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Case No: FD24P00320

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 15 November 2024

Before :

MRS JUSTICE MORGAN

GREAT ORMOND STREET HOSPITAL FOR CHILDREN
NHS FOUNDATION TRUST

Applicant

and

Neriman Braqi (1)
Ayden Braqi (2)
(by his CAFCASS Guardian)

Respondents

Debra Powell KC (instructed by **GOSH In-House Legal Team**) for the **applicant**
Cleo Perry KC and Frankie Shama (instructed by **Dawson Cornwell LLP**) **1st respondent**

Malcolm Chisholm (instructed by **CAFCASS**) **2nd respondent**

Hearing dates: 23-25 & 28 October 2024 and (in respect of Ceilings of Care only) 13th
November 2024

Approved Judgment

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MRS JUSTICE MORGAN

This judgment was delivered in private and a reporting restrictions order is in force. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mrs Justice Morgan:

1. Ayden is the youngest of his mother's five children. He has 3 older brothers and one older sister. His mother loves him with a devotion which is hard to put into words. He is much loved also by his wider maternal family, some of whom live in the United Kingdom some of whom live much further away and have willingly overcome significant practical difficulties to be able to visit him. In August he had his first birthday. His father's name does not appear on his birth certificate and the identity of his father is not known within these proceedings. He has had no involvement either in Ayden's life or in these proceedings.
2. The applicant NHS Foundation Trust ('The Trust') has applied for a declaration that it is lawful and in Ayden's best interests to discontinue the provision of life sustaining treatment including invasive ventilation. On August 2nd 2024 I listed the application for case management hearings leading to a final hearing with a time estimate of 3 days to commence 23rd October 2024. The application is opposed by Ayden's mother and supported by his children's Guardian.
3. Self-evidently from the declarations sought, there is at the heart of this case a family faced with a situation of desperate sadness. The youngest member of their family, Ayden, lies gravely ill in hospital. It has been a difficult hearing. Those who love him have had to sit through highly specialised medical evidence which has been distressing to them. It is notable that on occasion it has appeared to me that the evidence has been distressing to some of those medical professionals giving it. There has been a conspicuous effort by all counsel involved first, not to add in any way that it is possible to avoid, to the distress of Ayden's family in the way that the case has been conducted, and second, not to lose sight amid the technical evidence and the necessary forensic process of Ayden himself.
4. Ayden was born prematurely by induced delivery when restricted intra uterine growth and oligohydramnios (diminished amniotic fluid) was detected as part of his mother's antenatal care. Since at birth he was showing respiratory distress, he was admitted to and spent four days in the neonatal intensive care unit at the hospital in which he had been born. He was then discharged home to the care of his mother. His mother remained worried about his breathing and by the time he was eleven weeks old he had to be readmitted to hospital. There he suffered respiratory deterioration. The respiratory support he needed was increased first from high flow oxygen to continuous positive airway pressure ('CPAP'), escalating as his condition deteriorated further, to intubation and invasive mechanical ventilation. When he was not quite 12 weeks old, he was transferred and admitted in respiratory failure to the Paediatric intensive care ward ('PICU') at Great Ormond Street Hospital ('GOSH'). He remains there today.
5. There have been 2 attempts made to extubate Ayden. First on 17th November 2023 he was extubated from mechanical ventilation to CPAP. His respiratory distress had increased after an hour to the point where ventilation was again needed to address the respiratory failure and rising carbon dioxide levels. A week later on 24th November a further, and as it turned out less successful attempt was made. Since that short period almost a year ago no further efforts have been made at extubation.
6. Ayden's presentation and establishing its likely cause was a focus of very significant concern not only to his mother but to the clinicians who had care of him in GOSH. The

way in which Ayden presented by late November and notably his, by then, very limited ability to move - minimal movements of both knees, small movements of fingers and wrists and movement (described in oral evidence to me as akin to a shrug) of one shoulder – raised a suspicion of SMARD 1 (Spinal Muscular Atrophy with Respiratory Distress Type 1). The investigations carried out included Genetic testing the results of which, taken together with nerve conductivity results, electromyogram and diaphragm ultrasound established on 8th December 2023 that he has SMARD1.

7. SMARD 1 is an exceptionally rare genetic disorder. It manifests itself across a spectrum of differing severity. It causes profound and progressive muscle weakening. Since this weakening includes the muscles required for breathing it affects the ability to breathe unaided. Ayden falls at the severe end of the spectrum in respect of SMARD 1. He cannot breathe. Neither can he cough so as to clear secretions. Earlier in his admission to GOSH he had some gag reflex but that is not now present. He has no movement of any of his limbs.

The limited movement observed when he was tested for SMARD1 in November 2023 he has lost. He cannot turn or move his head but he is able to fix and follow with his eyes – though his ability to fix and follow across the full arc is also now diminished since the muscles of his eyes are weakened. The evidence of the medical witnesses as to his condition and prognosis is considered later in this judgment.

8. There is no treatment for SMARD1, it is degenerative, irreversible and life limiting. Alongside those features of the condition Ayden is, as far as all the evidence indicates, cognitively intact. He can hear. He can see. It is not expected that he will ever be able to speak. The evidence suggests that he had little or no ability to express himself in any way. There are reported occasions when it is said that he smiles, most often in the presence of his mother. There are occasions when touch or voice –again most often of his mother seems to soothe and console him. Notably there is uncertainty about when he might be experiencing pain since he is not able to do any of the things a child in pain might do to communicate that: he cannot make a noise; he cannot pull away or withdraw from something that is hurting him. He cannot cry out. One witness Dr ZK, told me in evidence that he sometimes seems to close his eyes as if he doesn't like something being done to him. Sometimes his heart rate increases in a way which might be an indication of stress but as appears elsewhere in this judgment there is uncertainty clinically about the extent to which that is a reliable indicator of what he may be feeling physically or emotionally.

