This judgment was delivered in private. 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, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Case No: FD14P05009

Neutral Citation Number: [2014] EWHC 1031 (Fam)
IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 04/04/2014

Before:

MRS JUSTICE THEIS DBE

- -

Between:

An NHS Foundation Trust	**Applicant**
- and -	
AB	
- and-	**1st & 2nd Respondents**
CD	
- and -	
EF (A Child) By His Children's Guardian)	**3rd Respondent**

- -
- -

Ms Fiona Paterson (instructed by **NHS Foundation Trust**) for the **Applicant**
Mr Andrew Hockton, (instructed by **Leigh Day & Co**) for the **1st & 2nd Respondents**
Mr Mike Hinchliffe (Cafcass Legal) for the **3rd Respondent**

Hearing dates: 26th & 31st March, & 3rd April 2014

- -

JUDGMENT

Mrs Justice Theis DBE :

Introduction

1. This matter concerns a little boy EF born on 16.2.13, who is just one year of age. He is the only child of AB and CD**.**

2. I made a reporting restriction order at the interim hearing last Friday which remains in place until further order. The effect of that order is that the child, the family, the hospital or doctors or nurses who have provided statements and reports or given evidence should not be identified.

3. These proceedings arise from a disagreement between the NHS Trust who are responsible for treating EF and the parents about what is in his best interests. He has an incurable neurodevelopmental disorder, the cause of which is unknown, despite extensive investigation, and has been in hospital since birth.

4. The disagreement centres on what steps, if any, should be taken following his extubation from the ventilator he is currently on.

5. I am deeply conscious how stressful a case such as this is, in particular for the parents. Despite the obvious difficulty of the situation they find themselves in the parents have conducted themselves throughout this hearing with great dignity, whilst paying close attention to the evidence which has dealt with such fundamental issues concerning their son. There can be little doubt they love him and are totally devoted to him. During his short life they have had to grapple with making difficult and profound decisions regarding his future care, which they have clearly done with enormous care.

6. It is of note that on many issues regarding EF's medical care, the parents and the medical treating team are in agreement. There have been numerous meetings where EF's future treatment plans have been discussed; the most recent was on Tuesday this week. Despite the differences between them they have maintained a working relationship which is clearly in EF's best interests and respected each others' position. The parents have been supported by a social worker whose presence and help has undoubtedly also been of assistance, particularly to the mother.

7. This case first came before me last Wednesday. I heard an interim hearing on Friday and conducted the full hearing yesterday. All of these events have taken place in just over a week.

8. I am very grateful to the doctors and nurses who have provided statements and reports and attended to give evidence. Their professional judgments have been put under intense scrutiny. They have remained in court to be on hand to assist with any developments as they occurred during the case.
9. I have had the benefit of experienced advocates who have not only been sensitive in the way they have approached the case, but have also been of considerable assistance in the written documents they have provided. I would like to record the court's particular gratitude to Mr Hockton and his instructing solicitors Leigh Day. They have represented the parents pro bono. They have done so with admirable skill which has enabled the parents to participate in the hearing in a way that was relatively less

stressful than if they had had to conduct the case themselves without legal representation.

10. EF has been in the paediatric intensive care unit (PICU) since 11 March 2014. Since that time he has been in receipt of ventilator support. The parents accept the medical consensus that EF has a neurological disorder that is not curable. They do not seek any further investigations to be undertaken regarding his underlying condition and, in particular, agree that he should not have a tracheostomy.

11. All parties agree it is in EF's best interests to be extubated. What they disagree about is what steps should be taken thereafter.

12. The Trust seek a declaration that after extubation all forms of respiratory and cardiac support will be withdrawn and withheld from him, save for those measures identified in the Emergency Care Plan and Symptom Management Plan which are (i) suctioning his upper airway; (ii) suctioning any airway secretions; (iii) administering oxygen to him through a face mask; (iv) increasing the oxygen administered to him through the face mask; (v) optimising his airway by positioning him appropriately; (vi) administering oral and intra-venous antibiotics; (vii) administering blood products. The extent, duration and manner in which any of these steps and measures are administered is at the discretion of the Trust medical staff alone.

