Neutral Citation Number: [2020] EWHC 185 (Fam)

Case No: SE19C02423

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 05/02/2020

Before :

MRS JUSTICE LIEVEN

- -

Between :

ROTHERHAM METROPOLITAN BOROUGH COUNCIL

Applicant

and

ZZ

First Respondent

and

X

Second Respondent

and

ROTHERHAM NHS FOUNDATION TRUST

Third Respondent

and

SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST

Fourth Respondent

- -
- -

Mr Sam Karim QC (instructed by **Rotherham Metropolitan Borough Council)** for the **Applicant**
Ms Caroline Ford (instructed by **GWBHarthills LLP**) for the **First Respondent**
Mr Stephen Brown (instructed by **MKB Solicitors**) for the **Second Respondent**
Mr Simon Burrows (represented by **Ward Hadaway**) for the **Third Respondent**
Mr Conrad Hallin (represented by **Capsticks Solicitors LLP**) for the **Fourth Respondent**

Hearing dates: **4 December 2019**

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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MRS JUSTICE LIEVEN DBE

Mrs Justice Lieven DBE :

1. This is an exceptionally sad case that came before me on a very urgent basis in Leeds on 4 December 2019. I made the declaration sought by the Applicant and not opposed by any other party. I reserved giving reasons given the importance of the case, the fact that the hearing finished late and I was in the middle of another case. I set out my reasons below for making the declaration sought.

2. The declarations I made on 4 December 2019 were;

> *3. Subject to paragraph 4 below, it is lawful and in X's best interests:*
> (a) *Not to be resuscitated in the event of a clinical deterioration; and*
> (b) *Not to have his treatment escalated to high dependency or intensive care, in particular not to be artificially ventilated.*
>
> *4. For the avoidance of doubt, nothing in paragraph 3 prevents X's treating clinicians from providing care or treatment that they consider at the material time to be in his best interests.*

3. X was born unexpectedly at Rotherham District General Hospital on 6 October 2019. The mother was unaware of the pregnancy and therefore had received no antenatal care. The mother took the decision to relinquish care of X at birth. The mother was unprepared for motherhood, not knowing that she was expecting X. She felt it would be in X's best interests to grow up in an adoptive family. She agreed to X being accommodated by the local authority and gave consent pursuant to s.20 Children Act 1989 for X to be placed with foster carers on discharge from hospital with a view to subsequently giving her consent for him to be adopted.

4. The Mother told the local authority that X was conceived after a one night relationship, and she did not wish to name the Father. She was also adamant that she did not want her parents, with whom she lives, to know about X's birth. It seems that her mother did later find out about the birth because of a letter being sent to the family home.

5. It was following X's placement with foster carers that he was diagnosed with hydranencephaly. This is a rare congenital malformation where some of the brain hemispheres are not fully formed but are replaced by brain fluid. He has the brain stem and some of the deep parts of his brain but nothing else is formed. Because the brain fills with fluid to fill the void, it is necessary to fit a shunt in order to drain the fluid.

6. The mother attended a meeting at the Sheffield Children's Hospital on 24 October at which she met the consultant Patricia De Lacey and signed consent for X to undergo surgery to have his shunt fitted, which took place on 13 November.

7. Due to X's condition, the local authority's plan was no longer one of adoption and a s.31 application was issued on 11 November, followed shortly by an application under the Inherent Jurisdiction on 12 November. An interim care order was made at a hearing before Mr Justice Williams on 13 November. X remains in foster care.

8. By an application dated 12 November, the applicant local authority sought declarations in the inherent jurisdiction as to whether it is in X's best interests to be provided life sustaining treatment (including resuscitation) in the event of a clinical emergency. On 13 November, Williams J granted permission pursuant to section 100(3) of the Children Act 1989, and in doing so, made a declaration that it was:

> *"lawful and in X's best interests to be provided with life sustaining treatment (including resuscitation) in the event of a clinical emergency until further order".*

In addition, the Court made an interim care order of the same date and consolidated the proceedings, i.e. the care proceedings and the inherent jurisdiction proceedings.