Preliminary Application

9. At the outset of the case Ms Perry KC and Mr Shama made an application for an adjournment. It was made in the form of a document served on the other parties and provided to me just before the scheduled start of the hearing. It is necessary for clarity of understanding to set out, in outline form, the basis of the application. The application to adjourn centred on what is called T3 data. Ayden as a patient on invasive ventilation in ICU, is linked up to a number of machines and monitors which capture readings of his physiology and functioning including Oxygenation and heart rate. At 5 second intervals, information is sampled from the machines and monitors and those samples captured as data. It is an entirely automated process and does not involve -as does the electronic recording system 'EPIC' used on the unit- any component of information being accepted, verified and uploaded by a human being. That simplified explanation

of T3 I have distilled from the evidence of Professor ZL. Professor ZL had carried out an analysis of 9 weeks of T3 data. The application to adjourn the hearing encompassed also an application for provision of the T3 data (which does not form part of the bundle of medical records) in order to respond to the analysis evidence of Professor ZL. It would be necessary, argued those for Ayden's Mother either for those representing her to analyse the T3 data or to seek permission for an independent analysis of it by a suitably qualified expert. In either case that would necessitate an adjournment and relisting of the hearing to some future date yet to be determined. There appeared to be, submitted Ms Perry KC '*a difference in analysis between Professor ZL and Dr ZM [Ms Braqi's own expert] depending on how the reviews were conducted and what questions they asked themselves*'. The T3 data was of particular relevance and interest in relation to the episodes of desaturation which Ayden experiences. Those episodes of desaturation are, submitted Ms Perry, fundamental to the case brought by the Trust in respect of the declarations sought. Ms Powell KC for the Trust who opposed the application, did not accept the characterisation of the episodes of desaturation as fundamental, rather she contended they are but one part of an overall clinical picture which led the Trust to apply for the declarations sought.

10. I refused the application to adjourn. I was not persuaded at that stage and without hearing the evidence of those clinicians caring for and or providing expert opinion evidence about Ayden that the T3 data was necessary evidence for the court to have to make a decision. It seemed likely, at the very least a real possibility, that some of those who were due to give evidence could productively be asked in cross examination about the T3 data, its relevance to the overall clinical picture, and the implications, if any, of its absence in relation to a best interests decision. I recognised that in consequence the time for cross examination of those witnesses would lengthen and furthermore that witnesses who were otherwise not required now might be. One possibility was that hearing the evidence might have the result that the T3 data was not required another was that it might demonstrate that the T3 data was, as contended, fundamental to the decision, and that carried with it the prospect of adjourning part heard. To the extent that this is properly to be regarded as a risk it was one I was prepared to take. I could not see how I could arrive at a fair and safe decision on the T3 data point on submissions alone. Recognising that case management is an ongoing process, I made clear in refusing the application to adjourn i) my intention to keep the T3 issue under review and to consider whether having heard the evidence the absence of T3 data represented a gap in the evidence required, and ii) that if Ms Perry wished to renew her application at that point she would be given the opportunity.
11. Once I had heard the evidence, most particularly that of Professor ZL I was satisfied that it would serve no purpose and add nothing to the evidential and forensic picture to adjourn for the production and/or interrogation of the T3 data. Prominent in my reasoning at arriving at that conclusion were the following features of Professor ZL's evidence:
 - a) he repeatedly emphasised the need to look at the whole picture and reinforced that the data alone did not suffice. As he put it '*Summary data shows you one thing but you need to be at the bedside to understand what is happening*'. Illustrating this point further, he explained that in his own analysis looking for life threatening desaturations (he had taken drops to 80% - from other clinicians I heard lower figures used), they could be found on the data but what was vital to know is how staff are responding and

what they are having to do. Are they giving an O₂ boost; Are they having to suction? Are they having to move to bagging? This clinical picture is all within the context, he reminded the court, of a child on a ventilator in intensive care where specialist bedside response to oxygen desaturation is near immediate. A data reading showing a fall in O₂ or the duration of a fall is not in itself key to the understanding of what is happening. In evidence it emerged that in addition to carrying out the data analysis he had on occasion had clinical responsibility for Ayden as part of the consultant rota.

b) Having done an analysis of 9 weeks of data, he explained when asked the process he had undertaken to do that analysis. His response to whether there would be value in analysing the T3 data for the whole period of 11 months admission additionally to the 9 weeks was that it *'wouldn't tell me anything I didn't already know'* and that again the best evidence of Ayden's situation including desaturations is what is clinically observed by those who are looking after him. He had not, when on rota with clinical responsibility for Ayden ever known a shift without desaturation reported.

12. I record that reasoning in relatively short form since the application for adjournment and for T3 data ceased to be an issue in the case. Ms Perry explicitly confirmed that she did not renew her application having cross examined, reviewed the evidence, and taken the opportunity to discuss this aspect of the case with her client before submissions.

13. At this hearing I have heard oral evidence from the following medical and clinical witnesses whose evidence, written and oral, is relied on by the applicant:

i) Dr ZK, a consultant in paediatric intensive care and lead consultant for Ayden;

ii) Dr ZQ, a consultant Respiratory Paediatrician;

iii) Dr ZO, a consultant Paediatric Neurologist;

iv) Professor ZL, professor of Paediatric Intensive Care;

v) Ms ZN, Physiotherapist;

vi) Ms ZP, Senior Nurse on the PICU where Ayden is treated;

I had also expert and clinical evidence from those who were not required to give oral evidence

i) Dr ZR, consultant in paediatric palliative medicine;

ii) Dr ZS consultant respiratory paediatrician (who had been the lead respiratory consultant for Ayden but by reason of her prolonged absence abroad was known to be unavailable in this part of the year and Dr ZQ gave evidence in her stead)

iii) Dr ZT Consultant in paediatric palliative medicine and chronic pain medicine.

I had in addition the second opinion evidence which had been sought from those at another hospital, of Ayden's Mother's preference, namely from Dr ZU, consultant in paediatric neurology, Dr ZV consultant in Paediatric Intensive Care and from Dr ZW, Consultant in paediatric respiratory medicine. There was also consultation of and the e mail view provided from Dr ZY, a paediatric pulmonologist in the United States of

America who had been contacted by GOSH and similarly in short form a view from Dr ZZ who is the director of an emergency department division of Neonatal and Paediatric Critical Care and semi intensive care at a hospital in Italy and who had been contacted by Ayden's family.

