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: FD15P00291

Neutral Citation Number: [2015] EWHC 1920 (Fam)

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 24/06/2015

Before :

THE HONOURABLE MR JUSTICE MACDONALD

- -

Between :

KINGS COLLEGE HOSPITAL NHS FOUNDATION TRUST	**Applicant**
- and -	
MH	**Respondent**

- -
- -

Mr Hallin (instructed by **Kings College Hospital NHS Foundation Trust Legal Services**) for the **Kings College Hospital NHS Foundation Trust**
MH appeared in person
Ms Logan (of Cafcass Legal) appeared as an advocate to the Court

Hearing dates: 23 June 2015

- -

Judgment

THE HONOURABLE MR JUSTICE MACDONALD

INTRODUCTION

1. At 6.45pm yesterday evening, 23 June 2015 I commenced the telephone conference hearing of an ‘Out of Hours’ emergency application by Kings College Hospital NHS Foundation Trust in respect of an 7 year old child, Y. The NHS Trust was represented by Mr Hallin of counsel.

2. Y’s father, Mr MH had been notified of the hearing and the Trust had made provision for him to attend in person by telephone. The father confirmed that he also spoke for Y’s mother Mrs LM. The father speaks English as a second language and I was concerned to establish that he had a proper understanding of the purpose of the hearing and could follow what was being said notwithstanding the technical nature of much of the information before the Court. Whilst the father’s English is not perfect, I adjudged that, in the urgent circumstances of this particular case, the father understood sufficiently the purpose of the hearing and was sufficiently capable of communicating his views to the court.

3. In circumstances where the NHS Trust were seeking authority to withhold treatment from Y and the father was seeking for such treatment to be administered, I was also anxious that the independent interests of Y were properly represented during the course of the hearing. In the circumstances, I arranged for Cafcass to be contacted regarding this matter. The court is extremely grateful to Ms Logan of Cafcass legal for agreeing to act at the hearing as an advocate to the Court.

4. At the conclusion of the hearing, having heard from Y's treating clinician, Dr E and from the father, and having heard submissions from Mr Hallin, the father and Ms Logan, I made a declaration pending this matter returning to court that it was lawful for the Trust, being in Y's best interests, to withhold from Y endotracheal intubation and invasive ventilation.

5. I further declared that, in the event of Y going into cardiac arrest, it was lawful, being in Y's best interests, for her not to receive cardio-respiratory resuscitation (CPR) and resuscitation drugs.

6. Finally, I declared that in the event that Y became severely distressed and / or was in pain due to further deterioration of her medical condition, it was lawful and in her best interests for her to receive pain medication (such as morphine) and / or sedation (such as Midazolam) for the purpose of relieving her pain and or distress, accepting that, in an end of life situation, such medications may reduce her respiratory drive and might therefore shorten her life.

7. Those declarations did not, of course, prevent Y's treating clinicians from providing medical treatment to Y that they considered to be in her best interests at any particular time.

8. As it was after 10pm when the hearing concluded, I gave my decision with very brief reasons before concluding the telephone hearing. I now set out in detail my reasons for making the order that I did yesterday evening.

BACKGROUND

9. Y is an 7 year old girl with a diagnosis of Spinal Muscular Atrophy type 1. Since March 2015 Y's condition has deteriorated in an acute manner. On 18

March 2015 Y was admitted to hospital following a cardio-respiratory arrest having been found unresponsive by her father who, unable to feel a pulse, began CPR. Following the paramedics taking over CPR and continuing that intervention for some 15 minutes spontaneous circulation was re-established. Y was admitted into Kings College Hospital paediatric intensive care unit (PICU) requiring increased respiratory support but no intubation. During this admission Y suffered two further episodes of severe bradycardia which necessitated chest compressions and manual ventilation on 19 and 25 March 2015.

10. Y made a good recovery and was discharged home on 2 April 2015. Whilst at home Y received some non-invasive ventilation. Sadly, within less than 24 hours following her discharge home Y suffered a further deterioration and desaturation. She was again found unresponsive, this time by the ambulance crew, and was diagnosed with cardio-respiratory arrest. CPR was once again commenced. Spontaneous circulation was established after some 16 minutes but her saturations remained poor and an ‘out of hospital’ intubation was attempted. This was unsuccessful. Y had to be ventilated by a laryngeal mask airway until her arrival at the Emergency Department. She was once again admitted to the PICU where her respiratory acidosis continued to worsen.

