Neutral Citation Number: [2020] EWHC 1606 (Fam)

Case No: FD20P00358

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 16/06/2020

Before :

THE HONOURABLE MR JUSTICE HAYDEN

- -

Between :

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	**Applicant**
- and -	
AB	
- and -	
SZ	**Respondents**

- -
- -

Mr Rhys Hadden (instructed by DAC Beachcroft LLP) for the **Applicant**
Ms Shabana Jaffar (Cafcass Legal) for **Z**
Hearing dates: 16th June 2020

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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 MR JUSTICE HAYDEN

This judgment was delivered following a remote hearing conducted on a video conferencing platform and was attended by the press. 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judgment) in any published version of the judgment the names and addresses of the parties and the protected person must not be published. 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.

Mr Justice Hayden :

1. This is an urgent application brought pursuant to the inherent jurisdiction, concerning Z, an infant of 8 weeks of age. The application by the Trust is for a declaration that it is in his best interests to discontinue intensive care and to commence palliative care. This decision is predicated on their conclusion that intensive care is now futile and there are no other procedures or treatments available. Moreover, it is considered that intensive care treatment is now placing an unbearable burden on Z.

2. As Z's father (AB) told me, Z was born at Pinderfields Hospital in Wakefield. He was premature, delivered at 33 weeks and 6 days. When the mother's (SZ) waters broke there were no neonatal beds available on the Jessop Wing of the Sheffield Hospital, which ordinarily would have admitted her. The following day mother and baby were transferred back to the Sheffield Teaching Hospital (the Jessop). On arrival, Z was admitted to the transitional care unit which, it has been explained to me, indicates a baby who was unwell and requiring neonatal care but not perceived as *"very seriously unwell*". However, on the second day, Z's situation deteriorated very dramatically and it was plain that he was gravely ill. He has been diagnosed with a condition which is known as necrotising enterocolitis known as "NEC". There is no real understanding of what caused this, save that it is most commonly seen in premature babies. It is noted that though Z was premature he was not *'conspicuously so'*. The NEC was, manifestly, severe and led to infarction of almost the entirety of the bowel. Inevitably, on 30th April 2020, a laparotomy was performed. Sadly, AB was not able to see his son for the first three days of his life in consequence of the restrictions required by the covid-19 pandemic public health crisis. The reality is that AB did not have the chance to see his son when he was presenting healthily. By the time father and son met Z was already in intensive care and had experienced considerable pain.

3. On 30th April 2020, during the course of the laparotomy (the only operation Z has received), it was not possible to remove the whole of the bowel. This was because Z was already *"too sick"* and there was concern about further protracting the duration of the operation. Had he at any other point in his development achieved a greater level of stability it might have been possible for the surgeons to undertake a second laparotomy to investigate the remaining bowel. I emphasise this because, for reasons which are entirely understandable, the father invests much hope in the possibility that what remains of the bowel may be functional. That question was put to Dr Kirsteen Mackay, from whom I have heard evidence. Dr Mackay is a consultant neonatologist at the Jessop Wing in Sheffield. She took over the care of Z this morning, 16th June 2020, from her colleague, Dr Pilling, also a Consultant Neonatologist on the neonatal ICU in Sheffield. It is important to emphasise that Dr Mackay has been involved with Z's care previously.

4. Dr Mackay told me the father was entirely right to raise the question concerning the yet unremoved bowel, at least logically. She was prepared to permit, as a possibility, that something of the bowel might well have survived. But, she told me, that had now become essentially academic because Z's health has deteriorated to the point where further surgical intervention would be life threatening and could not responsibly be undertaken. She described a baby whose life has now become medically futile.