13. The parents and EF's Guardian agree with this plan save that they seek further limited artificial ventilation in the event EF requires it.

14. The parents seek EF's reintubation, in the event he requires this, in the 24 hours following extubation. They accept following that time frame he should not be further intubated. However, after that they ask that bagging is available, but accept it should be at the discretion of the medical staff. Bagging is ventilation delivered by hand through a mask and by squeezing a bag.

15. On behalf of EF his Guardian, Ms R, does not support any further intubation. She considers the burdens of that intervention are not outweighed by the benefits, even for one occasion. However she does seek bagging in the first 24 hours after extubation. She accepts that it be administered in the discretion of the medical team.

Legal Framework

16. There is no disagreement regarding the legal framework within which I have to make a decision. The approach to this type of decision is highly fact specific.

17. I have to take into account all relevant matters treating EF's welfare, in the widest sense, as the paramount consideration in determining what is in his best interests. I need to undertake an objective analysis and look at the position from the child's point of view and apply the strong, though rebuttable, presumption in favour of a course of action that would prolong life.

18. Where treatment is likely to be futile, the presumption in favour of preserving life is rebutted. There is no obligation upon clinicians caring for the child to provide such treatment.

19. The relevant line of authority was encapsulated by Holman J in *NHS Trust v MB [2006] EWHC 507 at Paragraph 16*:

" But the law around this topic is now well established and tolerably clear and can, I believe, be shortly stated in the following propositions without the need for copious reference to authority. The essence of these propositions lies in the "intellectual milestones" to which the Court of Appeal referred in paragraph 87 of the reserved judgment of the court in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181

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 Lymington 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 Lymington 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 irrebuttable … 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.

19. The applicant considers that EF falls within the category of children described within the Royal College of Paediatrics and Child Health Guidelines (January 2014) who have only a limited quality of life and who will suffer an "inevitable demise."

20. The Royal College of Paediatrics and Child Health Guidelines provide that,

> *"**3.1.3.2 Limited quality of life: where burdens exceed benefits***
>
> ***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 e.g. use of invasive ventilation in severe 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, e.g. by deep sedation, its potential benefit may be significantly reduced. Other examples of particularly burdensome treatments include ECMO, renal dialysis and, sometimes intensive chemotherapy."*

Relevant Background and Evidence

20. EF presented with apnoeas (where he stops breathing) from the neonatal period. He has required intubation and ventilation on about 11 occasions since. He has been in hospital throughout his life, has had a number of admissions to paediatric intensive care units and has been under the care of the applicants, either directly in their hospital or through liaison with the hospital he has been discharged to.

21. It is not necessary for the purposes of this judgment to detail the extensive investigations that have been undertaken, as it is accepted his neurological condition is not treatable. There is an issue between the parties as to the extent of any recent deterioration. The Trust state this is part of his underlying degenerative neurological condition. The parents dispute this, they submit any deterioration is intermittent and may be caused or contributed to by secondary factors, such as infection.

22. EF had difficulties feeding since birth and since he was a few weeks old has been fed via a gastrostomy tube as he is unable to swallow properly.

23. He has been on PICU since 11 March. He was admitted to the neuro science unit in early February. His admission to the PICU was due to the fact he was having frequent apnoeas and bradycardic episodes (where the heart rate drops). Whilst on the ward he required frequent intervention to assist him with his breathing. When he arrived on PICU he was being hand ventilated (bagged), he was placed on a ventilator on a setting which breathes for the patient. This was changed on 13 March to CPAP (continuous positive airway pressure) which just supports EF’s own breathing, but does not given him any additional breaths should he stop breathing. He remains on that setting.

24. He has continued to have frequent apnoeas. In a recent record sheet over a 24 hour period at the end of March, which recorded apnoeas in excess of 10 seconds, he is noted to have suffered over 500 such incidents over that period. The majority of which were self-resolving although some required external suction and about 3 of those incidents required bagging, although this would have been administered through the tube rather than placing a bag over his face.