14. Within the lifetime of the proceedings it was known that Ayden's mother had in the latter part of 2024 instructed Dr ZM a consultant respiratory paediatrician to provide a report having seen and examined Ayden. She had not wished that report to be disclosed into these proceedings. I took the view that it should be and so directed when making the first case management order. No other party challenged the contents of that report in fact its conclusions are relied upon. Ms Perry did not seek to call Dr ZM. I made it clear to her that should she wish it, I would in the circumstances of this case be sympathetic to an application for permission to cross examine him. Having taken instructions, she was not instructed to make any such application.
15. I heard also the evidence of Ayden's mother, Ms Braqi the detail of which appears later in this judgment. His uncles, his mother's partner and other family members sat in the court during the hearing. I did not hear from any of Ayden's family members who came to court, but I could nevertheless see from the way they conducted themselves that they love Ayden (and his mother) very much and that they disagree (though they do so in a dignified and quiet way) with some of the views expressed by the clinicians and experts especially about Ayden's quality of life. Above all that they are supportive of Ms Braqi who finds herself in a position which is mercifully unimaginable to most parents.
16. There is a unanimity of view amongst the medical professionals, in which I include Ms Braqi's own instructed expert, as to Ayden's condition and prognosis and also of the burdens and benefits to him of continuing life sustaining treatment. Some have expressed themselves in starker terms than others, and some, especially those who have very frequent involvement with his day-to-day activities are more ready than others to regard some of the minimal movements he can still make – flickering of his eyes; eyes rolling up; closing his eyes - as perhaps indicative of discomfort, pain or dislike. Those small differences of expression or interpretation do not undermine the firm consensus. In those circumstances rather than set out in this judgment the detail of the evidence each witness has given, I am able to summarise the consensus.

The Medical and Clinical Evidence.

17. **SMARD1** – Ayden is affected by SMARD1 at the most severe end of the spectrum. Those who look after him at GOSH regard him as the most severely affected case of SMARD1 they have encountered. He has no head control or ability to turn his head to look around. The muscles in his arms hands and lower limbs are wasted. His fingers and feet are showing early evidence of contractures. His facial muscles have weakened to the point where he has limited movement of his mouth and some movement of his eyelids. He can still follow movement within his field of vision by tracking with his eyes. The tracking movement seems to some to be less than it was. The weakness of the muscles in his throat which has relevance to his respiratory situation means also that he is not expected to develop speech or vocal communication of any kind. He is fed through a naso-gastric tube. There are no known therapies to reverse the muscle weakness which has progressed thus far and none which could prevent further wasting. The deterioration of the musculature associated with breathing has had a devastating

impact on his respiratory system as considered later. There has been a marked deterioration in the range of movement he had when he was first admitted to that which he has now. The trajectory is one way.

18. His prognosis is poor. There are some reported instances of patients in whom the onset of symptoms of SMARD1 starts later and in whom the manifestations are milder and the course of progression likewise milder. Although it is right that there is no curative treatment for SMARD1 in those patients either, there are some management options, which are available within the context of the milder presentation. Most patients with the severe form that Ayden has, die within a few months of onset. It is known that in the United States of America, there is a trial of novel gene replacement therapy being undertaken. Those looking after Ayden at GOSH, knowing of it, made contact with the trial centre to see whether he might be considered for inclusion. He is regrettably not a candidate for the trial since it did not include infants who had already significant muscle weakness.
19. Breathing and Respiratory Issues - Since he cannot breathe unaided, Ayden is fully ventilated on PICU. He is completely ventilator dependent. He cannot take any independent breaths. He no longer shows any respiratory effort. He has a nasal endotracheal tube and is delivered high pressure ventilation at a rate of 28 breaths a minute. The pressure from the ventilator keeps his lungs inflated. Since he cannot cough at all to clear his airways he requires suctioning to clear secretions. In line suctioning (i.e. remaining attached to the ventilator) is preferred wherever possible to avoid him losing the positive pressure delivered by the ventilator. The processes of ventilation, suctioning and, when required, bagging, are not cost neutral in terms of his lungs. Three lobes of his lungs have collapsed. There is not, I was told, a direct correlation between their collapse and effective ventilated breathing since the other lobes in effect 'work harder' and there is some scope for regrowth/ expansion of remaining lung surface. Inevitably however there is an impact on his already compromised respiratory state. The continued functioning of his lungs – in the sense of receiving high pressure O₂ via the ventilator- is supported by specialist chest physiotherapy.
20. Physiotherapeutic needs - Ayden requires chest physiotherapy to mobilise or loosen secretions and then to remove those secretions by suctioning. For physiotherapy he is disconnected from the ventilator and attached to an anaesthetic bagging circuit. Breaths are given by the bagging circuit and then vibrational force is applied to his chest wall and a 'cough' mimicked to move secretions towards his tube. One cycle of chest physiotherapy is approximately 5 of these breath/vibration actions. Then he is reconnected to the ventilator and suctioned. Over the course of each 20 -30 mins of chest physiotherapy, he receives 4 cycles. He is repositioned between each pair. He requires this physiotherapy twice daily. It is essential to clear and keep his lungs open. It carries with it intermittent desaturations. It can only be carried out within an intensive care setting. Despite assiduous chest physiotherapy, he has collapsed lobes in both lungs. His situation is unusually severe and, in what, from the oral evidence I heard seemed to be a creative approach to trying to find effective ways to work with him, a machine called 'cough-assist' has sometimes been used, following discussion between his physiotherapist and his lead consultant. The cough-assist delivers a pre-set programme of positive pressure breaths followed by negative pressure, generating a fast expiratory flow, mimicking a cough (in some ways a more straightforward version of what is delivered by the bagging circuit/vibration/suctioning approach). Since Ayden

needed to have manual ventilation with an anaesthetic bag because he was frequently desaturating, that approach was felt safer and more appropriate than the cough-assist.

21. Stability and Desaturation Episodes - In addition to the episodes of desaturation (i.e. drops in the levels of Oxygen in his blood) which may occur when he is disconnected from his ventilator for purposes such as physiotherapy, Ayden has from time-to-time spontaneous desaturations. When this happens, it can sometimes be corrected by increasing the percentage of oxygen delivered. Or by suctioning. If this does not resolve it, the bedside nurses will call for medical help and immediately initiate 'bagging' using the *Ayers* rebreathing circuit - a specialised bagging system that is not used outside a critical care setting or theatres. It can only be safely operated by clinical staff who have had advanced training using it. The procedure involves taking Ayden off the ventilator. Within the broad consensus of evidence there were differences as to what level (i.e. numerically) constituted a serious or life-threatening fall. Some pitched it at 80% or below, some in the region of 50% +. The episodes have been associated with bradycardia. Whilst the desaturations continue, they are not always more recently associated with bradycardia. Elsewhere appears consideration of the evidence given about his heart rate anomalies.
22. Emerging from all witnesses in relation to the evidence of desaturation were two strands of significance: first that there has never been a time when Ayden was not having spontaneous desaturations and so has never, in that respect, been stable; second that the recoverability from these desaturations by intervention is to be seen within the context of the fact that his life is in the ICU, and so he is at all times a matter of seconds away from urgent intervention in response to an alert. The fear of the medical staff is that there may come an occasion even in that context when he cannot be recovered from what Dr ZK called '*the brink of death*'.
23. Pain and discomfort- There is nothing to suggest that Ayden does not feel and experience pain in the same way that a child who did not have SMARD1 would feel and experience pain. He has not the physical capacity to express that pain. This is not a child who can move his hand away from a sharp or painful stimulus or cry out to show something is hurting him. There is some small remaining thought that he can screw up his eye a little in response to the hard nasal tube which is likely to cause him pain when he is moved, but there is doubt about whether that is something that is an indicator of pain. As a result, the evidence before me is that it is difficult to assess when he is experiencing pain and discomfort.
24. In relation to his day-to-day life when thinking about the procedures Ayden must undergo and the pain he is likely to experience as a result, those looking after him have found it useful to have regard to how other patients, including other children, who are able to communicate have reported experiencing them. With that in mind; mechanical ventilation, is reported as feeling like a forced expansion of the lungs outside the patient's control. For Ayden ventilation is a permanent condition. The build-up of secretions which can't be cleared without suctioning is reported as feeling like *drowning*. Suctioning – of the sort Ayden needs very often - has been described by those who have experienced it as like a *knife* (children) or a *hot poker* (adult). The experience of desaturation to the person having it, is likened to the feeling of suffocating.
25. As to this aspect of the consensus, there are 2 important things: first that extrapolating what other children report feeling or having felt to this child with whom the doctors

