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NEUTRAL CITATION NUMBER: [2025] EWHC 413 (Fam)

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION



No. FD25P00056

Royal Courts of Justice
Strand
London, WC2A 2LL

14 February 2025

Before:

Mr Justice Harrison

Re C (A Child) (Life-saving Medical Treatment)

APPROVED JUDGMENT

Ms Victoria Butler-Cole KC (instructed by **Weightmans LLP**) appeared on behalf of the **Hospital Trusts**

Ms Eliza Sharron (instructed by **Irwin Mitchell LLP**) appeared on behalf of the **Parents**
Ms Eva Holland, solicitor, of Cafcass Legal appeared on behalf of **C** (through her children's guardian)

Hearing date: 14 February 2025

Mr Justice Harrison :

Introduction

1. C is a much loved and courageous little girl. She is aged just 14 months. It has been a privilege for me to see the lovely photographs of her which her parents have provided.
2. In her short life C has faced many challenges. The medical professionals involved in her care consider that she needs now to have a liver transplant in order to save her life. Her parents do not agree. The court is therefore asked by the hospital trusts responsible for her care to declare that such a course is in her best interests.

Background

3. C was born at 35 weeks. Soon afterwards she was diagnosed with a congenital growth disorder called Beckwith-Wiedemann Syndrome ('BWS'). This is associated with having a large tongue, abnormal growth of parts of the body, enlarged abdominal organs and an enhanced risk of childhood cancers, in particular before the age of two (the risk declines progressively towards puberty and then approaches the level of risk faced by the general population). She was also diagnosed with cat-eye syndrome, a rare genetic condition associated with a range of physical and motor difficulties and the potential for mild to moderate learning disability.
4. As a consequence, C now has a range of medical conditions. The most serious is a form of liver cancer referred to as hepatoblastoma. Other symptoms which she experiences include:
 - (i) A significantly enlarged tongue, which will require multiple surgeries to address;
 - (ii) Signature birthmarks to the face;
 - (iii) A left kidney which is bigger than the right;
 - (iv) A cyst to the left kidney;
 - (v) One leg which is bigger than the other;
 - (vi) Low density bones which have given rise to multiple fractures.
5. The cancer was first detected in an ultrasound scan in July 2024. Further scans revealed that C had sustained fractures in her ribs, forearms and back and that her bones have low density. The fractures are believed to be related to the underlying cancer.
6. Between August 2024 and January 2025 C has had a total of ten rounds of chemotherapy. The last two rounds were given in response to the concerns expressed by the parents at the prospect of a transplant. The treating doctors are clear that it is not possible for her to have further chemotherapy. It is also not possible for the tumour within C's liver to be cut out or 'resected': the part of the liver where the tumour is located and its presence in certain vessels within the liver means that were it to be resected no viable liver would remain.
7. The unanimous professional view of the doctors is that the only treatment option now available for C is to have a liver transplant. They are also clear in their view that without a transplant C will die as the tumour will start to grow again and metastasise; no treatment options would then be available. If she were to have the transplant, based upon other cases, it is estimated that she would have a 92 to 94% chance of survival at 12 months.

