



Neutral Citation Number: [2018] EWHC 127 (Fam)

Case No: FD17P00299

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 29/01/2018

Before:

THE HONOURABLE MR JUSTICE MACDONALD

Between:

Kings College Hospital NHS Foundation Trust **Applicant**
- and -

Takesha Thomas **First**
-and- **Respondent**

Lanre Haastrup **Second**
-and- **Respondent**

Isaiah Haastrup **Third**
Respondent

Ms Fiona Patterson (instructed by the **NHS Foundation Trust**) for the **Applicant**
Mr Ian Wise QC and Mr Bruno Quintavalle (instructed by **Barlow Robbins**) for the **First Respondent**

The Second Respondent appeared in Person
Ms Shabana Jaffar (of **CAFCASS Legal**) for the **Child**

Hearing dates: 22, 23 and 24 January 2018

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 MACDONALD

The judge has given permission for this version of the judgment to be published, including the names of the parties and of the child. There is a reporting restriction order in force in respect of this case. Permission to publish this version of the judgment is given expressly subject to the terms of the reporting restriction order.

Mr Justice MacDonald:

INTRODUCTION

1. Where, as in this grave and difficult case, a dispute arises between parents and treating doctors regarding the proper course of treatment for a seriously ill child, the court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place, on the grounds that it is in the child's best interests (see *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement between those with parental responsibility for the child and those treating the child (*An NHS Trust v MB* [2006] EWHC 507 (Fam)). The court has no power to require doctors to carry out a medical procedure against their own professional judgment.
2. The case that is before me concerns Isaiah Haastrup, a little boy aged 11 months old who is currently admitted to the paediatric intensive care ward of King's College Hospital. The solemn task with which this court is charged is that of determining whether it is in Isaiah's best interests for the life sustaining treatment from which he currently benefits to continue. The discontinuance of such treatment will, on the evidence before the court, lead to Isaiah's death.
3. The applicant in this matter is the King's College Hospital NHS Foundation Trust (hereafter 'the Trust'), represented by Ms Fiona Patterson. The First Respondent is the mother of Isaiah, Ms Takesha Thomas (hereafter 'the mother'). She is represented by Mr Ian Wise QC and Mr Bruno Quintavalle. The Second Respondent is the father of Isaiah, Mr Lanre Haastrup (hereafter 'the father'). He appears before the court in person, as he has done throughout these proceedings. He has presented his case in a forthright manner, but with concision and courtesy to the court in what must be, for him, extremely difficult circumstances. Isaiah is a party to these proceedings and his interests are represented by his Children's Guardian. Ms Shabana Jaffar appears on behalf of Isaiah.
4. The Trust applies, with the support of the Children's Guardian, for a declaration that the provision of life sustaining treatment is no longer in Isaiah's best interests. The application is opposed by the parents. Specifically, the Trust seeks the following declarations:
 - i) By reason of his minority the child, Isaiah Haastrup lacks capacity to consent to or to refuse medical treatment.
 - ii) It is the best interests of the child, Isaiah Haastrup that:
 - a) He is extubated and receives no further forms of invasive ventilation or non-invasive ventilation (including but not limited to positive pressure non-invasive ventilation known as BiPAP and CPAP and Optiflow (high flow oxygen)).
 - b) Further to the extubation referred to in paragraph (ii)(a) above, he receives palliative care only at the discretion of his treating clinicians.

- c) That the said extubation and palliative care referred to in paragraphs (ii)(a) and (b) take place either at King's College Hospital or a hospice where the child, Isaiah Thomas, will remain.
 - d) That in the event the mother and father wish the extubation and palliative care to take place at a hospice the child, Isaiah Haastrup, shall be transported there by ambulance accompanied by a specialist medical team only.
5. This matter was originally listed for final hearing on 15 and 16 January 2018. At the outset of that final hearing I heard an application by the mother to adjourn the proceedings in order to give her new legal team sufficient time to prepare the case, the mother having parted company with her previous legal team some three weeks before the final hearing was due to commence. Having heard the mother's application for an adjournment, supported by the father but opposed by Trust and the Children's Guardian, I granted a short adjournment of seven days to permit the mother's new legal team time to consider the papers, take instructions from the mother and prepare this matter for final hearing. Mr Wise and Mr Quintavalle are to be commended for the comprehensive manner in which they have presented the mother's case to this court.
6. At the hearing on 15 January 2018, the father also made certain representations with respect to disclosure and witness requirements for this hearing. Those matters were dealt with by the court as follows:
 - i) With respect to the father's submission that he had not seen complete editions of Isaiah's drug logs and drug book, I directed the local authority to provide copies of the allegedly missing documents and these were handed by Ms Patterson to Mr Haastrup in court. Mr Haastrup has carefully cross examined the witnesses called to give oral evidence at this hearing regarding the possible effect of Isaiah's drug treatments on his ability to breath on his own and his level of consciousness.
 - ii) With respect to the father's submission that the court should, if he was required to give evidence, hear from Dr B in person, I directed that Dr B could give his evidence by way of telephone link. In the event, Dr B attended to give oral evidence and was cross examined.
 - iii) With respect to the father's submission that the court should permit the cross examination of Dr C, I directed that the attendance of Dr C was not required in circumstances where she deals with historical matters and has had no involvement with Isaiah since August 2017. Save for referring to the contents of certain documents exhibited to Dr C's statement, I make clear that I have not relied on Dr C's evaluation of Isaiah's best interests in reaching the decision I have in this case, that evaluation being based on her involvement with Isaiah only up to August 2017.
 - iv) With respect to the father's submission that the court should require the attendance at court of L, a physiotherapist, I directed that the attendance of L (who had not been directed to file a witness statement) was not required in circumstances where P deals with those matters in her witness statement and worked with L.

Within this context, in determining this sad case, I have had the benefit of the following evidence.

7. I have received evidence from both of Isaiah's parents. The mother provided a detailed statement to the court and the father provided a statement adopting its contents. The mother gave oral evidence. The father choose not to give oral evidence, but made clear that he adopted all that the mother said in the witness box and made additional points during his closing submissions.
8. With respect to the evidence of Isaiah's clinical team, the court has before it statements of evidence from the following treating clinicians:
 - i) Dr C, Consultant Neonatal Paediatrician, by way of a statement dated 7 July 2017. I did not hear oral evidence from Dr C for the reasons I have already rehearsed;
 - ii) Dr K, Consultant Paediatrician, by way of statements dated 12 June 2017, 6 October 2017 and 8 November 2017. I heard oral evidence from Dr K;
 - iii) Dr G, Consultant in Paediatric Critical Care, by way of a statement dated 9 October 2017. I heard oral evidence from Dr G;
 - iv) Dr B, Consultant Paediatric Intensivist, by way of a statement dated 27 October 2017. I heard oral evidence from Dr B;
 - v) Dr R, Consultant Palliative Care, by way of statements dated 26 October 2017 and January 2018. No party required the attendance of Dr R;
 - vi) P, Clinical Lead Physiotherapist, by way of a statement dated 25 October 2017. No party required the attendance of P;
 - vii) Ms E, Nurse, by way of a statement that is undated. No party required the attendance of Ms E.
9. The court also has before it a number of reports commissioned by Isaiah's treating medical team from other doctors during the course of his treatment, which reports are exhibited to the statement of Dr C. This information comprises:
 - i) A report dated 12 May 2017 from Dr O, attending NICU consultant;
 - ii) A report dated 9 June 2017 from Dr T, Consultant in Paediatric Respiratory Medicine;
 - iii) A note dated 14 June 2017 from Dr H, Lead for Neurodevelopment.
 - iv) A report dated 24 July 2017 from the Evelina London Children's Hospital prepared by Dr Y, Consultant Neonatologist, Dr S, Consultant in Paediatric Neurosciences and Dr D, Consultant in Paediatric Intensive Care.
10. Finally, with respect to the evidence from the Trust, I also have before me a second opinion provided on 5 April 2017 by Professor F, Consultant Neonatologist at the John

Radcliffe Hospital Neonatal Unit in Oxford. In his report, Professor F confirms he has had no clinical input into Isaiah's care.

11. With respect to independent expert evidence, for reasons I will come to, the parents have found it very difficult to trust the evidence provided by the treating clinicians and on which the Trust relies in support of its case. In addition, in making an application for permission to rely on independent expert evidence, the mother raised the concern that there was a risk that the treating clinicians in this case are partial for the reasons examined by Ryder J (as he then was) in *Oldham Metropolitan Borough Council v GW and PW* [2007] 2 FLR 597 at [97].
12. Within this context, on 13 November 2017 I granted an application by the mother for permission to adduce independent expert evidence on the basis that such evidence was necessary in order for the court to resolve these proceedings justly. That independent expert evidence comprises reports from Professor Andrew Whitelaw, Paediatric Neurologist at St Michael's Hospital, Bristol and Dr Parviz Habibi, consultant in paediatric intensive care at St Mary's Hospital, London. I heard oral evidence from both experts. The independent expert evidence concurs entirely with the analysis of the treating clinicians and other doctors who have seen and assessed Isaiah during the course of his treatment.
13. At the conclusion of the first day's evidence, and notwithstanding that the court had already given the mother permission to instruct two independent experts, which experts had reported, Mr Wise handed up a statement from the mother's new instructing solicitor, Mr David Foster. That statement set out details of the steps Mr Foster had taken since being granted legal aid on 11 January 2018, and the steps that he understood the parents to have taken, to secure, without any reference to the court, further expert evidence. The statement from Mr Foster emphasised the limited time available to him to prepare the case and detailed the following matters:
 - i) That Mr Foster had sent to Professor Doctor M, a professor of paediatrics, paediatric cardiology and intensive care at a university hospital in Germany, certain reports from these proceedings and obtained his "brief opinion". The statement of Mr Foster exhibits a letter from Professor Doctor M dated 16 January 2018 and states that on 12 January 2018 a Dr N certified Isaiah as fit to be transferred by air ambulance to Germany. It is unclear from Mr Foster's statement whether Dr N examined Isaiah in person in this jurisdiction, although the father now contends that he did not, and provided his opinion that Isaiah was fit to fly on the basis of the papers provided to him by the father.
 - ii) That a visit to Isaiah in Kings College Hospital by Dr L, a professor in paediatric haematology and oncology at a university hospital in Poland and her colleague had taken place "last weekend", during which visit Dr L examined Isaiah. I will return to this matter in more detail below.
 - iii) That a conversation had taken place between Mr Foster and W, care managers who are said to look after children with "ventilation issues" and "do care packages for children with sensory needs".
 - iv) That conversations had taken place between Mr Foster and "a number of parents of children with severe difficulties as a result of cerebral palsy", including the

parents of a child in whom Mr Foster states that “comfort was seen through a calmer demeanour of the child through touch and human contact” and noting that the child in question “also enjoyed water”.

