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: FD17P00032

Neutral Citation Number: [2017] EWHC 241 (Fam)

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 14/02/2017

Before:
MS JUSTICE RUSSELL

- -

Between:

GREAT ORMOND STREET HOSPITAL FOR CHILDREN FOUNDATION NHS TRUST	**Applicant**
- and -	
NO & KK	**1st & 2nd Respondents**
and	
MK	**3rd Respondent**

- -
- -

Ms Susanna Rickard (instructed by in-house legal team at Great Ormond Street Hospital for Children NHS Foundation Trust)) for the **Applicant**
Ms Ruth Cabeza (instructed by direct access) for the **1st and 2nd Respondents**
Miss Shabana Jaffar (Cafcass Legal**) solicitor** for the **3rd Respondent through her Guardian, Kay Demery**
Hearing dates: 6th February 2017

- -

Judgment

The Honourable Ms Justice Russell DBE :

Introduction

1. Great Ormond Street Hospital (GOSH) for Children NHS Foundation Trust (the applicant) has made this application for a declaration that it would be lawful and in the best interests of the subject child MK for her a) not to receive or have given invasive or aggressive treatment in the form of cardiopulmonary resuscitation, inotropes, intubation and mechanical ventilation; and, b) not to have the insertion of intra-osseous needles, central venous-lines and further chest drains. Her parents the 1st and 2nd Respondents do not agree to this declaration being made. MK who is now almost 8 months old (she was born on 9th June 2016) is represented by her own solicitor and has a court-appointed guardian.

MK's condition and medical history

2. There had been a pre-natal diagnosis of hypo-plastic left-heart syndrome; this is a condition where the left side of the heart is not developed properly and there is only one pumping chamber. MK had another condition which complicated and compromised her health overall, restrictive atrial septum, when there is a significant obstruction to the blood coming to the lungs. The condition carries a very high risk of mortality and for this reason it was recommended that there should be termination of the pregnancy or comfort care after birth. The parents chose to proceed with the pregnancy.

3. MK underwent the first planned stage of surgery on 11th June 2016 at her parents' request. The surgery was extensive and required a reconstruction of the aorta, an enlargement of the hole between the top chambers of the heart (the atria) and a connection of a tube between the right pumping chamber and the long arteries. It was planned that this would allow the baby's lung arteries to grow until she was 4 or 5 months old at which point the second stage of surgery could be carried out. Following this MK was very unwell on the intensive care unit (ICU) and spent a prolonged period on artificial ventilation (either through ET or optiflow). She was then transferred to the high-dependency unit, but remained fragile requiring several re-admissions to ICU in GOSH before being discharged to the Chelsea and Westminster Hospital on 1st September 2016 where she remained as an in-patient. She was re-admitted to GOSH because of clinical deterioration on 21st September 2016 and discharged home on 13th October 2016.

4. During follow-up examinations on 28th October 2016 it was apparent that the lung arteries had not grown and remained very small, in addition to which the hole between the two pumping chambers had partially re-closed and the connecting tube looked slightly narrower. There followed further surgical intervention on 9th November 2016 to enlarge the hole and replace the tube. Despite an initial improvement in oxygen levels sadly, after this second surgical intervention, MK suffered complications; fat fluid draining from the lymphatic system (Chyle) accumulated in the space around her lungs requiring the placement of chest drains to remove the fluid which remained in place for prolonged periods. If left the resultant compression of the lung would have prevented the baby from breathing. In order to manage this symptom nutrition was put directly into a vein to stop feed going into the stomach.

5. To do this a central venous line (or PICC line) was inserted requiring MK to undergo a further general anaesthetic and to receive pain relief. The line became infected with propagation of the infection to the blood and the creation of large clots in the veins in the baby's upper body, problems with the blood flow and puffiness to the face and eyes. MK has had to been injected twice a day with an anti-coagulant Deltaparin in the subcutaneous tissue in her legs. This, in itself a painful procedure, requires a rotation of the injection site as the skin is often left bruised and/or bleeding. MK is caused great distress by the injections, which she anticipates becoming increasingly upset. The staff are aware that the injections are painful because they have been told this is so by older patients. MK is very distressed and difficult to console after these injections every day. As her blood has to be tested to monitor the drug she has her heels pricked at least once a day; and, when her central venous line was not functioning properly, she had her heels pricked up to four times each day.