(and I) are concerned does not provide certainty (to the extent that in medicine anything does). It is however the only means to try to assess his pain; second, that the fact that something is done often or as a matter of routine, does not mean that the experience of the pain of it is diminished. The chest physiotherapy which is essential for Ayden and which he experiences twice daily is delivered by a highly skilled and specialist physiotherapist and is painful. The physiotherapist told me, from her experience of delivering physiotherapy to other children, that infants who don't have Ayden's near complete paralysis of expression, very often start to cry when they see her coming towards them on the ward in anticipation of what is about to happen to them.

26. Where there was clear likelihood of pain for a procedure then pain relief is given for it. It is not feasible or acceptable simply to give pain relief as a constant medication having regard to the side effects in particular for the liver (paracetamol based) or stomach (ibuprofen based). Those side effects might be acceptable in a situation where there is a need to manage pain during a period of recovery following which pain relief may be discontinued. It is a quite different prospect where, as here, no such recovery is possible.
27. Autonomic Dysfunction -The physiological signs which might ordinarily be relied on by medical professionals as clear indicators of pain or stress or distress are in Ayden's case less safe. Indications such as a raised heart rate, blood pressure or sweating might to put it at a basic level compensate for his lack of vocal expression or ability to show purposeful movement in relation to painful stimulus. Those features are governed by his autonomic nervous system. The evidence was that over the more recent months of his admission he has shown signs of autonomic dysfunction. Autonomic dysfunction is a development which is expected as part of SMARD1 progression. His heart rate for example is higher than normal ranges would allow for. What follows from this is that it has become unsafe for those looking after Ayden to rely on signs such as a raised heart rate or sweating as clear indicators of pain, discomfort or distress. In relation to Autonomic Dysfunction words and phrases such as '*diagnosis*' and '*signs of*' were used interchangeably by witnesses. There was no dissent as to the presence and relevance of autonomic dysfunction. Dr ZK, when asked, did not regard it as requiring a label of formal diagnosis
28. Cognition and Awareness - His vision, his hearing and his cognition are believed to be normal. Although there were, Dr ZK suggested, on imaging some features which had an encephalitic quality, she inclined to the view that this should not be taken as an indication that his cognition was declining but that he was affected by a lack of stimulation. Whilst he, within the boundaries of a child so badly affected by SMARD1 is offered stimulation, all of that which would be stimulating to at this age, a toddler unaffected is unavailable to him. He does not have the same developmental path. The consensus of all of those looking after him is that the logical consequence to be drawn from his intact hearing, sight and cognition is that, although he cannot communicate anything about it, he has an awareness of all that is going on around him and all that is being done to him. He is as one witness put it to me '*there for all of it*'.
29. Burdens and Benefits of Treatment – there was the clearest consensus the burden of continuing with life sustaining intensive care treatment outweighs the benefits. Criticism was levelled by counsel that the medical witnesses – notably Dr ZK as lead consultant - had not articulated sufficiently the benefits and had focused too much on the burdens. It will be convenient for me to discuss this elsewhere.

30. Risk of an unpredictable Death – The risk that there may come an episode in which Ayden cannot be recovered from the brink of death was considered in the context of desaturations. Dr ZK elaborated on the risk that Ayden may die as a result of a medical emergency or episode in PICU. She gave that evidence in the context of being asked on behalf of the guardian about the possibility, on his mother’s case, of Ayden simply being allowed to ‘die naturally’. With noticeable emphasis she responded that *there is nothing natural about a death on a ventilator in intensive care*. Expanding on this she identified the fear that an episode of irretrievable collapse should it be at night or in the absence of his mother would mean he would die alone, amid the alarm and urgency of the crash team, subject to CPR, probably frightened, without the comfort of his family, and without palliative medicine and care he would otherwise have.

The Evidence of Ayden’s Mother

31. Medical and Clinical evidence is important. So too is that which I heard and read from Ayden’s mother. Ms Braqi has spent for almost a year now 16 hours or more each day at her son’s bedside. During the week she sleeps in a room in the accommodation provided for parents of seriously ill children across the road from the ICU. She takes a clear delight in him and, whilst there are limited ways she can bring stimulation to his life, she does so. Ayden cannot move his head but as he lies on his back he can still open his eyes, so she has obtained a projector so as to show animation on the ceiling. Watching that is something he can enjoy but also something he can do with his brothers and sister.
32. She ensures that he is, in a real sense, involved in the life of his family. His brothers and sister come at the weekends and during school holidays to spend time with him. I have seen photos of them surrounding him on his birthday and of 3 of the 4 of them lying on his bed with him to watch together *Cocomelon* animation projected onto the ceiling. In the background of a video clip I can see the youngest of his brothers sitting quietly playing on a tablet or similar, clearly well used to being there. Ms Braqi told me with a wry smile of her efforts, not always successful, to contain the children's physical energy and noise to a level better suited to an intensive care unit. She knows Ayden can hear and so she talks to him and reads to him – she is not, she told me, any kind of singer, so she does not sing to him, but sometimes music is played to him. His sister loves to read and so reads him stories.
33. She does all she can to make him comfortable. Routine, ordinary cares for a baby she will do, changing his nappy and dressing him. Several of those who have seen him have remarked on the care she takes selecting clothes for him. She does not do any of the procedures likely to cause him pain – like deep suctioning - but she is often there when other people are doing those things. She does not deny that there are times when he is in pain and discomfort though she thinks it is less than the clinicians think. She thinks that he sometimes sleeps through suctioning and knows that the clinicians do not agree that he does. She firmly believes that she is better able to read his cues and is more attuned to his needs. She says that he still smiles – less widely than he did when his facial muscles were stronger, but she says it is still there and as his mother she can see it. She also told me that sometimes she thinks he is trying to tell her something when she looks in his eyes. Sometimes, as she put it, when he is having something unpleasant or painful done to him, she thinks that when he looks at her, he is trying to communicate ‘*mum get these people away from me*’. She also thinks sometimes his eyes fill with

tears. She doesn't agree with his doctors that when his eyes are watering that doesn't mean he is crying in a way associated with pain or upset. She thinks it means just that.