- v) That Mr Foster and colleagues had contacted a number of schools with regard to sensory care.
14. No application has been made pursuant to FPR Part 25 for permission to adduce further expert evidence from Professor Doctor M or Dr N. The disclosure by Mr Foster of the reports in these proceedings to Professor Doctor M, and the disclosure of the papers by the father to Dr N does not fall within FPR r 12.73(1)(a)(vii) (communication to an expert whose instruction by a party has been authorised by the court) and no permission was sought from the court to disclose this information from the proceedings.
15. The position with respect to the examination of Isaiah performed by Dr L is, on the face of it, concerning. It would appear that Dr L (who, as I have noted, is described in Mr Foster’s statement as a specialist in paediatric haematology and oncology) attended King’s College Hospital with a colleague on 20 January 2018 in the company of the father and performed an examination of Isaiah. The Trust contend that the doctor and her colleague did not identify themselves as doctors, claimed to be friends of the parents and, in that way, gained access to Isaiah in intensive care. When I asked him about this matter, the father told the court that he had been contacted on 20 January 2018 by a “supporter” (by which he appeared to mean a member of the public sympathetic to the parents’ situation), which supporter told him that there were two doctors “in town” who would be able to help. The father attended the hospital with these doctors, one of whom was Dr L. He asserts that the doctors did identify themselves to medical staff. Upon the visit and examination being discovered, the Trust sought to establish whether Dr L and her colleague have a GMC registration with a licence to practice. It appears they do not. The Trust thereafter contacted the General Medical Council who advised the Trust to refer the matter to the Police in circumstances where an offence under the Medical Act 1983 s 49 may have been committed. The matter is now with the Police.
16. In any event, the court was not notified that an examination by Dr L was to take place. No application was made pursuant to the Children and Families Act 2013 s13(3) for permission to cause Isaiah to be medically examined for the purposes of the provision of expert evidence and no application has been made pursuant to FPR Part 25 for permission to instruct Dr L to prepare an expert report in these proceedings.
17. On the basis of the information contained in Mr Foster’s statement of 22 January 2018, both the mother and the father now seek a further adjournment of these proceedings to allow the evidence presaged in that statement to be further collated and examined before this court makes a decision as to Isaiah’s best interests. I will return to these matters in more detail later in this judgment when setting out my reasons for refusing that application to further adjourn the proceedings. Following the conclusion of the hearing, both the Trust and the father sent further statements to the court dealing with the circumstances I have described in the foregoing paragraphs.

BACKGROUND AND MEDICAL EVIDENCE

18. Isaiah was born at 1.26am on 18 February 2017 at King’s College Hospital by way of an emergency caesarean section as a result, it transpired, of the mother’s uterus

rupturing. Isiah was found to be in the mother's abdominal cavity by reason of that rupture. At birth Isiah presented as floppy, with no heartbeat audible, no respiratory effort and no response to stimulation. Isiah required resuscitation by way of ventilation and cardiac compressions. Resuscitation secured a heartbeat at 2 minutes and 50 seconds. Test revealed that Isiah had sustained a prolonged hypoxic insult and, in view of this, therapeutic cooling of Isiah was attempted to prevent further damage to his brain. With respect to the birth of Isiah, Professor Whitelaw observes as follows (emphasis in the original):

“Thus, at birth, Isiah had no audible heart, no respiration, no activity, no muscle tone and had biochemical confirmation of severe lack of oxygen following proven uterine rupture more than 45 minutes before. This is as near death as it is possible to get and still have heart action started by resuscitation. In former times, he would have been declared a stillbirth. In my 45 years of experience with neonatal medicine, I have never seen an infant in such a situation without very severe brain damage in the few infants who have survived long enough for the brain to be assessed.”

19. The parents plainly feel strongly about the circumstances in which Isiah came to be in his current parlous medical situation, strong feelings evidenced in particular during the father's closing submissions. However, as acknowledged by the mother in her statement to this court, with which statement the father concurs, in *these* proceedings those circumstances are relevant only insofar as they inform my evaluation of what is now in Isiah's best interests as far as his continuing medical treatment is concerned.
20. In the circumstances, save in so far as it might be relevant to the question I am charged with answering, it is not appropriate for me to make any observations regarding the standard of treatment received by the mother and Isiah during his birth and I make clear that I do not do so. It is however, readily apparent that the circumstances surrounding Isiah's birth have led to a breakdown in trust between the parents and the doctors charged with treating Isiah, a lack of trust that was articulated in particularly stark and plain terms during the hearing by the father.
21. To put it in simple terms, in circumstances where the parents hold the hospital responsible for Isiah's current condition and are seeking to hold them to account for this, the parents find it very hard to accept the decision of the same hospital that the time has now come to withdraw life sustaining treatment from Isiah. For the father in particular, it is clear that the resultant breakdown in trust has led to a situation where what for the doctors is a clear medical consensus based on careful and thorough scientific assessment, is for the father the product of what he considers to be, to quote him, “cronyism and nepotism”. Whilst I make no comment on the views on standards of care expressed in the following passage from Dr Habibi's report, Dr Habibi perceptively summarises the position as follows:

“Regarding the level of Isiah's neurological disability, there is a significant mismatch between the perception of his parents and the perception of the multidisciplinary team of health care professionals at King's College Hospital and professionals from other hospitals who have visited to assess Isiah. Isiah's state of profound neuro-disability is the result of alleged substandard care received at the time of birth, which has understandably has (*sic*) left his parents devastated at the loss of what should have been a joyous

occasion, the birth of their son Isaiah. They feel absolutely let down by the healthcare system, are understandably critical of the standard of care received at the time of birth and have good reason to be angry. In some respects, the parents' feelings can best be understood in terms of a state of suspended grieving over a period of 9 months. Intensive care personnel can also find it very challenging caring for patients left with profound neurodisability when there is no prospect of improvement. The day to day routine of intensive care can become an intense emotional burden when faced with what appears to be a hopeless situation. The stage is then set for misunderstandings in communication between staff and parents, which can result in an erosion in trust and breakdown in relationships."

22. Isaiah was admitted to the neonatal intensive care unit. The neonatal medical team determined that Isaiah lacked normal alertness, reflexes, movements and responses. An electroencephalogram (hereafter 'EEG') and a Cerebral Function Monitor (hereafter 'CFM') showed electrical seizures on a suppressed background. Professor Whitelaw opines that this presentation is confirmation of acute brain injury following severe hypoxia during labour and delivery. On 21 February 2017, a formal eight channel EEG was commenced. With respect to this examination, Professor Whitelaw comments as follows:

"3.5.2 A formal EEG with 8 channels was carried out on day 3 and showed a suppressed background with electrical seizures. Clinical examination by Dr H that day revealed no spontaneous movement, no reaction to pressure on the sternum, no gag reflex on deep suction of the pharynx. In light of the EEG report of electrical seizures, levetiracetam was increased on 21/2/17. The following days, 22/2/17 and 23/2/17, status epilepticus was noted on the continuous aEEG (CFM). This term means continuous seizure activity with insignificant pause between seizure activity for over 30 minutes. While occasional brief seizures are probably not harmful themselves, status epilepticus is believed to cause brain injury in its own right and is therefore important to treat. The rate of the midazolam infusion was increased and the dose of levetiracetam was increased.

3.5.3 Although the majority of infants with HIE do not go on to have epilepsy later in childhood, some do and Isaiah is in that group because he had such prolonged periods of seizures, including status epilepticus that were difficult to control even with multiple drugs. Because of the danger of recurrence of status epilepticus, it would be advisable to keep such a child on maintenance anticonvulsant therapy."

23. On 24 February 2017, an MRI scan was undertaken. The scan showed severe brain injury. Professor Whitelaw comments as follows with respect to the outcome of this MRI imaging:

"3.6.4 I note from Professor F's report that these images have been reviewed independently by two Oxford consultant neuroradiologists and their opinion was *'This MRI shows evidence of severe extensive hypoxic ischaemic injury were very extensive changes on Diffusion weighted image affecting basal ganglia and cortex, prerirolandic areas and temporal lobe and suspicious for changes in the brain stem.'*

3.6.5 The MRI findings described above in the basal ganglia are predictive of quadriplegic cerebral palsy and the cortical and white matter involvement predictive of other impairments especially cognitive and visual. The concern about the brain stem is particularly worrying as brain stem function is necessary to breath and to suck and swallow safely.”

24. On 24 February 2017, Dr O introduced to the parents the possibility of redirecting Isaiah's care onto a palliative regime. The parents were, however, clear that they wished intensive care treatment to be continued and for Isaiah's progress to be monitored. On 27 February 2017, an EEG showed no electrical seizures but continued to show abnormal periods of reduced activity. At the beginning of March 2017 physical examination showed increased tone in all four of Isaiah's limbs. Within this context, Professor Whitelaw notes as follows:

“This is a significant and worrying observation because any drug effect from the anticonvulsants or sedatives would tend to reduce, rather than increase tone. The pattern of increased tone at only two weeks was the first sign that Isaiah was heading towards 4 limb spastic quadriplegia.”

25. On 8 March 2017, following Isaiah being observed to have repeated jerking movements in his left leg, a further EEG was performed. The EEG did not indicate the abnormal movements exhibited by Isaiah were associated with seizures. Isaiah was commenced on a conventional dose of phenobarbital. The increased tone in his limbs persisted and he was also started on the drug Baclofen. During his oral evidence Professor Whitelaw, whilst acknowledging some hours may have passed since Isaiah's last dose of Baclofen, considered that when he examined Isaiah on 24 November 2017, Isaiah was stiffer than any other baby he had ever examined, and that the fact that it had been some time since his last dose of Baclofen when he was examined assisted in demonstrating what Isaiah's situation would be absent such medical intervention.

26. Approximately five weeks after Isaiah was born, and at a time when the parents had been advised to consider, and were considering, withdrawal of life sustaining treatment on the basis that Isaiah would not recover, Isaiah appeared to become more responsive. The mother and father consider that Isaiah's change in presentation was the consequence of an episode of diarrhoea that resulted in Isaiah not absorbing sedative medication. The father contends that prior to this point, the parents had come to reconcile themselves to palliative care and this was plainly an extremely important moment for the parents, standing as it did, in their perception, in contrast to the prognosis provided up to that point. Indeed, within the foregoing context, I am satisfied that this development, and the parents' explanation for it, is at the root of their current view that Isaiah will continue to make progress and that Isaiah's levels of consciousness are not the exclusive result of his brain injury but are down to medication he is being administered.