8. Statistically, the overall survival rate five years after treatment for children with hepatoblastoma who undergo a liver transplant or resection is 51%. That statistic is based upon old data and it is therefore possible that with developments in medicine the survival odds today are in fact higher. It was also helpfully explained to me by Ms Butler-Cole KC on behalf of the trusts that the survival prospects are influenced by a range of factors including the patient's attitude towards any treatment that may be required post-surgery. Included in the statistics, for example, are cases involving teenagers who have issues relating to the consumption of alcohol and whose failure to abstain from alcohol may lead to a negative outcome for them. These statistical subtleties give reason for cautious optimism in C's case, but it is not possible to quantify her individual prospects more precisely than the 51% number, as there is no published data which would allow the doctors to do so.
9. It is proposed that C should immediately be placed on a transplant list. She will be in the second highest category of priority. An offer of a donor organ may be received within hours although it may take up to two weeks. The surgery itself would take 8 to 10 hours. Thereafter she would be in hospital for at least a further month. Upon discharge, she would be closely monitored by a multi-disciplinary team, initially weekly. The need for surgery is urgent. As Ms Butler-Cole KC explained, there are markers which suggest that C's tumour is active.
10. As with all surgery, there are risks involved in the proposed procedure. It is not guaranteed to succeed. A second transplant may be required. The overall five year survival rate is, as I have recorded, put no higher than just over 50%. C will need to take medication in the long term and will be immunosuppressed, creating a higher risk of infection. The evidence is that such infections might require short hospital admissions but would not place a significant burden on C's quality of life.
11. I would like to pay tribute to C's parents. There is no greater challenge for a parent than having a child who has a serious life-threatening condition. They have been dedicated and loving parents throughout C's life and will continue to be so. It has been painful for them to witness their baby daughter's suffering. She has had extended stays in hospital, repeated medical interventions including tests performed under general anaesthetic and the insertion of a Hickman line into a vein near her heart. Aside from the chemotherapy, she receives other medication and fluids and requires regular re-dressing. For much of the time she is in pain, which has been treated with paracetamol and morphine. She is often in distress and wakes every hour throughout the night.
12. C's parents have an older child for whom they have caring responsibilities. They also work in order to support their family. The physical demands placed upon them of having to care for C are enormous. The emotional demands and anxiety created by having to witness her suffering are unimaginable. They deserve nothing but praise, for their unswerving devotion to their daughter. I echo the submissions made on their behalf and on behalf of the guardian as to the need for them to be offered support from professional agencies.
13. In opposing a liver transplant for C, the parents are not thinking of themselves. They want what is best for their daughter. They have witnessed first-hand the multiple interventions she has experienced which have not led to any tangible improvement in her life. Understandably, they have serious concerns about the prospect of C having a transplant. In particular, Ms Sharron emphasises that they are concerned about the following matters which they identify in the evidence of the doctors:

- (i) Following the surgery, C would be required to spend a few days on the paediatric intensive care ward, and then around 3-4 weeks on an acute ward until immunosuppression drugs had been established, and family training completed. She would find it hard to cope with a further extended hospital stay, now that she is she beginning to develop a sense of play and enjoyment within the family.
 - (ii) C will require long term immunosuppression treatment and follow up – her immunity will be compromised making her 40% more vulnerable to common infections and cancers (such as Lymphoma and skin cancer).
 - (iii) In the event of primary non-function, C may require a second transplant, requiring the whole procedure to be undertaken again.
14. The parents are also conscious that C is highly likely in due course to require multiple surgeries to reduce the size of her tongue and that she may also need leg surgery. She is at risk of developing kidney cancer until the age of seven (the evidence is that the lifetime risk for this is 7.9% and that it has a survival rate of 90%).
15. The evidence from the consultant geneticist, on the other hand, is that it would not be logical to reject a liver transplant on the basis that some of these problems associated with leg disparity might occur. Other patients with BWS have not been severely impacted by limb problems. Children with BWS usually grow up to be healthy adults with a normal life expectancy. The geneticist's evidence is also that more than 50% of children with cat-eye syndrome have normal intellect. Of the others, 73% have mild learning problems. The geneticist's opinion is that cat-eye syndrome should not have any adverse impact on C's life expectancy or quality of life.
16. The parents also point out the five year survival rate of 51% for young patients having a liver transplant does not account for the additional conditions from which C suffers. They are fearful at the prospect of inflicting further interventions and suffering upon their daughter on the basis of at most a 51% chance that she will survive for five years.
17. The parents are Catholics and have a strong religious faith. They do not want their daughter to die but have faith that without a transplant she will be healed by God. They identify with wider Christian values and have attended an online live healing stream to bring C closer to God. They say that they have witnessed first-hand the curative effect that the healing stream can have. It was made clear, however, that they have no religious objections to the proposed treatment. The relevance of their faith is that they believe that God will intervene to heal C if the treatment does not take place. I cannot assume that at her young age C would share her parents' religious convictions, but I take into account the cultural and religious environment in which she is being raised.

The Law

18. The legal principles which the court is required to apply have been helpfully set out in an agreed document which I incorporate into this judgment below. I am very grateful to all of the advocates, in particular Ms Butler-Cole KC, for putting together this document and for the submissions which were made orally to me.
19. The court has jurisdiction to make a best interests declaration in respect of medical treatment where the child cannot make decisions for themselves and there is disagreement between the

treating doctors and those with parental responsibility: see for example *Re B (A Minor) (Wardship: Medical Treatment)* (1982) 3 FLR 117.