34. Although others are troubled that moving Ayden from his bed to her for time to be cuddled causes him pain, she does not think that. She does not believe she sees any difference in him then, as he is moving, than any other time, though she reflected that she is not always looking directly at him when she is helping with the process of moving him which requires three people. Whilst she said that she agrees that what has been variously described as 'grinding' his teeth or biting his cheek, when he is lying in his bed, is an indicator of stress, discomfort or pain, she thought that occasions when injury was caused to the inside of his cheek by his teeth when he spent time in her arms was not such an indicator. On those occasions she thinks it is to do with different positioning as his cheek is flat against her and he cannot move his head.
35. She described to me how she felt that the doctors looking after Ayden should have looked into the feasibility of a tracheostomy in the early weeks after his admission. In this aspect of her evidence there was disappointment and something close to anger in the way she spoke of his treating clinicians. She felt she said that whilst the situation now was that no doctor would carry out a tracheostomy and the consensus was that it was not clinically viable, she thought it could have been done in those early weeks. Several times she described it to me as '*a missed opportunity*'. The issue of whether there should be a tracheostomy – which is what Ms Braqi still expresses herself as wanting for Ayden – is not one which is before me. She said that she understood that. Neither is there before me any consideration of whether there was ever an opportunity in those early weeks after he was placed on mechanical ventilation for Ayden to have surgery for a tracheostomy. What Ms Braqi's own comment tells me however, as confirmed by Ms Perry when I later asked her during submissions, is that the opportunity she believed there to have been she recognises is not now available. Without it, she knows he cannot leave ICU. In unambiguous terms she told me that on the PICU '*he is alive but at home he would be living*'. Knowing there to be no other option for him, she believes it remains in his best interest to continue to have Life Sustaining Treatment and to remain, for as long as his life may be, on a ventilator in the PICU.
36. She is a woman of religious faith. Asked how if at all her religious beliefs factored in her own view of what was in Ayden's interests, she said that *if God decides that it is time for Ayden to die then no medical doctor and no intervention could stop that: if it is Ayden's time to die then he will die.*
37. After she completed her evidence, she produced for the court a short video clip which her counsel submitted was one which her client said encapsulated her relationship with her son and in which Ayden's mother believed she could see him smile. I watched the very short clip which captured a moment of tenderness between mother and child and in which Ayden followed his mother's movements with his eyes.
38. The Children's Guardian appointed for Ayden has set out in her detailed report an account of her own investigations and visit to see him as well as the reasoning which led her to support the application made by the Trust. I do not repeat it here but I have read it carefully and accept it. She was unshaken from her view when she gave her oral evidence having attended throughout the hearing to listen to all of the evidence and remaining throughout submissions.

39. It is because it has not been possible for Ayden's treating clinicians and his mother to reach agreement that the matter comes before the court for a decision to be made about his life sustaining treatment. It is, mercifully, rare that clinicians and parents have to face having discussions about so grave a decision; rarer still that those decisions cannot be reached by considering together over time the options and arriving at a consensus as to how to proceed. It is worth remembering that because, an inevitable consequence of having to bring the dispute before the court is that it is then just that, a *'dispute'*. Within that context it is possible to lose sight of the fact that all of those involved want what is best for him. To the extent that there are applications contended for and resisted, it is about as far removed from a situation in which there are *'winners'* and *'losers'*; *'success'* and *'defeat'* as it is possible to imagine. The language of a *'dispute'* sometimes hides also that the Trust recognises and accepts that Ayden's mother loves him devotedly and would do anything for him; and that his mother likewise recognises that for nearly a year now, those looking after him have done so day and night assiduously and conscientiously doing their absolute best for him. Since they don't agree, it is for the Court to decide and in so doing the following principles derived from statute, case law and guidance apply.

The Legal Framework

40. The law in relation to the decisions I must make for Ayden is well settled and so unsurprisingly there has been little disagreement between counsel as to the applicable legal principles. An exception to this is the invitation Ms Perry and Mr Shama make to the Court to import from public law children proceedings and applications brought under s 31 of the Children Act 1989, the approach to decision making which became the focus of attention in *Re B (A Child)* [2013] UKSC 33, and subsequent authorities following *Re BS (Children)* [2013] EWCA 1146. Ms Perry urged upon me that there might be assistance to be drawn by analogy with that approach and urged also that, by analogy, this court should regard with caution, and should caution itself against, what she called a *'linear'* decision making process. I did not regard it as likely to be of assistance in making decisions for and about Ayden within the context of this application to do so by reference to the line of authorities relevant to other quite different applications and have not done so.
41. Ayden is little more than a year old. He is not a child who is even approaching the point at which he might be Gillick competent. He does not have capacity or competence to consent to or refuse medical treatment. A child's parent (here his mother), has parental responsibility and so has the power to give consent for her child to undergo treatment. Overriding control is vested in the Court exercising its independent and objective judgment in the child's best interests: *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480 per Ward LJ at 510F-G, 511A-B and 511E-F.
42. The Court of Appeal in *Re A (A Child)* [2016] EWCA 759; [2016] All ER (D) 183 said the following (§31), with reference to Lady Hale's judgment in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591: "*Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005.*"

43. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 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 from paragraph 39:-

“The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.”

44. I have had close regard to the helpful distillation of the applicable principles in *Manchester University NHS Foundation Trust v Fixsler and others* [2021] EWHC 1426; [2021] 4 WLR 95 (§56) where it was held that:

“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.” That aspect is something which resonates with the situation in this case where Ms Braqi’s strong wish that a tracheostomy should be performed cannot survive the unanimous medical view as to whether that procedure is viable.