6. MK had had several clinical deteriorations requiring urgent intubation, ventilation and transfer to the ICU for a variety of reasons including infections, re-accumulation of fluid round the lung or generalised fluid retention. On 1st January she narrowly escaped intubation and mechanical ventilation but had to be treated with a significant escalation of non-invasive ventilation. Fluid retention round the lungs is being controlled with very high doses of diuretic medication which are administered intravenously. The chest tubes have been removed. On the 1st February 2017 MK was re-admitted to the cardiac intensive care unit where she was receiving help with a high pressure of air (50% oxygen) pumped into her nostrils. It is the view of her treating cardiologist, from whom the court has heard, that MK's overall condition has deteriorated.

7. The most significant problem following surgery in November 2016 is that the lung arteries have not shown any signs of growth. This means that no further surgery can be carried out. The expected clinical course in a patient with MK's condition is for her condition to progressively deteriorate in a short amount of time, between a few days to several weeks. The medical team treating MK discussed the case at a joint surgical meeting and the consensus was that there were no further surgical options for MK. At the request of the respondent parents the applicant asked for further opinions from two renowned centres in the UK, Evelina Children's Hospital in London and the Birmingham Children's Hospital, as to whether any further surgical options were available for MK. In a response dated 28th December 2016 Evelina said *"We feel no further procedures can be realistically offered and would counsel for compassionate care."* In a letter dated 23rd December 2016, following a JCC meeting, a consultant paediatric cardiologist from Birmingham responded *"We unanimously felt the branch pulmonary arteries were too small to consider a cavo-pulmonary anastomosis and that the procedures you have already performed were the right procedures for [MK]. Very sadly we agree that there is no clear intervention that would help her further and we would support your plan for comfort care."*

8. All the medical opinion is that MK is not in a clinical position to receive any further surgical treatment and she is destined for an early death because of progressively lower oxygen levels with the likely occurrence of superimposed deterioration. The clinical team at GOSH considered that MK has no prospect of any good short or medium term outcome and that undertaking any invasive or aggressive treatment in the form of cardiopulmonary resuscitation, intubation and mechanical ventilation,

placement of an intra-osseus needle (which would have to be placed into the baby's tibia either by force or with the aid of a drill), placement of central venous lines (which require general anaesthetic) and placement of further chest drains would not be in her best interests. They accepted that a chest drain in the case of clinical deterioration could create some symptomatic improvement but that it would expose the baby to the pain of the procedure and the continuing pain of the drain itself, and to the risk of infection which would ultimately result in rendering her more fragile and prone to further deterioration.

9. The clinical team considered that it better met MK's best interests to offer her peripheral venous lines, antibiotic treatment (orally and intravenously), feeding by naso-gastric tube, intravenous fluid administration and total parenteral nutrition (artificial nutrition given through the blood stream) if central venous access remained present but not to place a new central venous line for that purpose. They would increase oxygen through a face mask and give MK palliative or comfort care to try to ensure that MK was not distressed or in pain at any time. Having discussed their recommendations with MK's parents it was clear that MK's parents felt MK should be given any procedure available if that would prolong her life for one day. MK's case was considered by Evelina Children's Hospital where her case was comprehensively reviewed previously. The above approach of GOSH was, in the opinion of Evelina, very rational and they said *"we fully endorse it."*

MK's current condition

10. When this case came before me on Monday, 6th February 2017, having previously been before Parker J on 24th January 2017, MK had been in a relatively stable condition for the intervening period, but the weekend of 4th & 5th February she had been moved to the ICU because she needed intensive care. Dr Giardini, who had seen MK at 08:15 that morning, told me that they had cut back her medication as much as they could but had had to increase the diuretic as she had an increase in fluid retention (the diuretics are given intravenously). The fluid retention had affected her ability to breathe and she was breathless; breathing at a rate of 63 per minute (it was explained that an adult would breathe at a rate of 30+ after strenuous exercise. MK was being given air through the optiflow and the amount of oxygen had been increased to 50%. The oxygen levels in her blood were dropping which means that her brain is not receiving sufficient oxygen.