9. The Rotherham NHS Foundation Trust and the Sheffield Children's NHS Foundation Trust were invited to intervene in this application and provide further clinical evidence.

10. The hearing before me on 4 December was listed to consider (a) whether the declaration should continue, be amended or discharged (b) further directions for the determination of this issue, and the (c) the role (if any) of X's extended family. Therefore, when the matter came before me it appeared that the two main issues I would need to determine were the Guardian's application for permission to instruct an expert, any other directions and what steps if any should be taken to identify the Father.

11. There were two medical statements before me. The witness statement of Patricia De Lacy (Consultant Neurosurgeon of Sheffield Children's Hospital) dated 28 November 2019, whose oral evidence I will refer to below. Her report stated that she was of the view that it would not be in X's best interests to be resuscitated "as he has a life limiting condition". The witness statement of Sundhar Kanagsabapathy (Consultant Paediatrician) dated 19 November 2019 states that X has a life expectancy of circa 12 months and that he is likely to have problems with feeding, seizures and chest infections. This clinician states that there is no "definitive curative medication or treatment", and that it would not be in X's best interests to be resuscitated.

12. However, on 30 November X was admitted to Sheffield Children's Hospital as an emergency. He had an infection in the shunt site and surgery was undertaken to remove the shunt that evening. X was being treated with antibiotics but I was informed that X's health had declined since Saturday and that he was experiencing fits and seizures.

13. At the time of the hearing before me X was extremely ill in hospital and had been experiencing seizures. In those circumstances the Applicant, supported by the Fourth Respondent (the treating hospital), asked me to make declarations in the form set out above. In the light of the change in X's condition since the reports were filed and the extreme urgency of the situation, I heard oral evidence from Dr de Lacey, the consultant paediatric neurosurgeon who had been treating X since shortly after his birth.

14. Dr de Lacey explained that X can breathe and control his heart rate, but he has no prospect of developing higher functions. She did not think that X could develop

hearing or vision as there was no structure linking his ears and eyes to his brain. She said that there was no prospect of improvement. She said it was not clear whether he could experience any pain. However, when the shunt was inserted he did appear to show irritability which was relieved by pain killers.

15. She said that the diagnosis was as certain as it was possible to be. It had been confirmed by an ultrasound which showed a large fluid space where the brain hemispheres should be. An MRI scan was then done which confirmed the diagnosis.

16. The shunt was needed because the skull plates were not fused and without any treatment the fluid would accumulate and the baby's head size would expand. This would not cause death but it would cause a problem in caring for the baby, because X would not be able to lift his head and he would get pressure sores. The purpose of the shunt therefore wasn't to save life but to alleviate symptoms such as pressure sores, possibly headaches and allow him to be optimally cared for.

17. Dr de Lacey explained that there was a high risk of infection from the insertion of the shunt. If infection occurs, as it had done, then that irritates the blood brain barrier and that is likely to cause seizures. She said that it was possible that the seizures caused pain or discomfort. However, she did also say that it was hard to assess pain in a young baby as they are likely to be more unsettled in any event.

18. The fact that X was having seizures presented a risk of deterioration neurologically, but he may also develop apnoea, breathing problems, and cardiac events. The fact that he was currently suffering from an infection and convulsions put him at high risk of further deterioration. Dr de Lacey said that there are different forms of seizures and they are not always easy to diagnose. Seizures can last for weeks or months but may in some cases resolve themselves.

19. In her witness statement Dr de Lacey had said that babies with X's condition rarely survived beyond a year. However, the condition is rare and therefore the information on life expectancy is necessarily small. This was at least in part because the condition would usually be identified during pregnancy and there would be a termination. She referred to the National Institute of Neurological Disorders and Strokes (NIDS), which recorded that most babies with hydranencephaly die before their first birthday. Reference was made to an Italian Journal of Paediatrics article in 2014 which recorded patients surviving into their 20s. I insert at this stage that it was wholly unclear whether the patients referred to in that article actually had the same diagnosis as X and it did not seem to me that I could place much if any reliance on this article.

