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Case No: FD24P00133

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Sitting at Birmingham Civil Justice Centre on 20-22 and 25 Nov
and at the Royal Courts of Justice on 26-27 Nov & 2 Dec

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 18 December 2024

Before:

MRS JUSTICE MORGAN

Between:

**BIRMINGHAM WOMEN'S AND CHILDREN'S HOSPITAL NHS FOUNDATION
TRUST**

Applicant

AND

1. KB

2. LB

3. FATIMA

(By her Children's Guardian, Faye Robertson)

4. NHS BIRMINGHAM AND SOLIHULL INTEGRATED CARE BOARD

Respondents

Katharine Scott (instructed by **Weightmans LLP**) for the **applicant Trust**
Julia Cheetham KC and **Eliza Sharron** (instructed by **Irwin Mitchell LLP**) for the **1st and
2nd Respondents**

Neil Davy KC (instructed by **Cafcass legal**) for the **Children's Guardian**
4th respondent neither present nor represented

Hearing dates: 20-22 & 25-27 November 2024 & 2 December 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. This judgment is given at the conclusion of a hearing about the best interest decisions to be made for Fatima, a ten year old girl who is presently a patient in Birmingham Women's and Children's Hospital ("BWCH"). Birmingham Women's and Children's Hospital NHS Foundation Trust ("the Trust") applies to the Court for declaration that it is i) not in her best interests to continue to receive life sustaining treatment in the form of ventilation (whether invasive or non-invasive) and ii) in her best interests to be extubated and for palliative care and treatment to be provided to her under medical supervision such that she suffers the least distress and retains the greatest dignity until such time as her life will come to an end.
2. The application is opposed by both of Fatima's parents. It is supported by her children's guardian.
3. This hearing is taking place 3 months short of Fatima's eleventh birthday. Her parents have four other living children. She is their eldest daughter. She has three older brothers, ranging in age from 17 to 15 and she has a younger sister. Fatima is in hospital now, but for much of her life has lived at home with her brothers and sister, looked after by her parents along with the help and support of her extended family. It has been transparently obvious at this hearing that her parents are proud of her, love her and value the contribution she makes to their family's enjoyment of life. It has been obvious also that for as long as it may be the case they fervently wish her to continue living as a member of her family. Her brothers are approaching adulthood. It is evident that they dote on their little sister. The eldest of them has talked of her as being the 'glue' that holds them all together.
4. This is the second time these parents have had to face the prospect of the death of one of their children. They had a son who, as appears later in this judgment was affected by the same genetic condition which now affects his sister. He was looked after at home and, his parents tell me, died in hospital but in circumstances where the those looking after him and his parents did not find themselves in court and at odds as to what was in his best interests. Even within the landscape of applications to withdraw life sustaining treatment, it is an especially bleak path that these parents travel having lost one child, knowing that Fatima too will die as a consequence of the same condition, but disputing the circumstances and timing of that inevitability.
5. It has been difficult for Fatima's parents to sit through this hearing and to listen to evidence, some of which has been intensely painful for them to hear. It is almost unimaginable to put oneself in the position of a parent listening to others discussing how and when their child should or might die. Whilst there is little that can be done to make hearings of this sort any better for parents, they can be made worse. The hearing has been conducted in a sensitive and respectful way by Counsel, each of whom has taken real and obvious care not to make anything worse in their approach to advancing their case and been thoughtful in their choice of words in so doing. Ms Scott whose case is directly contrary to that contended for by the parents has managed well the difficult task of putting her case honestly but with humanity.
6. There had been in the period immediately preceding this hearing, some very real difficulties with the production of medical and other records. That unsatisfactory state of affairs is to be the subject of a separate short judgment. The focus of this judgment

is Fatima. I confine myself here to saying only that the exemplary conduct of this case by Counsel has been in unnecessarily pressured circumstances and at significant personal cost because of that late production of documents.

Background

7. Fatima was born at term and appeared to be well, though her Mother realised early on that she may not be. At 26 days old she started to have seizures a combination of focal seizures and infantile spasms.
8. They were difficult in the early stages to control. She continued to have seizures. As now medicated her seizures are regarded as well controlled. Whilst typically, so the lead neurologist in the case considered in her written evidence, she has between 1 and 4 seizures a day each lasting less than minute other evidence suggests that there are now none or almost none noticed.
9. Fatima showed early onset developmental delay. She did not start smiling until the age of 6 months. She cannot sit independently, roll over or speak. She is able to move her arms and her head although there are differing views as to what her movements indicate. Her vision is impaired but not her hearing. It will be convenient to consider in more detail elsewhere in this judgment her current condition.

Genetic Testing and Diagnosis

10. A genetic test, microarray analysis carried out revealed that Fatima has inherited through both her parents a homozygous deletion at 16q23.1. What that means is that part of the expected genetic material in her DNA is missing. The region of imbalance contains proteins in NUDT7, VAT1L, CLEC3A and part of WWOX. 10. The clinicians at BWCH concluded that she has a WWOX developmental and epileptic encephalopathy (WWOX-DEE) related disorder, a serious neurological disorder of genetic/ inherited nature.
11. Fatima has the severe phenotype WWOX developmental and epileptic encephalopathy WWOX-DEE sometimes known as WOREE (WWOX related epileptic encephalopathy). Children who are affected, present in infancy with early onset developmental delay and intractable epilepsy (focal seizures, infantile spasms and generalized seizures). Development is profoundly impaired in all children with this disorder. None develop the ability to walk. Most remain non-verbal and with visual impairment which since it stems from optic atrophy typically deteriorates. Associated with this they have poor eye contact.
12. Patients have severe truncal hypotonia and peripheral spasticity and dystonia. Most children with the condition require gastric tube feeding. They are often microcephalic and have a round face with full cheeks and a short neck. Neuroimaging shows progressive atrophy of the brain (frontotemporal atrophy and hippocampal atrophy) with severe optic atrophy. Fatima has a presentation consistent with these features some aspects more pronounced than others. The condition is life limiting.
13. There are no curative or specific treatment options for WWOX-DEE either in the UK or internationally. Many, though not all affected, die during childhood, commonly from respiratory complications or sudden unexpected death.

14. There are few children who are born with this condition. The research base is not large. It so happens however that in the West Midlands there have been more children with the condition born than even a large teaching hospital trust such as this might expect to care for. The lead clinical neurologist told me she has looked after 6 including Fatima. One of them was Fatima's older brother who died 2 days after his first birthday. He had the same genetic profile as Fatima and many of the same features of the condition – though his hearing, unlike Fatima's was impaired and he had also been born with a cleft palate which she was not. The other children looked after by Dr W all died at the age of about 12 months or earlier. Fatima – who at this hearing is 10 years and 9 months old has lived markedly longer than any of them or than the assumed life expectancy which I have been told is of the order of 40 months.
15. The present admission to hospital dated from 1st June 2023. Before that, she had lived at home. Between 2014, and June 2023, she had had hospital admissions but had always returned home afterwards. The tenor of the clinical evidence at this hearing has been that hospital admissions for a child with WWOX-DEE are not unexpected. Her first admission to the paediatric intensive care unit (PICU) was in 2016. There followed PICU admissions in 2017 and 2018. In 2019 there was a long admission to PICU of 26 days (at this hearing several witnesses from PICU have characterised a 'long' stay as beyond 3 weeks). There were 2 admissions to PICU in 2020 the first for 53 days the second for 14. From the records it appears that the admission in August 2020 was the first occasion on which she had been intubated though she was successfully weaned off intubation and with some difficulty off non-invasive ventilation (NIV) to self-ventilation. On subsequent admissions she required NIV rather than intubation. In 2021 she was admitted to PICU for 26 days. There followed a period of some two years following her discharge home in April 2021 when there were no further admissions.
16. On 1st June she was admitted, having been unwell with an infection at home for a time, to the High Dependency Unit at the BWCH with low oxygen readings and fast breathing. Her condition required transfer to PICU and there she was given ventilatory support by NIV.
17. Fatima has been intubated since 10th June 2023. The circumstances in which she came to be intubated are ones which I pause to consider now because they have featured in the evidence called at this hearing and have had an effect on the trust in the relationship between the parents, most notably as I see it her father, and the Trust. It is my perception that those circumstances have also had a lasting effect on the ability of Fatima's parents to think about her situation as she now is, as distinct from the immediately precipitating events which led to her intubation. On June 10th 2023 there was an incident in which a nasogastric tube had been misplaced or displaced and as a result Fatima had aspirated drugs and feed.
18. It could not have been clearer when her father gave evidence that this incident coloured his thinking very strongly. As a matter of timing, Fatima was intubated following that incident and it is recorded in the notes that it was as a result of aspiration. It is accepted that it was the precipitating event for the intubation, at this hearing, Fatima's parents have been obviously convinced that but for that mistake she would not be reliant on a ventilator now. Her father said as much to me in the course of his evidence. Professor Hain made the point that aspiration is not an uncommon reason to be placed on ventilator but it is more often a matter of days taken to recover and not months. It is for him the fact that it has not been possible for her to be weaned from the ventilator that

is telling. I have reminded myself that the hearing before me is not one in which I am asked to consider whether for example there has been clinical negligence, or even the precise and immediate causation of Fatima's need for a move to intubation from NIV (to the extent that it is something beyond a consequence of her underlying condition). Ms Scott has reminded me that the nursing records in places suggest that the father had restarted the feed and Ms Cheetham counters that even if he had (which he denies) the responsibility for siting of the feeding tube lay with the staff. In the detailed written submissions for the parents, there is extensive consideration of the entries in the medical records and the significance to be attached to the event. At this hearing the significance, other than the fact that it was not organic neurological decline that required her move to intubation, is limited essentially to context. I am however struck by on the one hand the Father's palpable anger and on the other what I regret to say has been the flavour of dismissiveness that the evidence of some of the witnesses from the Trust has had in respect of that incident. Dr Ross Russell, a witness independent of the Trust, was explicitly clear when he was asked about it that it was a very serious event, 'a never event' i.e. an event which should never have happened and should have been used as a learning point. He readily accepted that he could see why the father was so keen to ensure that it should not happen again either to Fatima or to any other child. He explained how he would have arranged that learning experience in his own hospital had something similar happened there. I realise that it is easier for a consultant from a different hospital to acknowledge in this way the seriousness of an event such as this but it was nevertheless striking to hear how his answers differed in tone and detail from those of others in response to similar questions.

19. I have considered the evidence about the 10th June 2023 incident in more detail than I otherwise would, because it is important that Fatima's parents understand what I mean when I say that how it came about that she had to be intubated on that day, does not help me in making best interests decisions for her now. Even if this were the sort of hearing where I were deciding who was 'to blame' for the aspiration incident and its consequences, and even were it decided that the Trust was responsible, that would not affect how I think about the decisions to be made for Fatima at this hearing. That is not the same thing as saying that it doesn't matter what happened.
20. Fatima remains intubated. Ten days after her initial intubation she was successfully extubated onto NIV but after 16 days had to be reintubated. She was again extubated on 18th August 2023 onto NIV but required reintubation by 21st September 2023. On ventilation she is stable. There is no evidence before me of spontaneous desaturations as part of her presenting profile, the most recent spontaneous desaturation dates to August and was in the context of infection. There have been efforts to wean her off ventilation which it will be convenient to discuss elsewhere.
21. A scan of her brain undertaken on 8th September 2023 showed reduced white matter volume thinning of the corpus callosum and a dilatation of the ventricles

Judicial visit to Fatima

22. When this application came before me for the first time on 12th July 2024, Fatima's parents were anxious that they should not have to travel to London for any final hearing since that would involve them being away from their daughter's bedside for prolonged periods and unable to return quickly should the need arise. They were equally unhappy with the notion of joining by remote link which they did not think was a sufficient way

to participate in such an important hearing. I therefore arranged to hear the case at the court centre nearest to PICU treating Fatima. I offered to visit Fatima if her parents wished me to. At the wish of her parents – and confident that through Ms Cheetham they understood the purpose of such a visit- arrangements were made for me to visit Fatima. I went to see her at the end of a court day, accompanied by the child’s solicitor who attended to take a note. I had by then heard evidence of the lead consultant intensivist and those nursing witnesses from whom I was to hear but not yet from other medical witnesses or her parents.