5. It was hoped that after the first laparotomy there would be agreement between the treating clinicians and the parents in respect of a package of palliative care predicated

on the recognition of the futility of Z's situation and an understanding that further intervention would not be in Z's best interests. It has not been possible to achieve the degree of consensus that the clinicians aspired to but it is important that this is not interpreted as conflict. On the contrary it is clear that whilst the doctors and the parents have very different perspectives, there has nonetheless been a high degree of collaboration which is rooted in mutual respect. Indeed, it is clear that the Trust were reluctant to bring this application earlier because they continued to hope that a way forward could be negotiated by consent and the distress of the litigation averted. The decision to bring a case to court is always a difficult one. In these circumstances, I do not find it necessary or appropriate to comment as to the timing of the application, one way or the other. I would emphasise, however, that when balancing the decision to apply to the court, Trusts should always bear in mind the importance of the child being represented. Though Cafcass had been put on notice and had some familiarity with the case, they were not in attendance when the hearing began. The hearing was adjourned for a few minutes for a senior lawyer, Ms Jaffar, to join the hearing. No guardian was appointed.

6. I am told that SZ does not speak English well, although she has been present and has understood what has been going on. The father, speaking for both parents, articulates a sincere and heartfelt gratitude to the doctors who have been treating his son and, in particular, to the nurses who have been involved most intimately in Z's day to day care. The regime of that care is an onerous one, as Dr Mackay told me. It requires an additional bolus of pain-killing medication, even before routine turning can be undertaken. It is also important to say that a very complex cocktail of pain relief has been devised for Z. This has involved consultation with a pain relief specialist. It is notable that though she has been a consultant for 11 years, Dr Mackay has never been involved in treating an infant assessed as requiring such a complex and strong cocktail of pain relief. The consultant she works alongside has twenty years' more experience and she too has never been involved with a patient baby requiring a pain relief cocktail of this magnitude. This indicates, graphically, the degree and extent of the pain that Z is seen to be in. All involved, the doctors, the nurses and the parents are clear that Z has been in very significant pain for all but the first three days of his life. The parents invited me to meet Z. This involved me following AB's camera as he walked the short distance to Z's bed. The mother was too distressed to join us. Whilst I did this I required all those attending this remote court hearing to log off to afford Z his privacy. Whilst we were alone (though recorded) AB told me that he had been able to see for himself that his son had been in great pain and expressed fulsome gratitude to the doctors for devising the pain relief regime which he believes to have been effective for his son.

7. The mother is 38 years old. The father is 43 years old. He is an intelligent, articulate man with a detailed understanding of his son's circumstances. Z is his only son. It is a tragic irony that he was given a name (anonymised), that is associated with long-life in AB's culture. The second name, he told me, was chosen to indicate that he was a *'fighter'*. The couple have four children, three of whom are girls. One is 19 and at university. The other two, aged 15 years and 11 years are at school. It is obvious that the father is proud and ambitious for each of them. He told me that they had a son who would have been the first born but who died following a premature birth, now over twenty years ago.

8. In her evidence, which I found to be both sensitive and impressive, Dr Kirsteen Mackay told me that for all but those first few days, Z has lived in very considerable pain. Notwithstanding the enormous challenges that the hospital and the family have been under, it has been possible for the parents to be with their baby, whenever they can, wearing ordinary clothes (not PPE) and have been able to touch and soothe him. Despite the extent and gravity of his condition and the sedative effects of this power medical regime, both parents are clear that Z is responsive to their presence and touch and that he has sometimes grabbed their fingers. Dr Mackay indicates that she too believes this to be the case. These parents have, in the most challenging of circumstances, been able to comfort, love and care for their son in a way which has brought dignity to his compromised life. I have no doubt that they consider themselves to be very fortunate to have Z. If I may say so it is obvious that they are natural and instinctively skilled parents.

