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Case No: XX24P70044

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**  
**SITTING AT THE ROYAL COURTS OF JUSTICE**

Royal Courts of Justice  
Strand, London  
WC2A 2LL

Date: 26<sup>th</sup> January 2024

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**Before:**

**MRS JUSTICE LIEVEN**

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**Between:**

**A COUNCIL**

**Applicant**

**- and -**

**(1) AN NHS FOUNDATION TRUST**

**Respondents**

**(2) MG**

**(3) A CHILD (Z)**

**(Through their Children's Guardian)**

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**MR GOODWIN KC** (instructed by **A Council**) for the **Applicant**

**MR HALLIN** appeared for the **NHS Foundation Trust**

**THE SECOND RESPONDENT** did not appear and was not represented

**MS CHAPMAN** appeared for the **Children's Guardian**

**THE FATHER** appeared **In Person**

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**Approved Judgment**

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**MRS JUSTICE LIEVEN:**

1. This is, even by the standards of this court, a particularly tragic and awful case concerning a young child called Z, born in April 2022. The matter came before me on Wednesday and it was adjourned to Friday afternoon.
2. The Local Authority (“LA”) applies for leave to invoke the inherent jurisdiction in relation to the withdrawal of medical treatment and the provision of end of life care in relation to the child. Z was made subject to a care and placement order on 4 October 2022 in respect of both him and his twin brother, Y, who is now in foster care. The mother is the first respondent. She is not represented today and, for reasons that I will explain in a minute, she is not before the court. The father is the second respondent, but he does not have parental responsibility and is, therefore, not automatically a party. All concerned accept that he is Z’s father and he has been closely involved in what has been going on.
3. Z was represented today before me by the children’s guardian, to whom I am extremely grateful for her involvement in the case at very short notice.
4. The background briefly is that Z and his brother were born at 36 plus three weeks in April 2022 with cardiac defects, transposition of his arteries and a number of other really serious physical abnormalities. Although both twins had health issues, Z was the one who was far more seriously affected. He was transferred to a Children’s Hospital very shortly after his birth and he has remained in hospital ever since. He had a series of corrective cardiac procedures from very shortly after birth and spent a considerable amount of time in the paediatric intensive care unit. Relatively speaking, he was doing quite well in that unit and in November 2022 he was discharged from the intensive care unit to a ward in the hospital where there was a gradual process of weaning him off a ventilator. During that period, he was making real progress and consideration began to be given by the LA to moving him to a foster placement and a foster carer was identified. Albeit, it was accepted that he would need a high level of support. There is a reference in one of the statements before the court that says:

“Prior to [Z’s] cardiac arrest, his development was delayed, likely due to his underlying genetic diagnosis and prolonged hospital admission, but this was not significant. From a gross motor perspective, he was rolling to get around, sitting independently, reaching out of base of support and propping on to hands and reaching for toys.”
5. He had a brief further period in intensive care because of a respiratory infection, but then was discharged to a lower dependency ward.
6. I am not going to make any comments, although there are some in the LA’s position statement, about the level of supervision in that ward and the degree to which the staff were aware of the level of Z’s needs. In any event, on 16 July 2023, his tracheotomy tube became dislodged during a period when he was not being observed and that resulted in a cessation of his oxygen supply. It appears that he was then in a major and prolonged cardiac arrest for something like 15 minutes, which led to severe hypoxic-ischemic brain damage, ventilator dependence and very pronounced drug-resistant

dystonia and deafness. He was then re-admitted to the intensive care unit where he has been since.

7. I understand there is a Serious Event Review being undertaken by the NHS Trust and I have been assured today that that will be shared not just with the LA but also with the guardian.
8. The evidence both from the paediatric consultant in the intensive care unit, but also reflecting the unanimous view of all his colleagues who are caring for Z, is that Z now has very little, if any, quality of life. The position, as explained by the paediatric consultant, is that he is sedated for long periods of time and when not sedated is apparently in distress. It is impossible, given his condition, to wean him off either that level of sedation or off the ventilation.
9. On 4 December, the hospital convened a specialist multidisciplinary team with consultants from palliative care, respiratory physicians and physiotherapists, neurologists and other staff. The unanimous view was that he was not showing any sign of improvement and has no quality of life. I understand that, in fact, even since then there has been further deterioration. He suffers from significant periods of dystonia where he is in distress and, according to the paediatric consultant, he has an extremely poor quality of life. In those circumstances, the NHS Trust took the view that it was appropriate to move to a palliative care model and for Z's life to be brought to an end.
10. The reason this matter came before me on Wednesday is that the LA were extremely concerned about the parents' capacity to give consent to end of life treatment for Z. The position is that both parents are heroin addicts and both parents have a history of fluctuating engagement both with the care proceedings and with Z in hospital, although I note that the father came to the hearing on Wednesday, has come today and has subsequently been assessed by the Trust and everyone agrees that he has capacity. However, given that he does not have parental responsibility, he cannot formally in law consent to the treatment.
11. The mother's position is even more complex. The position on Wednesday was that the Trust thought that the mother did have capacity. She has apparently been engaged in conversations with Trust doctors, including, I think, a long and detailed conversation after the MDT meeting in December. However, the LA, who have knowledge of the mother through the care proceedings, were very concerned about whether or not she had capacity to make decisions about Z's end of life care. In those circumstances, the LA applied to the court on Wednesday for a capacity assessment to be ordered in respect of the mother, as well as for the inherent jurisdiction application.
12. I considered it was appropriate to order a capacity assessment. However, unfortunately but perhaps not wholly surprisingly, the mother has not engaged in that assessment and, indeed, has not, I believe, spoken to the LA since Tuesday. Quite apart from the fact the mother apparently has a history of non-engagement at certain times, it is hardly surprising in the circumstances that the mother has found this situation so overwhelming that she has defaulted to a position of non-engagement. I will return to the mother's capacity when I come to my conclusions.