25. Since EF has been on the PICU he has been sedated to ease the discomfort of having the tube and to prevent him dislodging it. This has been given ‘as required’; although the evidence suggests that he is sedated most of the time. He requires almost constant care, and has a 1:1 nurse allocated to him all the time. He is swaddled most of the time to make sure he does not try and pull out the tube. As well as basic hygiene care he requires pressure care to prevent him getting pressure sores, but he dislikes being placed on his right side and will cry. He has a full wash 1 – 2 times a day and is suctioned round his mouth and nose when required. He can’t be taken out of his cot. When he is awake he is described by one of the PICU nurses as having purposeful responses and will fix on you and follow you round. However, she reports it is rare he is awake and settled. She notes he recognises his parents and can be comforted by his mother, in particular.

26. The nurses from the neuro-science unit, where he was between February to March, describe his movements to have decreased significantly. He will follow them with his

eyes but his movements are far more restrictive, the main movement he did involved trying to remove the oxygen mask from his face or the bagging mask if he was being bagged. They have noted his desaturation and apnoea attacks have increased and are more prolonged. They describe isolated incidents of smiling, but otherwise report that EF does not respond purposefully to the care they administer. For example, when shining a torch into EF's eyes to check pupil size and reaction, he did not show normal signs of flinching and turning away or try and reach out to grab the torch.

27. I have statements from the following who are part of the current medical team treating him. Dr W, Consultant Paediatric Intensivist (who is one of team at the PICU), Dr V Consultant Paediatric Neurologist and Dr X Paediatric Respiratory and Sleep Medicine Consultant. In addition, I have four statements from the nursing team, two staff nurses and ward sister on the neuro-sciences unit and a staff nurse on the PICU. The Trust, with the consent of the parents, sought second opinions. I have seen reports from Dr Y, Consultant Paediatric Neurologist at Guys and St Thomas and Dr Z Consultant Paediatric Respiratory Consultant at the Royal Brompton.

28. Dr W, Dr V, Ms GH (staff nurse) and Ms IJ (ward sister) gave oral evidence on behalf of the Trust.

29. In his second statement Dr V states that he is able to make an accurate assessment of both EF's condition and prognosis. He said he presents with the following pathologies (i) central hypoventilation (ii) motor neurone degeneration (iii) evolving epileptiform abnormalities (iv) sick sinus syndrome.

30. It is his opinion that EF's condition appears to be deteriorating. He refers to each of the pathologies in turn.

31. In relation to central hypoventilation he states that Dr X, through the sleep studies, has identified a significant decline in EF's respiratory function. The most recent was in February. The sleep studies show a patient's respiratory patterns and, in particular, how well those patterns are maintained. The results of those studies have demonstrated that he is suffering from central sleep disordered breathing. This means that his control of his respiratory muscles is compromised, as opposed to him suffering from a problem associated with an obstruction or primary lung disorder. He was clear in his written and oral evidence that an infection would not affect his central control of breathing; the primary problem was central control of these functions from the brain.

32. Turning to motor neurone degeneration, he said EF had undergone repeated EMG testing and they have shown a decline from August to February. They have shown a widespread motor neurone abnormality within his swallow and peripheral muscles, including loss of nerve fibres supplying the tongue. This trend he concludes demonstrates that with time EF will not only have increasing difficulty moving, but also breathing. Were EF provided with respiratory and cardiac support on an indefinite basis (which may increase the length of his life), he is likely ultimately to lose all movement, including the ability to form facial expressions.

33. Evolving epileptiform abnormalities have been demonstrated by the changes noted in the EEG testing. EF has undergone 4 EEGs. The first in March 2013 was normal, the

second in June 2013 showed minor abnormalities, the third in November showed sharpened discharges which were more suggestive of an evolving epileptic disorder. The fourth in February this year showed clear evidence of background abnormalities with increased epileptiform components. There is no evidence of clinical seizures, but the overall appearance of the EEG was abnormal. These changes he says show evidence of evolutionary changes within EF's central brain processes. The most recent one showed electrical abnormalities which if the process continues will result in seizures, which will have an adverse effect on cognitive functioning.

34. Finally, sick sinus syndrome. EF is suffering from increasing episodes of bradycardia which are not always associated with his apnoeas. This suggests there is a disease process which is affecting his heart. The extensive cardiac investigations have resulted in a diagnosis of sick sinus syndrome, this is a description which indicates dysfunction of the intrinsic control of the heart. The recent EEGs have revealed frequent drops in his heart rate. He said this is caused by the reduction in EF's ability to maintain his heart rate, which is under electrical control.

