU Ward and the fact that it is impossible to exclude, at least primitive levels of pain, all point persuasively to the present treatment being contrary to H’s interest.

Legal framework

37. In the course of her helpful and succinct closing submissions, Ms Watson, on behalf of the Trust, submitted that the applicable law in this area is settled. I agree. The Court must ask itself one question: what is in H's best interests? The answer may be difficult, but the question is easily identified. The clearest iteration of the approach remains that of Baroness Hale in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2013] 3 WLR 1299 (para 39):

*“...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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.”*

38. It is important to remember that the Court in *Aintree* (supra) was considering the circumstances of an adult male. Accordingly, it was necessary to investigate what his attitude was, or would likely have been, to treatment. Where such an enquiry is made, the evidence will be discovered by consulting others who knew him, look after him, or are concerned in some way with his welfare. They will, very frequently, reveal the code by which he lived his life, what was important to him, and what his attitude to his present situation would most likely have been. To my mind, in the case of a 12-month-old child, who has experienced massive hypoxic ischemic brain injury, at 4 months of age, there can be little, if any, utility in such an enquiry.
39. Neither do I assume that H would adopt the same approach to his treatment as his parents. I do not consider it appropriate or fair automatically to attribute to H their views or cultural beliefs. It is important to absorb these conscientiously into the broad survey of the evidence, but it is not an automatic substitution. To my mind, in these circumstances, that would be to fail to respect H's individual autonomy. I can see no scope for any element of substituted judgment in the best interests' decision, most particularly when I set it in the context of the broad canvas of medical evidence. I entirely agree with and, of course I am bound by the analysis of Baker LJ in *Manchester University NHS Foundation Trust v Fixsler and others* [2021] 4 WLR 123 (at paras. 85 and 86):

*“85. When considering the child's assumed point of view, it is difficult if not impossible to attribute any views, including religious beliefs, to a very young child who has never had, nor will have, any cognitive understanding. ...*

*86. In my judgment, the judge was entitled in the present case to refuse to assume that Alta would share the values of her family in circumstances where she never has had, nor ever will have, the ability to understand anything of the original culture into which she was born. As he said (at para 95 of the judgment in this case) Alta is*

*“not of an age, nor in a condition to have knowledge of and to adopt her parents’ values, from which she could extrapolate a position on the complex issues that arise in this case.”*

*In the case of a very young child in Alta’s condition, the element of substituted judgment in the best interests decision is very limited and in this case is certainly outweighed by other factors, including in particular the fact that she is suffering consistent pain.”*

40. In his thorough and erudite closing submissions, Mr Davy, acting on H’s behalf, submitted that I should take the same approach to Dr Lumsden’s evidence as it is contended is set out in the judgment of MacDonald J in *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) (at para 175):

*“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.”*

41. In both his oral evidence and his most recent report, Dr Lumsden stated:

*“I have seen no evidence on either of my assessments that [H] demonstrates any self or environmental awareness. I do not believe it is possible to exclude that [H] might experience discomfort, pain, or pleasure at some level. But on the balance of probabilities, I believe this is unlikely.”*

When Dr Lumsden used the phrase in his evidence, “*the balance of probabilities*”, I indicated to him that, for my part, I rarely found that phrase helpful in this context. In the hospital situation, treating clinicians would, of course, factor in the possibility of the potential for pain in a patient. Such would be their working clinical approach. Indeed, I note that the care plan for H, in the event that the declarations are granted, specifically contains provision for palliative pain relief. Forensic medicine should rarely, if ever, differ from clinical medicine. It strikes me as inherently illogical to factor in the possibility of pain for a patient in hospital, but artificially to exclude it by the application of a legal test in the court room.

42. Mr Davy submits that I should show “*fidelity to the applicable standard of proof*” and conclude that H cannot, on the balance of probabilities, experience pain. For my part, 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.
43. Alongside consideration of the clinical evidence, the views of H’s parents and the expert evidence, it is important to respect H’s dignity. In *North West London Commissioning Group v GU [2021] EWCOP 59*, I analysed the following:
- “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”*
44. As I have reviewed the evidence in this case, it has become increasingly clear that H has received the most remarkable, attentive treatment and support from both the clinical team and the independent experts. The unbearable tragedy of these circumstances has, in my assessment, caused all those involved to go to every conceivable effort to do whatever could be done for H. At every turn, and from every discipline, this case reveals paradigmatic good practice. The parents should know that Judges rarely find themselves in a position to make such a comment. I make this observation not merely because it requires acknowledgment, but because I hope it can be of comfort to the parents in the future. Alongside this excellent medical care, has been parental commitment, the nature and extent of which, has been striking to every professional who has had the opportunity and the privilege to observe it. These, in combination, have preserved H’s dignity in circumstances where it could so easily have dissipated.



45. Ultimately, as the evidence compellingly indicates, H's very extensive brain damage has robbed him of the capacity of consciousness or awareness. He has been on a ventilator for over 8 months. There has been, in this period, from a neurological perspective, no sign at all of his being able to recover. There is no prospect of his leaving PICU, even on to the ward and no chance of his returning to his parent's home. The quality of H's life is reflected only in the love and care that has been showered upon him, whilst every effort has been made to treat him effectively. It is now clear that there is no such treatment and accordingly, his dignity threatens to be compromised. H was described by Dr Brierley as "*having sustained prolonged disorder of consciousness at the severest end of the spectrum encountered in children on any score*". Now that treatment is recognised, properly in my analysis, as both futile and burdensome, it cannot be reconciled with human dignity. It compromises the medical ethical principles of the treating team. It causes distress to all those involved.
46. That these young and loving parents have been unable to take this decision themselves is or ought to be readily understood by any right-thinking person. Sometimes, a loving parent is simply the least able to countenance such a course, even where it is, objectively, in their child's best interests. That is no criticism of them, far from it. As I watched them during the course of this hearing, it was clear that the many conversations with nurses, doctors, and the mediating team had led them to develop a real understanding of the issues. Mr B intimated in his evidence that whilst they could not agree with the proposed course, they would accept my decision.
47. For all the reasons I have analysed, I have come to the clear conclusion that the declarations sought by the Trust is in H's best interests and grant them accordingly.