Neutral Citation Number: [2021] EWHC 594 (Fam)

Case No: FD20P00798

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 15/03/2021

Before :

THE HONOURABLE MRS JUSTICE JUDD DBE

- -

Between :

The NHS Trust	**Applicant**
- and -	
The Parents	**1st Respondents**
-and-	
S **(through the Children's Guardian)**	**3rd Respondent**

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Mr Mylonas QC (instructed by **Hill Dickinson LLP**) for the **Applicant**
Mr Thomas (instructed by **Advocate**) for the **Respondents**
Mr Osborne for the child through the Children's Guardian

Hearing dates: 8-10 March 2021

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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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THE HONOURABLE MRS JUSTICE JUDD DBE

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.

Covid-19 Protocol: This judgment will be handed down by the judge remotely by circulation to the parties' representatives by email and release to Bailii. The date and time for hand-down will be deemed to be 10:30am on 15 March 2021. A copy of the judgment in final form as handed down will be automatically sent to counsel shortly afterwards

The Hon Mrs Justice Judd :

Introduction

1. This is an application by a hospital trust for declarations as follows:-

(a) That S lacks capacity to make decisions as to medical treatment;
(b) That it is not in his best interests to continue to receive life sustaining treatment including ventilation;
(c) It is in his best interests and lawful for such treatment to be withdrawn;
(d) In the event of a deterioration in his condition, it is not in his best interests to receive bag and mask ventilation, cardiac massage (with or without adrenaline), endo-tracheal reintubation, invasive or non-invasive ventilation, antibiotics (save in order to provide pain relief) or inotropic support;
(e) In the event of a serious deterioration in his condition, it is lawful for the treatment set out in (d) to be withheld.

2. The application is supported by the Children's Guardian. It is opposed by S's parents.

Background

3. S was born in June 2020, so he is almost nine months old. His parents told the Guardian that the pregnancy was uneventful and when the mother went into spontaneous labour at 40 weeks they had every reason to expect a healthy full term baby boy, a sibling for the father's older son who is 9 years old. Soon they were confronted with the unimaginably harrowing circumstances that something was wrong given the immediate and intensive response of the medical professionals following the birth. S was born without any heart rate, breathing movement, spontaneous movement of his limbs and with very poor colour and abnormal cord blood gas result. He required active resuscitation including intubation and ventilation, external cardiac massage, medications and blood transfusion. After about 30 minutes of resuscitation his heart rate achieved a normal level, but it took some 18 hours for him to have a sustained respiratory effort, even with ventilator support.

4. As a result of his severe lack of oxygen and blood supply to vital organs around delivery, S sustained a severe brain injury, diagnosed as severe perinatal hypoxic ischaemic encephalopathy. He was also born with an infection and was treated with antibiotics.

5. S has remained on the neonatal intensive care unit (NICU) since he was born. He has been ventilated since his birth and is fed by a nasogastric tube. He also suffers from seizures and is treated with anticonvulsants.

The law

6. The law in relation to the withdrawing of life-sustaining treatment is clear and well established. The welfare of the child is paramount. In *Re NHS Trust v MB and Others* [2006] EWHC 507 (Fam); [2006] 2 FLR 31 highlighted the following factors:-

(i) The decision must be objective; not what the judge might make for him or herself, or a child;
(ii) Best interests considerations cannot be mathematically weighed and include all considerations, which include (non-exhaustively), medical, emotional, sensory, (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations;

(iii) There is considerable weight or a strong presumption for the prolongation of life, but it is not absolute and may be outweighed if the pleasures and quality of life are sufficiently small and the suffering or other burdens of living are sufficiently great;

(iv) All cases are fact specific;

(v) The views and opinions of both the doctors and the parents must be carefully considered. Where 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 parent/child relationship.

7. In *Re A (A Child)* [2016] EWCA Civ 759 King LJ stated at paragraph 31:

> "Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life-sustaining treatment is now clear and well-established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 , Baroness Hale said at paragraph 22:-
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> "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 follows 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 towards the patient if they withhold or withdraw it"
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> And from paragraph 39:-
>
> "The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and the prospects of success; they must consider what the outcome of 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".

8. No single factor determines the outcome; it is important that the court takes an overarching view of the child's best interests. I have also read and take into account the Royal College of Paediatrics and Child Health Guidance on "*Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A framework for practice".*

The evidence

9. I have read all the documents in the bundle, including three reports by Dr. C, an independent report prepared by Dr. Simon Hannam, Consultant Neonatologist and

Head of Neonatal Services at Great Ormond Street Hospital. I have also read the Guardian's report and the statement of the parents. I heard oral evidence from Dr. C and the parents. The mother provided me with a photograph of S, and four video clips of him. In addition the Trust set up a video link so that I could see S in hospital, and have a brief look around the ward he is in.