11. By reason of Y’s worsening respiratory acidosis the decision was made to intubate her and she was intubated in theatre following gas induction. Y remained intubated for a period of 18 days. She was extubated on 21 April 2015. Prior to that extubation I was told by Dr E that there were a number of discussions with Y’s father and other family members regarding Y’s poor

prognosis and that, following these discussions, the father and Y's family were in agreement with a "one way extubation", i.e. that there would be no further attempt to intubate Y following her extubation should her condition deteriorate. I am told that the father and the family further agreed that should Y suffer a cardio-respiratory arrest she would receive only one cycle of CPR with one dose of adrenaline and would not receive re-intubation. The father did not appear to dispute that this was the position at that point in time.

12. The medical report provided to the court by Dr E for the purposes of the urgent hearing relates that examination of Y following her extubation, and in particular EEGs performed on her, indicated that she had a severe encephalopathy with no eleptiform activity. CT and MRI scans confirmed hypoxic ischaemic change in Y's brain. It was the assessment of Y's treating doctors that Y's neurological condition had deteriorated very significantly following her out of hospital cardio-respiratory arrest at the beginning of April. Dr E is of the view that the severe hypoxic ischaemic injury that has resulted in Y's severely altered neurological state is irreversible.

13. In that regard, doctors had noted that whilst Y had previously been verbally communicative and had made use of an iPad, Y now made no attempt at communication and showed no evidence of cognitive activity. Doctors considered that she no longer made any purposeful movement, that she was unable to communicate and that she was unable to fix and follow. Y had no independent cough reflex and therefore was unable to clear her own secretions.

14. Prior to 23 June Y remained in the paediatric high dependency unit and dependent on bi-level positive airway pressure, regular suctioning, chest physio and cough assist. Y had input from the respiratory, palliative care and critical care teams. Consideration was being given to whether a plan could be implemented to discharge Y home.

15. On 23 June however Y’s condition unfortunately deteriorated significantly and to the point where she required constant non-invasive ventilation. Her treating doctor, Dr E considered that Y would likely die at any time if not given invasive ventilation in the form of intubation and artificial ventilation. Dr E was very firmly of the view that such invasive ventilation would not be in Y’s best interests in circumstances where she would derive no benefit from it beyond her life being prolonged artificially in her irreversible neurological state, the prognosis for which was extremely poor. For broadly the same reasons, Dr E was further very strongly of the view that any attempt at CPR should Y suffer cardio-respiratory arrest would not be in her best interests.

16. The parents disagreed with this evaluation and considered that Y should be intubated and receive invasive ventilation. It became clear during the course of the hearing that despite the very clear overall prognosis for Y based on the results of the EEGs and the CT and MRI scans, the clear evidence of a stark neurological deterioration and Y’s level of respiratory acidosis, the father held the belief that invasive ventilation would enable Y to recover to the position she was in prior to her cardio-respiratory arrest at the beginning of April and to return home. The father also explained to me during the course of the

hearing that he felt that Y should receive CPR should she go into cardio-respiratory arrest.

17. Thus, a dispute had crystallised between Y's treating doctors and her parents. It is in these circumstances that the NHS Trust made an urgent application to the court for a declaration that, given Y's rapidly deteriorating state, the course of action favoured by Y's treating doctors was lawful.

THE DOCTOR

18. During the course of the hearing I had the benefit of a medical report from Dr E and heard from him. Dr E is a highly experienced consultant paediatric intensivist at the Trust's hospital. He has held this position since 2001. He is one of a consultant team of physicians responsible for Y's care. Dr E gave comprehensive, carefully considered and persuasive testimony.

19. Dr E told me that Y had minimal awareness. He stated that it was difficult, by reason of Y's altered neurological state, to ascertain whether Y had a response to pain. He however expressed the view that if Y had a degree of consciousness then further treatment would be painful and psychologically traumatic for her.