27. On 4 April 2017, Isaiah was examined by Professor F. In his report dated 5 April 2017, Professor F offers the following opinion:

“Having reviewed Isaiah's clinical notes, clinical examination and imaging, it is clear that he has sustained a severe profound hypoxic ischaemic encephalopathy as a consequence of uterine rupture. He was extremely acidotic at delivery, and was gravely ill with multi-organ failure in the first

24 hours. Unfortunately, in this setting whilst other organs can recover quickly, brain injury is often permanent and severe, Isaiah had the most severe clinical stage of hypoxic ischaemic encephalopathy (Samat Stage 3) initially. He had a pattern of severely abnormal brain electrical activity (burst suppression) which did not improve in the first 24-48 hours. These are all associated with very poor neurological prognosis. He had refractory seizures that were ultimately controlled only with three anticonvulsants (though they have since improved). His magnetic resonance imaging shows evidence of very widespread restricted diffusion – this is a pattern seen with cytotoxic cell oedma – indicating brain cells that are swollen and in the process of dying. His neurological examination at 6 weeks of age is extremely abnormal with markedly abnormal tone and reflexes.

Isaiah has sadly sustained severe global hypoxic ischaemic brain injury and already at 6 weeks of age has evidence of severe spasticity and motor dysfunction. Furthermore, his conscious state remains profoundly depressed and he remains ventilator dependent without any significant improvement. Isaiah is on appropriate doses of anticonvulsants and I do not believe that they are significantly depressing his conscious state (his phenobarbitone is in the therapeutic range) or adversely affecting his neurological examination.

In my view, if he were to survive, Isaiah would undoubtedly have extremely severe global motor disability with spastic quadriplegic cerebral palsy – a consequence of his severe basal ganglia injury apparent on initial imaging. I did not detect any evidence that Isaiah is generally aware of his surroundings. The combination of severe basal ganglia and cortical injury, with his ongoing severely abnormal conscious state lead me to believe that he will, in addition have profound cognitive impairment. He has apparent severe brain-stem dysfunction evident in his inability to manage his secretions and sustain respiratory effort.

Given the burden of his illness (profound neurological impairment), the burden of treatment (mechanical ventilation in a child with severe dystonia and poor airway control requiring very frequent suctioning) and the lack of benefit from continued treatment, it is my professional opinion that it is not in Isaiah's best interests to continue mechanical ventilation and intensive care."

28. A second MRI scan was undertaken on 24 April 2017. This showed loss of brain cells all over Isaiah's brain and, crucially, in his brain stem, the area responsible for consciousness, airway reflexes and breathing. In his oral evidence, Professor Whitelaw stated that having undertaken a longitudinal study at Bristol of a cohort of two hundred children who suffered hypoxic injury at birth, Isaiah's MRI scans are worse than any child he has seen, showing the loss of approaching half of his brain. In his report, Professor Whitelaw notes as follows in respect of the MRI scan on 24 April 2017:

"3.8.1 Isaiah had a second MRI scan on 4/4/2017 aged over 10 weeks. This showed the maturation of previously damaged areas of brain in a manner which is easier to recognise. This was reported "*This showed the expected maturation of the previous areas of abnormal signal change, with encephalomalacia (wasting and scarring) in both central motor regions. The*

basal ganglia and hippocampi were markedly shrunk in keeping with severe injury, there was considerable white matter volume loss. This can therefore confirm widespread extremely severe brain injury with cell death in the superficial and deep grey matter structures as well as the white matter and brainstem – almost the entirety of Isaiah's brain."

3.8.2 I have reviewed the MR images and am in complete agreement with the report above."

29. In addition to the second opinion provided by Professor F, other doctors not associated with King's College Hospital have considered Isaiah's case in the context of transfer requests made to Great Ormond Street Hospital (hereafter GOSH) and Evelina Children's Hospital in an attempt to address the issue of the parents' lack of trust in King's College Hospital. Within this context, on 14 June 2017, GOSH declined transfer. On 24 July 2017, Evelina Children's Hospital likewise declined to accept a transfer. That decision was based on a comprehensive assessment of Isaiah carried out by Dr Y, Consultant Neonatologist, Dr S, Consultant in Paediatric Neurosciences and Dr D, Consultant in Paediatric Intensive Care.
30. Their report was based on a comprehensive assessment, including examination of Isaiah and discussion with the parents. It is again useful to set out in full the conclusions of their assessment, which determined as follows:

"Dr Y, Dr S and Dr D are in agreement that, from history, confirmatory clinical examination and magnetic resonance imaging, Isaiah has suffered catastrophic brain injury with microcephaly and significant cerebral atrophy already evident on the neuroimaging. He has very abnormal and increased gross motor tone and severely reduced and abnormal movement. He has very reduced brain stem function.

Of most significant relevance for his survival, is the fact that he is unable to sustain adequate spontaneous ventilation off the ventilator, cope with the production of airway secretions, or demonstrate airway protective reflexes, making it highly unlikely that he will survive for any significant time once disconnected from life support.

With the severe clinical picture of bilateral cerebral palsy with overwhelming spasticity and already elements of early dystonic patterning clearly evident, even at this young age, no apparent social contact made by the baby during our examination, inability to suck and possibly swallow with no airway protective reflexes or adequate respiratory drive, "life" would only be at the cost of significant ongoing discomfort and technical invasion. Even at this early stage it is evident that even if he could survive off the ventilator Isaiah would have a profound movement disorder with considerable clinical, developmental and functional co-morbidity.

In addition, we do not believe that the current levels of potentially sedating medications – Levetiracetam and Baclofen – are having a significant depressive effect on his respiratory drive. Therefore, we believe that reduction in the dosage or cessation of the medication altogether will not have a significant impact on his likelihood of breathing spontaneously after

discontinuation of respiratory support. However, taking into account the wishes of his parents, Dr S expressed the opinion that further reduction in both Levetiracetam and Baclofen, with a view to trying to potentially stop them altogether over the space of 2 weeks, would be clinically reasonable, providing Isaiah does not manifestly show significantly increasing discomfort from abnormal tone or movements and he does not develop electromagnetically proven seizures.

It is our opinion therefore that it is not in Isaiah's best interests to continue intensive care and invasive respiratory support, because of the extensive burden of his illness (that of profound neurological impairment, hypertonia and movement disorder), the excessive burden of his treatment (ongoing need for mechanical ventilation and poor airway control requiring frequent suctioning) and the lack of benefit from continued treatment, as laid out in the Royal College of Paediatrics and Child Health document '*Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: a Framework for Practice.*'"

31. Isaiah was moved onto the paediatric intensive care unit at King's College Hospital on 8 August 2017. At this time, the medical team made clear to the parents that they would try and wean Isaiah off the ventilator and would try to reduce the medications controlling his dystonia (Baclofen) and his seizures (Levetiracetam) in response to parental concerns that they were sedating him and making him dependent on the ventilator.
32. Attempts at weaning Isaiah from the ventilator failed. I also note that during their examination, Dr Y, Dr S and Dr D had observed that when disconnected from the ventilator Isaiah showed infrequent and completely inadequate breathing movements. This was also the experience of Professor Whitelaw and Dr Habibi during their respective examinations of Isaiah. In oral evidence, Dr Habibi confirmed that, as a result of his permanently deranged basal functions, Isaiah demonstrated no useful respiratory drive that could be life sustaining and a complete absence of airway protective reflexes, giving rise to a high risk of infection even in an intensive care setting. Dr Habibi considered these findings consistent with the findings of the MRI scans, amounting to a physiological and anatomical correlation. Dr Habibi was "certain" Isaiah will never be able to breath on his own. When Professor Whitelaw carried out his examination, Isaiah's blood oxygen saturation fell below 80% after four minutes of being removed from the ventilator, due to inadequate breathing, and he had to be re-ventilated.
33. With respect to the attempt to reduce Isaiah's doses of Levetiracetam, Dr K says in his second statement that Isaiah suffered a major seizure when this anti-convulsant was reduced and that the dose was increased again. He confirmed this account during his oral evidence. A video EEG carried out on 21 August 2017 captured a seizure with video and EEG correlation and, accordingly, the treating team continued to optimise Isaiah's dosage of Levetiracetam. Professor Whitelaw notes as follows in this regard:

"3.9.8 An EEG recording was carried out on 1/9/17. This was reported: *In summary, the EEG is similar to previous recordings with an abnormal background suggestive of an epileptic encephalopathy secondary to the history of hypoxic ischaemic injury.* What this means in plain language, is

that Isaiah's brain was not seizing at the time of the recording (less than 60 minutes) but is ready to seize at any time. In view of this, Isaiah's previous status epilepticus and the fact that Isaiah had a cause for seizures, it was decided that the safest course was to continue with the Levetiracetam and try and optimise the dose"

34. On 18 September 2017, electrophysiological testing of Isaiah's visual pathways was carried out. Whilst the electroretinograms were normal, showing his eyes were able to *detect* light, visual evoked potentials from the brain were absent, indicating no demonstrable response in the brain to visual stimulation, and indicating profound injury to the visual pathways. Within this context, in oral evidence Professor Whitelaw stated that he was "one hundred percent certain" that Isaiah gains no useful perception from his eyes and opined in his report as follows:

"This indicates the pathways from the retina to the brain are not working and is entirely compatible with the extensive injury and destruction of the back of the brain and the repeated observation that he does not respond to any visual stimuli."

35. A meeting was held with parents on 27 September 2017. The parents were informed that it was not possible to wean Isaiah from the ventilator further as he was not generating sufficient tidal volume with his own breaths. The parents expressed a strong wish to take Isaiah home, whatever difficulties he may have, and stated they wished a tracheostomy to be performed and for him to be mechanically ventilated at home.

36. A best interests meeting was held by professionals on 28 September 2017. At the meeting, there was consensus amongst the medical team that there was no evidence to suggest Isaiah could interpret or have interaction with the outside world in a way that gave him pleasure. Clinicians were also in agreement that the degree of damage to Isaiah's brain was so severe that he would not make any substantial improvement in his condition, with no material change in functioning for seven months, that he could not be weaned off the ventilator and that long-term ventilation via a tracheostomy was not in his best interests. Further, non-invasive facemask ventilation was agreed by professionals to be clinically inappropriate as Isaiah had no gag or swallow reflex. In oral evidence each of Dr K, Dr G and Dr B confirmed their view that it was no longer in Isaiah's best interests to continue life sustaining treatment. Dr G, whilst conceding the importance of the parents' views, summarised the position as follows:

"If a child is not going to benefit from the treatment, and will not improve, and the ventilation will cause side effects that will cause pain and distress what does Isaiah get out of being ventilated. He is alive, but is it living? Can he enjoy, can he experience emotions. We have never seen this. Even he is able to gain some small comfort, is the weight of treatment increasing his discomfort, a discomfort we cannot treat."