35. In his oral and written evidence Dr V was clear that any infection did not impact on the conclusions he had reached regarding the deterioration in EF's condition.

36. In his statement Dr V states that once EF is extubated his prognosis is poor. On the balance of probabilities, he is likely to survive only a few weeks, although he accepted there was a possibility he could die within minutes or survive several months.

37. Dr V agreed that EF's cognitive functioning was difficult to assess. He said the nursing and physiotherapy staff consider since he has been readmitted to the applicant's hospital in February he has been less responsive. He has been hospitalised since birth and unable to enjoy the stimulation of normal experiences associated with early childhood.

38. In her first report, Dr Y raised the issue of further investigations that could be undertaken. As most, if not all, involved surgical procedures or general anaesthetic, no one, including the parents supported those procedures being undertaken.

39. In her second report she defers to Dr V who has had clinical management of EF as to the impact of any infection. She states,

> *"EF has had sequential EEGs which have on the most recent studies identified abnormalities not evident on earlier studies. I do not think that this in isolation would be sufficient to determine that EF has a progressive neurological disorder, because EEGs in any individual can vary from one day to the next, and because I did not see described abnormalities that would categorically place this in the domain of a degenerative disorder. Similarly although EF's EMGs which measure muscle electrical activity appear to have indicated progressive abnormality of motor nerve cells, this alone would be insufficient to categorically determine that EF has a neurodegenerative disorder in my opinion. Taken together with the clinical impression that EF has worsening apnoeas and bradycardias, the changes in EEG and EMG over time certainly support the impression of his clinicians that he has a progressive disorder. EF's condition is serious, he is*

unable to breathe consistently adequately, and therefore has needed recurrent ventilation. The episodes of bradycardia are further cause for concern as such episodes can sometimes precede cardiac arrest, and if the bradycardias are indicative of a neurological disorder the possibility that this may ultimately progress to cardiac arrest has to be viewed as a reasonable likelihood. I do not think EF has a curable neurological disorder.” She deferred to Dr V as the treating neurologist regarding any deterioration in EF’s condition, as he would have seen EF over a longer period of time.

40. Dr W is part of the team with overall control of EF’s care on the PICU. In relation to infection at the time of his recent admission on 11 March he said in addition to clinical observations (including temperature) there were blood and urine cultures and a chest x-ray. None of those matters pointed to either a bacterial or viral infection, but as a precaution he was put on antibiotics for the first two days. The only other feature was a temporary spike in his temperature 2 days later, since then there has been no objective evidence to indicate or support EF having an infection.

41. He was asked about the preparations that would take place for extubation. He described this as a multi-faceted approach. EF would be taken off his current sedation, there would be a chest x-ray, checks for fluid balance and any swelling that can be caused to the upper airway. The swelling would be considered through a clinical assessment by seeing is there is any air round the tube; if present it would indicate there was no swelling. If there was swelling it would be treated by steroids prior to extubation and 3 doses afterwards.

42. He described what would happen at the actual time of extubation. They would try and get EF as upright as possible; it would require a team of 3 – 4 people together with his parents. The actual removal of the tube would take about a minute but the preparation, including the removal of the plasters across EF’s face which secure the tube in place, may take a little longer.

43. His assessment of the success of the extubation is that it is *‘unlikely it will fail’* and he expects EF to be able to continue to breath with supplemental oxygen. He said this is mainly due to the care that will be taken in the preparation in advance of the extubation and the fact that EF’s current ventilator support is set at such a low rate. The rate is determined by EF himself through his own breathing.

44. His written and oral evidence is clear that following extubation he does not support any further artificial ventilation. He said this is the unanimous view of the medical team.

45. He does not support it in principle as there is no evidence that EF has a treatable condition and the distress and burdens involved in undertaking either of the artificial ventilation procedures is not, in the circumstances of this case, he says in EF’s best interests.