20. The test the court is required to apply is simply whether the proposed treatment is in the child's best interests. In *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410 it was said:

“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.”.

21. The welfare checklist in s.1(3) CA 1989 does not strictly apply, but in any event, the holistic best interests analysis that is required on an application under the inherent jurisdiction incorporates the checklist factors: *Fixsler & Anor v Manchester University NHS Foundation Trust & Anor* [2021] EWCA Civ 1018 (*'Fixsler'*) at para 80.

22. The following principles, derived from *Portsmouth Hospitals NHS Trust v Wyatt and Anor* [2005] EWCA Civ 1181 and *An NHS Trust v MB* [2006] EWHC 507, have been repeatedly cited, particularly in the context of decisions concerning young children who cannot express their own opinions about treatment:

- i) The judge must decide what is in the best interests of the child.
- ii) In making that decision the welfare of the child is the paramount consideration.
- iii) The judge must look at the question from the assumed point of view of the child.
- iv) There is a strong presumption in favour of a course of action that will be likely to preserve life but that presumption is not irrebuttable.
- v) The term "best interests" encompasses medical, emotional and all other welfare issues.
- vi) The court must consider the views of the doctors and parents.
- vii) Each case will turn on its own facts.
- viii) The court must conduct a balancing exercise in which all relevant factors are weighed. This is not a mathematical exercise but it is an objective one.

23. The following passage from paragraph 39 of *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591, a case concerning with withdrawal of intensive care from an adult, has been confirmed by the Court of Appeal in *Re A (A Child)* [2016] EWCA Civ 759 to apply in cases concerning children:

“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."

24. The views of a child's parents are not determinative, any more than the views of the treating doctors or the assumed view of the child.
25. Religious beliefs are part of the best interests analysis, but the court should be careful about ascribing religious beliefs to a very young child such as C, who does not have any understanding of such concepts: see *Fixsler* at para 85.
26. The court should consider the likely outcome of the proposed treatment. For example in *Manchester University NHS Foundation Trust v Fixsler and others* [2021] EWHC 1426; [2021] 4 WLR 95) it is said at paragraph 57:
 - vi)the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
27. It is important to note in the present context that in applying the best interests analysis there is a presumption in favour of life continuing.

Conclusions

28. As I have already made clear, I have the highest possible respect for the parents and their faith in God. As a judge, I am required to come to a determination as to what is in C's best interests on the basis of the evidence with which I am presented.
29. The evidence of the medical professionals is unanimous in recommending a transplant. Amongst other things, the point is made that children with BWS usually grow up to be healthy adults with a normal life expectancy. Some children with cat-eye syndrome have mild learning difficulties. At this stage it is not known whether this latter syndrome will affect C, but the evidence to date suggests that it will not have any adverse impact on her life expectancy or quality of life.
30. The recommendation of the medical professionals is also supported by C's children's guardian, who has approached the matter independently and carefully considered all of the advantages and disadvantages of the proposed treatment. She has canvassed the views of the parents and set out sequentially the list of burdens they have identified, before coming to her conclusions. She has been able to witness the loving relationships which C has with her parents, her sibling and her grandmother. The quality and strength of those relationships is much to the credit of the parents in particular.
31. It is submitted on behalf of the Trusts that in the circumstances of this case there is no reason to assume that C would want to refuse life-saving treatment. She has a good quality of life and despite the likely need for further intervention in future the negative factors associated with this do not come close to outweighing the benefits of continued life. I agree with that submission. I also agree with the submission that the prospects of success of the surgery are sufficiently high to be worth proceeding, despite the risks and burdens which surgery would entail.

32. Although it is impossible to be certain and the parents are right to point out that there are occasions when the predictions of medical professionals do not materialise, I am satisfied on the evidence that without treatment it is virtually certain that C will die. Whilst there is no guarantee, the surgery will afford her a good chance of having a long and fulfilling life. It is a chance which, in my judgment, she deserves. C and her parents have displayed great courage in their lives so far. The suffering which C has experienced should not, in my view be in vain, when with further treatment there exists the potential for her to have a good, long life. I commend the parents for having made clear that if the court were to come to the conclusion that the treatment is in C's best interests they will work with the professionals to support it.
33. It will be apparent that I do consider that having a liver transplant is very clearly in C's best interests and I grant the declarations sought.