23. I was met at the Paediatric intensive care unit by clinical staff and shown to her bedside by Dr SA. It is a busy unit accommodating children in need of critical care and has 31 beds. Some beds are in bays which are open some are in more private side rooms. Fatima has a bed in such a room – partly because she is colonised by pseudomonas bacteria. She has been in this particular room for quite a number of weeks now and it is thought of more or less as ‘her’ room though if there is an urgent need for it in the ward, children might have to move round. It is quite a large room though it feels smaller because of the space taken up by machines and monitors and the columns housing the means to power them. The ventilator is on the left of the bed looked at from the door. On the right is the monitor showing saturation levels and heart rate. At the back of the room is a chair which extends out to a makeshift bed where her father often sleeps when he is there overnight, and a small chest of storage space for family possessions. On one wall were some drawings done by I think her sister, on another work sheets relating to school ‘learning about winter’. There was also a reminder that Fatima sleeps in her own sheets and so they should not be taken to be laundered and exchanged in the hospital laundry. The room had the blend of the functional and the personal, characteristic of a child who is both very unwell and very much loved.
24. Fatima's father and mother and a nurse were in the room when I arrived. Her mother and father after an exchange of pleasantries withdrew to let me remain. Fatima was awake her face turned towards an i-pad which was playing cartoons of nursery rhymes (old Macdonald). She was dressed in what looked to me to be a new set of pyjamas dark red with a spot pattern and fastened with scarlet ribbon ties. Her thick glossy hair had been carefully plaited. The room was warm and she was lying on top of the sheets rather than covered. Although she was not wearing them at the time, on her bed were the splints which are used to try to prevent contractures. They were decorated with a flowered pattern covering. During the time I was in the room she remained awake; she moved her mouth; moved her tongue in and out and moved her arms. I did not introduce myself to Fatima or speak to her directly. Knowing that awareness is a live issue between the parties I was careful to avoid inadvertently straying into something that might be perceived as close to gathering my own evidence of that. As I left, I again exchanged pleasantries with her parents and thanked them for letting me visit Fatima.
25. There are no graver decisions made by a court than those made on applications of this sort. The weight of the responsibility of making them is matched by the knowledge that it is a privilege to assume it. In this case, since her parents had wanted me to, and it was possible to do so, it was a privilege also to visit Fatima.

Evidence

26. Unsurprisingly, given Fatima’s age and the fact that she has been affected by WWOX-DEE all her life, there is a great deal of medical evidence about her condition. Whilst

there is consensus amongst the clinicians, and instructed experts as to both her underlying condition and as to what should be the route of her treatment henceforth, there have been some differences of approach in their individual opinions. Issues have arisen and have fallen to be considered at this hearing about the way that some of the witnesses' views have been informed and arrived at. The consensus is less established across the wider range of those who have looked after Fatima when it comes to her level of awareness. It will be necessary to examine some of those issues in greater detail in this judgment than is often the case rather than to proceed on the basis sometimes possible of setting out at this stage a unanimity of professional, medical, clinical health care evidence and moving then to consider it within the determination of where the best interests decision falls in balancing the burdens and benefits for Fatima.

27. At this hearing I had oral and written evidence from the following witnesses:
- i) Dr SB, consultant in paediatric Intensive care
 - ii) Nurse SC PICU extended stay nurse
 - iii) Dr SD consultant paediatric Neurologist
 - iv) Dr SA, consultant in paediatric intensive care
 - v) Nurse SE
 - vi) Nurse SH
 - vii) Professor Hain
 - viii) Dr SF, consultant in paediatric respiratory medicine
 - ix) Ms SG, respiratory physiotherapist
 - x) Dr SK consultant in paediatric palliative care
 - xi) Ms SL play facilitator
 - xii) Dr Parker, consultant neurologist (instructed expert)
 - xiii) Dr Ross Russell, consultant intensivist (instructed expert)
 - xiv) The Children's Guardian appointed for Fatima, Faye Robertson
28. I had written evidence also from those who were not required to give oral evidence including:
- i) Nurse SQ
 - ii) Nurse SP
29. Second opinion evidence ultimately not required for oral evidence had been sought from another hospital and been given by Dr SN consultant Paediatric Intensivist and Dr SM Consultant paediatric neurologist.

30. In addition to the medical and clinical evidence called, I was provided with a very large amount of written material in the form of a trial bundle; an updated bundle of statements and other documents and exhibits filed and served more proximately to the trial; and 4 separate bundles of medical nursing and other health records (running in total to well in excess of 8000 pages). I have read carefully the written statements of all those witnesses who have made them. So far as the health records are concerned, I have been directed to those parts of them on which counsel each place particular reliance. I have also during the hearing when time permitted read into parts of those records. I have not read or even skimmed, every last page.
31. I heard also evidence from Fatima's father, from her mother and from her paternal aunt who has been a source of very great support to the parents not only emotionally but also practically since she has some background in legal work. She also in contrast to the parents is fluent in the English language and has, at various meetings helped them with discussions. The detail of the evidence I have heard and read from the family appears later in this judgment.
32. I do not intend to rehearse all of that which I have heard or read from either the professional or the family witnesses. To do so, even if practicable, would unnecessarily lengthen further an already long judgment. Rather I will set out that which has struck me as especially relevant and has affected my thinking and helped me to reach the conclusions I have reached.

Medical and Clinical Evidence

33. Fatima's underlying condition is one characterised by neurological decline. None of the medical and clinical evidence suggests otherwise. That which appears at [7] – [16] above is drawn from in large part the evidence written and oral of Dr SD, Dr SA and Dr SB. No one suggests that because she cannot be treated curatively and will decline and die as a consequence of her underlying condition, that makes it appropriate to withdraw life sustaining treatment.
34. Although her condition is life limiting and one of anticipated neurological decline, it is hard to predict what is likely to cause her death. Professor Hain agrees with Dr SD that seizures are what often leads to what he called a neurological death and so if that is avoided (as here where they are controlled) then the more usual course to death is a respiratory death, though he identified also the possibility of bowel failure.
35. It is yet more difficult to estimate when her death may occur, since it is so hard to make any real estimate of her life expectancy. There was a consensus that she has lived longer than had been thought likely. Dr SD's view (shared by Dr SA) is that she has far exceeded her life expectancy having put the mean at about 40 months and that in that respect she is an outlier by a significant margin. It is not easy to say why that is, but it may be, she thought, that the respiratory issues have arisen only relatively recently, and her epilepsy has not been uncontrolled in the way that for some children with WWOX-DEE can be the factor leading to early rapid neurological decline. Professor Hain too agreed that her life expectancy is difficult to predict given how long she has already lived. In the event that she is extubated he puts her life expectancy at a hours or a small number of days. If she has a tracheostomy and is discharged home he puts it at months or a small number of years. Notably not all of those from whom I heard were willing (for reasons discussed elsewhere) to make any estimate of her likely life expectancy.

Dr SA in his evidence spoke of having on occasion been '*humbled*' by predictions which had borne no resemblance to outcomes for children not expected to survive.

36. No doctor from whom I heard treated the question of epilepsy or seizure activity for Fatima as featuring amongst the burdens for her. Dr SD and Dr Parker speculated that the fact that they were not noted, might be indicative of a decline in the associated part of her brain.
37. All those medical and clinical witnesses who were asked (and were qualified to give a view on) pain considered that for Fatima the pain was attributable to the interventions and treatment of the condition rather than the underlying condition itself. Dr Parker, whose written evidence had spoken of her being in pain 24 hours a day, clarified that he meant episodes of pain in each 24 hour period and those episodes were from interventions. The likely course of the neurological deterioration, in the view of Dr SD included likely increase in the dystonia to a limited degree already seen; the prospect of increased and painful contractures was also an expected development in the event of decline – in this respect Dr SA identifies that splints have been prescribed to mitigate contractures. Professor Hain when asked was not able easily to say whether, and to what extent, these burdens by reason of the condition as distinct from the treatment would develop in her lifetime since both the expectancy of her life and the path of neurological decline are unpredictable. The significance of the collective view from the medical professionals as to pain is something considered in detail later.
38. Drs SB, SD and SA all favoured palliative care. Since they arrive at that conclusion, informed by the views they have come to about her ability to benefit or derive pleasure from continued life, that aspect forms part of the later discussion of awareness and responsiveness. Dr SK, whose specialist field is paediatric palliative medicine has given compassionate and thoughtful evidence about the circumstances in which Fatima's life would come to an end if life sustaining treatment is withdrawn. She was explicit both that she would wish to discuss with the family so as to accommodate as far as possible their wishes for Fatima's last hours and that she understood why the parents had not felt able to contemplate discussing that prospect with her. It is her hope that if the Court makes the declarations and the parents are faced with a reality rather than a hypothetical position, they will feel able to have discussions with her. It is quite obvious that the nature of her professional life means that Dr SK is well used to the impossibility for parents of contemplating in the abstract the manner of their child's death. I have every confidence that if declarations are made, that under her direction the palliative care path will be, as far as possible one which enables Fatima to die with her family around her and with any pain and respiratory distress associated with her death well managed.
39. There is no clinical reason why Fatima should not undergo a tracheostomy with a view to a return home on ventilation. It is not an option contended for by the Trust given the unified view of the treating clinicians and second opinion Doctors in favour of withdrawal of life sustaining treatment. Neither is it an option which is regarded as without risk. Dr SF gave evidence as to the surgery which in and of itself even for a child like Fatima is a technically relatively straightforward process, and of the recovery and transition on to stabilise on NIV and stepping down from PICU, which are not. Whilst he has looked after many children living at home with tracheostomy, he had not had a child as compromised as Fatima at home with a tracheostomy on NIV. However, this is not a case that falls into the category of those where i) no Doctor will carry out

the procedure and, ii) faced with that ethical position, no Court can or would seek to direct it. In this case the medical evidence was clear that this is the course that will be taken in the event that declarations are not made.

40. There have been a number of attempts between June 2023 and May 2024 to wean Fatima off invasive ventilation. These have not been successful. The collective view of the clinicians is that the failure of these weans is evidence of neurological decline and a failure of respiratory drive. Since the circumstances in which the weans were undertaken, the relevance and purpose of them has been an issue between the parents and the Trust, the detail is considered later.
41. Other aspects of the medical evidence, and in particular that which relates to decision making and to levels of awareness, it will be convenient to discuss later in this judgment

Evidence From Fatima's Parents

42. Whilst I have considered first the evidence from medical professionals and clinicians, the evidence I heard from those who are members of Fatima's family is just as important when I come to make decisions for her. Fatima was born 8 years after her brother had died and her parents had had 3 children in the intervening period who were unaffected. Her father told me of the joy he felt from the day that she, his first daughter was born in February 2014. They knew from birth of her difficulties but there was from his point of view no sense of disappointment or feeling that she was imperfect. *'A child like Fatima'*, he told me was to be regarded in his culture as *'a special child, a blessing and a gift from Allah. Those who take care of someone like Fatimah will have their reward in the next life'*. Fatima's mother had said that when told of her daughter's neurodisability she felt *'a sadness in my heart'* but went on to explain her positive view of life with her after that. Her father described how life had been at home with her and his pleasure coming home from a late shift at work seeing her wake and respond to him as he came into the room, sitting with her for a while before himself going to bed. He was hands on (my words not his) and involved in her care. He changed her, fed her attended to her medical needs. He was keen to impress upon me that he was proud of Fatima. She was never what he called *'left behind'* during family activities. When the family visited beaches over the United Kingdom, Fatima was included. They went together as a family to Saudi Arabia. When the family travelled overseas to visit family in Pakistan, Fatima was included both times and, although she picked up an infection on one trip in 2017, she recovered with no ill effects. The family also travelled together on holiday with Fatima to Dubai. Of course all of these trips were when she was not needing ventilator support. In submissions, Ms Cheetham drew the court's attention to the fact that some of the trips abroad of which the father spoke took place after her PICU admissions and at least one of them after a time when her treating clinicians had expressed the view, assessing her prospects, that it was not thought that she would be able to come off the ventilator.
43. He was from time to time in talking about her, overcome by emotion. Strikingly he spoke of a difficult conversation he had had with Fatima's younger sister who, as a young child struggling to understand her own family situation, observed that Fatima was her older sister but did not play with her like an older sister should. There is ample evidence that now the sisters are close and as the guardian described have found a relationship in which they spend a good deal of their time together physically close to each other. Fatima's younger sister has, so the guardian told me, come to an

understanding of how her older sister is not like other people's older sisters. It was clear from the father's evidence that helping her to that understanding had been a time of real emotional pain to him. I had the sense, that in part that may have had its roots in being confronted by the stark contrast between that which his younger daughter could, and would be able to do, and his elder daughter could and would not. In their written and spoken evidence Fatima's parents were clear that she is aware of them and responds to them; they told me that she smiles – especially for her father; that she becomes animated and opens her eyes when she hears her mother's voice arriving at the doorway of the cubicle; that she responds to touch by turning her head, moving her tongue in and out; that she knows when they are there and when they are not and that she is comforted by her mother's touch. Both Fatima's parents had filed statements in which they had set out in writing what they had wanted to say. Her mother had committed a great deal to writing (with which her father agreed) but said rather less in oral evidence. Her father had made rather shorter written statements but spent longer in the witness box. It was my impression that he was more comfortable expressing himself by the spoken word than in writing.