11. I was told that over the past few days MK had become very unsettled and irritable as a result of the deterioration in her condition; she was suffering from loose stools and was retching and vomiting with feed. There were signs of an alteration in her kidney function, with low potassium being observed and there was a high risk of cardiac failure which was a continuing risk. The frequency of vomiting was similar to that of a younger baby and was as a consequence of the extensive surgery she had had and her poor condition generally. Dr Giardini said that the central venous line through which she was being given diuretics was still working but that it was "limping" and needed adjustments to keep it functioning. These lines were meant to last for 6 to 8 weeks but this one had been in situ for 10 weeks. To replace it would necessitate a general anaesthetic, which carries considerable attendant risks on its own, and, together with the invasive nature of the surgery required the high risk to MK of failure outweighs any possible advantage to be gained by having a functioning intravenous line in place.

12. The doctor was asked a good many questions about the central venous line and it was suggested to him that it could be utilized to provide treatment in the event of cardiac arrest or to put in place a chest drain. In respect of the former, Dr Giardini said that if the central intravenous line was not working or ceased to function it would mean that access would be through an intra-osseus needle; either by force or by using a drill to get into the bone marrow. If it was a case of cardiac arrest, then there would not be time to wait for anaesthetic to act so that MK would suffer pain in addition to that she was already suffering. CPR would involve cardiac massage applying force on an infant who has already had her chest opened several times; it was, he said more likely not to be successful than to be successful and there was less than a 50% chance of resuscitation. Even if this baby did survive she would be weakened and would be likely to deteriorate again, only to have another cardiac or pulmonary arrest.

13. When cross-examined on behalf of the first and second respondent Dr Giardini said that the central venous line could not be used for two treatments at once; so, if MK had the chest drain replaced the line could not be used to give her the high doses she currently needs of diuretic which she needs to combat fluid retention; the antibiotics to counter infection and morphine to deal with the pain caused by the procedure. The baby would have to have a general anaesthetic if a chest drain was to be inserted; this painful procedure is one during which the recipient/child requires intra-venous morphine to be administered usually over a period of 3 to 4 days. MK's parents suggested that if there was a chest drain there would be no need for diuretics but the doctor explained to the court that there would be not only the risk associated with administering a general anaesthetic but other attendant risks such as that of penetrating a lung which would be fatal; there is fluid retention at every level, not just in the lung, and the drain would cause so much fluid loss that her condition would be seriously compromised by losing lymphocytes and proteins associated with clotting and her immune system. This would be another body going into circulation which would not just double the risk of clotting but produce a very high risk of further clotting. Dr Giardini was visibly anxious and concerned that he could not countenance the child undergoing such procedure for no good reason.

14. The doctor explained that they could not predict the life span of MK with any certainty, but that MK was on a moving course towards death and that the team had been very worried over the past few days. Some of her symptoms had worsened, such as her respiratory rate and some had been more stable. He accepted that her heart rate had been one such variable, but it was, he said not an accurate reflection of where the child was on her trajectory towards her death to consider any aspect of her condition in isolation when all variables were going in the same direction. MK was very unsettled and irritable as a result of her increased respiratory rate and the low level of oxygen in her blood. He did not think she was picking up her parents' anxiety as she was in the same state when they were not there and was too young (at barely eight months) to continue to react to anyone's mental state when they were not present. It was his evidence that MK's death could come at any time and that she was unlikely to survive for more than a few weeks at most.

Applicant's position

15. It is the applicant's case that to subject MK to further painful and invasive medical interventions in circumstances where her death is both imminent and inevitable will confer on her no medical benefit, cause her unnecessary pain, suffering and distress

and would not be in her best interests. The applicant has reached the decision that reorientation to palliative care would be in the best interests of the infant. The decision was reached after a meeting of the treating physicians and medical professional responsible for her care had taken place and that decision was reviewed by Evelina and Birmingham Children's Hospital. Her parents do not accept that such interventions, which they believe may prolong MK's life even if only for a very short time, should not be undertaken by the medical team. Their position is wholly understandable, as is the fact that they believe to make such a declaration now is premature and that any decisions should be made in consultation with them when MK's condition deteriorates and should be dependent on the extent of the deterioration of her condition. Equally understandable is their desire to latch onto specific symptoms and treatments in isolation in which they find some hope, but the fact is that MK is a very sick baby and the court must consider her condition as a whole as part of its consideration of the totality of her best interests: the term "best interests" encompasses medical, emotional and all other welfare issues; (see Re A below). In doing so I keep in mind that the court must exercise its own independent and objective judgment.