13. I also ordered on Wednesday for the Trust to use its best endeavours to get a second opinion in respect of Z's treatment. Although the Trust felt at the time that it was going to be extremely difficult to get a second opinion, I did not feel it was appropriate, in the tragic circumstances of this case, to allow a move to end of life care without the view of an independent expert. I am extremely grateful to the Trust, but even more grateful to Professor A from another Paediatric Children's Hospital, who has not just managed to produce a second opinion, but has also been to see Z and has set out an extremely helpful short report. Professor A's position is precisely in line with that of the treating clinicians. He considers that Z, effectively, has no quality of life and no possibility of any meaningful improvement, and in those circumstances he entirely supports a decision to move Z on to palliative care. Therefore, all the evidence in this case, and the opinions of all concerned, are unanimous in terms of what should happen.
14. The guardian, who again I am very grateful to for coming in so late and managing to produce a position statement and a careful consideration of the cases, is also of the view that palliative care is appropriate.
15. I intend to summarise the legal principles extremely shortly. They are set out in a judgment of the Court of Appeal *Re A (A Child)* [2016] EWCA 759, in particular Baroness Hale's judgment at paragraphs 22 and 39, and in the extremely well-known case of *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.
16. The case falls within the guidance given by the Royal College of Paediatrics and Child Health entitled "Making decisions to limit treatment in life-limiting and life-threatening conditions in children" issued in March 2015. That sets out three circumstances in which it is ethically permissible to consider withdrawing treatment as no longer being in the child's best interests: first of all, where life is limited in quantity; secondly, where life is limited in quality; and, thirdly, where there is informed competent refusal of treatment. For the reasons I am going to give in a moment, this case definitely falls into the second category where life is limited in quality.
17. Turning to conclusions, the first issue before me is what I do about the mother's capacity. In order for the court to rely on a decision of the mother that Z should be moved to palliative care only, I have to be satisfied that she has capacity and I also have to be satisfied that she gave informed consent. I am very conscious of the fact that the NHS Trust considers that she does have capacity and also relies on the presumption in favour of capacity under section 1(2) of the Mental Capacity Act 2005. I am, however, equally concerned that the case law suggests that, when a court is considering capacity, the more important the decision the more careful the court needs to be that the person in question has capacity, as well as being particularly careful that they can give informed consent.
18. The evidence in this case is very limited. I have the LA's deep concern about whether the mother has capacity. I have the Trust saying that they thought she did have capacity in December, but they were not undertaking a formal capacity assessment under the Mental Capacity Act. I am very conscious of the fact that, for the mother to have capacity, she must be able to process the information that is given to her. I am

not at all confident that she could process the information and I am equally concerned that she has not considered the information in any detail since December.

19. I consider it to be inappropriate to rely on a presumption of capacity in these circumstances where the decision is as to whether the mother's child is allowed to die. It does not feel to me judicially comfortable to rely on a presumption of capacity in those circumstances where I know that the LA, which has had considerable contact with this mother in the past, has such worries about her capacity. I am going to proceed on the basis that the mother does not have capacity. I am not going to make a finding she does not have capacity because I do not have the evidence, but, I think, I can make a section 16 decision and take an interim view that she does not have capacity. Even if she does have capacity to make the relevant decision, I am even more concerned that she cannot give informed consent, because I have very little evidence as to what information she was given in order to give informed consent within the meaning of the case law.
20. In those circumstances, it falls to the court to consider what is in Z's best interests and I make it entirely clear that I will make a best interests decision and I will not rely on parental consent. I do, however, take into account the fact that the mother, when she did discuss this issue and was given information, took the view that it was in Z's best interests to allow him to move to palliative care. I also take into account the fact that the father, albeit he does not have parental responsibility, reaches the same view, as does the LA and the guardian.
21. In terms of the best interests decision, sadly, I think there is very little doubt that this is a clear decision. There is a unanimity of clinical view, including a second opinion, that it is in Z's best interests to allow his life to end. The medical evidence is so overwhelming, as to the level of his suffering, as to the lack of hope of any improvement in the quality of his life and, importantly, as to there being no alternative care plan which could improve his quality of life, that, in my view, it is clear it is in Z's best interests for the palliative care plan to be approved and for me, under the inherent jurisdiction, to allow the withdrawal of medical treatment and the provision of end of life care. I give consent for that application to be brought and I allow the application.

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*(This Judgment has been approved by the Judge)*