46. The process of intubation is very distressing and, in his opinion, would be so for EF. It would involve further sedation and because there is difficulty in vascular access it would require an intra osseous needle to be put into his leg to deliver drugs. To re-insert the tube it is necessary to place a metal blade at the back of the mouth to enable

them to visualise the relevant area, prior to putting the tube in. Intubation is a very painful process; it has recently been described by a 15 year old on their ward as akin to having a sword thrust into his chest. The same boy described suctioning as feeling like he was being suffocated. Whilst Dr W accepts EF is not able to express his own views due to his age, he said that description gave an indication of what the procedure feels like which in his opinion, bearing in mind EF's underlying neurological condition, would not be in his best interests.

47. Turning to the alternative method of ventilation by bagging. This is where a mask is placed on the face and the attached bag is squeezed which forces air into the patient's lungs. He said the clinical consensus is that bagging would not be of any benefit to EF as it is an uncomfortable and distressing procedure and would not change the underlying neurological condition.

48. In his oral evidence he described the procedure in more detail. He said the bag used is larger than an oxygen mask and needs to cover the mouth and nose and as far as possible seal in the air being delivered. With a young child such as EF it often covers the eyes as well. He would need to be held in a position that ensures his airways are as clear as possible, pressure would need to be placed on the mask as it is put and secured on EF's face. He said most patients, if they have sufficient cognitive ability, will react by trying to remove the mask, which is indicative of how it feels. A tube goes to the back of the mouth and then air is delivered. There are risks of aspiration involved in this procedure. That is air going into the stomach which can produce an immediate response, particularly if there is food in the stomach. This can increase the chance of vomiting which for EF could have serious consequences. He said this was not a benign process, could be distressing and increase the risk of bradycardia. He said bagging is not used for protracted periods of time. It is often used as a prelude to intubation and part of resuscitation.

49. He rejected the suggestion by Mr Hockton, on behalf of the parents, that the time EF has been intubated is relevant to the chances of success of extubation. The parents experience when EF has been extubated previously is that when he has been intubated for longer periods he requires respiratory support during the first 24 hours, whereas when he has been intubated for a short period of time that was not required. However it did appear, somewhat surprisingly, that Dr W had not conducted any detailed investigation as to the records and circumstances of the previous extubations.

50. The written evidence from the two staff nurses on the neuro-science unit where EF was from early February until March set out their observations. The nurse who gave oral evidence was limited to a period of 4 consecutive nights in mid February when she was the 1:1 nurse allocated to EF. The other nurse has spent more time with EF and was on duty when he arrived on the ward. They describe an overall deterioration in EF's condition, in particular his movements, his overall alertness and the increase in his apnoeas and bradycardiac episodes. However, Mr Hockton rightly observes some of these descriptions are inconsistent with other entries in the medical records around that time.

51. The parents in their written evidence, together with the father in his oral evidence, describe more interactions from EF. They put this down to the fact that they are more constant figures in EF's life than the nurses who obviously work on a shift pattern and

actually spent little actual time with him. They feel that any deterioration has been related to periods of time when EF has had infections, which has distorted the picture and do not provide a secure basis to make such fundamental decisions regarding EF's future care. It is clear EF's mother spends a lot of time caring for EF, when he was on the ward she stayed with him and whilst she is unable to stay on the PICU, the family are given 24 hour access. I was able to see four video clips of EF; three when he was on the ward, one in January, the second in February and the third just prior to his admission to PICU. The most recent one was two days ago. The one in February, in particular, shows EF listening to his mother's voice, fixing her with his eyes and on occasion smiling in response to what she was doing. He was able to move his arms to the mid line and appeared to lightly grip her hand. The other videos show more limited responses. The parents feel the hospital has given up on EF.

52. What the father sought on behalf of the parents was one further reintubation, if required, within the 24 hour period after extubation. After that they accept EF should not be further intubated. This is based on their previous experiences of EF being extubated. On three occasions he has had to be reintubated within 24 hours of extubation. They said this has been in the context of occasions where he has been intubated for relatively extended periods. Where he has been intubated for only a few days his extubation has been more successful. He feels EF is sensitive to sedation, his reaction to it is not normal and that needs to be accounted for in the 24 hour period after extubation.

53. After that 24 hour period the father in his evidence sought indefinite bagging for short periods of time which in his experience were only for a few minutes at a time, generally to support EF when he has apnoeas.