20. He considered that whilst Y's was not inevitably a case of imminent death this was quite likely. Dr E was however very clearly of the view that, at whatever point death might now occur, Y was at a stage where she needed to be invasively ventilated if she was to survive.

21. With regard to Y's current quality of life, Dr E described this as very poor from a medical standpoint but conceded that it was good from the perspective

of her having a loving and supportive family who were acutely concerned with her wellbeing. In particular, Dr E acknowledged the value that Y would place on her own life and the view of the family regarding the value of Y's life.

22. With respect to the burden of the medical condition from which Y suffers, Dr E described Y as having an incurable neuromuscular disease which disease placed an intolerable burden on Y, pointing out that she was unable even to deal with her own secretions by coughing. He described her illness as "certainly burdensome". As described above, on top of her existing medical condition, Dr E was of the view that the severe hypoxic ischaemic injury that has resulted in Y's now severely altered neurological state is irreversible. Even if now intubated and invasively ventilated Dr E was clear that Y would not now survive outside a paediatric intensive care unit and would never get back on to a children's ward. Instead she would spend an unquantifiable period of time having her life artificially maintained on an intensive care unit.

23. As to burden upon Y of the treatment contended for by the parents, Dr E told me that Y would have to be deeply sedated in order to be intubated again as the procedure is painful and, due to her neurological deterioration, the doctors cannot be certain that Y does not feel pain. The doctor also made clear that further intubation and invasive ventilation would have a detrimental effect on the health of Y's lungs, which adverse effect would increase with each incidence intubation and invasive ventilation.

24. Within this context Dr E was of the clear view that intubating and invasively ventilating Y again would, in circumstances where invasive ventilation would prolong Y's life but not alter her prognosis, lead to a perpetual cycle of

intubation and extubation until the need for intubation and artificial ventilation was permanent. As such, the doctor was clear that treatment would provide little or no benefit to Y beyond achieving a situation where her life was artificially maintained by means of permanent invasive ventilation. In such circumstances, and given Y’s irreversible hypoxic ischaemic injury, Dr E considered it would be both futile and burdensome to Y to provide her with further invasive ventilation by way of intubation or to administer CPR.

25. In particular, Dr E was clearly of the view that Y should not be now treated in a manner that would consign her to a life on artificial ventilation and should be allowed to die naturally as she was doing. Whilst conceding that invasive ventilation would prolong Y’s life, potentially for a significant period of time, the doctor reiterated that he strongly felt that this would not be in her best interests.

26. By virtue of the urgent nature of the hearing the court did not have available to it reports detailing a second opinion or opinions regarding Y’s medical situation. Dr E stated that, prior to the decision to extubate Y on 21 April 2015 second opinions were obtained from Dr Andrew Bush of Imperial College London, Professor of Paediatric Respiratory Medicine and Dr Heinz Jungbluth, a consultant neurologist at the Evelina London Children’s Hospital. Dr E told me that Dr Jungbluth confirmed severe hypoxic ischaemic injury to Y’s brain and that Professor Bush opined that neither re-intubation nor a tracheotomy would be indicated if Y failed extubation. Dr E further confirmed that both second opinions concurred that, given Y’s state and prognosis, the extubation on 21 April 2015 should be a one way extubation

with no further attempt to intubate Y thereafter as it would not be in Y's best interests to keep her permanently and invasively intubated.

27. I of course have regard to the fact that those opinions were provided on a particular date and the doctors who expressed them could only comment on Y's presentation at that time. Dr E confirmed that he had not obtained a second opinion since Y was extubated on 21 April 2015.

28. In relation specifically to the issue of administering CPR Dr E stated that were Y to be given cardio-respiratory resuscitation in the event she arrested it was likely that she would simply arrest again. He described the prospect of CPR for Y as "horrible". The doctor described how, by virtue of the shape of Y's chest arising out of her Spinal Muscular Atrophy, CPR was a very complex intervention to administer. The issues with the shape of Y's chest had already resulted in her sustaining broken ribs during the course of necessary physiotherapy. Dr E was clear that further CPR for Y would not be a reasonable course of action in the circumstances of Y's marked deterioration.