45. At para [57] of *Fixsler* MacDonald J summarised (which summary was not disapproved by the Court of Appeal) the applicable principles in relation to medical treatment of non-Gillick competent children, where there is disagreement as to proposed treatment by those with parental responsibility. These are clearly relevant to me as I consider Ayden’s situation:

46. “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 patient's 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.” “The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.”

47. I realise that in this case the way in which the relevance of a parent’s view to a best interests decision was expressed by Holman J in that passage as ‘*wholly irrelevant*’ is likely to strike harshly the ears of Ayden’s mother. Whilst it amounts to the same thing in *Re A at [545] [F]* Ward LJ put it otherwise: ‘*Since the parents have the right in their exercise of their parental responsibility to make the decision, it should not be a surprise that their wishes should command very great respect. Parental right is, however, subordinate to welfare*’ [emphasis added].

48. In *Barts Health NHS Trust v Dance & Ors (Re Archie Battersbee)* [2022] EWHC 80 Hayden J noted the strong presumption in favour of life but also considered the concept of human dignity in the context of a child’s best interests:

“In North London Clinical Commissioning Group v GU (supra), I observed the following:

- i. Firstly, human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
- ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;*
- iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*
- iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
- v. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*
- vi. compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.”*

49. Ayden’s human rights are engaged. Those, rights, protected by the European Convention on Human Rights and relevant in the context of this case are; Article 2 (the right to life), Article 8 (the right to respect for a private and family life and Article 3 (protection from inhuman or degrading treatment).

Religious and Cultural Issues

50. When I consider the strong albeit rebuttable presumption in favour of life I hold in my mind that Ayden’s life is one which adds to the large sibling group and the wider extended family of which he is a loved and treasured member. See *Barts Health NHS Trust v Raqeeb and others* [2019] EWHC 2530 @ [169] “... *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 life. Within this context, Tafida's life has inherent value. It is also of value to Tafida herself, it is precious to her parents, sibling and family and even now it adds, in whatever small and incomplete way, to the body of collective human experience. Tafida is profoundly disabled but a life of disability is of equal value to all other lives."

51. Religious faith has a place in Ayden's family life – the values of his mother in terms of her religious faith and her strongly held belief in a God who will determine life and death are values I have heard and read. So in making a decision for Ayden the religious and cultural context of those decisions are certainly informed by those values but they are not determined by them; See *Fixsler and others* @ [70] - [71].
52. I have been referred by Ms Perry and Mr Shama to the recent judgments of Mr Justice Poole in respect of a child NR and reported as Re NR(A child: withholding CPR) [2024] EWHC 61; Re NR(A Child: Withdrawal of Life Sustaining Treatment [2024] EWHC 910 and Re NR(A Child: Ceilings of Treatment after Survival of Withdrawal of Life Sustaining Treatment) [2024] EWHC 2400. Fact specific though all decisions of this sort are, I hold in my mind the observation made by Poole J towards the end of the last of those judgments that '*...confident predictions are sometimes confounded and the Court must be vigilant and humble in the face of apparent certainty*'. I entirely agree.

Professional Guidance

53. This case is one in which those charged with making decisions medically for Ayden have had regard to the RCPCH Guidance. The Royal College of Paediatrics and Child Healthcare published the document, "*Withholding and Withdrawing Life Saving Treatment in Children*" in 1997. In 2015 revised guidance was published under the title, "*Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*." It has been considered by the President of the Family Division in Re Jake (A Child) [2015] EWHC 2442 (Fam), MacDonald J in Raqeeb and Poole J in Pippa. I have had it firmly in mind as I come to think about decisions for Ayden.
54. It is prefaced as follows:

*"We emphasise two important points so as to avoid confusion:
This document sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible—NOT circumstances under which such treatment must certainly be withheld or withdrawn.*

The document describes situations in which individual children should be spared inappropriate invasive procedures— NOT *types* of children to whom appropriate procedures should be denied."

There are three sets of circumstances in which the RCPCH advises that treatment limitation can be considered "*because it is no longer in the child's best interests to continue, because 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:

Brain stem death, as determined by agreed professional criteria appropriately applied

Imminent death, where physiological deterioration is occurring irrespective of treatment

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:

Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits

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

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.

III:- Informed competent refusal of treatment.

Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST

Arrangements to Visit Ayden

55. I had asked at a case management hearing whether anyone wished me to visit Ayden in hospital before I started to hear the case, on the basis, naturally, that the purpose of such a visit was to be clearly understood. His mother did want me to visit him and so arrangements were made. Regrettably by the time intended for the visit, seasonal virus infection made it impossible for me to enter a paediatric care unit and it was agreed by all that I would not visit. The matter was not revisited until during the time I had set aside for judgment, an enquiry came from Ms Braqi's solicitor as to whether I intended to visit. As things turned out the question was overtaken by the events of the postscript to this judgment. The end result was that I did not visit Ayden. That is a matter of regret to me - primarily because since his mother had wished me to do so and had wanted me to see him, I would not willingly have done otherwise.

Analysis and Conclusions

56. It is necessary for me to determine Ayden's best interests and whether I should make the declarations sought in the context of two stark options i) continued provision of life sustaining treatment within PICU with no prospect of ever leaving the unit ii) withdrawal of life-sustaining treatment with the expectation that the inevitable consequence will be that his life will come to an end.