9. It is nearly 7 weeks since the laparotomy. It has become clear, as Dr Mackay told me in her evidence, that the abdominal wall is now broken down. In fact, in her statement, presenting this application, she told me the abdominal wall had actually died, although she also described it, somewhat counter-intuitively, as *'slowly healing in parts'*. Z is in renal failure. He has a severe liver impairment and is producing virtually no urine. He receives large amounts of high pressure ventilation and is described as very *'oedematous'*. That means that there is an excess of fluid beneath his skin. In addition to all this, there is bleeding into the brain which runs the risk of cerebral palsy but that is of no concern to the parents in the sense that, if Z could survive, they would welcome his survival with cerebral-palsy rather than contemplate his death.

10. Until 1 o'clock this morning Z had two central lines in place, one of which provided nutrition, the other, fluid and highly concentrated pain relief medication. Unfortunately, at 1am one of those lines failed and Z is now left with a single line through which his entire needs require to be met but cannot be. The remaining line is only able to infuse minimal liquid to dilute the pain relief medication, nothing more can be provided.

11. In addition to the care offered by Dr Mackay and her colleague Dr Pilling, Z has also been seen by a consultant surgeon, a Mr Murthi, who concluded, unambiguously, that Z could not withstand further surgical intervention to insert another central line. When the situation with the now defunct second line was realised, the parents were contacted overnight by Dr Dyson, the consultant on call.

12. I have heard oral evidence from the father. He believes, as I have set out above, that because a small section of the bowel has not been examined then that might offer some prospect of survival. He believes that the oxygen levels he has been viewing on the ventilating machines indicate that his son might be able to breathe independently. He considers that his son has a strong heart and he wants to exhaust every conceivable option before the court yields to the plan advanced by the Trust. He believes the swelling has reduced. The reality though, as Dr Mackay tells me, is that Z is simply unable to breathe independently of the ventilator. She did not discount for a moment the father's view that the swelling may have reduced but she did check this morning with the nurses who know Z well and they were not of the same view. Though the family has agreed to limited interventions they will not agree to the withdrawal of ventilation. Much of that is driven by their profound Islamic beliefs. The father believes, and I am sure articulates this on behalf of his wife too, that whilst there is

breath, there is life. And while there is life, there is hope. I wish him to know that I deeply respect his beliefs.

13. The level of agreement between the parents and the clinicians extends to an acceptance that:

    i. There will not be any increase in ventilation;

    ii. There will not be any blood pressure medication;

    iii. There will not be any extra boluses of fluid;

    iv. There will not be any antibiotics.

14. It requires to be said that in this agreement there is, in my view, a reflection of this intelligent father's understanding of his son's parlous condition.

15. The clinical team are satisfied that there is no prospect of Z surviving. They identify the challenge as securing a death which is as comfortable, dignified and as free from pain as can practically be achieved. That is, in the circumstances of this case, on my understanding of the evidence, a continuing challenge. If the remaining central line stops working, it is highly unlikely that another line can be sited. Dr Mackay has, in her desire to work with the father, explored the possibilities, even to the extent of contemplating a sub-cutaneous line in an arm swollen by tissue full of fluid. Ultimately, she concluded that this would seriously compromise the provision of pain relief and would leave her very anxious as to whether any effective pain relief could be delivered. It is important to emphasise that this cocktail of pain relief medication, unprecedented in the experience of these two very senior consultants, indicates the extent of pain that Z has suffered and the risk that it will be revived if adequate pain relief mediation cannot be administered.

16. It is possible in the plan, contended for by the parents, that Z, attached to the ventilator, could survive for a few days. There can be no certainty that he could be given effective pain relief by any other route. Dr Mackay contemplated nasal pain relief and, in her statement, she considered administering pain relief via his cheek or by way of injection but that, as she described, is a far cry from this intensive regime of intravenous pain relief. Additionally, Z's circumstances would be further exacerbated in consequence of the inability to manage any fluids and/or nutrition in a baby who already has renal failure.