The medical evidence

10. Dr. C became involved in S's care when he was about two weeks old. He remains on the NICU. His condition appears to be stable with minimal breathing help on the ventilator and is tolerating nasogastric tube feeding.

11. MRI scans performed after his birth are consistent with severe neonatal hypoxia. Professor Mary Rutherford, the Consultant Perinatal Radiologist, described by Dr. Hannam as a world expert on the interpretation of neonatal MRI brain scans, stated that S had suffered extensive brain injury, associated with severe neurodevelopmental impairment in all domains. It is Dr. C's view that S will (100%) suffer global developmental delay, and it was very likely indeed (90%) that this would be severe. In his second report, Dr. C described the consequences of this as being that S is unlikely to ever be able to react in any way to anyone or anything. There is no indication that he derives pleasure from any source, but unfortunately there is evidence that he responds to the discomfort of his treatment including suctioning and turning. There is no prospect of him ever mobilising, he has significant sensory impairment affecting his vision and hearing, and he will never be able to perform any functions of daily living at all. He is unlikely ever to feed without either an NG tube or a PEG (feeding tube passed through the stomach wall). He has no intentional spontaneous movements.

12. There have been numerous multi-disciplinary meetings concerning S, attended by neonatal consultants and other neonatal professionals (nurses, therapists) and consultant meetings. On 14th October all the professionals present agreed that a withdrawal of life supporting treatment and a transfer to palliative care was in S's best interests.

13. When S was about 7 months old an attempt was made to assess him using the Bayley III Scales of Infant Development. Due to his abnormal neurology, it was not possible to score him on any items on the scales.

14. During his oral evidence Dr. C explained that it was the view of the entire team that the movements in S's limbs were reflex rather than purposeful, and that the same applies when he opens his eyes. Although Dr. C respected and understood the position of the parents he could not agree with them that S responded to touch.

15. The fact that S needs lower concentrations of oxygen now than he did at birth is explained by the fact that at birth he was extremely unwell with an infection and as a consequence of the hypoxia, not, very sadly because his overall condition is getting better. There is nothing very wrong with his lungs themselves, the problem is that the damage to his brain is such that he is unable to sustain respiratory effort. It is right that at one stage he managed to survive for 10 days with the assistance of CPAP (which supports respiratory effort as opposed to providing all of it) but his oxygen

levels began to decline and he had to be ventilated again. Since then attempts to wean him away from the ventilator have been unsuccessful.

16. Dr. C was absolutely clear that there is no prospect of any improvement in S's condition, which is underpinned by permanent and irreversible brain damage. In order to survive he will require the current care regime to continue, and as time goes on, there will be more and more complications. Questioned about the possibility of S being able to be cared for at home, he said that such could only be achieved if he had a tracheostomy and PEG feeding (which both require surgery) and 24 hour nursing care. If S was allowed to go home, Dr. C said it was a 'certainty' that he would be readmitted to hospital within days or weeks.

17. Dr. Hannam was contacted to provide a second opinion at the request of the parents. He visited S in hospital on 10th February 2021 and examined him in the presence of Dr. C. He noted that S's head circumference is now on the 9th centile, meaning that he has significant microcephaly when compared with his weight which is on the 99.6th centile. S did not appear to him to take any spontaneous breaths and was fully supported by the ventilator. He opened his eyes in the course of the examination but not in a way that suggested he was following or fixing on the external world. He made chewing and jerking movements with his jaw and had markedly increased tone in all four limbs. When a limb was passively moved the other limbs flexed, leading Dr. Hannam to believe that they were reflex responses rather than volitional efforts. He did note that S's pupils responded very slowly to light, which is a difference from an earlier finding, although Dr. C said that this had been conducted by the Consultant Opthalmologist who carried out a more detailed examination . Dr. Hannam concluded that S is 'certain to have an extremely abnormal global developmental outcome. It seems unlikely that he will ever be able to breathe without the support of a ventilator, or be able to feed. An EEG carried out at his request demonstrated that during stimulation he moved his limbs exhibiting stretching/arching movements of his back without producing any significant changes on the graph. Dr. Hannam opined that this meant that the limb movements he observed were not purposeful. The EEG also demonstrated diffuse cerebral dysfunction and a liability to seizures with multifocal discharges.

18. Dr. Hannam concluded that S has no prospect of having a meaningful quality of life in the future, and that he would need round the clock nursing. He would not be able to experience pleasure in terms of feeding, will have severe cognitive impairment, and he is unlikely to be able to see or hear. Although he said it was 'impossible to prove' he was concerned S was experiencing discomfort during the cares needed to keep him alive, having noted that his response to oral suctioning with movements of the jaw suggested that he reacted in some way to stimulation. He concluded 'To my mind, this means that continuing him on a ventilator would result in him having an unbearable existence as he is suffering'.