THE PARENTS

29. The father, who spoke on behalf of himself and the mother, was, understandably, anxious to ensure that everything that could be done for Y should be done. He told me that doctors should help a child who is breathing and should help a child who is fighting. As I have already alluded to, the father was firmly of the belief that Y would "get better" if treated by way of intubation and invasive ventilation. Whilst grateful to the doctors for all that they had done for Y the father considered that "intubation for a few days"

would restore Y to the position she had been in before she suffered her second cardio-respiratory arrest at the beginning of April.

30. As to Y’s current presentation, the father conceded that Y was now unable to speak. He hoped that Y could see him but was unsure if this was the case. Likewise, he hoped that Y could hear him but conceded that this may or may not be the case. The father appeared to accept that Y had deteriorated over the course of the 23 June with and that her chest had “*got worse*” and was now “*not good*”.

31. Within this context, and whilst making clear he trusted the doctors and that he was against Y suffering, the father made very clear that he wished for Y to be intubated and invasively ventilated. Whilst at points during the course of the hearing the father appeared to move slightly towards a concession that Y should not be artificially kept alive, the overwhelming tenor of the father’s evidence was that he wished strongly for Y to be intubated and that with a number of days of such treatment Y would get better. With respect to the administration of CPR the father made clear that his “decision” was that CPR should be administered because he wanted Y to “*have a chance*”.

32. It was clear to me that the father’s strong view that Y should be intubated and invasively ventilated, and that she should be given CPR were she to arrest, were driven by his experience of Y being resuscitated successfully at the beginning of April and successfully intubated between 2 April and 21 April. From the father’s perspective this episode of intubation was the reason that Y survived her arrest at the beginning of April. From the lay perspective of the father, and entirely understandably, further intubation at this stage, with CPR

if necessary, is thus the treatment by which the father considers that Y will once again "*get better*".

LEGAL FRAMEWORK

33. In most cases where treatment in respect of a child is to be carried out in accordance with the clinical judgment of the treating doctors, a declaration from the court regarding the lawfulness of such treatment is not necessary.

34. However, where a dispute arises between the parents and the treating doctors regarding the proper course of treatment for the child the court may grant a declaration under its inherent jurisdiction that treatment in accordance with the recommendation of the doctors is lawful on the grounds that it is in the child's best interests (see *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117). It is important to note that the court has no power to *require* doctors to carry out a medical procedure against their own professional judgment.

35. Where the decision is whether or not to withhold or withdraw life sustaining treatment for a child who is suffering a serious illness, then in seeking to identify the course of action that is in the child's best interests the court must, having regard to the fact that there is a strong (although not irrebutable) presumption in favour of a course of action that will prolong life, identify all of the medical, emotional and welfare factors that require to be taken into account on the particular facts of the case. In this regard, the court must consider not only medical welfare but all welfare factors.

36. Having identified all the relevant factors, the court must balance those factors and decide what course of action is in the child's best interests, having regard

to those best interests as the court's paramount consideration. In determining the child's best interests the court must consider the question from the assumed point of view of the child as a patient. In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests (see *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554).

37. Whilst the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment that obligation does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned (see *R (Burke) v The General Medical Council* [2005] EWCA 1003).

38. During the course of the hearing Dr E was referred to a recent publication from the Royal College of Paediatrics and Child Health entitled '*Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice*', published in March 2015.

39. The Royal College *Framework for Practice* provides that, in respect of the issue of withholding or withdrawing treatment, where there is parental or other opposition, parental equivocation or doubt as to parental capacity or a disagreement as to what is in the child or young person's best interests, an application should be made to court for a determination as to best interests. As noted above, the courts have made clear that this is the proper course of action to take where a dispute arises between the treating doctors and the parents (see for example *NHS Trust v MB* [2006] EWHC 507).