17. These parents, in my view, have won the hearts of those who are caring for their son. That is evidenced in so much of what I have heard and read. I have no doubt that the team has discussed repeatedly and endlessly with the parents whether they might agree to stop the ventilator in the event that the final line ceases to work and it becomes impossible to site another line. Without a line through which to give Z nutrition and hydration, I am told, the oedema will only worsen. This is because without fluids and nutrition (protein) renal failure will further deteriorate. Z is not passing urine at the moment and the result will be more oedema not less. All this compounds the difficulties of putting in any further line. AB told me that even if there were to be further expert opinion which arrived at the same conclusion as that of the treating clinicians he would still not be able to agree to the withdrawal of ventilation. This is essentially because it

is at this point the medical analysis collides with AB's religious beliefs. For the clinical team, that requires them to contemplate Z's death in painful circumstances. It is, they analyse, contrary to his best interests for him to die in such a way.

18. Dr Pilling has explained to the family that, even if they do not feel able to *'positively agree'* to removing Z from ventilator, they could consider allowing her to make that decision whilst effectively remaining neutral themselves. Sometimes, in these difficult issues of faith, that can be a workable compromise. That will not suffice for the father here and I entirely understand and respect the theological coherence of his position.

19. In the most difficult and challenging of times, these parents have sought to care and do their best for their very much wanted son. It is impossible not to feel for them and the pain they must be going through. It is immensely hard to dismiss the hope that they keep alive. But the approach in circumstances such as this must be to keep an unswerving focus on the best interests of the child.

20. The legal framework is relatively easy to state though always difficult to apply in applications as sensitive as this. I do not consider that an exegesis of the applicable Law is required here, indeed the risk is that to do so might eclipse the lode star which guides the Court's approach i.e. "the best interests of the child".

21. The test is encapsulated by Baroness Hale in **Aintree University Hospital NHS Trust v James [2013] UKSC 67**, namely:

> *"[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." ...*
>
> *"[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 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."*

22. In **Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410**, McFarlane LJ observed:

> *"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child*

> *must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."*

23. Z, though only 8 weeks of age, is an independent, autonomous being. I am entirely satisfied that if I were to yield to the father's suggestion I risk the real possibility, indeed on my assessment of the evidence a likelihood, of a painful, agonising death for his son. I cannot reconcile that with Z's best interests in circumstances where the careful and compassionate professional consensus reaches the compelling conclusion that Z's life is now futile.

24. These decisions are difficult enough in ordinary times. But a hearing via a video-conferencing platform creates its own particular challenges. The mother and father, who join the video hearing via their mobile telephone, have not always been in my constant view as I would have preferred them to be. I regret that it has not been possible for there to be proper eye contact between us. There are however, some advantages too. It was a great privilege to have been able to go to Z's bed (remotely) with such little intrusion for him or to those caring for him. I should like to thank the parents for inviting me to see him.

25. Though Z's face is now swollen, the mother has told the father that in those early days before he was on ICU and when the father was unable to see him, she thought he bore a resemblance to his father. That he is loved deeply is all too obvious.

26. I wish to record that although the father is not represented his analysis of the medical issues was concise, clear, focussed and the presentation of his case was sensitive and respectful. Ms Jaffar who attends as a senior solicitor from Cafcass Legal, not accompanied by a Guardian due to the urgency of the application, considered that the risk to Z of a slow and painful death if the course advanced by the father were followed is an unacceptable one and carries no real possibility of any advantage. She concluded that the alternative plan advocated by the father was objectively contrary to Z's interests. Ms Jaffar, for these reasons, supported the application of the Trust. I found her submissions to be helpful and focused.

27. Accordingly, I come to the conclusion that it is in Z's best interest to stop intensive care and commence palliative care. I am satisfied that intensive care is futile and that there are no other treatment options or procedures available. I am also clear on the evidence that intensive care treatment has now come to place an unsupportable burden on Z.

28. I know the parents will be profoundly distressed by my decision but I hope that they will understand my reasoning which is to be recorded in a transcript of this necessarily *ex tempore* judgment.