16. There is no conflicting medical or nursing evidence or opinion, nor have the respondents sought to adduce any. The court heard from the responsible treating cardiologist from GOSH. Dr Alessandro Giardini. The court also heard from the Staff Nurse from GOSH who is the designated link for end of life care and family support and a member of the Clinical Ethics Committee. She had prepared a "benefits and burdens table" based on the clinical notes and the input from the nurses responsible for directly caring for MK in hospital; the table was appended to her statement dated 23rd January 2017. The parents have responded to that table in their joint statement dated 3rd February 2017. I shall return to this below.

1st and 2nd Respondents' position

17. Entirely understandably, from their perspective, MK's parents want their daughter to survive and be with them for as long as possible. They accept that she will die soon but say that how soon cannot be accurately known; indeed, there is not any dispute about the fact that MK's death cannot be precisely predicted. Her parents say that she has survived longer than was anticipated by any of the clinicians and that they believe that she will continue to live for longer than the few weeks predicted by her doctors. It is their case that it is in her best interests for her life to be prolonged by use of the procedures that GOSH seek to withhold. They point to the positives in her life and say that she can and should continue to enjoy her life and if that means she has to endure the pain which would be part of the invasive and aggressive life-saving procedures, such as CPR, then it is worth it and in her best interests if they allow her to survive for longer no matter how short a time.

18. At the hearing on 24th January 2017 the parents asked for updating scans of the pulmonary arteries to establish whether there had been any change and/or improvement and/or deterioration. A cardiac ultra-sound took place on 26th January and the results, contained in Dr Giardini's second statement, are that there has not been any increase in growth of the pulmonary arteries.

Law

19. There is no dispute as to the law. The decision is one of best interests. The court is being asked by the applicant to make an order that certain treatment is to be withheld. In principle it is the responsibility of parents to make decisions on behalf of their child, including any consent to medical treatment or, as in this case agreeing for some treatment to be withheld. When, as here, parents do not agree with the proposed treatment or withdrawal proposed by the clinicians responsible for their child's care, the court can intervene and overrule their refusal even if it could not be said to be unreasonable *(Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242; guidance as to how the court should exercise that authority was set down by the Court of Appeal in *Wyatt v Portsmouth NHS Trust* [2005] EWCA Civ 1181 [87]; *"In our judgment, 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 irrefutable (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) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A)".*

20. The law is well established and there is no need for extensive reference to authority and case law. A dispute has arisen between the hospital and the parents and because of that the hospital applied to the court to make a decision, this jurisdiction can only be exercised in this case because MK as an infant child, lacks the capacity to make a decision for herself. This decision must be taken by applying an objective test in order to determine what is in the best interests of the patient, in this case MK. When considering her best interests, I include her medical, emotional, sensory perceptions (these in turn include her ability to give and receive love and affection, her pleasure, enjoyment of her surroundings, and her pain and suffering) and the human instinct to survive and prolong life; 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 so in the patient.

21. Notwithstanding the strength of that presumption, expressed by Lord Donaldson of Limington in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33, it is not absolute, as he said; "*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."*

22. In this case, as in all such cases, the decision is wholly based on the specific facts of the individual case. The views and opinions of the treating clinicians and medical professionals and the parents must be carefully taken into consideration. The parents have spent a great deal of time with their child, their views have particular value because they know MK so well; but I keep in mind that the view of any parent is

likely, however understandably, to be coloured by her or his own emotions, feelings and beliefs. The wishes of a parent may serve to inform and provide explanatory background as to the quality of the child's relationship with her parents but it is not necessarily relevant to an objective view of the best interests of the child.

23. I note too, the limitations of the court's powers as applied by MacDonald J in *Re Y (No 1)* [2015] EWHC1920 (Fam) at [34] of his judgment *"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."* Later he said [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).*"

24. In the case of *Re A (A Child)* [2016] EWCA Civ 759, to which I have made reference above, the Court of Appeal confirmed the law in this area while requiring great sensitivity and care, can be summed up in two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC67, [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."* At [39] she continued; *"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"*