37. During the course of the Best Interests meeting on 28 September 2017, there had been discussion regarding the difficult and important question of whether Isaiah feels pain and pleasure. Mr Wise cross examined the witnesses called to give evidence in some detail on this issue and Mr Haastrup also asked questions in this regard. The evidence given by Dr K, Dr G and Dr B, and the evidence given by Dr Habibi and Professor Whitelaw on the question of the extent to which Isaiah is able to feel pain or pleasure

was striking in its overall consistency. Within this context, the *medical* evidence given on this issue can be summarised as follows:

- i) The extent to which Isaiah is able to feel pain and experience pleasure (including comfort) is properly considered as a function of the extent to which Isaiah has conscious awareness. The overall tenor of the medical evidence was that *if* he is aware, Isaiah has an extremely low level of conscious awareness. Dr Habibi considered that he was able to detect *no* evidence that Isaiah is consciously aware. Dr B considered it likely that Isaiah had no higher function and only partially intact brain stem function.
 - ii) There is no *objective* evidence that Isaiah feels pain or experiences pleasure. In particular, with respect to pain, each of the medical witnesses cited the absence of the usual indicators of pain, including raised heart rate in response to pain, opening his eyes in response to pain, facial grimacing or other changes to his facial expression and an absence of recoiling from the source of pain. With respect to pleasure, the none or the treating clinicians, nor the experts had seen, or been told about, evidence that Isaiah feels or expresses pleasure, or seen any of the higher-level indications of pleasure such as smiling.
 - iii) With respect to *subjective* evidence of pain or pleasure, Isaiah stiffens when he is touched (particular on the top of his head) or injected. With respect to pleasure, there was a consensus that Isaiah could appear more relaxed when bathed. However, there is very real difficulty in determining whether these actions are the result of reflex responses or an indication of a conscious response, given Isaiah's extremely low level of consciousness. In particular, Professor Whitelaw cautioned against interpreting Isaiah's limited movements as a conscious response given the level in the nervous system from which such movements can originate, and the presence of dystonia. Within this context, Professor Whitelaw was clear that stiffening and apparent relaxation, especially if bilateral and purposeless, which he considered them to be, do not necessarily equate to consciousness.
 - iv) *If* Isaiah is able to feel pain and pleasure, Isaiah suffers from conditions, namely dystonia and limb spasticity, that are known to be very painful in cerebral palsy patients who are able to articulate their experience, which patients complain of a severe, cramping pain that brings them to tears. *If* Isaiah is able to feel pleasure then he will also, by reason of his dystonia and spasticity, be in pain. In such circumstances, in addition to any pleasure (including comfort) he feels, the burden of his pain would be considerable.
38. With respect to the mother's contention that Isaiah has an emotional connection to her, once again the stark medical consensus was that no indication of such a connection has been witnessed by medical staff. Within this context, Dr G's explanation for the difference between the stated perception of the mother and the stated perception of the doctors, echoed by other medical witnesses, is of particular note:

"The mother is an excellent mother and deeply loves her son. Her love is faultless. I can also see that sense that you want your child to survive, that you want things to mean there is a response. For the parent, it is understandable to me that any small response will be interpreted as positive,

even though it is not, or even if it is negative. The mother interprets what we consider to be a reflex to be voluntary...There is definitely an emotional connection from the mother to Isaiah, but there is no evidence of a connection the other way”.

39. On 18 October 2017, Isaiah’s hearing was examined. Tests on auditory pathways on 18 October, and again on 2 November 2017 demonstrated brainstem responses to auditory stimulation via the right ear but not the left. Doctors have not been able to reproduce response to auditory stimulus to either of Isaiah’s ears in a clinical setting. During his oral evidence, Dr K maintained his view that Isaiah shows minimal, if any responses to environmental stimulation and that it has not been possible, despite repeated attempts, to demonstrate a reproducible response to sound notwithstanding earlier evidence that Isaiah may respond to sounds made by a certain toy. Dr K stated that whilst Isaiah suffered a single insult and the injury resulting from it is static, the ramifications of the injury can change over time. Within this context, he was clear that positive responses in the early part of life may not be seen later.
40. Professor Whitelaw reported on 5 December 2017. Professor Whitelaw is Emeritus Professor of Neonatal Medicine at the University of Bristol. Whilst the father alleged that Professor Whitelaw’s examination of Isaiah was inadequate, that he had prejudged the case and that he was motivated in his conclusions by loyalty to the NHS and financial matters, I make clear I reject those allegations in their entirety as unfair, unfounded and unjustified. It is noted that, notwithstanding the father alleged that he had email communications corroborating his criticisms of Professor Whitelaw, and undertook to provide these to the court, the father has since indicated he is not in a position to provide those emails to the court.
41. Professor Whitelaw makes clear in his report that he has never worked for the Trust and does not have, nor has had, any collaboration with those at the Trust responsible for treatment of Isaiah. Professor Whitelaw has considered the court bundle, the four lever arch files of medical records on Isaiah. He carried out a careful and thorough examination of Isaiah. He has also considered the MRI imaging and has seen and considered the videos and photographs provided by the mother. Professor Whitelaw concludes as follows in respect of Isaiah’s present condition:

“4.9.1 Isaiah suffered severe near fatal hypoxia as a result of uterine rupture and has shown consistent evidence of severe brain injury since delivery. He has never, over 9 months, been able to breathe consistently off the ventilator, has none of the reflexes needed to protect his airway, cannot suck and swallow, has spastic/dyskinetic quadriplegia so severe that all four limbs are almost rigid in extension despite Baclofen, so that he cannot sit, roll over, hold any object, crawl or move his body in any way.

4.9.2 His medications, at the doses being used, are not capable of suppressing his breathing. He has absolutely no useful vision and shows no external signs of either pleasure or pain. As he does not show external reactions even to deep suctioning or to pressure, it is difficult to know if he can feel pain. He appears to have impaired hearing but this may be partial. When handled, he sometimes appears to respond but the movements are purposeless, usually bilateral and are probably coming from a low level in the nervous system.”

42. With respect of Isaiah's prognosis Professor Whitelaw opines as follows having examined Isaiah and considered the documentary evidence in this case:

"5.1 Prognosis after severe perinatal hypoxia has been actively studied since therapeutic hypothermia was introduced and our own group in Bristol has measured developmental outcomes up to at least 2 years in over 200 term infants who were cooled for this condition. The MR images give the best prediction of later outcome but continuous EEG over the first few days, and neurological examination in the newborn period are also predictive. In Isaiah's case, it was possible to say at about 10 days of age that, if he survived, he would have severe quadriplegia. What has emerged since then is that (a) despite good nutrition and good supportive care including physiotherapy, he has made no significant neurological or developmental improvement in 9 months, (b) his MRI at 10 weeks showed massive loss of brain tissue and (c) his brain is not able to sustain breathing without mechanical help. The brain injury on his second MRI is even more severe than any of the 200 surviving infants our team has followed in Bristol. Huge and important areas of brain have been lost and are not going to regenerate. Isaiah's condition is not going to significantly improve."

43. With respect to the application of the RCPCH Guidance, Professor Whitelaw concludes as follows:

"Yes, treatment is able to prolong life but:

8. Isaiah's life is limited with no overall qualitative benefit

8.1 Burden of Treatment

8.1.1 Mechanical ventilation via a tracheostomy involves having the trachea sucked out periodically because Isaiah is unable to clear secretions that accumulate in the airways. Having the trachea sucked out if one is conscious is very uncomfortable and stressful experience if one is conscious.

8.2 Burden of underlying condition

8.2.1 The severity of the brain injury includes the brain stem as well as the basal ganglia and thalamus. The developing cerebral palsy affects all 4 limbs, the trunk and also the muscles controlling breathing and swallowing. He is unable to sit up, let alone stand or walk. Spastic muscles produce muscle spasms. Most adults know how painful leg (i.e. calf) muscle spasms can be. In addition, Isaiah has involuntary (dyskinetic) movements which are also disturbing and uncomfortable if one is conscious.

8.3 Lack of ability to derive benefit from treatment

8.3.1 The severity of Isaiah's brain injury and his lack of improvement over 9 months indicate that, even if he were mechanically ventilated at home via a tracheostomy, he would not be able to: (i) derive pleasure (taste, smell and texture) from eating and drinking because he would have to be fed by tube into his stomach, (ii) communicate himself by speech or sign language,

because of the severity of his cerebral palsy, (iii) be able to understand speech or visual communication as his hearing is impaired and he has no usual vision as his brain is not able to process information from the retina, (iv) be able to learn to read or use a computer, even one using visual fixation, because of (ii) and (iii), (v) be able to take part, actively, in family activities, (vi) be able to learn productive skills or follow an educational course, (vii) I am doubtful as to whether if mechanically ventilated at home via a tracheostomy, he would derive pleasure from touch and stroking”

8.3.2 I thus have to conclude that, according to the Royal College of Paediatrics and Child Health guidance “*Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: Framework for Practice*” 2016, it is not in Isaiah’s best interests to prolong mechanical ventilation either in hospital or at home. It is in his best interests for mechanical ventilation to be withdrawn in circumstances where any possible distress is recognised or minimised.”