57. It seemed that by the time I heard submissions there was no longer any issue taken on behalf of his mother that the options for Ayden do not include any prospect of a life outside PICU. Since those options are rooted in his stability my conclusions in relation to that follow.
58. The issue of Ayden's desaturation episodes has been the focus of much attention at this hearing. They are a marker so far as his clinicians are concerned of his lack of stability. Although on behalf of his mother clinicians were referred to entries in the medical records where he is described as 'stable' and (as relevant in relation to pain) 'comfortable' the response from each witness asked was that has to be seen in the context of being a child in intensive care requiring constant invasive ventilation. The evidence I have heard and accept from all of those clinicians is that whilst he continues to have episodes of desaturation it is impossible for him to be stepped down from PICU, not even to a high dependency unit and thus certainly not home. His instability is also a component of the reasoning which leads those whose evidence written and oral on which the Trust relies are not prepared to carry out surgery for a tracheotomy.
59. Ayden's mother agrees that he experiences desaturations, but she suggests that they do not happen as often as the Trust suggests, and that they are relatively easily resolved often with no more than an oxygen boost. Dr ZK when asked about how frequently desaturations occurred and responding to the suggestion that it was being overstated by the Trust replied that it did not really much matter if there were 2, 20 or 200 a week, it only needed 1 from which he could not be resuscitated to have the result that he would die. I have heard ample evidence at this hearing from those looking after him of the continuing desaturations and I accept that evidence. I suspect, although I do not need to reach a firm conclusion about it, that the fact that he is nursed and looked after in so specialised a unit in which episodes of desaturation and the response to them promptly and before escalation, is so much part and parcel of day to day life that it may have the effect that the extent is masked.
60. At Dr ZK's direction the nurses were asked to record on paper episodes of desaturation and the steps needed to resolve it. The document was provided for this hearing being formally produced in evidence by senior nurse ZP. It is an interesting record. The mother says it shows that the desaturations are not as frequent as suggested. The witnesses for the Trust suggest that there is under recording: partly as intensive care units are busy providing the intensive care, partly as it is human error to overlook recording; and also because – in a reflection of what I heard from Professor ZL in another context there is a tendency to under record events. I treat that last with a little caution given the circumstances in which the lead consultant directed this document. The essential point about it for me at this hearing however is this: Even were I to take what appears on that document as the only instances of spontaneous desaturation requiring interventions to recover Ayden – and I do not - that alone would be sufficient to establish unequivocally that he continues to experience life threatening desaturations which i) require intervention to prevent his death and ii) mean he cannot be stepped down from ventilation in PICU.
61. In respect of the stark possibilities for him I have no evidence as to any view that he, an infant might have, or be expected to have, or how he might feel to be in this situation, and no evidence on which I can rely as to what he might want as distinct from what others might want for him

Benefits

62. Central to the decision I have to make is a balancing of the burdens and benefits to Ayden of his situation. That weighing in the balance of what are the benefits as well as what are the burdens is also part of the clinical analysis. Whilst I have to conduct my own analysis of the burdens and benefits, there were moments in the evidence when I reflected on whether the ‘benefits’ may have been underplayed in the thinking of the clinicians as they reached their own decisions.
63. By way of illustration Dr ZK was quite properly challenged by Ms Perry about a part of her statement in which she had said in relation to the benefits that the only benefit to Ayden of continuing life sustaining treatment is that *‘he would be alive’*. I could not easily understand reading that observation how it came to be made by so dedicated and committed a paediatrician whose anxiety to make things better for Ayden to improve his comfort, and whose worry that she and her team could not be sure whether he was in pain was palpable. It was a surprise to me that she had not appeared in writing at least to consider for Ayden that the touch of his mother’s hand the sound of her voice, the ways in which his family found to make his experience of being a member of that family a warm and loving one, as very real benefits to weigh against the all too apparent burdens. After hearing her oral evidence, I did not think she had simply dismissed or discounted them. Asked if she thought he took pleasure from being with his mother and having her proximate she did not instantly say yes but responded after a pause *‘I really hope so’*. At the time I heard Dr ZK’s evidence I had yet to hear Ms Braqi’s. I was very forcibly struck by the resonance with what Dr ZK had written when I heard Ms Braqi give her unprompted view that in PICU *‘he is alive but at home he would be living’*.
64. I came to the view that for Dr ZK the impossibility of knowing what he was feeling or appreciating was overwhelmingly worrying. I was reinforced in this view by her answer to Mr Chisholm when he asked whether Ayden was intact as to cognition hearing and sight – she seemed almost startled that anyone would ask that and clearly took that for granted, and thus also that he could hear, see and feel his mother with him. Families, she told the court are at the centre of the way in which GOSH PICU operates – there is no concept of visiting time. It is *‘a given’* that time with family is a benefit and an important one for all their patients and Ayden was no exception. Ms ZN likewise in speaking of the difficulties of moving Ayden and the worry that it was something that caused him at least discomfort, perhaps pain, was clear that the benefit to him of being in his mother’s arms was very much prioritised. My impression of her evidence was that to the extent that it might cause him pain and or discomfort, that was warranted by the benefit to him of moving to his mother for what is called cuddle time. I do not in any sense weigh lightly in the balance the benefits to Ayden of that part of his life he spends with his mother, his siblings and his wider family. His life has inherent value to his family.
65. I infer also, and I regard it on the evidence as an inference I can draw, that he will have an awareness that his mother does not do the things to him which are necessary to keep him alive but which cause him pain, but that she is a soothing presence to him, when those interventions have been done and staff withdraw. Also that she does the more ordinary things like changing his nappy, brushing his hair away from his eyes wiping his face to cool it which make him more comfortable. In short it is more likely than not that his experience of being with his mother is associated with feeling better. It is, I am satisfied, reasonable to conclude this, even though just as he cannot express pain,

neither is he able to express pleasure. I recognise that this is in contrast with the rest of his life in PICU which the lead consultant for him, who has worked for many years in the unit described starkly as '*pretty miserable*'. It is also relevant to my assessment of benefit that I am quite sure that Ayden knows that he is loved. What I described earlier as a moment of tenderness captured in the video clip illustrates, I agree, the bond between mother and son.

66. He has been on the unit a long time now. He is more than just a patient to those caring for him. The nurses decorated his room with his mother for his first birthday. Spontaneously in answering a question Nurse ZP blurted out '*we love Ayden*'. He is a child who has brought joy to those around him.
67. The Guardian, whose evidence I have not detailed but whose thoughtful and detailed report gave a vivid picture of Ayden, recounted in her report that at the time of her visit: *His bedside had silver and blue 'happy birthday' banners and bunting up from his first birthday the week before. His mother explained they had a photographer come in, family and staff sang him happy birthday and that she brought a cake, with battery powered candles appropriate for the ward. The décor and posters up around Ayden's bedside reflect the love and care of his family. There are family photographs, drawings and cards from his brothers and sister, and art the family have made with the on-site play team, such as an Easter themed painting, with Ayden's footprints in paint. He also had his birthday cards and a banner on display, including ones in Ayden's eyeline on the ceiling, showing how attentive his mother is to what he can see and experience.*
68. I give very considerable weight to the preservation of life. It is a strong factor in favour of continuing the ventilation which Ayden needs to keep him alive. He has not had the time to develop his own religious beliefs but in thinking about the strong presumption in favour of the preservation of life, I hold in my mind the evidence to which I have alluded earlier that his mother is a woman of strong religious belief. Had he lived at home with his brothers and sister he too would more likely than not be growing up within that faith. It is relevant that it is a Faith which has as a central tenet that life is God-given and sacred. Neither aspect means that the very powerful presumption is irrebuttable.