MK's Best Interests

25. In considering MK's case specifically I start by looking at the positive side of her life. Her guardian spent just over 3 hours on Bear ward prior to this hearing and had the opportunity to observe MK in the care of both of her parents. Her mother was holding her in her arms when the guardian arrived and she appeared to be sleepy. The guardian said how beautifully dressed she was and remarked on her lovely blonde hair and long eyelashes. When her father arrived MK recognised him, he kissed her and her eyes followed him and she smiled. The guardian observed MK was able to sit up, control her head, roll over to her side and reach for toys. MK was put in her high chair which she seemed to like, while her parents spoke privately with the guardian. She also had a visit from her godmother. Her guardian saw from her mother's gentle interaction with her baby, and father's apparent love and affection for MK as he

kissed and held her, that it was obvious that MK is a much loved and cherished baby. In her position statement the guardian said it was clear to her that MK is a baby who enjoys the time she spends with her family. She said, *"It is acknowledged by the nurses that she is a responsive, inquisitive and smiley baby and that all the nurses enjoy making a fuss of her."*

26. In addition to being MK's guardian and making welfare recommendations on behalf of this vulnerable baby, the guardian was able to give the court an independent and objective view of MK's situation. It is her parents' view that the current situation is one that MK tolerates reasonably well. Nursing staff told the guardian that the baby is not in constant pain but that the administration of twice daily injections is painful and distressing for the child. There is, she said, no reason to suppose that MK's cognitive abilities are impaired; although it is likely, having been in hospital for all but two weeks of her life, that MK is developmentally delayed. MK can see, hear and touch and responds to stimulus when her parents and her carers play with her. She is said to grab her parents' noses. She has been introduced to pureed food orally which is a new experience and seems to enjoy the taste of bananas, but she receives her nutrition through the Nasogastric tube (NGT). She is able to play and watch television. The parents try to ensure MK is rarely alone and she is said to enjoy company. It is the guardian's view that it is *"when her medical status declines that an advance decision needs to be made about what is in her best interests."*

27. It is clear that MK has an extended family that she recognises and, when they visit, she gets comfort and pleasure from their company as evidenced by her facial expression and general demeanour. MK's parents have employed nannies to provide care for the baby when they are not able to be there. She enjoys the company of others and is happy to see anyone who enters her bed space. MK is able to turn her head from side to side and is therefore able to relieve any positional discomfort in her head as well as track the activity going on around her. She can sit up, reach for toys and roll on to her side; but not on to her stomach, as a baby of her age would usually be able to do. MK communicates at a level appropriate for her age, smiling and babbling when happy and crying and grimacing when distressed. When she is stable she appears to be content for long periods of time. MK enjoys, and is happily distracted by, watching the television and listening.

28. To turn to the negative aspects of MK's existence, I start with the central intravenous line in place for the administration of drugs and fluids. MK is now able to have milk feed directly into her stomach via a NGT which means that although she gets no satisfaction from taking the milk by mouth MK is comforted by not being hungry. MK has remained stable for a period of weeks and had been transferred to Bear High dependency Unit as a step down from intensive care, however she is now on the cardiac ICU, again because of the deterioration in her condition.

29. The overwhelming nature of her condition means that MK has had, and continues to have, many burdens in her short life. She has had an infection in her stools which meant she was isolated from the other patients for some time and was placed in a cubicle on Bear ward until she was clear of infection limiting the number of visitors she has and meaning she had to spend periods of time on her own. MK is unable to roll on to her stomach or roll right over unaided, because of general weakness from prolonged illness, and from being oedematous. She is dependent on nursing staff and her carers to change her position regularly to prevent pressure sores and the attendant

discomfort of restricted mobility; she is likely to suffer positional discomfort despite regular repositioning by staff.

30. Reference has already been made to the fact that MK has been an inpatient in hospital for all but two weeks of her life, primarily in ICU or a high dependency ward (HDU) because of her terminal condition. The medication she is on (Vancomycin, Amikacin and Deltaperin), the changes in her renal function and the infection in her stools (which has caused increased levels of sodium and potassium in her blood) means that she can requires heel pricks every day in order to get blood samples. The results of the blood tests allow the medication to be titrated to prevent toxicity causing further damage to her kidneys, and ensure her "clot-busting" drugs are at the correct level (if it is too high there is an increased risk of bleeding; if too low, an increased risk of clot formation). MK's heels are becoming increasingly sore and this procedure causes her a great deal of distress despite measures taken to comfort her. There have been times when she has been having as many as four heel pricks every day, when the PICC line was not working as it should (it did not'bleed-back').