40. During the course of the hearing Mr Hallin referred Dr E to the Royal College *Framework for Practice* and in particular to the following passages of guidance as to the situations in which it is appropriate to limit treatment:

> “**B. Imminent death**
> Here, despite treatment, the child is physiologically deteriorating. Continuing treatment may delay death but can no longer restore life or health. It is therefore no longer appropriate to provide LST because it is futile and burdensome to do so. Children in these circumstances would be likely to derive little or no benefit from CPR. The aim should be to provide emotional and psychological support to the child and family and to provide them with privacy and dignity for that last period of the child’s life (see ‘Palliative care’ on palliative care).
>
> **C. Inevitable demise**
> In some situations death is not imminent (within minutes or hours) but will occur within a matter of days or weeks. It may be possible to extend life by treatment but this may provide little or no overall benefit for the child. In this case, a shift in focus of care from life prolongation *per se* to palliation is appropriate.”

41. Dr E was also referred by Mr Hallin to the passage of the Royal College Guidance that deals with concept of the burden of treatment:

> “**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 may be significantly reduced. Other examples of particularly high impact treatments include ECMO, renal dialysis and, sometimes, intensive chemotherapy.”

42. Dr E confirmed that he had relied on the Royal College guidance when arriving at his professional medical opinion that no further attempt should be made to intubate and invasively ventilate Y and no further attempt should be

made to resuscitate Y should she go into cardio-respiratory arrest. Whilst the guidance is not binding on the court, as Hedley J stated in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* with respect to the previous iteration of the guidance, it is guidance that is entitled to the closest attention and deep respect.

43. Finally, it goes without saying that these are immensely difficult cases for all involved, even more so when the decision to be made must be made as a matter of urgency. Whilst they are decided within a formal legal framework designed to ensure a decision is made in accordance with the best interests of the child it is important to remember at all times that the issue at hand is an intensely human one which engages a multitude of social, moral and ethical considerations. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

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

DISCUSSION

44. The ‘Out of Hours’ service is provided for applications that are considered to be urgent. The term ‘urgent’ in this context means that an order is required to regulate the position between the moment the order is made and the next available sitting of the court.

45. It should go without saying that, ordinarily, decisions of the gravity of that with which the court is currently concerned should be taken at a hearing in normal court hours and that the ‘Out of Hours’ service does not represent the ideal ‘venue’ for the same. Of course, exceptionally, there will be cases where the court has no option but to make a substantive decision out of hours to ensure the best interests of the child are safeguarded.

46. In the circumstances, at the commencement of the hearing I pressed Mr Hallin on whether this was a case that was so urgent that it required me, exceptionally, to determine an application of this nature by telephone in circumstances where, whilst having some notice of the proceedings, the father appeared before the court in person representing himself and the mother and where, whilst Ms Logan from Cafcass Legal had kindly agreed to act as advocate to the Court, there had been no time for a wider welfare investigation to take place.

47. Having considered the submissions of Mr Hallin, those of Ms Logan and having given the father the opportunity to make representations on the issue, I reluctantly came to the conclusion that the matter was sufficiently urgent to justify the court proceeding to determine the application pending the matter being able to return to court during normal hours. My reasons were as follows.

48. It seemed to me that the difference of opinion between the parents and Y’s treating clinicians was one that was both real and firmly established in nature and was one which, if not resolved, could impact adversely on Y’s best

interests by diverting the attention of the doctors, and indeed the parents, away from exclusive focus on Y’s needs at a highly critical juncture.

49. Further, and crucially, it seemed to me that the established difference of opinion between the treating clinicians and the father could come to assume acute significance at any point during the course of the night, and before the next available court hearing, in circumstances where intubation and invasive ventilation and/or CPR were the only means of preventing Y’s death, and where the evidence tended to suggest that there was, at best, significant uncertainty over whether, and at worst a real possibility that Y would die during the night. In such circumstances the difference of opinion needed resolution as a matter of urgency.

50. I was also satisfied that the difference of opinion was one that required resolution by the court. Whilst it is the case that a doctor cannot be compelled by a parent (and cannot be compelled by a court standing *in loco parentis*) to pursue a course of treatment that they consider not to be clinically justified, this case involved some subtlety in that the procedure that the father was seeking to persuade the doctors to take in this case was one that the doctors had to concede would prolong Y’s life, notwithstanding that the doctors felt this not to be in the child’s best interests. In such circumstances, the father firmly believed his position to be the correct one and the doctor felt, understandably, uncomfortable in simply overriding the express wishes of the parent.