44. Professor Whitelaw was asked to give specific consideration to the points raised by the parents’ case, and in particular the effect of the drugs being given to Isaiah on his current presentation. Within this context, Professor Whitelaw opines that this medication is not depressing Isaiah’s breathing or his level of consciousness. Professor Whitelaw makes clear his view that it is the damage to Isaiah’s brain and not his medication that is causing his breathing difficulties and his markedly reduced level of consciousness. Professor Whitelaw reiterated these views during his oral evidence, and his evidence concurs with the written and oral evidence of the treating clinicians. With respect to the parents’ contentions regarding the level of response and interaction Isaiah exhibits, Professor Whitelaw states that he carefully examined all videos and photographs sent by the mother and could not identify any alertness, purposeful response or communication. The court has also had the benefit of seeing the videos provided by the parents.
45. Further, Professor Whitelaw is of the view that stopping Isaiah’s medication would be reckless and, *if* Isaiah is conscious, probably painful. A reduction in Levetiracetam would, in Professor Whitelaw’s view, risk a life-threatening status epilepticus, potentially resulting in further damage to his already severely damaged brain. Professor Whitelaw further dismisses the proposition that Levetiracetam is the cause of seizure activity, pointing out that appropriate attempts were made to wean Isaiah off Levetiracetam but that he got worse, exhibiting a break through seizure. With respect to Baclofen, Professor Whitelaw considers that Isaiah requires an increased dose. He further posits that ceasing Baclofen would make breathing even more difficult for Isaiah as his ongoing dystonia would make it harder for his breathing muscles to function.
46. Dr Habibi reported on 12 December 2017. Dr Habibi is a consultant in paediatric intensive care and respiratory medicine at St Mary’s Hospital. He has a special interest in end of life care, decision making and conflict resolution between health care professionals and families. Whilst the father, once again, alleged that Dr Habibi’s examination of Isaiah was inadequate, his conclusion prejudged and that he was motivated in his conclusions by loyalty to the NHS and financial matters, I again make clear I reject those allegations in their entirety as unfair, unfounded and unjustified.

47. Indeed, in compiling his expert report, Dr Habibi examined Isaiah and spent three hours with the parents discussing Isaiah's case with them and seeking to understand their position *before* he read *any* of the medical records and reports in this case, to ensure he gained a fresh and independent perspective on Isaiah's case. He too, thereafter, considered the four lever arch files of medical records in relation to Isaiah and once again saw the video footage relied on by the parents. Having undertaken his careful assessment, Dr Habibi concludes as follows with respect to Isaiah's current condition:

"Isaiah Haastrup was 9 months of age when I saw him at Kings College Hospital PICU. At the time of his birth he suffered severe hypoxic ischaemic brain damage, which has left him with profound neurological disability, such that he has significantly diminished consciousness (Glasgow Coma Scale 5-6) and severely diminished respiratory drive, meaning that he will never become independent of assisted ventilation for life support. He has suffered severe global, cortical, white matter and deep brain structure damage that is the cause of his severe spastic and dysfunctional muscle tone, leading to frequent dystonic spasms. These are known to be very painful as evidence in other patients with cerebral palsy but have intact cognition/awareness. The damage to the brainstem structures is permanent and is in the location for the neural control centres for swallowing, airway protective reflexes and respiratory drive, which in Isaiah's case is seriously deranged, such that he does not have any airway protective reflexes such as gag or cough response and cannot coordinate swallowing and breathing without the risk of life-threatening lung aspiration."

48. With respect to Isaiah's ability to derive benefit from treatment and the burden of treatment upon Isaiah, Dr Habibi concludes further as follows:

"In my opinion, a tracheostomy is not an option to consider in Isaiah's case as it will serve no purpose. It will not facilitate weaning or transition from PICU to the community because his clinical condition is so severe, without any prospect of useful functional recovery, and no reasonable team would consider him for a long-term home ventilation care package.

.../

I have cared for patients with cerebral palsy who have required long-term ventilation in the home. Some have tracheostomy and gastrostomy. Even though some of them are severely neurologically disabled, it is possible to appreciate that they do have some quality of life, being able to respond to their environment, interact with their carer and demonstrate pleasure and convey signs when they are distressed and uncomfortable, so that their carer can attend to them properly. I am not aware of, and have never been involved with, children with a similar level of severe neurodisability as Isaiah has who have managed to be discharged home with the tracheostomy and mechanical ventilation."

49. Within the latter context, Dr Habibi was questioned extensively on what the appropriate treatment would be for Isaiah if the court declined to make the declarations sought by the Trust and what treatment options would allow him to be cared for at home. In response to both enquiries Dr Habibi's firm opinion was the same, namely that the

Level 2 ICU care that Isaiah is currently receiving is, and will remain, the only treatment option available for him. Within this context, Dr Habibi was clear that, whilst possible to achieve, Level 2 ICU care was not available at home, involving as it would the establishment of a “satellite” ICU bed at home with 24-hour nursing care.

50. With respect to the specific concerns raised by the parents concerning the impact of the drugs being used to treat Isaiah on his ability to breathe on his own, Dr Habibi concluded that Isaiah is not able to breathe on his own due to damage to critical centres of the brain responsible for breathing. He considered that there was no evidence that sedating drugs are responsible for his depressed level of respiratory drive. Indeed, Dr Habibi states that in 25 years of intensive care practice he has not seen patients unable to breathe because of normal/therapeutic levels of anticonvulsants and muscle relaxants and that, even in overdose, the drugs in question would not have this effect.
51. With respect to current position for Isaiah, during his oral evidence Dr K stated that Isaiah’s head is now not growing at the same rate as his body. Whilst at birth Isaiah was on the 99th Centile, and his body continues to be on the 99th Centile, his head is now at the 13th Centile, indicating that Isaiah’s head is not growing in line with his body. Dr K was clear that this is the result of Isaiah’s brain not growing. Dr K further stated that Isaiah has no ability to move by himself at all and cannot re-position himself.
52. Finally, by way of setting out the background to, and the medical evidence in these proceedings, the statement of Dr R sets out in detail the palliative care plan that the Trust would seek to implement in the event that the court concludes that the continuation of life sustaining treatment is not in Isaiah’s best interests. Dr R’s statement makes clear that, should his family wish, a children’s hospice has agreed to accept Isaiah for the withdrawal of treatment and for palliative care.

THE PARENTS’ EVIDENCE

53. The clinical evidence and the independent expert evidence is but one element of the evidence the court must consider. The evidence of the parents of Isaiah is an important part of the forensic picture insofar as it may further illuminate Isaiah’s position and presentation and the quality and value to Isaiah of any relationship he may be able to sustain with his parents. As I have noted, in this case, the court has before it a statement from the mother dated 10 November 2017 and a short statement from the father of the same date concurring with the contents of the mother’s statement. The court has also had the benefit of hearing oral evidence from the mother.
54. The mother gave her evidence in a dignified, straightforward and empathetic manner. Her love for Isaiah was manifest. There was plainly a strong religious component to the mother’s view of what should happen in this case. She made clear to me that she is a Pentecostal Christian and thus believes that it is not her right, or indeed anybody’s right, to say who should live and who should die. The mother told me that when “God wants to take a person, he will” and that we all deserve the chance to live. The father made clear in his closing submissions that he shares the mother’s faith in this respect.
55. Whilst expressing some criticisms of the care being afforded to Isaiah, the mother readily recognised the contributions of Isaiah’s medical team and their expertise on medical matters. The mother stayed away from some of the more outlandish and unevicenced claims alluded to by the father during the course of presenting his case,

including allegations of racism on the part of the medical team and attempts by them to deliberately harm Isaiah. The mother however, made plain that she does not agree with the consensus medical opinion that it is in Isaiah's best interests for life sustaining treatment now to be withdrawn.

56. Whilst I gained the impression that she struggles to reconcile herself with the severity of Isaiah's condition, the mother accepts that he has sustained a significant brain injury, will be severely disabled for the rest of his life and will need a significant amount of care. The mother is however, clear in her own mind that she is equal to this task with the support of family and her church. Within this context, the mother considered that the decision as to Isaiah's future care is for her and not for the doctors, the mother telling the court "It is for me to say I can offer him love, and I am a good mum and with the right training I can cope." The father, who lives separately from the mother, fully supports this position.
57. Having read her statement and listened to her oral evidence, it is clear from that evidence that underpinning the mother's position is a significant mismatch between her views and the views of medical evidence as to the cause of Isaiah's presentation and as to his prognosis. In this respect, the parents again present a united front.
58. The mother makes clear in her statement that, contrary to the medical evidence, the parents do not accept that it is not possible to wean Isaiah off his ventilator. Whilst accepting that a number of attempts have been made and that these were not successful, the mother and the father believe that the medication that Isaiah is being given is having an effect on his ability to breath on his own and that, were it not for this, he would recover his ability to breath on his own. They are each unable to accept the medical evidence that the level of damage to the respiratory centres of Isaiah's brain is of such magnitude that this will not be the outcome for Isaiah. The father informed the Children's Guardian that the parents believe that with more time, and reduction in his medication, everyone will be able to see what Isaiah can do, namely breath on his own.
59. The mother's statement makes the same point in relation to Isaiah's level of consciousness. Indeed, in her statement the mother contends that the "sole driver of changes in Isaiah's alertness is the level of his medication". In her statement, with which statement the father concurs, the mother details what she says is evidence of Isaiah becoming more alert when certain medications are reduced. Within this context, the parents remain of the view that the level of medication to which Isaiah is subject is not allowing the true picture of Isaiah's condition and abilities to become clear, and the fact that he is sedated has not been properly taken into account by doctors when arriving at a best interests decision. In her statement, the mother goes as far as asserting that when Isaiah shows signs of responsiveness his medication is increased. Neither parent is able to accept the consensus medical view that, in the doses being given, the drugs being used to treat Isaiah would not lower his levels of consciousness and that, even if they made him drowsy, drug induced drowsiness is qualitatively and quantitatively different to the depressed consciousness caused by his severe brain injury.
60. The parents also do not accept the evidence detailing the level of Isaiah's visual and aural functioning. With respect to the tests of his vision and hearing, the mother and father contend that those tests were not carried out at an 'optimal' time and thus have not given a true picture of Isaiah's abilities. With respect to the electrophysiological test of Isaiah's vision, the mother and father contend this was carried out when Isaiah

was receiving a highly sedative medication Midazolam and that therefore Isaiah was not sufficiently conscious or alert when the test was undertaken. In cross-examination the father continued to insist, notwithstanding the unanimous medical evidence to the contrary, that these matters fundamentally undermined the results of the electrophysiological testing of Isaiah's vision. The parents also dispute the results of the hearing tests performed on Isaiah.