44. Both Fatima's parents have a strong Islamic faith within which they are bringing up their children. It was in that context that her father spoke to me of her being a gift and a blessing. The parents have consulted an Imam and Islamic Scholars for moral guidance in respect of this application. He father told me that her life will endure for '*however long it is written*'. At an early stage in the hearing Ms Cheetham made it clear that whilst her clients were vehemently opposed to the declarations sought by the Trust they did not put their case as she expressed it on the basis of '*life at any cost*'. I became less convinced as I listened to the father's evidence that that was really so given the way in which he expressed himself. I asked him if he thought there were any circumstances in which he could consider that it would be the right thing for Fatima for her Life Sustaining Treatment to be withdrawn. Although in response he said a number of things and spoke at some length about looking after Fatima, he did not in fact give me an answer to that question. I was not sure whether it was that he could not contemplate any circumstances in which it would be right for Life Sustaining Treatment to be withdrawn or that he could not bear to contemplate the question. It was notable however that in this he contrasted with his wife. When Fatima's mother gave evidence, she told me that she did not think it was Fatima's time to die, but that if she thought it was the right time for treatment to stop, she would say so herself.
45. Fatima's paternal aunt, MB spoke warmly of her niece. She has been closely involved in her care since infancy. In both her written and oral evidence she was clear that Fatima was a child who was much loved and valued in the extended family. It was her evidence also that Fatima responds – by moving and smiling - when she visits, touches and speaks to her and to the presence of her parents. On occasions she has observed Fatima respond to stimulation. In her written statement she had described an occasion when Fatima had responded during play facilitation the previous month to the use of a rattle toy in a way reminiscent of a similar play at home. It is her perception that Fatima has an awareness of those around her and that though the signs may be subtle – especially to those who are less familiar with her who may miss them – there are signs of response.
46. Whilst I did not hear from her brothers and her sister directly, I heard about them and their views via the Guardian who had visited the home and who told me of her conversations with the other children. She spoke to Fatima's brothers separately from

their youngest sister because they are aware of the court proceedings and she is not. She described them as engaging young men, nervous about talking to her and on occasion with the eldest brother becoming a spokesman for all three. The word that was used to describe Fatima as part of their family home was ‘joyful’. That is an unusual word amongst teenagers speaking in English but I notice that it is used in the parents’ evidence translated from their own language and I think it is probably less unusual in the language of these teenagers’ home. In speaking to the Guardian, one of the younger boys gave their view about how Fatima is different now and described her as being ‘sad’ in hospital in comparison to how she used to be. Relating this evidence, the Guardian told me that the eldest brother had interjected – perhaps by way of reassurance – that she was *ok* and had *got used to it*. Fatima’s younger sister also spoke of her being *sadder* in hospital. From the Guardian’s meetings with all the other children of the family came good evidence that Fatima is someone who has always been a full part of her family’s life. They are used to her living at home with them and being part of their day-to-day life. The Guardian gave a telling vignette of the younger sister, sitting in Fatima’s bed in the parents’ bedroom and explaining that it is her sister’s place. Sometimes siblings of a very unwell child only know them by visiting them in a hospital setting. That of course is simply a family life in a different way. Fatima’s siblings however have experienced her (and she them) not just as they do now, in visits to PICU, but living at home, going on days out together, travelling abroad on holiday. Her absence is felt by all of them. They spoke of missing her and wanting her to return home.

Legal Framework

47. All Counsel agreed a legal framework which they invited me to adopt at this hearing. I have largely done so and express my appreciation of their collective efforts in providing it to me before the start of the hearing.

The General Approach

48. The general approach to applications regarding life sustaining treatment being provided to children is set out in by 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. 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.””

49. In Aintree University Hospital NHS Foundation Trust v James [2013] UKSC 67; [2014] AC 591 Lady Hale also made the following remarks about how ‘quality of life’ should be approached in the context of someone with permanent disabilities at paragraph 44]:

‘But where a patient is suffering from an incurable illness, disease or disability, it is not very helpful to talk of recovering a state of “good health”. The patient’s life may still be very well worth living. Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities. As was emphasised in Re J (1991), it is not for others to say that a life which the patient would regard as worthwhile is not worth living.’

50. As the Court of Appeal stated In the matter of Pippa Knight (a child) [2021] EWCA Civ 362 at paragraph [13]:

The approach to be adopted by a court conducting the necessary balancing exercise was summarised by Holman J in An NHS Trust v MB [2006] EWHC 507, [2006] 2 FLR 319, in a passage (at paragraph 16 of the judgment) that has been cited in many later cases, including by Poole J in the present case:

“i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment.

ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.

iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.

iv) The matter must be decided by the application of an objective approach or test.

v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These

include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.

vii) Considerable weight (Lord Donaldson of Lynton MR referred to "a very strong presumption") must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lynton in Re J (A minor) (wardship: medical treatment) [1991] Fam 33 at page 46 where he said:

'There is without doubt a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrefutable ... Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment... We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive.'

ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.

x) 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."

51. I have myself observed in other contexts most recently in GOSH v Braqi and others [2024] EWHC 2910 that the way in which Holman J expresses himself using the words 'wholly irrelevant' is likely to be something which is hard for parents who find themselves in the desperately sad position of these parents to hear. In Braqi I noted that in Re A Ward LJ made the same essential point but in a less starkly worded way at [545] 'Since the parents have the right in their exercise of 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. As appears below, Poole J in Knight by reference to the approach of the ECtHR in Gard and Others v UK suggested that Holman J's formulation of 'wholly irrelevant' is not consistent with that approach. I agree.

52. The Court of Appeal went on to set out the legal principles to be applied, as articulated in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 at [14]:

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

53. It is clear from the authorities (for example MacDonal J at §57 in Manchester University NHS Foundation Trust v Fixsler and others [2021] EWHC 1426; [2021] 4 WLR 95) that the Court must consider:

vi) 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.

54. As Poole J noted at paragraph 76 of Knight:

"Any proper assessment of welfare in a case involving life sustaining treatment ought to take into account the nature and extent of the interventions necessary to keep the patient alive. Clearly much greater weight should be given to the harm caused by those interventions if the patient can feel pain or discomfort. If Pippa were able to experience pain and discomfort when undergoing the multiple invasive procedures she undergoes each day, that would be highly material to the assessment of her welfare"

55. The burdens of treatment, and any pain or discomfort arising, must be balanced against the benefit that the child derives from continuing life. The degree of awareness of the patient is highly relevant to this and was a defining factor in the decision to maintain life sustaining treatment (by way of mechanical ventilation) in Re Tafida Raqeeb [2019] EWHC 2530 (Fam), where MacDonal J referred to the following matters:

134. *'In Airedale NHS Trust v Bland at 899 Lord Mustill further highlighted the potential for the difference between no awareness and some awareness to change the court's best interest evaluation:*

...I still believe that the proposed conduct is ethically justified, since the continued treatment of Anthony Bland can no longer serve to maintain that combination of manifold characteristics which we call a personality. Some who have written on this subject maintain that this is too narrow a perspective, so I must make it clear that I do not assert that the human condition necessarily consists of nothing except a personality, or deny that it may also comprise a spiritual essence distinct from both body and personality. But of this we know nothing, I have no doubt that the best interests

of Anthony Bland no longer demand the continuance of his present care and treatment. This is not at all to say that I would reach the same conclusion in less extreme cases, where the glimmerings of awareness may give the patient an interest which cannot be regarded as null. The issues, both legal and ethical, will then be altogether more difficult.”

161. ‘With respect to Tafida’s level of awareness, it is clear on the medical evidence that she has a very severe generalised cerebral dysfunction. Tafida has a sleep wake cycle, with eye opening and closing, her eyes can sometimes be maintained fixed in axis with a direct and consensual pupillary light reflex and a ‘dolls eye’ response that is equivocal but not entirely absent. I have taken careful account of the evidence of the parents that Tafida demonstrates some level of awareness and small incidents of volitional response, some of which they contend are evidenced on the videos to which I have given detailed consideration. Whilst I am satisfied that this evidence must be viewed with caution for the reasons I have already articulated, I note that Dr Smith in his report makes reference to video (also shown to the court) where Tafida appeared to lift her arm and turn it outwards to place rolled up bandage into the hand of her nanny and to his observations of Tafida moving her eyes to the location of her mother in response to voice and touch, although after two incidences of this, that result was not replicated. Within this context, there is a consensus of medical opinion is that it is not possible to exclude in Tafida some level of conscious awareness’.

173. ‘Within this context, and again having regard to the medical consensus of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction, the benefits for Tafida of continued life sustaining treatment include being at home, being in the care of her loving and dedicated family, and, insofar as she is minimally aware, gaining from such awareness as she has of those matters’.

56. In *Raqeeb* MacDonald J also found that in her resting state or standard condition, it is likely that Tafida did not perceive pain [163], that she was medically stable, and that if ventilated she was likely to live for another 10-20 years. The court also took into account that Tafida’s medical condition was substantially irreversible, and that if she continued to receive life sustaining treatment she would be likely to develop a range of other conditions such as drug resistant epilepsy, scoliosis with associated cardio-respiratory impairment, which may require surgery, partial or full hip dislocation, pneumonia with worsening respiratory failure, bone disease due to osteopaenia associated with pathological fractures, the development of renal stones, pressure sores, hypertension and malignancy. [para 162-164].
57. In *Knight*, Poole J distinguished Pippa Knight’s level of awareness, from that of Tafida in *Raqeeb*, which was relevant to the balancing exercise of whether to maintain life sustaining treatment:
58. ‘Applying the standard of proof, this court must assess Pippa’s best interests on the basis that she has no conscious awareness, whereas MacDonald J assessed Tafida *Raqeeb*’s best interests on the basis that she retained minimal awareness. In the present case there is a high degree of probability that Pippa has no conscious awareness. This distinction affects consideration of the benefits to Pippa of human interaction and loving care from the family’ [Poole J, para 82, *Knight*]. [Emphasis Added]

Views of the parents

59. It is well established by the authorities that the views of the parents inform, but are not of determinative weight in, the best interests analysis.
60. MacDonald J in Raqeeb described the views of the parents as ‘important’ noting:

[180] ‘The views of Tafida’s parents are important and fall to be considered within the foregoing context. The RCPCH Guidance recognises that:

“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”

[181] Further, whilst there is no requirement for the court to evaluate the reasonableness of the parents views before it embarks upon deciding what, objectively, is in the child’s best interests, as I have noted in Re T (A Minor)(Wardship: Medical Treatment) [1997] 1 All ER 906 at 916 to 917 Waite LJ observed as follows with respect to influence of the principle that, ordinarily, decisions affecting the length and quality of a child’s life will be taken for that child by the parents in the exercise of their parental responsibility:

“There is the scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare, widely accepted by the generality of mankind; and at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations, it is the duty of the judge to allow the court’s own opinion to prevail in the perceived paramount interests of the child concerned, but in cases of the latter end of the scale, there must be a likelihood (though never, of course, a certainty) that the greater the scope of general debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature.”

61. Poole J in Guy’s and St Thomas’ Children’s NHS Foundation Trust v Knight and another [2021] EWHC 25 (Fam), stated as follows at paragraph [98]:

‘I accept that the views of a parent on what is in the best interests of their child should be given due respect and taken into account, but that does not mean that those views should avoid proper scrutiny, let alone that they should be determinative ... There is a distinction between the views of a parent as to their child’s best interests or their child’s own wishes, and the independent wishes of the parent. ... I do take into account the judgment of the ECtHR in Gard and others v UK (above) to the effect that compliance with Art 2 of the European Convention on Human Rights does require the decision-maker to take into account the wishes of those close to the child when determining the child’s best interests, perhaps all the more so in the case of a young child whose own wishes cannot be ascertained. I also bear in mind that Ms Parfitt has an Article 8 right

to family life which ought to be considered. If so, parental wishes are not “wholly irrelevant”. Nevertheless, an objective assessment of a child's best interests should not be confused with the satisfaction of a parent's wishes, even if the wish to care for a child at home is wholly understandable’.

62. The authorities also make it clear also that the Court must weigh in the best interests balance the benefits of the child’s life both to the child and to the child’s family. In this respect I have been referred by Counsel to paragraph 69 of my own judgment in *Alder Hey Children’s Hospital v C* [2023] EWHC 1997 (Fam): *It is also important to place into the analysis of the benefits that C’s life has inherent value to his family*

Religious and cultural issues

63. An assessment of a child’s best interests in cases such as these must take into account the particular religious and cultural context and be informed by the values of the child’s family – see for example Macdonald J in *Raqeeb*:

173. ‘Further, I accept the submission that within the religious and cultural tradition in which Tafida was being raised, and whilst not by itself sufficient to justify the continuation of life sustaining treatment on the basis of Art 9 or otherwise, a further benefit of continued life sustaining treatment is that it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised and for which she had begun to demonstrate a basic affinity’.