51. Finally, having regard to the matters set out below, in circumstances where I was satisfied that it was in Y’s best interests at that point to make the

declaration sought, to have delayed that decision by some 12 hours until the matter could come back before the court during regular hours would have risked the very consequences for Y the court had concluded that it was in her best interests to avoid.

52. In reaching my decision yesterday evening I of course had regard to, and took into account, the intrinsic disadvantages of determining this matter by way of a telephone hearing out of hours. Those disadvantages included the absence of legal representation for the father, the absence of an opportunity for a wider welfare assessment and the absence of a second medical opinion on the specific issue before the court.

53. However, I was satisfied for the reasons articulated above that, on balance, Y’s best interests, which are my paramount consideration, required me to make a decision yesterday evening in order to govern the position between then and when the matter could return to Court. I was of course acutely aware that, in circumstances where there was a real possibility that Y would die before the matter could return to Court that the declaration I made would be final by default.

54. As I have already made clear, having heard from Dr E and from the father (as summarised above) and having listened carefully to the submissions of Mr Hallin, Ms Logan and the father, I was persuaded on the evidence then available to the court to grant the urgent declaration sought by the NHS Trust. My reasons for reaching that decision were as follows.

55. The sanctity of life is a fundamental, indeed sacred, principle from which there flows a strong presumption in favour of a course of action that will prolong

life. That presumption is not however irrebutable. That it is not recognises that life cannot be, and indeed should not be preserved at all costs in the face of its natural conclusion.

56. Life has unique value and it was important at the outset to recognise the value of Y’s life. It is valuable in many contexts. Y’s life is of course valuable to her. It is also very evidently valuable to her parents. It was plain from listening to the father how precious he and the mother consider the life of their daughter to be. It was also important to recognise that Y’s life is valuable because it adds to the collective human experience. Thus Y has a unique worth to herself, to her parents and intrinsically. Within this context I recognised that, all other things being equal and if competent to choose, Y would choose to live.

57. Within this context it could not be said in this case that the quality of Y’s life is one that must inevitably be assessed as poor. She has, as Dr E conceded, a good quality of life from her perspective of having a loving and supportive family who were acutely concerned with her wellbeing and are diligent in seeking to ensure that everything that can be done for her is done. Neither, having regard to the history given by the father, is the burden of Y’s disability one that has, prior to the episodes of cardio-respiratory arrest in March and April this year, resulted in Y having a poor quality of her life.

58. It was also important in this case to recognise the significance of the wishes of the parents of Y. As already noted, Y has the benefit of parents who are advocating strongly on her behalf that treatment that it is conceded will prolong her life should be given to her. The views of the parents must be

accorded great respect. The manner in which the views of the parents are treated in this case however also required a degree of caution.

59. As set out above, the parents believe that a further period of intubation and ventilation will result in Y recovering to the position she was in prior to her cardio-respiratory arrest in early April. No criticism whatsoever could be levelled (and no one seeks to level criticism) at the loving parents of a child who, having seen a series of treatments administered by doctors save the life of their child once, struggle then to understand why doctors now believe that it is no longer in the child's best interests to repeat that treatment when their child once again becomes mortally ill.

60. Forensically however, I was concerned by the father's apparent lack of understanding of the reality of Y's situation. At one point in seeking to justify the use of intubation and invasive ventilation the father stated that this should be done so that "*she can go home, she can go to school, be with her brothers and sisters*". Whilst from a purely human perspective it was impossible to criticise the father for this hope, that his clearly expressed wishes regarding the treatment of his daughter are grounded in an entirely unrealistic view of what that treatment could achieve necessarily meant that as a factor in my evaluation of Y's best interests the weight to be attached to the parental view was diminished.

61. Finally, as already articulated, I recognised within the context of the presumption in favour of a course of action that will prolong life that in this case the treatment advocated by the parents would, as Dr E had conceded,

have had the effect of prolonging Y’s life, together with the value and the positive qualities that life has as recounted above.