54. What the parents want is for EF to be given every opportunity to live for as long as he can without causing him significant harm. As the father so movingly said in his oral evidence he is aware of the discomfort but if the purpose is for EF's life, 3 – 4 minutes of bagging that may enable him to smile for a further month it should be taken. He accepted there were risks associated with bagging, but as he said *'there is a risk with everything we do'*.

55. Ms R, the Children's Guardian, has visited EF twice since her appointment last week. Her observations of the parents with EF were characterised by warmth and attentiveness. They had, in her view, been struggling a great deal with what is in his interests, but understandably wish to preserve his life even if this means some level of distress. As she observes it is the perceived level of distress that EF will experience and the benefits to him with continued breathing support in the medium term that is at the core of the differences between the Trust and the parents.

56. In her report she has helpfully set out a table of the benefits and burdens of continuing treatment.

57. In her oral evidence her final position, having heard the evidence, was that she did not support any further intubation as the burden of such an intervention outweighed the benefits, but she did support artificial ventilation by way of bagging limited to the 24 hour period after extubation. She acknowledged that the length of any bagging during that period would need to be at the discretion of the medical team.

Discussion

58. My task is to evaluate the wide canvas of evidence, to carefully weigh up the benefits and burdens to EF of the positions advocated by each party. EF is unable to make his own decisions and is dependent on others, and ultimately the court, to weigh the balance between the distress and pain he is likely to experience if he continues to be assisted with artificial ventilation compared to that of allowing him to leave his parents peacefully when the prognosis is that his long term prospects of survival are so bleak.

59. It is accepted that EF's neurological condition is not curable. There is an issue between the parties as to the extent of his clinical decline and whether that has been caused, or contributed to by, an infection that distorts the picture. I also have to take into account the difference between the descriptions of EF's presentation given by the nurses and the parents.

60. Looking at the evidence as a whole I consider it is more likely than not that EF's condition has and is deteriorating and that decline has not been distorted, or significantly distorted, by any infection. The overall picture as described by Dr V is that the deterioration they have noted when comparing the various investigations undertaken over the last 14 months and the particular features of the changes is that, when looked at all together, they would not be affected by viral or bacterial infection. Dr V was clear, for example, that the decline in the central control of EF's lungs and muscles was caused by difficulties in the central control from the brain and that would be unrelated to any infection. Dr V's evidence taken together with the evidence of Dr W about the clinical investigations regarding infection support the conclusion that EF's recorded deterioration is likely to be unrelated to infection and is more likely to be due to his underlying degenerative neurological condition.

61. The parents' account of EF's observed behaviour and reactions has not been challenged, but the underlying medical deterioration cannot be ignored. These inconsistencies in EF's degree of responsiveness was not surprising to Dr V, it is consistent with the overall picture of a child suffering from an underlying neurological condition that was deteriorating.

62. Whilst EF's current responses and interactions have been reduced by the fact he has been on sedation since 11 March the overall picture demonstrates that he has some cognitive functioning. He can open his eyes, fix and follow visual stimulus in all directions. In the recent past he has attempted to grasp either the doctor or his parent's hand, he can smile and babble although this is a lot less now. In so far as it is possible to tell there are no concerns regarding his vision and hearing, although his movements have decreased significantly, he has stiffness in the ankles and only minimal active knee extension. He recognises his parents. The mother, in particular, spends a lot of time with him. The father described it as 95% of the time. Dr V has known EF since March 2013. He has observed a deterioration in his movements. He considered he was cognitively intact, in so far as he was able to. That is likely to include pain, fear and sadness as well as pleasure from events and recognising people.

63. The burdens of his condition and further treatment are that his desaturation, apnoea and bradycardiac episodes have significantly increased. The bradycardiac episodes are

not solely related to the apnoeas. There have been more oral secretions that require suctioning and the administration of oxygen. It can take up to 3 hours to get the oxygen saturation level back to the appropriate level. He does not tolerate deeper suction and dislikes being placed on his right side. It is very likely that he will lose all movement. If he is intubated again he would require sedation as well as undergoing a distressing, frightening and painful procedure, he would require an intra osseous needle to be inserted into his leg for drugs and large plasters on his face to secure the tubes. Any CPR would cause pain and distress as well as possible injury.