64. Macdonald J further considered this aspect in in *Fixsler*:

“70. Within this context, the judgment of this court in Raqeeb sought to recognise that some of the wide range of considerations relevant to the evaluation of best interests, such as the role of religious belief, futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, will be ones that admit, as the best interests principle itself can admit, of more than one “right” answer capable of driving the best interests decision of the court, particularly in the absence of factors which tend to attract societal consensus, such as the undesirability of pain and suffering. However, and consistent with the long-established process of evaluation conducted by the court with respect to best interests, whether, in a given case, those more subjective or value laden factors will drive the best interests decision will depend on the totality of the welfare factors that fall to be considered in that case.

*71. In these circumstances, I have no hesitation in accepting the submission that an assessment of the various dimensions of Alta's best interests must take into account the particular religious, cultural and ethical context of this case provided by the fact that Alta is an Israeli citizen, the fact that the family intended to emigrate with Alta to Israel and the family's Orthodox Jewish beliefs and that the assessment of her best interests must be informed by consideration of the religious and cultural values of the family, and by recognition that religious and ethical frameworks governing these subjective factors differ (which reflects the position set out in the RCPCH Guidance set out in *Larcher V, et al. Arch Dis Child* 2015;100 (Suppl 2): s1–s23)).”*

The Perspective of the child

65. The starting point is to consider the issue of best interests from the perspective of the patient who in this case is a child.

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

[166] *I accept the submissionthat caution is needed when seeking to establish an assumed point of view for Tafida as a basis for taking account of her wishes and feelings. In relation to matters of thought, conscience and religion, children will move along a continuum from relying on the direction and guidance provided by their parents to ultimately having their own ideas and making their own choices about matters of religion and conscience. In the formative stages, their understanding will not be sophisticated. On the evidence available to the court, I am satisfied that this is the position in this case. I am satisfied that she would have had in February 2019 no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises. (Macdonald J, Raqeeb)*

[168]. *However, in this case I am satisfied that the subject matter of Tafida's assumed view must be framed somewhat more widely than the formulation contended for by the Trust having regard to the medical consensus between the doctors in this jurisdiction and in Italy of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction. Further, I must also bear in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that a child's attitude is often influenced by the views, beliefs and guidance of his or her parents. Within this context, whilst for the reasons I have set out above I am cautious about imputing to Tafida any sophisticated views generally given her age the levels of religious, I am satisfied that if Tafida was asked she would not reject out of hand a situation in which she continued to live, albeit in a moribund and at best minimally conscious state, without pain and in the loving care of her dedicated family, consistent with her formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability. (Macdonald J, Raqeeb)*

66. Whilst a child's perspective may well be influenced by the views of their parents, there is no presumption that this will necessarily be the case, particularly for a very young child. In Fixsler, at paragraph 96, MacDonald J noted :

"absent any evidence to assist the court in determining the extent to which Alta would adopt wholesale the views of her parents, I am satisfied that the furthest the court can safely go in seeking to place itself in Alta's shoes is to acknowledge that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents.....within this context, in discharging the difficult task of asking myself what Alta's attitude to continued life sustaining treatment would be likely to be, I am satisfied that, in circumstances where she has not developed any understanding of the faith into which she was born, and giving due weight to the fact that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents, it is

more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her."

67. In the subsequent appeal - *Fixsler v Manchester University NHS Trust* [2021] EWCA Civ 1018) Baker LJ stated at [85]:

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

68. In *Birmingham Women's and Children's NHS Foundation Trust v JB and KAB* [2020] EWHC 2595 (Fam); [2021] 1 FLR 1328, Hayden J offered the following observation in relation to the consideration of religious Faith in *Raqeeb*:

*"30. I am confident that Macdonald J, in *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530 (Fam) did not for a moment intend that a Trust should ever approach an evaluation of a child's best interests, in the context of medical treatment, as secondary to the wishes or religious beliefs of the parents. That would subvert the framework of the established law which preserves the interests of the child as paramount. Nor do I believe Macdonald J intended to sever medical 'best interests' from an overall evaluation of the child's interests. Such an approach would be artificial. A true and meaningful assessment of a child's best interests requires a conscientious survey of the wide canvas of his life, in which process the views of his parents concerning matters of faith, culture and more widely will be important but never a determinative factor."*

Professional Guidance

69. The Royal College of Paediatrics and Child Healthcare has published Guidance entitled "**Withholding and Withdrawing Life Saving Treatment in Children**" in 1997.

70. 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 is prefaced as follows:

"We emphasise two important points so as to avoid confusion: This document sets out circumstances under which withholding or withdrawing lifesustaining 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."

71. 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.

72. The factors under category II above are further defined in Guidance as follows:

'A. Burdens of treatments

Some forms of medical treatments in themselves cause pain and distress, which may be physical, psychological and emotional. If a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease. It is important that all options to relieve or overcome the negative effects of treatment are explored before proposing that it should be limited. However if such treatment can only be delivered at the expense of compromising the child's consciousness, for example, by deep sedation, its potential benefit maybe significantly reduced. Other examples of particularly high impact treatments include ECMO, renal dialysis and, sometimes, intensive chemotherapy.

B. Burdens of illness and/or 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 the potential or actual overall benefits in sustaining life. Some children have such severe degrees of illness associated with pain, discomfort and distress that life is judged by them (or on their behalf if they are unable to express their wishes and views) to be intolerable. All appropriate measures to treat and relieve the child's pain and distress should be taken. If, despite these measures, it is genuinely believed that there is no overall benefit in continued life, further LST should not be provided, for example, in advanced treatment-resistant malignancy, severe epidermolysis bullosa.

‘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.’

Ceilings of care

73. It had seemed at one point that applications in relation to ceilings of care might be made and fall to be considered at this hearing both at to the longer term and in relation to any unavoidable delay between the conclusion of the evidence, submissions and judgment. Whilst that has not been so, in contemplation that I might be asked to consider any ceilings of care at the point when this judgment is handed down, I have been referred to *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR 3995, in which the Court of Appeal said:

*“117. We would, however, as a matter of practice counsel caution in making declarations involving seriously damaged or gravely ill children which are open-ended. In the same way that this court said in *R (Burke) v General Medical Council (Official Solicitor intervening)* [2005] 3 WLR 1132 that it is not the function of the court to be used as a general advice centre (see para 21 of this court’s judgment), it is, in our view, not the function of the court to oversee the treatment plan for a gravely ill child. That function is for the doctors in consultation with the child’s parents. Judges take decisions on the basis of particular factual substrata. The court’s function is to make a particular decision on a particular issue.*

118. As a general proposition, therefore, we have reservations about judges making open-ended declarations which they may have to revisit if circumstances change.”

74. Poole J held in *NR* [2024] EWCOP 2400 (Fam) at paragraph 28(vii):

In my judgement, declarations about ceilings of treatment should only be made when they protect or enhance a child’s best interests. They should be worded so as to provide clarity for clinicians but that is not their purpose.

75. In the same judgment, Poole J noted at paragraph 35 as follows:

‘This case does not establish that the Court cannot rely on medical evidence as to the prognosis for a critically ill patient. It does show that medicine is a science of uncertainty. The Court has to deal with medical predictions and probabilities and such evidence is very valuable. A prediction should not be disregarded simply because it may prove to be wrong. However, confident predictions are sometimes confounded, and the Court must be vigilant and humble in the face of apparent certainty’.

I hold in my mind that in relation to rare conditions with very limited research base such as WWOX-DEE, predictions may well be confounded - at nearly 11 Fatima has already confounded some – and that Poole J’s enjoinder to be vigilant and humble is especially apposite.

76. Fatima’s Human Rights are engaged. Those rights which are relevant to this case and protected by the European Convention on Human Rights are : Article 2 (the right to life); Article 8 (the right to respect for a private and family life; Article 3 (protection from inhuman or degrading treatment).
77. It is of very great assistance for any Court making best interests decisions where there are differing views as to whether it is in a child’s best interests to continue to receive Life sustaining treatment, to have the benefit of the way in which others have determined similar issues. However as I observed in *GOSH v Braqi and others [2024]*, *‘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’*. By the time of closing submissions, Counsel indicated that that they were agreed that it was to the decision of MacDonald J in *Raqeeb*, that they would wish primarily (from differing perspectives) to draw my attention. I see that there is a resonance in the sense that both here and in *Raqeeb* questions of awareness and responsiveness assumed prominence. It is important to dispel any sense that the approach of the court should be to consider whether the levels of awareness and responsiveness fit within or align with other decided cases: for example MacDonald J in *Raqeeb* or again by way of example only Poole J in *Knight*.

Discussion

Religion and Matters of Faith and Culture.

78. Since Fatima is approaching her 11th birthday she has lived within the Faith of her family whilst at home. She has been visited by elders whilst in hospital and is clearly regarded as a member of that Faith community. I accept the unchallenged evidence of the parents on this point that it is a community within which there is a non-judgmental acceptance of disability. It is right for me to caution myself about the extent to which if at all she is now or was when living at home aware of matters of faith and belief.
79. Listening to, and reading, the way in which the parents each expressed themselves I formed the view that this is a family for whom their faith is a strong thread running through their lives and their thinking. A key component of that faith is the sanctity of life. I formed the view also that Fatima though still young is already, to the extent that she is able to be, a member of that faith by reason of her place in her family. Her Aunt

makes the point in her evidence that at ten she would not yet be expected to ‘perform’ her religion in the same way as others but that for a member of a practising Muslim family ‘*that perspective is inborn*’. I agree that all things being equal and absent the disabilities imposed on her by her condition her religious beliefs as a pre-teenager and young person would more likely than not align with those of her parents and family. Accordingly, I give the question of religious faith strong, though not determinative weight as I consider the application for the declaration sought.

80. There is a strong imperative to the preservation of life. Life is precious -whether viewed through the lens of Faith as by her parents, and so importing to ‘precious’ also the connotation of ‘sacred’, or whether viewed from a more secular or humanist standpoint from which ‘sanctity’ retains very significant value albeit unallied to the religious roots of the word. The instinct to survive and to live is strong. From this flows the principle that there is a presumption in favour of a course that will prolong Fatima’s life. A presumption but not an irrebuttable one. Linked to the concept of sanctity, is that Fatima’s life has inherent value. Her life is one of profound and irreversible disability but I hold in my mind that a life of disability is of no less value than a life without disability. It could not be clearer from the way in which her family have spoken - to the Court, to the medical professionals and, movingly in the case of her brothers to the Guardian - of their experience of having her as a daughter, a sister and a niece that her life is one which has inherent value to them. The acuteness with which they feel her absence speaks of what her presence means. Neither the sanctity of her life nor its well established value is absolute. Each and both are capable of displacement.
81. At the outset of this hearing, it was suggested that there were four possible options open to Fatima consequent upon the decision I reach at this hearing. Following the evidence Ms Scott and Mr Davy agreed, and Ms Cheetham did not have instructions to dispute, that there were in reality two. I therefore take the approach that I have to determine Fatima’s best interests and whether I should make the declarations sought within the context of two options i) in the event that I grant the declarations sought, withdrawal of life sustaining treatment with the expectation that the inevitable consequence will be that her life comes to an end ii) in the event that I refuse the declarations sought, surgery for a tracheostomy with a view to long term ventilation at home (in which long term is quantified variously as an estimate of some months or a small number of years).

Burdens and Benefits analysis

Burdens

82. Mr Davy KC on behalf of Fatima and her guardian submits strongly that it is important not to underestimate the burdens when carrying out a benefit and burden analysis. In his opening document he identifies that ‘*continued invasive ventilation in PICU would have all of the burdens associated with a tracheostomy [not supported by the Guardian] together with the additional burdens such as the need for ETT tube replacement but without the key benefit of potentially leading to a transfer home*’.
83. Fatima’s underlying WWOX-DEE condition in itself gives rise to burdens which, since it is condition of neurological deterioration, will increase. Consequences such as scoliosis and contractures will not improve and are more likely than not to worsen with time. The burdens required to treat, in a non-curative sense, her condition will likely also increase in tandem. I hold in my mind, that physiotherapy needs now may increase;

the need for suctioning may increase in the sense that she may require it more frequently. There is no prospect that she will cease to require suctioning – it is part and parcel of the interventions needed to keep her alive.