Burdens

69. The assessment of Ayden's pain is exquisitely difficult. I accept the evidence of those careful and dedicated medical professionals from whom I have heard that doing the best they can by reference to their experience of other children there are some things that they know must cause him pain. Pain and discomfort are on occasion used almost interchangeably by the medical professionals from whom I heard. It was my impression having asked Ms ZN about it that more often what is described as discomfort might better be understood by the rest of us as pain, but on any view a good deal of what Ayden can reasonably be expected to be experiencing as a result of what is necessary to keep him alive, is known objectively to be painful. The Trust does not suggest that Ayden is in pain all of the time – though the case advanced includes a recognition that it could not be detected if he were. It does however submit, and I am satisfied on the evidence, that he is often, repeatedly and unavoidably in pain.
70. I recognise that different patients have different pain thresholds and that there is no reason to think that that is any different for children. I am none the less satisfied that

pain falls heavily to be considered as a burden. As I listened to the evidence of the sensations of drowning and suffocating being akin to what is experienced from secretions, suctioning and desaturations, I formed the view that alongside pain, and discomfort in the weighing of burdens, so too fear should take its place. The impossibility of identifying whether things are or are not causing a child pain was clearly something which strongly affected all those from whom I heard about it.

71. His intact cognition, which is how it is that he is able to take pleasure and have the benefit of the company and solicitude of his family, by the same token means that he experiences all of the attendant difficulties of life on PICU. Not only the pain to which I have just referred but the experience of what was described to me in evidence as a place that can often, despite the efforts to keep it calm, be noisy and frightening – alarms go off, crash teams rush in, day and night patients are resuscitated or patients die. All of this Ayden experiences. Sometimes his mother will be beside him and he will sense things are ‘OK’ . Sometimes he will not.
72. In many cases pain is an inevitable part of a child’s life but can be managed. Amongst the most striking features of the evidence I have from the medical witnesses in this case is that they do not know if they are managing it.
73. I have not ignored what Ayden’s mother says about his pain. She told me that she agreed that he was sometimes in pain. I accept that in some respects she is likely to be better attuned to his cues. I do not accept however all of her own conclusions about pain, most notably her belief that he sleeps through the suctioning procedures. I prefer on this the evidence of the clinicians rooted as it is in experience of other patients. Very sadly the fact that his mother sees no sign that he is in pain is, I have concluded, reflective of his inability to express it, even to those who know him very well.
74. The fact that there is no medical or clinical evidence which supports the continuation of life sustaining treatment as in Ayden’s best interests is important but the assessment of what is in his best interests by consideration of the benefits and burdens of his life flowing both from his underlying condition and his treatment is for me. Assessment of those best interests embraces a wide welfare and social aspects of his life. Those are important and very significant aspects, and they are benefits which can displace in a determination of best interests the countervailing burdens in the analysis.
75. In my judgment having considered all of the evidence and balancing all of the relevant factors I am satisfied that it is not in Ayden's interest to continue to receive life sustaining treatment. The burdens of his underlying condition and the demands of the clinical treatments within the intensive care setting to keep him alive, drive me to the conclusion that it is not in his interests to continue to bear those burdens where I accept the unanimous view, supported by his guardian whose evidence I also accept, that there is no hope of meaningful recovery and an inevitable prospect of deterioration.
76. I am satisfied that whilst he can derive comfort and pleasure from the company of his family, the enormous burdens of his illness and the treatments associated with it outweigh even those very real benefits. Prolonging his life prolongs also for him the burden of bearing those benefits. He has had and I have no doubt would continue to have the very best of care at GOSH. I have taken account of the views of his mother that he should continue to have that care and her strong wishes in respect of this

application. I must however take an objective view of Ayden's best interests from his own point of view and from the point of view, in the widest sense, of his welfare.

Declarations

77. For the reasons given I am satisfied that it is in Ayden's best interests to withdraw his mechanical ventilation. On withdrawal it is anticipated that he will live a very short time. There will be defined limits to the treatment to be provided to him which will be set out following on from this judgment.
78. As anyone who has hoped or prayed at the bedside of a loved one who is not expected by their doctors to survive knows, sometimes they do. In this case, it is not expected that Ayden will live longer than minutes following extubation. I have been referred as set out above by those representing Ayden to the decisions in *Re NR*. The children for whom decisions have to be made by the courts in respect of life sustaining treatment are all individual children whose situations, whilst having a common thread of desperate sadness and tragedy in the proper sense of that word, are factually specific to them. So whilst I realise that what happened in *Re NR* may affect the hopes of Ayden's Mother in this case, those circumstances do not affect the way in which I have reached a decision on best interests for Ayden. I have reached the decision on the evidence before me.
79. All that I have been told leads me to understand that the withdrawal will take place in PICU and to believe that it will be with his mother at his side as she would no doubt wish. His mother has fought unstintingly against the declarations sought and has done so at very great emotional cost to herself. She could not have done for him more than she has. She does not have, and neither must she feel, any responsibility for the decision which is not hers but mine.
80. I will make the declarations accordingly that it is lawful and in his best interests for his mechanical ventilation to be withdrawn and to receive such palliative care and related treatment, including pain relief and anxiolytics, under medical supervision as considered appropriate to ensure that he suffers the least distress and retains the greatest dignity until such time as his life comes to an end.

Postscript:

81. At the conclusion of submissions I made known my intention to provide a written judgment in draft during the week of 11th November with formal hand down by the end of that week. I indicated that the draft should not be expected before the end of the day on 13th. On the morning of 13th November, I received an update from the Trust that Ayden's condition had unexpectedly deteriorated. He had developed a condition thought to be necrotising enterocolitis for which he was receiving treatment. Whilst no application was being made, the change in his condition was sufficiently marked that it was notified to all. Shortly after noon, my clerk received a further communication from the Trust's solicitor to the effect that Ayden's condition had now deteriorated to the point where an immediate and urgent application was made and a hearing requested in relation to ceilings of care. The e mail included the following '*Due to the quickly developing case, I have not been able to put the other parties on notice of this application.*' and copied in solicitors. I directed that the parties should be given notice at once and indicated that I would hear Counsel as soon after 2pm as they could be

present. By that time, I was able to provide the parties with a sufficiently finalised draft of this judgment and the decision I had reached on the declarations sought. For reasons it is unnecessary to detail here I made also declarations in relation to ceilings of care in the event of a further sudden deterioration.

Ayden 's mechanical ventilation was withdrawn on the morning of 14th November. He died shortly afterwards in the Rainbow Room, away from the PICU, and with his family around him.