31. Thus she has constantly suffered the pain and discomfort of blood being taken for multiple blood tests, the insertion of many catheters, peripherally and centrally with the result that her veins have become damaged by scar tissue and thrombosis (clotting) making it very difficult to gain access and to take blood. In turn this has led to repeated, unsuccessful attempts to extract blood, which cause MK great distress because of the pain and acute discomfort. While the central venous line (PICC) now bleeds back, the fact that it has been in place for so long means that it needs to be physically re-positioned to continue functioning further restricting MK's movement and causing additional discomfort. Replacing the central venous line would require a general anaesthetic, a surgical incision and the line to be sutured in place; this procedure would be extremely high risk and is unlikely to be successful. I have made reference to Dr Giardini's evidence above and will not repeat it here.

32. MK is dependent on high flow oxygen to maintain her blood oxygen at an acceptable level, without which there would be insufficient oxygen reaching her brain. The court was informed that previously she received 4 litres per minute of flow with 35% oxygen, but that she is now receiving 50% oxygen as her condition has deteriorated. The air is delivered to her nose through small plastic tubes which are held onto her face with plasters, and, although she is able to tolerate the tubing well it can cause sores in the nose and the plasters affect the skin on the cheeks. As with all babies MK finds the tape and tubing irritating on her face and nose, she attempts to rub them off which means the dressing needs to be changed at least once a day. Her skin is often red but unbroken. Naturally, MK does not like having the dressing changed. The need to deliver air further restricts MK's mobility as she is required to remain in her bed space within the ward.

33. MK frequently vomits, which causes her distress and increases the risk of her inhaling gastric contents into her lungs; lungs which are already compromised by poor blood flow. The effects of fluid retention to which MK is prone are set out above, but, in addition it makes her puffy and her skin is stretched and tight and sometimes the point where she is unable to open her eyes. The fluid retention extends to her lung tissue causing breathlessness and the very rapid breathing rates discussed above. MK has requiring increased support with her breathing either through increasing the optiflow

(as at present) oxygen or by placing her on a ventilator. MK becomes very distressed and anxious when she becomes breathless.

34. There can be little doubt that the anxiety is a sign of fear. The fear induced by breathlessness is atavistic and experienced by anyone, no matter how young or old, who is left gasping for breath. The distress caused by the anticipation of the painful anti-coagulant injection is also an expression of fear, this time it is fear of pain. It would be remiss to overlook the fear that is inculcated in MK by the daily injections and her increased breathlessness. Repeated pain is seldom experienced in isolation, it is invariably accompanied by fear and to overlook the fear which is a recurring feature of MK's existence would be to deny the reality of her daily experience of life. MK is required to have twice daily injections of Deltaperin, which breaks down clots. As is alluded to above this injection is into the subcutaneous tissue, the site has to be rotated around her limbs to minimise repeated trauma to the same tissue. Her skin is often left bruised and can bleed for prolonged periods after the injection. These injections cause MK great distress and she anticipates the injection coming. In addition to which she suffers repeated and daily pin pricks to her heels.

35. MK is unable to play or take part in play and physical stimulation appropriately for her age, because of her fragility and weakness, and by the constant presence of lines. She does enjoy company and can hold and examine toys and, when well enough, is clearly interested in her surroundings. This limited ability to take part in the enjoyment of play and stimulation that any baby of her age would do will be further curtailed as her condition deteriorates.

Mechanical or artificial ventilation

36. To put in place artificial or mechanical ventilation will require the insertion of a tube, itself an invasive and risky procedure for a child who has already undergone extensive surgery, as the tube is inserted via the mouth or nose and not infrequently causes trauma, it usually requires the administration of anaesthetic drugs. The tube is held in place with sticking-plaster tapes which have to be changed frequently. Its insertion requires MK to be immobilized and sedated as it would unpleasant for her and she would move to avoid the insertion of the tube and should she move, the tube may become dislodged. The tube requires regular suction, which would involve MK being disconnected from the machine and being hand ventilated, a catheter is then passed into the tube to suck out secretions, babies and children find this procedure very distressing. In order to tolerate mechanical ventilation MK would require an infusion of sedative drugs.

37. As described by Dr Giardini this intubation would be being performed on an infant who is not in a condition to tolerate much more intrusion into her small frame which has already undergone such extensive medical intervention. The risk associated with general anaesthesia and the likelihood that her system would be overloaded by the introduction of yet another foreign body which would produce a very high risk of further clotting. In addition, mechanical ventilation would significantly reduce such quality of life that MK enjoys at present and cause an increase in her pain and suffering because of the invasive nature of advanced respiratory support.