84. Fatima is reliant on ventilation. Some attempts to wean her have shown some success but not to the extent possible to step her down. Her respiratory drive is insufficient to breathe for herself. She can be disconnected from the ventilator for short periods (and has been in hospital) for the purpose of being moved across a room but at the moment, despite longer periods - including when placed on a bagging circuit during Dr SN's assessment - in the past, no more than that. Ventilation itself is uncomfortable and although in Fatima's case that is mitigated by the fact that the settings and her oxygen requirement are low it should not be lost that her lungs are undergoing inflation by mechanical and invasive means. Her lungs are in good condition, from the evidence I have heard at this hearing perhaps surprisingly so, but invasive ventilation long term may lead to stiffening which will make effective inflation and therefore effective gas exchange harder over time.
85. She requires chest physiotherapy to help loosen/dislodge secretions. This is not something she has had to have with a frequent regularity – Ms SG sees her in the order of once a week or once a fortnight. Nevertheless, it is a vigorous process so when she has it, it is likely to be experienced as at least uncomfortable, perhaps painful. There is evidence within the medical records which indicates that daily physiotherapy stretches cause her pain. I accept both that and the evidence of Dr Parker who observed that either at home or in continued PICU setting this is and will be a part of her life. The evidence in relation to dystonia which I heard from Dr SD is that it is likely that it lessens when she is relaxed in the presence of her parents. There are two things which are interesting about that aspect of the evidence from the perspective of a burdens and benefits analysis: first that since the effect is to lessen the dystonia (as she is more relaxed) it diminishes the pain consequent on dystonia; the second is that it demonstrates some awareness of and appreciation of the presence of her parents from which she derives comfort.
86. I have not heard evidence at this hearing that she is a child for whom being repositioned causes her pain, but I have heard that her developing scoliosis will increase the discomfort of repositioning over time. I accept also that if the scoliosis develops in the way that is expected one of the effects of that will be that the lung on the side of her body the curvature curves towards will be compressed into a smaller space and so will become more difficult to inflate by ventilation for effective gaseous exchange. The laws of physics being as they are, so Ms SG explained, the air pushed from the ventilator will take the route of least resistance into the larger available volume of the other lung.
87. Pain in Fatima is a significant component of the burdens to be weighed in the balance. I accept the evidence that Fatima's range of control over purposeful movement means she is not a child who can withdraw from a painful stimulus. She is sufficiently able to communicate when she is in pain such that the signals are understood and interpreted by the clinicians treating her as well as by her parents, though they are sometimes picked up quicker by those who know her well. By way of illustration, I heard of an episode during this hearing when Fatima's foot had become trapped in the wheelchair and whilst her discomfort had been noted, it was her Mother who identified the cause. Examples of how she communicates pain are grimacing; widened/startled expression about her eyes. Elsewhere in the medical records, arising from Ms SR's examination,

there has been a note or suggestion of a small noise made by Fatima and associated with pain although not in more recent times.

88. The Guardian told me how as she watched Fatima having deep suctioning, her face stiffened and her face looked shocked and she moved her arms up in a stiff way. It was very useful indeed to hear the Guardian's description of that episode as an observer who was neither a medical professional nor a family member. I accept the submission made by Mr Davy that it may be that some of the procedures undertaken on Fatima have become so much a matter of routine the effect of them may be less noticeable to those used to seeing them. His submission to the effect that there is value to that which comes from the eye of the beholder is one which is well pitched and which I have found helpful to reflect upon.
89. There are other ways in which it is possible to detect signs of pain in Fatima. In the example where her foot had been trapped her need for oxygen (normally at or minimally above that in air) had increased to 35. Dr SD spoke of it being possible clinically to detect markers in the blood of pain having been experienced. I heard no suggestion that indications of pain and distress outside her control i.e. governed by her autonomic nervous system were not reliable. Thus, a raised heart rate might indicate pain or discomfort experienced from a procedure. Heart rate is recorded in the nursing notes. Dr SN who visited Fatima on 27th September 2023 for the preparation of his second opinion report noted that her heart rate increased from a base of 83 to 113 as a result of suctioning, and took 20 – 30 mins to subside to its baseline. More recently the run of recordings in the nursing notes for the month of October 2024 show either an elevated heart rate – as high on occasion as figures in the late nineties - on suctioning or no discernible increase in the heart rate. Those notations are accompanied by very frequent recordings of a 'grimace' or 'pain grimace'; sometimes it is recorded that she moves her head away from the suction tube. That latter gave me cause to reflect on the consensus that this is a child who cannot withdraw from painful stimulus but I concluded that being able to turn a head slightly away from an implement being pushed into the Endotracheal tube is something subtly different. In some entries she appears not to be experiencing suctioning as painful either by reference to raised heart rate or by reference to her own response to it. On reviewing the evidence, I did not accept that Ms Cheetham's submission that Fatima has become accustomed to suctioning – and by inference that it is not to be counted as a burden at all or weighs minimally in the burdens analysis. I do however agree that in relation to suctioning it is not experienced by Fatima as uniformly and consistently painful. That is accepted also by Ms Scott for the Trust who does not seek to suggest that suctioning is always unavoidably painful. I hold in my mind however that this sort of acute and short-lived pain from a procedure is not something for which analgesic pain relief such as paracetamol can be used to relieve.
90. The burden arising from pain and discomfort on suctioning is important as Fatima requires and will continue to require suctioning. It is necessary to keep her alive – otherwise she will in effect drown in the secretions. The experience of those who have had (and can communicate about it) and of those who carry out suctioning, is that it is painful – at the very least uncomfortable. Mr Davy reminded the Court in submissions of the well-recognised description by adults who have had deep suctioning as being like a hot poker. At this hearing the evidence both of the professionals/clinicians to me and from her parents is that Fatima does not always seem to experience it as painful –

sometimes she does sometimes she doesn't. Dr SD thought that neurologically there might come a time when she was less able to experience it as painful or to experience pain at all. It was clear in her evidence that Dr SD was speaking then of experiencing pain rather than being able to express pain experienced. Dr SD was also clear that if Fatima were to cease to experience for example suctioning as painful at all that was not necessarily a positive thing overall since it was likely indicative of neurological decline. By contrast Dr Parker was of the view that she would retain to the end (or near to the end) the ability to feel pain. That divergence of opinion or respectable difference of professional opinion between 2 who are so expert in their field speaks perhaps volumes of the difficulty of knowing with anything approaching certainty how pain is experienced in the context of a neurologically compromised brain in the absence of communication.

91. As to pain in the wider sense, she is not a child on the evidence I have heard regarded by those who look after her as being in pain outside the pain of interventions such as suctioning or blood taking. That aligns also with the evidence I heard from Professor Hain. The nursing staff as a matter of routine record her pain scores and it is the case that rarely are they recorded as other than zero. Ms Cheetham relies heavily on that and has put it to several witnesses. I might have felt some caution regarding that recording had it been always zero since the FLACC score system for pain recording is not as well suited to children who are neurologically compromised. There are however occasions when those looking after her observe her to be in pain and the score is higher – 2 from time to time - and on those occasions, she is given analgesic pain relief.
92. Another aspect of the evidence which caused me to reflect on whether I should be cautious in relying on pain scores entered by nurses, was hearing the oral evidence of Nurse SE. Her evidence was that she did not think Fatima was in pain (as distinct from irritation or discomfort) because she would expect an experience to endure for 15 minutes or more to make it something she would call pain. Whilst I found her evidence in some other respects helpful, I did not think that she was someone on whom I could safely rely in relation to pain. Had she been the only nurse responsible for pain scores I would have been very hesitant indeed to accept them as reflective of Fatima's day to day experience and would have accepted the submission made in closing by the Trust that it might explain why the pain scores are often marked so low. Fatima is however looked after by a number of different nurses who are responsible for the pain scoring. It is a reasonable inference for me to draw - and I do so - that over so long an admission, were the pain scores, marked as they are, not reflective of the day to day experience of pain for this child it is more likely than not that one of the senior clinicians involved in her care - and notably Nurse SC who was the senior nurse clinician - would have noted and queried the discrepancy.
93. Drawing together the evidence as to pain: pain clearly falls to be weighed as a significant burden. The pain of procedures necessary to keep her alive, most notably deep suctioning, weighs with significant weight. That it is over in a matter of seconds does not diminish the experience of it, it only lessens the time for which it is experienced. I accept the evidence of Professor Hain that Fatima is living with many episodes of pain on a daily basis. Between those episodes of pain there are times when she is not in pain. I am satisfied that either continuing ventilation as she is in PICU or with a tracheostomy with a view to long term ventilation at home, the burden of pain and or discomfort associated with suctioning will continue.

94. On ventilation she is stable but if disconnected she will become desaturated. There is no strong evidence, in fact little if any, of spontaneous desaturation. The most recent instance recorded appears in August 2024 and is associated with a period of infection. That stability is important in terms of the options available for her at this hearing. She is regarded (though it is not an option favoured by the Trust) as a patient for whom surgery for a tracheostomy is clinically viable. In the event that I do not grant the declarations the Trust seek, that is the course that will be taken. From that it follows that one of the things that does not fall to be considered in the burdens is that of interventions to rescue her from spontaneous desaturations by reason of an instability on ventilation.
95. Within the context of benefits, it will be necessary to reflect on some aspects of Fatima's experiences which are less susceptible to empirical measurement and calibration and are of a more subjective quality. So too with some of that which is in the context of burdens. Professor Hain's evidence was that Fatima was likely to experience anxiety. Both Ms Scott and Mr Davy rely strongly on his oral explanation that anxiety is a primal human emotion present even where the cognitive impairment is significant. I agree that when considering the burdens the prospect of anxiety should not be overlooked. I am less persuaded by the Trust's submission that if she experiences anxiety, there is little that can be offered by way of reassurance. I conclude that it is more likely than not something which may be ameliorated by the proximity of her family. In this respect I draw on the evidence I heard from Dr SD in a different context about the way in which her dystonia is noticeably lessened when she is more relaxed in and by the presence of her family.
96. I accept the submission made by the Guardian that as a burden I must also consider the burden of 'separation' from her family in the sense that she will be whether at home or if in PICU dependent on (and connected to) machinery. Though Professor Hain, asked about this, said that he would not want to overstate this as a burden and that the separation would be less at home than it is on PICU.

Burdens falling to be considered in the event of a tracheostomy.

97. Mr Davy's submissions addressed the question of the burdens relating to the circumstances of a tracheostomy to which he says I should have regard given that this is the option which will follow from a refusal to make the declarations sought. I have had regard to those burdens which start with the need to undergo the surgical procedure and the recovery from it which will be attended by discomfort, analgesia notwithstanding.
98. There will be a period of transition in hospital following the tracheostomy to Ocean ward and then home. There has been disagreement as to whether this should be taken as 6-12 months (the Guardian's case) or 3-6 (the parents' case). I accept that on either it is an extended period and that it is not one which can be predicted with certainty. I have paid careful attention to those burdens set out in Mr Davy's written submissions, including the risk of return to hospital if infection develops, and to the submission made orally that the Guardian had in mind that even if the return home were to be made successfully after the period spent in transition in hospital it would be likely to be for a relatively short time with her family – at most a small number of years.

Benefits

99. As I consider the benefits side of the balance for Fatima I do so in the context of the alternative of her having a tracheostomy with a view to transition to long term ventilation at home since, if I do not make the declarations sought that is the intended path. It is right however that I should also consider what in effect are said by the applicant and the Guardian to be the benefits to her of making the declarations. Since I have set out in some detail the burdens of her condition and treatment I can much more shortly encapsulate the primary benefit attaching to the course contended for by those who support the declarations, which is that all of those burdens she will be spared. The context in which she will be spared it is that without Life Sustaining Treatment she will almost certainly die within a short period of hours or days. To be counted amongst the benefits, (and therefore in her best interests) on the case of the Trust and the Guardian is that that death will be one that is managed, predictable, so far as is possible in a place away from the busy PICU ward, with her family around her and with any pain or discomfort managed by those whose expertise lies in paediatric palliative care medicine.
100. The benefits of Fatima having a tracheostomy and long-term ventilation are different. She will continue to live. Ms Cheetham in her submissions makes the obvious but none the less powerful point that many people would consider life itself to be the ultimate benefit. I accept that point with the caveat that whilst many do, some – those for example in unendurable pain – do not. There is no possibility of evidence of any earlier expression of view by Fatima to draw on in this case to help me in thinking about from her perspective, what might be her view of her current situation. The very fact that there is professional guidance, and a balancing of benefits and burdens is in itself a recognition that to regard life as the ultimate benefit which eclipses all else would be the wrong approach. Notwithstanding that caveat, I accept the submission that continued life for Fatima where the alternative course is near certain death weighs strongly in the balance as a benefit and I hold in my mind in so accepting, the well – established strong although rebuttable presumption in favour of preserving life.
101. Following surgery to create the necessary opening, the insertion of the necessary tracheostomy tubing, and sufficient healing, Fatima will be able to leave the PICU where she has been a patient since June 2023. I accept that this will be possible within a reasonably short period of time. I further accept that whilst it is a step on an intended route to discharge home, discharge from the PICU which by its nature is characterised by busy, urgent life preserving interventions day and night to a ward that does not share those characteristics is properly to be counted as a benefit.
102. The ward to which it is intended she will be released ‘Ocean Ward’ is specialised in the care of children living with tracheostomy and is a place of transition. It is intended to be a more relaxed setting aimed at more closely resembling a home environment. In accepting, as I do, that a move to that ward on the evidence I have heard should be weighed as a benefit I caution myself and take into account that whilst from Dr SF the evidence I heard was that the ‘usual’ recovery period from tracheostomy is about 7 days there was a recognition that it might take a little longer. What is also required is that Fatima would have to be established on a home ventilator (which is properly to be understood as a ventilator for use outside the PICU rather than necessarily at home). That process may be achieved in a matter of 3 –4 weeks but might take as long as 3 months. A step down move out of PICU is I am satisfied to be considered as a benefit in the analysis. Sometimes in making best interests for children the consideration is not

whether there is the prospect of a move home but whether there is a prospect even of a step down to HDU. Notwithstanding the caveats, here a step down from PICU as a transition stage to a hoped for move to long term ventilation at home finds in my judgment its place amongst the benefits in the analysis.