62. However, in addition to the matters I have recited over the course of the last number of paragraphs which tended to weigh against the declaration sought by the Trust there were in this case, and very sadly, considerable and weighty factors on the other side of the balance sheet.

63. I accepted that Y’s current quality of life was now very poor from a medical standpoint. Y has an incurable neuromuscular disease, which disease places a heavy burden on Y by virtue of the manner in which that condition has been exacerbated by her recent deterioration and by virtue of the nature of the invasive medical treatment that is now required to keep her alive.

64. Within this context, whether the medical treatment contended for by the parents would represent an unacceptable burden for Y in the sense of causing her pain was difficult to establish on the evidence before the court. It was unclear in this case, due to her stark neurological deterioration, how aware Y was and whether she could feel pain or psychological distress (although, if she could, the evidence was that pain and psychological distress would be the result for Y of intubating and invasively ventilating her).

65. Notwithstanding this lack of clarity however, I was in any event satisfied on the evidence then available to the court that intubating and invasively ventilating Y again yesterday evening constituted a treatment from which Y was likely unable to derive benefit.

66. On the evidence then available to the Court, and in particular the evidence concerning Y’s current neurological state and the cause of the same, I was satisfied on the balance of probabilities that it was an unrealistic aspiration to believe that the treatment proposed by the parents would lead to any discernible improvement in Y’s overall prognosis, let alone the kind of improvement that the father hoped for. Such treatment would, I was satisfied on the evidence then available, prolong Y’s life but would likely not alter her prognosis. As such, Y would derive little or no benefit from the treatment contended for by the parents.

67. Further, I was also satisfied on the evidence then available to the court that if the parents’ course of action was preferred, the evidence before the court was clear that, following an episode of deep sedation in order to secure intubation and invasive ventilation, the likely outcome was an increasing cycle of intubation and extubation leading eventually to the need for permanent intubation and artificial ventilation. Thereafter the likelihood was that Y would be confined permanently to a paediatric intensive care unit. This would be the position for an unquantifiable period. Further intubation would also have a detrimental effect on the health of Y’s lungs.

68. Within this context I was satisfied on the evidence currently available that were the treatment contended for by the parents to be administered not only would it likely result in no benefit but would likely result in the imposition on Y of a grave, and ultimately irreversible, burden of treatment that could not be said to be in her best interests.

69. Finally, in my judgment an additional and important factor in the many factors I had to consider when deciding whether to entertain the treatment contended for by the parents is the dignity of Y. That is not to say that the parents had not considered her dignity but rather to recognise that the court should, in cases of this nature, consider the dignity of the child as a human being.

70. When it is recognised that life is ending, for many the concept of dignity becomes encapsulated by the idea of a ‘peaceful’ or ‘good’ death. Within this context, a comparison between the course advocated by her treating doctors, of being allowed to die peacefully if that is the natural course that her condition follows, and the course advocated by her parents, of further aggressive invasive treatment that is likely only to lead to her being kept on an artificial ventilator until a decision is taken to withdraw such treatment, led in my judgment to a clear conclusion. Namely, that the course favoured by Y’s doctors was the one most likely to ensure that Y enjoyed the greatest level of dignity and endured the least burden (not least because, as Dr E made clear, such a course would allow the parents to be physically much closer to Y than if she was intubated and invasively ventilated at this point).

CONCLUSION

71. The impulse to preserve life is a strong one, not only in parents of sick children but in us all. Overall however, in the circumstances described above and having regard to all of the evidence then available to the court, to the strong presumption in favour of prolonging life and to Y’s best interests as my paramount consideration, I considered that further aggressive invasive

treatment yesterday evening, even if necessary to prolong her life, could not be said to be in Y's best interests.

72. In my judgment it was not in Y's best interests at that stage to embark on a course of intubation and invasive ventilation that was likely only to lead to this little girl being artificially kept alive on a ventilator for an indeterminate period of time.

73. This meant that an action that would prolong Y's life would not be taken. I was however satisfied that the burden imposed on Y by taking such an action would significantly outweigh the benefits that would accrue to her by thereby prolonging her life.