<u>The parents</u>

19. S's parents are utterly dedicated to him and have shown him nothing but love and care throughout his short life. He was a much wanted child. The mother visits him every day, and the father several times a week. The parents are able to lift S onto their lap to hold and cuddle him.

20. The parents and Dr. C have had a very good relationship throughout the period S has been cared for by him. Indeed their relationships with all the staff are very good and appreciative. The parents have a great respect for the opinion of the doctors and the work of the team in caring for S; it is simply the case that they disagree as to what is in S's best interests.

21. Until the day of the hearing, the parents had no legal representation. Parents whose children are the subject of an application by the local authority to take them into care receive full non means and non-merits tested public funding but parents who face an application for the withdrawal of treatment from their child do not, despite the enormous significance of the decision to be made. Not only are these cases medically complex, but emotionally they are as hard as is possible to imagine for the parents. In this case, the father works and his wages mean that the family are over the limit for assistance with representation. Unsurprisingly, they could not afford to pay for a lawyer themselves. Upon hearing of their plight through counsel for the Hospital Trust, Mr. Mylonas QC, Mr. Thomas, counsel from Serjeants Inn Chambers stepped in to help and represent them for free. He assimilated all the documents and spent time discussing the case with the parents. He has represented them with the greatest of skill and care, ensuring that their case was properly put before the court and taking the burden from them of having to do it all by themselves. I am extremely grateful to him, and wish to commend him for what he has done.

22. The parents have spoken to various professionals, including Dr. C, Dr. Hannam and the Guardian. They also prepared a short statement for the court. In this they ask the court to take into consideration their request to take their son S home to continue to care for him. They state that they understand that he will need full time care and that they are 'committed to fulfil that role with love and happiness'. They state that they hope to see more progress in their son's state, and protect his right to live whatever his condition is. They state that he is a lovely fighting boy, and that at the beginning he needed the maximum amount of oxygen and was not responding to touch. Now he needs only the minimum setting and responds to touch as well as sometimes opening his eyes. They point to the fact that he managed to breathe for 10 days with the help of CPAP, which was a big surprise.

23. What the parents say in their statement mirrors what they have said to the other professionals. The mother told the Guardian that whilst they accepted the opinion of the doctors she held onto her dream that 'everything will be ok' and spoke of her conviction that S can recover. The mother also told the Guardian that S has moved in response to a cold wet wipe when having his nappy changed.

24. The parents also told the Guardian that they hoped S could go home on a ventilator and feel able to rise to the challenge of 24 hour care. They would like him to meet his brother and other family members. This has not been possible in lockdown in the NICU.

25. The mother gave oral evidence on behalf of both of the parents. She has visited their son every day, usually for two hours or so, and has been able to do such things as hold him, dress him, change his nappy, and sometimes to suction him. She said that S moves when he is touched, and indeed the videos do seem to demonstrate that. She said that when she touches or tickles his right leg he responds with the same leg that

she is touching and not the other one, and that when he opens his eyes she hopes that he is doing this to see if it is her. She really did not feel that the movement he demonstrates when she is touching or tickling him is by way of a reflex only.

26. When she was asked about S being able to feel discomfort and pain she acknowledged this, but drew an analogy with people who have to undergo painful or uncomfortable medical treatment for illnesses such as cancer. When S was not having any procedures done to him he is comfortable and stable. She said that whilst understanding that S will always have disabilities and complications she wished for him to be given a chance to survive, for he does things at his own pace and makes gradual progress. She believes that if he wished to give up the fight for life he would do so despite being on the ventilator, and explained that there was another mother on the unit who said that her baby had done this.

27. Movingly she told me that his life was precious and that he needed to be given the chance to show his progress and wake up, or to give up if he wished to do so. The mother told me that if S himself gave up she would rest more easily because it would be his choice, as opposed to treatment being denied to him.

28. The mother would like to be able to care for S at home if possible.

29. The parents have also explained that as people of faith they cannot relinquish their hope that S will make some sort of improvement, and believe it would be wrong for them to agree to the withdrawal of treatment.

Discussion and conclusions

30. In determining what is in S's best interests, I look at his welfare in the widest sense, including medical, emotional, sensory and instinctive matters. I also bear in mind the strong presumption for the prolongation of life. As the mother says of S, his life is precious.

31. The benefits to S of continuing treatment would be that he would be alive, and he could continue to experience the care and love each of his parents have for him. The doctors do not believe he is able to feel any pleasure or comfort, but if he is able to feel discomfort it seems likely that in some intangible way he must be able to feel the soothing touch of his mother (and father too) as he is held and cuddled.