103. The nature of Ocean Ward and the fact that although ventilated via tracheostomy she will be away from the invasive ventilator of PICU mean that Fatima will have more opportunity of stimulation and exposure to play therapy. I recognise that the extent to which this represents something that is a benefit to her is inextricably linked to the question of her level of awareness (as to which elsewhere in this judgment) but I accept the submission that it is something that offers her that potential benefit in a way that neither her present situation in PICU, nor the withdrawal of life sustaining treatment and death will.
104. Earlier, the burdens of the tracheostomy process which would have to be undertaken to make possible a transition home fell to be considered. So too I have concluded the incremental benefits of what might be termed ‘staging posts’ on the journey towards the aim of the greater benefit of a move home should take their place in the balance.
105. The purpose of the proposed move to Ocean Ward and the training envisaged for her family members there is to enable her to leave hospital and return home. Earlier in this judgment I had touched on my perception that Fatima’s parents, may find it hard to think of her, and her best interests as she is now. Should she return home her life will not be the same life that she had, or that they experienced her having before the admission to hospital. On the evidence it would be wholly unrealistic to expect her to benefit from the opportunity of international travel and holidays to family overseas that had been a part of her life before admission. So when her parents say that she will be able to resume her ‘joyful’ life it is important that neither I nor they consider the benefits and burdens analysis as if, all being as hoped in relation to the return home with a tracheostomy the clock will be, as it were, reset to pre June 2023 admission. It will not. I do nevertheless regard as having significant weight in the analysis that she will be at home and living within her family– which no one disputes will be far better for her; that whilst she will as the Guardian has pointed out in the consideration of burdens remain ‘separated’ by machinery from her family, she will be able to be moved from room to room in the home disconnected for short periods from the ventilator to do so; I accept also the submission that disconnection from a humidified circuit for 2 perhaps 3 hours will mean that in the better weather she can join her family in the garden or on a short outing. For a child who the parents say enjoyed the sensation of the sun on her face when the family went out together I accept that is an opportunity she could not have on PICU.
106. Whilst the foregoing are in my judgment matters which attract significant weight in consideration of benefits, the extent to which there is benefit of the emotional social and psychological character for Fatima, is linked to the question of her awareness and responsiveness. I turn now to consider that aspect.
107. In this PICU the Glasgow Coma Scale is used to record levels of awareness. Where normal level of consciousness is at 15, the scores recorded for Fatima across the length of her stay have been in the range 9 –12. The most recent recording within the papers provided for this hearing was that made on 28th October 2024 when it was 10. I have heard from some witnesses that they do not regard the scale as well suited to long term

neurologically impaired patients, it being intended and more commonly used in the intensive care context for patients in traumatic injuries. Whilst I accept, naturally, that view of the lead clinical intensivist, it cannot be without value evidentially or clinically, or the nurses looking after Fatima would not be directed to record her GCS scores. Since they are and they do, I accept that the scores are part of the evidence of her level of awareness.

108. The evidence also establishes that Fatima has distinguishable light sleep and wake states (observed by Ms SR) and a sleep wake cycle, for the support of which I have heard from Dr SD it was felt helpful to prescribe her melatonin.
109. There has been a very significant difference of view not only as between the family and the Trust but as between the witnesses called by the Trust itself as to the level of awareness and responsiveness Fatima has. Ms Cheetham submits that the difference amongst the Trust witnesses is starkly along the lines of those senior clinicians who see less of Fatima on a day to day basis and whose knowledge of her is less immediate and hands on – they suggest she has, and has had, little or no awareness ; and those who are at the bedside, know her better and see her more and who suggest that she has both awareness and shows some responses which have diminished over time. Ms Scott does not accept that. She has pointed to evidence from nurses who do not see awareness and to more senior staff who acknowledge some
110. Whilst I agree that it is not as stark as suggested on behalf of the parents – it is not the case for example that all nursing staff identify in Fatima signs of awareness and responsiveness, Ms Scott is right to say that some of them report nothing to indicate having seen signs of awareness – there is a difference. Dr SA did not accept – he said in oral evidence that he was ‘*not convinced*’ that Fatima smiles. Movements of her arms are in his view repetitive and reflex movements without purpose. He regards her as having no or virtually no awareness. Dr SB, had not seen Fatima smile or show any expression of pleasure whilst for example seeing or hearing cartoons played on her i-pad but did say that she had seen a positive interaction when Fatima has appeared to be comforted during deep suctioning by her mother’s hand stroking her face. Ms SG, the lead physiotherapist reported that she had seen neither expression of pleasure nor positive interaction from Fatima during her engagement with her – though she candidly acknowledged that her role in delivering physiotherapy means that she almost by definition is doing something to her that is not likely to be pleasurable or to elicit a positive response. Ms SC the senior nursing clinician in evidence said she had not seen a positive response to pleasure, she acknowledged that she had seen widened eyes and movements of arms and head but not in a way that she said she could ‘*wholeheartedly*’ put down to pleasurable stimulus. Dr SD had not herself ever seen Fatima smile and so did not feel she could comment on whether she did. She did acknowledge that she was calmer when her parents were present and, as I have noted elsewhere, agreed that dystonia was less when Fatima was more relaxed in the presence of her parents. This aside, her view was that Fatima showed no ‘*spontaneous or purposeful movement*’ and asked about responsiveness she responded that *responses to stimuli are often reflexes rather than responses*.
111. The view given by the senior clinicians of Fatima’s level of awareness and responsiveness was similar across the period of her intubation in PICU. That is to say what I heard from them was not that they had seen a very different picture early on and it had now altered. It is not wholly surprising that a lead clinician who might see a child

relatively infrequently or from the distance of the nurses' bay might not see the same indications of awareness as those who are more frequently at the bedside. If there is nothing to see then no one will see it, whatever their role, but if there are nuanced signs of awareness then they are more likely missed from greater remove. The Guardian speaking in her evidence of the smile that she had seen in October 2024, made the point that if you don't happen to be there when Fatima smiles you don't see it and it is hard to capture it otherwise.

112. What is significant about the fact that across her admission these lead clinicians who do not see or agree that there is any sign of awareness or responsiveness is that these are the senior clinicians whose collective view goes to the ethics committee and whose collective view arrives at the decision that an application should be made to discontinue life sustaining treatment. I have been unable to detect at this hearing when that decision was made. Neither have I been able to detect how, in arriving at the decision, the positives or benefits as well as the negatives or burdens were considered by the clinicians. That is because minutes or records are not kept of MDT meetings at which the parents are not present. What I can see however, is that the senior clinical team report to the ethics committee. On 7th November 2023, what was reported was that though others had seen signs of positive reaction, *medical staff have not seen Fatima display enjoyment*. Elsewhere I will consider what is to be made of words like 'pleasure' and 'enjoyment' in the context of the life of a child such as Fatima but I accept Ms Cheetham's submission that that is a surprising and troubling view reported to the ethics committee when it is set within the context of other evidence available at the time. I accept it is the view of the senior clinical team then as it is now.
113. Ms Cheetham submits that importantly there is a stark contrast between the view of the senior clinical team (now, and throughout her admission) and the picture emerging from the notes kept by the play facilitator Ms SL. On behalf of the parents it is submitted that the following aspects from the play facilitator's notes are powerful evidence of her awareness in the period from September and up to the end of November 2023. The entries to which my attention is drawn for that period are submitted to demonstrate the following taken from the parents' written submissions:
- i) Fatima enjoys watching nurse rhymes on the TV
 - ii) Fatima is able to communicate when she did not want something (for example, the TV being turned off, or the bead shaker)
 - iii) Fatima experiences excitement and intrigue at new items and experiences
 - iv) Fatima's smiles take place in response to positive stimulus, they are not simply random facial movements
 - v) Fatima moves her hands up towards her face/chest and moves her head side to side when she is engaged/excited ... in particular ... *'Every time I hit the triangle Fatima smiled, waved her head around and lifted her arms. It was evident that she enjoyed this sound a lot of purposeful interaction therefore'*. It is notable that these are movements which are reflected in Fatima's school profile as showing Fatima is curious or interested in something

- vi) Fatima was more animated by new experiences, becoming bored after a while with items she had initially shown excitement in.
 - vii) There are *many* examples of Fatima expressing pleasure and joy within the play notes
114. I accept that submission both as to the substance of the entries made by the play facilitator as to the observations she makes and records; and as to the way in which those observations contrast with the evidence of the senior clinical team's view of the observed signs of awareness. I have not heard from those compiling the school notes but I accept that their recordings of Fatima's movements when engaged [113 at (v)] are congruent with the play facilitator's. In accepting that submission and the observations of the play facilitator I have paused for reflection as to those aspects where repeatedly recorded are observations of movement of arms as a response of excitement or to stimulation. In the face of the clear view of senior neurological clinicians, that she lacks purposeful movement of her arms and hands so as to reach and grasp items - the classic example I was given was of a child trying to pull out an NG tube-, I was careful that in accepting the observed evidence of responses seen by this witness, I was not either elevating her evidence inadvertently to neurological expertise *or* accepting from her something that conflicted, other than by way of her own observation, with the evidence of the senior neurological clinicians. I am clear that I am doing neither. I accept the observations of response - which includes movement, characterised as excited or agitated - in response to a stimulus. Dr Parker when cross examined about the observations of Dr SN that Fatima's face lit up in response to play therapists session when he saw her with them on his visit, said that he would respect the observations of Dr SN as he is an experienced intensivist but that he would want to see the reaction as one that was consistent - which he explained meant repeated 3 or 4 times so as to be sure it was not a coincidence or reflex. Dr SN is indeed an experienced intensivist. He does not however have the benefit of repeated observations at the child's bedside over a number of weeks.
115. Ms SL's recordings are valuable observations since they are made by a health care professional whose role is to spend time with; interact and record what if any response is observed. They come of course from an earlier time in her admission and are not reflective of how she presents now. It is however notable to me that as at 11th November 2023 and in the entries following on for example 13th, 15th, 16th and 22nd November positive responses to stimulation are being elicited. It is notable because by then, there has been a referral to the ethics committee - which, it emerged at this hearing had not been provided with the observations made in play facilitation. There had also been by then I find on the balance of probabilities a consensus reached between the senior clinicians not just that it would be ethical to withdraw Life Sustaining Treatment but that it was their collective view that it would be in her best interests and that an application should be made to court to achieve that.
116. The reason I say that the consensus had been reached then even though in the absence of minuted MDT meetings I cannot tell when the decision is made, is that as early as 20th July 2023, within the records there is a recording of an MDT meeting at which the following is recorded '*we are concerned for Fatima, and think that when she is ready for extubation it is unlikely she will manage without the invasive ventil/reintubation for long.... It would be in the best interests of Fatima not to reintubate if she fails when she is ready* [emphasis added]. A week later, on 27th July 2023 at another meeting with the

parents appears the following: *‘as a medical group our feeling is that if Fatima has made no significant progress in that time we should start actively making plans to stop ventilation. We stressed that this does not mean ‘stop treating’ Fatima but that treatment would be directed towards comfort rather than life. supporting care .* There is also reference made by that time in the records to a need to obtain second opinions (ultimately Drs SM and SN) and to *‘if/when a decision is made’* to take her off the ventilator and the need in that event for an agreed plan for her management.

117. As to the decision, the submission is made by Ms Cheetham that on the balance of probabilities it had been made, not as at the time that the matter had been referred to the Ethics Committee (which met on 7th November), but by September, since it was at that stage, and coincident in timing with the instruction of the second opinion experts, that an assessment report was also sought by Ms SG, senior physiotherapist (following so it seems a decision by the MDT clinicians) from a neuro-physiotherapist Ms SR about Fatima’s awareness and responsiveness. It includes the following: *‘I have been asked to contact you as you both come to see TDK [a child subject of a similar application] when she needed a report as part of her court preparation, would either of you be able to complete this for FA? Basically PICU though[t] you did an amazing job and want something similar’*. Ms Cheetham suggested to Ms SG that, expressed in that way it was intended to convey the desirability of a similar outcome for Fatima as *TDK*. I do not agree that that is an inference I could draw.
118. Within the context of examining the decision making and the evidence of awareness and responsiveness however, there are two important aspects of the evidence arising from the commissioning of an assessment by Ms SR. *First* the notes of her examination which appear in the records do not reflect a picture of no or very minimal awareness. They record *‘distinguishable drowsy/light sleep and wake states; a range of facial expressions during calm and interactive periods that were different to expressions during stretch and assessment of range; a small smile when CPAP was removed and a frown and vocal sound when I was assessing her foot ankle and wrists’* . There was noted also that in a 30-minute period of wakefulness Fatima responded with opening eyes and touch to play opportunity; that she was alert for variable periods more notably when engaged, being touched and interacted with during songs and activities. The notes also contained a recommendation of reassessment at different times for a greater assessment and understanding. Other than a review by a different neurophysiotherapist in May of the following year (which recorded no change) there is no evidence that there was such a review. *Second* that an assessment report from Ms SR following the request and her examination of Fatima has never been produced: not as part of the medical records; not to the ethics committee or before me at or in preparation for this hearing. I have had a degree of caution about accepting Ms Cheetham’s submission that by September a decision had been made to apply to withdraw life support provided there was no different view taken by the ethics committee. I see why it is said however that it is hard to read otherwise the references at that stage to court proceedings. I am more confident however that the evidence points to the fact that by September the consensus to which I have made reference at [115] was already firmly established amongst the senior clinicians. For me the relevance of that firm consensus is the extent to which it may have affected i) the thinking about awareness levels ii) a willingness to reconsider Fatima’s situation over the following months.