THE LAW

20. Mr Karim QC and Mr Hallin, at my request, drew up an agreed note of the relevant law, and this is agreed by all parties. I am very grateful to them for their assistance on this. What I set out below is directly drawn from that agreed note.

21. Doctors are under a general duty to provide appropriate medical treatment, including life-sustaining treatment, to all patients under their care, including children.

22. It is accepted, however, that in certain situations, where it is in the best interests of a child, doctors can withhold or decline to initiate treatment, even where the inevitable

result will be the death of the child (see, for example, the Court of Appeal decision in Re B (a minor) (wardship: medical treatment) [1981] 1 WLR 1421; NHS Trust v MB [2006] EWHC 507).

THE 'BEST INTERESTS' TEST

23. In considering whether to make declarations rendering lawful the withholding of treatment to a child such as X the Court must weigh up the advantages and disadvantages of providing or withholding the various treatment options within that plan, and to balance them in order to determine where his best interests lie: Re J (a minor) (wardship: medical treatment) [1991] 2 WLR 140; 3 All ER 930; [1990] 2 Med LR 67.

24. There is no valid legal distinction between 'withholding' and 'withdrawing' life-sustaining treatment. The 'best interests' test applies to both situations: Airedale NHS Trust v Bland [1993] AC 789 at 866, 867 and 875.

25. When considering what is in X's best interests, the Court must exercise independent and objective judgment on the basis of all the available evidence (Re T (A Minor) (Wardship: Medical Treatment) [1997] 1 WLR 242).

26. There is a strong presumption in favour of the preservation of life, see e.g. In re M (Adult patient) (Minimally conscious state: withdrawal of treatment) [2012] 1 WLR 1652, paras 7, 220, 222. This does not displace the patient's best interests as the paramount consideration for the court.

27. The court will not order medical treatment to be provided if the clinicians are not willing to offer that treatment on the basis of their clinical judgment, see AVS and a NHS Foundation Trust [2011] EWCA Civ 7, per Lord Justice Ward at para 35:

> *"35… It is trite that the court will not order medical treatment to be carried out if the treating physician/surgeon is unwilling to offer that treatment for clinical reasons conscientiously held by that medical practitioner. The court's intervention is sought and is necessary to overcome a reluctance or reticence to undertake the treatment for fear that doing so would be unlawful and render him or her open to criminal or tortious sanction…."*

28. The Court's approach to X's best interests will necessarily be highly fact-specific and the courts have been slow to set definitive guidance on how to approach the 'best interests' test. For example, in NHS Trust v MB [2006] EWHC 507 Holman J said at paragraphs 106-107: 'this is a very fact specific decision taken in the actual circumstances as they are for this child and today… My sole and intense focus has been this child alone'. Nevertheless, in the same case Holman J provided a helpful summary of the principles in play when applying the 'best interests' test in such decisions, as follows:

[Where the] 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.

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.

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.

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

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.

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.

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.

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

29. As with determinations for medical treatment decisions under the Mental Capacity Act, when considering the best interests of a child under the inherent jurisdiction, medical best interests are not the only consideration. X's wider best interests (albeit including his medical interests) are determinative: Portsmouth NHS Trust v Wyatt [2004] EWHC 2247 and by analogy, Re MB (an adult: medical treatment) [1997] 8 Med 217 at 225 per Butler-Sloss LJ.

30. The key question is whether the treatment would be in the patient's best interests. In considering the same, relevant issues include, but are not limited to, whether the treatment would be futile, overly burdensome to the patient or where there is no prospect of recovery, Aintree University Hospitals NHS Foundation Trust v. David James and others [2013] EWCA Civ 65, per Sir Alan Ward at para 33.

31. Lady Hale in Aintree University Hospitals NHS Trust v James [2013] UKSC 67 also said that:

> *"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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."*

32. The views of doctors, other members of a child's care team and his parents should be taken into account to the extent that they touch upon the child's best interest, rather than their own interests or opinions.