CPR & chest drains

38. MK’s parents would wish CPR to be performed in the event of cardiac arrest or failure. CPR is rightly described as an aggressive act as the chest is compressed with such force that ribs may be broken. This court is aware that this is not uncommon when CPR is performed on infants and it is obvious that to have such trauma inflicted on MK whose chest has been subjected to open surgery make it less likely that she could tolerate the further intervention. MK’s condition is irreversible and as CPR is unlikely to be successful, it would ultimately be futile and is highly likely to significantly increase the suffering in her death. To perform CPR would mean that MK is likely to spend her last minutes alive surrounded by medical and nursing staff instead of being comforted by the people who love her and whom she loves.

39. Her parents also want a chest drain to be inserted. This requires an incision to be made in her chest to insert a tube between the ribs and into the space that surrounds the lungs, this tube is then moving with every breath that is taken. MK has already had extensive surgery to her chest. As Dr Giardini explained to the court in his evidence, all patients who have drains in require to be on morphine to make it tolerable. MK’s veins are very scarred, and in places clotted, so that the insertion of IV lines has become extremely difficult; on previous occasions multiple attempts have been unsuccessful. Access could be via intra-osseus needle either forcing or drilling a tube into the long bones in her legs or arms, but this is a short term solution and has to be weighed against the high risks involved which are likely to hasten if not cause fatality (see paragraph 13 above).

Conclusion

40. On behalf of MK’s guardian it was submitted that withholding the specific treatment set out in the application of the Trust would be in MK’s best interests. *“Resuscitation, intubation and mechanical ventilation and the associated procedures will, according to the medical evidence, cause significant pain and distress. It is also likely that mechanical ventilation if provided will, significantly reduce the quality of life that [MK] currently enjoys and will mean an increase in pain and suffering due to the invasive nature of advanced respiratory support. In [MK’s] case this will neither restore health nor confer any other benefit other than the prolongation of life itself. In these circumstances it is the guardian’s view that [MK] should not be subjected to further interventions other than those that are of a palliative nature.”*

41. MK’s guardian and her legal representatives had carefully considered the benefits to MK of receiving the treatment that her parents want in order to prolong her life. The conclusion that the treatments will not restore health is aphoristic but nonetheless true. MK cannot survive her condition and the decisions that have to be made about her treatment are made in that knowledge. Indeed, her parents were aware of it before she was born. In the absence of any medical opinion to the contrary the court accepts that the expectation is that she will die within days or a few weeks at most. She may live a little longer; there is no means by which her life expectancy can be precisely or accurately predicted. The court is being asked to consider what is in this child’s best interests for the very short time that is left to her.

42. There can be no doubt that MK is loved by her parents and that she loves them. She is, as her nurses say, a responsive, inquisitive and smiley baby and a delightful child

who makes the most of her world, limited as it is by her confinement in hospital. She is a child who has suffered and continues to suffer pain, distress and fear because of her condition and the perpetual treatment and care that she requires. She is a child who is dying and nothing can be done to reverse that process. All the treatments that her parents want her to have, for reasons which are set out in this judgment, carry with them a substantial or greater risk of contributing to her death or causing fatality given her already parlous condition.

43. Those treatments also carry with them the certainty of further considerable pain, suffering and distress. MK is very likely to feel fear and to be frightened by the procedures being carried out. It is most unlikely that she would want it to happen to her as the most that they might achieve is to delay her death by a very short time but in doing so she will be made to suffer very considerably when she could, and should, be allowed to end her life in as comfortable, pain-free and comforted condition as it is possible to achieve. There is a much greater likelihood of being able to achieve a relatively pain-free and peaceful end than there is of achieving anything other than very painful, frightening and ultimately futile intervention by proceeding with the invasive and aggressive treatments sought by her parents.

44. While the court can understand that MK’s parents wish the medical staff to carry out these procedures or treatment in an attempt to extend MK’s life the court is also aware that to do so is against the wishes of her doctors and her medical team for good reason; they are unlikely to succeed and will only cause elemental pain and distress for this baby who has already suffered so much. I have, as is set out above, considered all aspects of MK’s situation from her perspective in as much as it is possible for any court to do so. I conclude that the court should make the declarations sought by the hospital NHS Trust as it is not in MK’s best interests to carry out the intervention and invasive treatments which her parents seek; it follows that it is lawful for the treatments to be withheld.

45. This is my judgment.