61. There is also a significant mismatch between the medical evidence and the mother's evidence in respect of the extent to which Isaiah is responsive. In contrast to the medical evidence I have set out earlier in this judgment, the mother contends that Isaiah is more responsive than described by his treating team, which responses the parents believe evidence an ability to derive pleasure from his life. In her statement the mother contends that Isaiah responds to her voice, opening his eyes when she says, "Isaiah it's Mummy", and to the voices of his father and siblings, will lift his eyebrows and will open his eyes if there is talking nearby. Professor Whitelaw observed Isaiah half opening his eyes when the mother played music, although noted his eyes did not move. The mother also contends that Isaiah will shift to his right side if laid down on his left side, will turn his head and make small changes of position such as drawing up his legs and will kick and stretch out when he does not like something. The mother has kept a detailed diary, extracts of which are exhibited to her statement. In her oral evidence the mother outlined further matters that she contends indicate Isaiah is responsive, including that Isaiah's heart rate increases in response to pain and that Isaiah cries. The mother reports, as do the medical witnesses, that Isaiah appears to be more relaxed when being bathed and the parents told the Children's Guardian that they believe Isaiah is comforted by having a bath and by having his foot tickled. In answer to a question put by the father, the mother said, "I can only see subtle things for now but that is what I go by" and that "I do respect the doctors' opinion, I am not saying they are completely wrong but I want them to take into account my views and what I have seen".
62. The mother further contends, with the support of the father, that in contrast to the medical evidence before the court, Isaiah demonstrates a clear "emotional connection" to his mother and father and his siblings, again evidencing an ability to derive pleasure from his life. In addition to the matters recounted in the foregoing paragraph, the mother told the court that Isaiah responds positively when she cuddles him, that he has a favourite toy to which he responds by pushing out his legs, that he reacts to the touch of a soft ball on his feet, face and arms and responds to cartoons played on the mother's phone. The mother and father dispute the evidence of medical team that Isaiah does not interact with, and does not share an emotional connection with his parents on the basis that the treating team are not with Isaiah as regularly as the mother and do not try to interact with him.
63. As to the question of whether Isaiah is in pain, the mother "would not say that he is", provided his medication is properly managed. At other points the mother appeared to suggest that Isaiah might be in pain or discomfort but came back to the view that "it boils down to being on top of his medication." Within this context, as to Isaiah's quality of life, the mother told the court that "I am not a doctor, I see a child who is injured. He needs love, he needs care. I can give it". The mother told the court that the assessment of the medical team with respect to Isaiah's quality of life is "not right".
64. Within this context, the parents contend that it is possible to wean Isaiah off his ventilator and for him to return home. They contend that a further attempt should be

made to wean Isaiah and allow him to learn to breath for himself and that his medication be adjusted so that he is “as alert as possible” when this occurred. Even if it is not possible to wean Isaiah off his ventilator, the parents contend that it is in Isaiah’s best interests for him to have a tracheostomy to enable him to be ventilated at home. In any event, the parents submit that the court should adjourn these proceedings to allow them to bring before the court the evidence presaged in the statement of Mr Foster.

EVIDENCE OF THE GUARDIAN

65. The Children’s Guardian has provided a detailed and comprehensive analysis of Isaiah’s best interests having regard to the evidence that is now available. The Children’s Guardian has in addition spoken to the parents, Dr G, P and Dr K and has seen and observed Isaiah on 7, 29 and 30 November 2017 and 1 December 2017.
66. With respect to Isaiah’s level of response, the Children’s Guardian considers that, whilst observing a loving and gentle mother who spoke softly to Isaiah, handled him confidently during tasks and played him various sounds, he did not observe any physical movement or signs of communication. Specifically, the Children’s Guardian observed no response when P played the toy on its loudest setting next to each ear and no reactions when saw him having his nappy changed and being suctioned. The Children’s Guardian did however note that the mother was able to move Isaiah’s arms and legs with ease and without noticeable resistance when he was bathed. In his interactions with the parents, and his observations of their care of Isaiah, the Children’s Guardian was clear that the mother and father demonstrated themselves to be caring parents who have acquired a high sense of confidence in meeting Isaiah’s needs, concluding that “The level of diligence was heart-warming to observe”.
67. In his report, the Children’s Guardian undertakes an analysis of the benefits and burdens of continuing treatment for Isaiah. In recommending that the court make the declaration sought by the Trust, the Children’s Guardian observes as follows:

“[46] In much of my work I am asked to speak with children and report their wishes and feelings to the court regarding their parents’ own positions. I cannot of course do so with Isaiah and must rely on the evidence and my observations. Isaiah was born into a loving and caring family. Ms Thomas and Mr Haastrup are devoted to Isaiah and he has a special place in their family. Mr Haastrup has stated to me, “It is the care you give Isaiah that gives him quality of life...I can come here for the next five years. Coming here every day is not a burden.” I have no doubt as to how loved and cherished Isaiah is by his parents, and that they would do an exceptional job maintaining his care in the community. However, for Isaiah to remain in an irreversible condition with no prospect of any developmental change, as seen over the last ten months, I do not consider it in his best interests to prolong the current situation.

[47] The medical consensus is that continued ventilation is not in Isaiah’s best interest and it is with a very heart that I agree. For all the information available to me, I do not see how it can be in Isaiah’s best interests to have to endure the life that he currently leads absent any quality and plagued only with the burden of the procedures that keep him alive. I have been left profoundly struck by a comment that Dr G made during my interview, ‘Isaiah

is not suffering because he is not capable of suffering.’ Given Isaiah has suffered such a severe brain injury, tragically, he lives a life lacking any purposeful existence.”

LAW

68. The grave and emotive issues raised by these proceedings bely the relative simplicity of the law that the court is required to apply when deciding the application before it.
69. The legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not ‘*Gillick*’ competent is well settled. The following key principles can be drawn from the authorities, in particular *In 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, *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 starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patients attitude to treatment is or would be likely to be.
 - iii) 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. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

“This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism.”
 - 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) 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. 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.

- vi) Within this context, 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.
- vii) 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.
- viii) Each case is fact specific and will turn entirely on the facts of the particular case.
- ix) 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. In this context, in *An NHS Trust v MB Holman J*, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

“The views and opinions of both the doctors and the parents must be carefully considered. 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.”
- x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

70. Within the foregoing context, in *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:

“[22] 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.”

and

“[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.”

71. Most recently, in the case of *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ again reiterated that:

“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.”

72. In their helpful submissions on behalf of the mother, Mr Wise and Mr Quintavalle invite the courts attention to a number of additional passages in the decision of the Supreme Court in *Aintree University Hospital NHS Trust v James* and the decision of *In re M (Adult Patient)(Minimally Conscious State: Withdrawal of Treatment)* [2012] 1 WLR 1653, which they submit reinforce the principle that the court is not bound to follow the clinical assessment of the doctors, even if that assessment is unanimous, and make clear that when considering prospects of success, including the likely outcome for the patient of the treatment in question, the court is not concerned with whether the patient will recover fully but whether the patient would have a life that he or she would regard as worthwhile, that the fact that the patient has limited consciousness is not determinative of the application and that court is entitled to reach the conclusion that it is too soon to say whether the treatment in question is in the patient's best interests.
73. It is also important to recognise that Isaiah has a right to life under Art 2 of the ECHR. As I noted in *Re Y (No 1)* [2015] EWHC 1920 (Fam) at [37], the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment, but that that obligation does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned (see *R (Burke) v The General Medical Council* [2005] EWCA 1003).
74. Finally, the Royal College of Paediatrics and Child Health has issued guidance entitled ‘*Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice*’, published in March 2015. That guidance has been considered by many of the doctors who have had contact with Isaiah in this case, including the independent experts, and was considered by the President in *Re Jake (A*

Child) [2015] EWHC 2442 (Fam). With respect to the issues raised in this case, the Guidance states as follows with respect to the sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, as treatments cannot provide overall benefit:

“I When life is limited in quantity

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- A. Brain stem death, as determined by agreed professional criteria appropriately applied;
- B. Imminent death, where physiological deterioration is occurring irrespective of treatment;
- C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

II When life is limited in quality

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits;
- B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life;
- C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.”

75. In respect of circumstances where life may be of limited quality due to a lack of ability to benefit from continued life, the Guidance provides further illumination as follows:

“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. Although it is possible to distinguish these different groups of decisions to limit LSTs that

are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress.”

DISCUSSION

76. In this case, having considered carefully the evidence before the court and having listened very carefully to the submissions made by the parties, I have taken the difficult decision to grant the declarations sought by the Trust. My reasons for so deciding are as follows.

Application for Further Adjournment

77. Whilst Mr Wise and Mr Quintavalle advanced an application to further adjourn these proceedings as their secondary submission, their primary submission being that the application of the Trust should be dismissed, in circumstances where I have decided to grant the Trust's application, it is appropriate to begin with my reasons for refusing a further adjournment.
78. The application for a further adjournment is made on the basis that the court requires further expert evidence before it is in a position to determine whether it is in Isaiah's best interests for life sustaining treatment to continue. There is no Part 25 application before the court seeking permission to file further expert evidence. However, Mr Wise argues that the court requires further expert evidence (a) on what forms of sensory support Isaiah will benefit from, (b) on the “practicality” of Isaiah having a tracheostomy as a necessary pre-cursor to care at home, (c) on Isaiah's level of responsiveness, Mr Wise conceding that this would come from the same medical specialties that the court has heard evidence from at this hearing, and (d) on the feasibility of a “home care package”. Mr Wise submitted that the reason that this evidence was needed was to ensure the issues before the court are “properly explored”. I am not persuaded by this submission. Rather, I am entirely satisfied that further expert evidence is not *necessary* within the meaning of s 13(6) of the Children and Families Act 2014 for the court to resolve these proceedings justly and, in particular, to resolve justly the issues on which Mr Wise submits that further expert evidence is required.
79. In this case, Isaiah has been assessed by specialists from five different hospitals (King's College Hospital, London, the John Radcliffe Hospital, Oxford, the Evalina Children's Hospital, London, St Michael's Hospital, Bristol and St Mary's Hospital, London), including two independent experts in the medical disciplines most relevant to the court's decision, which independent experts the court permitted the mother to instruct and maintained the timetable for this final hearing to allow her to do so. Within this context, with respect to the specific areas which Mr Wise contends require further expert illumination, the court already has that evidence.
80. With respect to evidence on what forms of sensory support Isaiah will benefit from, the court has available to it the evidence of Dr K, a specialist in paediatric neurorehabilitation with extensive experience in this field. More fundamentally, for reasons I will come to, the evidence in this case makes plain that Isaiah will not benefit from sensory support. With respect to the “practicality” of a tracheostomy, in

principle, the practicality of a tracheostomy is not in dispute. What is in dispute is the far more fundamental question of whether continued artificial ventilation is in Isaiah's best interests and on that question the court has the necessary evidence. With respect to Isaiah's level of responsiveness, the court already has a plethora of evidence on which to reach its conclusion from Isaiah's treating clinicians, the independent experts and, importantly, from the parents. This evidence is quite sufficient for the court to come to a properly informed conclusion as to Isaiah's level of responsiveness, if any, without the need for further experts in the same specialisms to be instructed. As to the need for further evidence on the feasibility of a "home care package", once again, in principle, that it is possible to make provision for the ventilation of Isaiah at home is not in dispute (albeit it would require the unprecedented step of replicating Level 2 ICU care in the community). Rather, once again, what is in issue is the fundamental issue of whether it is in Isaiah's best interests to continue to receive such treatment at all.