ETHICAL GUIDANCE

33. The ethics of withholding or withdrawing life support are set out in a publication by the Royal College of Paediatrics and Child Health (RCPCH): "A framework for practice: Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (Vic Larcher et al, March 2015), which has superseded the previous guidance routinely used by practitioners and the Court : "Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice" (Second Edition) May 2004. This latest guidance provides, inter alia as follows in so far as it is relevant to X's case:

> *"**3.1.3 Situations in which it is appropriate to limit treatment***
>
> *The underlying ethical justification for all decisions to withhold or withdraw LST [life sustaining treatment] is that such treatment is not in the child's best interests. There are three sets of circumstances where it may be appropriate to consider limitation of treatment.*
>
> *1. Limited quantity of life*
>
> *If treatment is unable or unlikely to prolong life significantly, it may not be in the child's best interests to provide it.*
>
> *A. Brain death*
>
> *Death occurs when a child has irreversibly lost their capacity for consciousness and their capacity to breathe and maintain their cardiovascular circulation.*
>
> *…*
>
> *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.*

In both 'Imminent death and Inevitable demise' (above) the early provision of sensitive palliative care is ethically justified and in accordance with principles of good medical practice (see 'Palliative care').

2. Limited quality of life: where there is no overall qualitative benefit

Considering quality rather than quantity of life is more problematic because of potential or actual differences in views of the healthcare team and children and families as to what constitutes quality of life and the values that should be applied to define it.

...

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.

...

B. Burdens of illness and/or underlying condition

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

C. Lack of ability to derive benefit

In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. ...

> *Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress.*
>
> 3. Informed, competent, supported refusal of treatment
>
> *…[not relevant]*
>
> ***3.1.4 Spectrum of decisions and parental discretion***
>
> **….**
>
> *The concept of 'intolerability' of the child's condition should not be invoked to usurp a comprehensive 'best interests' assessment. It is neither a supplementary test to the 'best interests' test, nor a gloss to that test: Portsmouth NHS Trust v Wyatt [2004] EWHC 2247 at paragraph 24, endorsed by the Court of Appeal in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 at paragraphs 76 and 91.*
>
> *Although 'intolerability' may obviously be a relevant factor, it cannot provide a single determinative test as to best interests: R (on the application of Burke) v GMC [2005] EWCA Civ 1003 at paragraphs 61 to 63; Re L (A Child) (Medical Treatment: Benefit) [2004] EWHC 2731 (Fam) NHS Trust v MB (supra) per Holman J at paragraph 17.*

34. Although the Mental Capacity Act 2005 (as amended) has no legal application in the High Court's family or inherent jurisdiction, some guidance as to how to approach the 'best interests' test can be derived from section 4 of that Act.

35. Further useful summary guidance for the Court, with reference to case law, is provided in the above mentioned "A framework for practice: Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (Vic Larcher et al, March 2015) as follows:

> ***"2.3.4 The role of the courts in end-of-life decision making***
>
> *If agreement cannot be reached between parents, or those with PR, and healthcare professionals, legal advice should be sought from specialist healthcare lawyers. Taking legal advice, of itself, does not necessarily mean that court proceedings will follow.*
>
> *The court has inherent jurisdiction to grant a Declaration making it lawful for healthcare professionals to withhold or withdraw LST notwithstanding the absence of parental consent if this is deemed to be in a child's best interests.*
>
> *The court must exercise independent and objective judgment on the basis of all the evidence and consideration will be given to, amongst other factors:*

- *The likely quality of future life for the child with and without treatment.*
- *The intolerability of treatment or outcome.*
- *The relevant clinical considerations.*
- *The pain or suffering caused by the treatment.*
- *The pleasure a child may derive from its current life including the child's awareness.*

The court will conduct a balancing exercise in which all relevant factors are weighed. The court will assess the benefits and burdens of giving or not giving potential treatments and of maintaining or withdrawing certain forms of treatment in order to assess best interests.