119. On one level it might be thought that, whatever the position in the earlier part of her stay in PICU, the relevance is little now since those who were observing the sort of responses and awareness, I have accepted at [113-114] above are no longer observing them. Ms SL said when asked that she had not elicited the sort of positive responses to play reflected at [114] above since about May of 2024 though she could not be sure of the exact time. Interestingly on 22nd May of 2024, a Neurophysiotherapist Ms SS, reviewed Fatima after a referral from Ms SG who had thought there was more dystonia and pain. Dystonia was not found by Ms SS but her entry in the medical records, reads *'Variable presentation in comparison to reported concerns likely linked to multiple variables & triggers- likely to be changeable over different timeframes. Responses seen today in line with abilities on 20 September 2023'* [Emphasis added]
120. If I am satisfied that there is no, or next to no evidence of awareness and response in more recent times, and I am confident that its absence is indicative of marked neurological decline then for the purposes of the decision I have to make at this hearing it may not much matter if there had been available evidence which suggested significantly greater awareness at an earlier time than the senior clinical team had acknowledged. I have had the advantage of detailed evidence from a wide range of health care professionals. I have taken account also of course of what Fatima's family members say of her awareness and responsiveness to them. I have done so holding in my mind Mr Davy's submission that there may be a perfectly understandable desperate hope and longing to see positive responses. I realise that a desperate longing might well cause a parent to see a twitch of a mouth as a smile, or a movement that happens to coincide with their arrival one day as a response to it. Dr Parker warned that family members in situations such as this might over-interpret small gestures. From the witness box he gave his view that the *treating nurses* at the bedside are *the right people* to speak to the issue of Fatima's responsiveness saying *'I strongly recommend the court gets their testimony on responses'* I have found it invaluable to have at this hearing a wider range of evidence including that which comes from those who are not affected by desperate longing.
121. I heard live evidence from two of the nurses who are still looking after Fatima. The shift pattern operated in BWCH PICU is for a nurse to be 4 weeks one side of the ward (which appeared to be neurologically compromised children) and 4 weeks the other. So for 4 weeks at a time a nurse on shift looking after Fatima might see and interact with her daily; then not see her for time rostered off then see her again. Nurse SH described leaning over Fatima so as to be able to make proper eye contact when talking to her, because since her eyesight is known to be impaired and she lies on her back otherwise it is less easy to make a connection with her. She was clear that Fatima knows when her father arrives at night (from his work shift) and that she observed a difference in Fatima when her parents were present. The words she chose to describe the difference she observed were *'more confident'*. She described how on arrival of her parents, Fatima shows awareness of their arrival and pleasure in their presence. Nurse SH whose first language is not English put it in this way *'when they enter they call her name. She will open [her eyes] Really happy for that I think'*. Both nurse SH and Nurse SE whose observations of Fatima in this respect I accept, described her as recognising her parents, as being more responsive when they are there – Nurse SE identifying that she will *'respond less'* when they are absent. She contrasted also Fatima's appearing to be *'sad'* during the day before her parents' arrival and went on to say this: *'parents come and she started to cry – think missed them the whole day. That is the main concern.'*

When they talk in own language she will be fine. More comfortable. Whole day not reacting to us. When talking not sure understanding language. Mum and dad come. When she enters to room calls Fatima. When she heard mum or dad she starts to move or cry. Mum asks if she crying whole day. Say no just to your voice.'

122. I have thought long and hard about the implications of that answer. I make it clear that whereas the nurse reads into the reaction she sees to the parents' arrival that Fatima has missed them all day, I do not regard that as an inference safely to be drawn. I do however accept that there is a clear awareness of their arrival and response to it. I am further struck by the observation that there is a perceptible difference in Fatima, when she is spoken to in her parents' language, the language used in her home. In her written evidence Nurse SE had described Fatima as *more active* when her parents spoke to her in their own language. It chimes also with another observation made by the same nurse that Fatima appears to be more responsive when the nurses call her by a pet name: '*Pathuu*'.
123. The Guardian visited Fatima in hospital on the day of the PTR just short of 3 weeks before the final hearing. She has produced a most thorough careful and helpful report. I have made reference already at [86] above to the valuable insight her observation of Fatima's reaction to suctioning brings. In her visit she captured also the real sadness felt by one of the nurses who has looked after Fatima who spoke of the fact that she '*never gets better, she never will, it feels really sad*'. For much of the time she saw little response from Fatima to those who spoke to her, and none herself when she introduced herself, however then at paragraph 33 of her report she relates this: *I was fortuitous enough to be visiting when the 'Giggle Doctors' came to see her. These two women were dressed up in embroidered white doctor coats, flowery dungarees, with patterned Doc Marten boots, heavy bright make up, and had scarfs woven into their hair. They engaged with Fatima for around ten minutes with high pitched tones, and gentle fun and frolics. They sang songs, showed her an octopus (produced from a pocket) and made delightful mysterious noises. Fatima was positioned facing them but had been drifting to sleep before their arrival. She became more and more aware of their presence and remained open eyed throughout. Her hand/arm was moving, though not to reach out and her body was reacting. She then smiled the broadest of smiles several times that reached her eyes and lit up her face.* That observation has been the focus of much attention given what is reported and its proximity in time to this hearing. In answer both to her own counsel and when cross examined for the parents, she was clear that the smile was in response to what the 'Giggle Doctors' had been doing. In describing to me what she had seen she said *It was a smile and then I remember how I felt I remember thinking Oh she smiled* going on to say *The smile I saw was much bigger and a smile happens so instantaneously I was there and I saw it ...the smile is was bigger and broader and more alight that the ones I have seen in the five videos.* She was specifically asked by her own counsel in chief what her interpretation was of what she had seen was in response to what the Giggle Doctors were doing and replied *My interpretation was they come in they had been high energy and worked hard and all of a sudden she smiled in response.*
124. In earlier times and slightly different contexts, those appointed to report to the court for children subject of proceedings were sometimes referred to as 'the eyes and ears of the court'. Listening to this Guardian's account of her visit I was put in mind of that characterisation. Having since hearing her evidence received the parties submissions

however, I am struck also by the fact that this observation is one which is also usefully considered alongside Mr Davy's submission in relation to [86] above as to Fatima's observed reaction to pain. What I have described there as the value that may come from considering the eye of the beholder, so too here. I found this a powerful piece of evidence from a professional witness outside the family when I came to consider the difficult aspect of awareness and responsiveness. This was not the sort of subtle response that the unfamiliar might miss. Though interestingly Professor Hain, a person well used to assessing children in this situation said in evidence that when he visited to assess and entered her room he had *'the very definite impression that she was aware someone new had walked in and she was aware I was there'*.

125. A component in the thinking of those senior clinicians who regarded Fatima as having little or no awareness is that there have been a number of attempts to wean her off the ventilator but none have been successful. There is an issue as between the parents and the Trust as to whether I should or can safely rely on those failed attempts as evidence of significant neurological decline. The position of the Trust is that I can and should; the position of the parents is that the attempts to wean her have been made in circumstance which are not optimal and that this should lead me to be particularly cautious in relying on the failed weans as evidence of neurological decline. I turn now therefore to consider the evidence of the attempts to wean.
126. There are four occasions when attempts are made to wean Fatima from invasive ventilation during this admission. They are from 20th June to 7th July 2023; from 19th August to 21st September 2023; from 29th November to 8th December 2023 and from March to 29th May 2024. Ms Cheetham invites me to consider how each of them have been affected by circumstances which may have contributed to their failure. Those circumstances include but are not limited to what it is submitted are the potential effects, in combination, of the drugs prescribed and administered to Fatima at the relevant time
127. During the first attempted wean, Fatima was on Melatonin (2mg); Nitrazepam and Levetiracetam ('Keppra'). The evidence before me indicates that they are known to have drug interactions causing sedation and respiratory depression. The clinical witnesses asked about it acknowledged that potential but did not regard it as explaining the failure of the wean. On this occasion the attempt to wean was interrupted by intercurrent infection which meant Fatima required treatment with Nitrofurantoin (from 27.06.23 to 06.07.23) for a urinary tract infection and with Piperacillin and Tazobacterium between 27.06.23 to 08.07.23 for suspected Sepsis.
128. Just before the second attempted wean Fatima's dose of Melatonin dose was increased to 6mg. The purpose of Melatonin in PICU I was told was to regulate sleep patterns which are otherwise susceptible to disruption of the ordinary night/day sleep/wake cycles by the 24 hour busy and noisy nature of the ward. I heard evidence from some that it was not properly to be regarded as having a sedative effect though Dr SD talked about its value being that it caused drowsiness and helped with dropping off to sleep and Dr Ross Russell went further saying of Melatonin that his could cause a sedative effect and could reduce breathing. In addition to the increased Melatonin, she was having, as previously, Nitrazepam and Levetiracetam, and also Gabapentin. There is evidence that Gabapentin is known to have side effects of dizziness, drowsiness and respiratory depression. It is also known to have a drug interaction with Melatonin, in like form to that between Melatonin and Levetiracetam. Those clinicians asked about it

were again doubtful that the recognised side effects and potential for drug interaction adversely affected the outcome of the wean. Fatima's progress on this attempted wean was however also affected by an infection. Fatima was prescribed additional antibiotics and PRN paracetamol for the infection between 1st and 10th September 2023.

129. The third attempted wean which started on the 29th November 2023. Ms Cheetham submits that it is significant that that is the day after it a note appears in the records of an MDT meeting (including the parents) which records the outcome '*to court*'. To the extent that I am invited to read anything sinister into that coincidence of timing, I do not. Not least because elsewhere I have commented on the difficulty of knowing exactly when and how a final decision was made to go to court on account of the paucity of MDT minutes. Of more interest to me is that Dr SM, who had been instructed to give a second opinion report had advised in the context of optimising for weaning *withdrawing the benzodiazepines and ensuring other sedative medications or those that can affect muscle tone and power, are reduced or withdrawn*' Melatonin remained at the increased level of 6mg but Nitrazepam (which had increased from 50mg to 100mg between the time of the second and third attempted wean doubled in dose) was stopped completely on the day before the attempted wean. Gabapentin was not stopped until halfway through on 8th December 2023. In the event the point remains that until halfway through the trial Fatima was receiving it and then, abruptly she was not.
130. The detailed consideration of that aspect of this wean has relevance when I reflect on two parts of the evidence I heard. First from Dr SB I heard that both Gabapentin and Nitrazepam are associated with withdrawal when stopped and so gradual reduction is appropriate. There is no evidence that was so here. Second Dr Ross Russell noted the cumulative effect of sedative medicine in the system which reduces not immediately it ceases to be administered, but over time. In respect of this attempted wean, there is force in Ms Cheetham's submission that Fatima was not given a proper opportunity to wean without the presence of medication sedative in effect in her system.
131. The fourth (and final) attempt at a wean from intensive ventilation started in March 2024. It was more gradual than earlier weans and I have heard from Ms SG at this hearing was consultant led (which the others had not been). The attempt was to wean her onto CPAP. Although she continued to be on the 6mg dose of melatonin, she came to this attempted wean without the benzodiazepines or Gabapentin in her system. Fatima did well in the initial stages of this attempted wean such that by 7th May 2024 it is recorded that she was tolerating 18 hours on CPAP. There are numbered stages of the process and that level of tolerance is stage 10. Unfortunately, Fatima developed an infection on 8th May and her temperature increased. She was commenced on antibiotic (Ciproflaxin) and pain medication (Paracetamol and Ibruprofen) as she was observed to be in discomfort.
132. It is the parents' contention that the infection was precipitated (and therefore this attempt compromised) by the administration of Glycopyrronium in addition to Fatima's usual hyoscine patch. This is a drug which had been problematic for her when previously used. During this wean attempt the nursing notes recorded that it had made the secretions '*too thick*' which had been the earlier difficulty. The resulting advice recorded by the registrar is *Cut off glycopyrrolate and Prescribed 200mcg one off dose*. In the event, for reasons that are not clear that drug continued to be given to Fatima for three more days. It was agreed in her oral evidence by Dr SB that in the light of the clear direction it should not have been, though these aspects of the failed attempt to

wean had been absent from her written evidence. Glycopyrronium is a drug which had caused difficulty for Fatima in the past when its effect of thickening secretions had not been helpful to her. In those circumstances it was put to treating and expert witnesses that it had been wrong to prescribe again and continue during a weaning process a drug which had previously been problematic. The answers to that proposition were illuminating in the way they gave insight into how hard it can be to medicate effectively children with complex neurological and clinical needs which might have differing responses to different drugs or variations in titration of the same drug. I was struck by the way in which Dr Ross Russell ran through the relatively limited list of possible drugs available to someone treating Fatima; the advantages and disadvantages of using them, and by the way in which he arrived at the point where he responded that he might indeed have considered trying Glycopyrronium again. At a different time in altered circumstances, he explained it might be effective, or it might be the best available option.