81. Further, and within this context, although it would appear that Professor Doctor M has expertise in paediatrics and paediatric intensive care, the court already has independent expert evidence from a specialist paediatric intensivist, in addition to the paediatric intensivists responsible for Isaiah's care. With respect to Dr L, she is described as a paediatric haematologist and oncologist. Isaiah does not have any form of blood disorder or cancer, but rather labours under the effects of a catastrophic neurological insult. As such, it is plain that her specialism does not assist in this case. In the circumstances, I am satisfied that it is not necessary for the court to have expert evidence from either Professor Doctor M or Dr L in order to resolve these proceedings justly. With respect to allegations that Dr L misled fellow professionals at King's College Hospital in order to gain access to Isaiah, that she carried out a medical examination of Isaiah in breach of the applicable law in this jurisdiction and that she may have committed a criminal offence under the Medical Act 1983, I make no further comment about those allegations in circumstances where that matter is with the Police. However, as a matter of general principle, it goes without saying that to arrange for, and facilitate *clandestine* examinations of children who are the subject of proceedings is entirely inappropriate. Any examination of a child who is subject to proceedings with a view to securing further expert evidence should take place only in accordance with the law and procedural rules governing such examinations.
82. Before leaving the question of a further adjournment, there is one further matter that I must deal with. In making his submissions in support of another adjournment, Mr Wise argued that it was necessary for the court in this case to have additional expert evidence from *foreign* experts. Specifically, Mr Wise contended that, given both the gravity of the issues in this case and its potential outcome, and where, as Mr Wise put it, there may be different "cultural" approaches to these issues in other countries, this court would be greatly assisted by evidence of the approach taken to these difficult issues in other jurisdictions. I reject that submission.
83. There is a world of difference between a foreign expert who may have relevant medical or scientific expertise in diagnosing and/or treating the medical condition in issue, and whose evidence may therefore, on the facts of a given case, be said to be necessary to resolve the proceedings justly, and a foreign expert who simply takes the view that the medical, moral or ethical approach to these issues in this jurisdiction differs from that in their own jurisdiction or their own practice, and that the approach in their jurisdiction or their own practice is preferable. The *Guidelines for the Instruction of Medical*

Experts from Overseas in Family Cases 2011 acknowledge that evidence from the former may, depending on the facts of the case, be of assistance to the court. By contrast, an attempt to adduce evidence from the latter in a case of this nature is to be deprecated. Professor Doctor M spends a portion of his report dealing with the impact of Germany's history on the manner that these cases are said by him to be approached in that jurisdiction. It would be extremely unfortunate if the standard response to applications of this nature was to become one of scouring the world for medical experts who simply take the view that the medical, moral or ethical approach to these issues in their jurisdiction, or in their own practice is preferable to the medical, moral or ethical approach in this jurisdiction. This is particularly so where parents in the situation these parents find themselves in are understandably desperate to grasp any apparent life raft in the storm that is engulfing them.

84. For all the reasons I have given, I am entirely satisfied that it is not necessary within the meaning of s 13(6) of the Children and Families Act 2014 for the court to have the further expert evidence sought by the mother, or any further expert evidence in order to resolve these proceedings justly. In addition, a further adjournment of this matter will cause further delay for Isaiah. Such delay is not in his best interests in circumstances where, for reasons I will now come to, I am satisfied that continuing life sustaining treatment is not in his best interests. Accordingly, I decline to grant a further adjournment.

Isaiah's Medical Condition and Prognosis

85. As will be apparent from the very full summary of the evidence I have set out above, there is a stark difference of view between the medical witnesses in this case, which evidence is striking in its unanimity, and the view of the parents with respect to Isaiah's medical condition and prognosis. Having listened carefully to the evidence in this matter, I am satisfied that the evidence establishes that Isaiah's current medical condition and prognosis is as follows.
86. During his birth Isaiah sustained a severe and profound hypoxic ischaemic injury as the result of a lack of blood supply and/or oxygen to his brain. Isaiah remains on life support with a diagnosis of severe hypoxic encephalopathy as a consequence of uterine rupture. He is in the most severe stage of hypoxic ischaemic encephalopathy. The MRI scans undertaken in February and April 2017 show clearly evidence of very widespread restricted diffusion and loss of brain matter. The extensive damage extends to both the cortical and basal areas of his brain.
87. In consequence of his severe and profound brain injury, Isaiah is unable to breath by himself and remains fully ventilator dependent. Whilst he is noted to demonstrate some respiratory effort, this is intermittent and is not adequate to sustain his life with ventilator support. Regular attempts have been made to wean Isaiah off ventilator support but on all occasions, this has been unsuccessful. He is unable to maintain adequate gas exchange and normal vital signs in absence of pressure assisted breaths. Isaiah's catastrophic brain injury has also resulted in him having none of the reflexes that ordinarily protect the airway by way of a gag or a cough. In consequence, Isaiah requires, and will continue to require, regular suction for pooled secretions in his oropharynx. He is, and will always be, unable to feed himself and will require nutrition by way of a feeding tube.

88. A further consequence of Isaiah's profound brain injury, which encompasses damage is in areas responsible for control of movement and muscle tone, is that he has developed rigid tone, dystonia (a persistent and widespread cramp in his muscles) and severe four limb spasticity in keeping with a diagnosis of cerebral palsy. It has become very difficult to straighten his legs or to flex his arms at the elbows despite use of medication. Isaiah is currently classified at level V of the Gross Motor Function Classification System, which is a five-level system. Children at Level V are severely limited in gross motor function. Isaiah continues to demonstrate very little spontaneous movement. He has a predisposition toward seizures and potentially fatal status epilepticus.
89. The extensive damage to Isaiah's brain evident on the MRI scans also encompasses the visual and aural pathways in Isaiah's brain. Isaiah has no meaningful visual perception and, now, markedly reduced, if not absent, hearing. There is no evidence now demonstrating that Isaiah is able to see, hear or interpret anything of the outside world. Developmentally, Isaiah has minimal function in all domains tested and severe delay in all domains. He has not attained any of the expected developmental milestones and has a profound disorder of development.
90. There was much exploration during the course of the hearing as to the extent, if any, of Isaiah's level of conscious awareness. That exploration took place largely through the medium of examining the extent to which Isaiah demonstrates responsiveness to, and emotional connection with his parents, and the extent to which he may feel pain or pleasure, whether in the form of comfort, or otherwise.
91. With respect to the question of the extent to which Isaiah demonstrates responsiveness to, and emotional connection with his parents, I have listened very carefully to the parents' account of Isaiah's responses and have taken into account that they know Isaiah well and spend more time with him than any given nurse or doctor. The parents believe firmly that Isaiah responds to them and demonstrates an emotional connection to them in the manner I have described. It is important to note that there have been, at least in the initial phases of Isaiah's treatment, some areas of agreement between the evidence of the parents with respect to Isaiah's reactions, in particular in relation to his response to sound earlier in the course of his treatment and, more uniformly during the course of his treatment, to being bathed.
92. However, having regard to the careful and repeated clinical and expert assessments of Isaiah's current level of responsiveness, I am satisfied that the parents' evidence on this issue is, both understandably and sadly, heavily influenced by the flattering voice of hope and, as such, does not constitute reliable evidence that Isaiah is more responsive than described by his treating team and Dr Habibi and Professor Whitelaw. That this the position is in my judgment further demonstrated in the videos that the parents have provided to the court and which I have considered carefully. In those videos can be seen the effect generated by the coincidence of what are the repeated, purposeless movements described in the medical evidence and the parents' loving verbal interaction with Isaiah. In those videos it is, unhappily, easy to see how the optimism of parents, whose desperate wish is for Isaiah to survive and improve, leads them to believe that Isaiah is responding to what they are saying when, in fact, what is seen is a simple conjunction between the voices the parents and the purposeless movements consequent on Isaiah's catastrophic brain injury.

93. With respect to the issue of the extent to which Isaiah is able to feel pain or pleasure, having regard to the evidence I have recounted in this judgment, it is not possible to establish definitively whether Isaiah is in pain or experiences pleasure or to quantify or measure pain or pleasure. However, it is in my judgment important to note that the medical consensus is that, if Isaiah is aware, he has an extremely low level of conscious awareness and that, within this context, there is an absence of objective evidence that he feels pain or pleasure and real difficulty in interpreting Isaiah's limited movements, stiffening and apparent relaxation as a conscious response, given his extremely low level of consciousness and the level in the nervous system from which such movements originate.
94. In the circumstances, on question of the extent to which Isaiah is responsive to his parents or to pain or pleasure, I prefer the medical evidence. Within this context, it is not possible to reach a definitive conclusion on the *precise* level of Isaiah's conscious awareness, if any. However, the nature and extent of his brain injury, as demonstrated by his physiological presentation and corroborated anatomically by the MRI scans, is at the extreme upper end of the spectrum of severity. Further, for the reasons I have set out, over an extended period of time there has been no objective evidence of conscious awareness in the form of meaningful responses by Isaiah or definitive evidence that he experiences pain or pleasure. In the circumstances, and within the foregoing context, on the totality of the evidence before the court I am satisfied that Isaiah has a *profoundly* depressed level of consciousness and, if he is aware, he is more likely than not only to be minimally so.
95. Finally, it is important to note that *if* Isaiah has sufficient conscious awareness to feel pain, there was unanimity amongst the medical witnesses that he suffers from a condition, namely dystonia, that will result in him being in constant pain, which pain would be present notwithstanding any comfort he may experience, which he is unable to express and which is amenable to only partial relief.
96. Whilst the parents continue to cling to the view that Isaiah's true potential in terms of his breathing and level of conscious awareness are being masked by the drugs he is being given, I am satisfied on the evidence before the court that this is not the case. The parents have produced no cogent evidence to make good their case that Isaiah's current presentation is being driven by his medication rather than his catastrophic global brain injury. By contrast, there is a complete unanimity amongst the treating clinician's and the independent experts that Isaiah's medication is not the cause of his inability to breath on his own, or of his profoundly low levels of consciousness, supported by a clear correlation between the physiological and anatomical evidence in this case. For the avoidance of doubt, I reject any suggestion that Isaiah's treating clinicians have sought to introduce unrecorded medications into Isaiah's system in an effort to artificially lower his levels of consciousness.
97. I am satisfied on the evidence before the court that Isaiah has no prospect of recovery or improvement given the severe nature of the cerebral atrophy in his brain. The evidence before the court demonstrates that Isaiah will remain ventilator dependent and without meaningful awareness of his surroundings. Non-invasive ventilation by facemask is not appropriate for Isaiah as he has no gag or swallow reflex and consequently will be at risk of aspirating fluid and secretions. Isaiah thus has an *extremely* poor prognosis in terms of his level of disability. The continued mechanical ventilation that he requires will merely sustain his life with no chance of restoring his

health or providing benefit in terms of his prognosis. Moreover, the medical evidence is clear that Isaiah will be at significantly increased risk of potentially fatal chest infections (and associated repeat admissions into hospital were he to be cared for in the community) by reason of his need for continued artificial ventilation, Dr G being clear that his lungs already show evidence of chronic infection or disease. Isaiah would require a permanent feeding tube to be surgically fitted and possibly more extensive surgery to prevent reflux common in children who are chronically tube fed. In addition, the evidence is clear that his levels of muscle spasticity will increase, with the association likelihood that as his body continues to grow he will develop deformities, scoliosis and hip dislocation.