The court's approach in end-of-life decisions

In reaching decisions about withdrawing or withholding LST, the court adopts a strong presumption in favour of preserving life. The court will balance a number of legal principles, for example, the sanctity of life, the prohibition against inhuman and degrading treatment, the freedom of thought, conscience and religion and the right to family life. Case law has established that:

The principle of the sanctity of life is not absolute. Whilst Article 2 of the European Convention of Human Rights imposes a positive obligation to give LST, it does not impose an absolute obligation to provide such treatment if it would be futile and where responsible medical opinion is of the view that such treatment is not in the best interests of the patient.

The right to life is not the same as the right to be kept alive.

There is no obligation to give treatment that is futile or burdensome.

When individuals ask for treatment which the healthcare professional has not offered and which s/he considers not clinically appropriate for the patient, the professional is not obliged to provide it. Second opinions should be arranged and/or care transferred to another healthcare professional wherever possible.

Responsibility for deciding which treatments are clinically appropriate rests with the healthcare professional, who must act in accordance with a responsible body of professional opinion.

LST can lawfully be withheld or withdrawn for a patient who lacks capacity in circumstances where commencing or continuing such treatment is deemed not to be in their best interests.

2.3.5 Best interests

> *'Best interests' are not purely confined to considerations of best medical or clinical interests, but include other medical, social, emotional and welfare factors. The court is not tied to the clinical assessment of what is in the patient's best interests and it will reach its own conclusion on the basis of careful consideration of the evidence before it, ensuring that the welfare of the child is of paramount consideration.*
>
> *The court will weigh up the overall advantages and disadvantages of limiting LST, and undertake a balancing exercise to determine what the child's best interests are. In cases involving the withdrawal of treatment, the court will need to conclude 'to a high degree of probability' that it is in the best interests of the child for treatment to be withdrawn.*
>
> ***2.3.6 Quality of life and legal decisions***
>
> *Courts have recognised that quality of life determinations should be based on the individual circumstances of the person taking account of his or her perceptions without discrimination; quality of life that could be considered intolerable to one who is able- bodied may not be intolerable to one who is born with disability or has developed long-term disability.*
>
> ***2.3.7 Withdrawing treatment***
>
> *The courts will sanction the withdrawal of treatment in cases where continued treatment would be futile even though there is a presumption in favour of preserving life.*

Conclusions

36. By the end of the hearing all of the parties agreed that the declarations should be granted and Williams J's declaration set aside. As is set out above, the legal question I have to address is what is in X's best interests. X self evidently lacks capacity and it is not possible in the circumstances to assess his wishes and feelings. Ms Ford, on behalf of the Mother, does not resist the declaration being made.

37. Best interests is a broad ranging matter taking into account all relevant considerations. Very sadly in this case starting with the strong presumption of the preservation of life, all the factors tend in favour of granting the declarations. I fully accept Dr de Lacey's evidence. She was an excellent witness, giving measured and careful evidence, and plainly having an enormous expertise in her field.

38. X's quality of life is minimal if not non-existent. He cannot see or hear, and it seems probable that the only sensation that he does have is one of pain. He is not even in the arguably better condition of some desperately ill babies in that he can feel nothing. X does appear to be able to feel pain and discomfort. It seems likely that X can experience no pleasure.

39. The fact that X needs a shunt in order to drain the fluid from his brain means that he is in constant risk of infection. If there is an infection then he is at great risk of suffering convulsions, as was happening at the time of the hearing.

40. It is impossible not to feel that X's life is one of nothing but suffering. As is set out in the cases above, life itself is precious and there is a very strong presumption in favour of preserving life. But X's life is a truly tragic one and certainly reaches a threshold of intolerability.

41. I entirely accept Dr de Lacey's evidence that X's condition is permanent and wholly untreatable. When he gets an infection it can be treated, but his underlying condition of hydranencephaly is untreatable and irreversible. It will lead to his early death, and his condition will not improve. There is no possible doubt about his diagnosis.

42. His life expectancy is probably no more than a year on the basis of the literature. It is not impossible that X might live longer than that but given the small number of babies who are born with the condition, it is difficult to be certain about this.

43. For all these reasons I am clear that it is not in X's best interests that he should be resuscitated or that he should be given life sustaining treatment. I therefore grant the declarations sought.