Decision

64. Save in one respect, I have reached the conclusion that any further treatment given to EF over a significant period of time by way of artificial ventilation is unlikely to prolong life significantly. Whilst he has some limited quality of life now the fact is the burden of either method of artificial ventilation long term will, in my judgment, result in any benefits of that treatment, including the possibility of prolonging life, being far outweighed by the burdens. Thereby the strong presumption in favour of prolonging life is rebutted.

65. Further intubation, even on one limited occasion, will cause pain and distress to EF. The descriptions given by Dr W of the distress and pain that EF is likely to feel during the procedures involved in reintubation would not be in EF’s best interests as it is unlikely to prolong life significantly in the context of EF’s overall neurological condition. In addition, his quality of life when he is intubated is very poor. For example, he can’t leave his bed, will be sedated, will be at risk of pressure sores.

66. I have carefully considered the parent’s position of one further intubation within the first 24 hours. Mr Hockton makes the powerful point in his submissions that based on the parent’s past experience of reintubation following extubation the potential value of it prolonging EF’s life, albeit for a limited duration, affording him and his parents spending more time together tips the balance in favour of the burdens of such a procedure on a time limited basis being in EF’s best interests.

67. Whilst I have enormous sympathy with the views expressed by the parents, I do not agree. I have to look at the position of EF now. His life expectancy is limited and his decline is tragically inevitable and imminent. No further treatment can be offered to him. He is cognitively intact as far as the doctors are able to tell. Whilst he is still able to experience emotion, to make associations (for example recognising his parents) he is also likely to experience fear, pain and sadness. The burdens of reintubation both in terms of the actual procedure and the loss of quality of life, even once in the first 24 hours, are not in EF’s best interests. The potential value of possibly prolonging his life for even a short period of time is outweighed by the distress that is likely to be caused to him by undergoing such a procedure.

68. Long term the same applies in relation to bagging. Although it is a less invasive procedure than intubation, for the reasons outlined by Dr W it is still likely to be distressing, frightening and painful for EF. It also carries the risk of aspiration which can result in vomiting. This would be risky for EF as it may result in further respiratory distress and cardiac arrest. These burdens long term outweigh the benefits of such treatment, which is unlikely to prolong life significantly due to the underlying

medical condition. Also, long term it will be a procedure that is difficult to clinically manage without the option of moving onto to a ventilator. The more it is used, the more it will increase the distress for EF and increase the risks involved in the procedure, in particular aspiration.

69. The area that has caused me the most concern is the suggestion put forward by Ms R for there to be bagging available during the first 24 hours. This is based on the experience of the parents of previous extubations and respiratory difficulties EF has experienced within the first 24 hour period. Whilst bagging is invasive and carries risks it is less invasive than reintubation. The question is does that tip the balance the other way for that short time limited period?

70. On balance I consider it does. I have reached that conclusion for the following reasons:

    (1) The benefits EF may enjoy in the 24 hour period after extubation by being stabilised through bagging outweigh in that time limited period the additional burdens on him of ventilation by those means.

    (2) It is on the basis that it is done at the discretion of the treating team in consultation with the parents, so far as is practicable.

    (3) Whilst I accept Dr W's relative optimism about the prospects of a successful extubation, I also accept the evidence from the father about their previous experiences in the immediate period following extubations. The views of the parents in this context carry some weight.

    (4) I have considered the point made on behalf of the Trust that it may hinder planning as it creates some uncertainty and an artificial time period during which this ventilation support can be given. However, the time period is based in part on the experience of the parents about EF's reactions previously, which I have no reason to doubt. It carries with it the benefits of possibly extending his life in the short term to spend time with his family which would undoubtedly be for his benefit.

    (5) I am confident, based on the way the parents and the medical team have managed difficult decisions in the past that they will work together in EF's best interests.

    (6) Following this limited time period his care will be managed by the Emergency Care Plan and Symptom Management Plan.

71. In those circumstances I will make the declarations sought by the Trust with the additions made by Mr Hinchliffe on behalf of Ms R.