32. It is not hard to understand the parents' fervent hope that S will defy expectations and show some improvement in his condition. The medical evidence is, however, that the brain damage that he has suffered is permanent and irreversible. There is therefore no realistic prospect of S ever being able to breathe without a ventilator, to feed or be fed orally, or do anything for himself at all. He cannot and will not ever be able to see or hear. I can see why the parents believe that S's limb movements are more than reflex ones, but I accept, sadly, the medical evidence that this is not so. Although the mother in particular has been able to spend considerable periods of time with S in hospital, I believe that her longing to see a reaction in her son is likely to have coloured her observations. In all the circumstances the continuing artificial ventilation cannot, in my view, offer S the benefit of any chance of an improvement in his condition.

33. On the other side of the balance I must consider the burdens to S of continuing life sustaining treatment. The medical professionals are concerned that the measures required to keep him alive cause him discomfort and even pain. S has deep suctioning every two or three hours every day, his nasogastric tube is replaced every three days, and his NETT tube is replaced every three weeks. Replacement of each of these tubes needs to be followed by abdominal or chest x-rays to ensure they are properly sited. The fact that S moves his jaw in response to being suctioned suggests he does react and therefore in turn that he might well be able to experience pain and discomfort. S could have a tracheostomy and/or surgery to have a PEG tube inserted, but each of these require surgery which brings with it risks and the possibility of more pain and discomfort. The tubes would still need to be regularly cleaned and replaced and there is an ongoing risk of infection in any of these scenarios. In addition to the procedures I have set out above, S also has heel prick tests every two days and his body position changed regularly. He is on a variety of medication.

34. Beyond this, S faces longer term problems as he grows older. Getting larger he will be harder to move. He will be susceptible to contractures – spasms in the muscles which might lead to his suffering from dislocations or fractures, all of which are capable of being very uncomfortable and/or painful. As time goes by he will become more susceptible to suffering from epilepsy. He is likely to developing chest infections (aspiration pneumonia), and there is a risk of his suffering uncontrollable fits, apnoea and sudden cardiac arrest. Any of these could lead to his death, including his sudden death.

35. There are five options put forward by Dr. C on behalf of the hospital trust which range from continuing the current regime to cessation of artificial ventilation and palliative care. If I approve the plan put forward by the hospital trust (Option 5), it will enable high quality palliative care to be provided to S, including every treatment to try and reduce pain and distress when dying.

36. The parents argue that the court should endorse Option 2, and do not argue for Option 1. Option 2 would mean continuing with intensive ventilation and support care but not escalating treatment if S deteriorates further. They believe that this will give S the chance to carry on living, but also to relinquish life if he becomes sicker.

37. Option 3 would be for S to be extubated but re-intubated if he cannot manage. Option 4 would be to extubate him and give him Vapotherm or CPAP if he cannot manage, rather than re-intubating him.

38. Whilst Option 2 would relieve S of an escalation of treatment if he were to deteriorate, whilst he remains stable (which could be for a considerable period of time) things will continue as they are at the moment. Option 3 is much the same again. Option 4 would relieve S of invasive ventilation, but even if it was successful (which is highly unlikely) the other burdens in being kept alive would remain. The parents have said they would like S to be able to go home, but given the need for surgery and all the other risks, this is not a realistic option.

39. My heart goes out to these parents, who have to bear the pain and grief of what has happened to their beloved son. Hard though it is, however, I am clear that the only Option which is in S's best interests is Option 5, namely that life sustaining treatment

should be withdrawn and that S should be given palliative care and allowed to die in comfort and peace.

40. This is a case where the burdens and possible suffering that continuing treatment brings with it outweigh the benefits of prolonging life. In my judgment the treatment cannot bring about any real improvement in his overall condition. Although the preservation of life is a very important consideration, continued living means S being exposed to repeated medical procedures that may well be uncomfortable or even painful. If he lives long enough his condition may worsen, and either way he may die suddenly from apnoea or heart failure without time to administer palliative care to relieve any possible distress. I understand and respect the parents' views, including their religious views (which no doubt S would share) but it is not in his best interests to put him through so much simply to keep him alive even if he is able to experience some comfort from being looked after by his parents. If he were able to express any wishes about this it is difficult to believe he would choose this sort of existence for himself.

41. It speaks volumes about the parents and the medical team who have treated S that they have worked so well together and continue to do so despite the different views they hold. The care S has received in the Neonatal Intensive Care Unit has been of the highest quality. It is also right, as Mr. Thomas has said, that there is one area of his life in which S has been fortunate, and that is in having the unstinting love and devotion of his mother and father.

42. In all the circumstances I will make the declarations sought.