133. Fatima's progress on this attempt having been interrupted by the infection, I accept that there is some evidence to indicate Fatima was recovering strength: and on 28 May 2024 she is recorded as back to tolerating stage 9 of the numbered stages. On 29th May this attempt at a wean was halted seemingly following a decision at an MDT the previous day.
134. The way in which the parents case was advanced in relation to this attempted wean came close to suggesting that on this occasion Fatima was set up to fail. To the extent that this is what may be being suggested I reject it. It was also put more explicitly that the approach to this attempted wean was in the character of evidence gathering in support of the Trust application for declarations leading to withdrawal of Life Sustaining Treatment. The application to the court had been made shortly before start of this attempt.
135. Dr SB's evidence was that, at the time that there was an attempt to wean Fatima off ventilation on this fourth occasion in May 2024 that was with a view to achieving weaning successfully so that Fatima could return home to live with her family. It was not extubating (as is the case contended for by the Trust at this hearing) on a pathway to palliative care. A note from Dr SB's own ward round dated 19th March read '*attempt at weaning in preparation for court case*'. [emphasis added] Her evidence was that she did not know what that note meant and had no explanation for how her registrar had come to record that on her ward round. I could not easily reconcile her evidence that the weaning was a genuine attempt to get Fatima off the ventilator and home, either with this note from the ward round or with the fact that at the time the Trust's application was for a declaration which would have the result that life support would be discontinued and in the expectation that Fatima would die. So I asked her how I should make sense of that. Her response was that in the event that the weaning was successful the Trust would have withdrawn its application.
136. Drawing together all of the evidence I have heard and read about the attempts at weaning I have concluded that the attempted wean was, on each of the 4 occasions for different albeit interlinked reasons conducted at a time when Fatima was not (as she should be) optimised for the weaning. Infection intervened in three of the four; the third attempted wean was I accept one which was not carried out in a way which meant Fatima was without drugs with potential sedative effect in her system.

137. I have tried to confine myself to considering the relevance of those attempted weans to me as to whether I should accept the thrust of opinion relied on by the Trust that their failure is clear evidence of neurological decline and that such a decline is supportive of the view that Fatima has no or minimal awareness and so no ability to derive pleasure from life. There are, however aspects of the fourth attempt at a wean which I found perplexing when I heard Dr SB's evidence about it referred to at para [135] . I was left with the strong impression that transparency and honesty with the parents about the decision making and the intended purpose in relation to the last wean had been lacking.
138. In respect of the attempts to wean Fatima off intensive ventilation at [126] - [133] I have reached the conclusion that I should not rely on the failure of those attempts as indicative of significant neurological decline with the concomitant impact on assessment of awareness and responsiveness. None were performed in circumstances where she was optimised. I hold in my mind that it is the very nature of Fatima's condition that she will have been, since birth, neurologically declining but as to the evidence emerging from the attempted weans is concerned, I prefer and accept the submission for the parents to that for the Trust. I also of course, as far as it goes to the point about awareness and responsiveness, set it in the context of the wider evidence.
139. In examining the circumstances surrounding the attempt to wean Fatima in May 2024 I expressed reservations about the process. The decision making, and the transparency to and honesty with the parents of it, so far as my determination of best interests is concerned, is capable of being neither transparent nor honest without ultimately having an impact on my assessment of the benefits and burdens. The disquiet Dr SB's evidence caused me added to that which I had already considered at [115] above that she and some of her colleagues had already in their own analysis of that balance decided that the burdens were such that they sufficiently outweighed the benefits that application had been made to discontinue her life support. It is hard, when such a decision has already been made in the mind of a professional for that professional to look objectively at aspects of presentation which might go against that view. I do not see evidence of any reconsideration or revisiting of that burdens and benefits analysis at all in the period September 2023 to the time when the 4th wean is discontinued, or at any time.
140. It is the policy of this Trust so I have been told that MDT meetings held in the absence of the parents are not minuted. In my view that is a regrettable policy; not good practice and it does not accord with the Best Practice Guidance of the Royal College of Paediatrics and Child Health. It also means that it is impossible to see whether there were in fact discussions revisiting the view of, for example awareness and interactions.
141. It has been striking, as discussed earlier, that some of those medical and other professionals who are working with Fatima in May report and record a level of responsiveness which exceeds that of others who by then have been involved in making a decision that an application should be made to withdraw life support and who characterise Fatima as showing minimal awareness or nothing / staring into space. Consciously or otherwise, most likely otherwise, if a professional has arrived already at a conclusion in their own mind that a child's best interests are served by palliative care path to death, there is, as I see it, a real risk that that may affect the lens through which things like awareness and responsiveness are viewed. Assessment of those aspects is more subjective and less susceptible to calibrated measurement than other physiological assessments.

142. There is in my judgment a danger that that risk is magnified when a group of people who have arrived at the same view following discussions reinforce each other. As it happens, there has been a want of transparency as to how decisions have been made and the discussion which has led to them. That is not satisfactory but it is a subtly different point to the anxiety I have, surveying the totality of the evidence that is before me, about how awareness, responsiveness, and benefits have been weighed in the balance by those looking at Fatima's life, who have already reached a decision to invite the Court to declare it lawful for that which sustains it to be withdrawn.
143. In general terms, I accept the evidence that now, her awareness and responsiveness – which I regard as two different, though linked things are diminished. However since I have concluded that these features have throughout her stay been underestimated or under reported by some of the Trusts witnesses, and having regard to the evidence I have heard from others and is discussed earlier, I do not agree that they are at the minimal level the Trust invites me to accept. I also accept the well-pitched submission on behalf of the parents that I should be wary of assuming that a diminution of observable awareness and responsiveness is necessarily to be seen as neurological decline (or all neurological decline) since there has been a lack of stimulation; no formal referral for play therapy (for reasons that are not entirely clear) and the well-recognised effects - which Dr Ross Russell acknowledged- in terms of withdrawal from engagement, of a long stay in PICU.
144. Decisions in cases like this one are not made on the basis of medical evidence and the opinions of professionals alone. Were that so, the many cases in which there is unanimity of view (medically) would not require consideration or determination by a judge of the Division. Were that so, the involvement of the judge would amount to no more than a rubber stamp. That is not how it is. That is not how it is for good reason. A child, and her life, is not simply the sum of the very expert and skilled views of her own doctors and other doctors. Naturally a condition like [WVOX-DEE] is understood by those whose field it is and wholly alien to others – like me – whose field it is not. It is unsurprising therefore that to make sense of it, and to be informed of the likely implications for a child of having the underlying condition, a great deal of focus is on clinical and expert evidence. A child and her life, however in summation also embraces social, psychological and spiritual aspects which are outwith the medical field. It is often, though not always, the case that the preponderance of the 'benefits' in the burdens and benefits analysis falling to the Court are to be found there in those aspects of her life and the preponderance of the 'burdens' are to be found in the aspects of her life relating to the illness or condition and the treatment required to manage it.
145. One of the aspects of this case which has given me pause for thought in relation to benefits of life is: what does pleasure mean for Fatima?. '*Does she derive pleasure?*' witnesses are asked by counsel. Pleasure is a subjective quality. It is easy to understand pleasure in someone who is well; less so in someone who is not. To take a hypothetical example (away from Fatima) – For a sports enthusiast perhaps pleasure might come from playing or watching sport. In someone who becomes less well and cannot play any more, it is not difficult to see that pleasure might still come from watching it; if less well still, perhaps from lying in a hospital bed and listening to it ; perhaps listening and discussing it in the company of friends or family members who played or went to matches together when they could ; if less well still, unable to communicate verbally, perhaps showing signs of recognition when the sports broadcast is turned on and a

perceptible awareness that the friends they once played alongside have come into sit beside the bed in company with them. When does that experience cease to become pleasure or a benefit? I have found it useful to remind myself, by thinking in those theoretical terms, of the spectrum across which pleasure may be experienced and of the way in which pleasure may mean different things to different individuals, and for that matter different things to the same individual according to circumstances.

146. Fatima is not a child who has ever been able to run about, play with friends, talk or chatter, clap her hands in delight at a new experience but it has not been suggested to me that she was unable to derive pleasure from life before the current admission. So when I consider now what may be responses indicative of an ability to derive pleasure I do so within that context.
147. In this case I have found it useful to hear from those who are at the bedside and caring for Fatima whose observations as discussed at length earlier I accept. In thinking about those matters which I have attached weight to as benefits, I have reflected on the extent to which they are indicative of an ability to derive pleasure. The evidence of Fatima's reaction as she hears her mother's voice and the change in her when her family arrive is in my view not only to be counted as a benefit (in the language of the balance I must carry out) but also as an expression of some pleasure. Whilst I am cautious in attributing much to the movement of her arms when considering whether it is what has been variously described as 'purposeful' and 'functional' and on the evidence she does not reach out or grasp independently for items, I do not see that observed increased movement by those who report it as linked to a parents arrival falls to be dismissed in the same way. In my judgment, along with benefit of deriving solace and comfort from their presence, the touch of her mother's hand, her parents' voices, the security of her father's arms as she is carried from one side of the bed to the other to be winded and appeared to the Guardian to be comfortable held in the arms of the man for whom the notes record she reserves her biggest or broadest smiles; the attention of her brothers and sister are all sources of pleasure to her. I have discussed already the Guardian's observation of Fatima's response on 29th October and my conclusion that it is clear evidence of responsiveness. I regard it also as a response indicative of pleasure.
148. I have taken heed of Mr Davy's urging not to underestimate the burdens in the analysis. Prominent in the burdens [83 et seq] above is that of pain from interventions. I do not underestimate the significance of pain as a burden. In contrast with for example *Raqeeb* in which MacDonald J was able to proceed on the basis of no pain (and thus as a matter of logic nothing to weigh in the balance of burdens as regards pain) here there is a mixed picture of sometimes experiencing pain; the question to weigh is whether alone or with other burdens the component of pain is such that it displaces the benefits leading me to a conclusion that it is in Fatima's best interests for her life sustaining treatment to be withdrawn. I regard this case as finely balanced. I have thought long and hard about where the balance lies in considering my decision within which consideration it has been necessary to examine with particular care the evidence available to me of Fatima's levels of awareness and responsiveness. I have neither ignored the views of the eminent clinicians whose collective clinical view on the balance is that the burdens displace the benefits even if those benefits include the prospect of long-term ventilation with tracheostomy at home for (at most) a small number of years; nor have I underestimated the significance of pain.

149. Prominent in my thinking also has been the fact that Fatima's Guardian has through Counsel strongly contended that the burdens of Fatima's treatments and quality of life are such that continuance of her life sustaining treatment is not in her best interests. The Guardian has concluded that evidence of awareness and responsiveness, including her own observation discussed elsewhere, is outweighed by those burdens. That position taken by so experienced a social work professional, safeguarding Fatima's interests independently of the Trust or her parents, warrants considerable respect. Whilst the Guardian has been focussed on and given proper consideration to the burdens of Fatima's condition and treatment, I have formed the impression that there has been an undervaluing of the benefits to her and on the totality of the evidence I have come to a different view.
150. Having balanced carefully and with anxious consideration all of the wide canvass of medical, social, and psychological considerations emerging from the evidence, I am not satisfied that in the particular factual circumstances of this case it is appropriate to grant the declarations sought by the Trust. It follows that the application will be dismissed.
151. The consequence of that decision is that Fatima will undergo a tracheostomy with a view to a return home. That is not a path without risk or uncertainty and, as her Guardian has been astute to point out is one that carries with it its own burdens. I have not ignored those burdens but putting them into the overall burdens and benefits analysis I have found them to be outweighed by the prospect flowing from of a step down from PICU and intensive care and the prospect of a return home to a life lived, for as long as that life may be, within her family by whom she is deeply loved, whose presence has been a constant in her life, in whose presence and from whom I am satisfied she retains an ability to take some pleasure.