98. Within the context of Isaiah's prognosis, I accept the evidence of Dr Habibi that the only 'treatment' option for Isaiah is that which he is receiving currently, namely Level 2 ICU care. I further accept Dr Habibi's evidence that, whilst feasible to perform a tracheostomy on Isaiah, it would not be a practical option to seek to replicate a single Level 2 ICU bed that Isaiah would in any event continue to need at home in the community. In the circumstances, were he to continue to receive life sustaining treatment, I am satisfied that this would only be possible by Isaiah remaining in hospital for the duration of his life.

Best Interests

99. Within the foregoing context, and having as I must Isaiah's best interests as my paramount consideration, I am entirely satisfied that it is no longer in Isaiah's best interests to receive life sustaining treatment.
100. The starting point is for the court to consider the matter from the assumed point of view of Isaiah. The court must ask itself what Isaiah's attitude to treatment is or would be likely to be. This is not an easy task in relation to a child who has had, within the context of his age and his profound brain injury, no opportunity to form, or to express any point of view in respect his treatment or its impact on his quality of life. In seeking to ask myself what Isaiah's attitude to treatment would be, I have born in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability. I have also born in mind that a child's attitude is often influenced by the views, beliefs and guidance of his or her parents. However, Isaiah's likely attitude to treatment must also be evaluated against the fact that the prospect facing him is one of continued life sustaining treatment that will do not more than sustain him in, at best, a state of *profoundly* depressed consciousness in which, if he is aware, he is more likely than not only to be minimally so, with no prospect of improvement or recovery and the prospect of repeated chest infections, deformity scoliosis and hip dislocation. Within this context, in discharging the difficult task of asking myself what Isaiah's attitude to continued life sustaining treatment would be likely to be, I am satisfied that Isaiah's point of view would be that treatment that is capable of achieving only that which I have outlined would be very unlikely to be acceptable to him, particularly *if* he is feeling pain.
101. In reaching my decision as to Isaiah's best interests, I have also paid careful regard to the fact that there is 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 Isaiah. The sanctity of life is a fundamental, indeed sacred, principle from which there flows a strong presumption in favour of a course of action that will prolong

Isaiah's life. Continuing life sustaining treatment will, self-evidently, prolong Isaiah's life. The evidence before the court indicates that, subject to the risk of infection, Isaiah is stable on life support, and that, apart from his brain, his other organs are developing well.

102. The presumption in favour of taking all steps to preserve life reflects the fact that life has unique value and it is important to recognise the value of Isaiah's life. Isaiah's life is valuable in a number of contexts. It is of valuable, in itself, to Isaiah. It is also, evidently, extremely precious to his parents, his siblings and to his wider family. Finally, Isaiah's life is valuable because it adds, in whatever small and incomplete way, to the collective human experience.
103. I have also had regard in considering Isaiah's best interests to the fact that it is plain on the evidence before the court that Isaiah was born to dedicated, loving and caring parents. Isaiah's parents, his siblings and his extended family, have attempted to give him sense of love, human connection, belonging and identity notwithstanding his profound and irreversible brain injury. He has available to him two devoted parents who themselves have a supportive family and a supportive community and church. Indeed, having heard her give evidence, I am in no doubt that the mother is correct in her self-assessment that, subject to training, she could provide Isaiah with dedicated care and, were it to be in Isaiah's best interests to be cared for at home, that with highly specialist support the mother is more than up to that task. Were Isaiah to remain on life support in hospital, it is clear that he would remain visited and loved by his mother, two brothers and extended family. Within this context, I remind myself once again of the assessment of the Children's Guardian that:
- “Ms Thomas and Mr Haastrup are devoted to Isaiah and he has a special place in their family. Mr Haastrup stated to me ‘It is the care you give Isaiah that gives him the quality of life...I can come here for the next five years. Coming here every day is not a burden.’ I have no doubt as to how loved and cherished Isaiah is by his parents and that they would do an exceptional job in maintaining his care in the community.”
104. Finally, I have paid very careful regard to the views of Isaiah's mother and father. Their firm and unwavering belief that it is in Isaiah's best interests for life sustaining treatment to be continued shone through in their respective cases before the court. Neither could have done more to seek to persuade the court of their case in this regard. I have also considered carefully the mother's evidence regarding her strong religious beliefs with respect to the proper arbiter of decisions regarding life and death. The mother believes firmly that in Isaiah's life the world hears the still small voice of God, and that only God may decide whether Isaiah lives or dies. Her beliefs, shared by the father, should be, and are accorded respect by the court.
105. The matters I have recited over the course of the foregoing paragraphs tend, notwithstanding what I am satisfied would be Isaiah's view of continuing life sustaining treatment, to weigh against the declaration sought by the Trust. Very sadly however, there are in this case profoundly weighty factors on the other side of the balance sheet.
106. The presumption that life should be preserved is not irrebuttable. That it is not recognises that life cannot be, and indeed should not be preserved at all costs in the face of its natural conclusion. Isaiah's life is sustained mechanically and without mechanical

ventilation he will die. The burden on Isaiah of that irreversible position is a grave one. If kept alive he will continue to suffer from profound cognitive impairment, extremely severe global motor disability with spastic quadriplegic cerebral palsy. That situation will not change.

107. Within this context, Isaiah is not now, nor will he ever be able to engage in any meaningful interaction with the world around him. He will not be able to see or move independently and will have, at best, markedly reduced hearing with no objective evidence that he is able to make sense of anything he might hear. There is no wider objective evidence of his being aware of the environment or events surrounding him and no objective evidence that he is able to respond to external stimuli so as to take comfort or enjoyment from the world around him. This means he is, and will remain unable to derive pleasure from interaction with his parents and family and that he lacks the capacity to develop an emotional attachment to them. Tragically, Isaiah's profound and irreversible brain injury means that now, and in the future, he will not be able to enjoy any the fundamental benefits that life brings, including but not limited to the experiences of love, human connection to family and friends, development of a sense of identity and belonging and learning about and exploring the world. By contrast, to continue to be subject to life sustaining treatment will confine Isaiah to being kept alive for his entire life in an ICU, his life is sustained by machines in a world he cannot meaningfully perceive or connect with.
108. In addition to these matters, the maintenance of permanent, invasive life sustaining treatment will expose Isaiah to both the possibility of fatal infections and to the consequences of the evolution of his dystonia and muscle spasticity. With respect to the former, to continue life sustaining treatment would, on the evidence before the court, result in Isaiah being at high risk of infection as the result of mechanical ventilation due to increased risk of aspirating food, drink, oral secretions, foreign bodies and gastric contents. With respect to the latter, as he grows, he will therefore be at risk of deformations and permanent contractures, which may develop to hip dislocation, and scoliosis as a result of his dystonia and muscle spasticity. He will continue to suffer bladder and bowel incontinence and will continue to be tube fed. He will never feed orally. Once again, *if* Isaiah feels pain, to continue life sustaining treatment for Isaiah will be to continue to expose him to that pain.
109. Finally, in cases where the end of life is in issue, for many the concept of human dignity becomes encapsulated by the idea of a 'peaceful' or 'good' death. Within this context, a comparison must be drawn between the course advocated by Isaiah's treating doctors, of being allowed to die peacefully with appropriate palliation if, as is inevitable, that is the natural course that Isaiah condition follows, and the course advocated by Isaiah's parents, of a continuation of invasive treatment that will lead only to life being sustained without hope of recovery, with little or no quality of life and with the prospect of infection and increasing physical contortion.
110. In these circumstances, and notwithstanding the matters on the positive side of the balance sheet to which I have referred, I am satisfied on the evidence before the court that to continue life sustaining treatment for Isaiah will not result in his recovery and will condemn him to a life of profoundly limited quality. Within this context, in my judgment, the following extract from the RCPCH Guidelines *Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice* is of particular relevance in this case:

“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.”

111. Within this context, examining Isaiah’s best interests from a broad perspective, encompassing medical, emotional, sensory and instinctive considerations, and paying due regard to the fundamental, but not immutable principle of the sanctity of life, I am satisfied that it is not his best interests for life sustaining medical treatment to be continued in respect of Isaiah.

CONCLUSION

112. The RCPCH Guidance recognises “the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child”. In this case, the burden of that decision falls upon the court. In *Re Z (Identification: Restrictions on Publication)* [1997] Fam 1, the then Master of the Rolls, Sir Thomas Bingham observed as follows:

“I would from my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment. If that judgment is in accord with that of the devoted and responsible parent, well and good. If it is not, then it is the duty of the court, after giving due weight to the view of the devoted and responsible parent, to give effect to its own judgment. That is what it is there for. Its judgment may of course be wrong. So may that of the parent. But once the jurisdiction of the court is invoked its clear duty is to reach and express the best judgment it can.”

113. The sad but clear duty of this court is to come to a conclusion on Isaiah’s best interests on the totality of the evidence before the court. For the reasons I have given, I am clear in my conclusion as to where Isaiah’s best interests lie and, accordingly, I make the declarations sought by the Trust.
114. It is trite but true to observe that the court cannot imagine the emotional pain that the conclusion of the court will cause to the parents. It is my hope that, in due course, the parents will be able to derive some small measure of comfort from the knowledge that they have done all that they can for their much loved and cherished son to seek an alternative outcome for Isaiah.
115. That, with profound sadness, is my judgment.