74. Given that conclusion, and the likelihood that taking the action contended for by the parents yesterday evening would result in the commencement of the irreversible cycle of treatment described above being instigated, I was satisfied that the declaration sought should be made as a matter of urgency in circumstances where, at that point, the evidence was that death was likely imminent and the course of treatment I had found not to be in Y's best interests was the only means of prolonging her life.

75. For those reasons I made the order sought by the NHS Trust in the terms described at the outset of this judgment. I also joined Y as a part to the proceedings and invited Cafcass to appoint a practitioner from the Cafcass High Court team to act as Y's Children's Guardian.

76. Finally, I listed this matter for a further hearing before me. I was of course mindful of the observations of the Court of Appeal in *Wyatt v Portsmouth*

NHS Trust [2006] 1 FLR 554 at [117] deprecating the court getting into a situation whereby it revisits declarations made on the basis of a particular factual situation at a particular point in time, it not being the function of the court to oversee the treatment plan for a gravely ill child.

77. However, and whilst entirely satisfied that the declaration sought should be made as a matter of urgency, given that this hearing took place by telephone 'Out of Hours' in less than optimum circumstances, given that the father had not at that stage had the opportunity to obtain legal representation and given that Cafcass had had no opportunity to undertake a wider welfare analysis, it seemed to me that the justice of the case required the matter to return to court during normal hours for the Court to further consider the declarations made on an urgent basis. In the circumstances, I listed a hearing before me on 26 June 2015 at 10am to enable the father time to obtain legal representation and to have the services of an interpreter and to enable Cafcass to undertake some preliminary welfare enquiries.

POSTSCRIPT

78. The matter came before me for directions on 26 June 2015. Y remained alive but her condition was unchanged and critical. The Trust provided an updating report from Dr E setting out further details of the second opinions that had been provided by Professor Bush and Dr Jungbluth. The report detailed the continuing view of the treating clinicians that intubation and invasive ventilation remained entirely inappropriate. The Trust contended that the court had sufficient evidence to make the orders 'final' and sought the continuation of the orders made during the 'Out of Hours' hearing.

79. Ms Logan provided a Position Statement to the Court detailing the welfare enquires undertaken by the Children's Guardian. Having undertaken welfare enquiries and having visited Y in Hospital, Mrs Odze from the Cafcass High Court Team was of the view that the declarations made 'Out of Hours' were properly made and should continue. The Children's Guardian was however concerned to ensure that an updating second opinion was obtained from Professor Bush confirming Y's current respiratory position.

80. The father attended the hearing represented by counsel, Ms Clark. Due to an administrative error on the part of the court, an interpreter was not available at the hearing. Ms Clark however confirmed that, as had appeared to be the case at the 'Out of Hours' hearing, the father had a strong accent but a good command of English. He was content to proceed without an interpreter.

81. Having had an opportunity to take legal advice, the father agreed that the declaration that it was lawful and in Y's best interests not to receive CPR and resuscitation drugs in the event of cardiac arrest, and the declaration that in the event that Y became severely distressed and / or was in pain due to further deterioration of her medical condition, it was lawful and in her best interests for her to receive pain medication and / or sedation for the purpose of relieving her pain and or distress, were properly made and should continue.

82. The father however continued to contend that Y should, albeit now for a defined and limited period, be intubated and invasively ventilated in order to determine whether such treatment would be effective. In the circumstances, Ms Clark contended that before making the declaration as to endoctrachael intubation and invasive ventilation 'final' the court should secure updated

second opinions from both Dr Jungbluth and Professor Bush. Ms Clark recognised that both Dr Jungbluth and Professor Bush had been involved in the treatment of Y but made clear that the father did not seek second opinions from independent medical experts.

83. Given the remaining issue between the father and the Trust as to the efficacy of a time limited period of intubation and invasive ventilation, given that the question of the efficacy of such a time limited procedure turned on the question of the respiratory and neurological consequences of the same and in circumstances where the second opinions Dr Jungbluth and Professor Bush were given on 10 and 13 April 2015 respectively based on Y’s situation at that time, having heard the parties’ respective submissions I directed that the Trust request updating reports from Dr Jungbluth and Professor Bush and listed the matter for final hearing before me on 2 July 2015.